

“The current legal status of assisted dying is inadequate and incoherent...”

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THE COMMISSION ON ASSISTED DYING

The **Commission on Assisted Dying** was set up in September 2010 to consider whether the current legal and policy approach to assisted dying in England and Wales is fit for purpose. In addition to evaluating the strengths and weaknesses of the legal status quo, the Commission also set out to explore the question of what a framework for assisted dying might look like, if such a system were to be implemented in the UK, and what approach to assisted dying might be most acceptable to health and social care professionals and to the general public.

The Commission's terms of reference are as follows:

- to investigate the circumstances under which it should be possible for people to be assisted to die
- to recommend what system, if any, should exist to allow people to be assisted to die
- to identify who should be entitled to be assisted to die
- to determine what safeguards should be put in place to ensure that vulnerable people are neither abused nor pressured to choose an assisted death
- to recommend what changes in the law, if any, should be introduced.

The Commission on Assisted Dying engaged in a wide-ranging inquiry into the subject, which included: a public call for evidence which received over 1,200 responses from practitioners, professional bodies and members of the public; six public evidence meetings to gather oral evidence from experts and individuals with relevant experience; international research visits to four jurisdictions in which some form of assisted dying is legally permitted; original research on the relationship between suicide and serious physical illness and into attitudes on assisted dying among people from 'vulnerable groups'; and commissioned research on the effectiveness of legal safeguards, and the quality of palliative care, in jurisdictions that permit some form of assisted dying.

As far as possible the Commission has published all of the evidence received on its website at [www.commissiononassisteddying.co.uk](http://www.commissiononassisteddying.co.uk). The Commission alone is responsible for the conclusions published in this report, which are based solely upon the evidence it has received.

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# THE COMMISSION ON ASSISTED DYING

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We would also like to thank the Demos research and communications secretariat for their valuable assistance in coordinating the Commission's call for evidence, organising the Commission's public evidence hearings and outreach activities, processing and synthesising the many forms of evidence received and managing press and communications for the Commission, including the Commission on Assisted Dying website. In particular our thanks go to Louise Bazalgette, Secretary and Lead Researcher to the Commission; William Bradley, Researcher to the Commission; Beatrice Karol Burks, Demos's Head of Communications; Sarah Kennedy, Demos's Head of Events and Partnerships and to Julia Margo, Demos's Deputy Director for her role in initiating the project and providing guidance throughout. We would also like to thank Richard Reeves for providing the original impetus for the project, Phillida Cheetham for her support with the Commission's consultation and outreach activities, Sophie Duder for her assistance with the Commission's meetings and international visits and Ralph Scott for recording and disseminating the evidence sessions and managing the publication process for this report.

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We would like to thank Celia Grandison-Markey for her role in supporting the Commission on Assisted Dying in its early stages, including her thoughtful contributions at early evidence hearings and in the research visit to the Netherlands.

Finally, we could not have undertaken this extensive independent inquiry without the generous financial support of Sir Terry Pratchett and Bernard Lewis and we are very grateful to them for making the Commission on Assisted Dying possible.

The Commission on Assisted Dying  
January 2012



**Note from the Chair**

It has been a great privilege being the Chair of the Commission. I can't thank each individual Commissioner enough. The contribution each individual Commissioner has made from different standpoints has been immense. We have gone together on a journey, and although we did not all end up at precisely the same place, I could not have had more talented and congenial travelling companions. Louise Bazalgette and Will Bradley have done a simply stupendous job in organising our programme and reflecting our thoughts. My thanks to them and the individual Commissioners is profound and long-lasting.

Lord Charles Falconer  
Chair of the Commission on Assisted Dying



# The Commissioners

## Lord Falconer, Chair



Charles Falconer is an English qualified barrister and a partner in the US law firm, Gibson, Dunn & Crutcher, working out of their London office.

He spent 25 years as a commercial barrister, becoming a QC in 1991. He became a peer and the solicitor general in May 1997. He was a minister in the Blair government from 1997 to 2007 as Lord Chancellor, Minister of State for Criminal Justice, Sentencing and Law Reform and Minister for Housing, Planning and Regeneration.

He is chair of Amicus Horizon Housing Association, One Newcastle Gateshead Ltd, the John Smith Memorial Trust, Ravensbourne College and the Visitor of Queens' College, Cambridge.

He sits as a Labour peer in the House of Lords.

## Professor Sam H Ahmedzai



Sam H Ahmedzai is chair and head of the Academic Unit of Supportive Care at the School of Medicine in the University of Sheffield. He is an honorary consultant physician in palliative medicine, working in a hospital supportive care team for 15 years. Before that, he was medical director of the Leicestershire Hospice for nine years. He led the Adult Cancer Survivorship Project in Sheffield.

He chaired the European Association for Research and Treatment of Cancer groups 'Quality of Life' and 'Pain and Symptom Control'. He was founder of the Association for Palliative Medicine Science Committee. He is editor of the Oxford University Press book series on supportive care; the journal *Current Opinion in Supportive and Palliative Care*; the section on supportive and palliative care for *BMJ Clinical Evidence*; and he is expert adviser to NICE NHS Evidence.

Sam graduated from the universities of St Andrews and Manchester and received postgraduate medical training in oncology and respiratory medicine in Glasgow. His research interests are in pain control, nutrition and hydration, evaluation of quality of life and holistic needs assessment. He is particularly involved in developing 'symptomics' — the biological science of symptoms, distress and suffering. His university department has championed the voice of consumers in cancer research.

### **Lord Ian Blair of Boughton**



Lord Blair of Boughton was the commissioner of the Metropolitan Police from 2005 to 2008. His police career spanned almost 35 years and he held command positions in a number of forces for nearly 15 of those. He is now a writer, broadcaster and lecturer in the UK, the USA and India. He sits as a cross bench peer.

### **Sir Graeme Catto**



Graeme Catto is President of the College of Medicine and chairman of the Scottish Stem Cell Network and chairman of the Better Regulation Group, Universities UK. A former president of the General Medical Council, until 2005 he was vice-principal at King's College London, dean of the Guy's, King's College and St Thomas' Hospitals' Medical & Dental School and pro-vice chancellor, University of London.

After graduating in medicine from the University of Aberdeen, he obtained a Harkness Fellowship from the Commonwealth Fund of New York to study at Harvard University. He is an honorary physician with an interest in renal medicine, and has published widely on different aspects of nephrology and immunology.

Formerly chief scientist at the Scottish Executive Health Department, dean and vice principal at the University of Aberdeen and governor of the Science Technology Park in Qatar, he is currently president of the Association for the Study of Medical Education.

### **Dr Carole Dacombe**



Following her graduation from Bristol University with a medicine degree, Carole Dacombe completed a wide variety of hospital posts before completing a vocational GP training scheme. This led to nine years as a GP principal in the Bristol area. Throughout her hospital and GP work Carole was involved in working alongside patients and families dealing with incurable illness, and found herself drawn increasingly to this work, and keen to learn more about what could be achieved for people finding themselves in this situation.

Having made the decision to leave general practice and pursue this interest further, an opportunity arose for her to join the team at St Peter's Hospice in Bristol (initially as a part-time medical officer) — and she also enrolled to study for the (then new) postgraduate Diploma in Palliative Medicine at Cardiff University. She has now been at the hospice for 20 years, and has been the medical director for the past eight — with responsibility for managing the senior and junior doctors, along with the psychology, physiotherapy, occupational therapy, complementary therapy and pharmacy services.

She is a firm believer in multidisciplinary team working and also in community-based palliative care—which means maintaining the closest possible liaison between hospice teams and their local primary health care colleagues. Education is also a topic very close to her heart, knowing that specialist palliative care will only ever be directly involved in a relatively small proportion of patients who have incurable disease. Teaching, facilitating, advising and mentoring are therefore essential components of the outreach work for any hospice team.

Carole's day-to-day work involves a mixture of people management, clinical work within the in-patient unit, community teams and day hospice services, mentoring of junior medical staff, teaching and management work within the hospice executive team. In addition to these duties she also attends a number of local and regional meetings about the organisation and development of palliative care and end of life care services in Bristol and the South West. She has just completed two years of work as the clinical lead for end of life care in the Service Design Programme for Bristol, South Gloucestershire and North Somerset primary care trusts.



### **Dr Stephen Duckworth OBE**

Stephen Duckworth qualified as a doctor and completed a PhD investigating disability equality issues following an accident that resulted in him becoming an electric wheelchair user. Following this he founded Disability Matters Ltd where he was the chief executive for 20 years. He is a board member on the Olympic Delivery Authority, Board Champion for Equality and Diversity and Chair of the Health, Safety and Environment Committee. He also sits on the board of the Employers' Forum on Disability. Stephen currently works for a FTSE top 100 company as a director undertaking research to improve the development of global public service markets.

Stephen has worked as an adviser to ministers on disability rights and welfare reform. He has been very involved in the work of a group of Financial Service Authority regulated companies that provide ethical finance and insurance to disabled customers. He has also been a member of the Council of the University of Southampton and the Department of Health's National Quality Board.



### **Penny Mordaunt MP**

Penny developed an interest in politics when working in the hospitals and orphanages of post-revolutionary Romania for the year before and during her time at the University of Reading. She went on to be Head of Broadcasting at Conservative Central Office and Head of Foreign Press for George W Bush's 2000 election campaign. Outside politics Penny has worked in business and communications in the private, public



and charitable sectors; working for the Freight Transport Association, a national lottery distributor and Diabetes UK.

Since her election in May 2010 Penny has assumed the Conservative chairmanship of the All Party Parliamentary Group for Aging and Older People, and became the founding chairman of both the All Party Parliamentary Group on Life Science and the All Party Parliamentary Group on Choice at the End of Life. Penny is a member of the European Scrutiny Committee and has recently won election to the Defence Select Committee, a position for which her experience as a Royal Navy reservist will stand her in good stead.

### **Baroness Elaine Murphy of Aldgate**



Elaine Murphy is an independent (crossbench) life peer. She trained in medicine and psychiatry and was formerly Foundation Professor of Old Age Psychiatry at Guys Hospital (now part of King's College London). She was also a senior NHS manager and Vice Chairman of the Mental Health Act Commission. Afterwards, she chaired NHS trusts and subsequently a strategic health authority until 2006. She then became Chair of Council at St George's, University of London, and a board member of Monitor, the NHS Foundation Trust Regulator until 2010. She is Secretary to the All Party Parliamentary Group on Mental Health. She is also a vice-president of the Alzheimer's Society.

### **Dame Denise Platt DBE**



Dame Denise Platt is a member of the Committee on Standards in Public Life. She has wide ranging interests in the voluntary and public sectors. Until recently she was Chair of the Commission for Social Care Inspection; she has also been a member of the Audit Commission, and was the Chair of the Local Innovation Awards Scheme.

She has held a variety of posts nationally and locally in local government and social care. These include the post of chief inspector, Social Services Inspectorate, and Director for Children, Older People and Social Care Services at the Department of Health in England; Director of Social Services, London Borough of Hammersmith and Fulham; and Head of social services at the Local Government Association. She is a past president of the Association of Directors of Social Services. She currently holds voluntary positions as the chair of NAT (National AIDS Trust), trustee of the National Society for the Prevention of Cruelty to Children (NSPCC), trustee of the Adventure Capital Fund, governor of the University of Bedfordshire, member of the Advisory Board of the School for Social Care Research at the National Institute of Health Research and member of the Independent Review Board of the Cheshire Fire and Rescue Services. She has recently been appointed a trustee of the Lloyds TSB Foundation.



### **The Reverend Canon Dr James Woodward**

The Reverend Canon Dr James Woodward is an Anglican priest who over the last 25 years has worked in a number of settings including a hospital chaplaincy and as a non-executive director of a primary care trust. He is presently a canon of Windsor. He has written extensively in the area of pastoral and practical theology including books about illness, old age and death.

Some of his inter-professional interests are reflected on his web page ([www.jameswoodward.info](http://www.jameswoodward.info)) and he has collaborated with the Strategic Health Authority in the West Midlands in the generation of a web page designed to help people think about loss, change and death ([www.wellbeingindying.org.uk](http://www.wellbeingindying.org.uk)).



### **Baroness Barbara Young of Old Scone**

Barbara Young spent the first 20 years of her career in public relations and health services management. Latterly she managed a range of health districts in London. She was chairman then president of the Institute of Health Services Management from 1986 to 1988, and a King's Fund International Fellow in 1985/86 and 1990/91.

After 20 years in health care, she switched to an environmental career and has held posts as Chief Executive of the Royal Society for the Protection of Birds (RSPB), Chief Executive of the Environment Agency and chairman of English Nature. She is active in the conservation and environment voluntary sector. She has also served as vice-chairman of the British Broadcasting Corporation (BBC), as a board member of AWG plc, the water and infrastructure company, and as founding chairman of the Care Quality Commission, the regulator for quality in health and social care.

Barbara Young is a life peer in the House of Lords as Baroness Young of Old Scone, and is chancellor of Cranfield University. She is currently Chief Executive of Diabetes UK. Barbara has been interested in assisted dying for 20 years.



# Executive summary

## Terms of reference

The Commission's terms of reference are to:

- investigate the circumstances under which it should be possible for people to be assisted to die
- recommend what system, if any, should exist to allow people to be assisted to die
- identify who should be entitled to be assisted to die
- determine what safeguards should be put in place to ensure that vulnerable people are neither abused nor pressured to choose an assisted death
- recommend what changes in the law, if any, should be introduced.

It is not the role of the Commission to promote a change in the law.

## The Commission's conclusions

### The current law

The Commission considers that the current legal status of assisted suicide is inadequate and incoherent.

### The case for change

The Commission finds that there is a strong case for providing the choice of assisted dying for terminally ill people. Even with skilled end of life care, the Commission finds that a comparatively small number of people who are terminally ill experience a degree of suffering towards the end of their life that they consider can only be relieved either by ending their own life, or by the knowledge that they can end their life at a time of their own choosing.

### Providing adequate care and support and protecting vulnerable people

The issue of assisted dying cannot be viewed in isolation from the need for adequate health and social care or from the need to protect terminally ill people from the risk of abuse or indirect social pressure to end their lives, if such an option were to become available. Therefore if an assisted dying framework is to be implemented in the future, it must have these concerns at its heart and its purpose must be viewed as providing all people with access to high quality end of life care, and protecting vulnerable people from any kind of social pressure at the same time as providing people with greater choice and control regarding how and when they die.

### Core principles

In light of these findings, the Commission has developed a set of core principles that frame and run throughout their subsequent recommendations about a framework for assisted dying:

- Open discussion about death and dying should be promoted.
- Each person should be entitled to core rights in end of life care.
- Good quality end of life care should be available in all settings.
- All forms of discrimination in end of life care should be ended as far as possible, whether these are based on geographical location, physical condition, ethnicity or wealth.
- There should be more choice in how people die and clear and accessible information must be provided.
- There must be effective social support and protection for more vulnerable people.

### **Legal change**

The Commission has concluded that it is possible to devise a legal framework that would set out strictly defined circumstances in which terminally ill people could be assisted to die, while providing upfront safeguards to protect potentially vulnerable people. It must be a matter for Parliament to decide on behalf of our society as a whole whether to implement such a framework. The Commission has also identified other policies that would need to be pursued in parallel with the development of a new framework, in particular, improvements to health and social care services to support universal access to high quality end of life care. The Commission's recommendations on the key elements that should underpin a framework for assisted dying, and the more detailed framework set out below, are supported by all Commissioners, with the exception of the Reverend Canon Dr James Woodward, who believes that until greater ethical, moral and social consensus has been generated on this issue, it is not the right time to consider a change in the law.<sup>1</sup>

### **Key elements that should underpin a safeguarded framework for assisted dying**

These are the key elements that the Commission considers should underpin any future statutory framework for assisted dying:

- a good level of care and support services with properly trained health and social care staff
- clearly defined eligibility criteria
- the person concerned requests an assisted death on his or her own behalf, and has the capacity to make the request
- a doctor who, where possible, knows the person well and supports the person and their family through the process
- the person who requests an assisted death is fully informed of all the options available to them for treatment, care and support and still wishes to proceed
- an assessment to determine if the person meets the eligibility criteria is provided by at least two doctors who are wholly independent of one another
- detailed guidance on how lethal medication to be used for an assisted death should be stored, transported and administered in such a way as to ensure, as far as possible, no risk of abuse, constituting a danger to the public, or being stolen
- the patient must take the final action that will end their own life
- certification of the death expressly records it as an assisted death
- correct reporting of the assisted death to a national monitoring commission that reviews all cases and has retrospective powers to investigate whether individual cases complied with the law.

### **Eligibility criteria**

The Commission finds that a person should have met three eligibility criteria before they can proceed with requesting an assisted death:

- The person concerned is aged 18 or over and has a diagnosis of terminal illness.
- The person is making a voluntary choice that is an expression of his or her own wishes and is not unduly influenced by others.
- The person has the mental capacity to make a voluntary and informed choice, and the person's decision-making is not significantly impaired as a result of mental health problems such as depression.

### **Safeguards**

The Commission has identified eight principles for framing safeguards that should be included in a statutory framework for assisted dying:

- 1 Provide a decision-making model involving the assessment, advice, support and independent judgements of two independent doctors, with support from other health and social care professionals where necessary.
- 2 Ensure the person has been fully informed of all other treatment and end of life care options that are available and still wishes to proceed.
- 3 Ensure that the eligibility criteria are met.
- 4 Ensure that the person has a settled intention to die.
- 5 Ensure the safe storage and transportation of lethal medication.
- 6 Ensure the person has a reliable and supported assisted death.
- 7 Ensure that assisted deaths are reported correctly.
- 8 Provide monitoring and regulatory oversight by a national monitoring commission with powers to investigate cases suspected of non-compliance retrospectively.

### **Additional policy areas**

In addition to the conclusions set out above, the Commission considers that substantial improvements to health and social care services would be needed in parallel with changes to assisted suicide legislation. We also recognise that new legislation would be only one (albeit very important) piece of the picture. Professional training, guidance and support are essential features of all assisted dying regimes to promote responsible, exemplary practice and adherence to the spirit and letter of the law. The key areas that would need consideration are:

- the need for continuing government investment in improving end of life care
- the need for continuing use of the policy of the Director of Public Prosecutions (DPP) for prosecutors in non-terminal cases
- codes of practice specifying appropriate professional conduct for health and social care professionals involved in assisted dying
- supervision and support for doctors who are involved in cases of assisted dying.



# A summary of the Commission's analysis

## The Commission's conclusions

### The current law

The Commission considers that the current legal status of assisted suicide is inadequate, incoherent and should not continue, for these reasons:

- The current policy on assisted suicide accepts the principle of compassionate assistance with suicide, but because assisting suicide remains a crime it does not allow for open discussion or professional assessment and support for people contemplating assisted suicide.
- While assisted suicide remains illegal in England and Wales, there have been no prosecutions for the offence of assisting suicide since the publication of the Director of Public Prosecutions' (DPP's) policy on assisted suicide in February 2010,<sup>2</sup> although more than 40 cases of assisted suicide have been reported to the Crown Prosecution Service since 2009, and there is a public perception that assisted suicides that meet the criteria stipulated by the DPP policy are decriminalised.
- There is significant concern that assisting suicide remains an amateur activity, and that no prospective safeguards are in place to protect those who seek assistance, or who might feel themselves under pressure from others to seek assistance.
- The question of when cases of assisted suicide should be prosecuted is at the discretion of an individual official (the DPP) applying general guidelines rather than the letter of the law. If the DPP should change, the application of these guidelines could change.
- There remains considerable uncertainty about what conduct will attract criminal prosecution.
- The factors for and against prosecution make a special case of health and social care professionals. This is causing considerable uncertainties for professional people involved in caring for dying people.
- People criminalised by the legal prohibition on assisted suicide are currently treated as criminal suspects. This attracts certain procedural protections for them, but also brings with it the pain of being investigated and the threat of a criminal prosecution at the end of the investigative process. It is unclear why our society treats as criminal suspects the same people whom we do not have the inclination to prosecute.

The current situation, while being very distressing for families and unclear for health and social care staff, also lays a deeply challenging burden on police and prosecutors, which could be eased by a new statutory framework.



## **The case for change**

The Commission finds that there is a strong case for providing the choice of assisted dying for terminally ill people. Even with skilled end of life care, the Commission finds that a comparatively small number of people who are terminally ill experience a degree of suffering towards the end of their life, which they consider can only be relieved either by the ending of their life, or by the knowledge that they can end their life at a time of their own choosing.

## **Providing adequate care and support and protecting vulnerable people**

The issue of assisted dying cannot be viewed in isolation from the need for adequate health and social care or from the need to protect terminally ill people from the risk of abuse or indirect social pressure to end their lives, if such an option were to become available. Therefore if an assisted dying framework is to be implemented in the future, it must have these concerns at its heart and its purpose must be viewed as providing all people with access to high quality end of life care, and protecting vulnerable people from any kind of social pressure at the same time as providing people with greater choice and control on how and when they die.

## **Core principles**

In light of these findings, the Commission has developed a set of core principles that frame and run throughout our subsequent recommendations about a framework for assisted dying. They are discussed below.

### **Open discussion about death and dying should be promoted**

The Commission has uncovered a great deal of evidence that many people currently feel constrained about discussing their end of life choices. The Commission supports more open discussion about death and dying, at both an individual and a societal level. There is a societal need for much more open and accurate information about dying and end of life care, and better regulation and oversight of all end of life decisions.

### **Each person should be entitled to core rights in end of life care**

Every person should be entitled to receive the best end of life care available and appropriate to their needs wherever and whenever they are identified as approaching the end of their life. There is an urgent need for a culture change in health and social care services to ensure that people's core rights in end of life care are openly communicated and are supported at all times.

### **Good quality end of life care should be available in all settings**

There is limited progress in some parts of the country on the implementation of the End of Life Care Strategy.<sup>3</sup> Much more emphasis must be placed on generalist aspects of end of life care as well as specialist palliative and end of life care. The broader role of health and social care professionals in providing end of life care in all locations (including people's homes, care homes, hospices and hospitals) needs to be recognised and to receive more emphasis as a core component of their roles. There needs to be better coordination of end of life care and the pooling of social care and health care resources to meet patients' needs and spread resources more effectively. Best practice needs to be communicated more broadly.

**All forms of discrimination in end of life care should be ended as far as possible, whether based on geographical location, physical condition, ethnicity or wealth**

Progress has been made with the End of Life Care Strategy, but there is much to be done in providing better access to, and more uniform availability of, end of life care across the country. This must be borne in mind as further reform is planned for the NHS and financial restraints impact on the NHS and local councils. Certain social groups are at risk of receiving poor access to end of life care, including older people, adults with learning disabilities, adults with mental health problems including dementia, and adults with life-limiting conditions other than cancer. The evidence also emphasised the need to ensure that people can die where they wish to rather than facing an inappropriate emergency transfer to a hospital A&E department because of the lack of knowledge or basic care in their home setting. All health and social care staff with responsibility for people at the end of life (eg GPs, ward nurses, social workers, staff in care homes) must be aware of, and confident in, their role in giving people opportunities to discuss their end of life choices, and helping people to access the end of life care they want.

**There should be more choice in how people die and clear and accessible information must be provided**

This objective of giving people more choice in how they die is linked closely to the principles of improving open discussion and improving access to high quality end of life care. Choices might include the extent to which patients wish to discuss their illness, the treatments and support they might request or refuse and their preferences for where they wish to receive care and, ultimately, die. People need to be aware of which choices can be expressed as specific decisions (and recognised in law) and which can only be expressed as preferences. They should be aware of how decisions might be made on their behalf if they should lose the capacity to make decisions for themselves.

**There must be effective social support and protection for more vulnerable people**

Vulnerability is not just an issue in the context of assisted dying but in all end of life decisions that are made, such as ‘do not resuscitate’ decisions and decisions on withholding or withdrawing treatment (including nutrition and hydration) or administering palliative sedation. If we are to ensure that all people have opportunities to discuss their care and support needs and to receive the care and social support they need, we must be able to offer flexible options for both formal and informal advocacy.

**Legal change**

The Commission has concluded that it is possible to devise a legal framework that would set out strictly defined circumstances in which terminally ill people might be assisted to die, supported by health and social care professionals, and which would employ robust upfront safeguards to prevent inappropriate requests that did not meet the eligibility criteria from going ahead. A person who provided assistance when the strictly defined circumstances were not present would be liable to be prosecuted for the crime of assisting suicide.

The Commission proposes that Parliament should consider developing a new legal framework for assisted dying, as long as the other policy issues identified below were pursued in parallel with a new framework. This conclusion, the key elements that should underpin a framework for assisted dying, and the more detailed framework set out below, are supported by all Commissioners, with the exception of the Reverend Canon Dr James Woodward, who believes that until greater ethical, moral and social consensus has been generated on this issue, it is not the right time to consider a change in the law.<sup>4</sup>

### **Key elements that should underpin a safeguarded framework for assisted dying**

These are the key elements that the Commission considers should be included in any future framework for assisted dying:

- a good level of care and support services with properly trained health and social care staff
- clearly defined eligibility criteria
- the person concerned requests an assisted death on his or her own behalf, and has the capacity to make the request
- a doctor who, where possible, knows the person well and supports the person and their family through the process
- the person who requests an assisted death is fully informed of all the options available to them for treatment, care and support and still wishes to proceed
- an assessment to determine if the person meets the eligibility criteria is provided by at least two doctors who are wholly independent of one another
- detailed guidance on how lethal medication to be used for an assisted death should be stored, transported and administered in such a way as to ensure, as far as possible, no risk of abuse, constituting a danger to the public, or being stolen
- the patient must take the final action that will end their own life
- certification of the death expressly records it as an assisted death
- correct reporting of the assisted death to a national monitoring commission that reviews all cases and has retrospective powers to investigate whether individual cases complied with the law.

### **Eligibility criteria**

Should such a system be adopted in the UK in the future, we propose that a person should have met three eligibility criteria before they might proceed with requesting an assisted death:

- The person concerned is aged 18 or over and has a diagnosis of terminal illness.
- The person is making a voluntary choice that is an expression of his or her own wishes and is not unduly influenced by others.
- The person has the mental capacity to make a voluntary and informed choice, and the person's decision-making is not significantly impaired as a result of mental health problems such as depression.

## **A diagnosis of terminal illness**

The Commission proposes an eligibility criterion requiring a diagnosis of terminal illness. The Commission received evidence from many disabled people and does not consider that it would be acceptable to recommend that a non-terminally ill person with significant physical impairments should be made eligible under any future legislation to request assistance in ending his or her life. The intention of the Commission in recommending that any future legislation should permit assisted suicide exclusively for those who are terminally ill and specifically excluding disabled people (unless they are terminally ill) is to establish a clear delineation between the application of assisted suicide for people who are terminally ill and others with long-term conditions or impairments. The adoption of this distinction in any future legislation would send a clear message that disabled people's lives are valued equally.

The Commission proposes that in a future framework, 'terminal illness' could be defined as an *advanced, progressive, incurable condition that is likely to lead to the patient's death within the next 12 months*.

The Commission does not consider that any criterion based on 'unbearable' or 'unrelievable' suffering should be included in potential assisted dying legislation as we are concerned that a criterion based on suffering would be too unclear and subjective for doctors to assess; we believe it is only for the individual concerned to judge the extent of the suffering caused by their illness.

## **Voluntariness and absence of coercion**

The Commission accepts that there is a real risk that some individuals might come under pressure to request an assisted death if this option should become available, including direct pressures from family members or medical professionals, indirect pressures caused by societal discrimination or lack of availability of resources for care and support, and self-imposed pressures that could result from the individuals having low self-worth or feeling themselves to be a burden on others. The Commission does not accept that any of these forms of pressure could be a legitimate motivation for a terminally ill individual to seek an assisted death. Therefore, it is essential that any future system should contain safeguards designed to ensure, as much as possible, that any decision to seek an assisted suicide is a genuinely voluntary and autonomous choice, not influenced by another person's wishes, or by constrained social circumstances, such as lack of access to adequate end of life care and support. And that the choice made reflects a settled view (as opposed to a fluctuating or weakly founded view) that the person wishes to end their life.

## **The individual has the mental capacity to make a voluntary and informed choice**

A large number of submissions of evidence to the Commission identified capacity assessment as an essential cornerstone for any assisted dying framework. An important premise of the Mental Capacity Act 2005 is that a 'person must be assumed to have capacity unless it is established that he lacks capacity'.<sup>5</sup> However, in the context of such a serious decision as requesting an assisted death, the Commission considers that a formal assessment would be needed to ensure that the person concerned had capacity. The evidence given to the Commission made it clear that there are a number of factors that might

affect an individual's mental capacity, including temporary factors caused by physical or mental illness, and more permanent impairments such as a learning disability. It would be important that such factors were identified and that an assessment was conducted to explore whether the subject's decision-making capacity was significantly impaired.

Although the distinction between 'appropriate sadness' and depression in the context of terminal illness is complex, the Commission does not consider that a person with depression, whose judgement might be significantly impaired as a result of this depression, should be permitted to take such a momentous decision as ending their own life. Therefore we have suggested a range of safeguards that might be included in future legislation to screen applicants for depression, and take appropriate action to either treat this depression, or to prevent the individual's request for an assisted death from progressing.

The issue of whether people with dementia might be able to request an assisted death was also posed by some of those who gave evidence. We are sympathetic as a Commission to those people who are in the early stages of dementia, who might appreciate the security of knowing they could specify in a legal document the circumstances in which they would like to be able to end their life, once they had lost capacity. However, we consider that the requirement of mental capacity is an essential safeguard for assisted dying legislation; therefore the Commission does not propose any legislation that might allow non-competent people to receive assistance in ending their lives.

## **Safeguards**

The Commission has developed eight principles for framing safeguards that should be included in a framework for assisted dying:

- 1 Provide a decision-making model involving the assessment, advice, support and independent judgements of two independent doctors, with support from other health and social care professionals where necessary.
- 2 Provide a safeguard to ensure the person has been fully informed of all other treatment and end of life care options that are available and still wishes to proceed.
- 3 Ensure that the eligibility criteria are met.
- 4 Ensure that the person has a settled intention to die.
- 5 Ensure the safe storage and transportation of lethal medication.
- 6 Ensure the person has a reliable and supported assisted death.
- 7 Ensure that assisted deaths are reported correctly.
- 8 Provide monitoring and regulatory oversight by a national monitoring commission with powers to investigate cases suspected of non-compliance retrospectively.

Our reasons for selecting these categories of safeguard are set out below.

### **1 Provide a decision-making model led by doctors**

Our assessment of the body of evidence overall has convinced us that it is health and social care professionals who have the knowledge, skills and training structures that would be needed to implement a safeguarded system to permit assisted dying in the UK. Therefore, we do not consider that it would be necessary or desirable to involve a tribunal or other legal body in decision-making, as

proposed by some of those who gave evidence to the Commission. The system that we propose would have at its centre skilled professionals who can assess those who request an assisted death to confirm their diagnosis, explore their reaction to and understanding of their health condition, the motivation for their request, the voluntariness of their choice and their decision-making capacity. These are all skills that many health and social care professionals, and particularly doctors, use daily. The professionals assessing the individual's request would have a key role in informing this person of the available options for treatment, support and care, thereby promoting the uptake of end of life care. However, we do not envisage that it could ever be appropriate for health or social care professionals to offer assisted dying as an option; only the patients themselves should be able to initiate a conversation about assisted dying.

We propose that a safeguarded legal framework for assisted dying would require the involvement in assessment and decision-making of a minimum of at least two doctors. It would be critical that these two doctors were wholly independent of one another to ensure that the decision-making process was robust and to prevent collusion. Where possible the first doctor would be somebody involved in the care of the patient. The second doctor would need to be an experienced professional who could offer an independent opinion and was prepared to challenge the decisions of the first doctor if necessary. The two doctors would take responsibility for making the decision on whether an individual met the eligibility criteria. They would where necessary and appropriate consult other persons including other healthcare professionals involved in the care of the subject. In addition to satisfying themselves that the eligibility criteria were met, they (or in the case of safeguards 5 and 6 the 'first' treating doctor) would also be legally responsible for ensuring that safeguards 2, 4, 5, 6 and 7 were met in each individual case.

## **2 Ensure the person has been fully informed of all available options for treatment and care**

The Commission accepts the concern expressed frequently in the evidence they heard that a person might seek an assisted death without full understanding of the nature of his or her medical condition, how it would be likely to progress, or the alternative options for treatment or care that were available.

However, while we recognise the essential role that end of life care can play in relieving patients' suffering and supporting their families to care for them, we also do not think that a patient should feel compelled to accept treatment that he or she may find burdensome or unhelpful, in order to demonstrate that all options had been explored. For this reason, we recommend that people must be informed of all alternative options for treatment and care before they may proceed with assisted dying, but not that they should be required to experience this care.

If a person did go on to choose an assisted death, it would also be essential that they were fully informed about the assisted dying process, the medication and procedures that might be used, and any possible problems associated with the process (for example, if in exceptional circumstances the process might fail to end life).

Both doctors would be responsible for ensuring this safeguard had been met.

### **3 Ensure the first and second doctors have come to a decision independently about whether the legally required eligibility criteria are met**

Within the medical model of decision-making and support that we have proposed, the first and second doctor would be required to certify independently and document the fact that the safeguards underpinning these eligibility criteria had been met and that they had not identified any reason why the person should not be eligible to request an assisted death.

The first criterion requiring a diagnosis of terminal illness would need each doctor to certify that the person had an *advanced, progressive, incurable condition that is likely to lead to the patient's death within the next 12 months*.

The second criterion, requiring that the person requesting an assisted death made this request voluntarily and without coercion, would require both doctors to explore thoroughly the individual's motivation for requesting an assisted death and to provide evidence of this voluntariness.

The third criterion would require that the individual has the mental capacity to make an informed choice. We received evidence to the effect that capacity assessments are part of every doctor's usual responsibilities. If assisted dying were to be legally permitted in this country, it would be the role of the relevant professional bodies to develop a detailed code of practice for the assessment of mental capacity to safeguard decisions about assisted dying. Such a code of practice would need to include specific measures to identify people experiencing depression, or other psychological disorders that could potentially impair that person's judgement.

### **4 Ensure the person has a settled intention to die**

The Commission envisages that a person would only initiate the process of requesting an assisted death after considerable discussion with their doctor. We do not envisage that a formal process would be initiated until the person had made the decision that they would soon be in a position where they were ready to end their life. Given that the person concerned would need to have an advanced, progressive, incurable disease according to the proposed eligibility criteria, the Commission considers that it would be inappropriate to suggest safeguards that would require a very lengthy approval process at this point. However, it is also important that some time should be built into the process to ensure that the patient's decision cannot be made hastily, and that it is a settled decision to die, as opposed to a fluctuating wish.

The proposed safeguard is that a minimum time period of two weeks must elapse between the request being made by the subject, and the assisted death occurring. This is in addition to the requirement that the two doctors were satisfied that the subject had made the choice to have an assisted suicide, and that choice reflected a settled intention to die on the part of the subject. The Commission considers that where the patient's death was judged by the two doctors to be imminent (eg likely to occur within one month), they could in exceptional circumstances reduce the waiting period to six days, as long as they were satisfied the patient had the requisite settled intention.

Both doctors would be responsible for ensuring this safeguard was complied with.



## **5 Ensure the safe storage and transportation of lethal medication**

The Commission is concerned to avoid the potentially dangerous ramifications of allowing lethal medication to be kept in an unregulated manner in the community, in a private home, residential care home, hospice or hospital. The Commission has proposed a number of safeguards to ensure the lethal medication that would be required to bring about an assisted death would be stored and transported safely by suitably qualified professionals. If the medication was unused we recommend that the suitably qualified professional overseeing the person's death should be legally required to return the medication to the pharmacy.

This safeguard would need to be met by the treating doctor, and the pharmacy and suppliers involved in the provision of the lethal medication.

## **6 Ensure the person has a reliable and supported assisted death**

### **The type of assisted dying permitted**

The Commission recommends that if assisted dying were to be legally permitted, this could take the form of a terminally ill patient, who met the legal criteria, taking a dose of medication that would end their life. The lethal medication would be prescribed by the first doctor. The Commission is not recommending that any form of euthanasia should be permitted, therefore the patient him or herself would need to be able to take the action that will cause their death, as a clear expression of voluntariness. Appropriate practical support to take the medication should be provided if it is required by a terminally ill person with a physical impairment, but this could not take the form of another person administering the medication on their behalf. This is an important safeguard to ensure that the person who wishes to have an assisted death remains in control of the process throughout, and can change their mind at any point, and to make clear that the process being authorised is the patient ending their own life, not any form of euthanasia.

### **The prescribing doctor's responsibility**

The Commission considers that a doctor who prescribes lethal medication for the purpose of an assisted death should have ongoing responsibility for the care of that patient up to and including their death. Before the first doctor writes the prescription for the lethal medication, we recommend that this doctor and the patient should have agreed what support will be in place during the patient's death and how the patient will bring about their own death. The first doctor, or a substitute suitably qualified healthcare professional, would be responsible for ensuring that the medication was taken by the patient in a safe and suitable manner. The doctor must be satisfied of the arrangements made, and must be on hand (eg nearby although not necessarily in the same room) when the patient takes the medication.

### **Bereavement support for friends and relatives**

The Commissioners recognise that the quality of bereavement support available to friends and relatives can vary depending on the location of the death. Assisted deaths may be more likely to take place at home, which may make it more difficult for the friends and family members left behind to access the supportive infrastructure provided by hospices and hospitals. We therefore suggest that the first doctor with legal responsibility for assisting



the patient's death should have a continuing responsibility for supporting the patient's friends and relatives after his or her death. To facilitate this role, the doctor should ensure he or she has knowledge of the local bereavement support services that are available and where appropriate, should direct bereaved friends or relatives to these services.

## **7 Ensure the correct reporting procedures are followed after the death**

Following the patient's death, the doctor or other suitably qualified healthcare professional overseeing the death should be required to certify the person's death. This should be recorded on the death certificate in a way that would allow retrospective auditing to identify the cause of death. The doctor should also be required to report the death to a national monitoring commission responsible for regulating the practice of the law.

## **8 A national monitoring commission should provide monitoring and regulatory oversight to review whether individual cases complied with the law**

This national monitoring commission should be an independent statutory body that reports to the Department of Health. We envisage this as a post-hoc review body, as opposed to a court of appeal, which could have powers to investigate problematic cases where there are suspected compliance issues. We envisage that the monitoring commission would be national body with legal, medical and ethical input. It could have four main functions:

- to monitor and review every individual case for compliance with the law, taking further investigatory action in cases of potential non-compliance and referring instances of malpractice to the professional bodies or prosecutorial authorities where appropriate
- to encourage (and potentially fund) prospective independent academic research on the process and the consequences of the introduction of an assisted dying framework
- to publish anonymised information on 'difficult cases' to inform and develop doctors' professional practice in cases of assisted dying that might be regarded as particularly problematic
- to collect and publish national data on reported cases of assisted dying and publish an annual report to Parliament each year; findings from these reports could be used to inform ongoing policy development and at the end of the first five years, the monitoring commission could assist Parliament in conducting a full review of the law's implementation.

## **Additional policy changes to support the introduction of an assisted dying framework**

In addition to the conclusions set out above, the Commission considers that substantial improvements to health and social care services would be needed in parallel with changes to assisted suicide legislation if policy-makers were to ensure that all people approaching the end of life were to have access to high quality end of life care and — for those who wanted it — a robustly safeguarded process for requesting an assisted death. Both of the identified objectives of improving care and support for people at

the end of life and correcting the current unsatisfactory legal position on assisted dying should be pursued alongside each other but neither objective should be conditional on the other.

We also recognise that new legislation would be only one (albeit very important) piece of the picture. Professional training, guidance and support are essential features of all assisted dying regimes to promote responsible, exemplary practice and adherence to the spirit and letter of the law. Therefore our report also considers what policies and guidance would need to be in place to underpin effective assisted dying legislation.

Below are the key areas that would need consideration.

### **The need for continuing government investment in improving end of life care**

The Commission strongly supports the key aims of the End of Life Care Strategy for England and is convinced that sustained government investment will be required to improve access to high quality generalist and specialist end of life care, to be available to all who need it. These improvements should be made in parallel with new assisted dying legislation.

### **The need for continuing use of the DPP policy for prosecutors in non-terminal cases**

The powerful evidence the Commission has received from Tony Nicklinson and the police officers who were responsible for investigating the death of Daniel James has impressed on us the importance that people who agree to assist a non-terminally ill loved one, who has suffered a catastrophic life-changing event, to commit suicide for wholly compassionate reasons should continue to be treated by the law with compassion and understanding. Therefore, we suggest that the DPP's prosecution policy should continue to be applied to those cases that might fall outside the scope of the legislation that we are proposing for consideration (for example assisted suicides involving people with chronic illnesses or serious physical impairments who are not terminally ill).

### **Codes of practice specifying appropriate professional conduct for health and social care professionals involved in assisted dying**

The relevant professional bodies, including the General Medical Council and the Nursing and Midwifery Council, would need to develop codes of practice to guide appropriate professional conduct and specify appropriate training and levels of experience for professionals who take a role in assisted dying. We suggest that the 'second doctors' involved in safeguarding the assisted dying process should be required to have at least five years' experience after higher professional or specialist training and should be experienced in providing end of life care to ensure they have appropriate medical expertise for this role. The National Institute for Health and Clinical Excellence might provide guidance on the appropriate medication for the patient to use in ending his or her own life and the correct procedures to be followed, in consultation with pharmacologists and other practitioners.

## **Supervision and support for doctors who are involved in cases of assisted dying**

Doctors who are likely to be involved in the implementation of any future change in the law to allow physician-assisted dying should receive extra training, supervision and support. The areas in which doctors are most in need of these are:

- training in recognising 'terminal illness', not just in cancer patients but also in those with other chronic and life-limiting diseases
- training in recognising depression and in using suitable screening tools in the context of an interview to assess the person for depression and document the results
- training in being aware of the needs of bereaved friends and relatives and in accessing local resources and services to support these needs
- supervision in the implementation of any future medically assisted dying, especially in writing prescriptions, reporting procedures, record-keeping, and complying with annual reports and audits
- access to support with dealing with the considerable stress that may be associated with witnessing and participating as a medical practitioner in assisted dying, including peer support, regional groups and possibly a national helpline; the SCEN or LEIF networks in the Netherlands and Belgium, as discussed in chapter 8, might provide appropriate models for developing such support networks
- access to support for conscientious objectors, who may be under stress because of a request for assisted dying by a patient whom they might know very well but feel unable to comply with their wishes.





# Introduction

Assisted dying remains one of the most controversial and unresolved ethical issues of our time. It is rarely out of the news and campaigners call equally vociferously to maintain the legal prohibition on all forms of assisted dying, including assisted suicide and euthanasia, and to change the law to decriminalise one or both of these practices.

The Commission on Assisted Dying was set up in September 2010 to take a fresh look at how assisted dying is currently dealt with in English public policy and law, following the publication of the Director of Public Prosecutions' (DPP's) 'Policy for prosecutors in respect of cases of encouraging or assisting suicide' in February 2010.<sup>6</sup> This document has widely been recognised as constituting a significant change to public policy on assisted suicide, and while it may not have affected the fundamental legal status of assisting suicide, it has had a huge impact on public perceptions of the law in England and Wales, and public understanding of how the DPP makes decisions on whether it is in the public interest to prosecute individuals suspected of assisting a suicide.

Nearly two years since the DPP policy was published, this is an important moment to re-evaluate the approach to assisted dying that is currently taken in the UK.

## Definitions

The terminology surrounding assisted dying remains contested and different definitions tend to be used in different contexts. To ensure that the subjects under discussion remain clear, the Commission on Assisted Dying has used the following definitions throughout its enquiry and in this report:

- *assisted suicide*: 'providing someone with the means to end his or her own life'<sup>7</sup>
- *voluntary euthanasia*: 'ending another person's life at his or her own request'<sup>8</sup>
- *non-voluntary euthanasia*: ending another person's life 'when the individual is incompetent to consent to or refuse euthanasia and has made no prior decision'<sup>9</sup>
- *assisted dying*: a compendium that can refer to voluntary euthanasia and/or assisted suicide.<sup>10</sup>

## Terms of reference for the Commission on Assisted Dying

The Commission on Assisted Dying was set up to consider whether the current legal and policy approach to assisted dying in England and Wales is fit for purpose. In addition to evaluating the strengths and weaknesses of the legal status quo, the Commission also set out to explore the question of what a framework for assisted dying might look like, if such a system were to be implemented in the UK, and what approach might be most acceptable to health and social care professionals and to the general public.

However, the purpose of the Commission was not to recommend whether such a system should pass into law in the UK, or within which timeframe. The ethical perspectives on assisted dying at both ends of the spectrum remain polarised, and indeed they may be fundamentally irreconcilable. The Commission has not sought to resolve this ongoing ethical debate, which is a matter for Parliament to decide on behalf of the British public. Instead, the Commissioners have set out to understand the perspectives of all of those with a firm ethical position on assisted dying, across the spectrum of opinion, while focusing on collecting evidence that can provide insights into the practical issues that are at the heart of the debate.

For many people, the central issue is not whether assisted dying is fundamentally right or wrong, but whether it might be permitted or excusable in particular circumstances. This is the stance that the Director of Public Prosecutions seems to have taken in his prosecution policy, which weighs up public interest factors in favour and against the prosecution of those who assist a suicide.

In addition to exploring professional and public attitudes to assisted dying, the Commission has sought to focus its inquiry on the following practical issues:

- 1 How are the laws that prohibit assisted suicide and euthanasia currently working in practice? What are the advantages and disadvantages of the current approach to assisted dying in policy and law?
- 2 How are assisted suicide and/or euthanasia practiced and regulated in jurisdictions that currently permit some form of assisted dying?
- 3 If some form of assisted dying were to be permitted in the UK:
  - What system might exist to allow people to be assisted to die?
  - Who might be entitled to be assisted to die?
  - What safeguards might be put in place to ensure that vulnerable people are neither abused, nor pressured, to choose an assisted death?
  - What changes in policy or law might need to be introduced?

## **Setting up the Commission**

Demos responded to a tender from two private individuals, Terry Pratchett and Bernard Lewis, who are funding the Commission. The campaigning organisation Dignity in Dying brokered the relationship between Demos and those funding the Commission. Demos accepted the invitation to host the Commission with the firm understanding that neither the funders nor Dignity in Dying would have any further involvement in the running or outcomes of the Commission.

Demos invited Lord Charles Falconer to chair the Commission and Lord Falconer subsequently invited the other Commission members to join. The membership of the Commission, including the individual Commissioners' biographies, is presented in the opening pages of this report. With the aim of allowing a more nuanced approach to the issues, the Commissioners were not chosen on the basis of their pre-existing views, but according to the professional expertise they could bring to the task, such as knowledge of social care, end of life care, psychiatry, policing or law. In accepting their brief, each Commissioner agreed they would approach their task with an open mind, would base their conclusions on

the evidence they had heard, and were willing to consider these practical issues, as well as the broader ethical and social issues involved.

Unfortunately, some prominent individuals and organisations that are fundamentally opposed to any form of assisted dying being legally permitted in the UK have felt that the terms of reference of the Commission on Assisted Dying— which require open-minded consideration of these practical issues concerning the practice of assisted dying in the UK— have precluded them from participating in giving evidence. The Commissioners regret that these organisations have chosen not to take part, but are confident that the evidence they have received is of a high quality and sufficiently varied and detailed to enable the Commissioners to tackle the issues under consideration. Where possible the Commission has also considered evidence and commentary that is available in the public domain from expert individuals and organisations that did not take part. A full list of the individuals and organisations who gave oral evidence and also those who were invited to give evidence but declined or were unable to do so can be found in Appendix 1.

### **The call for evidence and other research activities**

The independent think tank Demos has performed the role of research secretariat for the Commission, coordinating activities to collect evidence from experts, professional bodies and other members of the public and conducting independent research to provide new evidence for the Commission. The main research activities that Demos undertook to collect evidence for the Commission on Assisted Dying are described below.

#### **A call for written evidence**

The Commission launched its public call for evidence on 30 November 2010. Over 1,200 pieces of evidence were submitted by practitioners, professional bodies and members of the public before the consultation deadline closed on 27 June 2011. Demos set up a website at [www.commissiononassisteddying.co.uk](http://www.commissiononassisteddying.co.uk) to host publicly all the evidence that was submitted and facilitate informed public debate.

#### **Oral evidence hearings**

Demos hosted six public evidence meetings at monthly intervals, at which 46 experts and individuals with relevant personal experience including academics, health and social care professionals, lawyers, police, professional bodies, regulatory bodies and advocacy groups gave oral evidence to the Commissioners. Each of these evidence sessions was filmed and made available on the Commission on Assisted Dying website. A full list of those who gave oral evidence along with those who were invited but declined or were otherwise unable to do so is included in Appendix 1.

#### **International research visits**

Demos organised international research visits to four of the jurisdictions in which some form of assisted dying is legally permitted. These trips were used to collect evidence on how well the specific approaches adopted in each jurisdiction were working. The four jurisdictions visited were:



- the Netherlands
- Belgium
- Oregon
- Switzerland.

Two of the Commissioners took part in each visit and they interviewed people with a range of expertise including practitioners, policy-makers and regulators to gather insights into public opinion on assisted dying in that country, professional attitudes to assisted suicide and voluntary euthanasia, perspectives on how well the legal and procedural framework for assisted dying was working in that country, which individuals were making use of it and any problems that had been identified. The interviews that took place were recorded and transcribed by Demos researchers to form the basis of a short report on each country. A list of those who took part in these interviews is included in Appendix 1.

### **Research on suicide and serious physical illness in the UK**

Researchers at Demos conducted a piece of investigative research into the role of physical illness as a risk factor in suicide in order to determine the number of people who die through suicide who also have a physical illness. This research included desk-based scoping research, freedom of information requests to all 147 primary care trusts in England, semi-structured interviews with 15 serving or recently retired coroners, a detailed case study of suicide inquest records in Norwich coroner's district, and interviews with expert organisations that could provide additional insights on the relationship between suicide and physical illness. The report, *The Truth About Suicide*,<sup>11</sup> was published by Demos in August 2011 and submitted to the Commission as evidence.

### **Research on attitudes to assisted dying among 'vulnerable' groups**

Demos undertook a programme of primary research to consult members of groups who are frequently considered as being put 'at risk' by a change in the law on assisted dying. Researchers conducted six focus groups and a number of additional interviews to explore attitudes to assisted dying among these groups: two with adults with terminal illnesses at a hospice in South London, two focus groups with disabled people in Preston and Solihull, one focus group with older people living in sheltered accommodation and one focus group with adults with learning disabilities. Demos also conducted additional interviews with the hospice service users to expand on comments made during the focus groups and conducted interviews with young people (aged 16–18) who took part in creative workshops at the hospice.

In addition to the focus groups, Demos publicised the consultation exercise via internet forums for people with terminal or critical illnesses and received 12 responses from individuals who wished to take part. Nine submissions were made by email from this group, and researchers conducted two phone interviews and one face-to-face interview. Most people who made contact through the forums had motor neurone disease. The findings from this research were submitted as evidence to the Commission.

### **Research on nurses' attitudes to assisted dying**

In addition to the research with 'vulnerable' groups, Demos also conducted research into the attitudes towards assisted dying among nurses.

Researchers conducted one focus group with specialist palliative care nurses and three additional one-on-one telephone interviews with nurses who worked in end of life care.

### **Commissioned briefing papers**

The Commission on Assisted Dying commissioned two expert briefing papers to inform its inquiry and provoke informed public debate. The first paper, ‘The effectiveness of legal safeguards in jurisdictions that allow assisted dying’, by Professor Penney Lewis and Isra Black from the Centre of Medical Law and Ethics, King’s College London, is divided into three parts:

- an explanation of the features of the legal regimes that regulate assisted dying in the Netherlands, Belgium, Switzerland and Oregon
- an exploration of the evidence for the effectiveness of individual safeguards in each of these regimes
- an evaluation of the evidence for the effectiveness of each safeguard, drawing on a detailed examination of the evidence in the second part.<sup>12</sup>

The second briefing paper, ‘Palliative care development in countries with a euthanasia law’, was provided by researchers at the European Association of Palliative Care.<sup>13</sup> Its purpose was:

- to investigate the standard of palliative care in jurisdictions where euthanasia and/or assisted suicide has been legalised
- to assess whether the standard has changed for better or worse since legalisation
- to assess how the legalisation of euthanasia and/or assisted suicide may have affected how palliative care has developed in that country.

Both papers can be found on the publications page of the Commission’s website at [www.commissiononassisteddying.co.uk/publications](http://www.commissiononassisteddying.co.uk/publications).

### **Seminar convened by the Arts and Humanities Research Council**

The Arts and Humanities Research Council and the Society for Applied Philosophy hosted a policy seminar on 7 September 2011, bringing together leading academics, humanities researchers, legal experts, medical experts, policy-makers and parliamentarians to discuss the ethical, religious, legal and practical implications of the DPP’s prosecuting policy for cases of assisted suicide. Speakers addressed the following two questions:

- What are the ethical, religious, legal and practical implications of the 2010 DPP policy on assisting suicide?
- What legal safeguards and procedures might need to be put in place if the UK were to implement a prospective system of regulation for assisted dying?

A summary of the seminar was written up and submitted as evidence to the Commission.<sup>14</sup> The full list of speakers and attendees can be found in Appendix 1.

## **The structure of this report**

This report draws on the evidence that the Commission on Assisted Dying has received between November 2010 and September 2011 to make recommendations to UK policy-makers about the approach to assisted dying that might be taken in the UK.

Section 1 draws on the body of evidence received by the Commission to explore the nature of the assisted dying debate as it currently exists in the UK, following the publication of the DPP's 'Policy for prosecutors in respect of cases of encouraging or assisting suicide' in February 2010. This includes academic evidence and professional perspectives on the current legal status of assisted dying, on the successes and failures that shape how people currently die in the UK, and the views of experts, advocates and members of the public on how assisted dying might affect groups which are frequently considered more vulnerable to a change in the law, such as older people, terminally ill people, physically disabled people and people with learning disabilities.

Section 2 draws on the body of evidence the Commission has received to look in depth at the practical issues that might be posed by permitting assisted dying in the UK. These include the issue of unequal access to health and social care and questions of how eligibility for assisted dying might be decided, what safeguards might be needed to protect the vulnerable, and how people might actually be assisted to die.

Section 3 presents the Commission's reflections on the evidence presented in sections 1 and 2 and the core principles that the Commission has developed on the basis of this evidence. It also recommends principles to underpin a legal framework for assisted dying, if such a framework should be adopted by policy-makers in the future, and the changes to law and policy that might be required to implement an effective system.





# THE ASSISTED DYING DEBATE IN THE UK



# 1 The current legal position on assisted dying

The legal and medical landscape surrounding ‘assisted dying’ — a term that refers to both assisted suicide and voluntary euthanasia — is complex and requires some explanation. Therefore, this first chapter sets the scene by mapping out the status quo in a number of areas including:

- the current legal status of assisted suicide in English law
- the legal framework surrounding medical end of life decision-making (including the doctrine of ‘double effect’, palliative sedation, withdrawing and withholding treatment, advance decisions to refuse treatment and voluntary euthanasia, ‘mercy killing’ and assisted suicide) and evidence of the rates of these practices
- numbers of ‘unassisted’ suicides among people with incurable illnesses in England
- UK public attitudes towards assisted suicide and voluntary euthanasia.

The chapter concludes by situating the UK’s approach to assisted dying in an international context, first sketching out how assisted suicide and voluntary euthanasia are approached in European case law and then providing an overview of jurisdictions internationally that legally permit some form of assisted dying.

## The legal status of assisted suicide in the UK

Under section 2 of the 1961 Suicide Act, encouraging or assisting another person’s suicide remains illegal and is punishable by up to 14 years’ imprisonment. However, in each case once the suspect’s actions have been investigated and the evidential stage has been passed (to demonstrate that the suspect had intentionally performed an act capable of assisting a suicide), the Director of Public Prosecutions (DPP) must then give consent before the individual may be prosecuted. This consent is given or declined following the prosecutor’s consideration of whether or not it is in the ‘public interest’ to prosecute.

In 2009, the House of Lords’ judgment in the legal challenge *R (on the application of Purdy) v Director of Public Prosecutions* obliged the DPP ‘to clarify what his position is as to the factors that he regards as relevant for and against prosecution’ in cases of assisted suicide.<sup>15</sup> In his oral evidence to the Commission, the current DPP, Keir Starmer QC, explained the process by which he developed the policy for prosecutors that was subsequently published in February 2010. This involved publishing an interim policy based on ‘the cases that were decided recently to see the sort of factors that were relevant in those decisions’,<sup>16</sup> and running a consultation exercise through which nearly 5,000 responses were received. In his evidence to the Commission in December 2010, Keir Starmer said that his consultation found:



*There was very strong support for nearly all of the factors in favour of prosecution, strong support for most of the factors against prosecution. The issue that was most significant in the responses was whether or not the status of the victim ought to be a relevant factor or whether we ought to concentrate on, as it were, the actions and the motives of the suspect alone. If there was a big change between the interim policy to the final policy it was really that.*<sup>17</sup>

Mr Starmer said that many organisations representing disabled people or individuals with disabilities had responded to the consultation on the interim policy with concern about the public interest factor against prosecution that the victim had ‘a terminal illness; or a severe and incurable physical disability; or a severe degenerative physical condition; from which there was no possibility of recovery’.<sup>18</sup> This was their concern:

*If you have that factor in as a factor suggesting you won’t prosecute, what that means is in Case A where all the facts are the same as Case B and the only difference is that the person who committed suicide had some terminal illness, severe or incurable disease, that will be the factor that tilts it. From our perspective, that suggests to us that we are less well protected because you wouldn’t prosecute if I fell within category A but you would prosecute somebody else.*<sup>19</sup>

Other respondents to the consultation commented that from a legal perspective ‘when you’re considering the criminal law it should be the conduct and the motives of the suspect that are paramount, not the status of the victim’.<sup>20</sup> These two arguments persuaded Mr Starmer that the factor relating to the physical condition of the victim should be removed from the policy.

The public interest factors in favour of and against prosecuting suspected cases of assisted suicide set out in the final policy of the Crown Prosecution Service (CPS) are presented in table 1.

Table 1 **Public interest factors tending in favour of and against prosecution in suspected cases of assisted suicide**<sup>21</sup>

	<b>Public interest factors tending in favour of prosecution</b>	<b>Public interest factors tending against prosecution</b>
1	The victim was under 18 years of age.	The victim had reached a voluntary, clear, settled and informed decision to commit suicide.
2	The victim did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision to commit suicide.	The suspect was wholly motivated by compassion.
3	The victim had not reached a voluntary, clear, settled and informed decision to commit suicide.	The actions of the suspect, although sufficient to come within the definition of the offence, were of only minor encouragement or assistance.
4	The victim had not clearly and unequivocally communicated his or her decision to commit suicide to the suspect.	The suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide.
5	The victim did not seek the encouragement or assistance of the suspect personally or on his or her own initiative.	The actions of the suspect may be characterised as reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide.
6	The suspect was not wholly motivated by compassion; for example, the suspect was motivated by the prospect that he or she or a person closely connected to him or her stood to gain in some way from the death of the victim.	The suspect reported the victim's suicide to the police and fully assisted them in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing encouragement or assistance.
7	The suspect pressured the victim to commit suicide.	
8	The suspect did not take reasonable steps to ensure that any other person had not pressured the victim to commit suicide.	
9	The suspect had a history of violence or abuse against the victim.	
10	The victim was physically able to undertake the act that constituted the assistance himself or herself.	
11	The suspect was unknown to the victim and encouraged or assisted the victim to commit or attempt to commit suicide by providing specific information via, for example, a website or publication.	
12	The suspect gave encouragement or assistance to more than one victim who were not known to each other.	
13	The suspect was paid by the victim or those close to the victim for his or her encouragement or assistance.	
14	The suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, a professional carer [whether for payment or not], or as a person in authority, such as a prison officer, and the victim was in his or her care.	
15	The suspect was aware that the victim intended to commit suicide in a public place where it was reasonable to think that members of the public may be present.	
16	The suspect was acting in his or her capacity as a person involved in the management or as an employee (whether for payment or not) of an organisation or group, a purpose of which is to provide a physical environment (whether for payment or not) in which to allow another to commit suicide.	

Reflecting on the nature of assisting suicide as an offence, Mr Starmer acknowledged its rather unusual status in law: ‘Under the 1961 Act there is obviously a broad offence of assisted suicide, it’s obviously peculiar because you’ve got aiding and abetting — using the old language — conduct which is not itself unlawful so you’re in very odd territory.’<sup>22</sup> However, he also pointed out that it is not unusual for the prosecution to have discretion over which cases are to be prosecuted: ‘There is a residual discretion for all offences whether to prosecute or not. This is a particular version of it. But it’s not unique by any stretch of the imagination; it’s the way our law operates.’<sup>23</sup>

Mr Starmer told the Commission that since the policy has been in place (February 2010, the final policy), there have been no prosecutions for assisted suicide.<sup>24</sup> He further expanded on this to explain that in the financial year 2009/10, the CPS received files on 19 cases and in 17 cases they decided not to bring a prosecution (one case was ongoing and one had been withdrawn by the police). In the financial year 2010/11, as of 14 December 2010 there had been 14 cases brought to the CPS, of which 11 cases were ongoing and in three cases a decision to take no further action had been made. Therefore, between April 2009 and December 2010 20 decisions had been made by the DPP not to prosecute suspected cases of assisted suicide, and a further 12 cases were still under consideration.<sup>25</sup> As of September 2011, more than 40 cases of assisted suicide had been reported to the CPS since 2009 but no prosecutions had been brought since the policy was published.<sup>26</sup>

When questioned about the 20 cases that had not been prosecuted between April 2009 and December 2010, Mr Starmer said that it would be ‘dangerous’ to try to describe a pattern, but:

*Broadly speaking they are acts within a family or broad family situation: compassionate acts by individuals who very often lived with the deceased for a good period of time. Very often in a relationship; often in a strong, loving relationship. Predominantly, that’s the category we’re dealing with here. Nearly all of them in that situation.*<sup>27</sup>

Mr Starmer followed this by emphasising to the Commissioners that it was the CPS’s role to apply the law, rather than to change it:

*We want to be transparent about the factors hence the policy, and apply it on a case-by-case basis. We want to avoid being too schematic because it’s not for me or the CPS to determine what the law should be. The law is clear and we’re simply being given discretion in individual cases.*<sup>28</sup>

The Commission on Assisted Dying held six meetings to explore various expert perspectives on the current legal status of assisted dying in the UK, posed questions about the DPP policy in its public call for evidence and also tasked Demos with undertaking research with social groups that are often identified as being particularly vulnerable to a change in the law on assisted dying, to explore their attitudes to the legal status quo. Insights gathered from these research activities are presented in chapter 3.

## The legal framework surrounding end of life decisions in the UK

### The doctrine of ‘double effect’

The General Medical Council’s (GMC’s) guidance for doctors *Treatment and Care Towards the End of Life* provides a summary of the key points of English case law that should guide doctors’ practice in end of life care. The first of these points is the principle that ‘an act by which the doctor’s primary intention is to bring about a patient’s death would be unlawful’.<sup>29</sup> The GMC guidance does not explicitly refer to the doctrine of double effect, but it is implied by this reference to the doctor’s ‘primary intention’. The doctrine of double effect ‘draws a distinction between impermissible intended consequences and permissible (merely foreseen consequences)’.<sup>30</sup> English case law and established medical ethics permit a doctor to administer medication or other treatment with the intention to relieve suffering even if it is ‘foreseen’ that the patient’s life may be shortened as a side-effect of the treatment. However, he or she may not provide treatment with the primary ‘intended consequence’ of causing death.<sup>31</sup> This legal position is summarised by the attorney general’s evidence to the Select Committee on the 2004 Assisted Dying for the Terminally Ill Bill: ‘[it is not murder] where a doctor acts to do all that is proper and necessary to relieve pain with the incidental effect that this will shorten a patient’s life’.<sup>32</sup>

Professor Clive Seale’s influential research on UK doctors’ end of life decision-making, which was published in 2009, included a survey question to identify deaths that had involved a ‘double effect’ decision by the doctor. Professor Seale’s survey defined a ‘double effect’ decision as one in which the doctor gave a patient drugs or other treatment with the ‘probable or certain knowledge that this would hasten the end of life or where the respondent reports partly intending to end life by these means’.<sup>33</sup> According to this definition, and based on the survey responses of 2,869 doctors who had presided over a patient’s death during the previous year, 17.1 per cent of deaths had involved a ‘double effect’ decision. In 15.1 per cent of these deaths the doctor reported ‘knowledge of probable or certain hastening of end of life’ and in 2 per cent of deaths the doctor reported ‘partly intending to end life’.<sup>34</sup>

### Palliative sedation

Palliative sedation, which is also referred to as ‘terminal sedation’ is recognised as a legitimate treatment option in end of life care.<sup>35</sup> It can be defined as:

*the monitored use of medications to relieve refractory and unendurable symptoms by inducing varying degrees of unconsciousness — but not death — in patients who, given their disease state, progression, and symptom constellation, are expected to die within hours or days.*<sup>36</sup>

Professor Clive Seale’s research has found that the use of the ‘continuous deep sedation’ form of palliative sedation is relatively common in the UK; the survey he conducted in 2007 and 2008 found that 16.5 per cent of deaths involved the patient being ‘continuously and deeply sedated or kept in a coma before death, using a drug such as midazolam’.<sup>37</sup> However, while palliative sedation may be relatively common in end of life care, it remains controversial. Professor Seale in his oral evidence to the Commission said, ‘It is very puzzling and has been disturbing to many people to hear that 16.5 per cent of deaths in the UK are accompanied by

continuous deep sedation until death.’ Professor Seale also observed that palliative sedation ‘is a recent practice in terms of medical history, in the palliative care setting’ and suggested that ‘it is a practice which requires much more investigation’.<sup>38</sup>

A further study that Professor Seale conducted using the same survey data to look in more depth at the characteristics of doctors who used continuous deep sedation found that it was more likely to be used when:

- the patient was younger (0–59 years old)
- the patient was in hospital (followed by private home or hospice)
- the patient was dying from cancer
- the doctor was non-religious
- the doctor supported the legalisation of assisted dying
- the patient had requested a hastened death
- another person requested the death be hastened (including relative or nurse).<sup>39</sup>

The research also found that in 17.6 per cent of the continuous deep sedation cases, the treatment was combined with another end of life decision that had demonstrated intention to end life ‘withholding or withdrawing treatment or providing a drug with the partial or explicit intention of ending life’.<sup>40</sup> However, continuous deep sedation combined with some intention to cause death was less likely to occur if a specialist palliative care team was involved in the patient’s care.<sup>41</sup>

Professor Seale’s analysis of the reasons why continuous deep sedation was started were mainly related to the patient’s symptoms (39.1 per cent had intractable pain, 24.6 per cent had intractable psychological distress and 42.2 per cent had another intractable symptom). However, in 5.4 per cent of cases a request by the patient for sedation was mentioned and in 10.4 per cent of cases the relative’s request for sedation was mentioned. Overall the study found that in just under a third of cases, continuous deep sedation began less than 24 hours before the patient died, in just under two-thirds of cases continuous deep sedation began between one and seven days before the patient died and in only 8.3 per cent of cases was the patient continuously deeply sedated for more than one week.<sup>42</sup>

Professor Seale commented in his oral evidence to the Commission, ‘In the Netherlands and Belgium for example this type of [continuous deep] sedation is often felt to be carried out as an alternative to euthanasia.’ He observed that rates of continuous deep sedation were particularly high in the UK, ‘considerably higher than in the Netherlands and Belgium, for example’.<sup>43</sup> However, he suggested that rates of continuous deep sedation are increasing in the Netherlands and Belgium, as euthanasia is ‘a very, very emotionally stressful thing to do’, therefore continuous deep sedation ‘is becoming a preferred alternative in those countries, because that does not involve killing the patient’.<sup>44</sup>

### **Withdrawing or withholding treatment**

The GMC’s guidance for doctors on decision-making in end of life care observes, ‘The most challenging decisions in this area are generally about withdrawing or not starting a treatment when it has the potential to prolong the patient’s life’.<sup>45</sup> Relevant treatments that the guidance identifies in this context include:

- antibiotics for life-threatening infection
- cardiopulmonary resuscitation
- renal dialysis
- ‘artificial’ nutrition and hydration
- mechanical ventilation.<sup>46</sup>

The guidance recognises that although doctors have a duty to preserve their patients’ lives, ‘In some circumstances these treatments may only prolong the dying process or cause the patient unnecessary distress.’<sup>47</sup> With reference to a number of legal precedents, the guidance observes that ‘the courts do not consider that protecting life always takes precedence over other considerations’ and sets out a number of principles to guide doctors’ practice. Some of the key principles identified by the guidance are set out in Box 1.

**Box 1 Key legal principles on withholding and withdrawing treatment<sup>48</sup>**

- *An adult patient who has capacity may decide to refuse treatment even if refusal may result in harm to themselves or in their own death.*
- *Life prolonging treatment can lawfully be withheld or withdrawn from a patient who lacks capacity when starting or continuing treatment is not in their best interests.*
- *There is no obligation to give treatment that is futile or burdensome.*
- *If an adult patient has lost capacity, a refusal of treatment they made when they had capacity must be respected, provided it is clearly applicable to the present circumstances and there is no reason to believe that the patient had had a change of mind.*
- *In the case of children or adults who lack capacity to decide, when reaching a view on whether a particular treatment would be more burdensome than beneficial, assessments of the likely quality of life for the patient with or without that treatment may be one of the appropriate considerations.*
- *A patient’s best interests may be interpreted as meaning that a patient should not be subjected to more treatment than is necessary to allow them to die peacefully and with dignity.*
- *All reasonable steps should be taken to overcome challenges when communicating with, or managing the care of patients with disabilities, to ensure they are provided with the treatment they need and that would be in the best interests of the patient.*
- *Clinically assisted nutrition or hydration may be withheld or withdrawn if the patient does not wish to receive it; or if the patient is dying and the care goals change to palliative care and relief of suffering; or if the patient lacks capacity to decide and it is considered that providing clinically assisted nutrition or hydration would not be in their best interests.*
- *In the case of patients in a permanent vegetative state, clinically assisted nutrition or hydration constitutes medical treatment and may be lawfully withdrawn in certain circumstances. However, in practice, a court declaration should be obtained.*

Professor Seale’s research on end of life decisions in the UK between 2007 and 2008 found that just over a fifth (21.8 per cent) of deaths involved withdrawing or withholding treatment (or ‘a non-treatment decision’). In

16.8 per cent of the deaths the doctor had made the non-treatment decision with 'knowledge of probable or certain hastening of end of life', and in 4.9 per cent of deaths the decision was made 'with explicit intention of hastening end of life'.<sup>49</sup>

### Advance decisions to refuse treatment

The British Medical Association describes the purpose of advance decisions as to 'allow competent adults to say what they would like to happen later if their mental capacity becomes impaired. These decisions become important once patients lose their mental capacity, are unconscious, or unable to communicate.'<sup>50</sup> The legislation surrounding advance decisions (also referred to as 'advance directives' or 'living wills') can be found in the Mental Capacity Act 2005. This statute defines an 'advance decision' as a decision that is made by a person aged 18 or over, when he or she has capacity to do so, that a specific treatment must not be carried out if:

- at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
- at that time he lacks capacity to consent to the carrying out or continuation of the treatment.<sup>51</sup>

Therefore, the advance decision is only legally binding if the person does not have capacity to give consent to a treatment at that time, and if it refers to the specific treatment and circumstances that have arisen. An advance decision to refuse life-sustaining treatment must meet additional criteria and is only considered legally binding if 'the decision is verified by a statement by [the person] to the effect that it is to apply to that treatment even if life is at risk', and if the statement is signed.<sup>52</sup> Results from a recent survey suggest that the use of advance decisions is still relatively low. A YouGov poll of over 2,000 adults in April 2011 found that only 3 per cent of respondents currently had an advance decision to record their wishes, although 60 per cent of the adults polled said that if they were dying with no prospect of recovery, they would only want to receive comfort care and would not wish to be kept alive through resuscitation or ventilation.<sup>53</sup>

The British Medical Association's policy document on end of life decisions explains that patients cannot demand or refuse treatments in an advance decision they could not demand or refuse in normal circumstances, for example, euthanasia or assisted suicide. It also highlights the fact that only advance decisions *refusing* treatment are legally binding, 'although advance requests or authorisation of specific treatment can be helpful, they lack legal weight if clinicians assess that treatment to be inappropriate'.<sup>54</sup> However, evidence from the Medical Protection Society (MPS) highlighted the issue that the use of advance decisions can in some circumstances blur the moral line between suicide and assisted suicide, presenting legal challenges for doctors. Dr Field of the MPS observed:

*If a patient has produced a valid advanced directive, if they were competent at the time, if they then attempted suicide, not assisted suicide... and somebody were to try to resuscitate them, that would effectively be an assault.*<sup>55</sup>

Therefore, a doctor might unintentionally become involved in a person's care during his or her suicide attempt while being legally barred



from providing life-sustaining treatment. Dr Field further commented on the legalities of such a situation:

*If they [the patient] make an advanced directive, it has to be abided by. And I think a doctor respecting that advanced directive, however the patient came by their death, or is coming by their death, whether it was legal or illegal, would have to respect that.*<sup>56</sup>

### **Voluntary euthanasia, ‘mercy killing’ and assisted suicide**

As observed above, assisted suicide is identified as a crime by the Suicide Act 1961 and is punishable by up to 14 years imprisonment. However, voluntary euthanasia or ‘mercy killing’ has no specific status under English law, which regards such action as murder regardless of whether the ‘victim’ had requested his or her life to be ended. As a Law Commission report observed:

*The law of England and Wales does not recognise either a tailor-made offence of ‘mercy’ killing or a tailor-made defence, full or partial, of ‘mercy’ killing. Unless able to avail him or herself of either the partial defence of diminished responsibility or the partial defence of killing pursuant to a suicide pact, if the defendant (‘D’) intentionally kills the victim (‘V’) in the genuine belief that it is in V’s best interests to die, D is guilty of murder. This is so even if V wished to die and consented to being killed.*<sup>57</sup>

As with any person, under English law a doctor who is involved in euthanasia or ‘mercy killing’ could be charged with manslaughter or murder if there was sufficient evidence.<sup>58</sup> If found guilty of murder, he or she could receive up to a life sentence.<sup>59</sup>

Deputy Chief Executive of the GMC Paul Philip explained that the GMC’s policy position on assisted dying is determined by the law: ‘Our position is that under good medical practice, our flagship guidance, doctors must follow the law. Assisted dying is unlawful and therefore we have hitherto not considered or opined in relation to the matter of assisted dying.’ He further commented:

*There is a fine balance between treating someone with the intention of prolonging their life and making a decision that actually, death is inevitable and therefore actually it’s the quality of life that is actually paramount at that point in time. But clearly it’s unlawful for a doctor to intend to kill a patient and therefore giving of medication etc with the intention of killing would be something which, de facto, would be actionable under our fitness to practice arrangements.*<sup>60</sup>

However, while it is illegal for doctors to practice voluntary euthanasia, Professor Clive Seale’s research with doctors in 2007 and 2008 indicated that relatively small numbers of patients die as a result of voluntary (requested) and non-voluntary (unrequested) euthanasia in the UK. He found that 0.21 per cent of deaths constituted voluntary euthanasia, where ‘following a request from a patient, a drug is administered with the explicit intention of ending life’. A further 0.3 per cent of deaths were identified as ‘ending life without an explicit request from patient’ (or ‘non-voluntary euthanasia’).<sup>61</sup> Added together, these rates of euthanasia make up approximately 0.5 per cent of all deaths. In his oral evidence Professor Seale observed that this rate



is 'actually lower than in other countries where the same survey has been done'.<sup>62</sup> He told the Commission:

*Although 3,000 [estimated cases of euthanasia in the UK each year] sounds like a lot, in terms of the number of doctors who ticked yes, it is a very small group, so it doesn't really justify any particular statistical profiling of that small group of survey respondents. It is a sample survey and so it is not a complete census of the whole population of deaths or of doctors. So there is a confidence interval around that estimate which suggests it could be a bit lower, it could be a bit higher. I think what one could reasonably conclude from this survey is that it does sometimes happen in UK medical practice but pretty rarely.*<sup>63</sup>

For Professor Seale, the more striking finding was that medically assisted suicide was not reported by any of the doctors in the survey, 'which suggests that if it does happen, it is extremely rare. It is much more likely to be euthanasia.'<sup>64</sup>

### Regulation of end of life decision-making

In response to Professor Seale's research data on the end of life decisions that are made by doctors, Professor Penney Lewis argued in her oral evidence to the Commission, and at the seminar at the Arts and Humanities Research Council, that rather than focusing solely on the ethical issues surrounding assisted dying in isolation, there is a need to scrutinise all end of life decision-making:

*One of my colleagues in the Netherlands, John Griffiths, has argued that what we really should be doing is regulating all medical behaviour that potentially shortens life, not just assisted dying; that the vast majority of medical decisions that result in someone's death are not regulated. And if you look at the data, we know that in approximately 40 per cent of all cases in the Netherlands and the UK, there is a medical end of life decision; the vast majority of those in both jurisdictions are either decisions to withdraw or withhold treatment or they are symptom alleviation, which the doctor believes potentially or probably hastens death (whether or not it does we will leave to one side.)<sup>65</sup>*

Professor Lewis conceded that 'politically' it would be difficult to impose a high degree of regulation over doctors' end of life decision-making, but the aim across all types of end of life decisions should be to ensure that individual patients 'make the decisions that are right for them rather than what is right for other people in their milieu or social expectations'.<sup>66</sup>

Bridget Robb of the British Association of Social Workers told the Commission:

*We don't want to see assisted dying in a vacuum, because actually there are a whole raft of decisions about how we support people through to death, which are too often put into boxes... One of the things that we would like to see out of this debate, whatever the eventual decision about the legality of assisted dying, is that there is a more holistic understanding of the different ways that people approach death. And that... in an increasing climate where people are encouraged to make their own decisions and take more control over their circumstances, that actually leads into people being encouraged, probably much earlier on, in the process to make decisions about what sorts of things they want to see in place by the time they die. And that should be seen as a part of the decisions about life, not just decisions about death.*<sup>67</sup>

### **The relationship between suicide and incurable illness**

Some of the evidence submitted to the Commission highlighted the comparatively overlooked issue of suicide among people who have a terminal or long-term health condition. As these suicides are not assisted by doctors or relatives and are therefore legal, they receive relatively little public attention. Debbie Purdy's evidence to the Commission expressed concern that the higher rate of suicide among people who have multiple sclerosis (MS) is neglected in the UK:

*MS is not terminal, but in Denmark where they have done research on suicide, it's at least 2.5 times the national average, and in Canada where they have done research on people who are specifically under the care of a neurologist, which suggests they have got a more active form of MS, 7.5 times the national average... And that just happens to be information I know of because I have MS. But we haven't done the research in this country to really seriously look at what concerns we should have and who should be protected, because at the moment nobody is protected. People are ending their lives early because they are frightened by what may happen.<sup>68</sup>*

Debbie Purdy suggested that a clearer legal framework surrounding assisted suicide and a greater openness to discussing suicidal feelings in the context of progressive incurable illness could play an important role in postponing or preventing suicides:

*I think it's important that we provide guidelines so that we can give people the care and support that they need not just to make the decision but also to not make the decision, and to make the decision to not to end their lives early. And unless we have clear laws I don't think we can offer that support. And I think that's a mistake we make.<sup>69</sup>*

A hospice medical director who agreed to give evidence to the Commission anonymously also drew attention to this issue of suicide in the context of incurable illness. He described his experience of having a patient with terminal cancer who did not want to experience her own physical decline, who chose to end her life prematurely:

*A patient I looked after many years ago... had breast cancer... Her loss of quality of life was, 'I take my dogs for a two hour walk every day, but I can only now manage an hour, that's unacceptable.' To the vast majority of my patients, that would be fantastic. She took an overdose, was found, came into hospital and was resuscitated. She was seen by the psychiatrists, she was of sound mind. She said 'Ok, that didn't work. I'm not going to do that again, I realise I can't have it.' Then she went home and, obviously planned it because she'd arranged not to have any visitors. She took tablets and did die. But when she was found, there was blood and vomit all over the house, so she probably took hours, if not a day or two to die. It must have been very unpleasant.<sup>70</sup>*

He also referred to a failed suicide attempt by another terminally ill patient in his care:

*I had a young woman who — it was obviously a suicide attempt — but she was on a syringe driver — it was 3 grams of diamorphine in it and it had just been set up for the next 24 hours. She said she rolled over in bed, and accidentally received the whole dose. She slept quite soundly but we didn't give her anything and she woke up.<sup>71</sup>*

The fact that this hospice medical director had experienced two suicide attempts by terminally ill patients (one of which was successful) suggests that suicide in the context of serious physical illness may be a fairly frequent occurrence nationally. However, whereas assisted suicide has a high profile in the media, and the number of cases of assisted suicide that the CPS investigates each year can be tracked, there is no publicly available national data on the number of people in the UK whose suicides may have been influenced by suffering related to physical illness. To fill this evidence gap, we commissioned Demos to undertake a study of the number of suicides that take place each year involving a person with terminal or chronic illness.

### **Demos research on suicide and physical illness**

The aim of the project was to investigate the proportion of the individuals who die through suicide in England each year had a terminal or other severe physical illness that may have been a factor in their suicide. Demos's research methodology for this study included: a desk-based scoping exercise to explore the relationship between suicide and various chronic and terminal health conditions; sending information requests to all primary care trusts (PCTs) in England (147), using the Freedom of Information Act to ask for information about suicides involving various types of physical illness or impairment; semi-structured interviews with 15 serving or recently retired coroners; and a detailed case study of Norwich county coroner's district.

Demos researchers found that 75 of the PCTs they contacted using freedom of information requests were unable to provide any data relevant to suicide and terminal illness. However, 29 PCTs provided some of the requested numerical data, and a larger number of PCTs provided some form of relevant qualitative or numerical data. Demos's analysis of the data provided by these 29 PCTs found that there was an average of 27.8 suicide deaths annually in each PCT area during the five-year period 2006–10 and that the proportion of all suicides involving various conditions was as follows:

- involving a terminal illness: 2.1 per cent
- involving chronic illness: 10.6 per cent
- involving physical illness: 8.2 per cent
- involving some specific form of physical illness or health condition: 21.4 per cent
- involving pain: 4.9 per cent
- involving physical impairment or disability: 3.3 per cent.<sup>72</sup>

Some PCTs had counted some suicides in more than one category (for example, in some cases the same person may have had a terminal illness and also a chronic condition). Therefore, it was not possible to add these figures together to create a total percentage of suicides involving some form of physical illness or impairment. However, Demos derived a conservative estimate from these findings that approximately 2 per cent of all suicides that take place in England are by people who are terminally ill, while approximately 10 per cent of suicides are by a person who is chronically ill.

Demos's detailed study of Norwich district's inquest records corroborated these findings by revealing that 25 suicides, out of the 259 suicides that took place in total over five years, involved a person with a diagnosed terminal or chronic illness. This amounts to 9.7 per cent of all recorded suicides during that

time (just under 10 per cent). In 18 of the 259 cases, the deceased person had a diagnosed chronic condition (6.9 per cent of all recorded suicide verdicts). In eight of the 25 cases, the deceased person had a diagnosed terminal illness (3.1 per cent of all suicide verdicts). One person (4 per cent of the sample) had both chronic and terminal conditions at the time of death. Medical conditions identified in the inquest records included Parkinson's disease, motor neurone disease, myalgic encephalopathy (ME), chronic arthritis, Huntington's disease, tinnitus, Alzheimer's and cancer.<sup>73</sup>

The semi-structured interviews with serving and recently retired coroners that Demos conducted also produced a number of important insights. These were the most important findings:

- Coroners vary in the extent to which they record information on physical illness in suicide inquest records. Therefore, inquest records may not accurately reflect the deceased person's health status and PCTs may be underestimating the scale of the problem.
- Coroners vary in the extent to which they are willing to cooperate with other agencies performing local suicide audits (with an inevitable impact on the quality of PCTs' suicide audits).
- Several coroners indicated they deliberately avoid probing into suspected cases of assisted suicide, often for fear of causing problems for the friends and family left behind. This suggests that the actual number of assisted suicide cases that take place each year may be higher than official records suggest.

Demos inferred from the numerical data collected from the PCTs and Norwich district coroner's office that approximately 10 per cent of suicides in England involve people with either a chronic or a terminal illness. However, it is likely that this figure may be a significant underestimate, as Demos also found anecdotal evidence that some coroners currently choose not to include relevant health information within their inquest records, which are frequently the main input to PCTs' suicide audits.<sup>74</sup>

According to national data, 4,390 suicides took place in England in 2009.<sup>75</sup> Demos estimated on the basis of these data that in 10 per cent of these suicides, or 439 individual cases, the deceased person was experiencing some form of serious physical illness as an influencing factor. Demos concluded that suicide among terminally and chronically ill people is much more prevalent, and a much greater issue than public policy currently recognises, and that much greater attention must be paid to improving medical, practical and psychological support to this group.

The quantitative methodology for this research did not make it possible to investigate the extent to which depression or other mental health problems affected these people's decisions to end their lives. However, the more qualitative elements of the research, including the detailed study of Norwich district's inquest records, indicated that depression played a significant role in some people's decisions to end their lives but might have had a lesser role in other cases. There was clear evidence of depression brought about by serious illness in the case of a 55-year-old man who died by walking into the road in front of a lorry in May 2008. He was a computer analyst and the inquest record noted that he was suffering from depression 'as a consequence of his medical condition', which included cancer in the neck and shoulder. In his suicide note this man had written, 'I feel so depressed and worthless.' However, in another case an 81-year-old male man

who took an overdose in November 2007 had chronic leg problems that were causing him considerable pain. He wrote in his suicide note, 'I want to be able to control when I die and be spared the indignity.' This man's inquest report did not mention any known history of mental health problems, therefore it is not clear to what extent depression might have influenced his decision to end his life. We will investigate further the relationship between depression and terminal illness in the context of requests for assisted dying later in this report.

### **UK public opinion on assisted suicide and voluntary euthanasia**

Surveys of attitudes towards assisted dying among the British public have found consistent majorities in favour of change in the law since the earliest surveys were conducted in the 1970s. Over time there has been a slight increase in support among the public for the legalisation of assisted dying, as demonstrated by surveys conducted by the Voluntary Euthanasia Society (VES) from 1976 onwards and periodic British Social Attitudes (BSA) surveys. However, closer analysis demonstrates that the extent of support for legalisation among the public varies according to the type of assisted dying that is proposed and issues regarding who might be eligible for such assistance. Support has generally been higher for legalising assisted dying for terminally ill individuals than for those with severe but non-life threatening conditions. There have also been findings to indicate that physician-assisted dying is viewed more favourably by the public than assistance by non-professionals, although findings have varied.

### **Public attitude surveys in the late 1970s and 1980s**

The earliest survey on public attitudes to euthanasia was conducted in 1976 by National Opinion Polls (NOP), commissioned by the VES. The question put to around 2,000 individuals aged 15 and over in this survey was:

*Some adults say that the law should allow adults to receive medical help to an immediate peaceful death if they suffer from an incurable physical illness that is intolerable to them, provided they have requested such help in writing. Please tell me whether you agree or disagree with this?<sup>76</sup>*

In 1976 more than two-thirds (69 per cent) of those polled supported this statement, with 17 per cent against and 14 per cent undecided.<sup>77</sup> NOP surveys repeating this question in 1985 and 1989 saw majorities of 72 per cent and 75 per cent respectively agreeing with the statement. British Social Attitudes surveys that were conducted around the same time, in 1984 and 1989, reaffirmed that there was steady and slightly increasing support for the statement. In response to the BSA survey's more simple question: 'Suppose a person has a painful incurable disease. Do you think that doctors should be allowed by law to end the patient's life, if the patient requests it?', 75 per cent of respondents agreed in 1984, and 79 per cent in 1989.<sup>78</sup>

A MORI poll of 1,808 people in 1987, sponsored by two anti-euthanasia organisations, also found that a majority of respondents (72 per cent) were in favour of legalising some form of assisted dying. Looking at a more detailed breakdown, 49 per cent supported 'euthanasia' for a patient 'suffering from a severe illness' who is in 'a lot of pain', while nearly a quarter (23 per cent) agreed with the statement 'Euthanasia should be made legal in all cases when the patient requests it'.<sup>79</sup>

### Public attitudes surveys in the 1990s

The trend of a large and incrementally increasing majority in favour of the legalisation of some form of assisted dying continued into the 1990s. Another survey by the NOP and VES was carried out in 1993, which this time found that 79 per cent of respondents supported assisted dying (compared with 72 per cent in 1985 and 75 per cent in 1989). The BSA survey was conducted again in 1994, and found that 82 per cent of the public agreed with a doctor being able to respond to a patient's request for assistance in ending their life (compared with 75 per cent in 1984 and 79 per cent in 1989).<sup>80</sup> The BSA report published in 1995 also delved into the specific responses in greater detail, finding that the highest support (86 per cent) was actually for a form of *involuntary* euthanasia, for individuals on life support who were not expected to recover consciousness, provided there was consent by relatives. Four-fifths (80 per cent) of those surveyed also supported the legalisation of euthanasia for those suffering from a painful and incurable terminal illness such as cancer. Support to have the choice of assisted dying extended to those with non-terminal illness fell off quite sharply: 42 per cent believed assisted dying should be an option for those with a painful but non-terminal illness.<sup>81</sup>

### Public attitudes surveys from the 2000s to the present day

More recent NOP and VES surveys in 2002 and 2004 found 81 per cent and 82 per cent majorities answered in the affirmative to the first part of the question: 'Do you think that a person who is suffering unbearably from a terminal illness should be allowed by law to receive medical help to die, if that is what they want, or should the law not allow them this medical help to die?'<sup>82</sup>

The 2005 BSA survey also demonstrated there was steady support among the public for assisted dying, but particular support for patients with terminal illnesses having this option made available to them: 80 per cent of respondents thought that assisted dying should be allowed for terminally ill patients, while only 45 per cent thought the same option should be available to people with incurable but non-terminal illnesses. Further analysis also demonstrated that the type of assisted dying most favoured by the public was voluntary euthanasia performed by a doctor; 80 per cent of people thought the law should be changed to allow this for terminally ill patients, while only 60 per cent agreed with doctor-assisted suicide and just 44 per cent thought that relatives should be allowed to undertake this role.<sup>83</sup> In the 2008 BSA survey 82 per cent of respondents thought that a doctor should probably or definitely be allowed to end the life of a patient with a painful incurable disease at the patient's request.<sup>84</sup>

A number of more recent public opinion surveys conducted in 2009 and 2010 have delivered similar results. A Populus poll for *The Times* in July 2009 found that 74 per cent of those surveyed thought that the law should be changed to allow doctor-assisted suicide in 'cases where an individual is of sound mind and has made unambiguously clear that they want to die and want or need help to do so'.<sup>85</sup> More than half (60 per cent) of respondents supported the legalisation of non-doctor (friends, relatives) assisted suicide. Of those who believed that the law should be changed, 13 per cent believed that assisted suicide should be legal 'without restriction' and 85 per cent believed that assisted suicide should be legal 'only in certain specific circumstances'.<sup>86</sup> Among those people who supported assisted suicide in 'specific circumstances', 95 per cent thought that assisted suicide should



be legal for people who are terminally ill; 56 per cent were in favour for people who were suffering extreme pain but were not terminally ill; 65 per cent were in favour for people with a degenerative condition who were not terminally ill; 48 per cent were in favour for people with a 'severe physical disability' who were otherwise healthy and 34 per cent for 'people who simply wish to die at the same time as a long-term spouse or partner who has a terminal illness'.<sup>87</sup>

A 2010 YouGov survey on behalf of the *Daily Telegraph* found that 88 per cent of the 3,874 people questioned supported 'assisted suicide' in at least some circumstances.<sup>88</sup> More than half (56 per cent) of respondents thought assisted suicide should be allowed if the terminally ill person made the decision themselves; 18 per cent thought that close family 'should be able to make the decision out of compassion'; and 14 per cent of respondents thought that assisted suicide should be allowed only in 'very exceptional circumstances'. Only 7 per cent of respondents thought that assisted suicide should not be allowed under any circumstances.<sup>89</sup>

A ComRes poll for BBC *Panorama* conducted on 31 January 2010 produced findings that broadly corroborated previous survey findings. While slightly more respondents supported doctor-assisted suicide for terminally ill patients as opposed to assisted suicide supported by a family member or close friend (74 per cent compared with 73 per cent), this preference was slightly reversed for non-terminally ill patients with a painful and incurable condition. Here 48 per cent agreed that a family member or close friend should be able to help them to die, while only 45 per cent agreed that a medical professional should be able to provide this assistance.<sup>90</sup>

Therefore, while responses from the British public to questions posed about assisted dying have varied depending on the precise wording of the question and the proposed identity of both recipient and assister, the message that has been consistently communicated is that a large majority of the UK public support the legalisation of some form of assisted dying for people who are terminally ill, and that the level of support has gradually increased over time.

## **Assisted dying in an international context**

### **The European Convention on Human Rights**

Interpretations of the European Convention on Human Rights by the European Court of Human Rights and by Law Lords in the UK have played an important role in the evolution of the law on assisted suicide in the UK. When Diane Pretty's request to the DPP that her husband should not be prosecuted if he assisted her to commit suicide was turned down, she took her case to the House of Lords and then to the European Court of Human Rights in 2002:

*The applicant [Diane Pretty] who [wa]s paralysed and suffering from a degenerative and incurable illness, alleged that the refusal of the Director of Public Prosecutions to grant an immunity from prosecution to her husband if he assisted her in committing suicide and the prohibition in domestic law on assisting suicide infringed her rights under Articles 2, 3, 8, 9 and 14 of the Convention.*<sup>91</sup>

The judgment made by the European Court of Human Rights (ECHR) held that none of the following articles of the Convention had been violated:

- article 2: the right to life
- article 3: the right not to be subjected to torture or to inhuman or degrading treatment or punishment
- article 8: the right to respect for a private and family life
- article 9: the right to freedom of thought, conscience and religion
- article 14: the enjoyment of the rights and freedoms set forth in the Convention without discrimination on any ground.<sup>92</sup>

However, while the ECHR did not consider that Diane Pretty's Convention rights had been violated under article 8(1), it concluded that her rights had been interfered with:

*The applicant in this case is prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life. The Court is not prepared to exclude that this constitutes an interference with her right to respect for private life as guaranteed under Article 8 (1) of the Convention.*<sup>93</sup>

The ECHR's ultimate decision to uphold the House of Lords ruling was based on the fact that: 'the restriction on assisted suicide was "in accordance with the law" and in pursuit of the legitimate aim of safeguarding life and thereby protecting the rights of others'.<sup>94</sup> The ECHR's ruling concluded that:

*The Court does not consider therefore that the blanket nature of the ban on assisted suicide is disproportionate. The Government have stated that flexibility is provided for in individual cases by the fact that consent is needed from the DPP to bring a prosecution and by the fact that a maximum sentence is provided, allowing lesser penalties to be imposed as appropriate.*<sup>95</sup>

Although Diane Pretty lost her case, this ECHR judgment that Diane Pretty's article 8(1) Convention rights had been interfered with by the UK's legal prohibition on assisted suicide later proved to be influential in the decision of the Appellate Committee of the House of Lords on the case of *R (on the application of Purdy) v Director of Public Prosecutions* in 2009. As we observed at the beginning of this chapter, Debbie Purdy's judicial review challenge to the DPP's prosecuting policy led to a ruling by the Appellate Committee that the DPP must 'clarify what his position is as to the factors that he regards as relevant for and against prosecution in this very special and carefully defined class of case' as exemplified by Debbie Purdy's situation.<sup>96</sup> Following this judgment, the DPP published his policy for prosecutors on assisted suicide in February 2010.

A more recent judgment by the ECHR has further clarified its position on the extent to which the ECHR might protect an individual's right to end his or her life. In the recent case of *Haas v Switzerland*, a Swiss national named Ernst G Haas who had had a serious bipolar affective disorder for 20 years and wished to end his life by obtaining sodium pentobarbital (the medication used for assisted suicides in Switzerland) found that he could not identify a psychiatrist who was willing to prescribe the drug to him. The Swiss Federal Court rejected his request to obtain the medication directly from a pharmacy as it ruled that 'a distinction had to be made between the right to decide on one's own death—which was not at issue—and the right to commit suicide assisted by the State or a third party'.<sup>97</sup> Mr Haas then made an application



to the ECHR arguing that 'his right to end his life in a safe and dignified manner had been violated' (under article 8 of the Convention) as a result of the conditions set by Switzerland for obtaining sodium pentobarbital.<sup>98</sup>

On 20 January 2011, the ECHR concluded, unanimously, that there had been no violation of article 8 in the case of *Haas v Switzerland*. However, the Court did recognise that Mr Haas's article 8 rights were engaged in these circumstances:

*The Court acknowledged that the right of an individual to decide how and when to end his life, provided that said individual was in a position to make up his own mind in that respect and to take the appropriate action, was one aspect of the right to respect for private life.*<sup>99</sup>

Therefore, the court held that while an individual had the right to decide how and when to end his or her life, he or she must have the mental capacity to make this decision and must be physically capable of following through the action to end his or her life. Effectively, the Convention does not protect any right to assistance beyond what is already legal under a particular state's law. The Court also acknowledged that most of the member states were more concerned to protect article 2 rights (the right to life) than article 8 rights (the right to respect for a private and family life) and 'concluded that the states had a wide margin of discretion in that respect'.<sup>100</sup>

### **International jurisdictions that legally permit some form of assisted dying**

The last two decades have seen significant legal change on assisted dying in a number of jurisdictions including three European states (the Netherlands, Belgium and Luxembourg) and two American states (Oregon and Washington). In Switzerland assisted suicide has been explicitly legal since the Swiss Penal Code came into force in 1942, as long as the assister does not have 'selfish motives'.<sup>101</sup> However, the development and expansion of right to die organisations such as Exit DS and Dignitas since the 1980s has demonstrated an important social change. This growth in Swiss right to die organisations has also has significant implications for other jurisdictions such as the UK, as the Swiss Penal Code does not restrict access to assisted suicide to Swiss residents and allows foreign nationals to travel to Switzerland to obtain assistance in dying.

Debbie Purdy's successful challenge to the DPP was made on the basis that she had the right to clarification regarding whether her husband Omar Puente would be likely to be prosecuted under section 2 (1) of the Suicide Act 1961 if he should assist her to travel to Dignitas in Switzerland to end her life. Therefore, the legal status of assisted dying in other jurisdictions such as Switzerland can clearly have an important knock-on impact on the domestic policies of other states. Professor Penney Lewis has characterised the DPP's publication of a prosecution policy on assisted suicide as 'informal' legal change:

*While Parliament has been unwilling to undertake formal legal change on assisted suicide, informal legal change has been accelerated by the House of Lords' surprising decision in Purdy, coupled with a DPP willing to create an expansive policy covering all assisted suicides rather than just those which take place in another more permissive jurisdiction. The DPP has done so by implicitly describing (albeit imperfectly through the use of factors for and against prosecution) a class of assisted suicides which are permissible.*<sup>102</sup>

Table 2 International jurisdictions that legally permit some form of assisted dying

Jurisdiction	Legislation permits	Statute
Switzerland <sup>103</sup>	Assisted suicide for legally competent adults, provided the assister does not have selfish motives. No requirement for residency.	Swiss Penal Code (1942).
Oregon <sup>104</sup>	Physician-assisted suicide for mentally competent patients aged 18 or over who are diagnosed with a terminal illness that will lead to death within six months. Candidates for assisted death must be resident in Oregon.	Oregon Death with Dignity Act 1994 (enacted in 1997).
The Netherlands <sup>105</sup>	Voluntary euthanasia and physician-assisted suicide. The patient's request must be 'voluntary and carefully considered' and the patient must be experiencing 'unbearable suffering with no prospect of improvement'. A minor aged between 12 and 16 requires parental consent. If a minor is aged 16 or 17, the parent must be included in decision-making. The patient must be resident in the Netherlands.	The Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001 (came into force on 1 April 2002).
Belgium <sup>106</sup>	Voluntary euthanasia (and assisted suicide although not explicitly included in the law). The patient must be 18 or over or 'legally emancipated' if aged 15 or older. The patient must be competent and conscious at the moment of request and the request must be voluntary and well considered. The patient must be in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident. The patient must be resident in Belgium.	Law on Euthanasia 2002 (came into force in 2002).
Luxembourg <sup>107</sup>	Voluntary euthanasia and physician-assisted suicide. Eligibility criteria are closely modelled on the Belgian law. The patient must be resident in Luxembourg.	Law on Euthanasia and Assisted Suicide 2008 (came into force in 2008).
Washington State <sup>108</sup>	Physician-assisted assisted suicide for mentally competent patients aged 18 or over who are diagnosed with a terminal illness that will lead to death within six months. Candidates for assisted death must be resident in Washington State.	Washington Death with Dignity Act 2008 (came into force in 2008)
Montana <sup>109</sup>	Physician-assisted suicide for mentally competent adults who have a terminal illness. The patient must be a resident of Montana.	No formal statute, but the Montana Supreme Court ruled on 31 December 2009, 'We find no indication in Montana law that physician aid-in-dying provided to terminally ill, mentally competent adult patients is against public policy.'

Chapter 3 will discuss in detail the legal and practical implications of the DPP's prosecution policy. Chapters 6, 7 and 8 in section 2 of this report will explore particular features of the assisted dying regimes in operation in the jurisdictions that the Commissioners visited while researching this report (the Netherlands, Belgium, Oregon and Switzerland). Table 2 provides a summary of the jurisdictions that currently permit some form of assisted dying and the main features of each regime.





## 2 The ethical basis of the assisted dying debate

Traditionally, the ethical basis for the assisted dying debate has often been set up as a binary conflict between the value of autonomy and the intrinsic value of human life. However, the evidence given to the Commission has demonstrated that each of these principles is more complex than it might seem, and these values have been analysed and discussed in numerous ways by those who gave evidence. For example, several witnesses discussed the nature of human autonomy and argued that genuine autonomy in life and death may be unachievable or even undesirable in the context of vulnerability, complex social relationships and unclear motivations. Another witness explored competing conceptions of the value of human life, which might be interpreted as ‘intrinsic’, ‘instrumental’ or ‘self-determined’, with each definition leading to very different conclusions.

A number of arguments that focused on the principle of compassion were put forward to challenge the moral justification of allowing a person’s suffering to persist unnecessarily at the end of life, without assisted dying as a recourse. However, other people who gave evidence suggested that assisted dying is a less compassionate, ‘easier’ option than persisting in helping a person to overcome their suffering through high quality end of life care.

The most frequently expressed ethical concerns about assisted dying were related to our duty to the most vulnerable in our society, including those who rely on social support to be autonomous and those with mental impairments who may rely on other people to make decisions about their best interests. Some people who gave evidence also discussed the appropriate ‘balance of harms’ in society. Contrasting views were expressed on the optimum ‘balance of harms’ between those experienced by one group of people (eg terminally ill or seriously impaired people who wish to have the choice of an assisted death) and the risk of harms to another group of people (eg people who might be made vulnerable to abuse by the legalisation of assisted dying).

Our analysis of the evidence submissions also found that the ethical value of ‘non-discrimination’ against disabled people was employed by those arguing both against and in favour of the legalisation of assisted dying. For some, the discriminatory attitude of our society towards disabled people makes it too dangerous to change the law to permit assisted dying. For others, the current legal prohibition on assisting suicide discriminates against disabled people by removing the means of assistance that people with significant impairments might need if they were to choose to end their life as a non-disabled person might. Some of those who gave evidence expressed the view that assisted dying should remain illegal, but argued that if some form of assisted dying was to be legalised, the law must be framed in such a way as to ensure that it was non-discriminatory towards people who have physical or mental impairments.

The discussion of medical ethics among those who gave evidence also reflected a broad variety of views. Ethical arguments against medical involvement in assisted dying particularly focused on doctors' responsibility to preserve life, and concerns about how the trust relationship between doctor and patient might be damaged should doctors take an active role in assisted dying. Ethical arguments in favour of doctors' involvement in assisted dying were also cited including doctors' responsibility to relieve suffering at the end of life that might be felt to be unbearable by the patient.

Each of these powerful and often conflicting ethical arguments will be fleshed out in more detail in the sections below on:

- autonomy
- the value of human life
- responding compassionately to suffering
- protecting vulnerable people
- the balance of harms
- non-discrimination in law and policy
- medical ethics.

### **Autonomy**

Evidence submitted to the Commission explored autonomy as a central ethical value in the assisted dying debate from a variety of perspectives including personal, professional and philosophical viewpoints. Debbie Purdy's evidence to the Commission approached the principle of autonomy from a particularly personal perspective, emphasising the huge value of individual autonomy to her own life:

*I want to be in control of my life, and that means I want to be able to live it as long as I can, but I want to be able to choose what quality of life is livable; I don't want somebody else to tell me that 'the quality of your life's ok, what are you complaining about?' I want to be able to make those choices myself. I want the help and support to make it.<sup>110</sup>*

Tony Nicklinson's evidence also drew broad philosophical conclusions from his personal experience, challenging the ethics of a legal framework that he argued prevents him and other disabled people from achieving self-determination over their own life and death:

*Everybody, whether or not they need assistance, should be able to determine their own future... Ethically, there is no greater issue than having the right to self-determination taken away just because one needs help to die. If this issue is resolved all other aspects of this topic fall into place. In fact a compassionate society would do all it could to help those people who need it.<sup>111</sup>*

Andrew Copson, Chief Executive of the British Humanist Association, suggested that the moral values of human dignity and individual autonomy should take primacy in the debate around assisted dying: 'Human dignity is not always commensurate with the extension of human life and that raises important ethical questions about human dignity and about the quality of

life that needs to be addressed.<sup>112</sup> In his discussion of autonomy, Andrew Copson recognised that autonomy in health care cannot be limitless, ‘not autonomy to such excessive lengths that people get to choose precisely what sort of prescription they want’, but argued that it should be prioritised where possible: people should have ‘a measure of choice, a measure of freedom, a measure of self-determination that is appropriate’.<sup>113</sup> A representative from the British Humanist Association elaborated on this position:

*Individuals should be allowed to decide on such personal matters for themselves; if someone in possession of full information and sound judgement decides that her continued life has no value, her wishes should be respected... To postpone the inevitable against the wishes of an individual with no intervening benefit is not a moral act. We believe that a compassionate society is one which respects and upholds in law people’s right to choose to have an assisted death if that is their considered and expressed wish.*<sup>114</sup>

The written evidence submission by the British Association of Social Workers (BASW) reflected on the value of individual autonomy from a professional perspective, arguing that choice over the manner and timing of one’s death was a logical progression from the ‘developments to afford service users and patients greater control over the manner of their assisted living, the encouragement to plan for losing mental capacity and the encouragement to actively agree or refuse treatment’.<sup>115</sup> In the BASW’s view these professional values draw on ‘ethical assumptions [which] are central to how we are supporting people to live their lives in twenty-first century England, and therefore provide the context in which each of us thinks about our own death and the death of those around us’. For the BASW, these cultural developments both within social care and broader society make it ‘a natural development that some people will want to influence and express a choice about the manner of their death. Some want to go further and arrange the manner of their death, and may need assistance to do so.’

Reverend Professor Robin Gill also highlighted autonomy as one of the central ethical values in the debate on assisted dying, but explored the complex relationship between individual autonomy and the wider social implications of personal freedoms. He observed the growing importance of autonomy as an ethos shaping modern health care:

*Autonomy, literally self-rule, is crucial to modern medical ethics and law. Most of us now take it for granted that competent patients should be able to make voluntary, clear, settled and informed choices about their medical treatment. In the more paternalistic past, doctors sometimes took decisions for their patients without consulting them properly. Today this is no longer acceptable, as the current white paper on equity and excellence makes clear. The Ms B judgment ten years ago clarified decisively that a competent patient does have the right to refuse even life-sustaining treatment.*<sup>116</sup>

However, Reverend Professor Gill also pointed out that while any discussion based solely around ideas of individual autonomy is likely to look favourably on the legalisation of assisted dying, the broader social impact of seemingly ‘autonomous’ actions must not be ignored. As he put it:



*In seeking to change the law to facilitate assisted dying for autonomous individuals in need of compassion and liberation from an otherwise burdensome death, can we be confident that life will not become more burdensome for other vulnerable people who also need our compassion?*<sup>117</sup>

Baroness Onora O'Neill's evidence also highlighted the philosophical and practical limits to the concept of autonomy. She began by identifying three very different conceptions of autonomy employed in public and political debate: 'Kantian autonomy', 'existentialist autonomy' and 'rationalist autonomy', and went on to explore their social and legal implications.<sup>118</sup> Baroness O'Neill explained 'Kantian autonomy' in the following way:

*For Kant, autonomy is choosing on principles that you judge everybody could choose on so it's a very moralised conception of autonomy... Kant did assume... that we are free to choose, that we have a capacity of choice.*<sup>119</sup>

However, she said that the more precise Kantian conception of autonomy 'plays almost no part in contemporary debate on medical ethics'. Instead, the more contemporary 'existentialist' and 'rationalist' conceptions of individual autonomy predominate public conceptions of autonomy. She defined an existentialist conception of autonomy as the belief that autonomy 'is mere sheer choice: any choice counts however good, however bad, however self-destructive, however informed, however uninformed; mere, sheer choice is what we're out to protect'. She suggested that the rational conception of autonomy can be one of two things: either taking a 'narrow' 'game theoretic view, the sort of thing you see in models of rational choice, in economics and the social sciences' or demonstrating that

*what really made autonomy rational was that it was reflective... that it was the sort of choice, which after you had considered the matter at some length, you would wish to endorse, so it was the choice that you wish to choose.*<sup>120</sup>

Baroness O'Neill then contrasted these 'endlessly complicated' theoretical conceptions of autonomy with a more practical approach to the concept of autonomy, which she said was inspired by the many letters she received from members of the public when Lord Joffe's Assisted Dying for the Terminally Ill Bill was being debated. She identified a marked division between the 'few very well argued and sophisticated letters by proponents of legislation to make assistance in dying lawful' and the

*very large number, probably twenty times as many, very much less sophisticated and educated letters, from people who said they were afraid of the legislation... They were people who were afraid that they would come under pressure from carers or nursing homes, perhaps family, to agree to be killed.*

This disparity led Baroness O'Neill to reflect on the limits to autonomy, commenting finally in her evidence to us:

*I do not believe that it is possible to draft adequate safeguards without invoking misleading and unrealisable fantasies about individual autonomy... Whatever one thinks about the legitimacy of assisted suicide it's not legislatable; not safely legislatable.*<sup>121</sup>

Three specialist palliative care nurses who took part in a Demos focus group as part of the Commission's call for evidence challenged the use of overly simplistic notions of autonomy in the assisted dying debate from both philosophical and professional perspectives. One of the nurses told us:

*I did a big piece of research on autonomy and sanctity of life. I think 'autonomy' is a word that we really bandy around, but do we really understand autonomy? We've almost been coerced into autonomy—you have the right to be an autonomous being, but do people really understand the implications of being an autonomous person, that it actually has a big effect on the next person. I know for sure, before I did this work I always emphasised patient autonomy, they must be autonomous. But if you think about it in contrast to sanctity of life, actually, we have to find a balance between the two. Maybe we don't in all situations have the right to be completely autonomous, because our neighbour may not have that right.*

Dr Richard Huxtable, Deputy Director of the Centre for Ethics in Medicine at the University of Bristol's School of Social and Community Medicine, also commented on the limits to individual autonomy:

*I agree that context must matter in terms of autonomy and there's been an unkindly, again I would say, a tendency occasionally to caricature autonomy as 'I want I get'. But of course autonomy properly understood will mean there are lots of 'I's all rubbing up against each other, who must be ensuring they are respectful of one another.'<sup>122</sup>*

However, commenting on 'the sheer wealth of support' for a change in the law to legalise some form of assisted dying, Dr Huxtable also asserted:

*To disregard the autonomous views of a large number of the public would be abhorrent... On that side there's that cluster of arguments, in addition to these general philosophical arguments, if you will, about respecting autonomy and the subjectivity of suffering.<sup>123</sup>*

The 'balance of harms' dilemma, which considers the extent to which it is permissible to constrain an individual's personal autonomy in a society that must accommodate many people's competing rights, will be discussed in more detail below.

### **The value of human life**

The value of human life is another fundamental ethical principle that lies at the centre of the assisted dying debate. As several people who gave evidence to the Commission highlighted, the value of human life can be conceptualised in different ways, which may lead to different conclusions about the acceptability of assisted dying. Dr Richard Huxtable explained to the Commission that the various ethical arguments about assisted dying relate to three main conceptions of the value of human life. These are conceptions based on the 'intrinsic', 'instrumental' and 'self-determined' value of life.

Dr Huxtable argued that each of these three categories relates to a particular position on the law regarding assisted dying:

*So first of all on the prohibitive side obviously, we have the appeal to the so-called intrinsic value of life, the idea that life itself is valuable and should not intentionally be brought to an end. On the more permissive side, of course, we've got the arguments that appeal to instead the instrumental value of life, in the sense that we refer to suffering and the like; so in that account we're not saying life itself is valuable, but rather that life of a sufficiently good quality is valuable. In other words life is an instrumental vehicle to other goods; if that vehicle is substantially broken maybe it's time to abandon it. But thirdly, and perhaps most prominently nowadays, we talk about the self-determined value of life whereby it's over to me to decide what counts for me or what doesn't count for me in terms of making life worth living or not.<sup>124</sup>*

Dr Huxtable then went on to consider the deficiencies of each of these three perspectives on the value of human life. Beginning with the 'intrinsic' value of life:

*There are some pretty fine lines drawn there and increasingly it's seen as quite a theological construct; and so one can immediately say, well, if I don't come from that faith-based perspective of, the sanctity of life, let's say, or I have no faith, then why should I buy into this set of beliefs?<sup>125</sup>*

Dr Huxtable described arguments made in favour of assisted dying that are based on instrumental and self-determined conceptions of the value of life as 'appeals to suffering and autonomy'. He commented on these arguments:

*Suffering can be seen as a very subjective matter. If, when we're talking about assisted dying, and this starts to bring us into the territory of today's discussion particularly, we are appealing to let's say a health professional to assist in that dying, then they need to at least sympathise with the quality of life judgement that the patient has reached. There needs to be some way of speaking to that health professional if they're going to have a reason for acting. And I would suggest, it might be only an incremental matter, but if you start there, with the allegedly subjective value of suffering, it's not such an extreme step to start talking about objectifying suffering and judging the value of other people's lives.<sup>126</sup>*

Dr Huxtable gave an example of an instance where he felt that a judgment based on the self-determined value of life had not been appropriate, referring to the Dutch Brongersma case 'in which an elderly gentleman was helped to die by his GP on the grounds of existential suffering or that he was "tired of life"'. With reference to this case, Dr Huxtable said:

*The Dutch have attempted to draw a boundary there and say this is not permissible behaviour, but I think logically, in terms of the appeal to autonomy, we can't rule that out. So how one is going to draw these boundaries is going to be very difficult at the outset.<sup>127</sup>*

The Commission also received submissions from a number of representatives of religious organisations that discussed their perspective on the value of human life and a written submission from the Arts and Humanities Research Council (AHRC), which held a seminar to collect evidence for the Commission on the ethical and practical implications of assisted dying in the context of the UK. Some of those who discussed their

Christian perspective on the value of human life conceptualised human life as sacred or, in Dr Huxtable's terminology, 'intrinsically' valuable. Brian Rowney, of the Independent Methodist Churches wrote: 'Many Christians view life as a gift from God, and the taking of life as taking what belongs to God.'<sup>128</sup> A GP who submitted evidence to the Commission anonymously commented:

*As a Christian I believe that God gives life and God takes it away. It is not for us to determine when someone should live and when they should die. As a doctor I have been involved with numerous patients at the end of life and have seen the different responses and reactions to the inevitable from both patients and family/friends... I believe for the majority people value life right to the end and that assisted suicide demeans life and dying.<sup>129</sup>*

Austen Ivereigh, a journalist from Catholic Voices, spoke of 'the principle that everyone is of equal dignity and worth' and explained that he opposed any change in the law to permit assisted dying because:

*It would offer the possibility of a rational decision about when and how to die. Any such rational processes inevitably involve considerations of the relative value of different kinds of life, and therefore cannot be 'rational', for the assumption behind it is an essentially irrational one: that the life is not worth living.<sup>130</sup>*

Robert Fieldson, a member of the Church of England clergy, also expressed the concern that assisted dying 'devalues human life'.<sup>131</sup>

Members of the Jewish faith have also traditionally opposed a permissive approach to assisted dying in the belief that assisted dying cannot be reconciled with the intrinsic value of human life. The Office for the Chief Rabbi noted in written evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill that the Jewish tradition places the upmost importance on the value of human life, 'viewing life as a precious gift from God, not something we can dispose of at will. Indeed, the value of human life is absolute and not relative to factors such as age and health.'<sup>132</sup> The memorandum also made reference to the prohibition against suicide contained within the Jewish legal code. Commenting more specifically on the 2004 Assisted Dying for the Terminally Ill Bill, the evidence stated:

*The Bill would enable, in specific circumstances, a terminally ill competent adult to request medical assistance to die. It would therefore introduce a form of euthanasia into UK medical law. Since Judaism regards human life as both absolute and infinite, it considers the deliberate termination of life as prohibited. Hence, in broad terms, Jewish law is opposed to euthanasia whether the physician acts with or without the patient's permission.<sup>133</sup>*

The traditional Islamic perspective on assisted dying is also very clear that it is not permissible for an individual to choose his or her moment of death. Giving evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill, Dr Khalid Hameed, a doctor and a Muslim, described the Islamic perspective on assisted dying:

*Islam... is very definite about human life... In Islamic bioethics, the physician has to render help regardless of the financial ability of the patient. He has no right to*

*terminate human life, none whatsoever and there is equally a very clear instruction to all followers of Islam, a very clear instruction against taking your own life.*<sup>134</sup>

Dr Hameed further noted that he believes the legalisation of assisted dying would lead to a dilution of human faith and religion:

*If you take away the central plank of life itself from what has been agreed, understood and accepted over centuries as God's gift to a man, it would be diluting religion as a civilising factor in our daily lives.*<sup>135</sup>

Commenting from his perspective as a doctor and a Muslim, Dr Hameed explained that if he were forced to give advice regarding assisted dying to a fellow Muslim patient, he would advise them as a believer that both the doctor and patient who participated in assisted dying would 'end up in hell'.

However, not all of those who put forward faith-based views on assisted dying explicitly conceptualised human life as being 'intrinsically' valuable. At the AHRC seminar Dr Brendan MacCarthy, the ethics, health and social care policy adviser to the Church of England's Archbishops' Council, put forward the Church of England's position on assisted dying as one that promotes 'the affirmation of life' rather than the absolute sanctity of life. The other values that Dr MacCarthy put forward to characterise the Church of England's position included 'caring for the vulnerable — including those who do not care for themselves', 'the concept of community, of bringing together a cohesive, compassionate society' and 'respecting individual choice'.<sup>136</sup> Dr MacCarthy concluded that 'the current law better addresses the goal of a coherent and compassionate society than does any change suggested to date'.<sup>137</sup>

Some of the other Christian views that were put forward described a more explicitly 'self-determined' conception of the value for human life. Sharon Morgan, a lay pastoral minister of the Church of England, commented:

*I see enabling somebody to die as a supreme act of mercy. Helping somebody desperate to be relieved of suffering, who has expressed the wish to die, for whatever reasons this wish has come about, fits with my Christian beliefs. Jesus Christ acted frequently in the gospels to bring peace and understanding to those marginalised by disease or extreme distress.*<sup>138</sup>

Reverend Canon Robin Morrison wrote to the Commission on behalf of members of the Bio-Ethics group of the Church in Wales. His submission observed that the sanctity of human life is rarely treated as an absolute value in our society, even among faith communities:

*Suffering is emotional and spiritual as well as physical. It is in the interrelationship of these dimensions of suffering that people experience their quality of life and their levels of dignity. Experiencing the sanctity of life may be possible regardless of pain and suffering for some individuals, particularly in the view of some faith communities, but no humane society wants to use this belief to legitimise or prolong suffering by their action or inaction. However, for most, if not all societies and faith communities, the sanctity of life is not treated as absolute in all situations and killing is allowed in times of war even in societies where the taking of life is seen as illegal*

*murder. There are clearly many contradictions in practice under the apparently absolute ethics of sanctity... There is still a need to address the demand for a new legal context around assisted dying and respond to real situations where particular individuals and relatives see this as the best way to express their deepest wishes.*<sup>139</sup>

The oral evidence that Rabbi Danny Rich, Chief Executive of Liberal Judaism, provided also offered a faith-based perspective on assisted dying that took a more 'self-determined' view of the value of human life. He said he was an adherent to the life-affirming tradition of Judaism and a believer in a benevolent God, but:

*It seems to me that it is morally defensible for an individual of sound mind to declare that the quality of his or her life is no longer worth the struggle. And that such a person may expect those who care for him or her, either personally or professionally, to assist in that process, and subject to appropriate safeguards, those who assist should not face criminal prosecution.*<sup>140</sup>

Rabbi Rich said that although his views might not represent the majority of the Jewish population, he believed that an increasing number of followers of the Jewish faith wish to explore this issue. Discussing the religious perspective that God is the giver and taker of life, he said:

*It's a nice, defensive fallback position, but of course we know that in many, many cases, we intervene, if I can put it crudely, to assist God in the process of life and death. Fertility treatment would be one example. Given the choice between prayer or chemotherapy, if I had cancer, I might chose chemotherapy, combined with prayer, or in place of prayer. And I think everybody would say it would be legitimate to choose chemotherapy rather than prayer. So we clearly see examples where I can only say that God as the giver and taker of life is assisted by human desire and the human mind.*<sup>141</sup>

### **A compassionate response to suffering**

Appeals to a compassionate response to human suffering ran throughout many of the submissions that were made to the Commission, although people differed in their views of what a compassionate response to suffering might constitute. Reverend Professor Robin Gill observed:

*Compassion, or better compassionate care, is to identify with those who are vulnerable and in need, and to be determined to help them if you possibly can. The DPP's Guidelines have motivation by compassion as a key feature. Those who argue for a further change in the law rightly use compassion (together with autonomy) as central to their case.*<sup>142</sup>

However, Reverend Professor Gill concluded this point by acknowledging the fact that one person's choice must always be balanced against its implications for other members of society.<sup>143</sup>

Baroness Mary Warnock stated in her evidence to the Commission:

*Everybody knows that in a civilised country, subject to the rule of law, one can't always have autonomy. One has to give up some freedoms in order to obey the law... I don't think the principle of patient autonomy is really a very strong ground [for assisted dying].*



Instead, she suggested, 'It's more a principle of compassion that should motivate people who want to secure for other people the kind of good death that they want'.<sup>144</sup>

Despite having stated a reluctance to use religious arguments, Baroness Warnock told the Commission:

*The narrative of compassion one finds in, for example, in the parable of the good Samaritan, seems to me to be an enormously important social value for people, whether they are Christian or Muslim or Jew or atheist, in the sort of society that we live in, which we have to recognise is based on largely Judeo-Christian values. Wherever they come from we all ought, I think, to take them seriously and compassion is one of those values. So I think it should be possible to incorporate the concept of compassion within the law.*<sup>145</sup>

The evidence submitted by Dignity in Dying, an organisation that campaigns to change the law on assisted dying for terminally ill adults who are mentally competent, and Debbie Purdy also argued for a change in the law to allow assisted dying in some circumstances as a compassionate response to human suffering. These submissions echoed Baroness Warnock's argument that a compassionate response to suffering should be recognised as one of the hallmarks of a civilised society. Debbie Purdy posed the question:

*As a civilised society, are we really saying that you have to live out your three weeks however much pain you're in and however much the people you love have got to see you suffering... Rather than ending it earlier?*<sup>146</sup>

The written evidence submission from Dignity in Dying made the argument that by accepting the principle of compassionate assistance with suicide in the Director of Public Prosecutions' prosecution policy, while at the same time legally prohibiting that assistance, the UK fails in its responsibility towards people who are suffering at the end of life:

*By giving formal recognition that in certain circumstances, people should not be prosecuted for helping someone to die, the policy effectively acknowledges that in certain circumstances assisted suicide is acceptable... Society must now ask if it is reasonable to accept the principle of compassionate assistance in this way, but to remain unwilling to deal with the reality (instead relying on Switzerland to manage the consequences of our law).*<sup>147</sup>

Dignity in Dying also make a distinction between assisted dying, which they define as helping people who are close to the end of life to die without suffering, and assisted suicide, which they define as assisting people to die who are not already close to death:

*The ethical case to permit assisted dying is that when a dying person is suffering unbearably, everything possible must be done to alleviate that suffering. Even with more or better palliative care, there are some people whose suffering, and consequent desire for an assisted death, cannot be alleviated. When someone is terminally ill and they have assistance to die, they control the manner and timing of a death that would otherwise be unbearable to them. This is not suicide and no dying person should have a duty to suffer.*<sup>148</sup>

However, other submissions of evidence criticised simplistic representations of the nature of compassion. Baroness Onora O'Neill's evidence to the Commission challenged what she referred to as 'fantasised conceptions of compassion'. She argued:

*Too many of these debates have glibly invoked some character called the wholly compassionate family, or the wholly compassionate carer, or the wholly compassionate physician. And while I do believe that there are incredibly compassionate and careful and caring people, I do not think we can assume that the generality of human life provides these exemplary or saintly figures of compassion.<sup>149</sup>*

Others who gave evidence questioned the conclusion that the correct compassionate response to unrelieved suffering might be assisted dying. The Royal College of Surgeons' response to the Commission's call for evidence wrote that while some patients' symptoms can be distressing for everybody concerned, 'a compassionate response to these situations should involve empathy and working hard to control symptoms and not simply to hasten death'. They also observed, 'It is unusual to encounter a patient whose symptoms are truly unmanageable and greater availability of palliative care expertise would help this further'.<sup>150</sup>

One of the specialist palliative care nurses who took part in a Demos focus group said that we must build a more compassionate society to respond to people's suffering:

*I would like to see our governments and our social reformists to make us a society that cares more about the people who are ill, who are disabled, who are vulnerable, that are dying, rather than come up with a quick solution. That's the heart of it for me, that we don't particularly do that. We're as guilty as the next person, we don't all care for our grandmothers and our aunties... but I guess that's what I'd like to see encouraged, rather than seeing assisted dying as the option.<sup>151</sup>*

Professor Tim Maughan, consultant clinical oncologist and Professor of Cancer Studies at Cardiff University, also questioned the assumption that assisted dying is the most compassionate option for people suffering at the end of life, suggesting that with 'expert care', many patients who initially make requests for assisted dying later 'don't want to pursue them'. He suggested that the option of assisted dying might cause additional 'anxiety and burden' for terminally ill patients.

### **Protecting vulnerable people**

The ethical principle that the most vulnerable people in our society must be protected from harm is also central to the debate on assisted dying. Peter Bailey, Global Diversity Practice consultant and trustee of the board of Leonard Cheshire Disability, explained to the Commission why he felt that a change in the law to permit assisted dying might make disabled people vulnerable to societal prejudice and perceived pressure to end their lives: 'There's no doubt in my mind that there is huge angst in society about the loss of capacity and function.' He said that from the perspective of a disabled person, he would question 'why it is that suicidal tendencies in non-disabled people trigger the possibility of being sectioned for your own good, but when we look at disabled people it's somehow expected and understood that you might want to kill yourself'.<sup>152</sup>



Baroness Jane Campbell, a prominent activist in the campaign group Not Dead Yet—UK, which seeks to ‘highlight disabled and terminally ill people’s fears and to ensure legislation prohibiting assisted suicide and euthanasia remains in place’,<sup>153</sup> declined the Commission’s invitation to give evidence before the Commission. However, she wrote to the chairman to explain that ‘disabled and terminally ill people have not and do not seek any change in the law’, and commented:

*Some disabled and terminally ill people seek a change in the law as necessary to protect them from a fate worse than death is understandable evidence of their fears for the future. At a time of cuts to health and social care support services, such fears are not groundless.*<sup>154</sup>

A written response to the Commission’s call for evidence by Simon Penhalagan expressed concerns that individuals:

*When at their most vulnerable and possibly already in a state of depression, could make decisions—or be coerced into making decisions—with regard to shortening their lives, which they would not have made when in a better state of mind. In the long term this attitude will lead to a devaluing of life as a whole in society, particularly with regard to the sick, the disabled and the elderly, and lead to people being valued for the contribution they make to the nation’s wealth creation, and their rejection and ultimate killing if this is limited.*<sup>155</sup>

Alice Maynard, chair of the disability charity Scope explained that Scope has ‘an absolute threshold which says disabled people have an absolute right to life and that any change in the law must protect that absolute right to life.’<sup>156</sup>

These considerable concerns about how assisted dying legislation might impact on specific social groups such as older people, disabled people, people with learning disabilities and terminally ill people will be discussed in much greater detail in chapter 4. At this point we will particularly explore the utilitarian ‘balance of harms’ argument that seeks to weigh up the arguments based on autonomy and choice (put forward by those who seek a change in the law to permit assisted dying) against the arguments based on the risk of discrimination towards or abuse of vulnerable people.

### **The balance of harms**

When he gave evidence before the Commission, Reverend Professor Robin Gill weighed up the three values of autonomy, compassion and liberation (which he suggested when taken alone did lead towards a permissive stance on assisted dying) against

*a fourth value or principle, variously identified as the common good, solidarity or social justice, [which] points beyond individual people’s lives (however deserving of our compassion) to society more broadly... This principle suggests a revised question: ‘In seeking to change the law to facilitate assisted dying for autonomous individuals in need of compassion and liberation from an otherwise burdensome death, can we be confident that life will not become more burdensome for other vulnerable people who also need our compassion?’<sup>157</sup>*

Therefore, Reverend Professor Gill's evidence concluded that the risks that the legalisation of assisted dying might pose to those who are vulnerable in our society cannot be justified by the benefits to those 'autonomous individuals' who wish to escape 'an otherwise burdensome death'.<sup>158</sup>

Professor Tim Maughan put forward a similar argument, commenting that the small number of people who would be likely to benefit from assisted dying legislation did not justify the risk to the much larger number of potentially vulnerable people:

*I recognise that there are many tragedies in life and that people respond to those tragedies in different ways. And that some people respond to the tragedy by wanting to have assistance to die. And this is of great concern and we cannot ignore these stories and these cases. Should we change the law because of them? I don't think so. Because I think that the evidence is: how many people have gone to Dignitas in the last 18 months? What was Keir Starmer's evidence? What was it — 20 patients the last year and 14 in this current year? We're talking about very small numbers of patients... the fact is these are small numbers and I believe that there are there are very many, very, very, very many more patients whose care would be in some way threatened if the law was changed... My view is that that should not, does not warrant a change in the law.*<sup>159</sup>

The specialist palliative care nurses who took part in Demos's focus group also shared these views about the relative risk of harm to vulnerable people in comparison to those who might benefit from assisted dying. One nurse said:

*It's a very small minority of people who would actually make use of it [assisted dying] and I think that for the sake of that minority, does everything have to change for everybody else, and do we have to put the vulnerable at risk?*

However, in their evidence others, including Lord Joffe, Debbie Purdy and Tony Nicklinson, rejected this interpretation of the optimum 'balance of harms' in our society, instead posing the opposite viewpoint. Lord Joffe wrote in his statement to the Commission:

*The unsubstantiated risks attributed to a change in the law by opponents of assisted dying must be weighed against the illegal and unregulated assisted dying practice taking place in the UK at present, and the suffering that will undoubtedly be endured by a significant number of patients who are currently denied the option to be lawfully assisted to end their suffering by ending their lives in a humane and dignified way.*<sup>160</sup>

Debbie Purdy argued that the risk of harm to vulnerable people posed by assisted dying legislation could be minimised by the inclusion of robust safeguards in law: 'I think it's not beyond our wit and wisdom to come up with solutions that provide support for people like me, and protection for people who would otherwise be pressured.'<sup>161</sup>

According to this argument, the significant benefits to people who require compassionate assistance to end their lives would outweigh any risks posed to potentially vulnerable people. Tony Nicklinson's evidence makes a point of rejecting paternalistic attitudes towards disabled people. He said that anybody with capacity should be trusted to make decisions on their own behalf:

*The nation is divided into two groups — those who are capable of making an informed, independent decision and those who aren't, as determined by the test of legal capacity. Those who don't have legal capacity cannot form a contract and because a legal document is an essential part of the scheme, are automatically excluded; they are thus protected.*<sup>162</sup>

Debbie Purdy and Tony Nicklinson also argue that the current law discriminates against disabled people by denying them the assistance they need to end their own lives; a choice that is not denied to non-disabled people who do not require assistance.

### **Non-discrimination in law and policy**

The ethical principle of non-discrimination offers another way of looking at the balance of harms argument. As with the previous ethical principles that have been examined, the principle of non-discrimination can be applied to arguments both in favour of and against the legalisation of assisted dying.

As observed above in relation to the risks posed to vulnerable people, many people who gave evidence to the Commission were concerned that discriminatory social attitudes towards people who are disabled or terminally ill might, if assisted dying were legalised, lead to pressure being put on these people to end their lives prematurely. One woman who has motor neurone disease, who gave evidence to the Commission anonymously, gave an example of discrimination she had experienced, when doctors and other people close to her had made negative assumptions about her quality of life:

*Every time in the past five years that I have been for a medical review or have changed doctors or seen a medical person or a solicitor or even a member of my family, I have been asked if I want to sign a 'DNR' [do not resuscitate]. And when I say 'No, in fact the opposite, I would like you to do everything in your power reasonably to resuscitate me', I'm looked at with shock and then even on occasion told what a horrendous quality of life I would have on a tracheotomy... I feel an increasing pressure not to have life-saving and expensive treatments and care.*<sup>163</sup>

This woman believed that the legalisation of assisted dying would simply provide more opportunities for doctors and other people to discriminate against her and other people with significant impairments by making negative judgements about their quality of life. Peter Bailey also argued that negative social attitudes towards disabled people can all too easily be internalised, leading to poor self-image and disproportionately increasing the risk of suicide for disabled people:

*It's not difficult to imagine how if you perceive yourself as a problem for everyone, that it's more likely that a disabled person would feel the best option is suicide. What's of crucial significance here is the level of negativity associated with this onset of impairment.*<sup>164</sup>

However, as mentioned above, Debbie Purdy and Tony Nicklinson promoted an alternative view: the decriminalisation of assisted suicide could address current discrimination against disabled people rather than exacerbate it. The discrimination that both Debbie Purdy and Tony

Nicklinson identify is that a non-disabled people may end his or her own life without threat of prosecution, but it is illegal for a person whose physical impairments mean they do not have the capacity to end their own life without assistance to seek such assistance. Debbie Purdy commented:

*I think we shouldn't be distracted by disability when we are talking about somebody's right to end their lives. And if they require help to do that, I think we've got to consider, to make sure that they have all the possibilities in front of them, all of the different options, and that society is aware that they have different needs because of disabilities, but I don't think we can allow somebody's physical disabilities to limit their choices. I want the same choices as you all have.<sup>165</sup>*

Saimo Chahal, the solicitor acting on behalf of Tony Nicklinson, described the legal challenge that he has initiated:

*Tony's legal challenge is to the blanket nature of the prohibition of killing in the law of murder, in so far as it applies to cases of genuine consensual killing. What is being requested in Tony's case is a Declaration under s.8 HRA [section 8 of the Human Rights Act] that the law, as currently framed, is incompatible with Tony Nicklinson's Convention rights under Article 8. Also, that Article 14 is engaged as the law discriminates against him as a person who is physically disabled and thus cannot take his own life without active assistance from another.<sup>166</sup>*

Tony Nicklinson has proposed to the Commission that the only way to address this discrimination is to provide disabled people with a legal option for requesting assistance to end their lives.<sup>167</sup> Notably the principle of non-discrimination leads Tony Nicklinson and Debbie Purdy to a conclusion about assisted dying that is diametrically opposed to others such as Peter Bailey or Baroness Jane Campbell.

Leading on from this, representatives from several organisations that represent people who have mental or physical impairments also argued that should the UK introduce any form of legislation to permit assisted dying, the approach taken in its implementation must not discriminate against disabled people. David Congdon, Head of Policy and Campaigns at Mencap, said, 'Mencap is opposed to changing the law to make assisted dying or euthanasia legal' and suggested that should the law be changed to permit assisted dying:

*From an equal rights point of view... then yes, one would have to say 'they [people with learning disabilities] ought to have the same right as anybody else', and one would fight to defend that, but there'd have to be the safeguards in place.<sup>168</sup>*

Dr Andrew McCulloch, Chief Executive of the Mental Health Foundation made a similar point on the importance of non-discrimination, stating that the Foundation does not have a policy position on assisted dying per se, but that it believes that any policy on this issue must not discriminate against people with mental health problems. For example, it should not be assumed that a person with a history of mental health problems must automatically lack capacity. We will return to this discussion of how assisted dying might affect potentially vulnerable people in chapter 4.

## Medical ethics

### The prohibition on doctors ending life

The Commission received a number of evidence submissions from doctors and professional associations that explicitly focused on the ethics of doctors' involvement in assisted dying.

As previously mentioned, Paul Philip, Deputy Chief Executive of the General Medical Council, said in his evidence to the Commission that the GMC does not have a policy position on assisted dying. Instead they emphasise that doctors must follow the law, and 'assisted dying is unlawful.'<sup>169</sup> The British Medical Association declined an invitation to give evidence before the Commission, but explained in their letter to the Chairman: 'BMA policy, made through the Association's democratic processes, is firmly opposed to assisted suicide and to doctors taking a role in any form of assisted dying.'<sup>170</sup>

A number of doctors who gave evidence to the Commission put forward ethical arguments opposing doctors' involvement in assisted dying and rejecting the idea that hastening a patient's death could be a legitimate part of a doctor's role. Professor Tim Maughan told us:

*The ethos of the health care environment is about health preservation, health recovery, rehabilitation; it is a life orientated health service. It's not a death service... My contention to you is that the health service is not the right environment for a death service.'*<sup>171</sup>

Another physician who submitted written evidence to the Commission anonymously commented:

*Hastening death of patients is not part of medical practice and any change in legalising killing or assisted suicide would damage the trust and relationship between patients and doctors and may harm the doctors themselves in taking on this role.'*<sup>172</sup>

He said that should assisted dying be legalised, it 'would be better if carried out by trained "assisted suicide practitioners", to keep this act separate from medical care'.<sup>173</sup>

In anonymous written evidence, a Glasgow-based GP said he thought assisted dying should be legalised:

*I think they [doctors] would inevitably become involved [in assisted dying] but this is part of the difficulty as it would profoundly change the doctor's role and could compromise their own moral standpoint which is fundamental to the trust placed in them to 'first do no harm'.*<sup>174</sup>

Written evidence provided by the Royal College of Surgeons echoed this viewpoint, should it become possible for medical professionals to facilitate assisted dying:

*It would fundamentally alter the role of the doctor and their relationship with their patient. Medical attendants should be present to preserve and improve life—if they are also involved in the taking of life this creates a conflict that is potentially very damaging.'*<sup>175</sup>

Dr Steve Dyer suggested in his evidence that the notion of patient choice only applies ‘when that treatment has been recognised as “safe”. If it is not “safe” then there is no expectation to offer it as a choice.’ Dr Dyer expressed concerns that should the choice of assisted dying be available, ‘a doctor would be effectively expected to offer this to his or her patient’, and that some patients could be extremely persistent in demanding particular treatments even if they clearly were not eligible.<sup>176</sup>

The physician cited above who submitted evidence anonymously made the argument that assisted dying is unnecessary, as legal options for ‘letting die’ exist already: ‘Self-suicide is an option for most people. Refusing food and hydration and accepting palliative sedation are already available to people. Assisting dying by actively hastening death should not be required.’<sup>177</sup> Reverend Professor Robin Gill examined the legal option of withdrawing life-sustaining treatment, referring to this as ‘the principle of liberation’ and citing the case of Anthony Bland as an example of its appropriate application:

*With modern nursing his insensate life might have been sustained for decades, had not the Law Lords’ judgment in 1992 allowed his treatment (including medically induced nutrition and hydration) to be withdrawn. I supported and still support this judgement, regarding it as an act of liberation, perhaps for Anthony Bland, and certainly for his family and for others since.*<sup>178</sup>

However, Reverend Professor Gill also observed that ‘subsequent analysis suggests that it [the Bland judgment] confused the prohibition of intentional killing in medicine (it does seem that the Law Lords wanted Anthony Bland’s life to end)’.<sup>179</sup>

### **The doctor’s role in relieving suffering**

Dr Adrian Tookman, consultant physician in palliative medicine, took a neutral stance on the issue of doctors’ involvement in assisted dying, explaining that he was willing to work within the legal framework for end of life care, whatever that might be:

*I want to give good care to the people I look after and the people I work with. I want to give good care, I want to make sure they get the very best care at a very vulnerable time of their lives, and I will operate within whatever framework is determined by society. Because that’s my job actually. [...] Indeed I think it is actually my responsibility and my duty of care to ensure that I manage my patients properly: they get the highest quality advice and we support them fully, through death and after death.*<sup>180</sup>

Similarly, Help the Hospices stated in their written evidence that ‘The priority should always be about caring for the individual and their needs within the established legal framework’, noting the important role of training and education in achieving ‘the best possible care and support’.

A number of doctors who gave evidence to the Commission went beyond this neutral position to argue that doctors’ responsibility to assist in relieving their patients’ suffering could justify the option of physician-assisted dying being made available as a legitimate part of medical care. Charles Bulman, a surgeon, commented in his written evidence to the Commission, ‘As a professional, I can recall numerous examples of patients who have requested



assistance to die and in almost every case I have felt that I denied my professional duty of care by my refusal to help.<sup>181</sup> Dr Elisabeth Macdonald, a retired consultant cancer specialist wrote in her evidence:

*It seems important that legislators are aware of the proper context and the full range of outcomes, some quite dreadful, currently experienced by patients and their families despite the availability of excellent palliative care... Partly on the grounds of humanity and partly from the stance of personal interest (in that none of us knows what our death holds in store) there is a case to be made for rethinking the law relating to our management of patients dying in severe distress and introducing medically assisted death with careful safeguards for the terminally ill who are suffering uncontrollably at the end of their lives.<sup>182</sup>*

A GP named Edward Southall who gave evidence wrote:

*Doctors should be able to provide their patients with a humane form of dying. In most cases this can be carried out by the patient themselves taking a medication given to them by the physician but in some circumstances might need to be administered by the Doctor.<sup>183</sup>*

The late Dr Ann McPherson, chair of the campaigning organisation Healthcare Professionals for Assisted Dying (HPAD), gave evidence to the Commission in the knowledge that the pancreatic cancer she was suffering from would soon cause her death. Dr Ann McPherson and her colleagues at HPAD stated in their evidence to the Commission:

*HPAD believes that healthcare professionals have a duty of care to their patients, which informs our belief that people should not have to suffer against their wishes at the end of life. Alongside access to good quality end-of-life care and the right to refuse medical treatment, we believe that terminally ill, mentally competent adults should have the choice of an assisted death, subject to legal safeguards.<sup>184</sup>*

In this evidence HPAD also argued that the prohibition on doctors assisting suicide in the UK has the potential to impact negatively on the doctor–patient relationship:

*In contrast, the fact that doctors cannot even discuss patients' desires for an assisted death under present guidelines seems to work against doctor–patient trust and the general principles of the End of Life Care Strategy of open discussion of death and fears related to death and dying. In effect, the law interferes with the doctor–patient relationship and as such a doctor cannot help or comply with patients' choices when they might most want help. Indeed, when they are at their most vulnerable, patients are not protected. In addition to being forbidden to discuss assistance, our members feel that by being unable to help people to die we are failing terminally ill patients who seek assistance. To us, such denial seems cruel and inhumane.<sup>185</sup>*

Notably, the Dutch 'defence of necessity', which was developed through a number of court cases in the 1980s and 1990s, recognises that doctors may legitimately perform voluntary euthanasia if the patient is experiencing 'unbearable and hopeless suffering' and they experience a conflict between

their professional duties to preserve life and relieve suffering.<sup>186</sup> This defence became the legal basis for the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, which came into effect in the Netherlands in 2002.<sup>187</sup> However, no such defence is available under UK law, which regards voluntary euthanasia as murder. The legal status of doctors and other healthcare professionals in relation to assisted suicide will be explored in more detail in the next chapter.





### 3 Perspectives on the current legal status of assisted suicide

The oral and written evidence submitted to the Commission during the past year has reflected a broad range of opinion on the effectiveness and appropriateness of the current law on assisted suicide under section 2(1) of the Suicide Act 1961, and the policy of the Director of Public Prosecutions (DPP) for prosecutors. To reflect this full spread of evidence we have divided this chapter into two parts: the first presents views that the legal status quo already meets the needs of our society and is an appropriate resting place for the law; the second explores views that the DPP policy is problematic and therefore requires further clarification or legal change.

#### **Evidence supporting the current DPP policy** **The law effectively balances competing demands**

As the discussion of ethical perspectives on assisted dying in chapter 2 has demonstrated, society's views on assisted dying remain polarised and there is an ongoing debate about the correct balance between competing interests. Some of those who gave evidence to Commission argued that the current compromise that has been reached in the law is the right one. Reverend Professor Robin Gill observed that 'The DPP's guidelines have motivation by compassion as a key feature' and suggested that they combine leniency — 'for five years people have not been prosecuted if they act compassionately' — with a concern to protect vulnerable people. He referred to the DPP guidelines as 'the last plank in place' and concluded, 'My own position now is that I really can't see what else we could reasonably want.'<sup>188</sup>

Dr Richard Huxtable referred to himself as 'a defender of the middle ground'; he thought 'the law roughly, but only roughly, is in the right place'. Like Reverend Professor Gill, Dr Huxtable suggested that 'the law adopts a nuanced compromise where it recognises that we are talking about prohibiting intentional killing or ending of life, but also dealing compassionately with those who do end lives in the situations you're addressing'. However, Dr Huxtable suggested that the law 'needs tidying up'. While Dr Huxtable would not support the decriminalisation of assisted suicide, he suggested that a different approach to euthanasia should be taken,

*going at least one step beyond the DPP policy and explicitly creating a legal category of assisted dying, mercy killing, call it what you will, and that would involve creating a specific offence, which could also be available as a partial defence to other charges like murder, manslaughter and the like... [assisted dying should continue] to be treated as a criminal matter, but dealt with more compassionately and leniently.<sup>189</sup>*

Dr Brendan McCarthy, who is adviser on health and social care policy to the Church of England Archbishops' Council, expressed a similar view at the seminar convened by Arts and Humanities Research Council.<sup>190</sup>

He argued that ‘the current law better addresses the goal of a coherent and compassionate society than does any change suggested to date’ and expressed concerns that a law to permit assisted dying would be likely to become ‘more relaxed as time goes on’ and cited the law on abortion as an example of this.

Professor Tim Maughan said in oral evidence:

*I think the current law has got it right... there are principles behind it which are very sound: doctors shouldn't kill their patients, doctors shouldn't be prescribing poison which kills patients, the vulnerable should be protected. These are fundamental principles and I don't think they should be changed.<sup>191</sup>*

David Congdon, the head of policy at Mencap, also thought that the DPP had ‘probably got the balance about right, in what is frankly a very difficult area’. He explained that Mencap had been concerned about the DPP’s interim policy, which included factors relating to ‘the person who wanted to die, whether they were disabled’ and that this might have ‘accentuated the slippery slope’. Therefore Mencap was ‘pleased that he moved away from that and looked more to the perpetrator’.

### **Prohibition combined with decisions to prosecute on a case-by-case basis**

The 1961 Suicide Act and DPP policy for prosecutors specify that while it is a crime to assist a person to commit suicide, even if there is enough evidence for a prosecution, the DPP must decide in each individual case whether a prosecution is in the public interest. DPP Keir Starmer QC giving evidence to the Commission said the process of ‘applying the policy to the cases on a case-by-case basis’ following the publication of the prosecution policy had been ‘difficult because these cases are all difficult’, but that ‘it does work reasonably well in practice’.<sup>192</sup> Reverend Professor Gill spoke approvingly of this feature of the law on assisted suicide, suggesting that a ‘current delicate balance’ had been achieved by the publication of the DPP policy and the DPP’s ‘continuing inspection of each case’.

Baroness Onora O’Neill commented:

*At present, [assisted suicide] is forbidden and it is unlawful and that's what gives the police the powers to investigate, noting that they do not prosecute very often and there are few prosecutions and few convictions.*

She said that she had considered the question of whether some individuals might be given ‘an advanced guarantee’ so that the person asking for assistance need not be concerned that their relative might be prosecuted. However, ‘for the sort of reasons I suggested about conflicts of interest and motivation, that could be quite a risky procedure and I would not be in favour of it’. Baroness O’Neill argued that decisions not to prosecute individual cases of assisted suicide would not bring the law into disrepute ‘because it is very difficult to bring certain sorts of prosecutions’. She said:

*The law is far more than an enabler of prosecutions and convictions. The law is also a symbolic system if you like, an indication that we are protecting people, even the vulnerable. That's what I would hope it can remain.<sup>193</sup>*

A disabled woman who took part in the Demos focus group in Preston who said she had mixed feelings about assisted suicide said she was in favour of preserving the current legal approach to ensure that robust protections were in place: 'I would keep it illegal, and then look at each case afterwards... I say this with some reservation though because the process is not perfect.'<sup>194</sup>

### **Maintaining the prohibition on assisted suicide protects vulnerable people**

The Commission found that the most frequently cited argument in favour of maintaining the current law on assisted suicide was that a clear legal prohibition on assisted dying reduces the risk of abuse to vulnerable people. Alice Maynard of the disability charity Scope told the Commission that Scope is officially opposed to any 'weakening' of the current prohibition on assisted suicide. However, she recognised that assisted suicide is a 'complex' and 'emotive' issue, and that disabled people hold strong views on both sides of the debate. She explained that Scope have formulated their policy position because:

*There are some very negative assumptions about disabled people's quality of life at the moment and there are inadequate support services and those can lead to people feeling under pressure to end their lives.*<sup>195</sup>

Peter Bailey, trustee of the board of Leonard Cheshire Disability, thought 'there should be no change in the current law on assisted dying', but suggested that if the law was to be changed, it should be made more restrictive rather than more permissive:

*I preferred it before it was moved to where it is now. I preferred it so there was no, even hint that this would be accepted in some way and we see so many cases come to court where someone has killed a disabled child, or a relative and it gets treated in a way which I think is somewhat lenient.*

Mr Bailey expressed concerns that if the law was to become more permissive towards assisted suicide this might impact particularly negatively on disabled people: 'Actually you would have additional opportunities and you would feel additional pressure and so it actually would be more unfair for disabled people.'<sup>196</sup>

Suzy Croft, a senior social worker at St John's Hospice told the Commission in her oral evidence, 'I don't feel there needs to be any change in the law around assisted dying.' She explained that as a society 'we are often invited to view disabled people with horror or pity. Disability is often deemed to be a state worse than death.' She felt that these assumptions are

*sometimes reflected, sadly, in the patients with whom I work. When people approach the end of their life they become increasingly impaired by their illness. They often are very resistant to going out in a wheelchair because they articulate that this is embarrassing and demeaning.*<sup>197</sup>

Suzy Croft was concerned that should assisted dying be an available choice, vulnerable people might choose it for the wrong reasons. However, she defined her objection as a practical rather than principled one:

*All things being equal, I do believe in freedom of choice. So I am not, I suppose, morally opposed to assisted dying. I think that my opposition is actually, I think, a very pragmatic one. I just don't think that it is safe or possible.*<sup>198</sup>

## **Evidence that the DPP policy and current legal status of assisted suicide are problematic**

### **The law on assisted suicide concentrates too much power in the hands of the DPP**

While some people who gave evidence to the Commission said they felt protected by the role of the DPP in presiding over every reported case of assisted suicide, others argued that this role concentrated too much power in the hands of one person and introduced unnecessary complexity into the process. Professor Raymond Tallis from Healthcare Professionals for Assisted Dying commented that since the publication of the DPP policy:

*Anyone who engages in assisted dying will, I think, feel more vulnerable to the lottery of the law, possibly, than they felt before. At least before they knew that there was going to be prosecution and they relied on juries to show compassion and mercy. It just seems to me that it has just made the situation more confused.*<sup>199</sup>

A disabled man who took part in one of Demos's focus groups said:

*What it boils down to is — Director of Public Prosecutions — why? Who elects him?... The legal system needs to be sorted out, you can't leave it to one man, unless that man's views are known before. For me, it's far too complicated in terms of the legal situation.*<sup>200</sup>

This man expressed concern that should another person be appointed to the role of DPP who had more hard-line views on assisted dying and interpreted the DPP policy differently, the leniency currently demonstrated in cases of assisted suicide could disappear overnight. Another participant said, 'It's like asking the Pope to make a decision [on] whether anybody can have a termination... Why should a lawyer make these decisions, there needs to be a much broader viewpoint.'<sup>201</sup> A woman diagnosed with a terminal illness who took part in the Demos research via email argued:

*Something so important should be a legal right, and not depend on the discretion of a certain individual. Even though the guidelines for prosecution have been published, there is no certainty for individuals that these will not change, or be interpreted differently by future DPPs.*<sup>202</sup>

### **A regulatory regime with robust safeguards would be preferable**

Others who gave evidence argued that by the time the DPP comes to investigate a case it is usually too late to prevent the assisted suicide from going ahead. According to this view it would be preferable to have a regulatory framework with robust safeguards to ensure that the person seeking an assisted suicide was making a voluntary and informed choice. Dr Tim Helme, a consultant old age psychiatrist, commented in his written evidence: 'The DPP policy does not provide any mechanism for additional consultation and supervision prior to the act, but actually discourages it.'<sup>203</sup>

Dignity in Dying shared this viewpoint, arguing in their written evidence:

*The prosecuting policy cannot provide sufficient safeguards to protect people, because all checks take place after a person has died, when it is too late to prevent potential abuse. In contrast, the assisted dying legislation that we propose would provide ‘up front’ checks and safeguards when someone requests help to die.*<sup>204</sup>

In oral evidence Professor Penney Lewis said, ‘I don’t think it’s possible using a factor-based regime like this to adequately regulate assisted dying.’ She argued that the criminalisation of assisted suicide is not necessarily effective in preventing cases from occurring, but it does limit the support that can be provided to both ‘victim’ and ‘suspect’:

*I would be in favour of a regime which has a form of regulatory oversight, that does not necessarily involve a criminal investigation for every case. The prospect of a criminal investigation... drives these sorts of activities underground and that generally results in a more distressing experience for everyone involved, including, as the DPP terms it, the victim.*

Instead, Professor Lewis suggested that ‘gathering evidence at a stage when you can actually engage with the person who is seeking assistance is of considerable value’.<sup>205</sup> Debbie Purdy told us:

*We shouldn’t be deciding after the fact whether or not we’re going to prosecute... I don’t think that decision should be made after somebody is dead because it is too late... The guidelines have been as clear as they could be given the law as it stands, but it still doesn’t give enough of a framework, that will mean that people’s lives are protected.*<sup>206</sup>

At the seminar convened by Arts and Humanities Research Council, Lord Warner raised the further problem that consistent failure to prosecute cases of assisted suicide that meet the ‘factors against prosecution’ identified by the DPP guidelines could ultimately undermine society’s respect for the law: ‘as the number of cases where no prosecution has taken place grows from the 34 cases to say 150 cases, many more will argue that the law is being brought into disrepute’. He suggested that over time this would put pressure on policy-makers to change the law.<sup>207</sup>

### **Absence of a factor based on suffering or medical condition**

Professor Penney Lewis and Professor Clive Seale both expressed concern that the DPP prosecution policy does not include a factor to limit eligibility for assistance according to the victim’s condition, such as terminal illness or significant impairment. Professor Lewis recognised that the DPP had removed the factor relating to the victim’s physical condition from the final policy in response to requests from disability advocacy groups. However, she argued:

*Without having any restriction on the victim’s condition or experience, for example his or her experience of suffering, the policy is now more liberal than most permissive regimes and fails to distinguish between on the one hand a terminally ill victim who is experiencing unrelievable suffering and a victim who is suffering from depression.*

Professor Lewis suggested that the danger of such an approach being discriminatory could be mitigated

*by considering, for example, the Dutch model, which instead of focusing on specific conditions that the victim suffers from actually focuses on the victim's experience of suffering and assesses that primarily from the victim's perspective.*<sup>208</sup>

Professor Seale said in his oral evidence that the DPP policy's approach of excluding medical practitioners from taking part in assisted dying, and failing to limit assistance to people who are terminally ill 'lays open the possibility of various abuses and problems':

*I don't really understand why the DPP in response to concerns from disabled people did not simply remove the mention of disability [from the final policy] and why he also removed terminal illness. I don't really follow the logic.*

Professor Seale pointed to a study by Bosshard on the practice of assisted suicide in Switzerland, where eligibility for assistance is not limited to people who are terminally ill. It showed

*sometimes people are assisted to die because they are elderly women who are tired of life, have no particular organic disease, or have something like arthritis, osteoporosis; in one case from Bosshard, he says 'general weakness, blindness or mental disorders, often depression'.<sup>209</sup>*

Professor Seale argued that because the DPP policy does not specify terminal illness as a requirement:

*It does seem to allow all sorts of people who we might consider vulnerable in this country, such as elderly... without organic diseases, to have assisted dying when perhaps that is a bit of a slippery slope.<sup>210</sup>*

### **The separate status of health and social care professionals**

When the DPP Keir Starmer QC gave oral evidence to the Commission, he discussed why he had included in his prosecution policy the factor in favour of prosecution that 'the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional':

*We thought that if the law remains unamended and in that form, it was important to distinguish between as it were one off acts of support or compassion and those that were engaged in the delivery of professional services or a business that would routinely, or more likely to routinely bring them into conflict with the law, because of the broad prohibition on assisted suicide... It's one thing to say, 'this is... a one-off compassionate act' compared with 'this is the provision of a service or a business', which inevitably involves a breach of the law.<sup>211</sup>*

If such a factor had not been included, Mr Starmer thought that 'Parliament might say we are really undermining the prohibition on assisted suicide'.<sup>212</sup>

However, while Mr Starmer was clear that this factor in favour of prosecution should only apply if the assister was acting in their professional capacity (as opposed to providing a family member with assistance to commit suicide), evidence provided by the Nursing and Midwifery Council (NMC) indicates that professional regulatory bodies may interpret this specific prohibition more broadly. Roger Thompson, Director of Nursing and Midwifery Policy and Standards at the NMC, commented:

*The issue for us is that you are a registered nurse and there are particular clauses within the code that certainly require you to uphold the law under any circumstances, but they also require you to uphold the good standing of the profession, whether you're on duty or not. So it's quite an important emphasis to make that you can't just switch that off and say, 'Well I'm not nursing now, I'm down the pub, I'm going to do something outrageous I don't care.' Well if that brings the profession into disrepute we might well take a view on it and there are a lot of very different circumstances that will be taken on.*

Therefore, if a health or social care professional assisted a relative to commit suicide in a private capacity and was not prosecuted, they might still find themselves subject to disciplinary action from their professional body. Oral evidence provided by Paul Philip, Deputy Director of the General Medical Council (GMC), also indicated that this was the case:

*The principle in GMP [good medical practice] is that doctors need to follow the law so the fact that the DPP doesn't prosecute does not mean that the doctor has not acted unlawfully. We may need to look at the bespoke situation and decide whether or not to do something about that. I suspect that in such circumstances, a doctor would find themselves being investigated under our fitness to practice procedures and could well be referred to a fitness practice panel for the panel to decide what the appropriate action should be... It would not matter in principle [if it was the patient's usual doctor or not], but we would need to look at the individual facts and what the interaction was and what advice was offered and what did the doctor know.<sup>213</sup>*

Simon Gillespie, Chief Executive of the MS Society, expressed concern about 'the perceptions of health and social care professionals that somehow they'll place themselves at risk with their regulator if they have those types of difficult and frank conversations with people that they're caring for'. This could mean that 'somebody in a very critical condition... approaching a very difficult phase of their life, may not be getting the support from health and social care professionals that they need and that they deserve'. Mr Gillespie referred to anecdotal evidence of 'a reluctance of healthcare professionals and social care professionals to engage with those sorts of discussions [about assisted dying], on the basis that people feel that even talking about the issue might render them liable to prosecution'. He explained that this problem was not limited only to doctors: 'One of the key relationships that someone with MS will have is with their MS specialist nurse, where that service is available.' However, a nurse might 'feel reluctant to have those conversations because of how they think that, you know, the Nursing and Midwifery Council for example might view their actions'.<sup>214</sup> Harriet Copperman, a retired nurse and specialist in domiciliary palliative care and member of Healthcare



Professionals for Assisted Dying, commented in her written evidence that “bending” the law in some instances and not others is entirely unsatisfactory. The law itself must be changed.<sup>215</sup>

### **Lack of clarity for health and social care professionals**

A number of evidence submissions expressed concern that the DPP prosecution policy was not sufficiently clear about what constituted ‘assistance’ under the policy and that a doctor or nurse’s concerns about breaking the law could make them unwilling to discuss assisted dying with patients, potentially damaging their trust relationship with patients and reducing opportunities to provide support.

Keir Starmer QC told us:

*We have been asked by a number of individuals to indicate whether conduct A, B or C would be a criminal offence. We are asked for that sort of advice a lot not just in this field but generally. And often it’s in complete good faith... But the position of the prosecutors has been historically that we won’t indicate in advance whether conduct is criminal or not... I do recognise that for professionals and others it can leave them feeling a little bit exposed when all they really want is some guidance... [but] we can’t give a cast iron guarantee that certain conduct will or won’t attract prosecution.<sup>216</sup>*

Dr Bown from the Medical Protection Society (MPS) told us, ‘We have an interest on behalf of our members in ensuring that there is clarity as to what is expected of them when they find themselves in difficult situations.’ Her colleague Dr Field explained that although the MPS does not receive many requests for advice on the law on assisted suicide, ‘it causes a disproportionate amount of anxiety’. Most of the calls about assisted dying were ‘related to the Dignitas organisation and the doctors’ involvement through their patients’. Dr Field said doctors’ concerns primarily related to three issues:

*First, working within the law; clearly. But also maintaining their patient confidentiality, which to them is one of their primary concerns. And finally, protecting the doctor–patient relationship at the time the patient is really the most vulnerable, the most vulnerable time of their life. And they often see that there is perhaps a conflict between those; between acting within the law, maintaining confidentiality and supporting their patient at a very difficult time, which is why they come to us.<sup>217</sup>*

Dr Field explained that the advice the MPS would give a doctor if their patient requested help in applying to Dignitas would be ‘a doctor cannot produce a report, because that would be seen... they would be liable for prosecution under the Suicide Act’. However:

*The request for medical records is different, because of course there is a duty to disclose, an obligation to disclose, in accordance with the Data Protection Act. And our advice to those doctors is, regardless of the fact that they know how those records are going to be used, they’re obliged to disclose them in those circumstances.<sup>218</sup>*

Dr Field commented that her advice to doctors had changed following the DPP’s guidance:

*Our advice up to the guidance from the DPP was that a doctor was unlikely to be liable for prosecution under the Suicide Act, if they kept this knowledge to themselves. They had a duty of confidentiality; it wouldn't necessarily be seen as facilitating an assisted suicide.<sup>219</sup>*

However, the MPS felt that 'the guidance imposes a duty on the healthcare professional and on the doctor to take reasonable steps to ensure that the patient is not being pressured into an assisted suicide'. As a result, the MPS now advises that doctors should 'disclose their knowledge to the relevant authorities'. However, Dr Field felt that this situation left many unanswered questions for doctors: 'should they disclose? When should they disclose? What is their position in relation to the law in this regard?'

Dr Field observed that greater clarity about the doctor's position with regards to the law would strengthen the doctor-patient relationship,

*because the doctor's then in a position to explain to his patient that he has... to some extent, a duty to disclose this information; that the law has made it clear that he is potentially liable in such circumstances, he's not doing this to disrupt the doctor-patient relationship, but this is how the law stands. And a patient is far more likely to accept the fact that a doctor has certain obligations or duties under the law and maintaining a good relationship than if the patient thinks that the doctor is just doing it because of a random judgement they've made.<sup>220</sup>*

Jane O'Brien from the GMC agreed: 'There clearly is an issue for doctors about what the law is and how they should understand it and there are some difficult areas in what constitutes assisting.' However, she reflected that 'we do think those are matters of law' as opposed to being areas in which the GMC could offer guidance. She explained that issues of whether a doctor can provide medical records under the Data Protection Act that may be used for a patient to travel to Dignitas 'are the difficult legal conundrums which the GMC is not empowered or equipped to answer'.<sup>221</sup>

Pauline Smith, End of Life Care lead for NHS West Midlands, expressed her concern that 'the current frameworks actually restrict people being able to talk about some of those issues', a view also expressed by Professor Joe Collier from Healthcare Professionals for Assisted Dying:

*The wording and the ambiguity and the difficulties are such that it means that we can't fully communicate with our patients when they are in a very vulnerable position. Others can, and that is the problem in a way. Others can who may not know as much — they may know as much, or more but they may not know what we know, as doctors. And that seems unfair to us and unfair to our patients.<sup>222</sup>*

Alan Cutkelvin Rees, who accompanied his terminally ill partner Raymond to Dignitas, told the Commission that his and Raymond's relationship with the GP had been very difficult: 'He never visited. At first his doctor was quite obstructive in providing us with the information that we needed to give to Dignitas, in relation to Raymond's application, namely, his medical records.'

Mr Rees explained, 'I could tell by his reaction that he [Raymond's GP] totally disagreed with what we planned to do.' However, the doctor did not discuss Raymond's decision with them or suggest any alternative treatment options such as palliative care. Instead, once they arrived at his office he simply provided them with copies of Raymond's medical records to send to Dignitas, while making his disapproval clear.

### **Problems associated with relying on amateur assistance**

Another key problem with the DPP policy frequently mentioned by those who gave evidence was that if doctors and other healthcare professionals are specifically prohibited from providing assistance with suicide, this puts an onus on friends and family members to provide assistance. However, as the right to die organisation Friends at the End observed in their written evidence, 'Killing oneself is extremely difficult', and amateur assisters may not have the knowledge, or emotional resources required to perform this role.

Dr Field from the MPS commented that 'We are aware of doctors being concerned that relatives have had pressure put on them to assist patients with their suicide. And the two situations I've been involved with were just such cases.' In Dr Field's experience, the problem was not with pressure being put on the patient to die, but 'the patient putting pressure on the relative, to assist them'. Peter Morgan, a social worker and member of the Practitioner Alliance Against the Abuse of Vulnerable Adults (PAVA UK), raised a related concern, observing,

*There is a general issue throughout this matter that relates to 'vulnerable adults' who are 'the suspect' as opposed to 'the victim'... Adults with a learning disability, a sensory impairment or a mental health problem could be put into the position of 'assisting' someone else to commit suicide without being fully aware of what they are doing while not lacking the capacity to understand it if appropriately informed.*

It is not clear in the DPP policy how such circumstances might affect the likelihood of prosecution.

Professor Penney Lewis expressed concern about the risks posed by assistance being given by amateurs:

*Assistance is likely to remain a relatively amateur activity, by which I mean someone with no medical training, carried out by people who have no experience in assisting death, and without the assistance or advice of professionals... This is worrying because unless the victim is fortunate enough to have a healthcare professional among their family and friends and that person is not treating them and therefore might escape prosecution, they're likely to end up in a situation which is quite burdensome on the suspect, or potential assistor, and also they run the risk of a botched suicide, of suffering during the death, and they lose out on the possibility of some form of medical screening, for example, for undiagnosed depression.*

Professor Clive Seale also expressed similar concerns about the potential for botched suicides:

*There is quite a lot of evidence from the USA and Australia, from the 1980s and 1990s where a kind of euthanasia underground grew up where by people were assisted to die by informal carers and in some cases enthusiastic medically qualified people, when AIDS was a terminal illness. And what happened here was there*

*were was a very frequent incidence of botched suicides with rather unpleasant and sometimes quite horrific consequences, which required better medical expertise to avoid or remedy. It seems to me that the DPP's guidelines preclude experts becoming involved in assisting dying, and that then runs this risk.*

Debbie Purdy argued that the DPP's preclusion of professional assistance increases the anxieties associated with committing suicide for people who are already in a vulnerable situation:

*If you choose to be at home, and all things being equal I would choose to be at home, [you have] the fear of not taking the right quantity or quality of drugs and ending up in a worse situation that I would be in anyway, and if any doctor helps me he is laying himself open to prosecution even under the guidelines.*

Dignity in Dying stated in written evidence that by removing the option of professional assistance in the UK, our legal system is effectively relying on the more permissive approach in Switzerland to fill this gap:

*Therefore the policy could be seen as discriminatory towards those who cannot afford, or who are not physically able to get to Switzerland, by leaving them facing the prospect of a more uncertain and painful suicide, and by continuing to deny them clarity in how the law will treat their loved ones.<sup>223</sup>*

### **Discrimination against people who do not have the capacity to end their own life**

As we have seen in chapter 2, in some of the evidence submissions it was argued that the current law on assisted suicide is discriminatory towards disabled people who are not physically able to end their own lives, 'because it takes away the right to determine where, when and how a person may die as soon as that person becomes disabled and needs help'.<sup>224</sup> Tony Nicklinson, who became paralysed following a stroke in 1995, commented:

*Such discrimination is wrong and would not be tolerated in any other situation. I wonder how the discrimination, when it is purely physical, squares with current legislation which states that it is unlawful to treat disabled people differently from those who are not disabled... A new law is required to reinstate this right of self-determination.<sup>225</sup>*

Saimo Chahal, the solicitor acting on behalf of Tony in his proposed judicial review claim against the secretary of state for justice, said:

*Tony's legal challenge is to the blanket nature of the prohibition of killing in the law of murder, in so far as it applies to cases of genuine consensual killing. What is being requested in Tony's case is a declaration under article 8 of the Human Rights Act that the law, as currently framed, is incompatible with Tony's Convention rights.<sup>226</sup>*

Ms Chahal explained:

*The current law disproportionately affects his [Mr Nicklinson's] right to personal autonomy as somebody who is too physically disabled to end his own life... In order to succeed in his claim Tony needs to demonstrate that some change to the law is required, even if it is a change that does not go as far as he would like.*

She said they were ‘invoking article 8 [under the European Convention on Human Rights] and 14 because of the discrimination element’.<sup>227</sup>

Debbie Purdy and Pauline Smith also argued that the law should not limit people with physical impairments from obtaining the assistance they might need to commit suicide. Debbie Purdy commented:

*The Disability Discrimination Act... intends that I should not be discriminated against. That as able bodied people, you shouldn't be able to do something that is prevented by my disability... and to be honest, ending my life is one of those things.*

Pauline Smith observed, ‘It’s legal to commit suicide and actually I think we would all be surprised by the number of people who make choices about their dying and commit suicide, we just don’t call it that’, but when people ‘are not able to do it on their own and need assistance, I think then that people don’t have the choices in quite the same way.’ She suggested that this inequality should be addressed.

Martin Green, Chief Executive of the English Community Care Association, expressed concern about there being unequal access to assisted dying or conversations about assisted dying for people who relied on paid assistants for social support:

*If we don't have a properly regulated system of personal assistance, what happens to the older person who is not in that space, who lives on the 22nd floor of a tower block in Tottenham, who never sees anybody but that person, who hasn't got the skills to be assertive and where do they go when they either want to challenge something the personal assistant does, or want to have a conversation about the end of life which might or might not be transferred by the personal assistant to the clinician or the clinician connected to the person?*

Martin Green and Bridget Robb were also concerned that in the absence of a legal route to obtaining professional support with assisted suicide, some people who employ personal assistants might be driven by desperation to ask their assistants to help them to end their life:

*We must protect personal assistants from being put in that position. They're employed by their employer, many of them won't be supported by professional associations or other groups who can give them this advice. It would be very, very hard for those individuals to say no.... [If we do not provide a legal system for assisted dying] we are going to leave some of the most vulnerable workers being pressurised to make some of these really difficult decisions and that is not fair for the service user, for the person that wants to make that decision about their own life, nor is it fair for those around them.*<sup>228</sup>

### **Disadvantages of travelling abroad to obtain professional assistance**

The written evidence provided by Dignity in Dying observed that ‘approximately 160 British citizens have been helped to end their lives in Switzerland’.<sup>229</sup> However, Pauline Smith from NHS West Midlands observed that this option is not available to everyone:

*At the moment we have a system where only some people can make that choice... if you can afford to go to Switzerland that's fine, but if you can't, then you're stuck within a system that doesn't even allow you to talk about it, never mind get access to it.*

Debbie Purdy also commented on the inequity of this situation:

*I don't think it's sufficient, because I still think it relies on for instance having enough money — the fact that I have a credit card that I keep clear to travel to Switzerland with. Not everybody is in that position, and I think that is a difficult thing. I don't think there should be a financial impediment to people utilising that.*

Some others who gave evidence expressed concern that if a person feels they are reliant on travelling abroad to obtain assistance to die, that person might feel compelled to make the decision to die earlier on, while they are still physically able to travel. A retired doctor who submitted written evidence to the Commission anonymously had personal evidence of this:

*Ann Turner [a retired doctor who obtained an assisted suicide at Dignitas] was a personal friend of mine and I admired her and her family. The need to travel abroad for the help she needed made her take the decision earlier than necessary if there had been a more liberal policy in this country.<sup>230</sup>*

Alan Cutkelvin Rees described the stresses involved in his experience of assisting his partner to travel to Dignitas:

*He [Raymond] was very ill travelling out. Dr Michael Irwin, who I assume that you are aware of, helped us to pay for the fee for Dignitas because both of us were claiming benefits, we had no money, no savings; we had no money to pay for the fee, which at the time was £2,200. And Dr Irwin's charity gave us £1,500 and then after Dr Irwin spoke to Mr Minelli [founder of Dignitas]. He said that he would accept a token amount from us so we actually paid £300. And without their help we couldn't have gone.<sup>231</sup>*

He said after Raymond's death he had

*various problems with some government departments regarding the funeral grant that I was entitled to because — I actually attended a tribunal twice. I appealed against their decision because they refused to give me the money on the grounds that his funeral was in Switzerland according to them, when it wasn't. It was in the UK. I eventually won the second tribunal.<sup>232</sup>*

The experience of travelling to Switzerland to access an assisted death was clearly very difficult for Mr Rees and his partner Raymond:

*Mentally it would have been far better for Raymond, knowing that it could have been done in the country of his birth and he was just totally disgusted that it wasn't. We did loads of research on assisted suicide or assisted dying, whatever you want to call it. And it was his choice; it was what he wanted to do. It was his choice, his body; he was the one suffering, no one else... If countries like Switzerland, for example, can have an assisted suicide procedure, done totally and utterly professionally and with lots and lots of compassion towards the people, then I can't see why the UK can't do that as well.<sup>233</sup>*



Bridget Robb from the British Association of Social Work suggested that as a country we don't believe that we should say to people, 'well you've got to travel the world if you want to be assisted in dying'. Instead 'we need to make provision within the UK for that to happen'.

### **The impact on friends and family of being treated as 'suspects'**

For some of those who gave evidence, the most damaging aspect of the DPP policy on assisted suicide is the fact that individuals who assist a loved one to end their life must experience the stress and strain of being treated as a 'suspect' in a criminal investigation, with the prospect of prosecution hanging over them for many months. In her oral evidence to the Commission Debbie Purdy explained the impact of knowing that her husband might be prosecuted for giving her the help that she needed to end her life:

*I now know that there is no way that I could get to Switzerland by myself without help, and that would mean I would implicate somebody else, and that is something I was not prepared to do. I was raised to take responsibility for my own decisions, and if somebody else was likely to face legal proceedings as a result of my decision, I wouldn't have let that happen, particularly not a person I love, and they would have been the only person that would have been prepared to take that risk.*

She said the DPP policy had increased her sense of security that her husband was unlikely to be prosecuted. However, she said that the DPP policy still did not provide enough security for her husband. She referred to a recent case in which a man from the north east of England had been assisted to travel to Switzerland by two people:

*The two people who accompanied him are still on police bail, 6–8 months later. Although they, I think, won't be prosecuted, it's very hard to grieve for somebody when you have had your house turned over and you are on police bail for something.<sup>234</sup>*

Dr Brian Payne, a retired consultant physician and geriatrician explained in his written evidence to the Commission that he had 'a very personal interest' in the issue of assisted dying:

*I have metastatic colon cancer, and while at present my condition is fairly good I have enough (too much) clinical knowledge to know how badly my life could end... Were I to be suffering intolerably with my symptoms I would wish it to be possible for my family and carers to support me in my dying, with active assistance.*

However, he felt concerned that in the current legal situation this might lead to his family having to experience 'an entirely inappropriate and distressing risk of intrusive police investigation as a result'.<sup>235</sup> Simon Gillespie of the MS Society also suggested that for bereaved family members such a police investigation 'is going to be pretty appalling for them as well potentially having just having lost a loved one'.

Alan Cutkelvin Rees said that after his partner Raymond's assisted suicide, the police had conducted their criminal investigation as sensitively as possible: 'I don't have a problem — didn't have a problem — with the police at all. They treated me with total respect. All the officers did.' This was clearly a very stressful experience for him nonetheless. Although ultimately Mr Rees

was relieved to find that ‘they didn’t charge me; they dropped the case’, he felt unfairly stigmatised by the process:

*[The police] also took my DNA, my photograph and my fingerprints, and I’m now in the process of trying to get them removed from the database because I consider that I’m not a criminal and I’ve done nothing wrong. Therefore, why should they have my DNA?... I don’t think I should have been arrested in the first place. I had not committed a crime.*<sup>236</sup>

Chris Broad gave evidence to the Commission about his own very difficult personal experience when his wife Michelle Broad, who was terminally ill, ended her own life and his family was subsequently investigated by the police under suspicion of having assisted her suicide. He explained that Michelle had been diagnosed with motor neurone disease and had made the decision ‘that she was not going to see this disease out, because it is a horrible disease’.<sup>237</sup> He told the Commission that the most stressful part of the experience before and after his wife’s death was the ‘fear of prosecution... My wife clearly didn’t want anyone to suffer when she had ended her life. And it was the fear of prosecution that was the main reason why she felt she had to go through this alone.’ Like Mr Rees, Mr Broad was very positive about the respectful manner in which the police handled their investigation. However, he told the Commission that the investigation had nonetheless had many stressful and upsetting elements: ‘Questions were asked of me and of my two children and they did take away evidence from the house, you know, computers and that type of thing. I didn’t realise that that was going to happen at the time.’ Mr Broad said that he understood it was necessary for the investigation to take place, but that he was most upset when the police removed personal items from the house, which were to be treated as evidence:

*Michelle had organised the end of her life remarkably well — left little gifts for her tennis club members and notes for me and the children, and what have you. And they just swooped up all of those things and took them away. I got straight onto the sergeant who was in charge and he was very apologetic, but said they were evidence and sorry that he hadn’t told me about those sorts of things, but he would get them back to me as soon as possible. And they were back within 48 hours, having photocopied and looked at the gifts and brought them back.*<sup>238</sup>

Mr Broad explained that he did not think his wife should have had to end her life alone:

*In a time like this anyone would need support who was facing such a traumatic time... I don’t know whether it was me wanting to have been there or whether I felt that she would have wanted someone with her at that time just to hold her hand... I feel that there should be an opportunity for patients who wish to end their life. I feel that there should be an opportunity for them to do that.*<sup>239</sup>

The Commission also heard evidence from Detective Inspector Adrian Todd and Detective Constable Michelle Cook from West Mercia Police public protection unit, who were responsible for investigating Daniel James’s parents following his assisted suicide at the Swiss Dignitas clinic in September



2008. Detective Inspector Todd said that during a meeting with adult social services that instigated the police investigation:

*We were told that Daniel [was] a 23-year-old man. He'd suffered a spinal injury during a rugby accident in 2007... He had become partly rehabilitated, but he'd gone on to make a number of suicide attempts. Following the fourth suicide attempt he actually declined any treatment. He was seen by a number of psychiatrists. We were told there were three psychiatrists who had seen him and they all felt that he had capacity.*<sup>240</sup>

Immediately after this meeting, Detective Inspector Todd and a colleague visited Daniel James's house to explain to Daniel James's parents that should they assist Daniel to end his life, they would be at risk of prosecution under the Suicide Act 1961. However, they found that Daniel James and his parents were not at home, and 'we then established that Daniel had gone abroad and we established that he had committed suicide at Dignitas'.

Detective Inspector Todd and Detective Constable Cook clearly did everything they could to minimise the upset to Mr and Mrs James caused by their investigation. After Daniel James's death, when Mr and Mrs James returned from Switzerland, Detective Inspector Todd explained, 'I chose not to arrest because I didn't think that was necessary on this occasion and I think the best thing we could do was be empathetic and compassionate' but it was necessary to interview Mr and Mrs James as 'we needed an account because evidentially we had quite a few gaps within the evidence chain there'. Detective Constable Michelle Cook interviewed Mr and Mrs James

*at a time to suit them because of course there was Daniel's funeral — there was all sorts of things to consider there — and we did everything at their pace. There was no need to rush things. Obviously we didn't want the situation to be worse for them.*<sup>241</sup>

Detective Constable Cook said it was difficult to conduct suspect interviews with Mr and Mrs James given the emotionally charged circumstances, but 'Mr and Mrs James were very dignified, very willing to cooperate and I think that sort of set the tone of the interview for myself and my colleague.' Detective Constable Cook also interviewed a third party who had financed the flights to Switzerland for the James family. Following these interviews, Detective Inspector Todd 'discussed the case in detail [with the Crown Prosecution Service] and we were quite satisfied that all three people had passed the evidential test'. He reflected, 'In many respects, that wasn't too complex. The complex part was the public interest test.'

Detective Inspector Todd told the Commission that he handed over the files on the case to the Crown Prosecution Service on 23 October 2008, and the Crown Prosecution Service decided not to prosecute Mr and Mrs James on the 9 December 2008. During the interim period, Detective Inspector Todd explained that Mr and Mrs James 'were really concerned, they genuinely thought they were going to go to prison. There was nothing we could say to them that would reassure them because we didn't know.' Detective Inspector Todd commented that the six week delay in informing Mr and Mrs James of whether or not they would be prosecuted 'certainly didn't help their situation and, at a very difficult time in their life, it made it very difficult'.<sup>242</sup>

In this chapter we reviewed the evidence submitted to the Commission on the legal status of assisted suicide following the publication of the DPP policy on assisted suicide. The next chapter will review evidence from health and social care practitioners on how the current legal status of assisted dying affects their relationships with patients and the potential positive and negative impacts that a change in the law in this area could have.



## 4 The assisted dying debate in the context of UK health and social care services

### **Access to end of life care, including health and social care services**

The most important recent policy development in end of life care has been the Department of Health's (DoH's) 2008 national End of Life Care Strategy, which aimed to improve access to high quality end of life care for all adults.<sup>243</sup> This very broad-ranging strategy identified 12 areas in which it would take action to improve the provision of end of life care in England:

- 1 *Raising the profile:* The DoH would work with the National Council for Palliative Care to raise the awareness of end of life care in our society and change people's attitudes to death and dying. This led to the Dying Matters Coalition being set up, which aims 'to support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make "living and dying well" the norm'.
- 2 *Strategic commissioning:* The DoH would develop a more integrated approach to planning, contracting and monitoring service delivery across health and social care.
- 3 *Identifying people approaching the end of life:* Improving the skills of health and social care staff (particularly those for whom caring for patients at the end of life is only one part of their work) to identify people who are nearing the end of life and ensuring they receive the care they would like.
- 4 *Care planning:* The DoH would make sure that people approaching the end of life have their needs assessed, their wishes discussed and their choices recorded in a care plan. The care plan should be accessible to everyone with an important role in caring for the person.
- 5 *Coordination of care:* The DoH would make sure that people nearing the end of life receive coordinated care across sectors (eg health and social care) at all times.
- 6 *Rapid access to care:* For people with acute needs, medical, nursing, personal care and carers' support services should be available 24 hours a day, 7 days a week.
- 7 *Delivery of high quality services in all locations:* Access to high quality end of life care should be available in all settings, including care homes, sheltered housing and ambulances.
- 8 *Last days of life and care after death:* The DoH would promote use of the Liverpool Care Pathway in a range of settings as a tool to improve the quality of support provided in the last days of life and after death.
- 9 *Involving and supporting carers:* The DoH would involve carers in decision-making, keeping them informed and providing practical and emotional support during and after the death.
- 10 *Education and training and continuing professional development:* The DoH would develop core competencies of health and social care staff to provide end of life care according to three main groups (those whose job is wholly focused on caring for people at the end of life, those who frequently provide end of life care, and those who infrequently provide end of life care).

- 11 *Measurement and research:* The DoH would improve measurement of the quality of end of life care as a lever for change.
- 12 *Funding:* The DoH would increase investment in end of life care to support the implementation of the strategy (from £88 million in 2009/10 to £198 million in 2010/11).

The End of Life Care Strategy identified a particular problem: while ‘most people would prefer to die at home. In practice, only a minority manage to do so.’ Therefore, a ‘vital sign’ chosen to measure the success of the strategy was the proportion of people who were dying at home, compared with those who die in hospital (18 per cent versus 58 per cent in 2008).<sup>244</sup> In 2010, the second annual report of the End of Life Care Strategy indicated that a small amount of success against this measure had been achieved as there was ‘a very slow trend away from deaths in hospital (55 per cent) towards death at home (20 per cent)’.<sup>245</sup> The 2011 annual progress report recognised that it is most important that people should be able to die ‘in the place of their choice’, which for some people might be in their care home if this was their usual residence.<sup>246</sup> Therefore, the ‘vital sign’ was revised to refer to the person’s ‘usual place of residence’. The 2011 report demonstrated there had been a continuing trend away from deaths in hospital. In 2010, 53.3 per cent of deaths were in hospital, 20.8 per cent at home and 18.5 per cent in care homes. Therefore, 39.3 per cent of people died in their usual place of residence.<sup>247</sup>

The Commission invited Professor Sir Mike Richards, National Clinical Director for Cancer and End of Life Care, to give evidence at a Commission meeting on the progress that had been made in achieving the aims of the End of Life Care Strategy, and the challenges that remained. When the Commission asked Professor Richards to sum up the strategy’s progress he said:

*At the infrastructure level, there is a huge amount we need to do. Training is one, getting the funding mechanisms right is another. I think also very importantly, how we measure whether we are making progress.*

He thought, overall, the strategy had been ‘welcomed’, and that there had been some change, but strategic health authorities

*haven’t yet made a large step change across the country and I think the area where we know we need to make the biggest change is probably in the hospital sector. It is where most patients die... and I think it is where we have the biggest cultural challenge... People in hospital medicine, and I speak having been in that area myself, are very much attuned to cure and to trying to make people live longer and may find this quite difficult. It comes right back to training from day one.*

When asked whether some groups were particularly disadvantaged in end of life care, Professor Richards replied, ‘There are a lot of groups who are disadvantaged, because in terms of specialist palliative care, it is the cancer patients if you like who are advantaged and almost everybody else is not.’ However, he made it clear that the strategy was about

*improving quality of care for everyone, irrespective of the location of care, whether it is a care home, a hospital, at home, in a prison, in a hostel, whatever, and for all conditions and all ages. It is a massive task but that is the aim.*

Professor Richards observed that pressures on resources for end of life care were likely to increase in coming decades:

*We are, interestingly at... a 50 year low in terms of the number of people dying each year. It was higher in 1950 and it has come down. It is now turning the corner and there are good projections through to 2030 and beyond, showing not only that the total number of people dying will go up in the country, but the age profile as you've indicated is going to change quite dramatically.*

He observed that as a result of this changing age profile, many more people would be dying when aged over 85, many of whom would be living in care homes, 'so that is the other area we need to get right'. Professor Richards recognised that the task of improving the quality of end of life care in care homes was starting from a very low base:

*A few years ago there was virtually nothing happening in terms of training care home staff in end of life care. That has changed, but as you well know there are 18,000 care homes in the country; it is a big task.*

He suggested that some care homes chains were already 'beginning to see the benefits of giving training in terms of staff retention. If you train the staff so that it is not so upsetting for them when the residents die, then the staff stay on.'

Professor Richards pointed out that the ten-year End of Life Care Strategy 'does not set out to try and do things for 2030 and beyond' but aimed to provide better care for people now and recognised that 'the problem is only going to get bigger in the future'. One important area was to improve the way that the quality of end of life care is measured:

*At the moment we do not have, I think, the right and the most sensitive measures of what the quality of care is. When we've got this new survey of bereaved relatives, I think that will be very valuable, because there are going to be sections of that survey that will say, 'was your relative at home for any of the past three months? Were they in hospital? Were they in a care home? Were they in a hospice?' etc. And there will be specific questions asked, so we will be able to see what the relatives say about the quality of care given in each of those settings.*

Professor Richards told the Commission about new evidence that the quality of cancer patients' end of life care varied according to the expertise of the nurses caring for them:

*We have just completed a cancer patient survey — 67,000 responses from cancer patients — all of whom had had an in-patient episode in the first three months of last year. The proportion who had confidence and trust in ward nurses was in startling contrast to the proportion who had confidence and trust in clinical nurse specialists. The clinical nurse specialist proportion was over 90 per cent; for ward nurses it was 66 per cent (from memory). That highlighted to me that there was an issue there. By the way, this may be cancer patients, but remember that cancer patients are located on just about every ward of every hospital. So I don't think it is necessarily any different for anyone else.*

Questioned about progress on improving the coordination of health and social care, Professor Richards responded:

*Have we made enough progress on that? No. Have we made some progress, both at a national level and at a local level? Yes. There are some places that have developed a pooled budget arrangement, which seems to me to be extremely sensible.*

This led to him reflecting on the forthcoming changes to how health care is commissioned:

*There will be a lot of emphasis on the GP consortia working with the local authority, through conducting a joint strategic needs assessment and then both sides have to be able to demonstrate that their action plans take account of the joint strategic needs assessment. The local authority side will be able to look at the consortium's action plan and [ask], 'Does that in any way reflect the discussions that we have had?' I hope that will lead to closer working between health and social care at the local level.*

Asked whether there had been a culture change for the better in the quality of hospital care during the last 10–15 years, Professor Richards replied:

*I don't think we have... I think that's why we are still getting reports like the Ombudsman's Report. And that is why I think we now need to say, 'This has to be an area that we really do focus on.'... I don't think that things have significantly improved in terms of that culture [the general culture of acute care] and that is something I think we really do have to look at seriously.<sup>248</sup>*

### **Unequal access to end of life care**

Professor Richards drew the Commission's attention to a review of palliative care funding that was soon to be published, which made a number of key points about problems with the current delivery of palliative care and the need to improve equality of access to high quality care. The first important point made by the review was on the level of geographical variation in funding for palliative care services:

*A recent survey by the Department of Health estimates that PCTs spent £460m on adult palliative and end of life care in 2010/11, with one PCT spending around £0.2m on specialist palliative care alone, and another around £21m. This variation means that one PCT spent approximately £186 per death on specialist palliative care, while another spent £6,213 and 61 per cent of all PCTs spend less than £1,000 per death.<sup>249</sup>*

The report also highlighted the varying levels of access to 24/7 community care. It observed that this was 'crucial to enable people to be cared for at home if they wish to do so', a key aim of the End of Life Care Strategy. However, 'in 2010, a Macmillan Cancer Support survey found that a full service of 24/7 community nursing was only available in 56 per cent of PCTs. Of the remaining 44 per cent, most provide 24/7 care to some but not all residents',<sup>250</sup> so the report concluded that greater investment in developing community services was needed.

Overall, the palliative care funding review calculated that around 470,000 people die in England each year, although not all of these people require 'palliative' (end of life) care. It estimated that each year around 355,000 people in England need some form of end of life care. When the authors compared those who receive specialist palliative care (about 171,000 people) with the total figure of 355,000 and accounted for the possibility that a certain proportion of these people were having their needs met by generalist end of life care, they estimated that 'around 92,000 people per year have unmet [specialist] palliative needs'.<sup>251</sup>

A number of other health and social care professionals who gave evidence to the Commission also commented on the problem of unequal access to high quality end of life care. For example, Suzy Croft, a senior social worker at St John's Hospice, told us:

*Although specialist palliative care is well developed in Britain, it is also based on a post-code lottery. It is unevenly distributed around the country. There is unequal access to it in terms of conditions: people with end stage heart failure, COPD [chronic obstructive pulmonary disease] and another range of conditions often don't access that care. Also, other groups who don't access it will be people from minority ethnic groups, homeless people, those with drug and alcohol problems, asylum seekers, refugees and prisoners with limited access to palliative care.*

She expressed concern that cuts to public services would exacerbate these problems:

*Coupled with these issues we are now facing a time of unprecedented cuts in the services and support for vulnerable people in our society. I meet people struggling to manage in their daily lives with lack of social support and services that do not fill the gaps.*

Ms Croft gave an example:

*Currently, in the borough in which the majority of the patients with whom I work live, there is now no meal preparation service offered for those receiving social care whatever their condition. I am currently working with a 32-year-old woman, dying of an advanced cancer, who is not well enough to cook a meal... The carers are not even allowed to make a sandwich for her.<sup>252</sup>*

Bridget Robb, development manager for the British Association of Social Work, described the same concerns that a reduction in social care funding would impact very negatively on many people's quality of life:

*This is a very tough climate that we are in and we are very, very concerned that the money that people will get through the benefit system, but through society generally, will put enormous pressures on individuals and on those who are trying to care for them.<sup>253</sup>*

Dr Adrian Tookman, a consultant physician in palliative medicine and medical director of a hospice, described the quality of palliative care services as 'patchy' and 'disparate'; while the aspiration is to have 'high quality services offered seven days a week, nine to five, with access to specialist advice, out of hours', the reality was that some hospitals were only operating a service 'five days a week, nine to five'. He said it is still the case that people with cancer are more likely to access specialist support



than people with other conditions: 'I still think there is a reluctance between many of my colleagues to manage highly complex patients, particularly with non-cancer conditions.'<sup>254</sup>

Martin Green, Chief Executive of the English Community Care Association, expressed concern about the standard and availability of end of life care in care homes and domiciliary care:

*So if you don't have that good primary care engagement, I think there's also a lot of misdiagnosis, around for example depression, which gets misdiagnosed as dementia, and there is this issue about a lot of people when they become old, you know, people say it's because you're old, and they don't start looking at whether it's a condition and they start to just put everything down to age. And the issue about depression and dementia, there's also a big issue I think about pain control generally, but I think certainly in care settings, and also more importantly I would say, because at least in care settings there are people around who can see and judge whether you have a pain response, but in your own home you might have two hours, at two points in the day, with a domiciliary care worker. What happens to you when you're in pain for the following 22 hours?*

He also highlighted particular challenges around dementia in end of life care:

*One of the elements of dementia is that it can often change people's personalities, their perceptions. So, in terms of where you position yourself in relation to an end of life care legal structure, there is a very difficult point when people who may have made advance decisions but later have dementia, to what extent are they fully engaged with that decision now? Though they may have been engaged with it previously. So that is a challenge in terms of how you develop an approach to this.*

Mr Green described the changing role of care homes in end of life care: 'People are now getting care home places literally at the end of their life and they are end of life care placements.' He expressed concern about the role of funding constraints in driving local authorities' decisions about care placements: 'The general premise is that you don't get a care home place if it's publicly funded until probably the last 18 to 24 months of your life.' In response to this growing role of care homes in providing 'end of life placements', Mr Green suggested that 'the planning, and the care planning particularly, should take account of that and the conversations about [end of life] preferences should start at the care planning stage'.<sup>255</sup>

Representatives from Scope, the MS Society and Action on Elder Abuse also challenged the quality of end of life care services that were available to particular social groups. Alice Maynard from Scope commented, 'There are serious inadequacies in support services. We know from the work that we do with disabled people, our service users and their families that there are negative assumptions made about disabled people.'<sup>256</sup> Simon Gillespie from the MS Society described end of life care as 'extremely patchy across the UK'. He emphasised the need for people to be able to have 'a frank discussion' with health or social care professionals and carers 'about what is going to happen next whenever that might be and what will happen after they've gone... [there are] significant issues about some of the practical points about where palliative care and end of life care is given'.<sup>257</sup> Gary Fitzgerald, Chief Executive of Action on Elder Abuse, said:

*I'd have to say to you, based on all of the reports that have come out over the last 10 years, all of the evidence we have got from our helpline, and I'll say both in social and health care, older people do not have a good experience, in general, of either health care or social care.*

He said experiences of older people in particular hospitals 'are indicative of an environment that does not recognise the human being in that older person, but sees them as a process'. Mr Fitzgerald suggested that ageist and discriminatory attitudes towards older people were underlying these failures in health care:

*Our assessment would be: ageism actually does sit at the heart of the problem but that ageism then lends itself to how we react either from a governmental point of view or a societal point of view. We would not tolerate some of what older people experience if we were talking [about] other groups in society. But there is a link between people's perception of age and death, an assumption, 'well they died because they were old weren't they', and that's not necessarily true.<sup>258</sup>*

### **Generalist versus specialist end of life care**

A number of health and social care professionals who gave evidence to the Commission emphasised the point that there is often a damaging misconception that 'end of life care' is the sole responsibility of specialist palliative care services, as opposed to generalist services such as GPs, care homes and domiciliary care providers. Professor Sir Mike Richards said:

*I think it is very important to think both about what we need to do in the specialist field, but what we need to do much more broadly beyond that. There are something like 5,500 people in the country [working in specialist palliative care], whose job it is to deal with people that are dying and that is exclusively their job. There are hundreds of thousands of health and social care professionals who will in some way or other give care to people who are approaching the end of life — every GP, every district nurse, almost everyone working in any department on medical wards in hospitals, whatever it may be. So there is a vast number of people. And of course, very importantly, the care home sector as well.<sup>259</sup>*

Pauline Smith observed that 'a lot of death and dying is generalist':

*Actually for a number of people who are dying, they are dying because they are old and they are frail... But we tend to think of things in a medical model, so they are in a disease and somehow the health care system is going to manage them and control them, but, I'm a human being and some of that needs to be outside of the health system.*

Ms Smith also commented on the importance of using the right terminology:

*Let's take palliative care out of the equation, because you're talking about specialist; not everybody needs palliative care. Let's talk about end of life care, because every generalist should provide that but they don't. So do they [disabled people] get access to it? Probably not, because not every generalist is very good about talking about the life journey and how that includes death and dying and what might happen at that.*

She thought it important to start conversations about end of life care earlier:

*We are in a situation where if you are just trying to intervene at the end, you are in a vicious cycle because not enough has been done further upstream. So, for me, upstream interventions are always important to focus on.*<sup>260</sup>

Martin Green emphasised the importance of improving the skills of workers in care homes, and the relationship between care homes and GPs, to ensure that people in care homes have adequate access to end of life care:

*Sometimes when people are in care settings, the relationship they have with their care provider is probably their most important and constant relationship in their life and so any thoughts people have about end of life, any discussions or debates they want to have, they'll often have them with their care worker... The challenge there is to get a level of consistency and quality into the workforce, and part of that's about the remuneration and professionalisation, which governments talk endlessly about and they seem to think status and long term engagement is disconnected from how much money is in the system and how much money is paid to each individual care worker... The engagement of primary care with, particularly, care homes is extremely poor. Often care homes cannot get GP and primary care services. They seem to be in some kind of no man's land between health and the community and nobody wants to take responsibility for them... It is a major challenge when you're dealing with end of life issues, some of which are very medically focused. If you haven't got very good support from clinicians, then it's very difficult for social care workers to lead on some of those issues.*<sup>261</sup>

### **Evidence that death is too often treated as an emergency**

Another concern frequently mentioned by those who gave evidence to the Commission was the fact that people's deaths were too often unnecessarily treated as an emergency, leading to people dying in stressful and unpleasant circumstances:

*Sometimes... because of the poor engagement with primary care and primary care services, people find themselves being blue lighted for their last few hours to an acute hospital, which is not perhaps the best way forward.*<sup>262</sup>

Martin Green acknowledged that work on improving end of life care in social care settings using the Gold Standards Framework and the Liverpool Care Pathway was bringing improvements and 'more people are dying in the care home'. However, there was still a tendency among lower skilled members of staff 'dealing with somebody who is going into a very serious medical condition, emergency position' to dial 999:

*That's why it's really important to have a very clear plan on what people's preferences are at end of life so staff can... enable people to have the end of life they want, rather than blue lighting and having their last two to three hours in an acute setting, which is not the best place to be.*<sup>263</sup>

Bridget Robb reiterated this point:

*So often from the circumstances of people I know who have gone through this, so often the support at the end of life is treated as an emergency... and sometimes that isn't always what people wanted. OK, there is a medical need, but they didn't want to be rushed into hospital, they didn't want to have the paramedics out treating it as an emergency. What they wanted was to be supported through a difficult transition.<sup>264</sup>*

Pauline Smith told us that the involvement of emergency services can prevent people's wishes for their end of life care being realised:

*We have had problems with our ambulance service not recognising an advanced directive that has been written by the person, who then becomes a patient and a 999 call is made by a relative but actually what they want is to not really go to hospital, they just need some acute management which hasn't been addressed properly... We are bad at that whole system.<sup>265</sup>*

### **A need for more open discussions about death and dying**

At the centre of many people's thoughts on how end of life care could be improved was the need to improve how death and dying are discussed at a societal and a personal level. Professor Sir Mike Richards told us:

*At the societal level we know that there are taboos about talking about death and dying and we believe that that impacts adversely on care. People don't know how to talk about it with their own families, so they don't initiate those discussions.*

He said the Department of Health has funded the Dying Matters programme 'to try and stimulate what I suppose now could be called a Big Society debate about end of life care and about getting people feeling more able to talk'.<sup>266</sup>

In her oral evidence Baroness Onora O'Neill said:

*We need to make dying less a matter of fear and isolation and pain. And that means better palliative care. And that includes better hospice at home, where home is able to take the strain, and these seem to me to be sort of practical needs, not cheap, but practical and can make a lot of difference. I also think, and this has something to do with medical education, it has to be regarded as not a matter of shame to fail to do heroic things to dying people. The default should not be always: let's have one more round of this, of this, of this. And I think that those are compassionate changes that we could make.<sup>267</sup>*

Professor Richards explained that measures to improve how health and social care professionals communicate about death must be at the centre of efforts to improve end of life care:

*I think the whole issue of how we communicate and how we train doctors, nurses and others to be able to talk better and feel more comfortable about having those conversations, I think this is the biggest single challenge that we have in this country. Because once you have done that, the second step is planning people's care, coordinating the care, delivering the care.<sup>268</sup>*

Bridget Robb also discussed the need for more open conversations, commenting,

*As professionals we [social workers] hope that your Commission and this ongoing discussion will perhaps give us all a bit of a push to be more constructive in our thinking with people about what is the role of professionals in supporting people as they come to their death.*

She admitted that too often social workers are ‘caught up in the denial of death as well as everyone else’. She suggested that greater transparency about death was needed:

*We put together all sorts of intricate care packages or support people in making all sorts of intricate decisions about the way people want to run their life but all of us have too often ducked the issue of, ‘well, how do you want this to end? How do you want your death to be supported? Who do you want involved and how do we make that happen?’, as though it doesn’t happen to us all.<sup>269</sup>*

Simon Gillespie told the Commission about the findings from research that the MS Society conducted in partnership with Parkinson’s UK and the Motor Neurone Disease Association to explore the provision of end of life care and ways of improving it. The research found that ‘social care professionals felt ill equipped to have the frank discussions that many approaching the end of their life wanted to have with them’. In response to this research Mr Gillespie said:

*I’d like to emphasise the importance of choice in palliative and end of life care and indeed exercising that choice depends on three key factors: the existence of genuine options, information about those options and support for the individual in making their decisions.*

He expressed concern that the GMC’s guidance for doctors on end of life care was too focused on prolonging life:

*I think that sets a tone in which having a conversation about assisted dying becomes very difficult. I think the wording that is used is ‘the presumption will normally require you to take all reasonable steps to prolong a patient’s life’. And those are the issues under which of course the GMC will potentially be taking somebody through a fitness to practice procedure if they don’t appear to be obeying those.<sup>270</sup>*

Pauline Smith also highlighted the difficulties for professionals in responding to patients who initiate discussions about assisted dying:

*The Department of Health is quite limited in the way we think about assisted dying. In fact, it’s made it even more hidden than it was. It provides a very medical and paternalistic model and it tends to focus on choice being around the setting for death and ignores too much else about decisions for death and dying.*

She explained that her work for NHS West Midlands was about ‘giving death and dying back to society and how do we support that’. She thought that issues of assisted dying and suicide were ‘much too hidden and

unarticulated and unvoiced. I am very concerned about the debate, which tends to polarise, and all it does is further polarise. And that's different to articulating and dialoguing.' Ms Smith discussed the work she has been doing to help practitioners to discuss these issues: developing 'guidance for staff about how they should allow people to be able to have those conversations even if it was against the law for them as practitioners to be able to assist in that dying'. She said that in a film she has developed as a training tool called *Dialogues in Dying*:

*We included assisted dying... as a way of being able to illustrate, when patients and carers raise this in sessions, how might staff respond and what are their responsibilities to do that... At the moment we are focusing very much on person-centred care, which is a counter culture to a paternalistic 'I do to you' model. So... we are doing a lot of that at the moment; on advanced care planning and living wills and being allowed to articulate that and it is meeting a lot of resistance.*<sup>271</sup>

### **Experiences of suffering and the desire for a hastened death**

Data from several recent studies show that in the advanced stages of cancer and non-malignant conditions associated with chronic pain, especially when patients are not receiving specialist care, the prevalence and severity of pain is still surprisingly high in our modern western society.<sup>272</sup> In Breivik's 2009 study covering 5,084 cancer patients in 11 European countries, 56 per cent reported suffering moderate-severe pain at least monthly. Most of these patients were not receiving specialist pain management. On average 72 per cent of cancer patients across the European countries surveyed reported pain, but surprisingly, in the UK the percentage was higher at 77 per cent. The authors found that pain associated with cancer was described as distressing by 67 per cent of patients, and an intolerable aspect of their cancer by 36 per cent; 32 per cent reported they felt so bad they wanted to die.<sup>273</sup>

Suicidal ideation in cancer patients is not just because of pain experience, as the 2010 literature review by Robson et al showed.<sup>274</sup> Other important factors that predispose cancer patients to a higher risk of attempting suicide — apart from potentially treatable psychological illnesses such as depression — include increasingly poor physical functioning, physical distress, hopelessness, gender, marital status and having specific cancers, notably lung, stomach, and head and neck cancer. These three cancer sites are often associated with high symptom burden including pain, breathlessness, vomiting and extreme weakness from poor nutrition.

In contrast to the Breivik et al survey in 2009, in the same year Laugsand et al studied 3,030 cancer patients who were receiving specialised palliative care in European palliative care centres.<sup>275</sup> Although they were under the care of experts, 32 per cent of patients overall still reported that their pain was moderate-severe, and they had the following symptoms: fatigue (51 per cent), generalised weakness (53 per cent), anxiety (30 per cent), depression (19 per cent), constipation (20 per cent) and breathlessness (16 per cent).

A small number of academic studies have set out to investigate which personal characteristics and circumstances might explain why some people with terminal illnesses express the desire for their death to come sooner, and others do not. A Canadian study by Chochinov et al published in 1995 set out to examine the presence and persistence of a desire for a hastened death in



200 people who had been diagnosed with terminal cancer.<sup>276</sup> The researchers developed a Desire for Death Rating Scale and used this to interview the patients, giving them a score between 1 and 6. They found that 8.5 per cent of the patients had a 'serious or pervasive' desire for death, rated at 4 or above on their scale. When they explored how the characteristics of these patients differed from the rest of the group, they found that a 'serious' desire for death was particularly associated with a diagnosis of depression; 58.8 per cent of the 'serious' group had a diagnosis for major or minor depression, while only 7.7 per cent of those who had no desire for death or a fluctuating desire for death had any kind of depression diagnosis. There was also some association between a desire for death and reporting a higher level of pain, although some people with a serious desire for death reported no pain at all. The study also found that a serious desire for death was weakly associated with lower levels of family support (but not lower levels of support from friends or professionals). The researchers were only able to interview six of the study participants who reported a serious desire to die at the follow-up two weeks later. They found that 'four showed a decline in their desire to die to the extent that they no longer scored above our operational cutoff for defining a serious and pervasive desire'. However, the other two participants still reported a sustained wish to die.<sup>277</sup>

Following Chochinov et al's study a number of subsequent studies attempted to replicate these findings. In 2007 a Canadian study by Rodin et al reviewed this body of research and found that among nine quantitative studies of the desire for a hastened death among cancer patients in a number of different countries and with varying sample sizes, the proportion of patients with a 'high' desire for a hastened death ranged from 0 per cent to 28 per cent.<sup>278</sup> Some of these variations may be explained by the fact that the study participants were receiving treatment in a broad range of settings and differed in the extent to which their illness had advanced, while a number of different research tools for measuring 'desire for a hastened death' were used. Rodin et al's study of 326 cancer patients who were expected to live for at least a further six months or more found that 37.1 per cent of the sample had no desire for a hastened death, 53.1 per cent had a low score, 8.3 per cent had 'mildly elevated' scores and 1.5 per cent had a 'high' desire for a hastened death. The study found that factors associated with the desire for a hastened death included:

*higher levels of depression, hopelessness, physical symptom, frequency, severity, and global distress, symptom distress, pain intensity, and pain interference... and with lower levels of physical functioning, spiritual well being... social support, self-esteem and living alone.*<sup>279</sup>

In 2011, Dr Annabel Price et al published the results of a study that examined the desire for a hastened death among 300 terminally ill patients who had been newly referred to a south London hospice in 2008.<sup>280</sup> The researchers used the same Desire for Death Rating Scale developed by Chochinov et al and the particular aim of this study was to shed more light on the factors that influence individual people's desire for a hastened death and to explore the extent to which the desire for a hastened death remained constant or attenuated over time. Initially 300 participants were interviewed and 213 participants were interviewed a second time four weeks later. This study found that at the time of the first interview 11 per cent of participants

had some desire for a hastened death and 3.7 per cent had ‘a more serious or pervasive’ desire for a hastened death. By the time that those who had any desire for a hastened death at the first interview were interviewed a second time, 35 per cent no longer had such thoughts. However, among those who had no desire for a hastened death at the first interview, 8 per cent had developed these thoughts by the second interview. At the second interview 14 per cent of participants overall had a desire for a hastened death, a higher proportion of the group than at the first interview. Only one participant had a ‘strong’ desire for a hastened death at both time points.<sup>281</sup>

The study identified a number of variables associated with the greater likelihood of a desire for a hastened death at the first interview. The first of these was that participants with non-malignant disease were more likely to have a desire for a hastened death than those with metastatic cancer. There was also an association between depression and desire for a hastened death; 63.6 per cent of the group with desire for a hastened death were identified as having some form of depressive disorder. There was also an association with suicidal thoughts, although almost a quarter of those with a desire for a hastened death did not have suicidal thoughts. People whose quality of life and physical, cognitive and social functioning scored higher were less likely to have a desire for a hastened death. Social factors including financial difficulties and lower levels of social support were associated with greater likelihood of a desire for a hastened death. Illness-related factors including having a symptom burden that had a greater affect on the individual’s identity or emotions, and a lower sense of personal control and control over treatment were all found to be associated with a higher likelihood of a desire for a hastened death. People who felt they had experienced a greater loss of dignity were also more likely to report a desire for a hastened death. However, contrary to some previous studies, religious observance was not found to be associated with the desire for a hastened death.<sup>282</sup>

The authors of this study observe that a number of remedies available through palliative care services, such as symptom control, treating depression and improving social support, might contribute to reducing the desire for a hastened death in people with progressive incurable illnesses. They also observe that patients with ‘a persistent wish for death’ made up only a small minority of those who communicated such wishes at any point during the research.<sup>283</sup>

Quantitative research by Professor Clive Seale has explored the frequency with which doctors who had recently cared for one or more dying patients encountered their patient(s) expressing the wish for a hastened death. This research found that in just under 10 per cent of cases the patient had expressed the desire for death. The doctors felt this wish had been ‘clearly’ expressed in 4.2 per cent of cases and ‘not very clearly expressed’ in 5.6 per cent of cases; 74 per cent of doctors thought that the patient’s desire or a hastened death had not reduced over time and 27 per cent thought that it had (21 per cent thought this was in response to the care provided). If the patient died in a hospice or palliative care unit, the doctor was less likely to think that the request had persisted, and was more likely to think that the care had influenced the reversal of the request (39.4 per cent compared to 18.2 per cent of deaths that took place in other locations).<sup>284</sup>

At a number of oral evidence sessions held by the Commission, we asked practitioners giving evidence about their experiences of patients having expressed the wish to have their death hastened. Pauline Smith explained the difficulties of discussing this topic with patients:



*What I get told, either when I am with patient [or] carer groups, I get told it informally, or staff tell me because they are not quite sure how to manage the situation. But we have never really asked, and I think even if we did, because it is not... it's almost not OK to say; I'm not sure we'd get a true reflection.*

Ms Smith said she had more direct experience of this issue when she had previously worked at a hospice:

*It's interesting that I was the one person where patients would say to me, 'I would quite like to talk about euthanasia'... so I know that people have these [thoughts], I think we just don't know how many.<sup>285</sup>*

Suzu Croft thought some patients have a fluctuating wish for an assisted death:

*I am actually aware of, I do know of or know about a couple of people who have gone abroad [to be assisted with suicide]. But mostly, I think when you talk to people, again they may say one day that they would like it and then the next day you find they are just on a different level altogether.*

Ms Croft expressed concerns that if assisted dying was legalised, people could find themselves on a formal route to access assisted dying before they had properly thought this through:

*It could be quite scary for people if they mentioned it and then suddenly they found they were in the middle of a formal process to formally discuss it, whereas in fact what often happens, as I said, is that you go back to talk to someone the next day and they are just talking about completely different things.<sup>286</sup>*

The Commission received many pieces of anecdotal evidence from people who had friends and relatives who experienced unrelieved suffering and requested assisted dying but could not receive it. Some of this evidence came from healthcare professionals who felt frustrated that they were unable to assist. Dr Edward Southall, a GP, told us:

*I recently watched my mother-in-law suffer for two years after a severe stroke that left her bed bound and aphasic, her worst fear. She kept asking for us to end her life so that she could end her misery. We were unable to help and so she suffered.<sup>287</sup>*

### **The role of end of life care in relieving suffering and the desire for death**

Three palliative care specialists including Professor Michael Bennett, Dr Adrian Tookman and an anonymous hospice medical director gave similar assessments of the symptoms that palliative care is and is not effective in treating. The hospice medical director told us the hospice was a lot better at getting on top of 'symptoms like [physical] pain, nausea and vomiting'. However, he recognised that some types of physical suffering can be harder to address: 'Patients do fear some physical symptoms such as weakness and lethargy and problems with their swallowing or breathing, the fear of suffocation.' Overall, he suggested that patients' suffering associated with loss of control was the most problematic:

*I would say that it's also patients who want to have control and they can see that they are deteriorating and then think 'I'm losing control, I want to have some control' [who suffer the most]. They almost feel that the only control they've got is control over their death — the control they'd like.<sup>288</sup>*

Professor Michael Bennett said that as specialists in palliative care, 'we can treat particular symptoms quite well and we might be able to alleviate pain or breathlessness, not always of course, but in general we can generally do a good job with that'. He also pointed to psychological factors as important in dictating how well a patient was able to cope with their symptoms:

*Someone's distress at the end of life is most often related to how they have coped previously throughout their lives with difficult or challenging situations. In other words, it's part of their make up rather than anything that's an environmental kind of issue perhaps.<sup>289</sup>*

Dr Adrian Tookman spoke about dealing with patients' symptom burden:

*Suffering, distress — existential distress, emotional distress — can be one of the most difficult symptoms to manage... There are a significant but small number of people in whom their symptom burden — when I say symptom that's the physical, emotional, spiritual, social etc — their symptom burden is such that they find it really difficult to cope with it, and we find it really difficult to cope with it too.<sup>290</sup>*

Another group of palliative care specialists emphasised the successful role that palliative care can play in reducing patients' desire for a hastened death. Professor Tim Maughan suggested that it is an individual's personality type, as opposed to the suffering they experience, that determines whether they ask for assisted dying: 'I think it is about the societal issue, in a sense it's about their personal issue. It's not about the medical issue particularly. It's about who they are.' However, despite the important role of the individual's personal characteristics, he suggested that in his experience a 'holistic approach to care in the cancer setting' could successfully overcome the desire to die. Overall Professor Maughan emphasised the rarity of requests for assisted dying and the fact that those requests he had encountered had not persisted over time: he had had 'only three in 20 years of practice, three people who clearly asked me for euthanasia. And in fact all three of those, the request evaporated.'<sup>291</sup> When Professor Hotopf and Dr Price gave oral evidence they explained that patients' desire for a hastened death could be influenced by 'a number of factors, particularly depression and more severe physical symptoms'. Like Professor Maughan, they observed that many of these factors 'are potentially remediable with good symptom control and psychological care'.

The policy position that the Royal College of General Practitioners articulated in their written evidence to the Commission stated the belief that 'with current improvements in palliative care, good clinical care can be provided within the existing legislation, and that patients can die with dignity.' On this basis, they conclude that 'A change in legislation is not required.'

The specialist palliative care nurses who gave evidence to the Commission anonymously also emphasised what palliative care could achieve in reducing patients' desire for a hastened death, with one nurse commenting:

*There are probably some patients who we come across who are just in the depths of depression because they've come into hospital, they know their time is short, they might be troubled by lots of symptoms and we see them at their first assessment they say 'I've just had enough', but that's a reflection of where they are psychologically, and then you often find that by being alongside them and helping with their symptoms, their mind changes.*

However, another nurse acknowledged that palliative care could not provide an answer in all cases: 'We're never going to stop everybody's suffering [but] we could help a lot more people if resources were increased.' This nurse suggested that while there was a small minority of people who might have unrelievable suffering, this did not justify the legalisation of assisted dying:

*There are always going to be those people with those horrible diseases and that terrible suffering we can't get to, but do we risk a huge population of people who are weak and vulnerable for the few?*

Other doctors and palliative care specialists who gave evidence to the Commission arrived at a different conclusion about the appropriateness of assisted dying as a choice for patients whose suffering could not be addressed by palliative care. Gerald Patrick McGovern, a retired NHS consultant psychiatrist, argued in his written evidence:

*Opponents of assisted dying freely admit that, at least in a small proportion of cases, terminal [suffering] cannot be relieved yet seem unable to realise that even a small number within a circumscribed community constitutes an enormous number the world over.*

In response to this problem he suggested that 'those with terminal illnesses or individuals with unallievable suffering from incurable conditions' should have access to assisted dying.<sup>292</sup>

Dr Elisabeth Macdonald, a former cancer specialist now retired from clinical practice, wrote to the Commission 'to challenge the assertion that all symptoms at the end of life can be successfully managed by modern western techniques of palliative care'. Identifying and describing four case studies of dying patients whose symptoms could not be relieved effectively by palliative care, Dr Macdonald suggested some patients' 'terrible predicament... is not currently soluble within the law', therefore the law should be reviewed to consider the potential for medically assisted dying with 'careful safeguards'.<sup>293</sup> Dr Ann McPherson was also of the view that 'good quality end of life palliative care can alleviate much, but not all, the suffering that the dying process can cause'. In response to this problem she argued that in some cases a terminally ill patient's wish to die could be supported as a valid personal choice: 'Assisted dying should be just one of the many options at the end of life. It should complement other end of life care. I think it should be part of very good palliative care.'<sup>294</sup> Harriet Copperman, a retired nurse specialist in domiciliary palliative care and member of Healthcare Professionals for Assisted Dying, also observed in her written evidence that 'whilst palliative care has helped many people, it will never meet all needs... without a change in the law we condemn some people to suffer in a way which we would never allow if we were truly empathetic'.<sup>295</sup>

The medical director of an English hospice who gave evidence to the Commission anonymously thought that there were probably were some patients who would benefit from being able to request an assisted death:

*There are definitely patients who have made a very logical—for them—and competent decision that the quality of their life is not worth living. For example, I looked after a man a month or two ago who had been very fit and active, he was an athlete, and he had a horrible melanoma, he looked as if he was nine months pregnant, he was bed-bound and there was cancer popping up everywhere. He knew he was dying and he just wanted it over and done with, he was really suffering. I had huge empathy for him because he wasn't going to get better.*<sup>296</sup>

However, he reflected that the number of cases where assisted dying might be an appropriate option 'is quite small... what I can't get round in my mind is how you would frame a law that would allow it'.<sup>297</sup> Dr Adrian Tookman did not give his opinion on the rights or wrongs of assisted dying but said, 'Personally, if society said it was the right thing to do, I would have no problem supporting my patients through that process.'

### **Quantitative studies of health care professionals' attitudes to assisted dying**

A study by McCormack et al in 2011 reviewed evidence of UK doctors' attitudes to assisted dying and identified 15 studies that were published between 1994 and 2009; 11 of these studies explored UK doctors' attitudes to voluntary euthanasia, and ten explored attitudes to physician-assisted suicide. The authors found that in ten out of the 11 studies exploring attitudes to voluntary euthanasia a majority of participants were opposed. In eight out of ten studies looking at assisted suicide, a majority of the participating doctors were also opposed. Six of the studies reviewed asked doctors whether they would be willing to perform voluntary euthanasia if it was legalised and eight studies asked doctors if they would be willing to perform assisted suicide. The mean percentage of doctors willing to perform voluntary euthanasia was 22.7 per cent, although the figure ranged from 12 per cent to 46 per cent across the six studies. The mean percentage of doctors willing to perform physician-assisted suicide was 24.9 per cent, with a range of 10 per cent to 43 per cent across the eight studies.<sup>298</sup>

A study that William Lee et al published in 2009 was one of the more recent pieces of research that McCormack et al reviewed.<sup>299</sup> This study particularly explored doctors' attitudes to assisted suicide and was based on a sample of 372 questionnaires returned by doctors including consultants and GPs. The study found that 39 per cent of respondents supported a change in the law to permit assisted suicide for terminally ill patients and 49 per cent were opposed to such a change, with 12 per cent neither agreeing nor disagreeing. Although 39 per cent of those surveyed supported a change in the law, only 31 per cent indicated that they personally would be willing to facilitate physician assisted suicide. Doctors who regularly worked with dying people and more religious doctors were less likely to support a change in the law to permit physician assisted suicide:

*The views of doctors who do not care for the dying are more like those of the general public, with 66 per cent of those never caring for the dying supporting a change in the law, whilst 72 per cent of those caring for the dying on a daily basis oppose it.*<sup>300</sup>

Professor Clive Seale's study of doctors' attitudes to voluntary euthanasia and assisted suicide, published in 2009, was one of the other more recent studies included in McCormack et al's review.<sup>301</sup> This study asked 3,733 doctors about their attitudes to assisted dying in two circumstances: when the patient has a painful terminal illness and when the patient has a painful chronic illness. The study found that 34 per cent of the doctors surveyed thought that doctors should 'probably' or 'definitely' be able to perform voluntary euthanasia to end the life of a person suffering from a painful terminal illness. A much smaller proportion, 18.5 per cent, agreed that doctors should be able to perform voluntary euthanasia to end the life of a chronically ill person. The highest level of support among the doctors surveyed, 35.2 per cent, was for physician-assisted suicide if the patient was terminally ill. Again, a lower proportion of doctors supported physician-assisted suicide if the patient was chronically ill: 21.7 per cent. On further analysis, this study found that there was a small but statistically significant association between 'caring for a higher number of people who die in a year, being a specialist in elderly care and being a palliative medicine specialist' and opposition to the legalisation of assisted dying. It also found that 'greater religiosity' most associated with opposing assisted dying.<sup>302</sup> Therefore, together these more recent studies by Seale and Lee et al suggest that the majority of doctors are opposed to the legalisation of assisted dying, while between one-third and two-fifths of doctors are in favour of a more permissive approach to assisted suicide if the patient is suffering from a terminal illness.

There have been fewer studies of nurses' attitudes to assisted dying and those that are available are of a more informal nature. In July 2009 the Royal College of Nursing adopted a neutral position on assisted suicide (moving from a previous position of opposition) in response to the findings of a three month consultation, which received more than 1,200 individual responses from nurses. The consultation found that 49 per cent of participants supported the legalisation of assisted suicide, 40 per cent were opposed and 9 per cent were neutral or did not express an opinion.<sup>303</sup>

Two professional publications for nurses have also conducted opinion polls with nurses but the methodologies used are unclear. A survey by *Independent Nurse* magazine published in April 2009 found that 64 per cent of respondents believed assisted suicide should be legalised. However, the survey had only a very small base of 108 respondents, of whom 67 per cent believed that terminally ill patients should be able to ask for assistance to end their lives if experiencing chronic pain. Nearly half (46 per cent) of the nurses polled said they would be willing to be involved in assisted dying for terminally ill patients.<sup>304</sup> A larger poll that the *Nursing Times* conducted in 2003, which received 2,700 responses, found that two-thirds of participating nurses thought that euthanasia should be legalised and 31 per cent supported nurses' involvement in assisted suicide.<sup>305</sup> Therefore, overall, consultations and surveys have suggested that there is broader support among nurses for assisted dying than among doctors, although the evidence on doctors' attitudes suggests that support also varies according to specialisation, with support for assisted dying lower among those who practise palliative care.

### **Assisted dying and the practitioner–patient relationship**

Those who gave evidence expressed a wide range of views to the Commission on the subject of how assisted dying might affect the practitioner–patient relationship. A greater number of evidence submissions focused on the doctor–patient relationship, but submissions also explored people’s relationships with nurses and social workers and their expectations of these relationships. Some evidence also considered the potential role of psychologists and psychiatrists in an assisted dying framework.

Reverend Professor Robin Gill highlighted the fact that the majority of British doctors are opposed to the legalisation of assisted dying: ‘I do not speak for the BMA, but after twelve years of working with the BMA, I believe that it does speak authentically for a majority of its members.’ He thought the BMA’s policy position of opposition to assisted suicide was based on doctors’ fear that ‘a change in legislation will badly affect doctor–patient relationships... I think they fear being regarded by their patients as someone who would be prepared to kill them, even with their consent, they are found fearsome.’ Professor Gill drew a parallel with vets, who ‘spend a lot of time putting animals down which are no longer wanted; that must cause them very considerable ambiguity’ and suggested that ‘when doctors reflect on that they sometimes think, “well that’s not a good place to be and I think that’s not where we should be in terms of our relationship to our patients”’.<sup>306</sup>

Professor Tim Maughan argued that if assisted dying was legal, this could interfere with the trust relationship between patient and doctor:

*It is the case that doctors have probably far too much trust in them by society, but that is what we deal with. Patients have a huge amount of trust in their doctors. And if doctors are engaged in this process, I think that that can be a major distorting factor that can change a lot of things.*

He suggested that if assisted dying was an available option, it would be difficult for doctors not to raise this with patients, which could have a very negative impact on this trust:

*I think if it is there as an option in the health care environment then, it inevitably has to be spoken about. And I think that could be misinterpreted by people as saying, ‘Oh, he’s put this on the list of options does that mean that he’s... thinking that’s where I’m at?’... All of those fears and things, I think they could be very alarming for patients.*

Suzy Croft thought that legalisation of assisted dying might change perceptions of palliative care and professionals working in palliative care: ‘I think a large proportion of patients would choose not to access their services.’ She also suggested that this might affect the working relationship between professionals:

*I think that kind of lack of trust that could then develop between professionals and patients might develop also between professionals in hospice and palliative care themselves, because I think that there would inevitably be divisions between those who were and those who were not in favour of assisted dying and suspicion around whether patients had been unduly influenced in their decision one way or another.<sup>307</sup>*



A palliative care physician who submitted written evidence to the Commission anonymously argued that assisted dying ‘erodes the therapeutic relationship’ if ‘the patient fears [the doctor] will offer suicide if nothing else is working or [the doctor] fears the patient will not wait to see if suffering/symptoms can be reduced by palliative interventions’.<sup>308</sup>

However, Paul Philip questioned the usefulness of discussing the doctor–patient relationship in general terms, pointing out that ‘every patient has a different relationship with the doctor and has very different expectations of the doctor and therefore to suggest that it is a homogenous group is probably not correct’.<sup>309</sup> Christine Kalus suggested that the success of practitioner–patient relationships is more dependent on the capabilities of individual practitioners, rather than being something that can be generalised to a whole profession: ‘Different people will have different comfort levels with having these conversations [about assisted dying].’ She commented:

*I was thinking of some district nursing colleagues that I might work with. I suspect... that some might be able to have the conversation and no, that some won't. Having an awareness of the gravity of the conversation, I would have concerns that a number of people wouldn't; [the conversation] could be dismissed.*

However, Ms Kalus suggested that practitioners’ aptitude for these conversations could be improved through training:

*Through my experience of having trained a lot of health professionals, albeit within an oncology domain mainly, in terms of having more difficult conversations, I think it's possible. I think it's possible for people to be able to have those conversations and facilitate them.*

Ms Kalus said one of her main concerns would be whether services had enough resources to ensure that conversations about assisted dying were conducted properly:

*I don't think there are enough resources around, and we know that we're in the face of significant changes and downsizing within the health system broadly and community services have been hit by that, so I think that that's quite difficult. How can you, if you're a pressured district nurse or GP or whoever, with a lot of people on your books to see that day, how can you find the time to have that conversation?*

Ms Kalus suggested that, overall, the important thing would be that patients could have ‘open conversations’ with health professionals about how they wanted to die:

*I think what patients and families want is to be listened to and to be heard as an equal in the interaction. And if we can do that then I personally believe that that could be a very constructive development. Because it's not as I understand it that we're talking, if assisted dying is legalised, it's not... something that we are offering, and saying, you know, ‘We can do chemotherapy, we can do this, we can do that, we can do assisted dying.’ It's actually something that is patient and family led. And I think they have the right to the respect to be listened to.*

She thought it was a matter of training, resources and willingness: ‘I mean not everybody will want to have that conversation and people may have moral or religious or all sorts of other objections.’ While patients may wish to discuss assisted dying, Ms Kalus suggested that ‘staff... have the right not to discuss it’.<sup>310</sup>

Dr Field from the Medical Protection Society suggested that, while the Society was neutral on the issue of assisted dying, the experiences of their clients suggested that if assisted suicide was legal, this might indeed strengthen the doctor–patient relationship because the doctor would then be

*working within a legal framework that is clearly defined and what he can and cannot do within that framework can be explained to the relatives, and the relatives know that there are limitations. It is not because of the doctor’s judgement, it is because the doctor has to work within a particular framework.*

Without greater clarity on the legal position of doctors assisting suicide, Dr Field was concerned that there may be antagonism between patients, relatives and doctors ‘if the patients and relatives feel that the doctor is being judgemental and that their actions are based on their personal judgement rather than their obligations within the legal framework’.<sup>311</sup>

Dr Anne McPherson and her colleagues from Healthcare Professionals for Assisted Dying also argued that the legalisation of assisted dying could improve the doctor–patient relationship:

*Far from patients losing faith and trust in their doctors, I think that many patients will see this as improving trust. As the law stands, we are not able to discuss these issues with patients, and HPAD believes that properly implemented assisted dying, using good communications skills will enhance that relationship.*

Dr McPherson referred to ‘a survey of European countries which found that trust in doctors was highest in the Netherlands where assisted dying is permitted’. She felt she was

*letting patients down by not being able to talk about these things when they were at their most vulnerable and actually wanted to talk to me about them. It put me in quite a difficult position and there were times when, certainly, other members of the team felt that I had stepped over the line of legality, although I hadn’t.*<sup>312</sup>

Joyce Robins, Co-Director of Patient Concern, agreed with Christine Kalus that the impact of assisted dying on the doctor–patient relationship ‘would depend a lot on the people involved’. She said the trust between older people and doctors is already at a low ebb:

*I don’t put any credence in this thing that people will then be scared, they will then be frightened, because my goodness people are frightened now, terrified of going into care homes, hospitals, so on and so forth, because they’ve seen on television before their eyes what actually happens to you there. [In] my elderly community down on the south coast, people are terrified.*

Instead of assisted dying adding to people’s fears about how they die,



she suggested that ‘it could take that away’.<sup>313</sup>

Some of those who wrote to tell the Commissioners about their experiences described similar concerns about the standard of end of life care on offer:

*As a Dutch citizen, living in England for nearly 50 years, but making regular visits to family in Holland, and having been with three of my closest family there when they died, I know that people there are treated as they should be. The law in Holland does not allow misuse of euthanasia. But people are reassured they can use it if necessary, and are treated more humanely. They are therefore not scared about their ‘end of life’, but are reassured that they have a say themselves, are protected by the law, and also don’t have to make a totally unnecessary journey to Zurich with distressed relatives... Elderly people here even in the 21st century are often disgracefully neglected in hospitals and care homes amounting to torture, because the above and palliative care are underfunded, and they don’t have enough qualified staff... The law in England should be changed to be clear and decisive, and allow assisted euthanasia for those who want it.*<sup>314</sup>

Another piece of evidence, this time submitted anonymously, also stated that the trust relationship with doctors in the context of end of life care is already poor for some people. The author described

*watching my aunt die over an 8 day period in hospital with the ‘help’ of the LCP [Liverpool Care Pathway], in pain throughout... When my aunt communicated to me that she was in dreadful pain, I insisted on pain relief for her final 5 days. It wouldn’t have been given otherwise.*

The author argued that ‘assisted dying is undoubtedly a great deal more humane than the LCP [Liverpool Care Pathway] where patients are routinely sedated but left to die in pain’.<sup>315</sup> This evidence supports the view that public trust in doctors and the broader health care system might increase if assisted dying was permitted, as patients and their relatives might feel they had reassurance that they need not die in pain.

Bridget Robb said in her oral evidence to the Commission that the British Association of Social Work’s policy committee, made up of social workers across the UK, had come to the conclusion that assisted dying ‘is an inevitable consequence of everything else we are doing about choice and control’. Some people would inevitably wish to have assistance to end their lives:

*Therefore we would much rather that as a society we were open and helped to think that through, rather than pretending that it wasn’t going to happen. And we would much rather that people were supported in their own countries, in their own localities, rather than being forced to travel the world to find somebody to do this for them.*

She suggested that if assisted dying was to be legalised, the process should not be over medicalised and assumed to be the sole preserve of doctors:

*I think we are looking for a more open system. We are looking for a climate where this is all right for anyone to talk about; it’s not just a narrowly defined group of people and a narrowly defined group of professionals. I think what we are looking for is a more transparent system that this is open to anyone who wants to make this decision.*

Ms Robb argued that if assisted dying was to be an available option, social workers could have an important role to play:

*There is a danger that social work is too regularly marginalised and I think that we do feel that we have a particular contribution — it's not an exclusive contribution — but we do have a contribution to make because these are complex situations; you are balancing rights and risks and legal and medical opinion and all the rest of it... At the end of the day you're coming down to a set of human relationships and how we support people through those human relationships, of both the individual who wants to make the decision and those around them and we do think that we have a particular role to play in that.<sup>316</sup>*

Martin Green also thought the policy movement in social care and health care towards promoting personal choice logically suggested a culture change towards permitting assisted dying:

*There is also a lot of work going on in care settings around end-of-life care and particularly around choices in end of life care. But all that work is focused on the experience at end of life and the choice around support and the process up to death, rather than choice about whether or not you want to end your life at a given point... In a way there is a bit of a mismatch between the rhetoric that is around, where everybody tells everybody that health and social care is all about choice; and it seems to me that it's about choice up to a point.*

Mr Green suggested that 'there needs to be far more clarity in the system when they're communicating with individual users about at what point the individual's power of choice extends, and at what point the state decides to deliver a position on end of life'. He argued that this clarity about what health and social care practitioners can and can't help with is particularly important 'for people who are finding themselves in care settings, very vulnerable, because they are not in the position to be able to make the informed choice and do it themselves'.<sup>317</sup>

## **How assisted dying might affect practitioners**

### **The personal impact of assisting death**

Many of those who gave evidence emphasised the emotional challenges that might be involved for professionals who were involved in assisted dying. Professor Clive Seale explained in his oral evidence that Dutch and Belgian doctors find euthanasia to be a very stressful experience.<sup>318</sup> The hospice medical director who gave evidence to the Commission anonymously said that he had 'huge empathy' for people who suffered significantly at the end of life and suggested 'people probably should have the right for euthanasia'. However, he asked, 'if it is an injection, who is actually going to give that?' He admitted that personally, 'I don't know if I could do it... because of the emotional burden. And it's also [the question of] where it would be done. I know that some of my colleagues would never do that.'<sup>319</sup> He urged that if assisted dying was to be legalised 'you'd have to look at the psychological support'. Christine Kalus also agreed that support systems for staff would be important: 'It has an impact on staff as well, a big impact. I mean we are people as well and it does affect us.'<sup>320</sup>

## Conscientious objection to involvement in assisted dying

Dr Adrian Tookman explained to the Commission that should assisted dying be legalised in the UK, it would be unrealistic to expect a consensus to develop among medical professionals about their role in assisted dying:

*I think you'll have very differing views from colleagues... I think they're very difficult views based on personal judgements. They're spiritual and religious thoughts and feelings... A lot of clinicians would find it incredibly difficult to be involved in the process of assisting patients dying. But I have to say equally there are some people would feel it is their duty to carry out what is determined by law and legislation.<sup>321</sup>*

Another hospice medical director thought that if assisted dying was legalised, 'I think we would have to have a discussion and the trustees would have to say whether they were prepared to allow it here [at the hospice]. If they were, then it would be discussed with staff.' He said that although he hadn't discussed this with his colleagues, 'my gut feeling is that some of my staff would not be comfortable at all'.<sup>322</sup> Some of the specialist palliative care nurses who were consulted as part of the Commission's call for evidence made it clear that if the law was to be changed, they would not be willing to be involved in assisted dying. One nurse said:

*I feel very fearful that our palliative care and cancer wards would be the place where people would come to have the medication and we would be part of that. That's what I fear the most, because I can't see in the UK where else it would happen.*

When asked where might be a more appropriate location for assisted dying, another of the nurses responded, 'I don't think we'd be happy for it to happen at all, really. I think for me, having that concept of it being... it is unthinkable that as a nurse, I would have a part to play in that'.<sup>323</sup>

In response to the evidence of mixed feelings among healthcare professionals, Dr Ann McPherson suggested that whereas 'there would be some in the medical profession who would kick very hard against it and continue to be against it', for others 'it would just become part of a change in the medical culture and clinical culture'. She suggested that following this process of culture change:

*In a few years' time people would wonder how we ever were not in this position, because I think that people would see that it was inhumane not to be able to help that small number of people who might want support at the end of life and assisted dying.<sup>324</sup>*

Professor Raymond Tallis argued that while the majority of doctors oppose assisted dying:

*There are sufficient doctors — I think most surveys show that about 30 per cent, perhaps middle 30 per cent do support assisted dying in anonymous surveys — so it seems to me that there would be enough doctors who would feel that they are not having something imposed on them to be able to deliver the service if required.<sup>325</sup>*

Dave Rossiter, a joint commissioning officer for a local authority and former chair of a local Samaritans branch, observed in his written evidence, 'All health care professionals have differing opinions currently but are obliged to work in line with legislation allowing for only minor deviations in approach and best practice opinions.' He suggested, 'While this [assisted dying] legislation may be more controversial than most there are comparatively controversial legislative responsibilities with regards to abortion, amongst other modern medical practices.' Despite differing professional opinions on abortion, he observed that 'all professionals registered with the GMC have the same legislative responsibility in the area of abortion' and suggested that health care professionals should decide how to deal with this professionally.<sup>326</sup>

J Stuart Hutton, a retired psychologist and social worker, recognising that some professionals would not wish to be involved in assisted dying, said:

*I do foresee a valid role for healthcare professionals who are ethically opposed to assisted dying to be part of a 'balanced' approach to help people to explore the possibilities for living prior to making decisions about dying.*

However, he cautioned that there should not be

*undue pressure being placed on the individual to make up their minds in either direction. The emphasis should be on exploring the options and coming up with decisions that are in the best interests of that individual and not the interests of those who wish to influence them.*<sup>327</sup>

We will discuss the various options for a conscientious objection clause that could be included in legislation to protect professionals in chapter 8.

### **The impact of assisted dying on professional practice**

When asked what impact the legalisation of assisted dying might have on the medical profession, Jane O'Brien commented, 'If you consider other big seismic changes, for example the introduction of the Abortion Act, it didn't cause the profession to fall to pieces.' She acknowledged that in the case of the abortion legislation, 'There are some doctors, a small but notable proportion of doctors, who wish to have a conscientious objection, who don't want to participate.' However, she felt it hadn't 'polarised the profession'; in fact, 'if you look at the way that the profession manages to encompass fairly major changes in the legal groundwork within which they are operating, my guess, and it would be a personal guess, would be it [the medical profession] would cope'. However, she was clear that this was a personal opinion and 'not a view of the GMC'.<sup>328</sup>

Paul Philip explained that the position of the GMC 'has been a fairly simplistic one: it's [assisted dying is] unlawful and we have never provided, never felt the need to provide any guidance for doctors'. However, he reflected that should assisted dying become legal:

*and some doctors had to think about what the issues were in applying the law, and some were prepared to do that, we would need to think as an organisation about whether or not it would be useful to provide some sort of guidance and some sort of framework.*

He suggested the GMC 'would be duty bound to assist the profession and to think about whether some guidance is helpful'. When asked what such guidance might entail, he responded, 'What we would do if we decided to actually develop guidance is to engage with the profession and ask them what they think is required.'<sup>329</sup>

Professor Joe Collier suggested that GPs might take a leading role in assisted dying if it was to be legalised within an Oregon-style framework: 'I think that in general, the general practitioner would write the prescription,... not always because there are people in palliative care in palliative care settings, but there would be a GP component.' However, he recognised that 'he or she would only do that with all the support we have outlined from the specialists who would give advice'. He suggested that assisted dying would become a part of everyday medical practice as opposed to being a niche role:

*If you look at the Oregon experience, and lets say that for every 100 people who die, there will be 50 doctors who sign prescriptions, so it is a very broad business and no one person is seen to be a specialist, as I say, there are 50 people, or 50 GPs who do this. So it will become a general part, I suspect, of practice.*<sup>330</sup>

The hospice medical director who gave evidence to the Commission anonymously thought that palliative medicine consultants would be better qualified to take a role assisting dying than GPs, as 'helping patients to make informed decisions is very much part of our raison d'être [as is] discussing difficult choices and not shirking away from those difficult subjects'. He pointed out that the average GP has ten deaths a year, and half their patients will die in hospital, 'so it's a very small number. I have about 250 deaths per year.'<sup>331</sup>

However, it is clear from the evidence we have received that doctors would not be the only practitioners affected by assisted dying. When Professor Clive Seale gave evidence to the Commission he commented on the finding from his research on the collegiality of British doctors:

*In the UK doctors are particularly collegiate; they like to share their decisions, not just with patients and relatives, but also with each other, and with nursing staff as well. There is a kind of joint quality to decision-making in the UK medical practice that is very marked compared to other countries.*

One of the benefits to this is that 'decisions don't go unscrutinised', but 'the collegiate quality is much more likely to occur in in-patient care, and perhaps is less likely to occur in home care, particularly in care in private households'<sup>332</sup>

Tony Hazell, chair of the Nursing and Midwifery Council, emphasised the key role that nurses now play in end of life care: 'In some really highly specialised centres nurses will actually be playing a much greater role perhaps than doctors.' He said that at a trust where he was formerly chairman, nurses 'were the actual centre of the care package that was being provided'.<sup>333</sup> Roger Thompson, Director of Policy and Standards at the Council, argued that the legalisation of assisted dying would have an impact on the professional practice of nurses as much as doctors, as

*the nurses are the people who have that sort of pivotal contact with patients and relatives, over longer periods than other medical practitioners. So they may not be always imparting that news, but in a vast majority of cases they will be the people picking up the aftermath of that and trying to help people understand what's been communicated to them... Nurses are facing decisions day-in, day-out about appropriate termination of treatment etc; this isn't something that is new for them, they're already very experienced in having to deal with that and having to support families in making very, very difficult decisions.*

He pointed out that nurses' and doctors' responsibilities increasingly overlap:

*There are many clinical situations where nurses play a really active part in that role which we would previously have seen as purely for medical practitioners... if it did develop into a legitimate form of care of assisting death, they [nurses] would be pivotal.*

He thought assisted dying would require

*highly specialised people managing extremely sensitive, difficult situations that demand technical skill but also high degrees of compassion and perhaps a little bit of detachment in order to survive longer-term working that way and being able to manage that, it's a really complex skill set. So I think there would be a lot in there for nurses.*

Like the General Medical Council, the Nursing and Midwifery Council would

*certainly expect to provide some very clear guidance in this area to the different decision-making processes and routes people might go down... I would see that nurses would play a very important part in that sort of question.<sup>334</sup>*

The specialist palliative care nurses whom Demos interviewed agreed with this assessment, explaining that any end of life decision involving assisted dying would be considered 'complicated', therefore 'it would be something that as palliative care nurses, we would definitely be involved in'. One palliative care nurse thought that this would affect her role because 'we would be asked for our opinion all the time, as we are now for lots of other difficult ethical decisions. I most definitely think we'd be asked for our opinion and guidance.' This was a particular concern for the nurses as they did not wish to participate in assisted dying in any way.

Bridget Robb suggested that the legalisation of assisted dying could impact on social workers as much as on doctors: 'I don't think that the challenges or issues for social work are any different to the doctors.' She emphasised the important role that social workers might play in exploring people's motivations for requesting an assisted death: 'For us there needed to be a separate process of people making it clear what they wanted and that the choice is theirs when they are making that shift from supported living to supported dying.' Ms Robb recognised that this role of supporting a person through assisted dying would be 'tough on professionals around them' **but** emphasised the importance that professionals should take on such a role rather than relatives or personal assistants:



*Dying challenges us all at times and I think that we are more comfortable that professionals are standing alongside people in that process, not leaving it to the unpaid or lowest skilled workers who are put under pressure to provide a service that they don't feel either adequately prepared for or legally protected about.*<sup>335</sup>

In their evidence Professor Matthew Hotopf and Dr Annabel Price particularly focused on the role that psychiatrists might play in an assisted dying framework, and the professional challenges that this could present. The first concern they raised, based on Dr Price's research with Oregon medical practitioners, was that if an assisted dying framework requires a patient to be referred to a psychiatrist for assessment, this

*may be interpreted by the patient as a potential refusal of their request, and is therefore set up as an adversarial process, which must be 'passed' in order to proceed, thus creating a situation in which it is very difficult to obtain an accurate picture of the patient's mental state.*<sup>336</sup>

They expressed concern that in such a situation, a patient might 'be deemed capable' although he or she may not have communicated 'sufficient information with which to assess other facets of capacity that may be relevant'. On further questioning Professor Hotopf observed:

*The remarkable thing, as an observation, is that in my time working in a palliative care environment, I have hardly ever had a problem with someone actually wanting to come and see me and talking and being open and being able to explore what's going on.*

Therefore the circumstances that Professor Hotopf and Dr Price envisage, with the psychiatrist taking on the role of 'gatekeeper' and the patient potentially feeling reluctant to engage in an assessment, might represent a substantial departure from their current professional experience.

Another concern that Professor Hotopf and Dr Price raised was that research has found that 'doctors with ethical objections to assisted suicide advocate higher thresholds for competence than do those in favour'. They were concerned that this might result in a less robust standard of competence 'should those doctors who conscientiously object remove themselves from the process'. However, despite voicing this concern, Professor Hotopf said that should assisted dying be legalised:

*I'm not advocating that psychiatrists don't have a role in the process of assessment and decision-making around end of life decisions — we do this all the time [but] a change in the law would lead to a whole range of different complexities, which would make a lot of one's clinical work much more difficult, because in a sense you have a situation currently where that is not an option, and therefore you work with what is an option.*

He explained that psychiatrists would find it very difficult to detach their own values from any assessment involved in an assisted dying process:

*I think as a clinician, if you are in the position of negotiating a decision one way or the other with the person, where you may have a strong feeling in one direction, I think it becomes quite clouded.*<sup>337</sup>

### **The relationship between end of life care and assisted dying**

Evidence that the Commission received was largely polarised between the view that the ethos and intentions of palliative care and assisted dying are in conflict and the view that palliative care and assisted dying share common aims and could have a complementary relationship in the context of UK health and social care. Suzy Croft said that assisted dying was

*a discussion which I almost feel that we can't indulge in yet as a society, because we don't have the social care. If we had a society where I felt that being old, disabled, having impairments, being sick, not being at work, but having other things to offer was valued and we had the kind of social care that people needed, then maybe it would be safe to look at it.*

Ms Croft expressed concerns that the infrastructure needed to support assisted dying would inevitably impact on the funding of palliative care:

*If assisted dying were legalised then I think the cost implications would be considerable because I think that, as well as the medical procedures and regulatory safeguards that you would have to have in place, there would need to be the same kind of education, training for professionals, emotional, social and practical support for patients and families, as there is currently offered within palliative care and hospice care. It would require a whole range of personnel from doctors, nurses, social workers and so on. And I don't think we could assume that it would be a cheap service, so decisions would have to be made about who is going to provide and fund this service.<sup>338</sup>*

However, Ms Croft was also concerned that assisted dying might be perceived as a relatively cheap and easy option compared with providing adequate health and social care services:

*If the resources that are needed to support people are diverted away to fund an assisted dying system my concern would be that inevitably it would be that system that would come to be seen as the one that offered the easy solutions... My plea would be that instead of concentrating on assisted dying we should be putting that effort into fighting for high quality health and social care services to support all those at the end of their lives, their carers and their families.*

To avoid the competition between palliative care and assisted dying that she envisaged, Ms Croft suggested:

*If legalisation was to take place then the procedures and services that were on offer would in my view, and from my experience, need to be completely separated out from hospice and palliative care services.*

She explained that hospice staff are aware that 'already some people, who know little of the hospice movement, come into the hospice (or perhaps resist coming into the hospice) fearful that euthanasia is already practiced'. During a support group Ms Croft ran previously, 'On one occasion several patients spoke about how much support they got from the day centre but commented they would never come into the hospice in-patient unit as they did not want their end hastened.'<sup>339</sup>



Professor Tim Maughan was also of the view that if assisted dying was to be legalised, 'it needs to be out of the health care environment'. He suggested that assisted dying could be a distraction from the important goal of improving palliative care:

*My hope would be that this Commission, if it's really concerned about people's dying experience, will strongly recommend both continued investment and research into positive aspects of caring for people who are dying. It's not just about assisted dying... The holistic person based approach to care... which palliative care supports, is very important here, and that should be our priority. Not, I believe, changing the law.*

Professor Maughan suggested that if assisted dying were to be supported 'outside the health care service, in some sort of system under the judicial department, outside the health department' then the negative impact on palliative care 'could be mitigated to a certain extent'.<sup>340</sup>

The specialist palliative care nurses whom Demos consulted were also concerned that efforts to legalise assisted dying would be 'taking time and resources away from what could be time and resources in palliative care'. However, a palliative care nurse called Zoe Clements argued that while many people were worried that if assisted dying was legalised, people would stop using palliative care and it would become a second option, she did not think this would happen; 'If the choice was there, palliative care would still be an option and would still be offered.' She suggested that fears that people would overwhelmingly turn to assisted dying were 'unfounded'.<sup>341</sup>

The written evidence provided by the British Association of Social Workers suggested that assisted dying and palliative care could be complementary if delivered with the right support:

*BASW—The College of Social Work—hopes that the recommendations from this Commission will promote systems which encourage active discussion and planning for death (assisted and non-assisted) as well as assisted living and give people access to the appropriate medical, legal and social work support for them to make informed decisions.*<sup>342</sup>

Pete Morgan, a social worker and member of the Practitioner Alliance Against the Abuse of Vulnerable Adults, wrote to the Commission:

*If the purpose of both assisted dying and end of life care is seen as the maintaining and enhancing the quality of life of the individual, there is no conflict. They are complementary means to the same end that should be used in partnership with the individual to enable them to live and die as they wish to, with dignity.*<sup>343</sup>

Margaret Branthwaite, a retired barrister and former consultant physician and anaesthetist at the Royal Brompton Hospital, also argued that assisted dying and end of life care are 'definitely not in conflict; assisted dying an infrequent option in the spectrum of measures available to secure a good death'.<sup>344</sup> Dr Philip Hartropp, a GP, wrote:

*I have been a full-time GP for 30 years now, and have no doubt that assisted dying would become part of terminal care of patients for the minority of patients that would probably request it. There should be no conflict [between end of life care and assisted dying].*<sup>345</sup>

Dr Ruth Cooklin, a retired psychiatrist and member of Dignity in Dying, also thought that assisted dying could have ‘a complementary relationship to end of life care’:

*Palliative care is vital for very sick people and I see no conflict between this and assisted dying. On the contrary, I see the two as both forms of care... Not everyone will want assisted dying, [but] its existence as a possibility will, in all probability, help many people to feel less anxious and desperate and so allow them to not choose such assistance.*

She distinguished between the purpose of palliative care as a form of support that ‘helps people on the way to their deaths’, while assisted dying ‘provides those individuals who want it with the freedom to choose more control over the manner and timing of their deaths’.<sup>346</sup>

Dr Ann McPherson, speaking on behalf of Healthcare Professionals for Assisted Dying, argued that for some palliative care specialists, a patient’s desire for an assisted death is wrongly perceived as a failure on the part of the palliative care service:

*A very eminent palliative care specialist said to me that when I had patients who still wanted assisted dying, she said, ‘well they couldn’t have been having very good palliative care’, absolutely not true, they were having superb palliative care. I certainly challenged her to come and see the people in Oxford who run a very good service, at the hospice there and with outreach. It wasn’t that they were not getting very good palliative care, they were terminally ill and they had had enough of being paralysed and they wanted to die.*

Dr McPherson argued that a patient’s death or assisted death should not be perceived as a failure of health and social care services; instead ‘it becomes a failure if the patient suffers an undignified death and we think that some of the deaths happening now are undignified’. She suggested Healthcare Professionals for Assisted Dying believe ‘assisted dying should be just one of the many options at the end of life. It should complement other end of life care... it should be part of very good palliative care.’ Dr McPherson explained:

*If you say you are for assisted dying, people assume that you are against palliative care. No one is against palliative care, we all want to have very good palliative care and it is terrible that it is not available to everybody.<sup>347</sup>*

Harriet Copperman, a palliative care nurse and member of Healthcare Professionals for Assisted Dying, suggested that ‘assisted dying should be an integral part of end of life care’ and argued that the social demand for assisted dying has increased because

*modern medicine has ‘interfered’ so much in natural disease processes and biological deterioration of the body, that what in the past may have been a relatively quick decline and death, is now frequently prolonged by years of slow and distressing decline.*

She envisaged that assisted dying would be ‘part of end of life care’. Professor Raymond Tallis endorsed this view, ‘We know from international

experience that assisted dying legislation has driven up investment in, and the quality of, palliative care' and suggested it would be 'a failure' if assisted dying should be delivered outside the health service:

*It is part of the therapeutic alliance with the patient, that you see that patient through and if you can't, then at least your partner in the practice could see it through... I don't think any one of us would like to outsource this even less to other professions.<sup>348</sup>*

### **Evidence from jurisdictions that permit assisted dying on the relationship between assisted dying and end of life care**

This section will review evidence gathered from the Commission's research visits to the Netherlands, Belgium, Oregon and Switzerland on the relationship between assisted dying and palliative care in these jurisdictions. It will also present the findings from a study by the European Association for Palliative Care that examined the quality of palliative care in jurisdictions that permit assisted dying and explored how palliative care had developed in these jurisdictions following legalisation.

### **Integration or separation?**

As the discussion above has demonstrated, there is an ongoing debate about what the relationship between palliative care and assisted dying might be in the UK if some form of assisted dying was to be permitted. Some of those who gave evidence, such as Professor Maughan, argued that assisted dying would have to take place entirely outside the health service. Others, such as Dr Anne McPherson, thought assisted dying should be 'part of very good palliative care'. The relationship between assisted dying and palliative care in jurisdictions that currently permit assisted dying is clearly influenced by many factors including the medical culture in that particular jurisdiction, the process of legal change, and the detail of exactly what the law permits. Here we will explore the evidence that Commissioners gathered during their research visits to the Netherlands, Belgium, Oregon and Switzerland on the relationship between palliative care and assisted dying in these jurisdictions.

### **The Netherlands**

Commissioners travelled to the Netherlands in March 2011 to interview researchers, practitioners and other experts in palliative care and practices around euthanasia. In the Netherlands, euthanasia is defined as 'the termination of life by a doctor at the patient's request, with the aim of putting an end to unbearable suffering with no prospect of improvement'.<sup>349</sup> Both euthanasia and physician-assisted suicide are permitted under the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, which came into effect in 2002. The process of legal change that led to this piece of legislation was extremely gradual; the legal principles that underpin the Euthanasia Act developed gradually through a series of court cases, which started in the early 1970s and continued throughout the 1980s. These emerging principles then began to be formalised into guidance for doctors and notification procedures in the 1990s. When Commissioners interviewed Gert van Dijk of the Royal Dutch Medical Association (KNMG), he commented:

*Here in the Netherlands it started with the doctors and then the politics followed... We recognised, a long time ago, that prolonging life is not always the best focus of medical treatment; sometimes it is best to let the patient go. We have a political culture, in which we feel, if something is going to be there it is better to guide it than to stop it.*<sup>350</sup>

Therefore, the approach to assisted dying in the Netherlands is very much integrated with broader systems for delivering end of life care, which usually takes place at the patient's home and is often provided by the patient's GP.<sup>351</sup> Eric van Wijlick, a senior policy adviser at KNMG, explained that 'from a government point of view, palliative care should be general care—and general care means every doctor has to have skills and have knowledge about palliative care and end of life decisions', but in more challenging cases, 'every GP and every doctor can consult a palliative care team. They will contact you, they will advise you and if necessary give bedside consultations.'<sup>352</sup> Bernadina Wanrooij, a GP at the Academic Medical Centre in Amsterdam, told the Commission that these supportive palliative care teams began to be developed in 1998 and they can now be accessed across the Netherlands, 'so you can pick up the phone and talk with somebody who knows more about palliative care'.<sup>353</sup> Gert van Dijk of the Royal Dutch Medical Association said that all Dutch people have a GP who 'plays an important role in their health care. And we have a very good system of palliative care.'<sup>354</sup> Agnes van der Heide, senior researcher at the Department of Public Health at Erasmus Medical Centre, told the Commissioners, 'In our survey of last year we asked patients to what extent they trust their physician to provide them with adequate care at the end of life and the large majority trusted their doctors.'<sup>355</sup>

However, Bregje Onwuteaka-Philipsen, Associate Professor at the VU University Medical Center, Amsterdam, gave a more nuanced view, commenting that this generalist system for delivering end of life care

*is good provided that all those general practitioners are really also interested and capable of doing palliative care. And I think that differs still. You must be lucky with the GP you have, I think, when you are in the last phase of life.*<sup>356</sup>

Bernadina Wanrooij explained that while systems for training and supporting GPs in delivering end of life care are now well established,

*palliative care is still developing in hospitals now. That is one of my tasks here in the hospital—I set up a palliative care team. We have been functioning now since about one year, to support the doctors and nurses.*

Gert van Dijk told us that in the Netherlands most euthanasia deaths occur at home, with the support of a GP, and the majority of patients have a cancer diagnosis. The report by the Regional Euthanasia Review Committees on cases of euthanasia that occurred in 2010 found that out of a total of 3,136 reported cases:

- 2,499 patients died at home
- 182 patients died in hospital
- 109 patients died in a nursing home
- 127 patients died in a care home
- 219 patients died elsewhere (for example in a hospice or at the home of a relative).<sup>357</sup>

Eric van Wijlick suggested that from a Dutch point of view a hospice is 'a kind of alternative for people who do not have the support at home'. Around 80 per cent of hospices in the Netherlands permit euthanasia, 'so euthanasia is not excluded because you are in a hospice'.

The experts whom the Commissioners interviewed made it clear that although doctors found the role of giving a patient euthanasia extremely demanding and a heavy responsibility, most Dutch doctors were in favour of the legalisation of euthanasia. Agnes van der Heide told us that the system is supported by most Dutch doctors: 'Not all doctors want to be involved or to perform euthanasia [but] the number of doctors who don't agree with the system or don't want to play any role in it is really very limited.' Gert van Dijk said:

*Here, 84 per cent of physicians have either performed it or are willing to do so. Current law is supported by 92 per cent of the population and so it has wide public support and I think that is very important.*

Bernadina Wanrooij appreciated having the support of the law: 'It feels very good for us as doctors that you have the support... I am not alone in this decision.' She said if a person is experiencing unbearable suffering at the end of life, 'you have this as an option and you don't have to do it secretly'.

Agnes van der Heide described the official position of the Royal Medical Association: 'It should always be the patient who starts the discussion about euthanasia, not the doctor.' Bernadina Wanrooij said that when training young doctors, she impresses on them that they must not take a request for euthanasia at face value: 'If someone asks for euthanasia, please start to explore where the question comes from. Why is it that you ask me? What do you see as euthanasia? What is the word meaning for you?' She thought GPs were very good at 'following or walking together with the patients towards the end'.

Several of the experts the Commissioners interviewed emphasised the importance of the longstanding relationship between the patient and their GP to the practice of euthanasia:

*The general idea under the system is that... most cases of euthanasia are performed by GPs and GPs mostly have a long standing relationship with their patients. Often patients are already familiar with their GP for years and years, people rarely change GP. They often have a quite close and long standing relationship, so the physician knows the patient, knows the family, knows the circumstances etc.<sup>358</sup>*

Gert van Dijk told us, 'we say there needs to be a close physician–patient relationship for euthanasia... [someone] who knows you mostly from the beginning of your disease', but this is not a legal requirement:

*Doctors just don't want to do it when they don't know the patient, they want to have this close relationship, they want to make sure it's the right thing and you only get to know that if you know the patient.<sup>359</sup>*

A number of people also emphasised the emotionally challenging nature of performing euthanasia. Agnes van der Heide said:

*I have talked to many GPs about this issue and I haven't met GPs who think it is an easy thing to do or a normal part of their practice. I only know GPs who think it is complicated,*

*it's emotional, a thing they wish to do as rarely as possible. So GPs are very much aware that it is really an extraordinary thing to do which doesn't become easier.*<sup>360</sup>

And Guus Fons agreed: 'Doing it is very stressful. It is always a very stressful event.'<sup>361</sup> Dr Christiaan Rhodius, a palliative care specialist at St Jacob's Hospice Amsterdam, endorsed this:

*I've been present with two [cases of] euthanasia being done. There [are] tears at every euthanasia and also among professionals, and I know of no professional who says it's an easy thing to do. And often they say I need a drink afterwards. You take the day off afterwards. It's a big thing.*

Gert van Dijk emphasised that it is not an obligation of the doctor and it is not the right of the patient: 'The doctor is *allowed* to perform euthanasia but he doesn't have to do it. If the doctor says, well I don't want to do it, then that's ok. And the patient doesn't have a right to it.' He said some doctors in the Netherlands have a conscientious objection to performing euthanasia: 'If he doesn't want to perform euthanasia, then he has to tell the patient right at the start of the disease and then the patient can still look for another doctor.'

However, Dr Christiaan Rhodius suggested that while a doctor may be unwilling to perform euthanasia, he or she should always be prepared to discuss it:

*Every doctor, whether there's a law or whether there isn't, or whatever, should be willing to talk with people about their possible wish about assisted dying, or euthanasia, or just dying in itself. So I would say it should always be possible to talk about it. Patients should be free to make any requests... Often, the fact that there's a possibility to talk is an enormous relief because people have a real burden; they're tensed, they have difficulty in thinking about the future or a lot of anxiety about suffocating or pain or other symptoms... Personally I'm not in favour of euthanasia, I do not perform euthanasia [but] I've learned that being able to talk, for patients, is such a relief that often people, they're not really interested in getting the euthanasia, they're interested in the attention, and somebody that would listen to them.*<sup>362</sup>

Those interviewed also made it clear that euthanasia is very much the exception rather than the rule in end of life care. Bregje Onwuteaka-Philipsen commented, 'Palliative care is for everybody in the last phase and euthanasia is only for those few people that ask for it.' Agnes van der Heide suggested that just knowing euthanasia is available as an option

*is often a relief for patients and then it is quite often that they don't need it anymore because they have the assurance of their physician, 'I will help you if you are in a condition which is intolerable, which is unbearable.'*

Bernadina Wanrooij acknowledged that some people thought that 'better palliative care would postpone the question [of euthanasia] for the patients'. However, she argued that when patients ask for euthanasia 'it is certainly not just that the symptoms are so hard to bear, or that they are not taken care of sufficiently'. Instead, it may be a sense of declining health and losing independence, so that the patient thinks 'this is not how I want



to go on and how I want to die—I was always a very independent person I want to keep that independence. I don't want to go to the end... I don't feel my dignity anymore.' Christiaan Rhodius wondered whether requests for euthanasia would decline 'if proper care, or proper attention for palliative care is given'. However, he made a broader argument: 'Sometimes we're so busy trying to *cure* people that we're doing things that do not improve the quality of life.' He suggested:

*Perhaps we should stop earlier and let nature run its course and, therefore, diminish situations where euthanasia might be appropriate [but I am] not especially afraid that less attention would be paid to palliative care. Because I think that euthanasia, the whole issue, is underlining the fact palliative care is a core and essential thing, which should never be, how you say, thought lower of than euthanasia.*

He said that in some cases, where a patient's suffering cannot be relieved, 'I think it's a good thing that it's actually there.'

Agnes van der Heide argued that 'allowing euthanasia, having a regulation for euthanasia, is not something that threatens the quality of end of life care or threatens the energy or money or whatever that is put in end of life care'. Instead, palliative care is the general path for supporting people at the end of life, while euthanasia 'is really the exception for a special group of people who really have their own ideas'. Both Gert van Dijk and Guus Fons pointed out that palliative care had actually improved in the Netherlands since euthanasia had been legalised. Gert van Dijk said, 'Now we have started later with palliative care, because there was a lot of criticism in the beginning of euthanasia... palliative care in Holland is not good so that is why people ask for euthanasia.' Guus Fons commented, 'We didn't have that kind of good palliative care and I think the Dutch people are people who really want to make their own decisions and I think that is very important and it is a very strong wish' and suggested that 'by knowing better the possibilities of palliative care, we will do even less euthanasia rather than more.' Bernadina Wanrooij emphasised the fact that palliative care in the Netherlands is still very much developing as a discipline without being inhibited by the legalisation of euthanasia:

*We really exponentially have been growing. In these courses that I have given, you see that people are very keen to know more about palliative care, even if the possibility for euthanasia or assisted suicide was there already. They were very keen to know more about palliative care.*

## **Belgium**

In 2002, the Belgian Parliament adopted a bill to legalise euthanasia, becoming the second country to do so after the Netherlands.<sup>363</sup> Euthanasia is defined in Belgian law as 'intentionally terminating life by someone other than the person concerned, at the latter's request'.<sup>364</sup> To qualify for euthanasia, the patient must be 'in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident'.<sup>365</sup>

When the members of the Commission visited Belgium in April 2011, those they interviewed explained that palliative care had already been well developed in Belgium before the legalisation of euthanasia. Professor

Bert Broeckaert, Director of the Interdisciplinary Centre for Religious Studies at the Katholieke Universiteit Leuven and specialist in end of life ethics, said that by the end of the 1980s Belgium already had 'a legal, encompassing framework that ensures that palliative care is or should be available everywhere'. Belgium had 30 palliative care regions

*where there is a palliative care network which is responsible for the organisation of palliative care in that region. And then linked to that palliative care network is a palliative home care team for each region, and then by law, in every hospital, you have a support team and you have also a kind of support team in every nursing home.*

Like the Netherlands, Belgium takes a generalist approach to palliative care, whereby 'palliative care should be supportive care; this should not take over from general health care, so this means we do not have hospices or things like that'. Palliative care is largely delivered by GPs, with advice from specialist teams where necessary:

*Every GP working here in this region, or every nurse, homecare nurse working in the region of homecare nursing team or every patient or family can phone or contact the palliative care team if they have a question or a problem... palliative care was very much in place before this euthanasia debate started.<sup>366</sup>*

Most of the interviewees made it clear that the timing of the Belgian Euthanasia Law was political rather than social, as in June 1999 the Christian Democratic Party lost power and 'this was seen and perceived by people of the other parties as a unique opportunity to change a few things'.<sup>367</sup> Professor Broeckaert suggested that the origins of the Euthanasia Law as a political compromise between six political parties had had consequences for the quality of the statute:

*The problem is that this law was made by politicians who are not very familiar with the issues, not very familiar at all with the medical world, even didn't know very much, didn't know hardly anything about euthanasia practice or euthanasia law in the Netherlands. So there were and there are a lot of things that could be improved, but they have not done so because of these political reasons, because they wanted to have it very quickly.*

Professor Herman Nys, suggested that while the majority of doctors wanted transparency in end of life issues, some doctors felt that 'a law was not needed because this could be easily done in the private sphere between physicians and patients'. He expected that doctors in French-speaking Wallonia are 'a bit more paternalistic than in Flanders, that the physician decides at the end of life whether to use a means to hasten death or not'. This is reflected in the different reporting rates in these two regions, which we will discuss in more detail in chapter 8.

Jacqueline Herremans, Director of the Right to Die Society in Belgium (ADMD), highlighted the fact that two other laws were passed in 2002 soon after the Euthanasia Law concerning the provision of palliative care and patients' rights: 'Our concern was to avoid this crazy opposition between palliative care and euthanasia. And so we decided to put these two topics together and to discuss these two topics together in the Parliament.'<sup>368</sup>



Kris van de Gaer of the Life End Information Forum (LEIF) explained that the law on patients' rights included provisions such as

*free choice to choose a medical practitioner, the right to choose your own institution and hospital and the right to have a copy of your medical file, the right to make a complaint when one of these rights wasn't respected. And also the right to refuse medical treatment.*

Mr van de Gaer thought this legislation facilitated patients' emancipation, enabling them to be

*more assertive, and more responsible, and I think that had huge consequences for medical practice in general, and that too was one of the reasons that doctors couldn't just do the things they did before.*<sup>369</sup>

Professor Broeckaert told us:

*We tried to use this euthanasia debate to put palliative care on the map. And we were very successful in that. As a result of the euthanasia law and the way we participated in the debate, the budget for palliative care doubled.*

His perspective on euthanasia was that adequate palliative care is always a precondition to the patient being able to properly consent:

*Whether you are for or against, talking about such delicate issues such as euthanasia, you would at least want to make sure that is a really serious informed decision by the patient. And so in that sense if you are in really terrible, physical pain for instance, you are not free to make a really autonomous decision. And in that sense we said you can only have euthanasia or you can only take euthanasia requests seriously if you make sure that people are receiving adequate palliative care and then they can make an informed decision.*

Professor Broeckaert said he had tried to ensure that a 'palliative filter' was included in the euthanasia legislation so that the doctor and patient were required to consult a palliative care specialist to ensure that all available options for treatment had been fully explored. While this provision ultimately was not included in the legislation (instead the physician is legally required to inform the patient of other options to euthanasia including palliative care), doctors or institutions are able to impose additional requirements on patients, and 'the majority of hospitals have this palliative care consultation as a compulsory element in their procedure'.

In Belgium institutions such as hospitals and care homes may opt out of allowing euthanasia on their premises. Professor Broeckaert told us most public hospitals are now largely secular and 'you would hardly find a hospital that would say never; you would find however a lot of hospitals that would say well euthanasia [is allowed] but only for terminally ill or euthanasia only if you respect this palliative filter'. However, Professor Herman Nys, Director of the Centre for Biomedical Ethics and Law at the Katholieke Universiteit Leuven, said some large Catholic nursing homes take a more strict approach and have 'publicly announced that in this home euthanasia is never practised'. Jaqueline Herremans said that although

euthanasia is now legal, there is never any obligation for the doctor to perform euthanasia; it is very much ‘the right to request’ rather than ‘the right to euthanasia’, as ‘it’s always possible for the doctor to say “no, it’s against my conscience, I don’t want to perform this act”’. This has led to some misconceptions among the public:

*Both the Dutch law and the Belgian law, it’s not written from the perspective of the patient, it’s from the perspective of the physician. Whereas the general idea, probably as a result of this political and ideological discussions, the general idea among the general population is ‘I have a right to euthanasia’.*<sup>370</sup>

Professor Deliens commented on the difficulty for doctors of practicing euthanasia, arguing ‘you have to really realise there is not one doctor who is in favour of euthanasia’. Kris van de Gaer told us:

*In reality you often see that it’s quite hard to convince a doctor to perform euthanasia on yourself.. I mean, it’s often that someone wants to die but you have got to be able to find a doctor that’s willing to perform euthanasia.*

Jacqueline Herremans explained that patients were sometimes frustrated if their doctor refused to perform euthanasia, particularly if this was the result of the doctor’s lack of familiarity with the process rather than an ethical objection:

*Some doctors are still afraid of something they don’t know... Some doctors are going to have a request for euthanasia once in their medical practice. So it’s a challenge really; it’s possible to be trained to cure some ailments but to answer to that kind of question very often they are not trained. And they are not ready; it’s a surprise for them.*

Kris van de Gaer said that sometimes a patient’s family would contact LEIF if they felt that ‘things are not moving fast enough... bad communication happens a lot’ and in some cases, a physician’s ethical objection to euthanasia might not have been communicated:

*There are really those situations in which that doctor says I will help that patient but I have moral objections, so I will help them with something like palliative care and with support and in that way, but I won’t ever perform euthanasia. So in those situations, it can be hard to find a solution because clearly what the doctor wants and what the patient wants are two different things. But luckily, that’s really a small minority.*

Professor Luc Deliens, Professor of Public Health and Palliative Care and Head of the End of Life Care Research Group at Vrije University, Brussels, explained why he believes the relationship between the doctor and the patient is fundamental to the delivery of euthanasia:

*You need to have a sort of long-term relationship, otherwise you cannot, well it’s difficult, for the physicians to go ahead with the patient when you are not completely convinced that this is the really authentic request by the patient, and that it’s a stable request also, and that there is no external pressure. And therefore, you have to know the patient very well.*

He said the delivery of palliative care through the primary care system is fundamental to how the Euthanasia Law works. However, Kris van de Gaer observed that in Belgium more people receive palliative care from a specialist rather than their GP, although GPs are taking an increasing role in both palliative care and euthanasia:

*I think you see an evolution here over the years that more and more questions is asked to a general practitioner. Because in the beginning you had about 30 per cent of euthanasia performed by GPs, and that now you see it half way I think. It's about 50 per cent.*

Interviewees had various views on the relationship between assisted dying and palliative care. Kris van de Gaer acknowledged that there had historically been a strong emphasis from the palliative care movement that 'every wish for a patient to have a euthanasia will disappear if only [he or she is] given enough palliative care'. Paul Destrooper, head of training at LEIF, also observed that a core value of the European Association of Palliative Care is 'strictly that palliative care will never shorten life'. Kris van de Gaer elaborated on this: 'Palliative care is not about shortening lives, it's about giving quality to the end of life.' However, he observed that palliative care has a greater impact for some patients than others:

*It's true that some people arrived here who really wanted euthanasia, but by being here, felt better, or safer, or, well, less frightened about what might happen, and it's possible that the wish for euthanasia disappeared. But some people came here for a few months, or a few weeks, who said, 'It's very nice here, I feel, but, well, now it's enough.' It's not because you don't give enough care. It's their decision. You've got to respect that. Even with the best palliative care it's their decision.*

However, Kris van de Gaer said that while palliative care and euthanasia were both valued by patients as options for end of life care, these two practices are fundamentally different 'because palliative care is not shortening lives; it's giving quality to lives at the end of life while euthanasia is a completely different thing. It's ending life.' He also suggested that 'euthanasia, it's not a kind of care. It's a decision taken by the patient'. Professor Nys believes palliative care and euthanasia are fundamentally different practices, 'Euthanasia is still a crime under certain conditions, while palliative care is just normal medical practice.' Professor Deliens thought about this relationship in another way: 'For me it's really part of the treatment. It's an option, the final option, when there is no other option.' If the patient cannot be cured

*then the only thing that remains to you is your value as a human being. And if that cannot be returned to you by palliative care, at the end of that same mechanism can be euthanasia. And that's why we don't believe that with [excellent] palliative care there will be less euthanasia.*

Kris van de Gaer said he thought the legalisation of euthanasia had had a positive impact on palliative care as 'people give more attention to end of life in general'. Professor Deliens described the value of integrating euthanasia within end of life health care systems:

*We have tried to integrate the whole euthanasia system within end of life health care systems. And that's very much a strength of the system in Belgium; it's completely integrated into the end of life health care system. And that's not the case in America; it's not integrated, it's separated. Just like in Switzerland. It's a separate system, apart from the regular health care system at the end of life.*

He suggested that the legalisation of assisted suicide, as opposed to euthanasia, might partly explain this: 'That's the big danger with assisted suicide; that you create a system outside your health care system. And that's the worst thing you can do from the point of view of quality of life at the end of life.' Professor Deliens argued that assisted dying 'should be integrated into palliative care' to ensure that the patient is fully informed of all of the options that palliative care can offer, so there is no 'separate road' for assisted dying.

### **Oregon**

The Oregon Death with Dignity Act (ODDA) came into effect in 1997, legalising physician-assisted suicide. It allows 'a physician to prescribe a lethal dose of medication for a mentally competent, terminally ill patient for the purpose of self-administration'. The patient must be an Oregon resident over 18 years of age, suffering from a terminal illness (defined in the ODDA as a prognosis of fewer than six months to live), and have voluntarily expressed their wish to die through two oral requests and one written request.<sup>371</sup> The act was the result of a Citizen's Initiative, which went to a referendum in response to public petitioning, rather than being led by the medical profession, as was the case in the Netherlands.

When Commissioners visited Oregon in May 2011, Deborah Whiting Jaques, CEO of the Oregon Hospice Association, described the relationship between hospice care and assisted dying under the Oregon Death With Dignity Act as a relationship of 'coexistence' rather than as an entirely comfortable or complementary relationship:

*A patient has the right to have hospice care and to use the Death with Dignity Act. Both are patients' rights in the state of Oregon, and it's our job, at the Oregon Hospice Association, to support that... we do not take a position either to oppose or to support the Death with Dignity Act. It is the law, and we support a patient's right to choose any legal option. And it is a hospice's right to choose how they practice medicine in the bounds of their community.<sup>372</sup>*

As a result, while hospice care and assisted dying 'exist in the same world', among practitioners there is an ongoing 'dialogue about how the two intersect'.<sup>373</sup> Ms Whiting Jaques observed that while this system of coexistence functions reasonably well, 'There remains tension with hospices, with individuals who work at hospices, and most hospices... have conscientious objection, [as] part of their [policy].'

The experts that the Commissioners met in Oregon were clear that end of life care is well developed in Oregon through its hospice network, and a high proportion of patients who are assisted to die under the Death with Dignity Act are receiving hospice care. Linda Ganzini, Professor of Psychiatry at the Center for Ethics in Health Care at Oregon Health & Science University, illustrated this with the fact that when the Death with Dignity Act

was first passed, 'even in 1994 we had, compared to the rest of the country, more people enrolled in hospice, we had the highest per capita morphine use in the country... The Portland area had the lowest rate of in-hospital deaths in the country', so people were going into hospice.<sup>374</sup> Barbara Glidewell, Associate Professor at the Oregon Health and Sciences University Hospital, also emphasised the high rate of morphine use and out-of-hospital deaths:

*When our providers feel that a patient may benefit from palliative care, that option is offered. Most patients may never think of, or ask about the option of physician aid-in-dying. Being made comfortable with palliation is very much desired by most patients... The goal is to be able to move terminally ill or patients with a life-limiting illness out of the ICU and into the regular ward. Most patients do not want to die in the hospital. They would like to die at home if that is possible.*<sup>375</sup>

Peter Lyon, medical director for the end of life support organisation Compassion and Choices of Oregon, commented on the positive impact that legalising assisted dying had had on the development and take-up of hospice care: 'I think that one of the best things that's come from having this law is how much better hospice has become in Oregon in the last 15 years.'<sup>376</sup> Gary Schnabel, Executive Director of the Oregon State Board of Pharmacy, said that since the Death with Dignity Act was passed, 'I think there's more awareness of end of life pain management and doctors are prescribing it more. A lot more aggressive pain management.'<sup>377</sup> Deborah Whiting Jaques explained that by law, patients 'need to be offered a referral to hospice at the time that they make their first enquiry about the Death With Dignity Act in our state'. This may explain the high take-up of hospice care among people who have assisted deaths: 'about 93 per cent of patients who use Death with Dignity are hospice patients, so a very high percentage'.<sup>378</sup> Peter Rasmussen, also a medical director for Compassion and Choices, told us 'I think in Oregon we have very good hospice care'; he did not think people chose assisted dying as a result of poor end of life care: 'I think they're really two separate questions.'

Barbara Glidewell pointed out that very few people in Oregon actually use physician aid-in-dying:

*The number of individuals who access the law is very low. In general, it is less than one half of 1 per cent of 10,000 deaths in a year, in Oregon. In 2010... it was a total of 65 people using the medication prescribed in 2010. As you can see, this is a significantly small number of individuals who will choose this as an option.*

The interviewees said the reason for this low uptake was that requests for assisted dying are always patient-led, and people will only request this assistance if they have a specific personality-type and perspective on their own dying process. Barbara Glidewell told us:

*Oregon physicians do not bring up the option of aid-in-dying to patients. This option is discussed only if the patient brings the question. The patient must be the person who initiates the inquiry and inquires about the process or his or her terminal eligibility to qualify to receive a lethal dose of medication to end their life. As my health care facility is a public corporation facility — not a faith based facility, it is obligated to provide any legal treatment option to a qualified patient...*

*Essentially, palliative care (symptom management) is always available to patients. There is a subset of patients, however, that appreciate the symptom management, yet they still wish to name the time when they would wish to hasten their death by taking a lethal dose of medication, legally prescribed.*

Deborah Whiting Jaques said medical staff know the personality type of people who seek assisted dying in Oregon:

*We know that nearly 100 per cent of individuals who get the prescription, say 'I want to be in control at the end of my life. It's my decision.' This is a self-determination issue. And 'I don't want to suffer.'*

And Barbara Glidewell said that for some, the option of assisted dying provides reassurance:

*Many patients want to obtain the medication in case their worst fears materialise such as loss of dignity and intolerable suffering. Others want it as their—I don't know if this is a term in the UK—'ace in the hole.' In other words, a back up plan, an insurance plan; as in the card game of poker. 'I've got an ace here and maybe I'm going to play my ace, if I need it,' do you see what I mean?*

Linda Ganzini emphasised the mostly psychological motivation for seeking assisted dying:

*That's the other thing our data shows us, they're quite physically asymptomatic when they've making their request. They're terminally ill, but they're looking down the road, and so it's not that people get a bunch of symptoms and say 'Oh, this is bad, I want to die'; it's that people say 'Oh, I could get those symptoms and that's going to undermine my autonomy.'*

Barbara Glidewell had found that patients drew comfort from initiating the process of assisted dying, even if they did not follow this through:

*It relieves the mind for some patients to just participate in an informative interview. They just want to know how the qualification process is conducted. Often such patients will be thankful for the information, and that is all they wanted.*

Deborah Whiting Jaques pointed out that 'seven in ten people who get the medicine do not take it'. These comments suggest that having ready access to the medication may provide psychological comfort even if it is never used.

The experts from Oregon were very clear that assisted dying is a difficult process for healthcare professionals to be involved with. Linda Ganzini told us:

*We've done interviews with hospice nurses and hospice social workers, physicians involved. They feel the burden of this, you know, it's not like another day at work... I've met physicians who were really initially very supportive of the law, and then they're involved in it, and they say, 'You know, I really dread being asked to do this again.' One of the reasons for this is that in order to make sure that they're comfortable and it's the right thing, they [physicians] lose a lot of boundaries with the patient.*



Professor Ganzini suggested that hospice teams provide a more supportive environment for practitioners:

*They have the option to refuse to be involved, and no one who is morally opposed to this needs to be involved. But they're much more set up to be supportive, and I remember in our study, the hospice and palliative care physicians who were involved were much more comfortable and not traumatised by this at all compared to the family practitioners.*

She thought that the physicians who were GPs in these small towns who didn't have a lot of deaths found it hardest to be involved in assisted dying.

The relationship of 'coexistence' between assisted dying and end of life care is illustrated by the various roles that hospices, hospitals, GPs and Compassion and Choices staff and volunteers play in the assisted dying process in Oregon. Barbara Glidewell told us, 'Hospital palliative care providers do not provide a lethal dose of medication for a hospitalised patient. They are consultants for management of comfort care.' However, it might be that a patient's processes of accessing palliative care and assisted dying happen in parallel: 'Both processes may be occurring at the same time. The patient may be going through the qualification process which is separate from the provision of palliative care symptom management.' She pointed out that assisted dying never takes place in the hospital because it's considered a public place and this is banned by the Death with Dignity Act: 'Only if the patient can be discharged to home or someone else's home, may they take the lethal dose of medication, if it has been prescribed after qualification.'

Most hospitals have a policy of conscientious objection and allow staff to refrain from being involved in certain procedures:

*These procedures or events may be: reproductive intervention, abortion, sterilisation, withdrawing of life support, and physician aid-in-dying.... Bedside or ward nurses are aware of this law, and may chose to participate in a conversation conducted by a physician, or not, depending on their own values. They may contact the physicians to mention the patient would like a referral to the palliative care team and/or have someone come by who will explain the qualification process for physician aid-in-dying.<sup>379</sup>*

Barbara Farmer said hospices must have a clear policy on assisted dying and staff at the Legacy Hospice 'can certainly choose to conscientiously object if they have a patient that is requesting Death with Dignity, and they can choose to not be providing service to that particular patient'. Deborah Whiting Jaques observed that most hospices are 'neutral' on the issue of assisted dying: 'I don't think any hospice in the state of Oregon other than perhaps one hospital system says we oppose and we do not support, we do not allow', but hospices' policies often prohibit hospice staff from certain types of involvement in the Death with Dignity Act:

*In hospice in the United States we have always said, one of our taglines has always been, that hospice neither hastens nor delays death, so we let nature take its course. Especially at the beginning when the law went into effect in Oregon, the conflict between 'we neither hasten nor delay death' with hospice seemed incongruous with 'we will allow our patients to choose, we take care of patients who choose to end*

*their own lives'. And where we have come in that discussion is saying in hospice that is still true. In hospice and palliative care we do not, hasten nor delay death. It is the patient's right, however.*<sup>380</sup>

Barbara Farmer explained, 'In our situation, because we're affiliated with the Legacy Health System, Legacy physicians cannot be the prescribing physician.' However, according to the Legacy Hospice's policy,

*We are within the law. At Legacy, we as professionals cannot physically assist that person in obtaining their prescription, in giving the medicine or any of that, but we can offer support and education, and we can be a conduit for them to be able to get the information.... We support the patient's right for self determination regardless of what that is.*

To fulfil this responsibility, the hospice might encourage the patient seeking assisted dying 'to be in contact with Compassion and Choices.

Then Compassion and Choices helps them, assists in that process of either identifying a physician, finding out the information in those types of cases.'<sup>381</sup>

Therefore Compassion and Choices of Oregon has an important practical role in facilitating the assisted dying process, as Peter Lyon explained:

*I think our main job is, when somebody calls and wants to use the law, then we are the ones that make sure that a prescribing doctor can be found and a consulting doctor, and if a psychiatrist is needed then we know from experience people who have filled those roles. We usually try to encourage whoever is taking care of that patient, that would be the first call, is to see whether they're willing to help... Most physicians receive requests for assisted dying so rarely, you never get used to the paperwork or remember where it was. So it's nice to be either directed to a website that Compassion and Choices has to get the information, or be sent stuff, a lot of us old doctors still aren't that computer savvy, and we still like to have a piece of paper!*

He said that the role of Compassion and Choices was to call up the doctor and see if they were willing, and make sure they know what the law is.

Most hospice policies would not permit patients to take their medicine to a hospice. This can cause tensions, as Ms Farmer observed:

*We serve patients in a Catholic-based adult foster care home... We have a patient there that has their medicine. The patient actually still tells us they are planning at some point on taking their medicine. That particular home will not support them there. So, our social worker's actually looking for another environment for that patient to move to in order to take their medicine. And where that patient is probably going to take their medicine is in a hotel room.*

Other tensions can be presented by the role of the prescribing physician.

Linda Ganzini commented on the difficulty people who live in rural areas have in accessing assisted suicide:

*It's much more difficult for people in rural areas to access assisted suicide because... if you're in a little town, there's only one or two physicians. They don't want to be known as the suicide doc. The confidentiality issues are very difficult in a small*



*doctor's office in those areas, finding a pharmacy willing to participate. So I think they don't want to take any risk around it.*

This can lead to doctors who are willing to prescribe lethal medication under the ODDA feeling type-cast: 'There seem to be a couple of docs in each community who are the most available' and he thought these doctors were often 'stigmatised':

*Speaking to these other doctors who are frequently available to help with the law, they're very sensitive to how they're being viewed in the community. And I hear that excuse more than any other, or that reason more than any other, when doctors say they don't want to participate because they're afraid of how they will be viewed by their peers, and I think by the community.<sup>382</sup>*

Some doctors might be willing to prescribe the lethal medication but as Barbara Glidewell put it, they 'do not attend the terminal event in the patient's home. They are not required to do so.' She thought this unwillingness may be explained as a 'fear of being misunderstood or unappreciated by their peers — being singled out as a physician who will participate'. The gap that opens up where doctors or hospice staff may be unable or unwilling to participate in the act of assisted death is often filled by volunteers from the organisation Compassion and Choices. Barbara Glidewell said, 'If the hospice agency is faith-based, they may prefer to remain outside the patient's room while the patient ingests the medication, then return to support patient and family as the patient expires.' Barbara Farmer told us:

*We don't automatically go [to be present at the death] but if our staff member [has a] relationship with the care giving nurse or social worker, and they would like their support there, and then it's up to the practitioner to be present if they would like to, and we honour that. More often than not our staff or multiple staff are there. Usually Compassion and Choices is there.*

Deborah Whiting Jaques observed that the presence of Compassion and Choices volunteers could be an important source of support because 'the level of training and experience is going to be greater with Compassion and Choices'.

The Compassion and Choices volunteers also described this collaborative relationship with the hospice teams:

*Their hospice care givers, if their clients choose to use the law, are not allowed to be present when they take the medication. Some of them choose to come to meet with the client before, and they leave the house while they take the medication and then they come back in.*

While hospice staff usually can't be present at the death, the volunteers said they can provide important medical support if the process does not go to plan and the family needs additional support:

*We're trying to work more with the hospice people so that if hospice is involved in the process and knows that it's happening, if it starts to take a while, the medical director here in Portland will call the hospice and say, you know, it's been 50 hours and the family's being a little concerned, can you stop by and reassure them.*

Therefore, while the various agencies evidently work together in Oregon to coordinate care and support for terminally patients who choose to have an assisted death, the assisted dying process does not seem to be integrated with processes for providing end of life care to the extent that it is in the Netherlands and Belgium.

### Switzerland

According to the Swiss Penal Code, which entered into force in 1942, assisted suicide is not regarded as a criminal act if the person assisting is motivated by altruistic considerations, and the person assisted is a competent adult.<sup>383</sup> In these circumstances, assisted suicide can be performed by either physicians or non-physicians, although euthanasia is illegal.<sup>384</sup> The law does not give physicians a special status in assisting with suicide, and since the 1980s right to die societies such as Exit Deutsche Schweiz and Dignitas have played a prominent role in providing this assistance. However, a doctor's prescription is needed if lethal medication is required. According to the Swiss Federal Office of Justice:

*Where assisted suicide organisations use drugs such as Natrium-Pentobarbital (NaP), they must consult a doctor authorised to prescribe such drugs, who, in turn must comply with the provisions of the Federal Act of 3 October 1951 on Narcotics (NarcA; SR 812.221), the Federal Act of 15 December 2000 on Therapeutic Products (TPA; SR 812.228).*<sup>385</sup>

This requirement exists to control dangerous drugs, 'not because of a view that assistance with suicide is a function of medicine'.<sup>386</sup>

The Commission visited Switzerland in May 2011 and met a number of experts, practitioners and policy-makers to discuss the approach to assisted suicide in Switzerland, its relationship to palliative care and the respective roles of doctors and right to die organisations. It quickly became clear that assisted suicide has a very ambivalent relationship to end of life care and that although some doctors play a role in writing prescriptions and an even smaller number of doctors might provide support during a patient's suicide, assisted suicide is largely something that takes place outside the health care system. There is clearly an ongoing debate on the subject of whether it is ever a doctor's role to assist a patient's suicide.

Georg Bosshard, who is a medical practitioner and Associate Professor for Clinical Ethics at the University of Zurich, began by explaining the Swiss system of palliative care, which takes a 'generalist' approach to delivery:

*In the UK you have specialised doctors for palliative care... but we have much more the approach to train... normal GPs in palliative care and also as I am a nursing home doctor in many cases I am just doing palliative care. I don't wait for end stages of lung cancer to have my patients sent to a palliative care unit. We are the palliative care unit.*

Professor Christian Kind, President of the Central Ethics Committee at the Swiss Academy of Medical Sciences (SAMS), explained that concerns that people might choose an assisted suicide because they did not receive appropriate end of life care has recently spurred the improvement of palliative care in Switzerland:

*In 2006, the Swiss Academy of Medical Sciences has made directives on palliative care in the intention to promote palliative care, but then it was also a federal councillor, the Minister of Health, who was very much concerned about the idea of assisted suicide, and he launched a national campaign for palliative care. There is now a national statute for palliative care, how to promote palliative care, there is much going on.*

He commented that Switzerland's development of palliative care is 'behind very much, but there is much going on now'.

Georg Bosshard argued that while palliative care might play a role in reducing a person's wish to die, the idea that palliative care can eliminate all suffering is 'empirically wrong' because assisted dying is a matter of self-determination:

*Even if you have the best palliative care you have patients saying 'that is very fine but I just do not want it, I want to die at home I want to control the circumstances of my death, because it's not about pain and symptoms it's about controlling my own death'.*

Professor Christian Kind had the same view:

*What I've heard from general practitioners involved in care at the end of life, that according to their personal experience, there are many patients in whom the wish to die can be alleviated by good palliative care. But that there is a small minority where this just doesn't work. These people say, 'Well, I don't suffer from my disease very much, I'm not desperate or anything, I just want to die.'*

Dr Markus Zimmerman-Acklin, Vice-President of the Central Ethics Committee at the Swiss Academy of Medical Sciences, made a slightly different point, suggesting that the aims of palliative care and assisted dying are the same: 'Autonomy, individualism, self-determination and a good quality of life until the end.' However, while Dr Zimmerman-Acklin suggested that the aims of palliative care providers and right to die organisations are the same, 'You can't bring it together.' Professor Kind suggested that the basic question when people don't agree is whether one should alleviate suffering by killing the sufferer or by helping that person kill themselves:

*This doesn't make sense to me and many others, because by taking one's life of course his suffering is eliminated but so is the person, whom we wanted to help in the first place. It's just not the right thing to do, not the logical thing to do.*

Professor Bosshard explained that while terminal sedation might be used in palliative care as 'a response to pain and symptoms... where other kinds of symptom treatment do not work anymore', assisted suicide has 'a much, much broader context and most of the demands for assisted suicide as a core issue it is not the pain and symptoms, the core issue is independence, dignity'. He thought doctors do not necessarily feel that independence and dignity are medical issues within their realm of responsibility.

Professor Kind from SAMS said that as a doctor:

*My duty is first to the quantity and/or quality of life of my patient. And if I see or if my patient sees that my treatment doesn't bring him any good, or brings more harm than good, it's my duty to refrain from this treatment. But it's not at all my duty to put an end to his life.*

The policy of SAMS is that assistance with suicide belongs outside the medical profession:

*We think it should not be the doctor's responsibility. The doctor's responsibility should be to help people to make a different choice. If they persist in their choice to die, then it would be better to have some other solution than a medical one.*

However, while SAMS discourages doctors' involvement in assisted suicide, this is a legal practice: 'The prescription of a lethal dose of pentobarbital is currently tolerated by authorities, if issued by a physician respecting certain minimal conditions. Most doctors do not engage in this practice, but a willing minority keeps the system going.' Therefore, there is an ongoing ambivalence in Switzerland about whether it is appropriate for doctors to be involved in assisted suicide and the role of right to die organisations. Bernhard Sutter, a board member of the right to die organisation Exit Deutsche Schweiz, told us that while SAMS had established that assisted suicide is not the role of the medical profession, 'still doctors have been writing these prescriptions, have been helping their patients, and there was not a problem for those doctors, this was more like a guideline'. Therefore more recently SAMS has changed its guidelines so that in certain cases it is considered acceptable for the doctor to help: 'This of course was for us, for [right to die] associations, a great step forward, of recognising there is actually medical help involved.'<sup>387</sup>

Dr Zimmerman-Acklin observed that as a result of the controversy surrounding some of the Swiss right to die organisations, 'There is a governmental pressure on physicians to engage more in the whole process, because it would be the safer way for the government', but argued this is inappropriate:

*The historical idea in Switzerland, of our article 115, is not hastening death. It's not about helping people to die in a better way. It is about the right to die as a fundamental right of citizens: if somebody would like to go, he or she has the right to do it. It's a non-medical way to die... and that's the reason why physicians haven't yet regulated it in a manner like Oregon or Belgium or others.*

Dr Zimmerman-Acklin further commented that while the High Court has ruled that 'there is a right to die, even for psychiatric patients, and there have to be two opinions of experts', there was no consultation with experts and physicians to see 'if they would like to take that job. It's a kind of playing with a hot potato: about who will take this very difficult part.'

Christian Bretscher, a former congressman with personal experience of Exit DS, observed that doctors 'are not very happy to have patients that could probably have the wish to die with Exit', and Bernhard Sutter said doctors involved in assisting suicides are subjected to a lot of scrutiny:

*It puts them at the centre of a legal discussion. After someone dies with Exit the coroner comes and the state attorney comes, and the police are there, and of course the name of the doctor shows up and if there has been any mistake, he could be in trouble.*

Professor Kind suggested it is unjust if society says, 'Doctors, this is a problem, you limit it as far as possible and then you regulate it so that no-one else is disturbed.' He thought this was not fair.

Professor Bosshard observed that with higher levels of immigration in Switzerland and greater cultural diversity among doctors, there is a greater divergence in cultural attitudes to assisted suicide:

*For example in my nursing home we have a lot of staff also from Germany, Poland and Romania. And if we were to have a case of assisted suicide on our ward, we would have to bring all these different views together and this would turn out to be very difficult. So it is not easy to find a real GP today who is willing to do it, even more difficult than 20 years ago I'd say.*

He said there are practical limits on where assisted suicide can take place as most Swiss institutions do not allow assisted suicide to happen on their premises:

*The hospitals usually do not allow it to happen; also in nursing homes — we have a policy in our nursing homes: assisted suicide is in principle allowed, but it happens very, very rarely and it is not something that works easily in the institutional context. Usually in almost all cases it is something at home and the involved doctor is the GP, that's the normal way.*

However, Bernhard Sutter, board member of Exit Deutsche Schweiz, said that around half of care homes in Switzerland do permit assisted suicide to take place on their premises:

*This came originally from the nurses and staff working in those homes; they were the ones who went to their directors and managers and said: 'Come on, it's inhuman if somebody who is dying has to be put into an ambulance, has to be driven out into some place where they can die. These people have been living in these homes, maybe for couple of years, they have all their personal belongings, all their furniture in there and it's their home.'*

Official public homes for the elderly in Zurich allow assisted suicide for legal reasons:

*From a legal point of view... in Switzerland if you live in these places it's like you're renting an apartment, so it's your home. And in your home you are allowed to do what you want as long as it's legal, and it is legal in Switzerland; so there is no way you can forbid it to somebody who is renting a room in an elderly home, not to do it there. So from that point on, more and more homes have followed that principle.*

Bernhard Sutter suggested that the lack of privacy in hospitals makes it impossible to allow assisted suicide, 'I completely understand that you cannot have assisted suicide if people are next to you, so it might be difficult for the hospitals to always organise a room where they can be there by

themselves.’ Mr Sutter further observed that most people would prefer to have their assisted suicide at home, but ‘of course there are some people who do not have a home anymore because; as I said, they might have been hospitalised for a long time’.

Those the Commission interviewed explained that in many cases a physician’s involvement is limited to writing the prescription for the lethal medication. Professor Bosshard suggested that in around 50 per cent of cases it’s the person’s GP who writes the prescription and in the other 50 per cent of cases it is a doctor affiliated to the right to die organisation. Mr Sutter suggested it was preferable for a patient to ask for assistance from a doctor with whom they had a pre-existing relationship:

*The doctor knows, for example, if the patient is suffering from terminal cancer and then the patient goes to the doctor and says, ‘Listen, I’ve thought about it, I still have another four months to live but I suffer, I don’t want it, would you please give me the prescription for pentobarbital?’ And then he [the doctor] does the prescription or he doesn’t, that’s up to the doctor.*

Professor Kind said ‘many physicians find it difficult’ to assist with the suicide itself and ‘even more doctors would find it difficult to write a prescription *and* assist the whole process’, which is why right to die organisations are needed. Christian Bretscher emphasised that there could be complicated relationships at work that might inhibit a doctor’s involvement:

*Let’s take our example again. My mother being in this hospital, all the doctors around her wanting to do more surgery but not wanting to let her die. There is our family doctor, some ten kilometres away, who accepted our wish, but what is this family doctor going to do against the doctors in the hospital... The hospital does not want to help, but there’s a family doctor who says, ‘Well, if I need to I will’ — and then he has to fight to make his mother’s wish come true, and that’s not possible at all.*

In such a situation, he suggested, ‘You need the organisation that is with you and helps you.’ Mr Sutter pointed out that once a patient has obtained the lethal medication ‘you absolutely do not need Exit’. However, GPs tend not to have experience with this medication and may need guidance, ‘They want to be sure they don’t wake up again, they want to make sure they don’t have damage to the brain or something.’ Professor Bosshard agreed that ‘most GPs know very, very little about assisted suicide’. In many cases, the doctor also is not willing to be present during the death. Therefore, ‘the right to die societies are as successful as they are because doctors keep out in most cases. So it’s not that the population basically likes the right to die societies, but there is nobody else doing it.’

Professor Bosshard argued that the involvement of GPs in assisted suicide is preferable to the involvement of right to die societies, but,

*the key issue for Switzerland and for many other countries is that you can resolve the issue that basically doctors don’t have any incentives to participate. You must find a way to bring doctors to do something that they basically do not like so much.*

He suggested that the best way to encourage doctors’ involvement would be to provide more support, rather than more regulations:



*I think in the end the regulations do not help us doctors. What helps is to have colleagues and that it is possible to discuss their cases, their real cases and in the [Dutch] SCEN network you can discuss cases.*

### **The impact of assisted dying on the funding and development of palliative care**

In the absence of existing concrete evidence on the impact of assisted dying on the funding and development of palliative care, the Commission invited the European Association on Palliative Care (EAPC) to deliver a report assessing the standard of palliative care in the European jurisdictions where euthanasia and/or assisted suicide has been legalised — Belgium, the Netherlands, Luxembourg and Switzerland. The report had two main aims: to investigate whether the standard of palliative care has changed since legalisation, and to discover whether legalisation of euthanasia and/or assisted suicide has affected how palliative care has developed.<sup>388</sup>

The report's authors reported various impediments to the development of a coherent picture of palliative care provision across Europe. This was because there were gaps and inconsistencies in the data available in different countries; differences in the relationship between assisted dying and the law across different jurisdictions; and a lack of an international framework for assessing the quality of palliative care. The report's findings therefore had to be drawn from the indicators that were available rather than comprehensive measures of palliative care quality. However, the wide range of indicators used, combined with a detailed review of the literature, allowed the authors to develop several firm conclusions about the standard of palliative care in jurisdictions where euthanasia and/or assisted suicide are legal.

Section 1 of the EAPC's report contains a comparative analysis of indicators of national palliative care developments. The researchers compared indicators from the jurisdictions mentioned above with three other European countries: Germany, France and Spain. The indicators used in the report were: the availability of specialist palliative care resources, for example, specialist palliative care beds and home care teams; attendance at EAPC conferences by professionals in palliative care; bibliometric parameters related to palliative care literature, for example, the number of research publications including the words 'palliative care'; the ratio of deaths at home; and classifications and rankings of palliative care development by international bodies.

The report's authors found that while it was too soon to determine conclusively the impact of legalising assisted dying on the availability and quality of palliative care, there was a range of positive indicators. For example, the proportion of palliative care beds in the Netherlands and Belgium is greater than in all the surrounding countries except the UK.<sup>389</sup> The research also found that in 2005 the level of palliative care in Belgium, the Netherlands and Switzerland was comparable to that in Germany, France or Spain, and that the financing and development of palliative care services in the Netherlands and Belgium has been advancing continually over the last five years.

Section 2 of the report reviews scientific literature on the development of palliative care in Belgium and the Netherlands. Although much research into palliative care has been carried out before and after the legalisation of assisted dying in these two jurisdictions, little had focused on the impact of the introduction of laws on assisted dying on the quality or development of

palliative care services. However, using the available data, the researchers were able to conclude that the standard of palliative care in jurisdictions that have legalised assisted suicide is comparable to that in countries where assisted suicide remains illegal. For example, a study by Piers et al in 2009 on the general availability of palliative care for geriatric patients in 21 European countries concluded that Belgium and the Netherlands were among the countries with the best availability of palliative care.<sup>390</sup> A study by Pereira raised questions about the lack of formal training and recognition of palliative care as a medical sub-discipline in Belgium and the Netherlands, contrary to countries like the UK, Australia and USA, and suggested this may indicate there is undeveloped palliative care.<sup>391</sup> However, these findings were countered by a EU report by Martin-Moreno et al in 2007, which identified under-development of standardised palliative care training in Belgium but numerous training courses in the Netherlands.<sup>392</sup>

The scientific literature review also found significant evidence that the standard of palliative care has improved in Belgium and the Netherlands since their respective laws on assisted dying were introduced. In particular the report cites a study by Bernheim et al, which observed that the Belgian Palliative Care Act passed in 2002 has boosted palliative care development and improved palliative care practice.<sup>393</sup> One retrospective survey based on physicians certifying a representative sample of death certificates found that the intensified alleviation of pain and other symptoms at the end of life had risen strongly in Flanders and Belgium. For example, in Flanders the rate had risen from 18.4 per cent of all deaths in 1998 and 22.0 per cent in 2001 to 26.7 per cent in 2007.<sup>394</sup>

The report concluded that palliative care is currently well developed in countries in which assisted dying and/or euthanasia are legal, with no evident disparity in the provision between these countries and other European nations. The authors wrote, ‘The idea that legalisation of euthanasia and/or assisted suicide might obstruct or halt palliative care development thus seems unwarranted and is only expressed in commentaries rather than demonstrated by empirical evidence.’ However, the report also notes that because euthanasia and/or assisted dying in these countries has only been legal for a short time it is not yet clear whether the legalisation of assisted dying might have a longer-term impact. The authors therefore call for nations which are ‘considering legalising euthanasia or assisted suicide [to] establish equitable, accessible and affordable palliative care and ensure a broad national structure for the provision of palliative care services’.<sup>395</sup>





## 5 Assisted dying and vulnerable groups

As previous chapters have highlighted, it is essential that any discussion of the possible future legalisation of some form of assisted dying in the UK should consider carefully the impact that such legislation might have on the most vulnerable people in our society. Therefore, this chapter will begin by exploring the concept of vulnerability and the varying ways that this term has been interpreted by those who gave evidence to the Commission.

Some of those who gave evidence emphasised the view that vulnerability is something that is experienced at an individual level, and can be increased or mitigated by personal, social and societal factors, as opposed to being associated with a particular ‘group’. However, most of the evidence the Commission received focused on the impact that assisted dying might have on particular groups perceived to be especially vulnerable to a change in the law on assisted dying, such as older people, people with terminal illnesses, disabled people and those with learning disabilities. Therefore, the main body of this chapter will review evidence submissions that explored the impact that the legalisation of some form of assisted dying might have on people from these social groups. In each case the evidence reviewed will include insights gathered from a broad range of sources including academics, advocacy groups, health and social care professionals and members of the groups in question.

The final part of the chapter will review evidence derived from jurisdictions that permit assisted dying on how assisted dying has affected particular social groups, and explore whether any evidence of potential abuse or more subtle forms of vulnerability has emerged.

### **Who might be considered ‘vulnerable’ in the context of assisted dying?**

Some of those who gave evidence emphasised that vulnerability is not a characteristic of particular social groups, but something that anyone can experience to a greater or lesser extent at different points in their life. Social factors that might increase or reduce an individual’s vulnerability might include income, education level, psychological resilience, personal relationships and access to social support or health care. Professor Bobbie Farsides of Brighton and Sussex Medical School stressed this point at the AHRC policy seminar on assisted dying, when she highlighted the limitations of considerations of vulnerability based on particular ‘vulnerable groups’. She argued that an individual’s vulnerability may be a permanent state heightened by disability or illness, or could be a temporary position induced by other social factors. It is therefore possible to be vulnerable without falling into one of the recognised categories. Instead, the discussion needed to focus on shared responsibilities and social representation.<sup>396</sup>

Christine Kalus, a Macmillan consultant clinical psychologist and lead psychologist in specialist palliative care for Portsmouth City PCT, told the Commission that in the context of terminal illness

*vulnerability is something that is either inherent because of the disease state, or whatever is going on for the person, and that may or may not be related to age... I don't think we should see any group as a homogenous group and all the evidence from social gerontology is that we actually get more different as we get older, not more the same, so I think that's kind of important to remember. But also that people may have vulnerability put on them, if you like, through poverty, through poor life chances, through all sorts of other factors that we may be exposed to in our lives.<sup>397</sup>*

In its written evidence, the British Geriatrics Society argued simply, 'Once quality of life becomes the yardstick by which the value of human life is judged, the protection offered to the most vulnerable members of society is weakened.'<sup>398</sup> Thus anybody subjected to negative assumptions about their quality of life might be considered vulnerable in the context of assisted dying legislation. Bridget Robb, development manager for the British Association of Social Work, also expressed her concern about the potential vulnerability of any person who requires social support, in the context of cuts to social care budgets:

*The pressures that people feel that they ought to take their own life in some way and certainly the pressures for carers to say, 'we can't cope any longer', I think are going to be very real and very tangible and this is certainly something that we are very concerned about.<sup>399</sup>*

However, Dr John Anderson, a retired GP, thought discussions about vulnerability in the context of assisted dying can be over-simplistic, neglecting the vulnerability that also might be caused by a person's fear of a bad death:

*I do not consider that the word vulnerable applies only to those who might fear having their lives terminated against their will. The many others who, under the present legislation, fear the possibility of lingering painfully and uselessly on with no hope of a merciful release are also vulnerable.<sup>400</sup>*

## **Older people and assisted dying**

### **Evidence from advocacy groups and health and social care professionals**

Older people were one of the 'groups' of people most frequently mentioned by those who gave evidence as being potentially put at risk by a change in the law to permit assisted dying. The reasons given for older people's greater vulnerability included: discriminatory attitudes towards them; inadequate health and social care for older people; the desire of some older people not to be a burden on their relatives or society as a whole; the unwillingness of some older people to spend their savings on care later in life; and the potential for abuse motivated by family members' desire to inherit an older relative's savings.

Gary Fitzgerald, Chief Executive of Action on Elder Abuse, brought to the Commission's attention a study published by Action on Elder Abuse with the support of the Department of Health in 2007.<sup>401</sup> The study sought

to identify the prevalence of abuse and maltreatment of older people and found that 4 per cent of older people in the UK were experiencing some form of abuse.<sup>402</sup> In his oral evidence Gary Fitzgerald explained that according to the latest figures, 8.6 per cent of older people living in the community are experiencing some form of elder abuse.<sup>403</sup> He explained that this presents serious issues in relation to assisted dying about

*feelings of worth and value of older people within society and... the linkage between how people feel and the decisions that they take and the environment and circumstances that are around them... It's about constraint and it's about undue influence and it's about, how do we define the circumstances in which we can be satisfied that a decision that's taken actually is taken for the right reasons, in the right context?*<sup>404</sup>

Describing the impact of this failure to care for and respect older people, Gary Fitzgerald said:

*We are creating situations in society, at the moment where we are giving older people an existence, not a quality of life. As a result of that, it's not surprising to me that I see a very strong link between depression of older people and their experiences of abuse and I think we have to be careful that we are not actually, from a societal point of view, creating the environment where older people feel, 'I want to give up, I don't want to continue living, this is too much for me.' We are creating that situation. If we create the right environment around them, they may feel differently. So, I think there is an issue, for us, about cause and effect and consequences of societal decisions.*

Mr Fitzgerald also highlighted the vulnerability of older people to 'degrading relationships', arguing that while such controlling relationships might usually be associated in people's minds with partner relationships and domestic violence:

*That does extend to older people in family dynamics and family relationships as well, where an older person can actually end up being placed in a situation where they appear to be making decisions in isolation, independently, but actually are heavily influenced by what's taking place within the family unit around them.*

He said the abusive relationships that some older people are subjected to can be particularly overlooked in the context of poor health:

*[The] inherent assumption that age is automatically equated with death makes it much harder to unpick the reasons behind a death having taken place... I see too many incidences coming through my helpline where the reasons why somebody has died have actually been linked to an abusive situation or environment, but the cause of death on the coroner's note is not necessarily the same. I will give you an example of what I mean by that. A lack of quality care leading to a pressure ulcer, which leads to septicaemia, which leads to someone's death, will often have on the death certificate the septicaemia without the understanding of the interlinking causes that caused that to happen in the first place.*

Mr Fitzgerald also described the considerable risk of abuse to older people motivated by financial considerations: 'In one year my helpline took records of over £31 million [that had] been stolen or defrauded from older people, almost exclusively by sons and daughters, a tremendous amount of that being through intimidation, threats', although direct coercion was not always to blame. In some cases older people

*will make bad decisions because they want to benefit their family... So they are actually not making decisions based on what's best for them; they are making decisions on what they believe to be best for the wider and extended families.*

He thought in the context of these various potential vulnerabilities, it would be dangerous if an older person's request for an assisted death was to be accepted at face value without a deeper exploration of that person's motivations:

*If we respond to somebody's depression or isolation in the context of assisting someone to die, without looking at, 'how have they arrived, what's the pathway that has lead them to how they're feeling?' then I don't think we're doing justice to the complexities facing older people.*

However, while Mr Fitzgerald powerfully articulated the potential risks to older people posed by assisted dying legislation, he said the board of Action on Elder Abuse 'took the decision not to form an opinion on the principle of assisted dying' because it was felt to be outside the organisation's remit: 'There doesn't seem, to us, to be any inherent abuse issue contained with the principle of choice in relation to assisted dying.' It was difficult to take a firm stance on assisted dying in the abstract, as opposed to commenting on a particular proposed approach.

The written evidence provided by Suzy Croft, a senior social worker at St John's hospice, also highlighted the inadequacies of health and social care for older people:

*The lack of care and support for older people at the end of their lives has been well documented. The recent Health Service Ombudsman's report has criticized NHS staff for treating elderly people without compassion, condemning many to die in unnecessary pain, indignity and distress.<sup>405</sup>*

Ms Croft emphasised that older people do not have equal access to palliative care:

*In 2005 a report, 'End of Life Care', commissioned by Help the Aged, showed that inequalities in palliative care mean that the opportunity to go into a hospice declines with age, as does the chance to die at home. Only 8.5 per cent of older people who die of cancer do so in a hospice, compared with 20 per cent of all those with cancer. Older people in nursing homes are also discriminated against in that they are far less likely to access specialist palliative care, or be admitted to a hospice.*

As mentioned in chapter 4, Ms Croft thought we could not afford to contemplate assisted dying as a society until we have a foundation of adequate health and social care in place for everyone who needs it.<sup>406</sup>

Karen Rodgers, a former care assistant who provided written evidence to the Commission, described how old, sick or otherwise vulnerable people can internalise their families' and staff members' negative social attitudes towards them, leading to the sense that they are a burden:

*I have worked as a care assistant at a care home and during the course of my work became more and more concerned about how our society is already marginalising and failing in respect and appreciation for the elderly, sick and vulnerable. Many are already being given the clear if unspoken message that the world would be better off without them. We talk so often these days about promoting self-esteem and respect for others yet I was distressed to see how many of the people I supported had no feelings of self-worth as a result of experiencing very little respect or even consideration from others. 'I am such a burden', 'I am in the way', 'You'd all be better off without me' were phrases I heard with distressing regularity. It was not that these people wanted to die; it was that they were voicing opinions they perceived were held by some of their family members and people who worked at the home.<sup>407</sup>*

She wrote that a responsible society must be able to guarantee an adequate level of care to those who need it:

*Round-the-clock care cannot depend on the goodwill of individuals but rather on a system that recognises and actively promotes its duty to protect the most basic rights of the weakest members of society. I dread growing old or getting sick under a system that does not do this.*

Ms Rogers argued that assisted dying and end of life care are 'in complete conflict', concluding 'Legalising assisted dying would make this country a very unsafe place for many vulnerable individuals; the legal and moral imperative to provide palliative care is a vital remaining defence of our society's humanity and sanity.'<sup>408</sup>

The written evidence provided by the British Geriatrics Society also emphasised the negative impact of low quality care, and the feeling they are not valued by society, on older people's decision-making processes:

*In the experience of many geriatricians, the feeling of many older people that life is unbearable in its later stages is a direct result of the reaction of others to their frailty and the care and treatment they are afforded. Our concern then is that many older people, because of the care given to them by society in general and the NHS and Social Care system in particular, will perceive themselves as a burden and feel under pressure to end their lives.<sup>409</sup>*

Martin Green, Chief Executive of the English Community Care Association, expressed his concern that many older people living in care homes do not have opportunities to discuss their thoughts about death with people they trust:

*When you start to have those fears and anxieties but you're being taken out of lots of contacts, who do you tell that you have those fears and anxieties? What you do is, you take them on board yourself, and you sit with them, usually quite isolatedly.*

While campaigns such as Dying Matters seek to stimulate conversations about death, if a person lives in residential care without ready access to good health services, ‘where does that conversation go?... there is a major challenge around how you interface primary care with care services. Because if you don’t, there is nowhere for that conversation to go.’ Mr Green suggested that assisted dying might not be accessible or workable for older people living in care homes, as a person might be depressed and feel they had ‘no other option... to come out of that situation’. However, they would ‘need quite a lot of support to start thinking about how that translates into an absolutely final decision... I don’t see that there’s that in the system at the moment.’<sup>410</sup>

Dr Martin Curtice, a consultant in old age psychiatry, said assisted dying was frequently raised in his working life:

*In the last couple of years older people have been mentioning to me now and again, ‘Oh I wish I could have a way out.’ And obviously I’ve got to be very neutral on the subject, but it’s an increasing thing that they don’t ask me about, they just mention.*

Relatives of people with severe dementia sometimes commented ‘that their loved one really would not have liked this and if there is any way to cease their life, they would like that’. Dr Curtice observed that, statistically, assisted dying would be likely to affect older people more than other age groups, and recognised this effect in Oregon: ‘The average age of people, you’re right, who do end their lives in Oregon... the actual average median age is 72 — so you’re right, it’s the older person.’ However, he did not think that a law on assisted dying would particularly disadvantage older people or put them at risk: ‘I think the law would apply equally... in any new legislation, I can’t see it being any big issue for older people.’ He thought the most important issues might be around mental health, as rates of depression tend to be higher among older people, and symptoms of depression can be difficult to distinguish from physical ill-health: ‘Certainly people can present depression with physical symptoms and within older people that’s not uncommon. You can present with pure physical symptoms when in actual fact is a depressive disorder that’s underlying it.’<sup>411</sup> Dr Curtice also discussed appropriate approaches to assessing mental capacity and voluntariness, which we will return to in chapter 7.

In his oral evidence Professor Clive Seale drew the Commission’s attention to his research on medical end of life decision-making (also discussed in chapter 1). This research shows that older people are not statistically at a greater risk of medical decisions that hasten death:

*These more recent surveys suggest that that category of vulnerable person [older people aged 80 plus] appears not to be receiving decisions that might hasten their deaths. So it suggests that even though various means are available to doctors that can hasten death in some circumstances, that particular group is receiving a very low level of those decisions, which suggests that the slippery slope of vulnerable people coming into pressure in a world where decisions that can hasten death are available, these people are not sliding down the slippery slope, so it does suggest that things are OK on that front.’<sup>412</sup>*

This research suggests that if doctors were to approach assisted dying legislation in the same manner in which they currently approach end of life decision-making, there is no evidence that people in the oldest age groups would be disproportionately affected in comparison with other age groups.



## Older people's views on assisted dying

The July 2009 Times Populus Survey, which provided its results broken down by age group, found that 77 per cent of people aged 55–64 and 70 per cent of people aged 65+ felt that the law should be changed to allow doctor assisted suicide along the lines of what is practised in Switzerland; 21 per cent of the 55–64 age group and 26 per cent of the 65+ age group were against a change in the law along these lines. Among the respondents who favoured the legalisation of assisted suicide in certain circumstances, 89 per cent of 55–64-year-olds and 90 per cent of people aged 65+ felt that assisted suicide should be legalised for people with terminal illnesses. There was less support for the choice of assisted suicide for 'people suffering in extreme pain, even if not with a terminal illness', with only 17 per cent of the 55–64-year-olds supporting this and 23 per cent of the 65+ group.

Participants in the focus group Demos ran with older people living in sheltered accommodation were also largely in favour of a framework to allow assisted dying in certain circumstances, although one woman opposed assisted dying in all circumstances on religious grounds. The participants who felt that some form of assisted dying should be legalised gave a range of reasons for supporting a change in the law. One prevalent view was the importance of individual agency and choice; as one female participant aged 70 put it: 'I believe that if that's what somebody wants, they should have that choice.' A woman aged 72 said, 'If there is no hope left, this should be an option.' Compassion was also cited as an important factor, both for the pain and suffering of the individual and for the prolonged suffering caused to their family.

Several of the participants believed that in some circumstances assisted dying might be preferable to losing autonomy and becoming a burden on others. One male service user aged 87 said: 'I feel that if a person is bed-ridden, has to be washed, and cannot do anything for themselves, then they are no use to themselves or anybody else and they should be allowed to be put to sleep.' If the individual is capable of deciding what they want, that is what matters: 'What is life if you can't smile or be happy?' Another male participant aged 79 argued that euthanasia should be brought in because the health care system can no longer cope with the growing numbers of older people needing care: 'Hospitals are full of people that can't look after themselves, nobody visits them, they are shouting and screaming.'

However, other participants expressed concern about the negative influence that inadequate health care or limited resources could have on older people's decisions regarding assisted dying. A male participant aged 63 commented:

*I don't think that older people get the quality of care that they deserve in hospitals and that quite often people die in hospital because of lack of care... It's difficult for any person individually to be aware of what the pressures may be on them emotionally... In a sense the hospitals are assisting people with dying by not giving them the care to keep them alive. We've all got examples of it. So they are assisting dying and it should be noted somewhere.*

The woman who was opposed to assisted dying also expressed the concern that limited resources could affect doctors' decisions about when assisted dying might be appropriate for older people: 'They might decide it's your time to go because you're 75 or 70 and you're in and out of hospital a lot and you've used a lot of medicine.'



As the Times Populus survey discussed above demonstrated, the vast majority (90 per cent) of people aged 65+ who supported assisted dying believed that it should be available for those with terminal illnesses. The survey found there was less support for eligibility for people suffering from impairments or other long-term conditions (23 per cent of the 65+ age group). The opinions that older people expressed in the Demos focus group were also split between these positions. About half the group thought that eligibility for assisted dying should be limited to people who were terminally ill; a woman aged 72 commented that if an individual had cancer, or another terminal illness, they should have the choice of an assisted death. However, several participants felt that eligibility to request an assisted death should be related to the level of a person's suffering rather than being limited on the basis of terminal illness.

Two participants expressed more controversial views in favour of non-voluntary euthanasia, where a doctor or family member might make a decision on behalf of a patient who had lost consciousness. A man aged 80 commented 'If I was a vegetable lying in a bed, very unlikely to regain consciousness, I'd say flick the switch any day', while a man aged 79 said that one of his friends was bed-ridden, incontinent and could not feed himself: 'he is absolutely finished'. He expressed frustration that his friend's family and friends are praying for an end, but there was nothing they can do as the law says that his friend cannot be put to sleep.

Opinion was split on the specific question of whether a person, like Tony Nicklinson, who was not terminally ill but had significant impairments and wished to have an assisted death for this reason, should be able to do so. The 63-year-old man said the situation of an adult with a long-term disability who consistently said they would rather not be alive because they were completely dependent on other people to have a reasonable quality of life was not significantly different from that of an individual with a terminal illness who wanted to die gracefully and with dignity. He thought the issue 'is more about suffering' than diagnosis, but observed, 'It's very difficult to know where they would draw the line on assisted dying.'<sup>413</sup> Another participant referenced the example of Stephen Hawking: 'I don't think we must ever give up hope; there's always hope... You might be suffering at the moment, but you never know, it might change and you might do brilliant things.' A third participant said that it shouldn't matter whether you were disabled or not; if you want to die you should be able to die.

The majority of the older people we spoke to did not seem to think that assisted dying posed a risk to them, but some expressed concerns on behalf of other older people. A man aged 80 told us:

*There's always a risk when you get somebody really old, that the family wants to knock that person off to get their money... I know an old lady. She is way into her 90s... and she is really wealthy. And I'd hate to think that... her brain is OK, her body is not. There is that possibility.*

The member of the group most opposed to assisted dying invoked the slippery slope argument, suggesting that a change in the law to permit assisted dying could have an impact on the way that society values all older people: 'If it becomes legalised half of us wouldn't be sitting here. They would be getting rid of all the old ones to keep the young ones in. They'd be paying no pensions out, the Government then.'

The Commission also received a large number of written evidence submissions from people who gave powerful accounts of personal experiences that had shaped their views. Some of them cited the suffering of their parents or other elderly loved ones as instrumental in forming their opinion that assisted dying should be permitted. For example, a woman named Susan Thomas told the Commission that her mother, having become increasingly frail, had ended her life by refusing to eat, and her father had then committed suicide on his third attempt by placing a bag over his head:

*My abiding sadness is that I could not help them in their time of greatest need... That my dad had to die alone in the middle of the night, bag over face. So this is why I had to write to you. Assisted dying must be legalised. I, for one, will never stand back again, if a loved one needs help to end a life which has become unbearable.<sup>414</sup>*

### **People who are terminally ill and assisted dying**

As the surveys of public opinion quoted in chapter 1 and surveys of doctors' opinions quoted in chapter 4 have shown, assisted dying in the context of terminal illness tends to be one of the less contentious areas of the assisted dying debate. However, the evidence that the Commission has received from palliative care specialists highlights the range of personal and external factors that might make a person more or less vulnerable in the context of their illness, and the great importance of issues such as mental capacity, social pressure and availability of good quality care to the debate on assisted dying in these circumstances.

One of the major risk factors identified by those who gave evidence is whether a terminally ill person's expressed desire to die is interpreted and explored in the right way, and they receive any support they might need. The clinical oncologist Professor Tim Maughan told the Commission that people who have been diagnosed with a terminal illness often 'go through great emotional turmoil' and can fluctuate in their wishes 'from day to day, or from week to week, or from month to month.'<sup>415</sup>

Several of the people who gave evidence emphasised the difficulties that exist in distinguishing between a desire for death that is made as a rational response to a prognosis, and a desire for death that may be a manifestation of treatable clinical depression. Dr Annabel Price of the Institute of Psychiatry at King's College London told the Commission:

*The desire for death is associated with a number of factors, particularly depression and more severe physical symptoms, many of which are potentially remediable with good symptom control and psychological care... We have also recently published data from a study looking at the prevalence of depression and associated factors with depression in patients at the end of life. So it is certainly something that is very relevant to us, both in research and in practice... It is not always easy in somebody who has multiple physical symptoms, to be able to determine how much those are due to depression and how much those are due to the physical illness itself, and actually how much overlap there is.<sup>416</sup>*

The medical director of a hospice who participated in an interview with Demos but wished to remain anonymous pointed out the risks associated with the difference between articulation and intention:

*With some people it's definitely a cry for help. I think—if you've got a physical symptom, it's ok to say, 'I've got pain, I'm feeling sick.' I think especially in our modern society, we're not really on top of our spiritual side. People don't have the language to say, 'I'm scared of the afterlife, I'm scared of what's going to happen.' So, that's a way of... instead of saying 'I'm scared', they'll say 'I want to die', and that allows the conversation to go that way. So some people definitely think I use it as a way of saying 'I'm hurting.'*

He pointed out that people often change their minds about the treatment they might want or not want to receive, as they adjust to their illness:

*I think there are also patients who want to have control. Often MND [motor neurone disease] patients think they like the idea that they could say 'I want to die now.' Over the years I've dealt with a lot of MND patients and you'll have a conversation like 'I can't imagine what it would be like if I become paraplegic or quadriplegic. If I get to that stage, I would want to die.' Then you see them get to that and they get a chest infection that could carry them off quite nicely and you have a discussion... 'You've said this in the past, do you want treatment?' and they say 'oh yes'. So the goal posts keep changing.*

Matthew Hotopf and Annabel Price of the Institute of Psychiatry at King's College London described the way patients' suicidal intentions change and fluctuate as 'the phenomenon of response shift'. They told the Commission:

*This will be familiar to many psychiatrists. Distress and suicidality often fluctuate over time, and even in those who have made a serious suicide attempt, further attempts are uncommon. In the field of end of life care, response shift is also a familiar phenomenon, with patients being able to adapt over time to circumstances they would have thought unbearable prospectively.*

Christine Kalus, Macmillan consultant clinical psychologist and lead psychologist in specialist palliative care for Portsmouth City PCT, also emphasised the complexity of the emotions that people experience at the end of their lives, and the risk that these emotions might be misinterpreted:

*I think that shame, not just about the disease, not just about what's happening, not just about the impact that becoming more disabled as a result of illness may be having on the rest of the family, the issue of burden I think is extremely difficult—am I becoming more burdensome? But also, shame, that perhaps we've carried with us for acts of omission or commission, throughout our lives, that we've actually perhaps been able to mask while we're getting on with our busy day-to-day life, but the time that is afforded through being very ill, perhaps not being able to get out of bed, many of those memories—we talk about life review process—many of those difficult memories may come back as well. And often, my experience is that it's those memories that occlude the person's vision of themselves and others, often more than the physical.<sup>417</sup>*

Professor Tim Maughan highlighted the possibility that making assisted dying an option for patients with terminal illnesses would create a burden of expectation:

*Just think about this: as a dying patient or a patient with a prognosis, there'll be some people who are very clear that they want assisted dying. There'll be other patients who are very clear that they don't want that; they have a principled objection to it. But I suspect that for many people in the middle it will be a grey area, where they're not sure what they feel and that they may come to a decision this week that they don't want to have assisted dying, but next week they're feeling a bit more uncomfortable or things are going badly at home or something—and the option comes up again. And it's kind of like the magnetic pull of that continuing option, and I'm concerned that that in itself might be a burden to patients that we don't really think through.*

Rebecca Coles-Gale, clinical psychologist for Portsmouth City PCT, told the Commission that patients often need to talk through the idea of assisted dying in order to come to terms with their illness:

*There are so many people that I can think of over the four years that I've been working in palliative care who fit what you're describing so aptly in the sense that they might talk about not wanting to be here anymore, that they've had enough, but it's actually about having that conversation and how they themselves can move to a different place. And it's not by encouraging them to move; it's by bearing witness to what they're experiencing without judgement.<sup>418</sup>*

Many of the evidence submissions that the Commission received from members of the public came from people who were either suffering from a terminal illness or whose parents or partners had had a terminal illness. Several people pointed out that although in many cases palliative care is very effective at relieving pain, it does not work for everyone, and in these cases it might be appropriate to explore assisted death. Nicola Wood described her partner's death in these terms: 'Palliative care could not keep pace with his changing need adding to the indignity he had to endure and the fact that

I was finding it difficult to cope caused him further distress.<sup>419</sup>

The submission from LP Mitcham made a similar point:

*I have heard some say that there is no need to be in pain with modern medicine. However, my own experience is somewhat different. My mother had stomach cancer with bone secondaries. She could not eat anything other than liquids and was in continual pain, despite medication. My mother in law had numerous ailments, which caused her pain over a large number of years. In recent years, the painkillers stopped working. She was in pain every day and for the last two years of her life, she had no quality of life and frequently said she wanted to die. If I reach that stage, I want to be able to die, peacefully and with dignity, at a time of my choosing, either at home or in a pleasant hospital or hospice.<sup>420</sup>*

### **Terminally ill people's views on assisted dying**

Some previous research has indicated that attitudes towards assisted dying might be more positive among people with terminal illnesses than among the rest of the population. A study by Chapple et al in 2006 found that people who are suffering from terminal illnesses felt strongly that UK law should be changed to allow assisted suicide or voluntary euthanasia. Following interviews with 18 people who were close to the end of life, the authors said:

*Those who had seen others die were particularly convinced that this should be a right. Some had multiple reasons, including pain and anticipated pain, fear of indignity, loss of control and cognitive impairment. Those who did not want to be a burden also had other reasons for wanting euthanasia. Suicide was contemplated by a few, who would have preferred a change in the law to allow them to end their lives with medical help and in the company of family or friends. The few who opposed a change in UK law, or who felt ambivalent, focused on involuntary euthanasia, cited religious reasons or worried that new legislation might be open to abuse.<sup>421</sup>*

Studies in the USA have also found that people with terminal illnesses are more likely to support assisted dying than people without terminal illnesses. In Oregon, Ganzini et al's 1998 study of patients with amyotrophic lateral sclerosis (ALS), a disease that causes gradual paralysis and respiratory failure and results in death in three to five years, found that 56 per cent of the patients surveyed would consider assisted suicide. Carried about before 1997 Death with Dignity Act came into effect, the study found that those who would consider assisted suicide were more likely to be men, have a higher than average level of education, and be less likely to be religious than those who would not consider assisted suicide.<sup>422</sup> A similar study carried out in 2002 by academics at the University of Ottawa, Ontario, found a higher positive response for assisted dying (both assisted suicide and euthanasia) among patients receiving palliative care for advanced cancer than among the general population. In this study 73 per cent of those surveyed believed that physician assisted suicide or euthanasia should be legalised. Of those who were against legalisation, religious and moral objections came highest up the list. The top reasons cited for legalisation were the individual's right to choose (43 per cent), pain (43 per cent), diminished quality of life (35 per cent) and suffering (24 per cent).<sup>423</sup>

The research Demos conducted with terminally ill service users at a hospice found a similar consensus: while not necessarily wanting to make use of assisted dying themselves, the majority of the people Demos interviewed emphasised the importance of individual autonomy and the right to choose, and stated that people who were suffering from terminal illnesses ought to have the option of assisted dying available to them.<sup>424</sup> One female service user who had a progressive neurological condition that had caused her to develop significant physical impairments and made it difficult for her to speak said: 'I feel strongly that people should have self determination; they should have the right to control what happens to them in the course of their lives.' This woman described why a terminally ill person might particularly require assistance to end their life:

*The trouble is when you most need help, when you most need it to happen and you can't carry on, then you're not in a position where you can do it yourself. If you've got a terminal illness, and it's progressive, and you most need to end the thing, you're least capable of doing it yourself. When you've got an illness that's progressive, and you're frightened of the outcome, then you want to end it. And people are frightened that they won't be able to do anything themselves.*

A male hospice service user focused on his desire to maintain his autonomy when he explained why he thought assisted dying should be allowed: 'If I got to a stage where I couldn't manage myself, then I would want to pass on. I wouldn't want my grandson and everyone around the bed, wondering.'

On the subject of who might be eligible to request an assisted death, one service user focused on the individual's view of their own quality of life, saying: 'I believe that if the person themselves says "I can't take anymore", then it should be possible. That's how I feel. I've got no other feelings about it.' Another focused on the individual's experience of suffering:

*When you think about it, it's a big thing to do. There's all these people trying to save lives, and then someone trying to lose it, it's a bit of a body blow. But then people are suffering, and that's not justice. They say there's a God and that but why do people have to suffer? Some of these people have been to hell and back. I do think should be offered assisted dying, but you should make sure they mean it. You've got to be 100 per cent.*

Another service user's described the emotional journey that he experienced when he was first diagnosed with cancer:

*I wanted to end it. Blow my brains out with a shotgun. But, the doctor said to me, you've got a month to a year, but you won't make a year. So you think, why bother? But that was 18 months ago, so, it all depends on yourself. If I hadn't of thought of my kids, I'd have done it.*

Although this man was relieved that he had not ended his life, he thought 'you should be able to do it if you want' but not that 'you should give someone the actual right to do it'.

Some people highlighted the strain that end of life decision-making and bereavement can have on relatives. A female service user commented on the recent death of her husband: 'Having buried my husband, I feel like an absolute murderer, in a way. He could have dragged on for another few days, but it was my decision, not to give him any more food or water.' She thought assisted dying should be an available option because 'if it was legal you'd be able to have guide-rules, whereas at the moment you just have people's opinions', though having experienced her husband's death, 'I can see the difficulty about giving people the choice.' Another service user Demos spoke to was also ambivalent about the role of family members in the decision-making process for assisted dying:

*Should the family be consulted? I don't know. In the case of a husband and wife, that's another matter altogether. I think it has to be discussed with them, but whether they have any say in it... I don't know.*

Some other hospice service users who supported assisted dying explained that their opinions had been informed by their experiences of deaths in their close family. One male service user told the interviewers:

*At the end of my father's life, the doctor had to give him injections every day. And I'm certain that at the end of his life he helped him. And I couldn't say nothing, so I just said 'Thank you doctor.'*



Another service user said:

*We were 13 in my dad's family, and I've seen at least six of them die, I've been at the bed when they've died. And it's not a nice thing, when they're in pain. Anyone who is in pain should be given the right to end it.*

The two people with progressive incurable illnesses that Demos spoke to who opposed the legalisation of assisted dying cited their religious (in these cases Christian) faith as a factor in forming their opinion. A male service user commented:

*I don't believe in doctors and things like that. Life should just run its course... Nobody should take somebody else's life. We've got our own lives, and when the time is right you should be at peace with yourself. If I was dying, I'd sooner die peaceful. No injections or anything. I watched my own wife die. And she was in agony; she had cancer. But she died peaceful. And that's the Irish way.*

And a female service user said: 'It's not right that people are helped to die. It should be up to God.'

None of the people whom Demos interviewed at the hospice reported themselves as ever having felt under pressure to refuse treatment or to make an advance directive asking not to be resuscitated. However, Demos researchers separately interviewed a woman with motor neurone disease who was recruited through an online support forum. This woman said that she had experienced pressure from people around her to make an advanced directive requesting that she should not be resuscitated. She was against any change to the law on assisted dying because she was worried that it would increase the pressure on her to choose to die. Describing her current situation she said: 'I feel an increasing pressure not to have life-saving and expensive treatments and care. Every time I turn the news on, I'm faced with another example of how I'm perceived as some sort of leech.' In addition, her own experience of dealing with medical professionals had led her to the opinion that legalisation would be 'dangerous':

*You've got these professional medical people urging you towards saving money. I don't think the doctors individually are consciously thinking in those terms, but if there is an ethos that is persuading people that the sensible kindly option is to take 'an easy option' then I fear that that would be encouraged.<sup>425</sup>*

Therefore, while the majority of those interviewed were in favour of terminally ill people having the choice of an assisted death, a small minority were strongly opposed to this option being made available.

### **Disabled people and assisted dying**

The debate around whether some form of assisted dying should be legalised in the UK has elicited a particularly strong response from some disability advocacy groups, many of whom strongly oppose any change in the law. The reasons for this opposition are manifold, but they particularly focus on concerns that negative social attitudes to disability among the medical

profession, the general public and disabled people themselves could put pressure on disabled people (either external or self-imposed) to choose an assisted death.

The Not Dead Yet UK alliance, led by Baroness Jane Campbell, Dr Phil Friend and Dr Kevin Fitzpatrick, was set up in 2006 to ‘highlight disabled and terminally ill people’s fears and to ensure legislation prohibiting assisted suicide and euthanasia remains in place’.<sup>426</sup> As observed earlier in the report, Baroness Campbell declined to give evidence to the Commission. However, the views and aims of Not Dead Yet UK are made clear on their website, ‘We believe that legalising assisted dying will inevitably lead to increasingly adverse judgements about the quality of life of disabled people.’<sup>427</sup>

Baroness Campbell has previously very powerfully given voice to these concerns in her evidence to the Select Committee on the 2004 Assisted Dying for the Terminally Ill Bill when she argued

*there is absolutely no distinction between those of us described as ‘terminally ill’ and those of us described as ‘disabled’. The two are so inextricably linked that the terms are interchangeable the eyes of the public.*<sup>428</sup>

Baroness Campbell said she was ‘an individual whose life could be put at risk should assisted dying become legalised in this country’. She explained the nature of this risk in her written evidence to the Select Committee, which described her ‘devastating’ experience when she was admitted to hospital in 2003 with pneumonia and a need for emergency treatment. At this time, two of the consultants who treated her told her they assumed that if she experienced respiratory failure, she would not wish to be resuscitated with a ventilator. Baroness Campbell wrote that this experience, and other work she has conducted with disabled people, demonstrates that ‘decisions regarding life-saving treatment are often made in an environment of ignorance and discriminatory attitudes towards and about disabled people’.<sup>429</sup>

David Congdon of Mencap emphasised that people with disabilities are too often placed in a position where they are not adequately consulted about decisions around end of life care. In particular he highlighted the problem of disabled people being given inappropriate ‘do not resuscitate’ notices. He explained that these notices are often ‘put on way outside the legal requirements, so not obviously following best interest decision-making when that should be followed’. He said:

*If you’re going down the road [of assisted dying]; going down the road of DNR [do not resuscitate] is difficult enough, ‘do you want to be resuscitated’ is quite a question to ask someone if they can’t fully comprehend. And that’s why we would argue the slippery slope argument is really a very powerful one.*

As cited previously in chapter 2, Alice Maynard, chair of the disability charity Scope, explained that Scope’s policy position is to oppose a change in the law to allow assisted dying:

*We don’t support any weakening of current levels of protection that are offered under the legislation for people who don’t wish to end their lives [but recognise] that it is a very complex issue. It’s a very emotive issue and... there are some very strong views held by disabled and non-disabled people alike on both sides of the debate.*



Ms Maynard explained that Scope's overriding concern is about the impact that negative social attitudes towards disability and poor service provision could have on disabled people's decisions about assisted dying. Therefore,

*we have an absolute threshold which says disabled people have an absolute right to life and that any change in the law must protect that absolute right to life. And so that's the threshold against which we judge any changes that would be made to the law.<sup>430</sup>*

Suzy Croft, a senior social worker at St John's Hospice, also made the point that negative messages are 'consistently given out, about disability and sickness'. She expressed concern that people who become impaired as a result of their illness can often internalise these discriminatory attitudes and as a result they be 'very resistant to going out in a wheelchair because they articulate that this is embarrassing and demeaning, "I have never been like that, I don't want to be like that"'. It is wrong they should feel this embarrassment:

*A lot of disabled people who look like that go to work, pay their taxes, have families, friends, go on holiday, are members of the Commission and so on... The disabled people's movement has argued very strongly that disabled people are not awarded the rights and responsibilities that they deserve in our society.*

In this context the legalisation of assisted dying could be dangerous for disabled people.

Simon Gillespie, who gave oral evidence on the behalf of the Multiple Sclerosis (MS) Society, told the Commission that the MS Society does not take a position on whether assisted dying should be legalised, because attitudes to assisted dying among people with disabilities are still a relatively unknown quantity:

*I think worthy of note at this stage is that research in 2006 indicated that, for those severely disabled by their MS, they rated their quality of life, in many cases, worse than death. But of course that didn't give any indication within that on whether in fact those people would be interested in assistance with dying or not. So whilst it clearly has a significant impact on a large number of people, what we don't have is any information or systematically gathered information on peoples' views on assisted dying.<sup>431</sup>*

He also emphasised the importance of not assuming that people's opinion will be determined by their illness or disability:

*MS affects people in all sections of the community, so there is no single view of people with MS about whether assisted dying is a good or a bad thing; something they would or wouldn't consider; something they would accept or would not accept if it were to be applied in the case of other people.*

This is further complicated by the fact that:

*Many people with MS experience cognitive impairment or depression during the course of their lifetime and clearly that could be relevant to the work of this Commission. And of course that might affect their ability to make informed decisions. Often those symptoms are overlooked, ignored or mistaken by healthcare professionals.*

He pointed out that ‘people with MS are just as likely as the rest of the population to have other issues, for example learning difficulties, dementia or other conditions such as cancer’.<sup>432</sup>

Peter Bailey, a trustee of Leonard Cheshire Disability, said his oral evidence would primarily focus on assisted dying from a disabled person’s perspective, and that in his view there should be no change in the law: ‘I think my main concern is that if the opportunity for assisted dying were made available, that this opportunity for some people, may become an obligation.’ A study by Southampton University had found that among ‘newly disabled people’ (eg those who had experienced an accident or illness such as a stroke), 90 per cent of the studied group experienced a significant negative change in their perception of themselves, after the onset of their impairment. Mr Bailey told us:

*They saw themselves as a problem to themselves, to their families and to society at large. So everywhere they went, every action they took, they were continually in this mindset that they were a trouble, a nuisance, a burden. It’s not difficult to imagine how if you perceive yourself as a problem for everyone that it’s more likely that a disabled person would feel the best option is suicide.*

Mr Bailey also spoke of the ‘shock’ among disabled people following Daniel James’s suicide:

*We all knew that it was too soon. If Daniel had had more time we don’t think he would have ended up in Dignitas... In practice, I think this means that we need to be protected; protected from ourselves at times.*

However, Mr Bailey also recognised that disabled people’s views on this issue are far from uniform:

*My understanding is that there is a whole diversity among disabled people [in their attitudes to assisted dying]... I have to say that my perceptions are that, and I hope this doesn’t sound disparaging in some way, but the more politicised disabled people are, the more likely they seem to me, to argue against changes in the law.<sup>433</sup>*

Debbie Purdy made a similar point about the diverse range of opinions expressed by disabled people on assisted dying: ‘People with disabilities are pretty much the same as everybody else in that we vote BNP, Tory, Liberal Democrat and Labour in pretty much the same numbers as able-bodied people.’ She believes most disabled people support a change in the law but suggested that compared with non-disabled people

*we are more conscious of the restrictions that have to be there and the protection that has to be there embodied in law, because we know from experience — not because of any magic of being in a wheelchair — but our experience of people who make assumptions about the quality of our own life.<sup>434</sup>*

Debbie Purdy argued we should not assume that people with physical impairments lack the mental capacity to decide whether they wish to live or die: ‘We need to make sure that protection is offered to anybody who does lack capacity to make those decisions’, and disabled people who

have capacity should be able to make decisions about their lives that other people might not approve of:

*I don't think the assumption should be that if I make a decision that some people don't like, then the assumption is, 'well therefore you clearly don't have capacity because I don't like your decision'... As a disabled person I don't want my rights to be reduced because the choices I may make aren't liked by a lot of the public... I don't see why I should be perceived as vulnerable and have to prove my ability and capacity in order to be taken seriously. I think the assumption should be that if I make a reasoned argument, that reasoned argument should be considered for what it is, and the fact that my legs don't work shouldn't... be perceived as being a weakness on my part mentally. My physical weakness is not mental.*

Tony Nicklinson suggested that society's refusal to assist the deaths of those who lack the physical capacity to commit suicide is a moral failing:

*We have a law which: condemns me and others like me to a life of misery; makes my wife (or anybody else) a murderer for simply carrying out my wishes; puts people in jail for up to 14 years for helping someone to commit suicide; makes me wish for a fatal condition; makes me consider starvation as a way out and sends society's cripples abroad to die. Tell me, just what is compassionate about that? Who will defend such a law? What sort of person might he be? Who can defend the indefensible?<sup>435</sup>*

Tony Nicklinson's wife Jane told the Commission that the current law is restricting Tony Nicklinson's rights rather than protecting him:

*We do understand that there are people out there who need to be protected without a doubt; but at the moment they are being protected at his expense, his rights are been taken away from him and he can't see how anyone can see that is right, it's not just.<sup>436</sup>*

Peter Bailey said he recognised that some disabled people might feel they are discriminated against because they cannot end their lives without assistance:

*I can't square that circle... We have to live with all sorts of difficulties and imperfections and I accept that would be one. But what people say to me is that there wouldn't be many people in that situation. This is not a huge complication. It's a relatively modest difficulty.<sup>437</sup>*

### **Recent surveys of disabled people's attitudes to assisted dying**

The National Centre for Social Research (NatCen) submitted its 2005 British Social Attitudes survey to the Commission as evidence. This survey 'examined public attitudes towards three forms of assisted dying — voluntary euthanasia administered by a doctor, physician assisted suicide and voluntary euthanasia administered by a relative'.<sup>438</sup> To identify how views on these issues varied between various social groups, individual respondents were given a 'scale score', which was calculated according to 'the total number of these scenarios where the respondent said that assisted dying should "definitely" or "probably" be allowed by law'. Therefore, an individual's 'scale score' is higher if they believed assisted dying should be allowed in a larger number of scenarios.<sup>439</sup>

NatCen's report on the 2005 survey explained that its findings differed from those of a previous survey conducted in 1995, which found that disabled people were more likely to support assisted dying than non-disabled people. In 2005 the average 'scale score' of disabled people was 'slightly below' that of non-disabled people, at 2.4 compared with 2.6. However, this score still indicates that on average disabled people 'definitely' or 'probably' supported assisted dying in 2.6 out of the five scenarios they were questioned about.<sup>440</sup> This is a far cry from the stance of outright opposition to assisted dying in all forms that is promoted by some advocacy groups and campaigners.

The Scottish Disability Equality Forum surveyed its members about assisted dying in May 2010 to inform its written submission to the Committee considering the End of Life Assistance (Scotland) Bill. It found that 'Overall, slightly more than half of those who responded to the consultation were in favour in principal [sic] of some kind of relaxation of laws criminalising assisted suicide'.<sup>441</sup>

In March 2011 Scope conducted a poll to explore disabled people's attitudes to assisted dying, asking disabled people 'How concerned or otherwise would you be about a change in the law to legalise assisted suicide?' The poll did not suggest particular scenarios such as doctor-assisted suicide or suicide assisted by a relative, nor did it specify whether the person assisted to die was terminally ill or otherwise. This poll found that 53 per cent of disabled people said they would be 'very' or 'slightly' concerned about a change in the law to legalise assisted suicide, and 35 per cent of those polled said they would be 'not very concerned' or 'not at all concerned'. The poll also found that if assisted suicide was to be legalised, 35 per cent of respondents would be concerned about 'pressure being placed on you to end your life prematurely', 70 per cent of respondents would be concerned about 'pressure being placed on other disabled people to end their lives prematurely' and 56 per cent of disabled people would be concerned about it being detrimental to the way that disabled people are viewed by society as a whole.<sup>442</sup> This suggests that disabled people are more concerned about the risk to other disabled people than they are about the risk to themselves, and that there are broad concerns among disabled people about how they are viewed by society.

### **Focus group discussions with disabled people**

The campaigning organisation Not Dead Yet UK comments on its website, 'The collective voice of disabled people on these life-and-death issues has not yet been heard.' However, the evidence already reviewed indicates that this 'collective voice' might not exist, as disabled and terminally ill people evidently have a range of views on assisted dying, from being strongly opposed to assisted dying, to being strongly in favour of a more permissive approach to assisted dying in law. Other disabled people believe that assisted dying might be permissible only in particular circumstances.

The research Demos conducted with disabled people also uncovered varied views on assisted dying among disabled people. Overall, Demos found that participants in the two focus groups with disabled people were more likely to be wary of the legalisation of assisted dying — or to reject it on principle — than participants in the focus groups with older or terminally ill people. However, despite these concerns, a majority of the disabled participants thought there were some instances in which assisted dying should be permissible. One focus group member said: 'If somebody

is in excruciating pain with no hope of recovery, prolonging life is not being helpful. We should not keep somebody alive just because we are uncomfortable with assisting them in their death.’ Another person agreed: ‘If somebody is in constant pain and there is no way to relieve that, they should be allowed to ask for assistance in their dying.’

Of those who thought that assisted dying might be permissible in some circumstances, not everybody thought that the legalisation of assisted dying was the correct response as they valued the fact that under the current law cases of assisted suicide are considered individually by the Crown Prosecution Service, which they thought provided certain safeguards. However, one participant said that euthanasia already takes place in the UK covertly—‘it does happen, it does go on’, therefore a change in the law to allow assisted dying would be a positive move as it would enable more safeguards to be put in place: ‘I think if it was legal and done properly and maybe done like people write a will, which surely you can write, “If this ever happened to me...”’

Some people thought that people with terminal illnesses were the only group who should be eligible for an assisted death. Discussing the case of somebody who had become disabled following an accident, one participant commented: ‘That’s a completely different ball game to somebody with a terminal illness because the issues are so, so different it’s untrue.’ Another participant supported the legalisation of assisted dying for people with some specific diseases and thought legalisation would allow for more effective formal safeguards to be put in place: ‘Let’s have it cast-iron, let’s have thresholds.’ Another person thought that assisted dying might be more feasible for people with long-term degenerative conditions as they could take time to consider their wishes, and to take part in whatever assessment process might be needed:

*My heart tells me no but my head tells me yes... In particular... hereditary degenerative conditions, in particular I’m thinking Huntington’s, and motor neurone as well, the patients who suffer those diseases, there is time to put those measures in place. If somebody knows they have that condition years in advance, it allows them to prepare themselves.*

However, some participants did not single out people with terminal illnesses as presenting a special case for assisted dying. Some people in the group found the concept of eligibility criteria too limiting or potentially discriminatory, and preferred the idea of assessing all requests individually. One person commented:

*I think it is all subjective. I don’t think any panel of people can assess the unique situation that another person lives in. It is a very difficult thing to limit or restrict. I think they should have the right to die, but to avoid some people being taken advantage of it might mean safeguarding the process so strongly that some people are denied that right. I wouldn’t have the authority to say where the line should be drawn. But I would say that if somebody is in constant pain and there is no way to relieve that, they should be allowed to ask for assistance in their dying. With some levels of pain you can’t think, cannot watch TV, cannot have a conversation.*

An important theme that recurred throughout the focus group sessions with disabled people was a concern about discriminatory social attitudes

towards disability, and the negative assumptions made about disabled people's quality of life. As one participant pointed out: 'The social perception of people with a disability is generally a negative one. So when people, such as Daniel James, get placed in a situation where their life has changed, they see no other option but death.' During one of the sessions three of the participants spoke of having felt suicidal at some point in their lives, but agreed that this had just been a phase, and it would not have been helpful or appropriate for assisted dying to be have been available as an option to them. Several participants made a link between suicidal feelings and the negative view of disability prevalent in mainstream society. One participant noted, 'People probably think that most of us in this room have a reduced quality of life. It's those people who will be prone to depression if they acquire a disability.'<sup>443</sup> One participant expressed concern that inadequacies in health and social care might lead people to feel they had no other choice:

*I just think people will make decisions for the wrong reasons. We're not a very caring society, we purport to be very caring on the surface, actually nobody gives a monkey's anymore. We purport to be very caring in helping people to end their lives but actually how about we make it so that people don't feel that's their only option in the first place?*

Another expressed concern that assisted dying could become a slippery slope, giving the example of abortion law: 'It's going to become very much like abortion, it started off with a very good reason and is now a shambles and used as a method of control.'

Others in the focus groups argued that the current legal status of assisted suicide discriminates against disabled people who — unlike non-disabled people — might not have the physical capacity to end their life without assistance:

*I think it is a little bit unfair to make a distinction between somebody who is able bodied and somebody who is disabled. If someone is able bodied but very depressed and they want to go and kill themselves they can. Whereas if someone is disabled they are put under all this stress, when all they want to do is what someone who is able bodied could just go out and do. I don't think it is fair to make that distinction.*

One person commented, 'Right now, if I wanted to, I could go and walk out in front of a bus. Why should someone who hasn't got the capacity to do so be deprived of the right to do so?'<sup>444</sup>

Another participant, who had a hearing impairment, emphasised the importance that if a legal process for assisted dying was introduced it should be equally accessible to disabled people and non-disabled people. She called for safeguards to facilitate effective communication, 'especially for older people who are hard of hearing, the deaf and the blind'. She thought effective methods of communication were essential to avoid 'mistakes made and communication breakdowns'.

During the focus groups Demos asked participants whether a person in Tony Nicklinson's situation — who has very significant impairments that cause him considerable suffering and who wishes to end his life — should be legally permitted to seek assistance with suicide. There was a notable difference in responses between the focus groups with disabled people and those with older



people and terminally ill people. A much larger proportion of the disabled participants said they would be very concerned about assisted dying being an available option for people who become disabled through illness or accident, particularly if they had experienced this change very recently. One female participant who had various chronic health conditions commented on Daniel James's situation:

*Is it not inevitable that if somebody is suddenly made quadriplegic or paraplegic they will feel like they do not want to live. You have to try everything that is available. You cannot just after six months say 'right, there's nothing out there for me' unless you have actually tried everything that is available, and have got the right support around you.<sup>445</sup>*

Some of the disabled participants said they were aware from their own experience that people may express the wish to end their life as a cry for help, without genuinely wishing to follow this through. One young man commented:

*There are times when you say you want to die, but you don't mean it. You may be mentally incapacitated for whatever reason; you have been through trauma or a major operation. I had a major operation and was in intensive care. I said I did not want them to resuscitate me, but I didn't mean that. I needed the safeguard.*

A second participant concurred:

*From a personal point of view, I have in the past asked to be allowed to die, or asked somebody to kill me, and I don't think I have ever really meant it. Quite often the situation that you're in is not going to be permanent even though you may think it is. You perhaps cannot see the light at the end of the tunnel.*

Therefore some participants thought robust safeguards should be in place in an assisted dying framework to test the individual's capacity; others thought assisted dying should not be on offer at all.

### **Adults with learning disabilities and assisted dying**

The issue of how any change to law on assisted suicide might affect adults with learning difficulties is particularly complex. In addition to the many serious considerations around mental capacity, social pressure and compulsion expressed in evidence to the Commission, a representative of one of the organisations that gave evidence also argued that, should the law be changed to allow some form of assisted dying, it would be discriminatory automatically to exclude people with learning difficulties from pursuing this option.

David Congdon, Mencap's head of policy and campaigns, explained that Mencap opposes a change in the law to permit assisted dying because they see the risk of people being coerced into seeking an assisted death as too great:

*We're concerned that changing the law to legalise assisted dying or euthanasia could lead to people with a learning disability dying against their will by being coerced into it or because of collusion between relatives and doctors. Because of this Mencap is opposed to changing the law to make assisted dying or euthanasia legal.<sup>446</sup>*

David Congdon gave examples of existing situations in which people with learning disabilities are discriminated against:

*We come across so many situations where the right of a person with a learning disability to live, can be questioned. There are questions that are sometimes raised when very small premature babies are born: should they be allowed to live? Should they be given the medical interventions to start with to enable them to live a life? And at the back of [people's minds], sometimes in some of the debates is, 'Well they're going to cost society a lot. Should they be allowed to continue to live?'*

He explained that these issues run throughout health care: 'There are issues when doctors say to parents, "what are you bringing that person in here for? What's their quality of life?" And the assumption being that they've got no quality of life.'

Mr Congdon explored the potential link between negative perceptions of disabled people among the medical profession, and poor health outcomes:

*There's a lot of evidence on health outcomes: people with a learning disability die younger than other people and obviously with certain degrees of disability that would be expected. But a lot die of respiratory failure and the experts have argued, and we've got all the evidence on this, that they die of different [things] from other people. What is harder to prove, in all honesty, is the causal effect. They get access to health care; they go to hospitals, they go to doctors; the suspicion is that they don't always get the interventions that they should get.*

Mr Congdon explained that the problems people with learning disabilities experience in achieving equal access to health care are also evident in the context of palliative care, where effective communication between the doctor and patient can pose particular difficulties:

*People with a learning disability identified as having a palliative need then face being treated by professionals who while being trained in end of life care may have little understanding of learning disability and consequently lower confidence in working effectively with them... A classic example is that where patients cannot communicate, that poses a real problem of diagnosis. And then you get the failure really to understand what the legal requirements are under the Disability Discrimination Act of 'reasonable adjustments'. So typically, most people understand but don't always follow that you need to use accessible language, signage, all of those sorts of things, longer appointments. Well, I regard those as being the things frankly that should have been done ten or 15 years ago.*

Mr Congdon said recent research has identified 'a number of cases where people with [a] learning disability have not received adequate end of life care'. Therefore, Mr Congdon had a number of concerns about how a change in the law to permit assisted dying might affect people with learning disabilities, including the potential for discriminatory attitudes among medical professionals or inadequacies in communication to influence or limit people's choices. However, as mentioned in chapter 2 of this report, Mr Congdon argued that should assisted dying be legalised, it would be essential 'from an equal rights point of view' that people with learning disabilities would not be automatically excluded from being eligible, but would be subject to the same safeguards as any other member of society.<sup>447</sup>



### Views on assisted dying from people with learning disabilities

We are not aware of any previous research that has been conducted with adults with learning disabilities to explore their attitudes to assisted dying. Demos ran a focus group with adults with learning disabilities, which highlighted some of the challenges involved in researching attitudes among this group. During the session the Demos researchers played a television clip from *Emmerdale* that dramatised a scenario in which a man became paralysed following an accident and asked his mother to help him end his life. The researchers then explained the definitions of assisted suicide and voluntary euthanasia using basic vocabulary and the group discussed these concepts for some time. Demos found most of the group experienced some difficulty in understanding and discussing these concepts.

Overall it became clear during the session that there was a split of opinion in the group, between those who believed that assisted dying was a matter of personal choice, and others who felt that assisted dying might be dangerous or could place too much of a burden on people's families. One female participant was strongly in favour of a change in the law. She said, 'Get the law in, it's better to have the law. Other countries have got it, why can't we get it?' When asked: Why do you think we should have a law like that? She responded: 'Because a lot of people want to die. They go to court and try and fight it, and the courts say "No, sorry, you're not allowed to do that, you can go to another country."' A male participant felt that in 'extreme cases', perhaps where individuals were paralysed, people should be allowed to choose to die: 'If people want to pass away, it's up to them.' Another male participant was strongly against a change in the law, and expressed a concern that making assisted dying legal would be dangerous, and would lead to a rise in the number of people being murdered.<sup>448</sup>

The film clip from *Emmerdale* precipitated a discussion about whether assisted dying should ever be available for a person who had developed a significant impairment following an accident. Most of the participants felt that Jackson, the character who was asking for an assisted death, should not be allowed to die. Most people thought that better health and social care would be the most appropriate response to this situation: 'I think he should get a social worker to help him, a carer'; 'He needs to go to the hospital to get it treated and get his life back.' However, as observed above, two participants did think that a person in this situation should be able to choose whether they wished to end their life.

Another concern that emerged during the session was about the impact that a change the law might have on the doctor-patient relationship. Several respondents felt that doctors should be concerned with curing people rather than ending people's lives. Describing what he thought the role of doctors should be one participant told us: 'They help you out. Help you to stay alive.' Two participants expressed a fear that, if the law were to change, doctors might move into administering involuntary euthanasia. One female participant said: 'When I'm ready, I will. I don't like people putting words in my mouth. Saying, "Oh, die." I say, "No. When I'm ready. When it comes."' Another expressed a fear that 'they are going to give tablets to all the elderly, the old pensioners and that'. Many of the participants had experience of taking medication regularly and one participant's engagement with the issue focused on the importance of taking this medication in the appropriate dosage.

Participants were also concerned about the potential impact of assisted dying on the individual's family. Those participants who agreed with allowing some form of assisted dying were clear that medical professionals rather than family members should be responsible for assessing and administering assistance to die. One male respondent said that it was 'Too emotional for the family members, they should get help, call 999.' A female participant also raised concerns about the effects of assisted dying on friends and family members, commenting: 'Families do get worried.' Another female respondent was concerned about the potential effect of Jackson's death on his mother. 'She's only got one boy, and she don't wanna lose him. If she loses him, how's she gonna cope with her grief?'

### **International evidence about assisted dying and vulnerable groups**

Assisted dying has now been legal in some jurisdictions for more than a decade and there is an increasingly substantial evidence base to draw on when investigating whether the legalisation of assisted dying impacts disproportionately on more vulnerable people. In this section we will draw on academic evidence exploring this relationship and evidence that Commissioners gathered during their research visits to the Netherlands, Belgium, Oregon and Switzerland.

One of the key pieces of research that has influenced the debate on how assisted dying might affect vulnerable groups is a study from 2007 conducted by Margaret Battin et al at the University of Utah.<sup>449</sup> It used data from Oregon and the Netherlands — two jurisdictions in which physician-assisted dying has been legal for a substantial period of time — to assess whether there was any evidence that the legalisation of assisted dying had put vulnerable people at risk of undue influence or abuse.

Battin et al's report defines the 'slippery slope' argument as the assumption that all people suffering from terminal illnesses are at risk from 'abusive forces', pressuring, manipulating or forcing patients to request or accept physician-assisted dying. Proponents of the slippery slope argument have expressed concerns that as a consequence of these 'abusive forces', in jurisdictions that permitted assisted dying, vulnerable groups would be more likely to receive an assisted death. To investigate these claims, Battin et al analysed the annual reports from the Departments of Human Services in Oregon and the Dutch government in the Netherlands to see whether particular vulnerable groups were over-represented in the data.

The groups that the study focused on were older people, women, the uninsured (inapplicable in the Netherlands, where everyone is insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, and people from racial or ethnic minorities. Having looked at all of the available data — which the authors noted were of varying quality — the report found no evidence of heightened risk among these groups. The study's analysis using more robust data found that older people, women and people with no health insurance, were at no increased risk from assisted dying. For example in Oregon, people aged 18–65 were over three times more likely to have an assisted death than those aged 85+. In the Netherlands, rates of assisted dying were lowest among people aged over 80. The more robust data did, however, show that people with AIDS were at an increased risk from assisted dying.

The findings from less robust data (partially direct, partially based on proxies) found no evidence of people with low educational or socio-economic status, or people from racial or ethnic minorities, being disproportionately represented among the people having assisted dying. It also found no evidence of increased risk to people with non-terminal disabilities or chronic non-terminal illnesses. In Oregon, assisted dying is only available to people with terminal illnesses. In the Netherlands just 0.2 per cent of patients who received euthanasia or assisted suicide were estimated to have foregone more than six months of life.

The findings based on inferential or partially contested data found no evidence of heightened risk to patients with psychiatric illness, including depression and Alzheimer's disease. Although there was no direct evidence that depressed patients in Oregon were at an increased risk, the study noted that not all patients were evaluated by mental health professionals. In the Netherlands, 'a majority of Dutch physicians consider assisted suicide for psychiatric patients acceptable in some circumstances', but physicians in the interview section of a 1995 study cited depression as the predominant symptom of patients requesting euthanasia in just 3 per cent of cases.

In conclusion, the study's authors found no evidence to justify

*the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups... the joint picture yielded by the available data in the two jurisdictions shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges.<sup>450</sup>*

Citing the findings of this study, Professor Penney Lewis commented in her evidence to the Commission that there is some evidence there isn't a systemic risk to members of vulnerable groups, 'but that doesn't mean it's not a risk in individual cases'.<sup>451</sup> Professor Raymond Tallis of Healthcare Professionals for Assisted Dying also referred to this study, commenting that among the small number of people in Oregon who have had assisted deaths, 'there was an overrepresentation of the kind of people who were used to getting their own way, you know, feisty people and middle class, well off etc. So quite the opposite of what was expected.'<sup>452</sup>

An important aim of the Commissioners' visits to the Netherlands, Belgium, Switzerland and Oregon was to investigate whether vulnerable people were being put at risk of abuse by the legalisation of assisted dying in these jurisdictions. We will explore the detailed safeguards that are employed in each of these jurisdictions, and evidence of their effectiveness in protecting potentially vulnerable people in chapter 7 of this report. However, the broad consensus among those interviewed in each of these jurisdictions was that it is not vulnerable people who lack capacity or who are experiencing pressure from others who are actually having assisted deaths. Instead, as Professor Georg Bosshard observed during the visit to Switzerland, it is usually better educated, more articulate people who are able to access an assisted death:

*It's quite clear from the findings in Oregon that on average they are on a very well-educated level; the same certainly holds for Switzerland. You know I have been working for eight years at the Institute of Legal Medicine, I have seen more*

*than 400 cases of assisted suicide, and normally they are very well educated and there is evidence on that, not so much from Switzerland but from Oregon, and also evidence that in order to get euthanasia you must be verbally quite well educated. If you are able to convince your doctor that you are not a psychiatrically ill person but that you are mentally well then you get euthanasia; if you are not then bad luck for you. So the whole debate on vulnerable people, I mean it's important, but it doesn't really capture the practice of today because it's something that only the better-educated people usually get.*<sup>453</sup>

Eric van Wijlick of the Royal Dutch Medical Association concurred:

*The mentally handicapped are practically excluded from these kind of decisions because in the Netherlands... the voluntariness of the request is very important. You should tell it to your doctor, you have to communicate about it and the doctor has to investigate whether the request is your own; it's authentic, it's consistent.*<sup>454</sup>

Agnes Van der Heide, senior researcher at the Erasmus Medical Centre in Rotterdam said that in the Netherlands, 'the idea that older people may feel pressured and may feel threatened by this system — it is not really an issue in the current society. People are not afraid of that.' Professor Bregje Onwuteaka-Philipsen, recognised that people who receive euthanasia are often in older age groups, but argued this 'has less to do with the age and more that it is cancer and they are competent'. Dr Gert van Dijk made the further observation that people who request euthanasia are comparatively a 'younger population' in they are usually aged between 60–70, whereas 'the people who get terminal sedation are usually older' and are more likely to be in their 80s. Dr Bernadina Wanrooij and her colleague Dr Guus Fons said the question of whether a person requesting euthanasia might be concerned that they are a burden to their family 'is mentioned in our discussion... extensively... We try to explore whether that is one of the reasons people ask for euthanasia. So that we get it on the table.' If it emerged that a person seeking euthanasia felt themselves to be a burden, 'I don't think doctors would support an action.' We will explore further evidence of this assessment and filtering process in chapter 7.

In Oregon, Professor Ganzini said that the idea that disabled people might experience increased social pressure to request an assisted suicide was 'completely untrue', as 'people are not offered assisted dying. They come out of the woodwork and insist on it'. Professor Barbara Glidewell of the Oregon Health and Sciences University commented, 'In my opinion, our doctors have become very skilled at assessing the dynamics of the patient–family situation when they conduct the interview.' She argued that people's family relationships were far more likely to deter them from choosing an assisted death because they would be worried about telling their relatives about their decision. She said that people who choose assisted suicide do so as a firm statement of autonomy, rather than as a result of external pressure: 'Often they will say something to the effect... "I just want to name the day when I'm done because waiting for the day to come when I will die is just too much"... It is really an affirming choice.'<sup>455</sup>

In the Netherlands, where it is not legally required that the person requesting euthanasia must have a terminal illness, a person with a long-term condition or impairment that was causing 'unbearable suffering' could be

eligible to request euthanasia or assisted suicide. However, Dr Gert van Dijk commented that ‘the people that get euthanasia are not handicapped people. They have to suffer and they have to ask for it themselves; it’s not other people saying you should have euthanasia, people are asking for it themselves.’ Eric van Wijlick at the KNMG said requests for euthanasia where the person was not terminally ill would be investigated extremely carefully over a period of time and that it would be essential that the person was experiencing ‘actual suffering’ rather than anticipating suffering, and that ‘in practice doctors will hesitate a lot’. He said that the most important thing is that Dutch people trust their doctors and are confident that the right procedures and checks and balances are in place to prevent abuse. Professor Bregje Onwuteaka-Philipsen pointed out that it is unusual for people to request euthanasia or assisted suicide if they are not terminally ill; some people will request euthanasia in the very late stages of motor neurone disease, but this is very unusual among people with long-term conditions such as multiple sclerosis that progress very slowly.

In Belgium, members of the Federal Control and Evaluation Commission on euthanasia emphasised the fact that the vast majority of euthanasia cases involve people who are terminally ill, and most lives are shortened by a matter of days or a few weeks rather than by months or years.<sup>456</sup> Professor Herman Nys endorsed this: ‘Looking at the statistics of the commission it’s a very, very limited percentage of people [who have chronic as opposed to terminal conditions and] if it happens it is very limited.’ When asked if disabled groups in Belgium have expressed concerns about the euthanasia legislation, he said ‘I never heard of it’, saying that in Belgium the argument that disabled people’s lives might be devalued by euthanasia legislation ‘has never... been put forward by patient groups, no.’ When asked if disabled or chronically ill people in Belgium might be under any direct or indirect social pressure to end their lives, Professor Luc Deliens replied, ‘No, there is no evidence in the system here in Belgium, there is none at all. Not in the Netherlands, not in our system, there is no evidence.’ Professor Lieve Van den Block from the End-of-Life Research Group at Vrije University explained that physicians tend not to agree to perform euthanasia if the patient cites the feeling of being a burden as part of their motivation in requesting it, suggesting that the system is able successfully to screen out inappropriate requests that do not meet the eligibility criteria.

The two issues that our expert interviewees raised during the research visits as ongoing subjects of controversy or concern regarding vulnerable people’s involvement in assisted dying related to the increased vulnerability of people with mental health problems that might affect their capacity. In the Netherlands and Belgium there is an ongoing societal debate about whether people who have dementia should be able to make an advance request to receive euthanasia in the future once they have lost capacity. As we will explore in chapter 6, this is currently prohibited by Dutch and Belgian law as euthanasia may only be requested and received by a competent patient. While the interviewees noted this debate, they explained that the law was very unlikely to be changed in this respect, despite demands from some patient groups. In Oregon some interviewees also particularly highlighted the ongoing concern that some patients who request, and receive, assistance to die might have had untreated depression influencing their decision and thus reducing the voluntariness of their request. In the next section of this report

we will examine in more detail how these issues of dementia and depression are currently dealt with in jurisdictions that permit assisted dying, and evidence of the effectiveness of the safeguards that are currently in place.

In section 2, chapters 6 and 7 will pose the question of which eligibility criteria and safeguards might be most appropriate if assisted dying was to be legally permitted in the UK, and will consider evidence of how effectively the assisted dying frameworks that are currently used internationally are protecting vulnerable individuals. Chapter 8 will explore other practical considerations that might need to be addressed regarding the implementation of such a law in the UK, such as training, support, monitoring and evaluation.



**PRACTICAL ISSUES POSED  
BY A LEGAL FRAMEWORK  
TO PERMIT ASSISTED DYING  
IN THE UK**





## 6 Determining eligibility for assistance

All jurisdictions that permit some form of assisted dying include in their legislation some characteristics that individuals must fulfil before they can be considered eligible to receive assistance. The Commission heard evidence from organisations and individuals in the UK and abroad about the benefits, disadvantages and ethical issues associated with the many ways that eligibility for assisted dying might be legally defined. This chapter will outline the evidence the Commission has received to inform this question of which eligibility criteria for assisted dying might be included in UK legislation if such legislation was to be adopted. The issue of how such criteria might be enforced will be considered in chapter 7, which explores the potential use of safeguards in an assisted dying framework.

### **A legal age of eligibility for assisted dying**

The first of the 16 public interest factors in favour of prosecution in the Director of Public Prosecutions' (DPP's) prosecuting policy on assisted suicide states that 'the victim was under 18 years of age'.<sup>457</sup> The Commission heard evidence from a number of individuals and organisations who supported the use of the age of majority in defining eligibility for assisted dying. Tony Nicklinson's scheme for assisted death limits eligibility to those aged over 18: 'The Scheme is open to all British adults and is thus not discriminatory. The law doesn't make any distinction between adults—a person is either an adult (18+) or not.'<sup>458</sup> Dignity in Dying also stated in their written evidence to the Commission that they campaign for 'terminally ill, mentally competent adults (aged 18 and over) to have the choice of an assisted death'.<sup>459</sup>

However the Commission also heard evidence that assisted dying should be an option to those under the age of 18. Zoe Clements, a palliative care nurse who gave evidence to the Commission, thought that young people are fully capable of making a decision about an assisted death. She explained that she had formed this view through her experience of seeing 14-year-olds dying from leukaemia, who understood exactly what was happening to them. Ms Clements argued that as one can refuse medical treatment from the age of 16, this should also apply to making a decision about an assisted death. Oliver Crocombe, a member of the public who submitted evidence to the Commission agreed that anyone who has mental capacity and is over the age of 16 should be eligible for assistance to die.<sup>460</sup>

Demos's research with young people found they were reluctant to set limitations on a minimum age of eligibility for assisted dying. Some of the young people felt that 'children shouldn't be able to have that decision. They need to be grown up and wise, to know they don't want their life anymore.' Others expressed more equivocal views:

*I think when it comes to this question you need to treat everybody equally, no matter their age or gender, you have to take everyone's difference into account. Because if you say to someone, 'You're only 17, you have to wait for a year', that person might suffer, for a year... I think you'd probably have to go through a lot more talking, and a longer process [with someone under the age of 18]. But you still shouldn't have the option taken away from you.<sup>461</sup>*

The legal age of eligibility for assisted dying varies between the four jurisdictions visited by the Commission. In Oregon and Belgium only those aged over 18 are eligible for an assisted death, as in Lord Joffe's Assisted Dying for the Terminally Ill Bill. However, in Belgium the euthanasia law also covers 'emancipated minors' — those over the age of 15 who have been legally emancipated by a judicial decision.<sup>462</sup> The reports of the Belgian Federal Control and Evaluation Commission (CFCE) indicate that there have been only four cases that involved a patient aged under 20, with no reported cases involving minors.<sup>463</sup> The debate over whether or not under 18s should be eligible for euthanasia became heated during the parliamentary proceedings of the Belgian Act, with a number of organisations, including the Belgian Order of Physicians, criticising the decision to exclude those aged under 18.<sup>464</sup> Professor Herman Nys, whom the Commission met on their visit to Belgium, thought that it would be preferable to move to a system akin to the Netherlands. He argued this would take into account the wishes of a younger demographic of patients while still including the parents in the decision.

In Switzerland children do not have the required legal capacity to be eligible for an assisted suicide but as Penney Lewis and Isra Black note in their briefing paper for the Commission, the position of adolescents is unclear.<sup>465</sup> Membership of Exit DS, the largest right to die society in Switzerland, is only open to those aged over 18. Bernard Sutter told the Commission that the majority of individuals join Exit DS between the ages of 40 and 50.

In the Netherlands, the euthanasia law does allow patients under the age of 18 to request an assisted death. A doctor can honour the request of a patient over the age of 12, provided they are 'considered capable of a reasonable understanding of his interests'.<sup>466</sup> For those between the age of 12 and 16, both parents (or guardian) must also agree with the individual's decision. For those aged 16 and 17, parents (or guardian) must be consulted, but do not necessarily need to give their consent.<sup>467</sup> Cases involving those under the age of 18 are rare. In their briefing paper for the Commission, Penney Lewis and Isra Black note that 'no RRC [regional review committee] judgments involving patients younger than 30 have been posted on the official website, although only selected judgments are ever posted'.<sup>468</sup> The first case of an individual under the age of 16 receiving assistance was reported to a regional review committee in 2005 and remains the only case of a minor to have been discussed in the committee's annual report.<sup>469</sup> This case involved a 12-year-old suffering from cancer. The review committee ruled that the doctor had met the due care criteria.<sup>470</sup>

### **The applicant's physical condition and experience of suffering**

As previously identified, jurisdictions that currently permit assisted dying demonstrate considerable variation in the eligibility criteria they impose to identify the circumstances in which it might be considered permissible for one person to assist another person to end their life. This section will explore what approach might be taken in UK law — if assisted dying was to be legally

permitted—to defining eligibility for assistance according to the individual’s physical condition or experience of suffering. The Commission visited four different jurisdictions that permit assisted dying to investigate the implications of each of their approaches. The legal criteria that are used in these jurisdictions to define eligibility for assisted dying based on the individual’s condition or experience of suffering are set out in Box 2 for reference.

**Box 2 Eligibility criteria relating to the patient’s physical condition and experience of suffering in the four jurisdictions that the Commission visited**

*Switzerland: According to the Swiss criminal code, assisting a person to commit suicide is ‘punishable only if done for selfish motives’. The law makes no mention of any necessary medical preconditions.<sup>471</sup>*

*Oregon: The Oregon Death with Dignity Act 1997 states that the doctor with primary responsibility for the treatment of the patient must ‘determine that the patient has an incurable terminal disease that will produce death within six months’.<sup>472</sup> There is no requirement in the act relating to the individual’s suffering.*

*The Netherlands: Under the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, a doctor must be satisfied that the ‘patient’s suffering was unbearable, and... there was no prospect of improvement’.<sup>473</sup>*

*Belgium: Article 3 of the Law of Euthanasia of 2002 requires that ‘the doctor ascertain that the patient who makes a current request is in a “medically hopeless situation” characterised by “persistent and unbearable physical or mental suffering that cannot be alleviated” and that this is the result of a “serious incurable disorder caused by illness or accident”’.<sup>474</sup>*

*If the use of an advance request is to be permitted, the patient ‘must be suffering from a serious, incurable condition caused by accident or illness and he must be “irreversibly unconscious” according to the current state of medical science’.<sup>475</sup> In cases where an advance request is used there is no requirement of ‘unbearable suffering as it is assumed that an unconscious patient is not capable of suffering’.*

### **The use of ‘terminal illness’ as an eligibility criterion**

As this report established in chapter 1, opinion polls conducted in the UK in recent years have consistently demonstrated a higher level of public support for assisted dying if eligibility for such assistance is limited to people who are terminally ill. In the 2005 British Social Attitudes survey, 80 per cent of respondents thought that voluntary euthanasia performed by a doctor should be allowed for a person ‘with an incurable and painful illness, from which they will die—for example, someone dying of cancer’, while only 45 per cent thought the same option should be available to a person ‘with an incurable and painful illness, from which they will not die’.<sup>476</sup> When asked about the acceptability of physician-assisted suicide, again, there was more support (just under two-thirds of respondents) among respondents for allowing physician-assisted suicide for a terminally ill patient than for a non-terminally ill patient (just over a third).<sup>477</sup>

The 2009 Times Populus poll found that 74 per cent of respondents supported doctor assisted suicide in some circumstances. Among these people, 95 per cent thought that assisted suicide should be legal for people who are terminally ill; 56 per cent were in favour for people who were suffering extreme pain but were not terminally ill; and only 48 per cent were in favour of this choice for people with a 'severe physical disability' who were otherwise healthy.<sup>478</sup> The 2010 ComRes poll for the BBC found that 69 per cent of respondents thought a family member or close friend should be allowed by law to help a person with a painful illness or condition from which they *will* die to commit suicide without fear of prosecution but only 46 per cent thought that this should be allowed for a person with an incurable and painful illness from which they *will not* die.<sup>479</sup>

Demos's qualitative research with so-called 'vulnerable groups', including older people, terminally ill people, disabled people and people with learning disabilities, also found that while a very broad range of views on assisted dying were represented, there was a consistently higher level of support for assisted dying as an option for people who were terminally ill than for people with non-terminal chronic illnesses or physical disabilities.<sup>480</sup>

However, although there seems to be considerable public support for the idea of making assisted dying available as an option in cases where an individual is terminally ill, a number of expert witnesses who gave evidence to the Commission highlighted the difficulties of defining and identifying cases of 'terminal' illness. Dr Ann McPherson from Healthcare Professionals for Assisted Dying (HPAD) said in her evidence to the Commission that 'there are many different ways of defining terminal illness and I think that is one of the problems. We know that it is very difficult to predict what is going to happen to people.'<sup>481</sup> In their written evidence to the Commission, HPAD representatives gave details of how they favour a definition of terminal illness based closely on that of the Assisted Dying for the Terminally Ill Bill: 'a progressive illness which, in the opinion of the attending and the consulting physician, cannot be reversed by treatment and is likely to result in the patient's death within a few months'.<sup>482</sup> Professor Raymond Tallis, also representing HPAD, expanded on these difficulties in relation to chronic conditions:

*It is difficult when you have a chronic illness that is a continuous thing, rather than having step-by-step progression. It seems to me in that context, I think you anticipate that someone will not live more than a few months, as your best guess.*<sup>483</sup>

Dr Adrian Tookman, a consultant physician in palliative medicine, discussed the fact that diagnosing dying has become more difficult as medical practice has advanced. He noted that identifying 'that time when a patient is entering into a phase of their illness where there are irreversible changes taking place and they are going to die and it is fairly clear... is becoming increasingly difficult.'<sup>484</sup> A medical director of an English hospice also considered the difficulties of defining terminal illness:

*What is your definition of 'terminally ill'? We are all going to die, so when do you call something a terminal illness? For example, Huntingdon's can be a devastating disease or MND [motor neurone disease]. They may have five years, but do you say that's terminal?*<sup>485</sup>

Gary Fitzgerald, Chief Executive of Action on Elder Abuse, argued that an eligibility criterion focused solely on a diagnosis of terminal illness without any requirement that the person must also be suffering might be conceptually incoherent:

*If we are talking about assisted dying in relation to a terminal illness, with just a few months for someone to live, that seems, by itself, to be insufficient, [for example] 'I've got a terminal illness, somebody tells me I've got three months to live, I want it ended now', by itself doesn't seem to us to be very consistent with the argument, 'I want it ended now because of other factors: I'm in pain, the quality of my life is so poor that I can't continue any longer in this fashion.'*

However, he also recognised that a rationale based on suffering might lead to a broadening of the scope of what was permitted:

*That's an argument that could be made, I think, about chronic illnesses as well. And if we link it to pain and quality of life, then we are into a much wider debate... than is immediately comfortable for people in general.<sup>486</sup>*

However, although there are inevitably challenges involved in defining what is meant by 'terminal illness', the General Medical Council's recent guidance for doctors on end of life care offers a practical approach to identifying when a person might be considered 'terminally ill' or otherwise potentially in need of end of life care:

*For the purposes of this guidance, patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:*

- *advanced, progressive, incurable conditions*
- *general frailty and co-existing conditions that mean they are expected to die within 12 months*
- *existing conditions if they are at risk of dying from a sudden acute crisis in their condition*
- *life-threatening acute conditions caused by sudden catastrophic events.<sup>487</sup>*

The legal requirements relating to the applicant's physical condition and experience of suffering vary between jurisdictions that have legal assisted dying regimes. Oregon is the only jurisdiction that the Commission visited where a diagnosis of terminal illness is a legal eligibility requirement for accessing an assisted death. In Oregon's 1997 Death with Dignity Act, terminal illness is defined as 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgement, produce death within six months'.<sup>488</sup> Analysis of the deaths of individuals who had a physician assisted death under the terms of the act between 1998 and 2010 show that 81 per cent of patients had cancer, 8 per cent had amyotrophic lateral sclerosis (ALS) and 4 per cent had chronic lower respiratory disease.<sup>489</sup>

The Oregon Death with Dignity Act has been criticised for not containing a requirement of suffering. John Keown, Professor of Christian Ethics at Georgetown University, has argued that the lack of requirement for suffering, 'let alone be suffering severely and unbearably' makes the act 'the most permissive regime for [assisted suicide] yet devised'.<sup>490</sup> However others argue that in limiting eligibility to the terminally ill, the

act is far more restrictive than the laws in Belgium and the Netherlands, as non-terminal patients with progressive neurological diseases such as motor neurone disease are ineligible according to the act if their prognosis is longer than 6 months.<sup>491</sup>

The terminal illness requirement contained in Lord Joffe’s Assisted Dying for the Terminally Ill Bill 2005 was closely modelled on Oregon’s Death with Dignity Act. In the 2005 bill, terminal illness was defined as

*an illness which in the opinion of both the attending and the consulting physician (a) is inevitably progressive, (b) cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily), and (c) will be likely to result in the patient’s death within six months.*<sup>492</sup>

As shown in Box 2, there is no requirement in the Dutch legislation that the person requesting euthanasia must be terminally ill, but the attending physician must have been satisfied that the patient’s suffering was unbearable, and that there was no prospect of improvement.<sup>493</sup> Gert van Dijk, a member of a Dutch Euthanasia Review Committee, told Commission members that there had been considerable debate over the need to include a requirement for terminal illness in the legislation, but that it was ultimately rejected because of the widely held belief that ‘the source of the suffering doesn’t have to be a terminal illness’.<sup>494</sup> In practice, the majority of reported cases in the Netherlands involve patients suffering from cancer. In 2009, there were 2,636 notifications to the five regional euthanasia review committees under the 2001 act. The proportion of deaths reported under the act involving particular medical conditions are presented in table 3.

Table 3 **Proportion of deaths that were reported under the Netherlands’ Termination of Life on Request and Assisted Suicide (Review Procedures) Act in 2009**<sup>495</sup>

Condition	Cases
Cancer	2,153 (82%)
Cardiovascular disease	54 (2%)
Neurological disorders	131 (5%)
Other conditions	168 (6%)
Combination of conditions	130 (5%)
<b>Total number of cases</b>	<b>2,636 (100%)</b>

Like the Dutch example, there is no requirement in Belgian legislation that the patient must have a terminal illness to be eligible for euthanasia. According to the Belgian law, the patient must be in a ‘medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident’.<sup>496</sup> Professor Bert Broeckeaert, Director of the Interdisciplinary Centre for Religious Studies at the Katholieke Universiteit Leuven and an expert in end of life ethics, told the Commission that he

thinks the law in Belgium should be restricted to the terminally ill and that the reasons that the Belgian euthanasia law was not drafted to include this restriction were political:

*If the law had not been passed in such an ideological atmosphere there would have been more serious consultation with specialists, with the medical world, with the palliative care world, with ethicists, with lawyers. Then I would think that things would have been different.*<sup>497</sup>

Jacqueline Herremans, however, President of the Right to Die Society in Belgium and a member of the Federal Control and Evaluation Committee (FCEC), noted that the FCEC favoured the broader approach of the act in using a criterion based on suffering as opposed to terminal illness. Professor Luc Deliens, from the End-of-Life Care Research Group at Vrije University in Brussels, told the Commission that in practice the majority of cases of euthanasia in Belgium involve a patient who is suffering from a terminal illness – only approximately 6 per cent of all reported cases of euthanasia in Belgium involve an individual *without* a terminal illness. Research by Smets et al showed that between 2002 and 2007, 83 per cent of reported cases of euthanasia in Belgium involved patients who had been diagnosed with cancer.<sup>498</sup>

As observed previously, the Swiss Penal Code states that assistance with suicide is only unlawful if the assister has selfish motives. There is no mention of the patient's medical condition,<sup>499</sup> or any requirement that the patient must be terminally ill.<sup>500</sup> However, in practice, the supply of lethal medication is regulated by the federal narcotics law under which physicians may only administer, dispense or prescribe lethal medication within the limits of accepted professional and scientific practice. Accepted practice is set out by the Swiss Academy of Medical Sciences (SAMS) in its guidance on medical ethics. While these guidelines are not legally binding, they are often referred to in case law and they suggest that a doctor should only assist an individual's suicide if he or she has a terminal illness.<sup>501</sup>

However, Professor Christian Kind, President of the Central Ethics Committee of the SAMS, told the Commission that little progress had been made in trying to restrict access to assisted suicide to terminally ill patients as recommended by his organisation. He explained the difficulty that the SAMS had in drafting these guidelines:

*We wanted... to maintain that it is not a medical task to assist suicide, and not condemn the doctors that do it out of compassion for their patients that they are in a long-standing relationship with and which they would like to help.*

In recommending that assisted suicide should be restricted to the terminally ill, Christian Kind said the SAMS was attempting to strike a compromise between

*situations where there is such a long-standing relationship and where it can be really an act of compassion to [assist in a suicide], and not extended to situations where somebody comes in and says 'Good morning doctor, I am sick of life, please give me a prescription of sodium pentobarbital.'*<sup>502</sup>



Other individuals whom the Commission met in Switzerland were not in favour of limiting eligibility for assisted suicide to the terminally ill. Andreas Brunner, chief public prosecutor of Zurich canton, said that he was content that the law does not require an individual to be terminally ill. Ludwig Minelli, founder of Dignitas, one of Switzerland's five right to die societies (notable for its acceptance of foreign nationals) has argued widely for the extension of the right to die to anybody with mental capacity, describing it as the 'last human right'. In written evidence to the Commission, Dignitas representatives stated:

*There are 'categories' of suffering individuals who should be eligible for assistance, yet who are not affected by a terminal illness per se, such as paraplegics and quadriplegics or patients suffering from Parkinson's, multi system atrophy and Chorea Huntington... Without doubt, such patients are experiencing severe suffering which can lead them to wish to end their life. In such cases, the wish for an accompanied (assisted) suicide is a personal choice which must be respected.<sup>503</sup>*

Silvan Luley, an employee of Dignitas, explained to the Commission that because the regulation of assisted suicide in Switzerland is predominantly implemented by doctors, doctors are free to decide on what conditions a patient must have for them to be willing to prescribe them with a prescription for lethal medication. In practice, some doctors will only consider cases where an individual is terminally ill. Furthermore, the majority of initial suicide requests come from individuals with a terminal illness. Bernard Sutter, a board member of Exit Deutsche Schweiz (Exit DS), another of Switzerland's right to die organisations, also told the Commission that around 70 per cent of the people that come to Exit DS for assistance with suicide have a terminal illness. Professor Georg Bosshard observed that in Switzerland 'you have around 30 per cent of people not being terminally ill'. Only around 50 per cent of those who have an assisted suicide are cancer patients, which is 'very low' in comparison to other jurisdictions.<sup>504</sup>

In their written evidence to the Commission, the Swiss Federal Office of Justice referred to data published by Exit DS on the circumstances of individuals whom they had assisted with suicide in 2009. Of the 217 individuals, 43 per cent had cancer, 22 per cent had 'polymorbidity' and 8 per cent were suffering from chronic pain. A small number of cases (fewer than ten) involved individuals with other conditions, including heart disease, amyotrophic lateral sclerosis, multiple sclerosis, Parkinson's and lung disease.<sup>505</sup>

### **Significant impairment as a criterion**

In his written evidence to the Commission, Tony Nicklinson, who has 'locked-in' syndrome following a stroke that he experienced in 2005, argued that everybody who is mentally competent should have the right to end their own life. Mr Nicklinson developed his own proposed scheme for assisted dying and submitted it to the Commission, arguing that this would 're-instate th[e] right [of disabled people] to self-determination'.<sup>506</sup> This scheme was

*intended to be used only by those people who need assistance to commit suicide (disabled), thereby restoring equality with people who do not require such help (non-disabled). It is not intended to be used by non-disabled people, and the expectation is that they won't because they can already take their own life quite legally.<sup>507</sup>*

Mr Nicklinson said that any scheme that restricts eligibility to the terminally ill is discriminatory.

However, as discussed in chapter 5, the Commission also heard from a range of individuals that any regime for assisted dying for which eligibility extends to individuals with a significant physical impairment could impact negatively on disabled people. Professor Raymond Tallis, representing Healthcare Professionals for Assisted Dying, cautioned against extending eligibility criteria for assisted dying beyond those that are terminally ill, commenting:

*I think that there are genuine dangers in extending the scope of assisted dying to people who are not terminally ill, who are disabled. All those things that disability groups fear, I think that it would certainly play into those appropriate fears.*<sup>508</sup>

In primary research Demos found that many disabled adults would be concerned about assisted dying being available as an option for people who become disabled through illness or accident. As previously discussed in chapter 5, the disabled people who took part in this research were particularly concerned about the potential that should assisted dying be legalised, a person who developed an impairment for the first time, perhaps as a result of illness or accident, might request an assisted death before they had had time to adapt to their new circumstances. There was also a clear concern that disabled people might choose an assisted death through lack of adequate support or a feeling that their lives were not valued by society.<sup>509</sup>

The End of Life Assistance (Scotland) Bill, which was introduced by Margo MacDonald MSP on 20 January 2010, sought to legalise assisted dying for individuals who are either terminally ill, or ‘permanently physically incapacitated to such an extent as not to be able to live independently’.<sup>510</sup> The bill was heavily criticised for this ‘wide catchment area’.<sup>511</sup> Care Not Killing voiced concerns about the message that this legislation might have sent to disabled people: ‘It [the bill] says: “If you cannot live without help, you are a candidate for having your life ended.” Ms MacDonald [the bill’s primary sponsor] may be well intentioned, but this bill is simply too dangerous’.<sup>512</sup> This bill was also criticised for implying that the lives of disabled people are of less value than non-disabled people and for reinforcing the discriminatory stereotype that disabled people have a poor quality of life and should therefore be given assistance to end their lives.<sup>513</sup>

As observed above, within the terms of Swiss law, an individual who wishes to end their life because of suffering caused by a physical impairment could be eligible for assistance with suicide. At Exit DS a person might be eligible for an assisted suicide if they have an ‘unreasonable disability’. At Dignitas the term ‘unacceptable disability’ is used.<sup>514</sup> Here, the autonomy of the patient, as opposed to the nature of the underlying illness, is considered to be the most important factor.<sup>515</sup> A study published in 2003, led by Georg Bosshard, looked at Exit DS’s records of suicide cases they had assisted with between 1990 and 2000. It found that 21 per cent of cases involved a non-fatal medical diagnosis, such as arthritis, blindness or general weakness.<sup>516</sup> A study published in 2008 indicates that assisted suicides involving a non-fatal medical diagnosis rose following this period and now account for around 30 per cent of all cases.<sup>517</sup> Evidence submitted to the Commission by the Swiss Federal Office of Justice

indicated that in 2009 three individuals who were tetraplegic received assistance to die from Exit DS.<sup>518</sup>

Silvan Luley from Dignitas, explained to the Commission that if a patient has a medical diagnosis relating to their disability, Dignitas is able to assist them in finding a doctor to write a lethal prescription. Bernard Sutter's comments suggested that instances of Exit DS assisting the suicides of non-terminally ill disabled people are relatively unusual:

*All I can tell you is what we see in the patients who die with our organisation's assistance. It's rarely those disabled and depending people who seek our help. It's the same as in Oregon. If you look at our statistics or those in Oregon you'll see it's the rich, it's the white, it's the well educated, it's particularly the non-depending who opt for self-deliverance.*<sup>519</sup>

Eric van Wijlick, senior policy adviser at the Royal Dutch Medical Association, told the Commissioners that the terms of the Dutch euthanasia law could potentially accommodate individuals who have a severe physical impairment caused by an accident, who wish to have an assisted death. If the patient was suffering from serious pain, for example severe back pain, that could not be alleviated, this individual could potentially seek euthanasia if their suffering was unbearable and the physician was convinced the suffering could not be alleviated.<sup>520</sup> However, as mentioned above, such cases are comparatively infrequent and the majority of requests come from people who are terminally ill.

### **Unbearable or unrelievable suffering as a criterion**

In addition to the difficulties associated with defining terminal illness, the Commission also heard evidence about the difficulties of making an objective medical judgement on the extent of another person's suffering. Dr Adrian Tookman noted that while suffering might be intuitively easy to understand, it can be much more difficult to define in words:

*I think by suffering, I think people understand it, that mixture of symptoms and existential distress and fear about the unknown and those things we handle on a day-to-day basis but that are quite difficult to articulate.*<sup>521</sup>

Similarly, Help the Hospices explained in their written evidence to the Commission that 'Pain and suffering are much more than physical in nature'. Therefore, they suggested that 'the concept of total pain provides a helpful clarification of a potentially subjective definition of "unbearable suffering".'

Dr Elizabeth McDonald, an oncologist and co-author of the book *Easeful Death*,<sup>522</sup> stated in her submission to the Commission that 'the concept of unbearable suffering remains difficult to assess and has not yet been adequately defined'. She notes that a medical definition of unbearable suffering was described by Cassell in 1982 as 'the state of severe distress associated with challenges that threatened the intactness of the person'.<sup>523</sup>

A number of people who gave evidence told the Commission they thought a person's quality of life or experience of suffering should be more significant in the context of assisted dying legislation than their life expectancy. The medical director of an English hospice who gave evidence anonymously emphasised the importance of asking how the patient *feels*:

*If you really think that the patient has a couple of years [to live], for example someone with MND [motor neurone disease], they can have a pretty hellish couple of years. They could have a year or two with very incapacitated life, so do we say to them 'you can't have it [assisted dying]', when another person who had a much better quality of life, but seems to have something that will kill them in a couple of months, can have it?*<sup>524</sup>

Simon Gillespie, Chief Executive of the MS Society, also asserted that quality of life could be an important principle in this context. He commented that if we were considering eligibility for assisted dying, 'we [would] need to start looking at what the impact of the condition is on somebody's life and particularly what impact it has on the quality of their life'. Such an approach to eligibility might include people with non-terminal conditions such as multiple sclerosis, which can cause considerable suffering. He reflected, 'I think that people would say... people's quality of life is really important.'<sup>525</sup>

Peter Morgan, a social worker from the Practitioner Alliance Against the Abuse of Vulnerable Adults, emphasised in his submission to the Commission that where eligibility criteria relate to a person's quality of life, it is imperative that the individual concerned makes the judgement on how much they are suffering, not a third party such as a doctor: 'The decision as to whether suffering is "unbearable" should lie with the individual, it is and has to be a subjective judgement.'<sup>526</sup> David Congdon from Mencap also challenged the appropriateness of a doctor making an assessment on behalf of the patient about whether their suffering was unbearable. He argued that such an approach could be dangerous: 'Quite often assumptions are made about quality of life that really are quite inappropriate. It's very hard, actually, to judge someone else's quality of life... It is their life. It's the quality to them.'<sup>527</sup>

The eligibility criteria defined in the Assisted Dying for the Terminally Ill Bill required that the attending physician must have concluded that a terminally ill patient was suffering unbearably as a result of their terminal illness.<sup>528</sup> Unbearable suffering was defined in the bill as 'suffering whether by reason of pain or otherwise which the patient finds so severe as to be unacceptable'. When giving evidence to the Select Committee that examined the bill, Lord Joffe explained that this definition of 'unbearable suffering' was intended to be subjective: 'It is that particular patient's suffering which is the subject matter of his decision.'<sup>529</sup> This sentiment was repeated in his oral evidence to the Commission, when he stated: 'It's not an objective judgement which the doctor has to make; it is a subjective decision.'<sup>530</sup> The definition also encompasses suffering other than from physical pain, for example existential suffering, such as the loss of dignity and self-worth, which may result from a terminal illness. In his oral evidence to the Commission, Lord Joffe said he thought suffering was not mainly about pain, 'but very considerably it's [about] existential suffering'.<sup>531</sup> The Select Committee that examined the bill concluded that in any future assisted dying bills, 'consideration should be given to including a test of "unrelievable" rather than "unbearable" suffering or distress'.<sup>532</sup>

Lord Joffe also raised the issue of whether the anticipation of suffering should be valid grounds on which to ask for an assisted death, or whether the person should need to have already experienced the suffering. He made reference to the case of Mrs B, which concerned a paralysed woman on a life

support machine. Lord Joffe paraphrased Judge Butler-Sloss's High Court judgment on this case, which determined: 'It's totally unreasonable to say that the person has to experience the suffering before they can make up their mind to refuse medical treatment'.<sup>533</sup> Lord Joffe argued, 'It's always a question of what the patient's view is on the matter and the patient's decision.'

The 2010 End of Life Assistance (Scotland) Bill contained no requirement for the applicant to be experiencing unbearable suffering, but instead the bill's eligibility criteria restricted requests to an individual who is terminally ill or physically incapacitated to the extent that he or she 'finds life intolerable'.<sup>534</sup> The bill's explanatory notes state that 'intolerability' had not been further defined in order that the test might remain subjective and be determined by the patient. The Committee that examined the bill heard from a range of witnesses that the subjectiveness of the term 'intolerability' was a significant drawback: 'How could it be ascertained or measured, given its dependence on many unspecified factors including the psychological, emotional, physical, spiritual and social?'<sup>535</sup> It was also noted that an individual's state of mind can change or fluctuate in line with what they can tolerate at any given time.

As observed above, Dutch and Belgian legislation base the eligibility criteria for their euthanasia legislation around the concept of 'unbearable suffering'. Professor Penney Lewis has noted that in the case of the Dutch euthanasia law, 'the source of the patient's suffering may be either somatic (that is, stemming from a physiological disorder) or non-somatic'.<sup>536</sup> The Dutch Supreme Court established a precedent in 2002 in its judgment on the *Brongersma* case:

*Doctors may not perform euthanasia or help with suicide unless the request comes from a patient suffering from a medically classifiable physical or psychiatric sickness or disorder. Simply being 'tired of life' is no basis for doctors to act.*<sup>537</sup>

Agnes van der Heide said the Dutch public is largely satisfied with the terms of the current euthanasia law and the potential to extend eligibility for euthanasia to people who are 'tired of life' is not widely supported by the public; it is mainly among the activists from the voluntary euthanasia movement that that issue is discussed.<sup>538</sup> However, Professor Bregje Onwuteaka-Philipsen said some ambiguity remains in relation to what suffering might legitimately be considered both 'unbearable' and 'medically classifiable'. She referred to 'tired of life cases' as 'a difficult... boundary situation where the law doesn't forbid it, necessarily'. In some cases, a person with a number of minor ailments might be viewed by one doctor as simply 'tired of life' and therefore ineligible, while another doctor might consider the individual's conditions to be medically classifiable. These comments suggest that a criterion based on 'unbearable suffering' can leave a great deal of responsibility to the individual practitioner's judgement.

## **The applicant's mental capacity and mental health**

### **Mental capacity**

During the research visits, the Commission found that most practitioners and commentators in jurisdictions that permit assisted dying regard mental capacity as an essential eligibility criterion. Mental capacity is

legally required as a qualifying condition for an assisted death in all of the jurisdictions that the Commission visited: the Netherlands, Belgium, Oregon and Switzerland (see Box 3).

**Box 3 Criteria relating to mental capacity in jurisdictions that the Commission visited**

*The Netherlands: ‘The patient must be competent to make a request for an assisted death and the attending physician must consult a psychiatrist if he or she suspects the patient is incompetent’.*<sup>539</sup>

*Belgium: The patient must be ‘legally competent and conscious at the moment of making the request’.*<sup>540</sup>

*Oregon: The attending physician must determine that the patient is ‘capable—able to make and communicate health care decisions’.*<sup>541</sup> *The attending or consulting physician must refer the patient to a counsellor if he or she suspects the patient ‘may be suffering from a psychiatric or psychological disorder, or depression causing impaired judgment’. The assisted suicide may only take place under the Oregon Death with Dignity Act if the counsellor decides the patient does not have such a condition*

*Switzerland: The person who is assisted with suicide must have mental capacity for their act to be considered suicide. The physician must examine the person seeking assistance and assess their capacity. This test is set out in the Civil Code.*<sup>542</sup>

Gary Fitzgerald of Action on Elder Abuse said he thought a rigorous test of capacity should lie at the heart of any safeguarded process for assisted dying: ‘the capacity of somebody to be able to make an informed decision on what they’re [doing]’.<sup>543</sup> Professor Raymond Tallis, representing Healthcare Professionals for Assisted Dying, also spoke about the central importance of capacity to eligibility for assisted dying:

*I think that it [the requirement of capacity] is very important... It seems to me that if we let go of the idea of having mental capacity at the time when the assisted dying is offered, if we let go of that then I think that we are in trouble. And that is why I think that the slippery slope arguments are irrelevant because it is a very clear dividing line between the sort of thing that we would support and moving on to other things; we wouldn’t somnambulate down the slippery slope simply because the legislation would be very clearly different. I personally would actually oppose it and it is very clear in my mind the difference.*<sup>544</sup>

Simon Gillespie from the MS Society spoke about how individuals with multiple sclerosis (MS) might experience either depression or other cognitive issues during their lifetime, which might affect their mental capacity. He explained that because MS affects the central nervous system, the brain is vulnerable, therefore the condition can significantly affect cognitive abilities:

*In common with a lot of other conditions... there is the issue whether somebody has the mental capacity to make that type of decision [about an assisted death]. What I’m indicating is that, potentially, the capacity to make that type of decision will be influenced by the fact that either depression and/or cognitive impairment... are significant for a significant number of people with MS.*<sup>545</sup>



Mr Gillespie told the Commission there was a risk that individuals with MS might experience fluctuating decision-making capacity, which could potentially complicate decisions regarding eligibility.

The Commission's attention was drawn to the issue of the mental capacity of individuals with a learning disability by David Congdon from Mencap:

*Quite a lot of people with a learning disability... like to try to please in answering questions. So they will say yes to the question. And so they can often incriminate themselves through their inadequacy in terms of communication... There is that real danger... that people will incriminate themselves, by wanting to answer the question to satisfy the question that's being asked, yes, or simply to get away.<sup>546</sup>*

He contended that it is therefore not a huge step to assert that there is a danger of such behaviours occurring in relation to decision-making around issues of health and therefore assisted dying.

However, Mr Congdon said people with learning disabilities might not necessarily lack mental capacity, since the test for *lacking* capacity is 'quite a high bar in a sense'. He argued that from an equal rights perspective, people with learning disabilities should not be automatically excluded from eligibility for assisted dying:

*The safeguard should be in there, of advocacy, to test out whether that is really what they want; that they're not being coerced. That would seem to me to be a balanced approach... if they are in unbearable pain and they've come to the view (if we had a law) that they wanted to die, and all those safeguards [had been] checked... I think [that] would then be fair.<sup>547</sup>*

The 2005 Assisted Dying for the Terminally Ill Bill specified that the person requesting an assisted death must have 'capacity', according to the definition provided in the 2005 Mental Capacity Act:

*A person lacks capacity in relation to being assisted to die if at the material time he is unable to make a decision for himself in relation to that matter because of an impairment of, or a disturbance in the functioning of, the mind or brain resulting from any disability or disorder of the mind or brain.<sup>548</sup>*

The Assisted Dying for the Terminally Ill Bill specified that if the attending or consulting physician thought that the patient might lack capacity, 'the attending physician shall refer the patient to a consultant psychiatrist, or a psychologist, who shall be independent of the attending and consulting physicians, for an opinion as to the patient's capacity'.<sup>549</sup>

### **The interaction between mental health and mental capacity**

Some of those who gave evidence, such as the consultant psychiatrist Dr Tony Zigmond, suggested that the process of assessing mental capacity in relation to assisted dying should be relatively straightforward in comparison to other health-related decisions, as 'the decision to die has a clear outcome'.<sup>550</sup> However, a number of pieces of evidence suggested that it can be far more difficult to unpick the interaction between psychological disorders and mental capacity. For example, it might be very difficult to determine whether a psychiatric disorder such as a treatable depression is affecting a person's

decision-making capacity and therefore influencing their desire for an assisted death. Simon Gillespie told the Commission that many people suffering from MS and other similar long-term conditions experience either cognitive impairment or depression during their lifetime, and these symptoms can often be overlooked, ignored or mistaken by healthcare professionals.

Andrew McCulloch from the Mental Health Foundation told the Commission that given the prevalence of mental health problems in our population, it is essential to consider how mental health problems might affect decisions on assisted dying. He noted that around 1 per cent of people suffer from a severe mental illness and around one in six or seven people has a common mental disorder. Furthermore, people with severe mental illness have a higher morbidity rate and are statistically more likely to become ill than the population as a whole. He noted the complexity of eligibility for assisted dying for individuals who have had a psychiatric diagnosis and observed that a person's capacity might 'depend on the person's life history, their current status, the illness they suffer from which could have different impacts on their capacity and the fact that people with enduring mental health problems often have fluctuating capacity'. To illustrate this final example, he described how a person can have capacity 'most of the time, but they lack capacity for part of the time, or around certain issues such as eating — anorexia, for example'.<sup>551</sup>

A number of academic studies cited in chapter 4 of this report identified a very close relationship between terminal illness, depression and the desire for hastened death. For example, Price et al's 2010 study in the UK, cited earlier, found that 63.6 per cent of their study group who had a desire for a hastened death had some form of depressive disorder.<sup>552</sup> However, Christine Kalus pointed out that not everybody who wishes to have an assisted death is necessarily experiencing any form of mental health problem:

*One must be aware that not all people who request assisted suicide are (or have) been in psychological therapy, and... we cannot assume that they have a depression or other psychological difficulty, or psychiatric disorder that is negatively impacting their decision to request assisted dying.*<sup>553</sup>

A recent study of the prevalence of depression in requests for assisted deaths has also observed that 'depression does not necessarily make patients incompetent and there is little evidence on whether treatment will be acceptable to patients at the end of life, or will change end-of-life decisions'.<sup>554</sup>

Researchers have found that a level of 'appropriate sadness' or depression is very common in terminally ill patients approaching the end of their life.<sup>555</sup> Dr Andrew McCulloch outlined the difficulties in separating out this close relationship between depression and terminal illness:

*Of course depression is a consequence of having a terminal illness quite obviously. There's almost a tautology between [the two] and there's something about depression that is quintessentially similar to being ill and the nature of illness is often to be a bit depressed. It's a chicken and egg situation sometimes.*<sup>556</sup>

Dr Annabel Price observed that there is an ongoing debate in the psychiatry research literature about the distinction between 'normal' or 'appropriate' sadness and clinical depression:



*The major issue [is]... where on the continuum you actually give somebody or label somebody with a diagnosis of depression, which warrants treatment perhaps with an anti-depressant or with psychological therapy.<sup>557</sup>*

Professor Matthew Hotopf also posed the question of whether a depressed person who wished to have an assisted death, whose depression had been identified but had not resolved following treatment, would then be eligible for assisted dying or not:

*You are left then with a dilemma about are they in that authentic group who you want to, as it were, give the benefit of the intervention, or are they excluded from it? And I think that's a troublesome dilemma.*

Dr Andrew McCulloch argued that it would not be appropriate to limit assisted dying to those individuals who are *not* depressed:

*In a perfect sense... because if I think about depression questionnaires, it wouldn't be normal or sensible to be actually perfect on all of those the whole time anyway, but if one had a terminal illness as well, it doesn't make sense. So I think this is a very, very difficult issue.<sup>558</sup>*

We will return to this issue of screening for depression in chapter 7, as part of our investigation of the use of safeguards in assisted dying legislation.

### **Dementia and eligibility for assisted dying**

Dementia is another challenging issue in the context of assisted dying that presents overlapping issues concerning mental capacity and mental health. Dr McCulloch observed in his oral evidence:

*Some people who suffer from dementia have said that they would like to have this option of assisted dying... The difficulty here is that the progress through the illness and the length of time that it takes, particularly the final stages... [could lead to] dangers that someone might express a desire to die when they had capacity, but maybe it was a long time before they actually developed the tertiary stage of dementia when they actually said they wanted to die.<sup>559</sup>*

In such circumstances, he pointed out, 'you have a practical issue as well: do they really want to die? And then you have various legal issues about the lapse of time and what it all means.' Combined with the gradual reduction in mental capacity that is caused by dementia, Dr McCulloch thought issues like 'pressure from relatives', 'quality of care' and 'financial resources' could 'create a sort of set of pressures in the older person's mind':

*This is a mental health issue, so you could set up a situation where the older person felt they were being herded towards death really. Whereas in fact they could have some quality of life; their life was valuable to them, valuable to others, the quality was still there and yet just having this here almost has a risk for older people.<sup>560</sup>*

Freda Humble submitted written evidence to the Commission, stating that she was in the early stages of dementia:

*I would like the Commission to address the subject of ‘competence’ and the way in which persons suffering with mild dementia can certify their intentions in advance — in a totally effective and legal document. A document which will remain valid even when my condition has deteriorated. This would release me and many people in my condition, from a state of constant worry and anxiety.*<sup>561</sup>

Demos’s research exploring attitudes towards assisted dying among people who are terminally ill found also found that dementia patients were sometimes identified as a group that could particularly benefit from having the choice of an assisted death. For example, one male hospice service user suggested that the option should be available to ‘people with terminal illnesses, and people with dementia, that’s a terrible illness’. However, a terminally ill man whom Demos contacted through an online forum observed, ‘If you have got Parkinson’s or Alzheimer’s, there will come a time when people won’t see you as a suitable candidate, even if you have stated clearly your desire to die at a certain point of deterioration.’ Therefore, he suggested that ‘there ought to be a provision for a half-way house somewhere along those lines’.<sup>562</sup>

### **Dementia and assisted dying in other jurisdictions**

As we observed above, in the Netherlands, case law and the guidelines of professional medical organisations indicate that unbearable psychological suffering can, in some cases, justify the termination of life.<sup>563</sup> Therefore, it is sometimes considered permissible in the Netherlands for a person with dementia to seek an assisted death. In 2004, the Dutch Minister of Justice recognised that a person who has dementia can experience ‘unbearable and hopeless suffering’ due to the ‘fear of further deterioration and the risk of not being able to die with dignity’.<sup>564</sup> The Dutch regional review committees (RRCs) ‘have taken the position that suffering due to dementia can be a legitimate ground for euthanasia pursuant to an advance request’.<sup>565</sup> The Dutch RRCs reported that in 2009 they reviewed 12 notifications of euthanasia involving patients in the early stages of dementia and in all cases concluded that the physicians had acted responsibly.<sup>566</sup> In 2010, the RRCs received 25 notifications of cases of euthanasia or assisted suicide that involved people who had dementia:

*The patients were in the initial stages of the disorder and still had insight into the condition and its symptoms (loss of bearings and personality changes). They were deemed decisionally competent because they could fully grasp the implications of their request.*<sup>567</sup>

The 2010 report by the RRCs cautioned that ‘physicians should normally treat requests for termination of life from patients suffering from dementia with additional caution’ and patients ‘at a more advanced stage of the disorder are less likely to be decisionally competent’.<sup>568</sup>

However, it is not currently permissible in the Netherlands for a patient with dementia to make an advance request for euthanasia, to be acted on once that person is in the late stages of dementia and has lost capacity. Dr Gert van Dijk told the Commission that ‘there has to be a request... in the later stages [of dementia] there are no requests anymore’. According to the Dutch

euthanasia framework, ‘only the person himself can judge if the suffering is unbearable. So, if he can’t say it anymore in a case of progressed dementia then it is out of the question. That is one of the safeguards.’<sup>569</sup> Agnes van der Heide, a senior researcher at the Department of Public Health at the Erasmus Medical Centre in Rotterdam, observed that public opinion in the Netherlands increasingly favours the extension of the legal eligibility criteria for euthanasia to include patients with dementia. However, she did not believe that the system was likely to change to accommodate this more liberal view of eligibility for euthanasia.

Lewis and Black’s briefing paper for the Commission observed that in Belgium people with dementia are also ineligible for euthanasia as the patient must be ‘legally competent’. There are some circumstances in which euthanasia can be requested using an advance decision, but ‘since the triggering condition is unconsciousness, advance requests will not be applicable to many scenarios of future incompetence, including dementia’.<sup>570</sup>

The two requirements of the Oregon Death with Dignity Act that a person who wishes to use the act must have ‘an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months’ and must also be ‘capable’, defined as having ‘the ability to make and communicate health care decisions to health care providers’, mean that a person with dementia is unlikely to qualify for assistance.<sup>571</sup> However, if a person in the early stages of dementia was ‘capable’, and had a concomitant terminal illness, they might be eligible for aid-in-dying under Oregon’s legislation. Julia Gies, a nurse and a member of the Oregon Nurses Association, observed that the act’s requirement of a six-month prognosis means it is only available for those individuals who are already ‘quite ill’.<sup>572</sup> She expressed concern that a relatively short time-frame of the required prognosis prevents the growing cohort of individuals who are suffering with early stage dementia, who still have mental capacity, but might have a prognosis of around two years, from having an assisted death: ‘Those are the times when people really suffer, that’s profound suffering, and this law’s not available to any of those people.’<sup>573</sup>

The Swiss legal framework permits people to request an assisted suicide ‘because of a mental disorder (eg life-long depression)’. However, in such cases a psychiatrist must provide a psychiatric evaluation. ‘The evaluation must provide evidence that the patient’s desire to die is not the expression of a curable, psychiatric disorder but is a well-considered and permanent decision based on rational judgment (Swiss Federal Supreme Court, 2006).’<sup>574</sup> Therefore, a person in the early stages of dementia might legitimately request an assisted death in Switzerland. However, there is no provision for the use of advance decisions in the circumstances of advanced dementia and, as set out in Box 3, the Civil Code requires that a person must have mental capacity in order for an assisted suicide to be considered a legitimate suicide.<sup>575</sup>

### **An informed and considered choice**

A range of individuals identified the need to ensure that a person’s request for an assisted death was fully informed and not based on any misinformation, for example regarding an inaccurate prognosis, as a prerequisite for an assisted dying framework. Dr Annabel Price gave an example of a case where a patient’s expressed wish for an assisted death was, in part, influenced

by misinformation about the care he would be likely to receive when his condition worsened. The patient, who had motor neurone disease, had a strong wish to end his life and continually asked clinicians for assistance to die. Dr Price described the case:

*When we talked in depth, it became clear that he had been told at some point earlier in his life that what happens to you when you go into a nursing home is that if you are incontinent, then the nurses will punish you by putting you in a bath of cold water. And he was terrified that because he would lose the ability to speak, that he wouldn't be able to apologise or to be able to explain himself and he wouldn't be able to extricate himself from the situation; and that his wish for death was in part driven by this terrible fear of what would happen to him once he was no longer in control of his communication.*

Although Dr Price allayed his fears this 'did not remove his wish for death and did not stop him talking about his wish for assisted dying', but 'it did reduce his level of distress'.<sup>576</sup>

Rebecca Coles Gale, a clinical psychologist in specialist palliative care at the Rowans Hospice, told the Commission that in her experience of working in palliative care there were a large number of people who had stated they did not want to live any longer, but as a psychologist she thought it important to have a conversation with these people in order to understand what was driving this wish and to help 'move [the patient] to a different place. It's not by encouraging them to move; it's by bearing witness to what they're experiencing without judgement'.<sup>577</sup>

The Commission also heard evidence that attitudes to assisted dying, and a person's stated desire for an assisted death, can change over time, in response to a range of factors. Simon Gillespie from the MS Society described two possible examples of how opinions might change:

*Some people who would think that assisted dying might be an option for them very early on in their condition... may change their minds and go back the other way and actually say, 'To hell with this! I'm going to hang on and get the best out of life that I can do.' And there are others clearly who think, 'Well I'll think about that later on.' [They may] disagree with it totally, but may feel differently... if it gets to the stage that some of the more severe symptoms take a grip on them.<sup>578</sup>*

Research by Annabel Price et al, previously discussed in the report, which investigated the desire for a hastened death in patients receiving palliative care, found that patients' desire for a hastened death tends to fluctuate over time.<sup>579</sup> Professor Tim Maughan also noted that some people experience a fluctuating wish to die and can be 'very variable in their decisions', therefore he expressed the concern that 'whatever it is put in a safeguard may not turn out to be the long-term view'.<sup>580</sup>

Martin Green, Chief Executive of the English Community Care Association, argued that the complexities of the process of assisted dying are not as important as ensuring that the process is clear and accountable with the checks and balances at each stage to ensure that the individual is constantly re-engaged in their decision to choose an assisted death:

*We all have days when we make a decision and then the day after we realise we wish we hadn't made it. And so it has to be a process. And my slight concern is, if you set up all these wonderful bits of a system, the focus will become the system rather than the process of engaging somebody in making a decision.*<sup>581</sup>

Drawing on evidence generated in jurisdictions that permit assisted dying, Dr Martin Curtice told the Commission about the importance of fully informing patients about the risks associated with any assisted dying process. He pointed to the statistics in Oregon, which indicate that patients do not always immediately die when they ingest the lethal medication:

*They've had three cases, out of 525 in Oregon up to the end of last year, where the patient didn't die; they woke up 60–80 hours later, and died several days or even two weeks or three months later.*<sup>582</sup>

Therefore, he argued that it is important not only that a person should be properly informed about their prognosis and other options for treatment, but also that they are aware of any risks associated with the assisted dying process.

Box 4 describes how the four jurisdictions the Commissioners visited ensure that a request to die is informed, considered and voluntary.

**Box 4 How Switzerland, Oregon, the Netherlands and Belgium ensure that a request to die is informed, considered and voluntary**

*Switzerland*

*Although the Swiss law contains no direct safeguards to ensure that a request is informed, considered and voluntary, the right to die organisations impose their own conditions. At Exit DS, assistance is only available to individuals whose 'desire to die is stated persistently'.<sup>583</sup> Furthermore, as part of an agreement drawn up between Zurich Canton and Exit DS, in order to ensure that a request is informed and constant, 'conversations with the person in question [must occur] "over several weeks" by the assistants in suicide and the treating physician and without the presence of next of kin or others who might exert pressure'.<sup>584</sup>*

*Oregon*

*There are four requirements:*

- *The patient's request for assistance must be made orally and in writing, and witnessed by at least two individuals, who must attest that 'to the best of their knowledge and belief the patient is capable, acting voluntarily, and is not being coerced to sign the request'.*
- *The oral request must be repeated not less than 15 days after the initial request.*
- *No fewer than 15 days can elapse between the patient's initial oral request and the writing of a prescription.*
- *No fewer than 48 hours can elapse between the patient's written request and the writing of a prescription.*

*The primary doctor must:*

- *determine that 'the patient makes the request voluntarily'*

- *‘ensure that the patient is making an informed decision by informing him or her of the medical diagnosis and prognosis, of the potential risks associated with the medication, and of feasible alternatives such as palliative care, hospice and pain control’*
- *inform the patient that he or she can rescind the request for medication at any time.*<sup>585</sup>

#### *The Netherlands*

##### *The primary doctor must:*

- *hold ‘the conviction that the request by the patient was voluntary and well considered’*
- *have ‘informed the patient about the situation he was in and about his prospects and the patient holds the conviction that there was no other reasonable solution for the situation he was in’.*

#### *Belgium*

##### *These are the requirements:*

- *The request must be ‘voluntary, well-considered, and repeated, and not the result of any external pressure’.*
- *The doctor must ‘explain to the patient his or her medical condition and life expectancy, and discuss options other than euthanasia, such as palliative care’.*
- *‘Both patient and doctor must conclude that no alternatives to euthanasia are available and that the patient’s request is completely voluntary.’*
- *The doctor must be ‘certain of the durable nature of the request for euthanasia’.*
- *The doctor must ‘discuss the request with any relatives chosen by the patient’ and ‘be certain that the patient has had the opportunity to discuss his or her request with any person he or she chooses’.*<sup>586</sup>

In the Netherlands, the ‘due care criteria’ require that a patient’s request must be ‘voluntary and carefully considered’.<sup>587</sup> The doctor is required to inform the patient fully about their situation, including their ‘prognosis and the possibilities of curative or palliative treatment’.<sup>588</sup> Agnes van der Heide, from the Erasmus Medical Centre in Rotterdam, told the Commission that a typical patient will have discussed a request for euthanasia with their doctor many, many times:

*Often it is a process of months and, in the end, when both the attending physician and the patient, and often also the family, think, ‘Well now is really the moment.’ Then the independent physician is consulted and in many cases the situation is really very clear, the patient is really clear headed.*<sup>589</sup>

The regional review committees highlight as good practice this process of full and open communication between the patient and their doctor, conducted over a good length of time where possible.<sup>590</sup> Gert van Dijk pointed out that, typically, patients will have spoken to their doctors at length about their desire for an assisted death, long before the official process commences: ‘Sometimes it’s a year or two years that the doctor and the patient have talked about it.’<sup>591</sup>

Dr Christiaan Rhodius, a physician at St Jacob’s Hospice in Amsterdam, described the process they follow at the hospice if a patient makes a request for an assisted death. If, for example, a patient said to a night nurse they wanted an assisted death, this would not immediately

initiate a formal process. The nurse would inform other members of the team, who would inform the patient's doctor, who would then be able to speak to the patient about how they are feeling to better understand what was driving the patient's request. Dr Rhodius said it is through these discussions that it could be determined whether the request was a genuine request, or a 'cry for help'. Dr Rhodius believed that the system was effective in screening out inappropriate requests, as '99 per cent of the requests or hints made towards euthanasia do not end in euthanasia'.<sup>592</sup>

In Oregon, the attending physician must ensure that the patient requesting an assisted death is making an informed decision. Dr Peter Rasmussen, a medical director at Compassion and Choices of Oregon, with a wealth of experience in helping patients make use of the law in Oregon, told the Commission about his experience in identifying requests from individuals that clearly were not properly informed, or that in some cases did not arise from appropriate motivations. He referred to one specific case where he believed that a patient wanted an assisted death as a means to punish his family:

*One guy said this: 'I'm going to this Oregon Death with Dignity thing, that'll show them!' And that was real obvious. But there are things like that, where my sense is that they're using this to kind of punish people.*<sup>593</sup>

### **A free and voluntary decision**

A number of witnesses from whom the Commission heard evidence stated that an extremely important eligibility criterion was the need to ensure that a request for assisted dying is made voluntarily by the patient and not as a result of external coercion. As mentioned previously in chapter 5, Gary Fitzgerald told the Commission that Action on Elder Abuse would be very concerned about the potential for coercion in the context of assisted dying.<sup>594</sup> Bridget Robb from the College of Social Work told Commissioners:

*The issue of ensuring that people aren't inappropriately pressurised to take this course of action is obviously something that we are very concerned about, because we do see so many circumstances where people are under pressure. Whether it's the lack of services, or pressure within the family, or sometimes pressure within themselves that they feel this is what they ought to do.*<sup>595</sup>

A specialist palliative care nurse interviewed by Demos spoke of her experience of family pressure experienced by patients when making end of life decisions, for example about treatment options, commenting that she witnesses patients experiencing family pressure, 'all the time. People wanting to die and their families not wanting them to die, or the other way around'.<sup>596</sup> A second nurse said, 'We very often question motives of why families are pushing for certain things and you really sometimes get the feeling that their motives aren't completely honourable'.<sup>597</sup> The medical director of an English hospice, giving evidence to the Commission anonymously, also spoke of his experience of family pressure on patients in end of life settings:

*Most relatives put pressure on patients to have treatment. I think that it's more common that the families push the patient to stay alive, whereas the patient may think, for example, that chemotherapy is hideous and that they don't want any more.*<sup>598</sup>



Dr Tony Zigmond, a consultant psychiatrist, referred to his personal experience in order to describe the complexities behind decisions and relationships when someone is dying:

*My mother, aged 89, wished to refuse all medical treatment as she wished to die. She would say this to staff in the care home and to doctors, but always said the opposite to me. Following discussions between us all, she said that she knew I wanted her to live and she didn't wish to let me down. Time and open discussion can clarify many things.*<sup>599</sup>

Suzy Croft, a senior social worker at St John's Hospice, echoed Dr Zigmond's evidence, stating the importance of recognising the complexity and difficulty of family relationships:

*Social workers are used to having to advocate on behalf of a patient whose family may be pressurising him/her to go into a hospice/nursing home/hospital because that is easier for the family rather than in the best interest of the patients. Often families are doing this because they are under great strain, both emotionally and financially and very occasionally because they simply no longer want to accept the burden of responsibility and care.*<sup>600</sup>

Christine Kalus, lead consultant clinical psychologist in specialist palliative care at Solent NHS Trust, asked in her written evidence whether the question over whether a patient is making a free and voluntary decision is one that is only relevant to assisted dying:

*We may also need to ask ourselves [the same question] in other health care contexts, for example, when offering patients potentially 'dangerous' treatments for cancer... that have potentially harmful and often long-lasting side effects. It seems to me that this question is as relevant in those situations as in the issue of assisted dying, and we know that many professionals struggle to give a less than positive spin when offering such treatments.*<sup>601</sup>

Despite this she argued that in relation to assisted dying,

*one may not always have sufficient knowledge about the individual making the request, regardless of how rigorous the assessment undertaken may be, and one may then need to approach the multidisciplinary team who have been involved in the care of the patient, and family members if appropriate or possible.*<sup>602</sup>

### **Indirect social pressure**

Those who gave evidence raised the issue of indirect forms of pressure to have an assisted death as frequently as mentioning more direct forms of pressure or abuse. A hospice medical director explained in his anonymous evidence to the Commission that patients will frequently say 'I want to die because I'm a burden on my relatives and I'm using up all of the money.' He reflected, 'How much that is a cry for help I'm not sure, because they know [assisted dying is] not available, and whether that would change if it was available? I don't know.'<sup>603</sup> The specialist palliative care nurses Demos interviewed also raised the issue of patients not wanting to feel they are a burden at the end of their lives: 'A lot of our patients will talk about not wanting to be a burden on their family.'<sup>604</sup> Dr Martin Curtice noted how he has experience of older people



who are in a care home who feel a burden on not just their families but also the care home. Dr Curtice said these feelings can stem from the patient's own volition and are not necessarily related to coercion.

Dr Ann McPherson, founder of Healthcare Professionals for Assisted Dying (HPAD), told the Commission she believes a desire for an assisted death based on the individual feeling they were a burden, either on their family or society, is not a good enough reason to be granted their wish since it is an indication that the decision is not free and voluntary, but based on an element of indirect and undue pressure by society. She argued that in these situations the desire for an assisted death is in fact an indication of the insufficient care provision for that particular person.<sup>605</sup>

Professor Joe Collier, also from HPAD, shared these views to an extent, noting that when a patient feels they are a burden, often what is required is good palliative care. However he also suggested that doctors must recognise the need to honour patients' views:

*We have been patronising for a very long time, and if people have a view, they have a view... and you [a doctor] have to be very careful and you have got to recognise that people's views are what they are. We have to respect and not be patronising by saying, 'I'm afraid you can't have that view.' What we have to remove is abuse, excessive pressure, unreasonable pressure, but once we have accepted that their mind is sound, and they have a right to make up their mind up, we must honour that position.*<sup>606</sup>

In written evidence to the Commission Dr Tony Zigmond argued that a wish for an assisted death driven by a desire to not want feel a burden on family should be respected:

*Personal autonomy means that if I, as a capacitous person, make the decision that I wish to die for the benefit of others (what parent wouldn't give up their life to save their child?), or in order not to be a burden, then that should be my right.*<sup>607</sup>

Suzy Croft also drew attention to the potential of indirect social pressures to affect decision-making around assisted dying:

*As the Association [for Palliative Care Social Work] said, add together the intense pressure on increasingly scarce resources and coupled with a lack of access to palliative care, it is hard to resist the idea that were assisted dying to be legalised, in the future people may face pressure not to be here and not to be a burden on their families, particularly if they are old, or poor, or members of a minority group.*<sup>608</sup>





## 7 Identifying what safeguards might be needed in legislation

### **Access to health and social care to support an informed choice**

In many of the evidence submissions that the Commission received respondents argued that access to adequate health and social care is fundamental to a caring society, regardless of whether or not assisted dying is an option. Bridget Robb, representing the British Association of Social Work, said, ‘If we are going to make this move [towards assisted dying] then there has to be equity of access [to health and social care] somehow or another.’ She told the Commission that significant reforms to health and social care would be needed to achieve this. If a system was to be set up to support an individual’s informed choice about an assisted death, this would need to be ‘a structure that is well known to people; that this is how you access it if you want this support’. She suggested that an ‘end of life board’ or another similar structure should be established that people could apply to and log key documents of consent, or advance decisions:

*People just have to know where to go. It wouldn’t be good enough to just say, ‘oh well a local solicitor sets up this service’, or, ‘a local GP practice thinks it’s a good idea, but actually nowhere else has it available’. We need to find a structural way through that.<sup>609</sup>*

Martin Green, from the English Community Care Association, highlighted the fact that many older people in residential or domiciliary care are currently excluded from health care, including primary care from GPs, and noted this might risk people in such care settings from accessing assisted dying. He told the Commission, ‘The issue there is that people won’t get access to have the conversation with the clinician or the support person or whoever, and I think that’s probably the biggest challenge.’ Professor Raymond Tallis, speaking on behalf of Healthcare Professionals for Assisted Dying, suggested to the Commission that in the context of an assisted dying framework, if there was evidence that a patient who requested an assisted death had not been receiving the best possible care, ‘it must be the duty of the team to requisition that care’. Asked whether it is always possible for a patient to access palliative care, he said, ‘I have never had a time where I couldn’t get hold of a palliative care team.’<sup>610</sup>

When discussing the question of whether an assisted dying framework should require a patient to experience specialist palliative care before being able to make an informed decision about an assisted death, Dr Ann McPherson said, ‘Not everyone is going to be able to get it delivered by a palliative care person.’ As a result, she thought that in line with any developments around legislation for assisted dying in this country, ‘It is very important that... we make sure... that palliative care is available in all sorts of different ways, anyone in hospital ought to be able to get it.’ She praised the practice at the John Radcliffe hospital in Oxford, where when they think

someone is terminally ill, 'they try and get the palliative care team to come and talk to the doctors who are looking after them as to how they can make sure they are delivering the best possible care to them'.<sup>611</sup>

The evidence reviewed in chapter 4 of this report has shown that in jurisdictions that permit assisted dying, 'palliative care and euthanasia/assisted suicide are closely intertwined'.<sup>612</sup> The expert briefing paper provided by the European Association for Palliative Care (EAPC) gave a number of examples of this close relationship in the context of Belgium:

- Euthanasia and assisted suicide are often 'bound together in legislation and regulations' with palliative care.
- The Belgian Medical Disciplinary Board requires doctors to first offer a patient palliative care if they request euthanasia.
- Many hospitals and other facilities apply a 'palliative filter' to applications for euthanasia, whereby a specialist palliative care team must be consulted when a patient requests euthanasia.<sup>613</sup>

The EAPC briefing paper emphasised the hugely important role of palliative care in the context of assisted dying, in supporting the patient to make an informed choice and to explore other options for pain relief and care. It noted evidence from Belgium to suggest that in some cases palliative sedation is being used as an alternative option to euthanasia.<sup>614</sup> However, the EAPC briefing paper also cites numerous studies to indicate that 'palliative care does not systematically prevent euthanasia/assisted suicide requests', that 'there is such a thing as palliative futility' and that 'psychosocial and existential' suffering 'and even refractory pain cannot always be dissipated by palliative care'.<sup>615</sup> Therefore while it is essential that patients should have knowledge of the options for end of life care that are available to them before making any decisions about assisted dying, this evidence indicates that it could be counter-productive and cause unnecessary suffering if too many procedural barriers were put in place to exhaust all other options before a request for assisted death might proceed.

### **The use of a 'palliative filter' safeguard in jurisdictions that permit assisted dying**

At the same time that the euthanasia law was introduced in Belgium, legislation was also passed to enshrine in law a universal right to palliative care. The euthanasia law requires that patients requesting euthanasia be made aware of the option of palliative care, but this is not considered to be a 'filter' as there is no requirement that a specialist in palliative care must be consulted.<sup>616</sup> While the law does not require specialist consultation, one study found that in 2007 palliative care specialists were consulted in half of all cases of assisted dying in Belgium.<sup>617</sup> These high levels of consultation may be driven by the fact that a number of Belgian institutions have developed their own policies requiring a mandatory consultation with a palliative care team when a patient requests euthanasia.<sup>618</sup> The Catholic organisation Caritas Flanders, an umbrella organisation that covers 65 per cent of the general hospitals and 40 per cent of nursing homes in Flanders, requires a patient to have had a specialist palliative care consultation in order to be eligible for euthanasia.<sup>619</sup>

During the Commission's visit to Belgium, Professor Bert Broeckert told Commissioners that he considers the lack of an obligatory palliative care

filter to be a fundamental flaw in the Belgian euthanasia law because the average doctor might have limited knowledge of the palliative care options that are available: ‘If you’re an average GP in Belgium, you see maybe three, four, five dying patients a year, so how would you ever be able to have enough experience?’ He was a strong advocate of such a palliative filter when the euthanasia law was being developed and told the Commission that he believed the legislation was not amended to include the filter for purely political reasons: ‘It was rejected, precisely only because of [the] political reason that... if you are going to have this amendment, then [the bill] must be returned to the senate and then it takes it another six months.’<sup>620</sup>

Like Belgium, there is no explicit ‘palliative filter’ in Oregon’s assisted dying legislation. However, the Oregon Death with Dignity Act requires that the attending physician must inform a patient who wishes to request an assisted death of:

- his or her medical diagnosis
- his or her prognosis
- the potential risks associated with taking the medication to be prescribed
- the probable result of taking the medication to be prescribed
- the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.<sup>621</sup>

Therefore, there is a requirement that people who request an assisted death explore what palliative care could offer them as part of this process. The experts the Commission met in Oregon confirmed — perhaps counter-intuitively — that the process of requesting an assisted death can increase people’s access to specialist end of life care services. Barbara Coombs Lee, President of the right to die organisation Compassion and Choices, said, ‘We are the first to get people [into a] hospice.’<sup>622</sup>

In Oregon there are no data on the rate of consultation with a palliative care team or the number of referrals to palliative care for patients who have received assistance to die, but the 2010 report by the Oregon Public Health Division demonstrates that between 1998 and 2010, 88.7 per cent of the 525 individuals who received assistance to die had been enrolled in hospice care. In 2010 92.6 per cent of the patients who had physician-assisted death were enrolled in hospice care. Penney Lewis and Isra Black observed in their briefing paper to the Commission that this statistic suggests that assisted dying is not chosen as an alternative to palliative care in Oregon.<sup>623</sup>

### **Safeguards to prevent a hasty decision**

In addition to putting in place safeguards to ensure that people who request an assisted death are well informed about their medical condition, and alternative options for end of life care, some jurisdictions that permit assisted dying include provisions in their legislation to ensure that people cannot make the decision to request an assisted dying in haste.

In the Netherlands there are no explicit time limits built into the process of making a request for euthanasia, but as Griffiths et al observe in their book *Euthanasia and Law in Europe*:

*The Regional Review Committees are of the view that a concrete request should generally be made some time before the euthanasia is carried out. A very short*

*period between the first concrete request and carrying out euthanasia — even ‘less than a day’ — is only acceptable in exceptional circumstances.*<sup>624</sup>

The Belgian Law on Euthanasia of 2002 stipulates that if the patient is expected to die in the near future, the doctor should ‘have several conversations with the patient spread out over a reasonable period of time’,<sup>625</sup> but does not define what a ‘reasonable’ time period is. In cases where the patient’s death is not considered to be imminent, the Belgian legislation requires that the patient’s doctor must allow a month to pass between the patient’s initial request and the day when the euthanasia is performed.<sup>626</sup> In Oregon, the Death with Dignity Act requires that 15 days must pass ‘between the patient’s initial oral request and the writing of a prescription’.<sup>627</sup>

Gary Fitzgerald from Action on Elder Abuse argued that a waiting period over which a decision can be considered is fundamental in determining an informed and considered choice, despite the potential challenges of scheduled delays in an end of life scenario: ‘We need to understand that the decisions are sound and that people actually want to stick with those decisions. There needs to be an ongoing opportunity to reverse decisions.’<sup>628</sup>

### **Safeguards to assess the condition of the person**

In her oral evidence to the Commission, Professor Penney Lewis suggested that any regime for assisted dying should include either a condition relating to the victim’s physical condition or to their experience of suffering. As mentioned previously in chapter 3, Professor Lewis criticised the DPP’s prosecuting policy on assisted suicide for failing ‘to distinguish between on the one hand a terminally ill victim who is experiencing unrelievable suffering and a victim who is suffering from depression’. She argued that this means the UK ‘is now more liberal than most permissive regimes’.<sup>629</sup>

One of the greatest difficulties in limited eligibility to terminal illness as a safeguard concerns the complexities in ensuring accuracy in diagnosis and prognosis (the doctor’s prediction of the likely outcome of the disease) of a particular illness. These difficulties were powerfully illustrated through an anecdote from Professor Tim Maughan in his evidence to the Commission:

*David, in 1991, was diagnosed with a spinal tumour, in severe pain, paralysed; in the opinion of his three specialiste was undoubtedly incurable. And he was requesting, very firmly, that he wanted to have euthanasia. And that was not legal. So he would almost certainly have fulfilled all of the regulatory, all the safeguards that were certainly around the Joffe [bill] when that was being considered. He was given radiotherapy to try and relieve his pain. Surprisingly, and contrary to all expectation, he was cured.*<sup>630</sup>

Speaking specifically about prognosis, Professor Maughan said,

*I think we do it [prognosis and judging when a patient is dying] appallingly. The longer I practice, the more experience I have, the less good I am at it. Or at least I realise how bad I’ve always been at it... I mean you’re probably aware of the data that 4 per cent of people on the Liverpool Care Pathway (those expected to die within 48 hours) get better and recover, so even when you are really convinced that*

*this patient is going to die in the next two days, still you're wrong. Doctors are very bad at it and I don't think training will necessarily make people better at it. I think we need to be quite humble about this.*<sup>631</sup>

Dr Adrian Tookman, also spoke about the Liverpool Care Pathway, but pointed out that if a patient on the pathway does not die within 48 hours it does not necessarily indicate that the medical team is unable to give an accurate prognosis:

*Just because people are put on the Liverpool Care Pathway it doesn't automatically mean they are going to die. There are many patients who are started on it. It substitutes the notes, and it is good practice. And we have many, many examples of patients who are put on the pathway and then taken off the pathway again.*<sup>632</sup>

Dr Steve Dyer, a consultant in palliative medicine, pointed to evidence in his written submission to the Commission that 'closeness to death influences decision making on the part of physicians in agreeing with assisted dying. It is also well known that doctors often over estimate prognoses of their patients.' From his experience in specialist palliative care, 'there is a small but significant sub-group who despite my attention to every medical truth relating to them completely defy my prognostic expectation'.<sup>633</sup> Dr Dyer gives the example of a woman with advanced ovarian cancer with peritoneal spread who diagnosed with six months to live. However she lived for over four years, even managing to make a number of trips to Australia.

Peter Bailey also told the Commission that he is uneasy with terminal illness as a criterion, making reference to a famous case recently of a man diagnosed with terminal cancer and given a prognosis of only a few months to live who was still alive two years later:

*So what does terminal mean? You know people find it hard to give you an expire-by date and so I'm a bit wary about the concept of terminal. If you think about motor neurone disease for example, [it is a] terminal condition, but look at Steven Hawking.*<sup>634</sup>

Lord Joel Joffe said that while he agrees that it is impossible for doctors to be 100 per cent accurate when making prognoses, he would argue that a definition of terminal illness based on a prognosis of six months to live is reasonable—the risk that the patient may actually live for longer than this is one that would need to be taken.

Research looking at the accuracy of doctors' abilities to predict survival times in terminally ill patients indicates that predictions are, in general, over optimistic. A 2003 study that reviewed over 1,500 cases of prognoses from in terminally ill cancer patients found that actual survival times were 30 per cent shorter than predicted survival times.<sup>635</sup> A more recent study of 616 deaths from cancer found that the median survival time after diagnosis of the patients who died was 6.5 months, compared with a median doctor predicted survival time of 12 months.<sup>636</sup>

Chapter 6 described evidence heard by the Commission on the difficulties of defining and diagnosing a terminal illness. The Commission also heard evidence about the ways in which healthcare professionals can



ensure that diagnoses and prognoses are as accurate as possible. Dr Adrian Tookman told the Commission that taking a multi-professional approach is an important way this can be done:

*Often decisions aren't made by one person when someone is dying, that diagnosis is made by a team of people. Observation from the nurses, speaking to the patient, speaking to the relatives. It is not a decision for one person. It is a multi-professional approach.*<sup>637</sup>

### **Safeguards used internationally to ensure that eligibility criteria relating to the individual's condition are met**

In the Netherlands, Belgium and Oregon it is the role of the patient's doctor to determine whether they meet eligibility requirements based on their condition (eg either a terminal illness criterion or evidence of 'unbearable suffering' with a physical or psychological origin). In Switzerland, where there are no legal eligibility criteria based on condition, right to die organisations take a greater role in determining whether the person meets the organisational criteria.

In Oregon, where a patient must be suffering from a terminal illness to qualify under the Oregon Death with Dignity Act (ODDA), Susan King, Executive Director of the Oregon Nurses Association, noted that there are challenges associated with accurate prognosis, but observed that doctors are more likely to overestimate than underestimate a patient's prognosis: 'What physicians believe to be a population that is six months from death is probably more like two months from death.'<sup>638</sup> In his comparison of assisted dying regimes, Guenter Lewy argues that this requirement for a patient to be diagnosed with a terminal illness may be more favourable than a requirement for suffering, because suffering

*is a largely subjective criterion, whereas the presence of a terminal condition is a matter of empirical determination... even if a terminal patient is not yet suffering acutely, concern, not to say fear, or suffering that lies ahead may itself induce severe distress.*<sup>639</sup>

As observed above, in Belgium, there is no terminal illness requirement: the applicant must be in a 'medically hopeless situation' characterised by 'persistent and unbearable physical or mental suffering that cannot be alleviated' and that this is the result of a 'serious incurable disorder caused by illness or accident'.<sup>640</sup> However, additional procedural requirements are imposed if the patient is 'clearly not expected to die in the near future'.<sup>641</sup> In such cases, in addition to building in a month's waiting period, the attending physician is required to consult a psychiatrist or a specialist in the relevant illness in addition to seeking the usual second opinion from another doctor.<sup>642</sup>

Experts have noted that the definition of the criteria for the patient's suffering in Belgium includes both subjective and objective elements. If a patient is suffering from a serious and incurable disorder this can be measured objectively, but the medically hopeless situation must be measured by the subjective 'persistent and unbearable' suffering of the patient. It is the patient alone who must determine that the suffering is persistent and unbearable and the role of the doctor is only to accept or the patient's assertion.<sup>643</sup> A number of individuals whom the Commission met in Belgium spoke about the difficulties associated with applying eligibility criteria for assisted dying that require the

determination of a patient's suffering. Professor Bert Broeckeaert detailed some of these difficulties, primarily the subjective nature of suffering. He argued that while some doctors will ensure that all treatments have been offered to patients in an attempt to relieve the suffering, other doctors will more likely respect the desire of the patient, through a broader interpretation of the wording of the law:

*The problem is that these words 'unbearable suffering' and 'cannot be alleviated' are used in such a broad way that at this moment if you go to the right physician and you happen to have a medical condition, you will have euthanasia, no problem at all. So in that sense it's very broad and very open.*<sup>644</sup>

Professor Lieve Van den Block, from the End-of-Life Care Research Group at Vrije University in Brussels, spoke about her research which looked at how doctors assess unbearable suffering. She found that doctors more often consider suffering to be unbearable when it is physical in nature, such as pain: 'They less often grant the request when the suffering is more psychological or existential or social.' As Professor Luc Deliens further explained, 'The more subjective the suffering is, the less likely the physician will be to go ahead.'<sup>645</sup>

As we outlined in Box 2 in chapter 6, in the Netherlands, for a patient to be eligible for euthanasia, his or her suffering must be unbearable and there must be no prospect of improvement. Gert van Dijk, an ethicist based in the Erasmus Medical Centre in Rotterdam, explained that the two elements of the suffering criteria in the Netherlands differentiate between the patient's subjective experience of suffering (that it is unbearable) and the judgement of the doctor (that there is no prospect of recovery). Dr van Dijk told the Commission that there is a growing debate in the Netherlands over whether an individual who is suffering from a large number of small medical problems — a state often considered as being 'tired of life' — could be suffering unbearably and therefore be eligible for an assisted death. Noting the subjective nature of suffering, Dr van Dijk told the Commission, 'It's not actually that the concept of unbearable suffering is changing. What is changing is what people consider unbearable suffering.'<sup>646</sup>

### **Assessment of mental capacity**

Mental capacity has repeatedly been cited as a central safeguard in proposed UK assisted suicide legislation. But as Dr Annabel Price argued, assessing capacity not simple and decisions made about a person's capacity 'cannot be seen as definitely clear-cut, objective and reliable'.<sup>647</sup>

Thinking about what framework should be used to assess a patient's mental capacity in the context of making a decision about an assisted death, Martin Green from the English Community Care Association suggested that the Mental Capacity [Act] framework should be used: 'I would use it from the perspective of saying there's a judgement that this person has the capacity.'<sup>648</sup> Dr Martin Curtice, a consultant in old age psychiatry, also argued that in assessing capacity, the starting point would be presumed capacity under the Mental Capacity Act.

However, Dr Andrew McCulloch thought the current system under the Mental Capacity Act would be an inadequate tool to effectively assess capacity in relation to making a decision about assisted dying: 'I think that the testing would need to be very, very robust indeed and as such you'd have to have very well-designed testing instruments and you'd have to couple that with people

with knowledge, giving a variety of views.’<sup>649</sup> He noted how such an assessment would be resource intensive, requiring a multidisciplinary team of clinical psychologists, psychiatrists, social worker and family members. He also believes that a single, simple capacity measure, for example one currently used in the care of older people, would not be appropriate in the context of assisted dying.

Time was identified as a key element in the capacity assessment process by Dr McCulloch:

*You couldn't do it quickly and I think it would be inappropriate to do it quickly, because then you'd have the risks of fluctuating capacity misleading you... I think in all cases [assessment] would have to [take place over a period of time] because you couldn't just assume that what you heard on one day was actually representative of the person as a whole. So that would be a critical safeguard, gathering evidence at different points.*<sup>650</sup>

Christine Kalus, a clinical psychologist in specialist palliative care, spoke about the difficulties associated with assessing mental capacity in end of life situations:

*I think... where people clearly lack capacity, in a sense that's much easier. I think for people that... live in the hinterland, where they maybe have capacity [but] they move in and out of having capacity. I think that's much more difficult. And... it can only presumably be by definition through a process of managing the case notes and looking at case notes and looking for consistencies, or continuities and discontinuities of what people are asking for, how people have talked about their wishes, whether they have an advanced directive that hasn't been revoked.*<sup>651</sup>

Ms Kalus suggested that capacity assessments ‘should involve consensus decision making by a multidisciplinary team (where possible), and a robust assessment taking into account the legal, medical and psychosocial aspects of the patient’s situation’.<sup>652</sup>

Dr Tony Zigmond, a consultant psychiatrist with academic expertise on the Mental Capacity Act, also detailed some of the challenges around assessing mental capacity in his written evidence to the Commission. He notes that the difficulty of assessing capacity varies, depending on a range of factors, such as the complexity of the decision, the certainty of the differing outcomes of differing courses of action and time available. However Dr Zigmond observed that ‘capacity decisions in relation to assisted dying can be made over a period of time and with as much consultation and investigation as is required’.<sup>653</sup>

If mental capacity is required in order to be eligible for assisted death, a key question posed by Professor Matthew Hotopf and Dr Annabel Price from the Institute of Psychiatry at King’s College London, is: ‘How much capacity is required to make a decision to end one’s life?’<sup>654</sup> They note that one view within the profession suggests that because mental capacity is decision specific, decisions that carry a greater risk require a greater level of capacity than trivial ones. This was a view shared by Dr Martin Curtice, who told the Commission that if the Mental Capacity Act were used, a patient would have to have a high threshold in order to make a decision about an assisted death. However Professor Hotopf and Dr Price point out that some consider this view paternalistic: ‘Patients are allowed to make trivial decisions, but are denied more serious ones as the capacity bar is set higher.’<sup>655</sup>

The DPP's prosecuting guidelines on assisted suicide make use of the Mental Capacity Act. One of the public interest factors in favour of prosecution is that 'the victim did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision to commit suicide'.<sup>656</sup> However, because of the retrospective nature of the policy, mental capacity must be assessed in retrospect. In his oral evidence to the Commission, Keir Starmer QC described how this is done:

*[Capacity] is something that has to be investigated. It, classically, is investigated by the police talking to witnesses who knew the deceased, looking at what evidence there is that's available as to the state of his or her mind. Also looking at what medical evidence is available. Each case varies but... there may be evidence from a medical practitioner saying, 'I had the following discussions etc and it seemed to me that X clearly had capacity.' So far it hasn't caused us a great difficulty but capacity always can and no doubt in some case in the future it will be something that we need to look at very carefully.*<sup>657</sup>

However, Professor Penney Lewis told the Commission that she believes there is a strong argument for prospective assessment of mental capacity in this context:

*We generally do prospective assessment in a medical context, so if we were talking about other decisions that result in the patient's death, for instance, a patient refusing life sustaining treatment, there would be a prospective assessment; the doctor would be assessing the patient's capacity at the point in which the decision is being made.*

She noted that there are other situations where capacity assessments are made retrospectively, for example with advanced decisions, where an attempt is made to determine whether the person had capacity at the time of making the decision, but concluded, 'It would be better if we could assess all aspects of the request in advance.'<sup>658</sup>

Dr Annabel Price explained how different proposals put forward in the academic literature regarding the details of how structured a test for mental capacity must be range from the very unstructured at one end of the spectrum — an informal interview — to a proposed guideline, at the other end of the spectrum, based on up to ten formal interviews. Dr Price argued that finding the right balance on this spectrum, where the outcome from an unstructured approach could be subject to influence from the underlying values of the medical practitioner conducting the assessment, while an overly structured approach could place too great a burden on an already seriously ill patient, is difficult.

### Who might assess mental capacity?

Professor Matthew Hotopf and Dr Annabel Price note in their written evidence to the Commission that ‘all registered medical practitioners should be able to assess capacity, but psychiatrists are often asked to provide a second opinion when the decision being made has serious or very significant consequences’.<sup>659</sup>

Dr Andrew McCulloch spoke about which medical practitioners would be able to detect when a person’s mental capacity is being affected by emotions or abnormal thinking. Psychiatrists and clinical psychologists would be best placed to carry out such assessments, and that it is not something that any doctor would necessarily have the right skills and knowledge to carry out:

*There’s a proportion of GPs with a very low level of knowledge around mental health and a very low level of knowledge around issues like mental capacity and decision-making. If they’re going to be centrally involved then the quality of that would have to be raised... we’re not there at the moment.*<sup>660</sup>

There was some disagreement among those giving evidence about which healthcare professionals are best placed to conduct this assessment. Professor Hotopf and Dr Price pointed out that the length of time a clinician has known a patient will affect the judgement of that patient’s mental capacity. Christine Kalus argued that a healthcare professional would be better able to assess a patient’s capacity if he or she knew the patient well. However, a hospice medical director giving evidence to the Commission anonymously said that he did not think it was necessary for a doctor to know a patient well when assessing their competence to make a specific decision about their health care:

*I think it’s the skills of the doctor. Because I only work on the in-patient unit, my average length of stay is 13 days. We are dealing with very difficult conversations and decisions and often it is the first time I have met that patient. So I think it is the skill of the practitioner to be able to get that rapport and work with the patient.*<sup>661</sup>

In their written evidence, Professor Matthew Hotopf and Dr Annabel Price note that a crucial question is whether or not a judgement of mental capacity can be made that is free of values:

*The values and beliefs of the assessing clinician are likely to have a bearing on the assessment process... how much they sympathise with the patient’s situation or circumstances and how ‘understandable’ they find the decision-making process or even the presenting psychopathology in context.*

As referenced earlier in chapter 4, Dr Price also pointed to research that suggests that doctors with ethical objections to assisted suicide require ‘higher thresholds for competence’. Therefore, if these doctors refuse to take part in assisted dying, this could lead to ‘a less stringent standard of competence’ which could have the effect of diluting the safeguards included in legislation.<sup>662</sup>

### Safeguards to assess mental capacity and identify mental illness

A number of witnesses the Commission heard from spoke about the difficulty of developing a safeguarded process for assisted dying for individuals with cognitive impairments, such as dementia. Martin Green, for example, explained why he took this position:

*Not least because we know that people have positions that change over a lifetime, and if you're in a position where you've got dementia and you can't communicate your view, how do you know that the decision you made five years ago is the decision you want today? We've all been down this road... where you think 'oh, I wouldn't want to go on and I wouldn't want to do this' and then suddenly you're in that position, and you think, 'yes, I can just about manage this because the positives are better than the negatives'. So we all change our positions over a lifetime, and that's why I think the end of life debates, discussions and the way in which we frame this, have to be about a constant conversation and it's difficult to have that when people have got cognitive impairments.<sup>663</sup>*

Dr Tony Zigmond believed that individuals with a cognitive impairment who lacked capacity, such as people with significant learning disabilities, should not be eligible for assisted dying and might be blocked from any process through an initial capacity assessment. However, he noted that it is more difficult to identify where the presence of a mental disorder is significantly impairing a person's decision-making, despite that person ostensibly retaining mental capacity. As Dr Martin Curtice pointed out, 'Major depression in itself, if you apply the Mental Capacity Act, does not automatically mean you lack capacity, but it's highly likely to influence your decision-making.'<sup>664</sup>

Dr Andrew McCulloch further exemplified these difficulties with the example of individuals who suffer from anorexia, where

*the person has a very fixed belief system around one issue which is life threatening. Often they either have or appear to have complete capacity in every other area... but lack capacity... around certain issues such as eating.<sup>665</sup>*

Witnesses referred to the case of Kerrie Wooltorton, a young woman who swallowed anti-freeze and then when she arrived at a hospital presented doctors with an advanced decision refusing treatment. Following a decision that she was cognitively capable of refusing treatment, therefore providing treatment against her wishes would amount to 'assault', Ms Wooltorton was not treated, and died of poisoning.<sup>666</sup> Dr Andrew McCulloch noted that it appeared that Ms Wooltorton 'was suffering from something like a combination of depression and abnormal personality traits'. He was very concerned about the case:

*I feel that often in these cases, we're talking about young people who have maybe a mixture of depression and some abnormal personality traits or tendency towards personality disorder, and their beliefs about themselves are very negative, they are very confused, they go on over time, but otherwise in some cases, they don't have a lack of general cognitive capacity.<sup>667</sup>*

Professor Matthew Hotopf, speaking with reference to the same case, told the Commission that he believes the case exemplifies the fact that judgements about capacity and the extent to which a mental disorder might be affecting a person's decision-making are never black and white: 'I think opinion probably would be quite divided [on the presence or lack of a clear-cut psychiatric disorder] if one had the opportunity of assessing her as a group of psychiatrists or other practitioners.'<sup>668</sup>



Dr McCulloch noted how the case shows a fundamental flaw in our thinking about capacity as just an intellectual function: ‘and it is not. It’s a holistic function, a combination of the intellectual, emotional, perceptual and so on and how that reasoning comes together. This young lady appears to be a perfect, unfortunately, example of that.’ He argued that the test of capacity in relation to assisted dying, especially in cases where a person may have a mental disorder, but appear to retain capacity, is potentially dangerous if the capacity test is too intellectually orientated, if it doesn’t take enough account of the person’s personal history and so on.<sup>669</sup> Therefore, an assessment of mental capacity in isolation from assessment of other mental health conditions that might influence or impair judgement might be too basic a tool for judging whether a person is capable of making a genuinely autonomous choice.

Dr McCulloch stated that a key challenge in developing a safeguard based on mental capacity within an assisted dying framework is not so much about people who lack capacity completely, as these cases are relatively easy to identify. Instead, he noted that there exists a

*particular risk with people who have marginal or rapidly fluctuating capacity, as some people with severe mental illness do. And they may be prone to paranoid thinking or they may be prone to self-neglect, so I think that would have to be addressed.*

He argued that a safeguard must be in place to identify those people who ‘actually have a false belief about their worth and their right to carry on existing, which is a possible symptom of depression’.<sup>670</sup>

Dr Tony Zigmond gave details in his written evidence about how the presence of mental disorder can complicate assessments of capacity in a range of ways. It is important first to understand that the law treats people with a mental disorder very differently: a patient suffering from a mental disorder who still retains full decision-making capacity can be forced to have medical treatment against their will. However, Dr Zigmond pointed out that identifying whether an abnormal mental phenomena is affecting a person’s ability to make a decision, despite that person still retaining mental capacity, is a judgement that must be made, and ‘is assessed all the time by psychiatrists and other healthcare professionals’.<sup>671</sup>

The fundamental question for Dr Zigmond in relation to capacity must be the same for a person with a mental illness as for one who isn’t mentally ill: ‘Does this person retain decision-making capacity or not in relation to their request for assisted dying?’<sup>672</sup> Dr Andrew McCulloch was asked whether there might need to be different thresholds for people with a history of mental health problems, but argued that assumptions can’t be made about the individual when they are being assessed and therefore a two-tier system would not be an effective starting point. Instead, ‘You need a robust capacity test for everybody going, if they were going into this process.’<sup>673</sup> Dr McCulloch also spoke about the ways in which impaired decision-making can be identified:

*You would have to look at that [the quality of ideas] I think, I don’t really see what else you could look at. That would also apply to people with a previous history of psychosis who were not currently psychotic obviously at the time.’<sup>674</sup>*

## The use of safeguards to detect psychological disorders

In chapter 6, the need to distinguish between appropriate sadness that is common among individuals suffering from a severe physical illness who may be approaching the end of life, and clinical depression that is affecting a person's decision-making capacity, was discussed. As Christine Kalus stated in her evidence, 'Depression can affect one's capacity to make decisions or to behave... in all sorts of ways'.<sup>675</sup> The Commission heard evidence from a number of experts about the safeguards that might be required in practice to identify individuals who retain capacity, but for whom a major depressive disorder might be impairing their decision-making. Ms Kalus identified the importance of an assessment process, whereby an individual requesting an assisted death should have a conversation with an expert, 'to help them clarify their own thinking'.<sup>676</sup>

Dr Annabel Price spoke about the difficulties associated with distinguishing between a major depressive disorder that requires treatment and low-level depression in patients with a long-standing physical or terminal illness. Noting that it is not always easy in patients with complex physical symptoms to determine which symptoms are the result of depression, and which are due to the illness itself, Dr Price explained that it is 'often the more cognitive and emotional symptoms of depression that can help us to be more confident of a depression diagnosis.' Dr Price explained how a psychiatrist would approach this in practice:

*What one would do is to take a very careful history, to gather as much information as possible from the patient, from the family, and from other medical practitioners involved in the patient's care, perhaps to look at previous history of depression, and whether any treatment has helped in the past. And putting all of that together, it may then be possible to be more confident of the patient perhaps having a diagnosis of depression, and then offering treatment. And sometimes if that treatment is helpful, and often it is, reassessing frequently, and then to look at change of symptoms over time.*<sup>677</sup>

The difficulties of identifying depression in the context of a person's request for assisted dying will be looked at in more detail below, drawing on evidence derived from Oregon.

Whether or not all individuals should be required to undergo a mandatory psychiatric assessment when requesting assisted dying was contested in the evidence heard by the Commission. Dr Andrew McCulloch argued that he would prefer a mandatory psychiatric assessment, in order that individuals with a history of psychiatric illness are not discriminated against and to ensure that no one is

*slipping through the net. So I think... it's very helpful to look at the mental health issue for the whole of the population that might come forward for assisted dying, rather than to say it's for some sort of special sub-group.*<sup>678</sup>

Dr Martin Curtice, too, suggested that, with reference to the data from Oregon where it is clear that there is a significant component of depression in those individuals having an assisted death, that without a mandatory assessment, patients with a depressive disorder are receiving assistance to die before having undergone any treatment for their depression.



However Professor Matthew Hotopf told the Commission that he believes a safeguard requiring all patients to see a psychiatrist as part of a process of assisted dying is flawed for two reasons. First:

*It will either lead to a situation where you will have a very tick-box approach to the whole assessment — and the proposals from Oregon of actually getting people to fill out a questionnaire on depressed mood is just fundamentally flawed, because you are just not going to get authentic evidence, I don't think.*

Second, this safeguard would result in a self-selection issue:

*You have psychiatrists who would be proponents of a change in the law doing the work, the conscientious objectors fall out, and it becomes an assessment of whether you have got dementia or not, or delirium or not, I suppose. It's fairly clunky, and I don't think really a safeguard in the sense that one might really be wanting to get a deeper understanding of the individual's mental capacity.<sup>679</sup>*

Professor Hotopf and Dr Price further expand on their argument that a mandatory psychiatric assessment as a safeguard is not likely to have its desired effect. Dr Price had carried out research with people experienced in conducting psychiatric assessments in Oregon:

*There is often a good deal of resentment by the patient that they have to have the assessment. The assessment is therefore not likely to be set up to provide an environment where the patient is able to explore their decision and the emotional and psychological basis of it, but potentially becomes more adversarial. If a patient does not want to disclose information material to a psychiatric assessment, the assessor may be able to ascertain little more than the 'surface' of the mental state and given that such a patient is unlikely to present with significant cognitive impairment, they are likely to be deemed capable with little to indicate the contrary.<sup>680</sup>*

Professor Hotopf suggested that given the choice between a mechanistic safeguard to determine capacity and detect the potential influence of a mental disorder, such a mandatory psychiatric assessment would not be as favourable as relying on a clinical relationship between a practitioner involved in a patient's day-to-day care and the judgement and skills of the practitioner.

Christine Kalus and Dr Rebecca Coles Gale voiced similar concerns to Professor Hotopf over the effectiveness of a safeguard requiring a formal assessment in end of life situations:

*The assessment of depression within palliative care itself is very difficult, and there are many confounding variables that mitigate against the use of formal assessment tools. One author, having undertaken a review of the literature concluded that the 'best' assessment is to ask the patient if they are depressed. Similarly, those psychological practitioners who work from a holistic and/or existential perspective would also argue that it is difficult to maintain compassion and an empathic position with the patient if we have to use formal assessment protocols with patients at the end of life.<sup>681</sup>*

## Assessment of mental capacity and mental health in jurisdictions that permit assisted dying

The Oregon Death with Dignity Act (ODDA) does not require all patients to undergo a mandatory psychiatric assessment, but specifies that ‘a counselling referral must be made if either the attending or consulting physician suspects that the patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgement’.<sup>682</sup> Oregon’s annual reports on the ODDA detail how many applicants each year were referred for counselling. In a paper for *Living and Dying Well*, Dr David Jeffry and Madeleine Teahan commented on the trends in the number of referrals for counselling: in 1998, five of the 16 physician-assisted deaths (31 per cent) had previously been referred for psychiatric counselling; in 1999, 10 of the 27 deaths (37 per cent) had been referred. However by 2009, none of the 59 deaths had been referred for counselling. In 2010, the most recent year for which data is available, one of the 65 patients who died was referred for formal psychiatric or psychological evaluation.<sup>683</sup> The authors questioned whether this might be evidence of doctor-shopping, and suggested that ‘a physician who is prepared to process an application for PAS might perhaps be less inclined than others to regard such a request as a pointer to possible psychological disorder or depression’.<sup>684</sup>

A 2008 study by Professor Linda Ganzini et al identified evidence that some people who undertook an assisted suicide in Oregon had diagnosable (and potentially treatable) levels of clinical depression.<sup>685</sup> This led the authors to question whether the safeguards employed in the Oregon Death with Dignity Act are sufficiently robust: ‘The current practice of the Death with Dignity Act in Oregon may not adequately protect all mentally ill patients, and increased vigilance and systematic examination for depression among patients who may access legalised aid-in-dying are needed’.<sup>686</sup> This evidence has prompted debate on the ethics and practicalities of the Oregon model of assisted suicide internationally, including in the UK.<sup>687</sup> However, it is important to note that, as another study has observed, ‘most people with major depression retain competence to make medical decisions’.<sup>688</sup> Therefore, the important issue is whether or not those who had major depression had sufficient mental capacity to make the decision to end their lives, or whether their decision-making was impaired.

Some studies have also suggested that for psychiatrists to make a successful assessment of a patient’s competency, they would need to have an existing relationship with that patient. One study found that only 6 per cent of psychiatrists in Oregon thought they could accurately assess in a single meeting whether a patient’s decision to have an assisted suicide was affected by psychiatric factors.<sup>689</sup> This suggests that if people seeking an assisted death had to have a mandatory psychiatric assessment with a psychiatrist who was previously unknown to them, such an assessment might have limited value.

The Commission met a range of experts and practitioners in Oregon and asked them how they go about assessing patients who request an assisted death for depression and about the evidence (cited above) of a sharply declining trend in the percentage of people who are referred for a psychiatric assessment. Professor Linda Ganzini, Professor of Psychiatry and Medicine Senior Scholar at the Center for Ethics in Health Care at Oregon Health & Science University, gave details of the research project she conducted which found that 20–25 per cent of a group of almost 60 people who were in the process of requesting assisted suicide met the criteria for ‘major

depressive disorder'. Of the 18 people out of this group who went on to receive lethal prescriptions, three had major depressive disorder. These three patients who had been diagnosed with major depression all took the medication and died soon after receiving their prescription.<sup>690</sup>

These findings had made Professor Ganzini anxious:

*They were quite determined... to die. So the question is, how did they get missed?... Because they also are this character type: crusty, independent, 'my way or the highway', and it's so loud that people miss the depression... they didn't come across as depressed, the typical depressed patient.*<sup>691</sup>

Professor Ganzini does not think a mandatory psychiatric assessment should be required for all patients seeking an assisted death, but believes that all patients requesting an assisted death should be screened for depression, using a structured tool such as the PHQ-9 questionnaire. The Commission heard evidence that some hospices in Oregon are using such tools to screen new service users for depression routinely. Barbara Farmer, medical director of Legacy Hospice, said that at her hospice, 'we will automatically do a depression screening on any of our patients that come on board'.<sup>692</sup> This screening tool is similar to others used commonly in the UK context, such as the PRIME-MD, a sub-scale of the Primary Health Questionnaire, used to detect psychiatric disorders, based on diagnostic criteria for depression.<sup>693</sup>

The experts the Commission met in Oregon offered a number of theories to explain why the numbers of psychiatric referrals might have reduced over time. Barbara Glidewell, Associate Professor of Internal Medicine and Geriatrics at Oregon Health & Sciences University, challenged the conclusions drawn by some commentators that the declining trend in the numbers of psychiatric referrals made in the context of the ODDA are evidence of the slippery slope in action: 'The physicians are very sensitive to evaluate patients, looking for signs of depression or other factors that should be explored.' She suggested that counter to the assumption that the process fails to detect depression, 'those patients who request access to the ODDA have already been screened for signs of depression or other factors that would prevent them from being qualified'.<sup>694</sup>

Dr Peter Rasmussen, a medical director at Compassion and Choices of Oregon, an organisation that provides consultation and advice services for individuals and professionals in relation to the ODDA, told the Commission how the frequency of psychiatric referral among his patients requesting an assisted death has changed over time: 'When the law first became available, I was very cautious. It was something totally new to me... I wanted to be very, very careful. So I insisted that every patient had a psychiatric evaluation, just for my own comfort.'<sup>695</sup> Since then, as he has gained more experience, Dr Rasmussen has not required patients to undergo a psychiatric evaluation: 'If I feel somebody isn't qualified [for an assisted death] because of a psychiatric illness, I would just stop it at that point.'<sup>696</sup>

Inez de Beaufort, a member of a Dutch Euthanasia Review Committee, said there are cases where severe depression is the primary cause of suffering for the patient, but they are extremely rare. They involve 'patients who have had a long, long, long psychiatric disease that they cannot live with anymore and it is then that their suffering is as bad as physical suffering'. She noted

how these patients are likely to have undergone ‘all the treatments imaginable and they usually have tried all the therapeutic options and all the pills and electroshocks and... still find life too hard’.<sup>697</sup> Dr Gert van Dijk said that in all cases involving a patient with mental health problems, a psychiatrist will assess the patient in order to determine that the request for an assisted death is not a symptom of the disease. In cases of where the person is in the initial stages of dementia, the Dutch regional review committees recommend that one or more experts is consulted, ‘preferably including a geriatrician or a psychiatrist, in addition to the independent physician... The physician must take additional care in reaching his decision and must make clear to the committee how it was reached.’<sup>698</sup>

Patients whose suffering derives from a mental illness are also eligible for euthanasia under Belgian law, but the number of requests from psychiatric patients is low.<sup>699</sup> Furthermore, the specific procedural guidelines of some Catholic institutions do not allow such cases.<sup>700</sup>

Accepted medical practice in Switzerland, as laid out by the SAMS, previously stated that a doctor, examining a patient’s request to die, must be certain that the patient’s condition was ‘indisputably leading to death’.<sup>701</sup> However in 2006, the Federal Supreme Court held that ‘a serious, incurable and longstanding mental disorder could cause an individual to suffer to the extent that he no longer regarded his life worth living’.<sup>702</sup> Since this ruling, assistance for individuals suffering from mental health problems has been lawful. The representatives of the SAMS explained that in such cases, the patient must still be lucid and a psychiatrist must ensure that ‘their wish to die is not a symptom of their illness’.<sup>703</sup> Although a mandatory psychiatric approval is not required for all cases in Switzerland, cases involving a mental illness do require an intensive psychiatric assessment.

Exit DS relaxed a previously held moratorium on providing assistance for individuals suffering from mental health problems in 2004.<sup>704</sup> Bernard Sutter told the Commission how these cases are very rare, with his Exit DS assisting around two such cases per year. These cases go through an extended process of assessment, often taking a year or more and require confirmation from more than one psychiatrist, who must confirm ‘that [the patient is] fully competent and that every treatment has been tried and nothing has helped them’.<sup>705</sup> He noted how the psychiatrist must confirm that the ‘wish to die is not just a side effect of their illness but it comes from prolonged and severe suffering’.<sup>706</sup> Specifically in relation to patients with Alzheimer’s, Mr Sutter said, ‘We can only help a person suffering from Alzheimer’s [when] they are fully competent. That means they have to die at the point where they still have a good quality of life’.<sup>707</sup>

Dignitas also provides assistance for individuals suffering from a mental illness. Silvan Luley told the Commission that Dignitas receive a large number of requests from individuals with mental health problems and that these cases are dealt with in the same way as with requests that stem from a physical illness: ‘Any suffering, mental or physical, which is proven by the [patient’s] medical records is something which we can look into and if we do find a doctor ready to assess the case and possibly write a prescription for the lethal drug, we can accompany that person.’ Mr Luley pointed out that this is always conditional on the patient having mental capacity and the physical ability to take the medication him or herself. Dignitas also requires an additional two-month waiting period to

be included in the process for all individuals suffering from mental health problems. Although the numbers of individuals suffering from mental health problems who have an assisted death are low, Dignitas have in the past provided assistance for patients suffering from bi-polar disorder and schizophrenia.

In their assessment of the effectiveness of mental capacity as a safeguard in foreign jurisdictions that permit assisted dying, Lewis and Black conclude that ‘as a safeguard, the capacity criterion appears to be effective in ensuring that incompetent individuals do not receive assisted dying’. In the Netherlands and Belgium, the relevant reviewing bodies determined that the capacity criterion was met in all recent reported cases. They note:

*In Switzerland, prosecutions have occurred in cases where there have been doubts over the individual’s capacity, although all of these prosecutions have involved mentally disordered individuals and (as in Oregon) there is no evidence of refusals on the grounds of incapacity in individuals suffering from somatic illnesses.*<sup>708</sup>

### **The role of advance decisions or ‘living wills’ in a safeguarded process**

Whether or not an individual should be able to make an advanced decision to request assisted dying was a contentious issue among those who gave evidence to the Commission. A number of written submissions the Commission received were in favour of a system by which an individual could make an advanced decision about an assisted death. Freda Humble, for example, asked the Commission to address ‘the way in which persons suffering with mild dementia can certify their intentions in advance – in a totally effective and legal document’.<sup>709</sup> However Lord Joel Joffe noted that in his proposed legislation, there is no possibility of making an advanced request for an assisted death: ‘In relation to the assisted dying legislation, the only significance of an advance directive might be that it indicates a wish. But the advance directive is otherwise irrelevant.’<sup>710</sup>

Healthcare Professionals for Assisted Dying does not support the possibility of such an advanced request. As Ann McPherson told the Commission:

*I don’t think that we would support that, at the moment... Because a living will is terribly important to indicate to family and health professionals what that patient wants. And most people with a living will actually do have capacity and it would mean that you wouldn’t resuscitate, for example, which is very different from assisted dying.*<sup>711</sup>

Professor Raymond Tallis explained HPAD’s reasoning behind their position:

*Living wills are about refusing treatment, not requisitioning treatment and you can’t requisition in advance that you will have a heart transplant, for example... It becomes a point of capacity; of course capacity has to be present at the time that the assisted dying is enacted. So if I said I wanted assisted dying when I was 50 and then was demented at 80, I am sorry to say, a) I couldn’t requisition it in my living will, and secondly it wouldn’t be valid, because I wouldn’t have capacity.*<sup>712</sup>

### Providing support and advocacy

The Commission heard from a number of individuals about the potential to use advocates in a safeguarded system for assisted dying. Gary Fitzgerald spoke about the effectiveness of independent mental capacity advocates under the Mental Capacity Act: ‘Certainly on those cases that we have been involved in, we have found that the way in which they have operated, the way in which they have engaged, has actually been beneficial.’ He argued that such advocates are not just useful for safeguarding older people, but for any adult ‘in a vulnerable situation that takes away their ability to act independently or make independent choices’.<sup>713</sup>

Mr Fitzgerald also noted how, as well as requiring advocates, a safeguarded system would need to build in effective support for the individual making a decision about an assisted death. He noted how it was important to think about how best to engage the individual in exploring the decision they are taking and that the best placed individual to undertake this exploration is not necessarily the person’s GP, but could be a care worker, who knows the person better and ‘can actually be in a much better position to know about the needs, the circumstances, the feelings, the decisions of the older person’. Mr Fitzgerald argued that this role of who is providing support should not be artificially restricted to a specific healthcare professional.

David Congdon spoke about the potential use of advocates in a safeguarded system for assisted dying for people with learning disabilities in order to ensure that a decision an individual is making is really the decision that the individual wants to make. He thought this advocate must be someone who understands the individual and what their needs and wishes are, ‘so it’s not just someone who is seeing them for the first time that day’. He noted from his experience that ‘if you get to know someone with a learning disability, you can actually help them to take what can be difficult decisions’.<sup>714</sup>

Bridget Robb, representing the College of Social Work, argued that social workers would have an important role to play in supporting people to make difficult decisions at the end of life:

*The sort of role that we would [be] looking for is that in a world where people are being encouraged to make their own decisions, being encouraged to take responsibility for their own care and their own life circumstances; that when things are complicated, whether they are complicated by their personal circumstances or whether they are complicated in the sense that there are just difficult decisions being made, that we would want a process that people can sort of refer themselves to or be referred to that helps them to work through that. And we would think that this decision about end of life, for some people at least, is part of that process. Now we feel that we have a professional role that we can play in that.*<sup>715</sup>

### Safeguards to ensure voluntariness and detect coercion

In chapter 5 the potential impact of assisted dying on certain groups considered at risk of experiencing societal discrimination or other forms of social influence that might result in a people feeling pressurised to end their lives was discussed. The Commission heard evidence from individuals who feared older people or people with learning disabilities might be coerced into making a decision about assisted dying against their will. In chapter 6, evidence



related to the importance of a voluntary and free choice as an eligibility requirement for assisted dying was discussed and the eligibility criteria related to a free and voluntary decision contained in legislation for assisted dying from other countries laid out. Attention will now turn to the potential strategies that could be used to detect and prevent coercion in relation to a person's choice to have an assisted death and the legal safeguards that can be put into place to ensure voluntariness and prevent coercion.

As Simon Gillespie from the MS Society told the Commission, it is important 'to make sure of course that there are protections in place... to make sure that people somehow weren't exploited or essentially pressurised into making this decision'. He described the archetypal MS sufferer, who is statistically more likely to be a woman, perhaps looked after by her partner who is likely to feel a burden on that person:

*That can be a very difficult emotional relationship and in fact that bond between the carer and the person that they're looking after is a very, very tight and close one... where they [can] feel a burden; they don't want to let this person down and they... may feel that they want to allow this person, their carer, to have a bit more of a life back.<sup>716</sup>*

Dr Martin Curtice, during his oral evidence to the Commission, was asked how easy it is, in his experience, to detect coercion that might be influencing someone's decision-making. He said that he believes that it can be difficult. He noted that research suggests that doctors find it difficult to make the required assessment from a one-off meeting with a patient: 'History and context is everything when you discuss this; absolutely everything.' He described a recent case he had been involved in, 'a chap who was being financially abused by his carer, who was his friend, and we just didn't know. We'd met with the carer loads of times; if you want to be devious about it, you can be.' Dr Curtice concluded:

*In general terms if you are aware and try and be alert and aware for it and about it then that helps tremendously. The person can obviously say, 'I don't want you to talk to anybody else'; they can say, 'you have to respect my confidentiality' if you thought they were making a reasonable decision.<sup>717</sup>*

A specialist palliative care nurse interviewed by Demos spoke about the importance of good communication skills in order to detect whether a family member is influencing a patient's decision:

*I think that sometimes families are protecting one another. So, for instance if a patient is wanting to die, but the families aren't wanting them to, they're not talking together. I've found that by good communication skills and unravelling those reasonings, if you can bring that family and patient (or vice versa) together, then it's almost a relief for both parties to be able to talk together. I think a lot of the time people aren't given that opportunity to have somebody to help them to try and talk together, because both parties are frightened.<sup>718</sup>*

Christine Kalus noted how in a case where there are genuine concerns about coercion, for example from a patient's family, 'a specialist psychological assessment would help determine key issues within the individual or family dynamic'.<sup>719</sup>

Bridget Robb, representing the College of Social Work, sketched out a process by which it might be possible to determine whether a choice was both voluntary and informed:

*For me, it's a bank of documents that people are logging somewhere to say, 'over time I have considered this. This is the basis on which I am making my decision. This is the support that I have put in place to ensure that those around me are not put at risk by my asking them to do this, so I have taken due account of the impact on those people who are actually going to provide me with this support.' But if we could do that, it begins to move to a safer place.*

Ms Robb repeated the suggestions from other individuals regarding the benefits of using a multidisciplinary team:

*The idea of having people from different professions coming together to provide some checks and balances and some professional challenge to each other as to how this can work — that is the sort of process that we were envisaging.<sup>720</sup>*

Gary Fitzgerald from Action on Elder Abuse told the Commission that to be effective a safeguard to prevent coercion must involve an active investigation of whether or not there is coercion, not an assumption that there is no coercion. He quoted Lord Justice Munby who in the High Court, in relation to a learning disability case he was looking at under the Mental Capacity Act, said:

*'There has got to be an active investigation to establish that there is not coercion. Not an assumed conclusion that there is no coercion.' There has got to be a demonstrable step that says we have looked into this and we have concluded that there is no coercion. And there has got to be clearly articulated and demonstrable evidence of why people are making the decisions they are making. If we stand back from this having said, 'yes we are going to move forward', we have got to know that people's reasons for making those decisions are sound reasons; they understand them, they are sensible logical reasons, in so far as any of us make sensible, logical reasons, but they are not based on the wishes or the value to somebody else.<sup>721</sup>*

Mr Fitzgerald further noted how the context of Lord Justice Munby's comments about the need to actively intervene stemmed from seeing too many incidences

*where the position of somebody was accepted at face value and very little attempt was made to actually validate where that decision was coming from. His point again, as I understand it, was if the state is going to intervene, one, the state has to be clear that the intervention will be to improve the experience of the person, and second, that whatever action is taken has got to be demonstrably better than the circumstances somebody would have been in. And I think those are quite valid.<sup>722</sup>*

Mr Fitzgerald believes the investment of *time* is crucial in the assessment of undue influence:

*What we very often see are major decisions, and the collaboration by organisations in major decisions, within such a short time span, that it actually isn't reasonable or possible for a full understanding. So, major decisions need time to be considered.*



He suggested that to safeguard the process effectively, any investigation into coercion should not be rushed and those involved should be able to talk to friends and relatives in order to fully understand the individual's life, their environment and their circumstances. In doing so, it will be more likely that a better understanding of why a decision is being made will emerge.

Bridget Robb told the Commission that social workers could have an important role to play in safeguarding against involuntary decisions and coercion as social workers commonly deal with people in extreme circumstances: 'both individuals in their circumstances and their friends and family and carers and neighbours in extreme circumstances who don't see a way forward in caring for this person or in living along side this person any longer'.<sup>723</sup> In such situations, the role of the social worker is to enable people to go on living, but often social workers help people through discussions about death and dying and provide support throughout the process.

Andrew McCulloch from the Mental Health Foundation also spoke about the role of social workers in detecting coercion:

*That's why I mentioned social workers actually, because often they undertake, well in the past, they used to years ago anyway, undertake home visits and assess families and so on and so forth. So yes, one of the markers would have to be to look for coercion and to look for vulnerability to coercion, which I've already mentioned, which again you can look for but it's not 100 per cent certain.*<sup>724</sup>

In oral evidence Professor Penney Lewis said that the close doctor-patient relationship is an integral to how the Dutch system deals with the issue of voluntariness:

*Dutch people tend to have quite lengthy relationships with their GPs. And it's often the GP who is providing end of life care, and I think if you've known someone for 40 years then your ability to assess their capacity and voluntariness is much better than if you've known someone for two clinic appointments in the last year.*

However, this 'really significant' feature of the Dutch system isn't necessarily the case in the UK, where there is more of a team-based approach to general practice, and people frequently change their GP, 'So we should be wary of simply transposing that system to our system when we don't have that kind of relationship'.<sup>725</sup>

In the Netherlands, Dutch case law requires a long-standing relationship between the doctor and patient to ensure the doctor knows the patient sufficiently well to assess 'whether his request is both voluntary and well-considered, and whether his suffering is unbearable and without prospect of improvement'.<sup>726</sup> Professor Lewis noted that in Oregon the relationship between patient and doctor is much less likely to be a long-standing one. A study by Ganzini et al in 2000 found that 27 per cent of doctors responding to their questionnaire (38 of 143) had known the patient for less than a month at the time the patient requested assistance with suicide. The 2010 report on the ODDA found that the median duration of the patient-physician relationship was 18 weeks with a range of 0-1,905 weeks.<sup>727</sup> However, rather than being evidence of 'doctor-shopping' (whereby a person whose eligibility for assisted dying is in question approaches a series of doctors until one finally approves their request), the expert interviews in

Oregon gave the impression that the relatively short length of relationship indicated by these reports is more likely to be a consequence of patients finding that their doctors have a conscientious objection to assisted dying, or are unwilling to participate because of the risk of reputational damage.<sup>728</sup> In the first year in which statistics were published on the ODDA, the Oregon Public Health Division's report found that 'six of the patients who chose physician-assisted suicide had to approach more than one physician before finding one that would start the prescription process'.<sup>729</sup>

### **The use of safeguards to prevent coercion in jurisdictions that permit assisted dying**

Box 2 in the previous chapter gave details of the eligibility criteria from foreign jurisdictions that are required in order to ensure that people requesting an assisted death are making a free and voluntary decision and are free from coercion. In the Netherlands, the law states that the patient's request must be 'voluntary and carefully considered'. Professor Penney Lewis has pointed to national data on the reasons for why requests for euthanasia are turned down in order to provide an indication of how this criterion is applied:

*In 2005, 29 per cent of all concrete requests were carried out. Again in that year, physicians cited a lack of a voluntary request as the reason for not granting the request in 6 per cent of ungranted requests (approximately 4 per cent of all concrete requests).*<sup>730</sup>

Bregje Onwuteaka-Philipsen, Associate Professor at The VU University Medical Center, Amsterdam, believes that doctors have an important role in determining if a patient is coming under undue pressure when requesting an assisted death. She told the Commission that there is currently a debate in The Netherlands over whether a doctor should be required to speak to a patient alone, without the presence of family members, about the patient's desire for an assisted death and the cause of their suffering. Some doctors believe they are able to make a judgement as to whether it is necessary to consult the patient alone, but Ms Onwuteaka-Philipsen argued that she would prefer if all doctors spoke to their patients alone, as a matter of protocol. She noted how the guidelines for physicians from Support and Consultation on Euthanasia in the Netherlands (SCEN) state that a doctor should speak to the patient alone, but that it does not always happen.<sup>731</sup>

Ms Onwuteaka-Philipsen said it is common for a patient's family to disagree with a patient's wish to have an assisted death. Her research has found no evidence of families pushing patients into making a decision. She noted that in some situations, families put pressure on patients to continue with certain treatments, when the patient may not wish to do so, implying that individuals often feel pressurised by family members to stay alive, not to die. Gert van Dijk also told the Commission that he believes that financial or family pressures on individuals do not constitute a problem in the Netherlands.

Dr Christiaan Rhodius told the Commission that he has experienced cases where it was clear that a patient's family was voicing the request on the patient's behalf and that it was easily picked up: 'Often if you have a conversation you'll see that the patient in fact is quiet, and the family is pushing to get the euthanasia. I'd say that it shows very quickly if it isn't the request of the person himself.' He believed that in such cases, through a more

in-depth conversation with the patient, without the presence of the family, it is possible to detect a flawed request that is not what the patient desires and therefore prevent the patient from continuing with the required process.

In Oregon, to ensure voluntariness, an individual's request must be made in writing and two witnesses must attest that the patient is acting voluntarily and not being coerced to sign the request.<sup>732</sup> Data from Oregon show there have been a small number of referrals to the Oregon Board of Medical Examiners based on non-compliance with the requirement of the act that two witnesses attest that the request for assisted suicide is being made voluntarily. In their briefing paper for the Commission, Lewis and Black note that in 2001 a doctor was referred to the Oregon Board of Medical Examiners for providing only one witness signature on a patient's request form, despite other witnesses being in attendance. Between 2002 and 2010, five more referrals to the Board were made, but in these cases it was not reported if other witnesses were present. Lewis and Black conclude: 'It is not known whether non-compliance with the witnessing requirements is indicative of a lack of non-voluntariness'.<sup>733</sup>

The Commissioners asked each of the individuals they met in Oregon whether they were aware of any evidence of direct or indirect pressures on individuals to seek an assisted death. None were aware of any evidence to suggest that this was the case. It was repeatedly said that those who have an assisted death in Oregon seek it out, they demand it and that they want to be in control. Deborah Whiting Jaques, CEO of the Oregon Hospice Association said, 'It's not the infirm, poor people who are using Death with Dignity. No one is having their parents killed because they're a burden'.<sup>734</sup>

Barbara Coombs Lee, President of Compassion and Choices, told the Commission that in her experience individuals seeking an assisted death are often afraid to talk about making use of the law with their families, because they are afraid that their families will be horrified. Dr Katrina Hedberg, from the Oregon Health Authority, also told the Commission that the evidence suggests that pressures on individuals commonly work in the opposite direction: it is often the patient's family who does not want the patient to die. Barbara Coombs Lee further explained her belief that the evidence base from Oregon — which suggests that vulnerable groups have not been pressured into having an assisted death and that assisted dying had not harmed public safety or impacted on end of life care — carries enough weight to have influenced the recent decision over physician-assisted suicide in Montana: the courts recently ruled that physician assisted suicide in Montana does not violate public policy and that doctors are therefore safe from prosecution if they assist patients to die.

In Belgium, the patient's request for an assisted death must be completely voluntary and 'not the result of any external pressure'. In a study that looked at all reported cases of voluntary euthanasia over a five-year period (2002–2007) researchers found that in all the cases reviewed, there was a voluntary request.<sup>735</sup> The experts and practitioners whom the Commission met in Belgium believe that this requirement is being adhered to. Paul Destrooper, moderator at the Life End Information Forum (LEIF), told the Commission:

*It's important to describe that here euthanasia is always a voluntary act. And not once, you have to ask for it several times, and formally in writing... You have to pick yourself, and you also have show to the others, to the other care givers, the doctors and such like that it's your decision, and it's not somebody else.*<sup>736</sup>

Professor Leive van der Block, of the End of Life Care Research Group at Vrije University in Belgium, told the Commission about a forthcoming piece of research looking at the reasons behind patients' requests for euthanasia. One of the reasons given was not wanting to feel a burden on the family. In the cases where this was given as a reason, either the request was more likely to be rejected by the doctor, or the patient was more likely subsequently to withdraw the request. Professor van der Block suggested that this shows that, 'when the physician feels that there is pressure or that the patient asks it because he thinks he is a burden, then he will not grant it that often'.<sup>737</sup>

Penney Lewis and Isra Black suggest that discussions between the patient and more than one physician, as occurs in the Netherlands, Belgium and Oregon, are likely to be more effective in determining voluntariness than a discussion in whereby only one physician must assess the patient, as is the case in Switzerland.<sup>738</sup>

### **Responsibility for making decisions about whether an individual meets the eligibility criteria**

Those who gave evidence to the Commission put forward a range of models to suggest how decisions might be made about the eligibility of individual applicants for assisted dying. These models fell roughly into four categories: legal models, models that would share decision-making between legal and medical agencies, solely medical models, and models that would require input from a mixture of medical professionals and non-governmental organisations.

#### **A legal decision-making model**

The evidence submissions that put forward legal decision-making models mostly described the institution of some kind of legal tribunal, or some variation on the current DPP guidelines. Tony Nicklinson submitted a legal model of his own creation to the Commission, which is designed to be used by adults over the age of 18 who have been resident in the UK for over six months, and is restricted to people with mental capacity but who lack the physical capacity to take their own lives. The assisted dying scheme that Tony Nicklinson put to the Commission stated:

*Applications may [also] be made by people who believe they will need assistance in the future because they suffer from a degenerative condition, such as, for example, Alzheimer's disease or Motor Neurone Disease. In this case, the application must contain relevant medical justification of such a view including testimony from at least two independent qualified doctors.*<sup>739</sup>

Tony Nicklinson suggested that people who wanted an assisted death should make a living will, which 'describes how the Applicant intends to comply with the law and contains other relevant information such as, perhaps, the arrangements regarding resuscitation or the number and type of medical staff in attendance'. The applicant would then be required to engage a lawyer, who would assess whether the applicant had the necessary legal capacity. The assessment process would take the form of a judicial review in an open court, during which the judge would rule on whether the will was valid, and hear evidence on whether the applicant had been subject to any coercion. A period of three months would then need to elapse between the judge ruling that a will was legal and the will becoming valid.<sup>740</sup>

Nick Wikeley, a Judge of the Upper Tribunal (Administrative Appeals Chamber), offered the Commission some advice on how a legal decision-making process situated in a tribunal might work, if this were to be chosen in preference to a medical model. He laid out three possible judicial routes which might be considered appropriate — the High Court Family Division, the Court of Protection or a tribunal model — adding:

*Judge Denzil Lush [has] set out a number of weighty reasons why [assisted dying] was the sort of issue which was only appropriate for determination by a High Court Judge of the Family Division (all of whom are also assigned to the Court of Protection), rather than the Court of Protection more generally. Family Division judges obviously have experience and expertise in ‘life and death’ cases and there is a strong argument that a judge of that status is required for dealing with such important and critical issues, not least in ensuring public confidence. There are, however, issues around access to justice in terms of the ability of individuals acting without professional representation to use High Court procedures.*<sup>741</sup>

Judge Wikeley also described the ways in which tribunals might be able to provide a good forum for decisions about assisted dying:

*Tribunals already deal with vitally important questions about individuals’ lives. For example, judges and members sitting in the Health, Education and Social Care (HESC) Chamber of the First Tier Tribunal (FTT) make decisions about mental illness, individual liberty and public protection, including cases where there is a background of a criminal conviction (restricted patient cases). Judges in the Immigration and Asylum Chamber of the FTT make decisions which, indirectly at least may be life and death decisions.*<sup>742</sup>

He explained that a particular advantage of using a tribunal system for making decisions about eligibility for assisted dying was that tribunals are designed to be accessible to litigants who are representing themselves. However, he also acknowledged several disadvantages: ‘There may, of course, be an issue about whether individuals would be willing to serve in such a capacity’ and ‘there may also be issues about whether courts and tribunals can respond swiftly enough in cases where time is a critical issue’. To illustrate this point, Judge Wikeley cited a report published by the Administrative Justice and Tribunals Council and the Care Quality Commission in March 2011 called *Patients’ Experiences of the First-tier Tribunal (Mental Health)*.<sup>743</sup> This report found that ‘despite the tight statutory timetable for such appeals and other targets, delays remain a substantial factor in many patients’ negative experiences of the tribunal process’.<sup>744</sup>

The solicitor Lucy Scott-Moncrieff, who sits as a mental health tribunal judge, explained to the commission why she felt that tribunal could be an appropriate method:

*You’ve got to have criteria for decision-making, and a legal process requires you to go through those criteria in a sort of orderly way, and make sure that nothing’s missed out, and a tribunal with a legal chair, but not just a legal decision-maker, I think is the best way to ensure due process, and it’s due process that’s going to provide protection and provide safeguards.*<sup>745</sup>

On the question of whether a tribunal model would require an inappropriately lengthy legal process she said:

*I don't actually think that an enormous number of people will want to do this whereas mental health review tribunals are a sort of mass process, with 20,000 hearings a year and I don't think you'd be getting anything like that. And also, of course, people who are terminally ill and very close to death and want to speed up the process, that would be an emergency situation, but for a lot of people, the fact that it took a bit of time would be no bad thing. They would be people who would be expected to have thought about it for quite some time. And one of the things that the expert would be looking for was that this was a sort of well thought out desire and not an impulsive desire following on from a crisis that could be overcome, or whatever. So I don't see that really as an issue.<sup>746</sup>*

Ms Scott Montcrieff recognised that medical advice would be important to the decision-making process in many cases: 'I mean of course, you need medical evidence about the person's condition, if they believe that they have a terminal illness, well, you need to know that that's correct, for instance.' However, she argued that 'if you have somebody who doesn't have a terminal illness but who has some other cogent reason for wanting to end their lives, that's not necessarily a medical issue, it could be a spiritual issue. So you need the right expert, rather than it just being to do with medicine'.<sup>747</sup>

Robert Robinson, a solicitor who gave evidence in conjunction with Lucy Scott Montcrieff, pointed out the psychological advantage of a legal decision making model involving a court or tribunal:

*It provides a mechanism for making a decision which otherwise would fall on the shoulders of an individual professional, or an individual family member, or whatever, and I think there is a benefit in that, and certainly in the mental health field, if I can go back to that, the role of the tribunal, for example, in making decisions about the discharge of people who may present risks to others, that that decision is made by a court-like body, I think makes it easier to make that decision than otherwise.<sup>748</sup>*

Some of the people whom Demos interviewed during their primary research with vulnerable groups also felt that a tribunal would be the most appropriate method of determining who should be eligible for an assisted death. For example, one woman whom Demos spoke to at a hospice in south London responded to the question 'Who do you think should decide whether someone is eligible for an assisted death?' in the following way:

*You'd have to go through — not necessarily a long term of, you know, bureaucracy, of finding out the whys and wheres... A tribunal... Doctors as well, obviously giving their input. But mainly a tribunal. Like, [people who have] nothing to do with the situation... But [also with] the input of the doctor in dealing with patients — the quality of life.*

A terminally ill person whom Demos recruited through an online forum and interviewed by email during their research also proposed a legal model for decision-making, suggesting: '[The] Court of Protection and official solicitor have a role in protecting the interests of certain people, although the processes are often cumbersome and unduly slow. Perhaps looking at this role would be a starting point'.<sup>749</sup>



### A combination of legal and medical models for decision-making

In some cases people who gave evidence to the Commission suggested that a combination of legal and medical models might be the most appropriate approach. Arguments for mixed decision-making models were made by people who felt that a single legal or medical model might fail to offer sufficiently robust safeguards, might be too restrictive to be appropriate to all situations or might not provide the required expertise. One participant in Demos's focus group with older people said: 'It is such a major decision, you need a range of people, such as a doctor, social worker [and a] policeman, to agree.'<sup>750</sup> A disabled person who participated in one of Demos's focus groups suggested that a panel of legal and healthcare professionals would be the most appropriate people to decide who should be eligible for an assisted death, while another disabled person whom Demos consulted suggested that people who were involved with day-to-day care, rather than higher level management should be involved in the decision-making process.<sup>751</sup>

In their written evidence to the Commission, Penney Lewis, Roger Brownsword and Genevra Richardson of King's College London proposed a 'twin track' medical and legal framework for assisted dying that would provide 'prospective legal immunity' for authorised individuals who were willing to assist another person to die. Under this regime, instead of allowing the DPP to make decisions about whether the assister should be prosecuted *ex post*, the decision would be made *ex ante* by an adjudicative tribunal or panel. If questions were to arise after the event there would also be a provision for some *ex post* audit or review. This system would provide clarity for individuals on their legal position in advance, unlike the current situation in which clarity is only available after the act has been taken and the assister is at risk of being prosecuted. It would also allow examination of the vulnerability of the person requesting suicide to take place before rather than after the act. The authors argue that the change from the current legal situation to their *ex ante* model would be 'substantively neutral', since the substance of the legal position would remain unaltered.<sup>752</sup>

Penney Lewis, Roger Brownsword and Genevra Richardson wrote that in their opinion the regulatory regime should involve willing physicians in the assisted dying framework, as this would increase the likelihood of mental disorders being diagnosed earlier rather than later in the process.<sup>753</sup> However, taking into account the possibility that some people might not wish to involve a medical professional in the decision-making process, they suggest the pragmatic solution of a 'two-track system of prospective authorisation'. In the first option, a 'track for physician assistance', a physician would decide whether the patient met the legal eligibility criteria, and would then seek a second opinion from an independent medical professional who was a member of a specially appointed medical board to provide confirmation. The second option, a 'track for non-physician assistance', would allow a person who wished to have their suicide assisted by a friend or family member to apply to a tribunal for prospective legal immunity for their chosen assister. The tribunal would decide first whether the applicant's case met the legal criteria, and second whether the chosen assister was 'a fit and proper person' for this role.<sup>754</sup>

In her oral evidence Professor Penney Lewis told the Commission that 'some form of tribunal would be useful in cases that don't involve physicians', but voiced reservations about the practicalities of a system based around a tribunal model:

*If you think about the burdens of a tribunal, I think you need to be in a situation where even if you design a relatively light touch tribunal, you have to recognise how stressful it is to go before a tribunal like that. We might well say that in certain circumstances we are sufficiently worried about this decision, that that level of intrusion is warranted.*<sup>755</sup>

Professor Lewis also explained that a tribunal model might be more suitable in some cases than others, depending on the medical condition of the person seeking assistance. She said that in cases where the person's death was imminent, a tribunal model might be unnecessary and potentially too slow-moving. However, she observed that in Belgium 'they distinguish between cases where there is a terminal diagnoses and cases where there isn't, and there's more scrutiny for the cases where there isn't'.<sup>756</sup> She also suggested that a tribunal model could be appropriate in 'any cases where there is conflict':

*The code of practice under the Mental Capacity Act identifies... cases where court involvement is desirable. One of the categories is cases where there's conflict between the medical team and the family, or conflict within the family. So that's another model.*<sup>757</sup>

The written evidence submitted by Dignity in Dying proposed a model for assisted dying that would combine both medical and legal elements of decision-making. At its simplest, 'a patient would make their request to two doctors whose role would be to check whether the patient met the eligibility criteria and safeguards set down in legislation'. However, 'If the doctors are in doubt or disagree about whether the patient qualifies for an assisted death, they would refer the patient's case to the Upper Tribunal for a decision.' The document explained:

*We believe this model offers robust safeguards to protect the interests of vulnerable people, without putting the majority of terminally ill people seeking assisted dying (with more clear-cut circumstances) through an overly legal/judicial procedure... Under this model doctors would also benefit from having the ability to refer cases to a legal/judicial forum should they disagree, or have doubts about an individual's eligibility for assisted dying.*<sup>758</sup>

When Sarah Wootton and Davina Hehir from Dignity in Dying gave oral evidence, they told the Commission that a tribunal system could be accommodated reasonably easily within the existing system:

*If there was going to be a tribunal then you would expect it to be part of the tribunal service. There is this infrastructure of tribunals already and there are thousands of doctors and psychiatrists and social workers and lawyers who are tribunal judges already. So I would think it would become part of that if that was the route.*<sup>759</sup>

Dr Field of the Medical Protection Society also made the case for a multidisciplinary medical and legal system for assisted dying:

*In terms of how a law might work from the doctor's perspective, again, that is not for us to comment on, save for two things. The first, for the protection of our members, is that anyone actively involved in the process, whether on a panel*



*to assess suitability for assisted suicide or whether a member of the team in fact delivering it clinically, that this should be a multi-disciplinary team; that there should not be a doctor acting alone. And the second plea is that perhaps there should be the protection, or the system, the team should be answerable perhaps to a judicial body. In our submissions to, our written submissions to the Commission, we suggested that perhaps this might be a function of the Court of Protection. But really that's probably not for us to say. It's a thought to put to you.<sup>760</sup>*

### **A medical decision-making model**

Other people who gave evidence to the Commission argued that a decision-making model authorised solely by doctors would be more appropriate than a medical-legal hybrid model. Anne McPherson from Healthcare Professionals for Assisted Dying (HPAD) told the Commission:

*Our group is against having a tribunal. We felt that it ought to be doctors involved, not a tribunal and that is where we differ from Dignity in Dying. I think Dignity in Dying saw it as an option, we don't see it as an option... Because we feel that doctors who are looking after patients are the ones who will know those patients best and I feel those are the ones who should be making the decision.<sup>761</sup>*

Professor Raymond Tallis pointed out that the medical decision-making model that HPAD had proposed in its written evidence would include a number of legal elements:

*[T]here are already safeguards; you have the attending physician, you have got the consulting physician, the second opinion independent, you have got a witness statement, so you have got the law present as it were, and psychiatric opinion if necessary.<sup>762</sup>*

However, he explained that HPAD was against a tribunal model because 'there becomes a trade off when you put in so many safeguards it actually becomes an obstacle to people availing themselves to assisted dying, even if you could have a tribunal meeting at short notice'. He also argued that a legal decision-making model 'would... make it something totally different, it would make it not part of medical care. Suddenly this is something a bit dodgy so it needs to appear before the law.<sup>763</sup>

Professor Penney Lewis observed that 'a peer-review-based system for medical professionals is much more likely to have the support of those medical professionals who are willing to take part', while recognising that those who would consider being involved in assisted dying were 'not by any means all of the medical profession'. She also suggested that a medical decision-making model would be 'more consistent with similar approaches to other, we might say other controversial, medical decisions in the UK such as abortion'.<sup>764</sup> Professor Lewis described succinctly the medical decision-making model they use in the Netherlands:

*In the Dutch model there is an assessment of capacity, prospectively, of the request, of the suffering, there is the consultation to confirm all of the criteria and all of that happens before the euthanasia or assisted suicide takes place. And indeed in many cases there is no euthanasia or assisted suicide, either because the doctor has decided that the criteria aren't met or because the patient dies before that can happen.<sup>765</sup>*

### **A medical decision-making model in combination with non-governmental or volunteer-based organisations**

Two of the jurisdictions the Commission visited combine a medical decision-making model for assisted dying with input from non-governmental or volunteer-based organisations. In Switzerland and Oregon assisted dying is seen primarily as an extension of the rights of the individual and only secondarily as a service provided as part of the health care system. Because assisted dying is not comprehensively integrated into the health care system in either of these jurisdictions there is a place in both cases for non-governmental, non-medical organisations to take on a supporting role.

In Switzerland suicide assistance is generally carried out by non-medical right to die societies, with 92 per cent of all cases of assisted suicide in Switzerland involving a right to die organisation.<sup>766</sup> However while a doctor's support is not necessary for the act of assisting death, it is needed for the prescription of life ending drugs. Therefore, once a right to die organisation has performed an initial screening of the person to ensure that he or she is a suitable applicant, a doctor must be willing to prescribe the lethal medication.<sup>767</sup> The experts that the Commission visited in Switzerland were united in believing that regulation should not occur within the penal system, but through the conduct of right to die organisations or through doctors' adherence to the SAMS guidelines. However, these guidelines are not legally binding<sup>768</sup> and 'there is no Swiss legislation pertaining to organised assisted suicide that determines, for example, eligibility, the procedure to follow, the monitoring measures, etc'.<sup>769</sup> Therefore, as observed previously, Swiss right to die organisations have a large degree of discretion to decide on the eligibility criteria that will determine the circumstances in which they will agree to assist with a person's suicide.<sup>770</sup>

In Oregon the Death with Dignity Act provides clear eligibility criteria for assisted dying and the assessment process is largely administered through the medical system. However, Oregon's health care system has not developed internal processes for supporting doctors with this role, therefore many of the patients and medical practitioners are supported by the voluntary organisation Compassion and Choices of Oregon, which provides legal and medical consultation to doctors and pharmacists involved in assisted dying. This non-governmental organisation has come to play a key role in helping patients to find willing physicians and assisting patients and physicians to abide carefully by the law.<sup>771</sup>

Several of the young people that Demos interviewed during their focus groups supported the idea of a specially designed, non-medical system similar to that in place in Oregon. One young man told the researchers, 'There could be a workforce, like an industry, sort of thing... It should be separate, but linking with doctors.' Other young people in the same group suggested that doctors, social workers and psychologists should work together to assess a person's mental state and assess their eligibility for an assisted death. One young woman said: 'It shouldn't just be a doctor, it needs to be a specialist thing.' There was a strong sense in this group of young people that assisted dying should be a holistic service provided by people outside the healthcare profession: 'If someone does bring up the issue then somebody should come and visit, and spend time with them, and try and really understand them. Rather than just a doctor'; 'It needs to be a whole service, a specific service, like a social worker.'<sup>772</sup>



## 8 Procedural issues

### **Which type of assisted dying might be legally permitted?**

Many of those who gave oral evidence to the Commission expressed a preference for assisted suicide rather than voluntary euthanasia as the vehicle for assisted dying if some form of assisted dying was to be legalised, usually because assisted suicide requires the individual to self-administer medication and can therefore act as an additional check that the individual is making a voluntary choice to end his or her own life. Representatives from Dignity in Dying wrote in their written evidence that in their proposed scheme, ‘The patient would self-administer the life-ending medication, ensuring they make the decision and are in control of the final act’.<sup>773</sup> Lord Joffe referred to this as ‘the final safeguard’ in his written evidence: ‘The patient is free to change his or her mind but if they wish to end their lives they must self-administer the drugs. This is the best possible evidence of voluntariness’.<sup>774</sup>

As observed in chapter 4, surveys by Professor Clive Seale and other academics have found that among doctors, support for assisted suicide tends to be slightly higher than support for euthanasia.<sup>775</sup> Professor Joe Collier of Healthcare Professionals for Assisted Dying said that HPAD supports assisted suicide as opposed to voluntary euthanasia as it empowers the terminally ill patient rather than the doctor to end the patient’s life:

*The doctor in our scenario doesn’t do anything, the patient ultimately decides. What the doctor will do is write up a prescription and it is for the patient to say yes or no. So we don’t do anything more than help and aid... So in principle the question of choice and the question of reality is theirs in the end, we would just be supporters of the position and provide the wherewithal, and of course the support, as indeed one does in any palliative care.*<sup>776</sup>

Several of the medical practitioners who gave evidence thought voluntary euthanasia could be too difficult for the doctor or could have too great an impact on the delivery of health care. The hospice medical director who gave evidence commented, ‘If it is an injection, who is actually going to give that... I don’t know if I could do it.’ Professor Tim Maughan indicated that if either assisted suicide or voluntary euthanasia was to be legalised, his preference would be for the Oregon system, as ‘it is not active engagement in the ward, which I think could have a tremendously detrimental effect on health care, it’s something where you’re giving the medicines to patients to take it at home’, but he had reservations about the ethics and practicalities of the system in Oregon.

Tony Nicklinson wrote in his statement to the Commission, ‘once the need for help is established and it is the clear and considered decision of the applicant, the amount and type of help given is somewhat academic’, but suggested that euthanasia might be considered to be more controversial than

assisted suicide: ‘I won’t ask for euthanasia even though it makes sense to do so’.<sup>777</sup> While Mr Nicklinson did not recommend that voluntary euthanasia should be made available, he was clear that whatever legislation he envisaged being in place should have the explicit purpose of being used ‘only by those people who need assistance to commit suicide (disabled)’. Therefore he evidently envisages a type of assistance being made available that could overcome barriers of physical impairment to enable the individual to self-administer lethal medication.<sup>778</sup>

Many of the members of the public who submitted evidence to the Commission thought the distinction between assisted suicide and voluntary euthanasia was not important, making comments such as ‘Whatever is best for the patient’<sup>779</sup> and ‘Whatever medical assistance is necessary to provide a quick and painless end to their suffering’.<sup>780</sup> One woman said in written evidence, ‘The physical difficulty might be a factor giving rise to a fixed intention to die: it would be grotesque if such a person was ineligible for that reason... It is hard to see why people would choose AS if VE were offered’, indicating that for a terminally ill person, assisted suicide might present much greater practical difficulties and require more exertion on the patient’s part than voluntary euthanasia.<sup>781</sup>

The terminally ill adults who took part in Demos’s research had no clear preference for legalising assisted suicide or legalising voluntary euthanasia, but some hospice service users were concerned that the legalisation of assisted suicide on its own might be insufficient if a person was not physically able to end their own life. One person said:

*The trouble is when you most need help, when you most need it to happen and you can’t carry on, then you’re not in a position where you can do it yourself. If you’ve got a terminal illness, and it’s progressive, and you most need to end the thing, you’re least capable of doing it yourself.*<sup>782</sup>

At Demos’s focus group with disabled people in Preston, some people were also concerned about equal access to assisted dying for disabled people:

*I think it is a little bit unfair to make a distinction between somebody who is able bodied and somebody who is disabled. If someone is able bodied but very depressed and they want to go and kill themselves they can. Whereas if someone is disabled they are put under all this stress, when all they want to do is what someone who is able bodied could just go out and do. I don’t think it is fair to make that distinction.*<sup>783</sup>

However, as with many of those submitting written evidence to the Commission, the disabled people who took part in Demos’s focus group in Solihull did not seem to be concerned about the distinction between voluntary euthanasia and assisted suicide. One person said: ‘It’s up to the individual to choose for themselves. It depends on their particular needs’.<sup>784</sup>

## Approaches to the act of assisting dying

### Assisted suicide in Oregon

In Oregon the Death with Dignity Act specifies:

*An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner.*<sup>785</sup>

The act does not specify the exact means of taking the medication, though it refers to ‘a qualified patient’s act of ingesting medication’, indicating that the medication should be ingested, as opposed to being injected into the bloodstream. Under this legislation the patient is usually prescribed 90 capsules of 100 mg of the barbiturate secobarbital.<sup>786</sup>

Once a doctor has approved a patient’s request for lethal medication under the Death with Dignity Act, there is no formal guidance on how the medication should be taken, although the statute specifies that the doctor must ‘counsel the patient about the importance of having another person present when the patient takes the medication... and of not taking the medication in a public place’. Barbara Glidewell explained:

*The voluntary ingestion of the medication is to be done in a private home, witnessed and often with a health care provider present. A few nursing homes may allow this on their premises, but generally they do not.*<sup>787</sup>

Data published by the Oregon Public Health Division demonstrate that the individual’s self-administration of the medication and death is in some circumstances supervised by the doctor who provided the lethal prescription, in some circumstances by another health-care provider, and in some cases by no provider. In 2010, the prescribing doctor was present when the medication was ingested in 30 per cent of cases, another provider in half of cases and no provider in 20 per cent of cases. At the time of death, the prescribing physician was present in 9.4 per cent of cases, another provider was present in 30 per cent of cases and no provider in 61 per cent of cases.<sup>788</sup>

The data published by the Oregon Public Health Division indicate that medical involvement in the moment of death is declining: in 2010 prescribing physicians were present at the time of death for six patients (9.4 per cent) compared with an average of 20.3 per cent of cases between 1998 and 2009.<sup>789</sup>

Barbara Glidewell said physicians may be unwilling to attend the ‘terminal event’ in the patient’s home out of ‘fear of being misunderstood or unappreciated by their peers—being singled out as a physician who will participate’.

In cases where a health care professional is unable or unwilling to be present during the death, a trained volunteer from the voluntary organisation Compassion and Choices of Oregon will often assist the patient’s death. A volunteer from Compassion and Choices described how the assisted suicide takes place:

*The client will take an anti-emetic medication first, and wait an hour at first, and then we would separate the capsules, and it takes quite a long time, to get the powder out, and then, when they’re ready, we’ve found that orange juice seems to be the best mixture. It’s very bitter, and they can swallow some juice or something*

*afterwards, but they're asleep within two minutes, and in a coma within five usually, and then the actually passing can take anywhere between ten to fifteen minutes, to several hours, depending on how much they've eaten.*<sup>790</sup>

The volunteer said family members are 'so grateful not to have to hand the medication to their relative, and to have someone who knows the process, who reassures them, that can answer questions for other relatives who choose to be there'.

There is some scope within the law to support assisted suicide for patients who cannot swallow using a feeding tube, but the law is very clear that the lethal medication must be self-administered:

*This particular client had ALS [amyotrophic lateral sclerosis], Lou Gehrig's disease, and he was pretty much paralysed, he had a feeding tube, and what I did was I separated the capsules and mixed it just enough to put in his syringe, that it was fluid enough, so that it would actually flow. And then he placed his hand on it and he pushed... he has to be able to do it, otherwise we can't help. The law is very specific.*<sup>791</sup>

There is always medical back-up:

*We always have medical back-up. There's always someone on call when there's a hastening, so we have somebody to call, and if it's a difficult client for our team, I always assign one of our medical people with another team member. So that we have a doctor or a nurse... especially if it's a tube feeding or a PEG tube of whatever, so that we have that kind of reassurance.*<sup>792</sup>

The experts the Commission consulted in Oregon described advantages and disadvantages to the approach to assisted suicide that is used in Oregon. Barbara Coombs Lee, President of Compassion and Choices, argued that an important advantage of assisted suicide is that the doctor need not take practical responsibility for the patient's decision to end their life:

*When a physician writes a prescription for a life-ending medication and gives it to the patient, they do not actually intend the patient to take it. They hope the patient doesn't take it. They hope the patient derives so much peace of mind from having it, that they die a natural death. So how can you say that the intention of the doctor is to cause death? The intention is to improve the quality of life and provide peace of mind.*<sup>793</sup>

An advantage of the limited role of the doctor in assisted suicide is that once the prescription is issued, the process leading up to the death can be driven by the patient. A volunteer from Compassion and Choices observed,

*The whole process is about the client, whether they involve their family, whether they involve their friends, whether they let the hospice caregivers know or not, is entirely up to the client, we're simply there to support the process for the client.*

However Barbara Glidewell pointed out that an important practical disadvantage of assisted suicide is that 'a neurologically impaired patient, such as an ALS [amyotrophic lateral sclerosis] affected patient, even though he or she wishes to use the law, may not be able to... administer the medication to their self'. However, Linda Ganzini suggested that while



taking the very bitter tasting medication may be unpleasant and difficult, this can also be perceived as an additional safeguard:

*The whole thing is about not making it too easy... The issue is putting drag on it, and making it so that only the most determined people get through... The trade-off is that the alternative would be a lethal injection or a lethal infusion, and that puts a whole new group of people potentially at risk. So this is an option for a subgroup of people, but we can't assure that... everybody's going to get an equal opportunity. There's intrinsic unfairness in it, that's the way, we've set the bar there.*

Barbara Farmer, Director of Legacy Hospice, also commented that it is 'a safeguard as well that that person is actually taking their own medicine versus someone else administering that medicine.'<sup>794</sup>

More frequently problems have arisen if the patient has regurgitated the medication or it has otherwise failed to cause death. In 2010 one person regurgitated the medication and two people re-awakened after taking the prescribed medicine.<sup>795</sup> Both patients later died from their underlying illness.<sup>796</sup> One of the patients reawakened after 24 hours and died five days later. The other patient awakened 3.5 days after ingestion and died of his or her underlying illness three months later. Such an experience could clearly be distressing for both patients and their families. The published data also demonstrate that a long period of time might pass between the ingestion of the medication and the patient's death. In 2010 there was a median time of 35 hours between the patient ingesting the medication and death. The range was from 5 minutes to 53 hours.<sup>797</sup> Without medical supervision, this length of time before death is likely to be very stressful for the individual's family. The volunteer from Compassion and Choices said that hospices can play a valuable role here: 'If it starts to take a while, the medical director here in Portland will call the hospice and say, you know, it's been fifty hours and the family's being a little concerned, can you stop by and reassure them.'

### **Assisted suicide in Switzerland**

In Switzerland, as in Oregon, assisted suicide is legal, but the Swiss Penal Code is very clear that voluntary euthanasia is illegal and is punishable as 'death on request'.<sup>798</sup> Assisted suicide organisations use drugs such as Natrium-Pentobarbital (NaP), which must be prescribed by an authorised doctor.<sup>799</sup> A briefing provided to the Commission by the Swiss Federal Office of Justice lists the five assisted suicide organisations in Switzerland:

- Exit Deutsche Schweiz (Exit DS), an association established in 1982, which has around 52,000 members and only assists people who live in Switzerland
- Exit Association for the right to die with dignity (Exit ADMD), an association from the French-speaking part of Switzerland, established in 1982, which now has more than 15,000 members and only assists Swiss residents
- Dignitas, an association established in 1998 with around 5,700 members, which mainly assists clients from other countries
- Ex International, established in 1996 with around 700 members, almost all of whom are German nationals, although it publishes little information about its activities
- Verein Suizidhilfe, an association established in 2002 of which very little is known.<sup>800</sup>

It is usually the role of the representative from the right to die organisation to oversee the necessary preparations for the assisted suicide. This may include mixing the lethal medication in a glass of water. As the role of Compassion and Choices demonstrated, this assistance when the individual is administering the medication is important; there is evidence that when the Swiss right to die organisation Exit DS was first set up, people who took the lethal medication without assistance did not always die.<sup>801</sup>

When Commission members visited Switzerland, Bernhard Sutter, a board member of Exit Deutsche Schweiz, described the role of Exit DS as ‘members helping members’. He said, ‘The assistance is basically holding your hand and the human part and making sure that you do not make any mistakes in committing suicide.’ Exit DS always works with 15 grams of pentobarbital, but Bernhard Sutter explained that some cases of assisted suicide can be more problematic than others:

*We know what cases we have to watch. One of those cases, I mentioned before, intestinal problems, where for example in the bowels, there are pockets, and where it cannot absorb the medication, so if the person takes it and it goes into one of those pockets, he doesn't fall asleep in 3 minutes and he's not going to be dead in 15 minutes. So we know these diseases and we suggest to take it with an infusion; it's a medication which you have to drink. There are so many people who shake, from their disease, and then if they spill half of it you have to really watch it, and you have to see that they don't spill.*<sup>802</sup>

As in Oregon, to make it clear that the action is assisted suicide and not euthanasia, the volunteer from the right to die organisation cannot physically cause the person to ingest the medication; this action must be taken by the person him or herself. Studies have shown that while in the early days of right to die organisations' activities, those committing suicide were expected to swallow the medication, more recently alternatives methods have been developed to assist people who have difficulty swallowing. In Switzerland it is now considered legally permissible for a volunteer of the right to die organisation (usually a nurse) to put an intravenous drip in place. The volunteer can then put the lethal dose of barbiturates into the fluid within the drip:

*All this is viewed as a preparatory activity. The legally crucial act is the last step of this procedure, opening the tap of the drip or tube. This last step must always be carried out by the individual wanting to die and this must be attested to by a witness.*<sup>803</sup>

### **Voluntary euthanasia and assisted suicide in the Netherlands**

The Dutch law of 2002 made voluntary euthanasia and assisted suicide legal, if performed by a doctor who adheres to the requirements of due care. The requirements of due care are identical for voluntary euthanasia and assisted suicide, the only difference being the nature of the final action. Euthanasia or assisted suicide is normally carried out using the method, substances and dosage recommended in *Standaard Euthanatica* (2007), the guidelines drawn up by the KNMG. In cases of euthanasia, the guidelines recommend intravenous administration of a coma-inducing substance, followed by intravenous administration of a muscle relaxant. Which substances and dosages should be used to terminate life on request

and which should not be stated in the guidelines. Gert van Dijk explained, 'With euthanasia, the doctor administers the drugs by IV [intravenously] and with physician assisted suicide the doctor hands over the medicine and the person drinks it themselves'.<sup>804</sup>

Assisted suicide is still therefore a highly medically driven process. Gert van Dijk said, 'It has to be a physician, we feel, because it is a medical problem. So, the only person who is able to judge the hopelessness of the situation is the doctor. I mean, who else can decide?'<sup>805</sup> Unlike in Oregon, where the doctor who prescribes the lethal medication is not required to be with the patient when they take it, in the Netherlands, the doctor must be physically present with the patient when assisting a suicide and must not leave the patient to take the medication alone.

Despite official guidance from the Royal Dutch Medical Association (KNMG) expressing a preference for assisted suicide over voluntary euthanasia where possible, in practice, voluntary euthanasia is much more common. Of the 3,136 cases reported to the review committees in 2010, 2,910 involved voluntary euthanasia while only 182 cases were assisted suicides, and 44 cases involved a combination of both practices.<sup>806</sup> Eric van Wijlick, senior policy adviser at the KNMG, told the Commission why the majority of cases involve euthanasia, despite these guidelines:

*[It] has... to do that most of the patients are... at the end of the stage of cancer so in a very bad condition and no one wants to take the chance that by a physician assisted suicide — a patient has to drink a very bitter substance — that they will throw up, they will fall asleep... You [the doctor] want to be sure, you want to do it good.*

He noted how the reports of the review committees show that around 20 per cent of assisted suicides involve some complications that requiring the doctor to intervene and give an injection (as indicated by the 44 cases in 2010 which involved both voluntary euthanasia and physician assisted suicide). Bregje Onwuteaka-Philipsen told the Commission that patients are often too weak to swallow the liquid required for an assisted suicide:

*You have to drink a full cup of something that is bitter, and that can be a lot if you're really ill... People can vomit from it. It's less sure that you will actually also die of it in a certain amount of time.*<sup>807</sup>

Agnes van der Heide, a senior researcher at the Department of Public Health at Erasmus Medical Centre, said the KNMG's guidelines promote assisted suicide as the preferred option 'as then the control is really with the patient'. Dr van der Heide has investigated why there is a preference among doctors for euthanasia:

*[It] seems to... do... with the fact that physicians feel responsible, they feel that they should have control over the situation. Once they have decided to do this, they want to do it as best as possible and as controlled as possible, and that is why they often prefer to give an injection instead of assisted suicide.*<sup>808</sup>

Bregje Onwuteaka-Philipsen also spoke about the desire of doctors to maintain control over the situation. She told the Commission that doctors prefer euthanasia since they feel a duty of responsibility to ensure that the

process ‘happens correctly’. The exception to the preference for voluntary euthanasia is in cases where the suffering stems from a mental illness. If a doctor is involved in such cases, it is more likely that the form of assistance is assisted suicide.

### **Voluntary euthanasia and assisted suicide in Belgium**

In Belgium, the Euthanasia Law specifically omits assisted suicide, but in 2003 the Belgian Order of Physicians decided that assisted suicide is equivalent to euthanasia as long as the eligibility and due care criteria of the Euthanasia Law are followed by the attending physician.<sup>809</sup> The Belgian Federal Control and Evaluation Committee agreed to this view the following year and now accepts cases of physician-assisted suicide as falling within the scope of the Euthanasia law.<sup>810</sup> However, the law has not been amended to reflect this acceptance of physician-assisted suicide. A number of the experts the Commission met in Belgium expressed concern about this ambiguous legal status of assisted suicide. Professor Luc Deliens argued that developing a clear position with regard to assisted suicide would constitute an important improvement to the law, enabling ‘doctors to more clearly discuss with their patients which option they wanted and open up a greater choice of method for both doctor and patient’.<sup>811</sup>

Professor Herman Nys also criticised the nature of the practice of euthanasia in Belgium. He told the Commission that there is little uniformity in practice with regard to euthanasia law in Belgium, since one of the provisions in the law is that a doctor may impose, in addition to the legal conditions, their own conditions for carrying out euthanasia, such as the ‘palliative filter’, which is a requirement of some, but not all institutions. Professor Nys believes this can be confusing for patients and their relatives because the variation in the application of the ‘palliative filter’ means that eligibility for and barriers to receiving euthanasia can vary considerably from institution to institution. On the other hand, it gives flexibility and ‘the possibility to implement the law in a pluralistic way’.<sup>812</sup>

The Belgian Law has been criticised for not include a requirement that the doctor use due medical care when carrying out euthanasia. John Griffiths and colleagues have suggested this means there is no statutory ground on which the Federal Control and Evaluation Committee (FCEC) can develop standards on the drugs to be used, or enforce a requirement that the doctor must be physically present during an assisted suicide, which is the case in the Netherlands.<sup>813</sup>

### **The rate of assisted dying in jurisdictions that permit assisted suicide or voluntary euthanasia**

The select committee that examined Lord Joffe's 2004 Assisted Dying for the Terminally Ill Bill estimated in 2005 that if the Oregon legislation was enacted across the UK we could expect around 650 deaths from assisted suicide each year. It estimated that if the Dutch system was replicated in the UK, we might expect approximately 13,000 deaths through voluntary euthanasia and assisted suicide each year.<sup>814</sup> We have calculated a more up-to-date estimate below of how the approaches taken in different countries might extrapolate to the context of England and Wales in the present day. Of course it is not only the method of assisted dying that would affect the proportion of deaths that are likely to take place within an assisted dying framework; the eligibility criteria, safeguards, medical practice and societal attitudes would all be likely to exert a strong influence.

There are no official data in Switzerland on the numbers of assisted suicides that take place each year, as the rate of assisted suicide is not collected centrally. Griffiths et al observe that there are approximately 62,000 deaths in Switzerland each year and academic studies suggest that between 0.3 per cent and 0.4 per cent of these are assisted suicides. This figure increases to 0.5 per cent of all deaths if suicide tourism is included (assisted suicides that involve non-Swiss nationals).<sup>815</sup> We have calculated figures below based on the Oregon model of assisted suicide, for which more accurate data are available.

The annual figures published by Oregon's Public Health Division show that in 2010 65 people died from ingesting lethal medication under the Oregon Death with Dignity Act (ODDA). This corresponds to 20.9 ODDA deaths per 10,000 total deaths.<sup>816</sup> As set out in table 4, this rate of assisted suicide would approximate to 1,031 deaths annually in England and Wales, based on the 493,242 total deaths registered in England and Wales in 2010.<sup>817</sup>

There were 134,235 deaths in the Netherlands in 2009<sup>818</sup> and 2,636 deaths by euthanasia or assisted suicide.<sup>819</sup> This works out at a rate of 1.96 per cent or 196 per 10,000 deaths. Table 4 calculates the estimated rate of deaths by euthanasia or assisted suicide that would take place in England and Wales under a similar assisted dying framework, an estimated 9,686 deaths each year.

A study by Bilsen et al found that in 2007 1.9 per cent of deaths in Flanders were caused by voluntary euthanasia.<sup>820</sup> A more recent survey estimated that 2 per cent of deaths in Belgium were caused by euthanasia or assisted suicide.<sup>821</sup> Therefore the proportion of assisted deaths in Belgium is roughly comparable to the rate of 1.96 per cent of deaths in the Netherlands and would be expected to produce a roughly comparable rate of assisted deaths in England and Wales, as set out in table 4, if the Belgian system was adopted.

Table 4 **Estimated number of annual deaths that would take place by assisted suicide or voluntary euthanasia if legalised in England and Wales, based on death rates in Oregon and the Netherlands**<sup>495</sup>

<b>Rate of assisted suicide in Oregon and estimated equivalent in England and Wales</b>	
Number of deaths under the Oregon Death with Dignity Act (ODDA) in 2010 <sup>822</sup>	65
Rate of ODDA deaths per 10,000 total deaths in Oregon <sup>823</sup>	20.9
Equivalent total number of annual deaths by assisted suicide in England and Wales <sup>824</sup>	1,031
<b>Rate of voluntary euthanasia and assisted suicide in the Netherlands and estimated equivalent in England and Wales</b>	
Number of deaths by euthanasia or assisted suicide in the Netherlands in 2009 <sup>825</sup>	2,636
Rate of termination of life on request or assisted suicide per 10,000 deaths <sup>826</sup>	196
Equivalent total number of annual deaths by voluntary euthanasia or assisted suicide in England and Wales <sup>827</sup>	9,686

### **Training and guidance for health and social care professionals**

The Commission heard from a range of witnesses about the importance of training and guidance in end of life care for health and social care professionals in general, and in assisted dying in particular, if it became part of normal medical practice. The late Dr Anne McPherson, representing Healthcare Professionals for Assisted Dying, told the Commission that all GPs should have training for end of life care and assisted dying, and this will become increasingly important as more ‘people will possibly die at home and will be looked after by primary care, so all GPs and community nurses will need much more discussion and training within that’.<sup>828</sup>

The requirements and potential cost implications of this training were outlined by Suzy Croft, a senior social worker at St John’s Hospice, in her written evidence to the Commission:

*If assisted dying were to be legalised then...the cost implications might be considerable. As well as the medical procedures and regulatory safeguards that would need to be in place there would also need to be the same kind of education and training for professionals and emotional, social, practical and bereavement support for patients and families that is currently offered (particularly by social workers) within current hospice and palliative care provision. This would require a range of personnel from doctors to social workers/bereavement counsellors and so on. We cannot assume it will be a cheap service to provide.*<sup>829</sup>

Bridget Robb spoke about the ways in which she envisaged the College of Social Work provide support for its members should they engage in assisted dying in the future:

*I would anticipate that we would have a part of our college membership for people who are involved in this work who would be providing mutual support for each other, who would be able to give ongoing advice to other people who are coming into this for the first time. So I would see this as becoming a much more explicit part of our professional function of being able to support our members who are involved in this work.<sup>830</sup>*

Few professional bodies have published guidance on professional conduct with regard to assisted dying; the recent publication of new guidance on assisted dying by the Royal College of Nursing in October 2011 is a notable exception. The guidance, ‘When someone asks you for your assistance to die’, details how nurses and health care assistants should respond to requests from patients related to assisted suicide. Reinforcing the fact that assisting suicide is illegal and clearly setting out the legal position of health care workers, the guidance provides practical examples of how to deal with difficult conversations, recognising that nurses and health care assistants are often the members of staff whom patients and their families feel most comfortable talking to about assisted dying.<sup>831</sup>

The guidance notes that it is important not to ignore such requests, and that requests should prompt discussions about what other care options might be available, or to provide help for the patient to prepare an advanced decision to refuse treatment. It attempts to define more clearly what might constitute ‘assistance’ in a case of assisted suicide, an issue that has caused considerable anxiety since the publication of the DPP’s prosecuting guidelines, as demonstrated in chapter 3. If a patient persists in asking for information about assisted suicide ‘it is important to make it clear that you cannot do anything that would shorten their life or provide information about or assist in contacting such organisations’.<sup>832</sup>

Those who gave evidence to the Commission in jurisdictions that permit assisted dying thought it important to provide professional guidance on the practical aspects of implementing assisted dying legislation for all professionals who might take a role in assisted dying, including doctors, nurses, social workers and pharmacists. Different jurisdictions have adopted different approaches to this, and medical professionals are expected to adopt varying levels of responsibility for assisting deaths.

### **The Netherlands**

The Royal Dutch Medical Association (KNMG) has supported euthanasia since the 1980s and its guidelines have been influential in the development of both medical practice and the law.<sup>833</sup> In 1984, the KNMG published a policy statement on euthanasia, stating that euthanasia undertaken by a doctor should be considered acceptable provided that the doctor had met the ‘requirements of careful practice’, broadly similar to the due care criteria now enshrined in law. These dealt extensively with the requirements a physician should take into account before being allowed to perform euthanasia or assisted suicide. The guidelines have been updated regularly and they continue to provide guidance to physicians who are confronted with a request for euthanasia or assisted suicide.

In 2007 the KNMG published *Standaard Euthanatica*, which provided guidelines on the method, substances and dosages that should be used to perform euthanasia. The KNMG’s latest publication,



‘The role of the physician in the voluntary termination of life’, sets out the role, responsibilities, possibilities and limitations of doctors regarding the voluntary termination of life, ten years after the law was passed. The publication notes that over this ten-year period standards and practice have developed considerably, and the guidance seeks to outline the progression of these developments for practitioners.<sup>834</sup>

The Royal Dutch Pharmaceutical Association (KNMP) also issued guidelines well before the codification of the practice by law in 1987 (updated in 1994, 1998 and 2007) on the preparation and use of drugs for euthanasia and assisted suicide outlining: the right of the pharmacist not to dispense lethal drugs, the requirement to consult the doctor before dispensing and the requirement to hand the drugs directly to the doctor.<sup>835</sup>

Eric van Wijlick, a senior policy adviser at the KNMG, told the Commission that his organisation is currently developing guidance for doctors about communicating end of life decisions:

*Doctors should also know that if a patient is in this sort of condition then it might be the wish of the patient not to be sent to hospital, not to do certain procedures... you should discuss about it when you think that's important. So we're making a brochure on that with all those kind of questions; questions about euthanasia and assisted suicide. For some they are important, for some not, but it forces doctors to think... We have a list on it with explanations of words so that doctors and patients use the same language and they understand each other because words like palliative sedation or going to sleep or I will help you — what do they really mean? You should be clear on that.*<sup>836</sup>

Gert van Dijk spoke about the training Dutch medical students receive on euthanasia, noting that it is not a major aspect of their training, because of the rarity in which doctors are likely to perform euthanasia and because it is predominantly GPs who require this training. However Agnes van der Heide noted that over the last five or ten years there has been a growing focus on this area. All medical students are informed about the legal system on end of life decisions, but ‘only when they have graduated as a medical doctor and go into training for general practice or for a clinical speciality [are they] really confronted with the situations’.<sup>837</sup> She said:

*It is useful that they [medical students] know how the system is and what the regulations are and what they could be confronted with in their future as a practicing physician, but I don't think the pre-medical doctor phase is really very important to go into much more detail than that. Because they have first to see the patients and know what it is to talk to terminal patients.*<sup>838</sup>

## Belgium

Unlike in the Netherlands, the legalisation of euthanasia in Belgium did not have strong support from the medical profession and professional associations before the legislation was passed. The Belgian Order of Physicians, the statutory regulator of the medical profession, had previously rejected assisted dying, with the Code of Medical Deontology prohibiting doctors from assisting patients to die.<sup>839</sup> The Order of Physicians considered and consulted on the modification of its code over a period of three years. This now states that ‘a physician should mention all possible options and provide any medical and moral assistance

required'.<sup>840</sup> Therefore the official stance on the issue of assisted dying is one of neutrality. Whereas in the Netherlands, the KNMG has played a central role in developing procedural norms in the practice of euthanasia, the Belgian Order of Physicians 'has shown no willingness to bear any responsibility for either the content or the maintenance of the new norms... [The Belgian Order of Physicians] considered legal regulation undesirable and was of the opinion that it would be better if the euthanasia question were left entirely up to individual doctors'.<sup>841</sup>

Jaqueline Herreman, President of the Right to Die Society in Belgium (ADMD), told the Commission about the effects of the lack of engagement from the Order of Physicians: 'In the past there were really no standards.' This included a lack of official guidance on, for example, the medication that doctors must use in assisted dying. Despite this lack of legal or uniform standards for doctors practising euthanasia in Belgium, Ms Herremans is reassured that good practice and standards are developing, as a result of the work of the Forum for End of Life Information (LEIF) and the ADMD's End of Life Forum. These are two consultation programmes that provide specialist training in end of life care and euthanasia practice in order to provide support for doctors, although neither organisation is associated with the official medical body. Ms Herremans noted that the Belgian government is increasingly interested in the question of euthanasia and she hopes that in the future the government might support the establishment of a committee with palliative care doctors, GPs and right to die societies, and a library of information and resources on euthanasia. This could place the training work that LEIF and EOL provide on a more official footing, enabling the organisations to provide official diplomas to doctors who have completed training in euthanasia.

A number of experts the Commissioners met in Belgium also spoke about the requirements of effective professional training. Professor Luc Deliens argued that an effective system of education on assisted dying should be in place for doctors before a law comes into force: 'There needs to be already a practice starting up, guidelines, protocols... this requires work to be carried out in medical schools.' He explained that while some universities do train medical students in this area, it is not yet a requirement and the most training in this area is 'post-academic'. The representatives of LEIF that the Commission met also spoke about the absence of basic training for doctors in euthanasia. The role of the LEIF organisation in providing specialist training in this area is discussed in more detail below.

## Oregon

Interviewees told the Commission that before the Oregon Death with Dignity Act was passed, end of life care was already reasonably advanced in Oregon. In 1995, for example, the Oregon Health Sciences University developed a comprehensive end of life care curriculum for medical students. Deborah Whiting Jaques, CEO of Oregon Hospice Association, told the Commission that she believed that training in end of life and palliative care is now well developed in undergraduate medical curricula. End of life care is integrated into the American medical school experience for new physicians currently being trained, but there is still 'work to be done to educate practising physicians who have been in the field for some period of time, about hospice and palliative care'.<sup>842</sup>

Following the implementation of the law, the Task Force to Improve the Care of Terminally Ill Oregonians and Oregon Health and Sciences University produced a guidebook to the Oregon Death with Dignity Act for health professionals. Most recently revised in 2008, this is a resource for health professionals and institutions to navigate the implications for practice of the Oregon Death with Dignity Act (ODDA), and to 'present ethical and practical guidelines to enhance compassionate care whether or not a physician or health care system is willing to participate in providing a prescription as set forth in the Oregon Act'.<sup>843</sup> The aims of the Task Force are to:

- share information, experience and understanding of available resources for the care of terminally ill Oregonians and assist in the development and coordination of services where needed; through open and respectful communication to facilitate understanding of diverse viewpoints and cooperate to improve the care of all terminally ill persons and their loved ones
- facilitate the development of professional standards relating to the Oregon Death with Dignity Act that will protect vulnerable persons; set standards for quality care of the dying; and respect the values and privacy of persons in need of care, health care professionals and health care systems
- develop and coordinate educational resources on all aspects of the competent and compassionate care of terminally ill patients for the health care community and the general public
- foster relationships and networking on issues related to compassionate care of the terminally ill.<sup>844</sup>

The guide contains practical information about the act and guidelines for practice, which cover a range of aspects of the law including hospice, palliative care and comfort care; patient rights and responsibilities; mental health consultation; and pharmacists and pharmacy-related issues. But because of the small size of Oregon, it is still very rare for a doctor to assist a patient to die and it appears that the system continues to rely heavily on the experience and knowledge of Compassion and Choices of Oregon. As Deborah Whiting Jaques explained:

*It's hugely significant [for a doctor to partake in an assisted death] and that is one of the reasons that we rely so significantly on Compassion and Choices, because they have the real time experience. They and their volunteers have the opportunity to be there, to be of help when, even if a hospice said 'yes, it's fine, you can be there when the medicine is taken', the level of training and experience is going to be greater with Compassion and Choices.*<sup>845</sup>

The role of Compassion and Choices in providing a resource for physicians, families and patients is discussed in more detail below.

### **Support for professionals and families**

The Commission heard from a range of witnesses about the importance of support for professionals and patients' families should assisted dying be legislated for. Dr Andrew McCulloch, Chief Executive of the Mental Health Foundation, stressed:

*I think that however we do this, it's enormously stressful for families. They will feel guilt, they will feel anxiety. They will have to go through a bereavement process that, in the case of assisted dying, is almost a sort of planned bereavement process, which I suspect in some cases may make matters worse... it would depend on individuals, but I think attention needs to be given to the mental health of the family.<sup>846</sup>*

He argued that policy, but not necessarily legislation, would need to provide ways in which people can find the support they need; both the individual seeking an assisted death and their relatives.

Participants in the research conducted by Demos with vulnerable groups thought it important to recognise the emotional impact on family members who are asked to assist a loved one die. One participant said:

*The problem I have with [assisted suicide] is that if you asked me to help somebody close to me take their life, I could do that, but I don't know how I would react to it, if I would have a nervous mental breakdown the next day.*

An individual taking part in a focus group of disabled people commented: 'We get a lot of people phone us up at the Samaritans years later, who have assisted somebody, played on their mind and it's driven them crazy. Everybody's got a conscience.'<sup>847</sup> As mentioned previously in chapter five, Demos's focus group with adults with learning disabilities started with the screening of a clip from *Emmerdale* where a mother assists her son (Jackson) to die. One of the female participants in this focus group was very concerned about the potential emotional impact that assisting with Jackson's death could have on his mother.<sup>848</sup>

The international jurisdictions visited by the Commission have developed various systems to support patients, families and professionals. Compassion and Choices in Oregon, for example, plays a role in supporting the whole process of assisted suicide, including providing volunteers who can help patients prepare their medications, but also advises doctors on how to report an assisted death in the correct way. The Dutch doctor network from Support and Consultation on Euthanasia in the Netherlands (SCEN) has a more limited role in providing expert consulting doctors and does not support patients or families.

### **The Dutch SCEN network**

In an attempt to boost the availability of suitability qualified doctors to act as consultants in cases of euthanasia, and to improve the quality of the consultation, the KNMG established the Support and Consultation on Euthanasia in Amsterdam (SCEA), programme, with funding from the Dutch Government, to train a group of doctors as specialists consultants for euthanasia cases. SCEA consultants were intended to provide informal advice and formal consultation. The success of the project led to the establishment of a county-wide network: Support and Consultation on Euthanasia in the Netherlands (SCEN). Gert van Dijk explained why KNMG believed the project was necessary:

*What happened is that doctors would call their colleagues or they would call somebody who had already seen [the patient] and this is a difficult job. It was too cosy and we thought it was necessary to have special people who are actually trained*

*to do this, who can judge the suffering of the patient in a more structured way, so they have to be more experienced with it.*<sup>849</sup>

A study from 1992 found that GPs predominantly used a partner in their practice for the second opinion and only consulted a doctor they didn't know for a second opinion in 5 per cent of cases.<sup>850</sup> However, since the establishment of the SCEN network, there are now around 600 doctors across the country trained to be expert independent consulting doctors in cases of euthanasia or assisted suicide. SCEN doctors must have performed euthanasia and most have 10–20 years' experience. A number of doctors are on call at any one time, in order to provide an independent opinion and assessment of a case: 'The SCEN doctor, by definition, is always independent. If he wasn't, he wouldn't come. He would say, "No, no, I know this patient; you have to call somebody else".'<sup>851</sup>

Dr van Dijk said regional review committees are more likely to approve a case when a SCEN doctor gave the second opinion:

*It is actually better to call a SCEN doctor because you get less questions from the review board and the person has experience with it and his independence is secured. If you call somebody else, the board is going to ask well, 'how were you sure that he was independent?'*<sup>852</sup>

The individuals the Commission met in the Netherlands were very supportive of the SCEN project. Gus Fons, a gynaecologist, said, 'The way we organise with the SCEN doctors is very good, because they are experienced to have a second opinion'.<sup>853</sup> Bernadina Wanrooj spoke about the importance of a strong support system for doctors, in order to ensure that the right procedures are being followed: 'It forces doctors... to do it in a proper way, because you have to tell to an independent person or an independent organisation what you did and why you did it'.<sup>854</sup>

Eric van Wijlick described how a doctor becomes part of the SCEN network. Applications are considered by a committee, and applicants must either be a GP or medical specialist with experience in palliative care. Successful applicants then receive three days of training on the role of the SCEN doctor, concentrating on the values and ethics of being a SCEN doctor. After the training, the committee decides whether or not the doctors become SCEN doctors. Successful doctors become part of a regional group (each of the 32 Dutch regions has a SCEN group). A doctor seeking a consultation from a SCEN doctor gets in touch with the relevant regional group and the on-call SCEN doctor is contacted. At this stage, if the SCEN doctor knows the doctor requesting a consultation, he passes on the request to an alternative member of the SCEN network, so 'the independence of the request is guaranteed'.<sup>855</sup>

Dr Christiaan Rhodius, a doctor at St Jacob's Hospice in Amsterdam, explained to the Commission how the SCEN doctor has a practical role in ensuring that the primary doctor has planned to carry out the euthanasia according to due care criteria: 'The second doctor checks if the doctor is secure enough on details'.<sup>856</sup> It is less of a support role, and more of an official role, with the first doctor taking responsibility for supporting the patient and their family. As Dr Rhodius described to the Commission in reference to a recent case:

*We just came from talking with the husband of a woman who was thinking about euthanasia, and we made a plan for Wednesday or for Friday to talk, more, over a longer period. And then I explicitly asked if family members would be willing to take part in that conversation, because I would like them to know what's happening. And also the bereaved will be the ones left behind. So, obviously a person can decide for themselves whether he or she want euthanasia, but still you would like them to be in contact with the people who will be left behind, in order to make it some sort of a collective decision.*<sup>857</sup>

The successful model of the SCEN network has since been expanded to encompass nurses, a project which went live in early 2011. Eric van Wijlick described how the KNMG was aware that nurses were poorly educated in end of life decisions and their consequences, and said a SCEN programme for nurses would improve knowledge and standards. The programme acts as a telephone support system for nurses who may be confronted with an unfamiliar end of life situation. Bregje Onwuteaka-Philipsen further explained how the SCEN nurse programme functions:

*The idea is that if a nurse has a problem or a question they can call another nurse to get advice. Because it's not like really a consultation it's really a telephone call: 'I have this problem, what are the rules what can I do?'*<sup>858</sup>

She noted how there was evidence that nurses had been making decisions and administering medicine they were not qualified to carry out, such as giving morphine, and the education and support provided by the SCEN nurse programme will, to an extent, play a role in protecting nurses: 'They should... not be the one that in the end does give the medication in such a way, because it's such a huge responsibility for a decision you didn't make.'<sup>859</sup>

### **The role of LEIF and EOL in Belgium**

A similar programme to the SCEN network in the Netherlands was established in 2003 in Belgium: the Forum for End of Life Information (LEIF) was set up in the Flanders region of Belgium to provide advice, consultation and support to doctors who receive requests for euthanasia but may have little prior experience. Unlike the Dutch SCEN network, LEIF was not originally funded by the Belgian Government, but is a voluntary organisation. Since its formation, it has received some government funding for the 'LEIFline', a telephone line for the public, which provides information about end of life issues, such as advanced care planning, or difficulties with finding a doctor who is willing to perform euthanasia.

The Commissioners met two representatives of LEIF, Paul Destrooper and Kris van de Gaer, during their visit to Belgium. They explained that since 2003, LEIF has trained more than 300 doctors in end of life issues and many of these doctors have developed expertise in palliative care. Understanding the full range of palliative care options available is an important feature of LEIF doctors because of the nature of the law requiring an exploration with the patient of the alternative options to euthanasia. LEIF also provides training in conducting euthanasia, ethical decision-making, palliative sedation and withdrawal or withholding of treatment.



The representatives told Commissioners how LEIF set up a training programme when euthanasia was legalised that was mainly attended by GPs:

*GPs [often] don't have a team to work with. And sometimes decision-making is harder and they don't have the luxury like a specialist working in a hospital who can ask for the experience of a colleague. Those GPs they've got solo practices that work on the round. And I think that the pressure with which they cope when they are asked by a patient to perform euthanasia when they don't have any experience can be immense. And I think, certainly in those situations a LEIF physician is asked for.*<sup>860</sup>

Kris van de Gaer emphasised that this was the major difference between LEIF and SCEN in Holland: while the SCEN doctors take an increasingly official role in ensuring that safeguards are adhered to correctly, LEIF physicians more often take a supportive role: 'LEIF [doctors] give support to general practitioners or to the others'.<sup>861</sup> They have also begun to provide training in order for doctors to provide expert second opinions on cases.

An equivalent organisation, Médecins EOL (Forum End of Life), has recently been set up in the French-speaking area of Wallonia with help from the Belgian right to die society, ADMD. Jacqueline Herramans told the Commission how EOL has held six sessions of euthanasia training to date, with roughly 50–70 doctors in each course, training a mixture of hospital doctors and GPs.<sup>862</sup>

In 2006, LEIF set up a second pilot programme to give advice and training to nurses and improve communication between multidisciplinary teams involved in euthanasia. Paul Destrooper explained how nurses can often be involved in cases of euthanasia, since patients will make a request to the nurse, who must then inform the doctor of the request, or nurses can even be asked to perform certain actions. Kris van de Gaer said nurses can therefore be placed in difficult situations:

*The nurse is sandwiched between what the doctor wants or doesn't want to do and what the patient wants... it's quite frightening if you see how often that nurses are asked by the doctors to perform euthanasia... or things that might lead to [euthanasia].*<sup>863</sup>

It is therefore crucial that nurses understand the nuances of different end of life decisions, such as the different between withholding medical treatment, euthanasia, or palliative sedation: 'It's very important for that nurse that he or she knows what those decisions are about'.<sup>864</sup>

### **The role of Compassion and Choices of Oregon**

Compassion and Choices of Oregon provides two distinct services around the Oregon Death with Dignity Act (ODDA). The first of these is legal and medical consultation to doctors and pharmacists whose patients ask for help to die. Compassion and Choices explains the mechanics of the law for those who do not have previous experience and their two medical directors, retired professionals with experience of the ODDA, provide medical advice to professionals.

The second role is in providing support to individuals who wish to use the provisions of the law, and their families or carers. The organisation recruits, trains and supervises teams of volunteers — the Client Support Team — to provide direct care and assistance to those undergoing the process



of requesting an assisted death. Volunteers receive a day of training and are then required to attend a meeting every three months for between two and four hours. Each volunteer is then mentored. One of the volunteers the Commission met in Oregon said, 'We're a full service facility, it's not just the act of giving the medication, it's taking care of the client and their family'.<sup>865</sup> Another of the volunteers spoke about the make-up of the Client Support Team:

*The volunteers that I know are not young people. I mean, I'm going to be 75, and we're all of an age, I don't think somebody in their twenties would be ready to do this... And most of us have been with people who have passed, I was with my dad right after he died, and my brother died when he was young, so death has been something that most people, when they're of an age, have experienced, so we have a perspective on it that a young person might not.*

The volunteers spoke about the nature of the help they provide:

*The difficulty that I have found in this last client was that their regular doctors and oncologist were not supportive of their process to appeal to this. So we had to find a prescribing physician, and the person, the client has to see that prescribing physician.*<sup>866</sup>

As explained previously, if an individual's doctor does agree to prescribe them with lethal medication under the provisions of ODDA, the volunteers can also take a role in assisting the individual to take this lethal medication at the point when they wish to end their life. They also frequently play a role in supporting the family in the aftermath of the individual's death and making practical arrangements such as getting in touch with the coroner.

### **The role of right to die organisations in Switzerland**

In Switzerland, where assisted suicide takes place largely outside the medical system, there is little in the way of support available for professionals or doctors, and the right to die societies such as Exit DS and Dignitas tend not to take a role in providing professional support to doctors as Compassion and Choices do in Oregon. The Commission heard evidence that the volunteers or 'carers' provided by Dignitas have a strong role in providing support and assistance to individuals seeking an assisted suicide before the event and to their families and loved ones after the event. Alan Cutkelvin Rees, whose partner Raymond received assistance to die at Dignitas, told the Commission that the staff at Dignitas 'were more than helpful to us; even after Raymond passed away, they were still in contact with me'.<sup>867</sup>

Georg Bosshard told the Commission about his desire to see more effective support systems put in place for doctors in Switzerland, making reference to the importance of the programmes such as SCEN and LEIF in providing a network of doctors with the knowledge and expertise to participate safely in assisted suicide. Dr Bosshard commented that currently 'most GPs know very, very little about assisted suicide'. In the seminars he has given to GPs on the subject, doctors have asked him questions such as 'recently I wrote a prescription for somebody who wanted to die but I did not personally discuss the subject with this patient, was I right in doing so?', suggesting that doctors who participate in helping patients with suicide have very little understanding of their professional responsibilities in this area.<sup>868</sup>

## Conscientious objection for professionals

Most witnesses from whom the Commission heard evidence advocated the requirement, in any legislation on assisted dying, to make allowances for professionals who do not wish to participate. Bridget Robb pointed out how there would certainly be some members of the College of Social Work with an ethical objection to assisted dying and they would want reassurances they could opt out of a system. She believes legislation should give them that entitlement, but does not think this extends to opting out of talking about death and dying, since all healthcare professionals need to be able to do this comfortably.

This view was shared by Pauline Smith, the end of life care and dementia lead for NHS West Midlands, who argued that whether practitioners choose to opt out or not,

*Every practitioner should listen to, 'I would like to talk about this [dying]'.... They say, 'Well actually... I don't feel able to listen further, but I will refer you to somebody else who will.' I think you need to do that.<sup>869</sup>*

She considered it important that all professionals have this dialogue, independent of their underlying beliefs about assisted dying.

Healthcare Professionals for Assisted Dying stated in written evidence:

*Arrangements will need to be made to allow those with strongly held convictions to opt out (with conscientious objection not limited to doctors but also available for all those working in health care settings)... The conditions and arrangements for opting out will need to be set out clearly in the legislation to ensure that any patient requesting assisted dying, and whose doctor conscientiously objects, is not disadvantaged.<sup>870</sup>*

In oral evidence, Dr Ann McPherson made it clear that she fully supports the right of the patient to seek a second opinion, as with the Abortion Act. Professor Joe Collier suggested there could be a list through which a patient could find a doctor willing to participate if their own doctor objects in principle.

Dr Field from the Medical Protection Society told the Commission that representatives of the Society feel there should be provisions for conscientious objections within a law on assisted dying, and spoke about the nuances of conscientious objections:

*The extent to which conscientious objection should be provided for is actually an ethical matter. Is it an absolute one? Or is it one as provided by the GMC at present for terminations of pregnancies, for example, that there is a duty on the doctor to draw the patient's attention to where they can get those services or that advice, if they can't provide it themselves?<sup>871</sup>*

They believe that these are questions to be resolved by the General Medical Council (GMC), rather than the law, and that law should limit itself to the provision of the basic clause.

Paul Philip, Deputy Chief Executive of the GMC, thought the GMC's guidance on the abortion legislation 'seems to work quite well. And that is that you have an obligation to point them in the direction of someone who can help them with the issue, if you conscientiously object to providing the

treatment yourself'.<sup>872</sup> When pushed on whether a conscientious objector should be required to provide information about alternative sources of advice, he said there would be some doctors who are 'so against [assisted dying] that they would see a conscientious objection as being absolute and would see it as not making any provision to refer to anybody else'.<sup>873</sup>

Lord Joffe's Assisted Dying for the Terminally Ill Bill (2004) contained a clause exempting a person with a conscientious objection from taking any of the action the Bill sought to authorise. This included 'employment immunity to persons with conscientious objections from being obliged to participate in any way in the process of assisted suicide or euthanasia provided for in the Bill'. It also contained the requirement of the 'attending and consulting physicians with conscientious objections to "take appropriate steps to ensure that the patient is referred without delay" to attending or consulting physicians who do not have such objections'.<sup>874</sup>

In his evidence to the Select Committee that examined the Bill, Lord Joffe spoke about the difficulty of this clause, to which the Joint Committee on Human Rights had previously drawn attention, when it suggested that 'an obligation to refer a requesting patient to a colleague could nonetheless be regarded as an infringement of conscience'.<sup>875</sup> Lord Joffe accepted that an alternative 'conscience clause' would need to replace that contained in his original bill, placing responsibility on the patient for finding a doctor without conscientious objection.

The Commission did not find that doctors are under any obligation to participate in assisting patients to die in any of the jurisdictions they visited. In Switzerland, doctors are able to object to providing a medical opinion for a patient as part of normal medical practice. If the applicant is objectively legally eligible for assistance, but his or her own doctor does not wish to participate, the right to die organisation they are registered with can refer the applicant to a doctor who will assess the patient and prescribe the lethal dose if this is considered appropriate.<sup>876</sup>

In the three other jurisdictions conscientious objection is a fundamental part of the legislation for assisted dying. Eric van Wijlick, a senior policy adviser at the KNMG, told the Commission, 'There is no obligation for doctors [to perform euthanasia]... no one is forced to do it'.<sup>877</sup> This is explained in more detail in the latest KNMG guidelines, which outline what doctors are and are not obliged to do:

*Patients have the right to request euthanasia, but physicians are not obligated to grant their request: fundamental objections to euthanasia and assisted suicide must be respected... However, professional standards do dictate that physicians give their patients clear and timely information about their personal views. It is therefore important that physicians first clarify for themselves if they would in principle be willing to perform euthanasia or assisted suicide. The KNMG holds the opinion that if a physician is not prepared to consider a euthanasia request from his patient then he also should not initiate the procedure. In that case, it is his duty to put his patient in touch with a colleague who does not have fundamental objections to euthanasia and assisted suicide. Though there is no legal obligation to refer patients, there is a moral and professional duty to provide patients with timely assistance in finding a physician (for example, within the clinic) who does not have fundamental objections to euthanasia and assisted suicide.*<sup>878</sup>

Gert Van Dijk also emphasised that performing euthanasia is not an obligation of the doctor, nor is it the right of the patient to have euthanasia. Instead, 'the doctor is *allowed* to perform euthanasia but he doesn't have to do it. If the doctor says, well I don't want to do it, then that's OK'.<sup>879</sup> He spoke about the difficult situations that conscientious objection can cause for the patient when they are terminally ill:

*There is no doctor who will accept you if you are terminal and so we always say the doctor has to be very clear about that. If he doesn't want to perform euthanasia, then he has to tell the patient right at the start of the disease and then the patient can still look for another doctor.*<sup>880</sup>

The ODDA supports conscientious practice and respect by stating,

*No health care provider shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the provision to a qualified patient of medication to end his/her life in a humane and dignified manner.*<sup>881</sup>

Barbara Farmer, Director of the Legacy Hospice in Oregon, told the Commission that her staff are free to opt out of assisting a patient in making arrangements for an assisted death if they object to the practice in principle.

As well as doctors and other healthcare professionals, in Oregon pharmacists may conscientiously object to assisting a suicide. Gary Schnabel said: 'Ultimately we ended up with a system where there was a required connection between the prescriber and the pharmacy to determine that there was actually a pharmacist in that location that would participate'.<sup>882</sup> Other experts the Commission met in Oregon spoke about the difficulties some patients experience if their doctor objects to providing assistance, especially in rural areas where there are only a small number of doctors. Judge Jones said if the only doctor in a rural area objects in principle to assisted dying, it can be difficult for an individual to know where to find a doctor who would be willing to provide assistance. Professor Linda Ganzini also spoke about these difficulties:

*Well, because if you're in a little town, there's only one or two physicians, they don't want to be known as the suicide doc. The confidentiality issues are very difficult in a small doctor's office in those areas, finding a pharmacy willing to participate. So I think they don't want to take any risk around it.*<sup>883</sup>

The Belgian Law makes provision for conscientious objections to safeguard the role of the doctor, stating that no doctor may be compelled to perform, or assist in performing, euthanasia. If the attending physician refuses to participate he or she must tell the patient and give details. If the refusal is based on medical reasons, this should be noted in the patient's medical record. The doctor is then obliged to pass on the medical records to another physician as chosen by the patient or carer.

Kris van de Gaer, a representative of LEIF, spoke about his experience of situations where this happens: 'In those situations, it can be hard to find a solution because clearly what the doctor wants and what the patient wants are two different things. But luckily, that's really a small minority'.<sup>884</sup> He noted that it is more common that the GP is unwilling to assist the patient because they lack experience, but that a doctor is unlikely to admit that to the patient:

*So sometimes patients call us, or the family of patients call us, and then when we can call the GP, and we can propose that something like LEIF physicians you can give support with an experienced person. And then most of the time we see that that's a workable solution.*<sup>885</sup>

## **Regulation and oversight**

### **Transportation and storage of lethal medication**

In Oregon, unlike in the Netherlands and Belgium, doctors may not administer the lethal medication themselves, and because of the ethical and social qualms about assisted suicide their role is frequently limited to writing a prescription. The legislation currently leaves it to the patient or a representative to pick up the prescription and there is no timeframe within which this medication must be taken, or provisions for it to be returned, if unused, to the pharmacy. Consequently, commentators in the UK and in Oregon have expressed concerns about inadequate arrangements for the safe storage and transportation of lethal medication for the purpose of assisted dying. Professor Tim Maughan told the Commission he had 'considerable concerns about... what happens to those medicines once they are at home, when the patients do take their medicines'.<sup>886</sup> Professor Linda Ganzini also voiced concern over the fact that patients take the medication to their home and may not necessarily take it immediately, or even at all: 'One of the things that makes me anxious is people getting these lethal prescriptions that are sitting around their house, for weeks to months... that's a big lethal dose of medication to have sitting around somebody's house'.<sup>887</sup>

Gary Schnabel from the Oregon Board of Pharmacy also identified this element of the ODDA as problematic: 'Once that drug is dispensed... it belongs to the patient, and there are no requirements'.<sup>888</sup> Katrina Hedberg said there is nothing within the ODDA that deals with whether or not the patient takes the medication and what happens if they do not take it. The pharmacy has the power to take the medication back from the patient if they feel it is in the public interest, and patients are advised to keep the medication in a locked cupboard or to return the prescription to the pharmacy for destruction if it is not taken. However, as these are guidelines rather than legal requirements, regulation remains problematic. In Switzerland, between the point when the pharmacy dispenses of the medication and the suicide, the lethal medication is usually held by the right to die society. Georg Bosshard has argued that this is a safer process than the patient keeping the medication at home, as occurs in Oregon.<sup>889</sup>

### **Reporting and monitoring**

The reporting procedures and requirements of the assisted dying regimes visited by the Commission vary from jurisdiction to jurisdiction. We will briefly summarise the approaches taken in each jurisdiction to reporting assisted deaths and monitoring adherence to the law.

#### **How is the death reported?**

In Oregon, within seven days of writing a lethal prescription, the primary doctor must submit a range of information to the Oregon Department of Human Services (ODHS) in order to demonstrate compliance with the ODDA, including a copy of the patient's written request for medication to end their life, an attending physician's compliance form and a psychiatric

or psychological consultant's compliance form, if an evaluation was performed.<sup>890</sup> Pharmacists are also required to provide information to the ODHS within ten days of dispensing a lethal prescription, including the names of the patient and the prescribing doctor, the name and contact details of the dispenser, and the dates the prescription was written and dispensed.<sup>891</sup>

The patient's death certificate does not directly indicate that the cause of death was from lethal medication, but lists the underlying disease as the cause of death.<sup>892</sup> However a separate, discrete box is marked on the death certificate, which shows the authorities that the death was the result of an assisted suicide. Barbara Glidewell explained to the Commission that this occurs in order to protect the patient's privacy. The ODHS then confirms the deaths and provides demographic data by linking these physicians' reports to the death certificates of the patients.<sup>893</sup>

In Switzerland, when a right to die organisation assists a suicide, the police and coroner are notified and an inquiry is conducted, as in all cases of unnatural death. If the inquiry finds that no crime has been committed — primarily identifying whether or not there was a selfish motive — the case is closed and the death is officially recorded as suicide.<sup>894</sup> Prosecutions can also be brought if doubts are raised about 'the patient's competence to make an autonomous choice'.<sup>895</sup>

Following an assisted death in the Netherlands — either by voluntary euthanasia or assisted suicide — the doctor who provided the assistance must report the death to the medical examiner (coroner), using a form prescribed by the law to inform the examiner that the death was the result of non-natural causes.<sup>896</sup> In this report, the doctor provides a full account of the entire decision-making process which must demonstrate compliance with the due care criteria of the law. The medical examiner submits the reported case, along with the results of the post-mortem, to the relevant regional review committee, whose role is to assess whether or not, based on the doctor's report, the doctor has acted in accordance to the law and the due care criteria.

In Belgium, the law requires a doctor who has performed euthanasia to fill in a detailed registration form to submit to the Federal Control and Evaluation Commission (CFCE). This form is split into two parts: the first is confidential and contains the patient's personal information and the name of the doctor who performed the euthanasia; the second is assessed by the Committee and includes details of the patient's medical condition, including the nature of suffering, the request, the procedure undertaken and the drug used. As in Oregon, the death certificate does not contain reference to euthanasia, but instead the death is recorded as resulting from the underlying medical condition.

### **The role of monitoring organisations**

In Oregon, the reported cases are linked to their associated death certificates by the ODHS, allowing the patient's death to be confirmed, and data to be provided on the demographic characteristics of the patient, such as their age and level of education.<sup>897</sup> Using the department's authority to conduct special studies of morbidity and mortality, ODHS also collects information from the physician after the patient dies: whether the patient took the medication and, if so, additional information including whether they were enrolled in a hospice; the motivating factors for their assisted suicide request; the times to unconsciousness and



death after ingestion; and whether there were any adverse reactions.<sup>898</sup> As physicians are not required to be present at the actual death, ODHS collects information from health care providers and volunteers who were present, when this is possible.<sup>899</sup>

The recorded data is reviewed annually and a statistical report is published each year. In their briefing paper for the Commission, Lewis and Black observe:

*The data provided in the Annual Reports in Oregon appears significantly to have declined in quality between 1998 and 2010. While the Oregon Department of Human Resources had stated in its first report that subsequent reports were likely not to contain the level of detail provided in the first study, the reports from 2007 onwards provide considerably less detail than those in previous years.*<sup>900</sup>

The ODHS is required to report physician non-compliance with the ODDA to the Oregon Board of Medical Examiners. Between 1998 and 2010, 22 doctors were referred to the Board for non-compliance. This non-compliance is almost exclusively of a clerical nature, with common mistakes including incomplete or late reporting forms, or incomplete witness forms, such as missing signatures.<sup>901</sup>

Katrina Hedberg explained to the Commission that while the ODHS reports issues of non-compliance to the Board of Medical Examiners for relatively minor mistakes in the reporting procedure, the Board maintains a separate standard, based on whether or not the physician acted in 'good faith'. She said the Board often makes contact with the doctor and asks questions about the way in which they provided assistance, and the Board has not found that any of the 22 reported doctors were not acting in 'good faith'.<sup>902</sup>

In their briefing paper for the Commission, Lewis and Black note:

*It is not known whether non-compliance had any consequences for the physicians who were referred, although in 2007 and 2009, the Board of Medical Examiners found no violations of 'good faith compliance' with the DWDA [Death with Dignity Act], and thus 'did not sanction any [of the 12] physician[s] for 'unprofessional conduct'.*<sup>903</sup>

A number of potential problems have been identified with the reporting system in Oregon. The procedure has been criticised for its inability to determine the number of requests for assisted suicide that are turned down, since only data from prescribing doctors are collected.<sup>904</sup> Experts have also noted that the reporting procedures lack any mechanism to detect under-reporting of assisted suicides, since the data is only based on reported cases.<sup>905</sup>

However Katrina Hedberg told the Commission that the data in the reporting system are likely to be complete for a couple of reasons: first, the system is designed in such a way that there is a strong incentive for doctors to report, because if they follow the steps outlined in the law and file the necessary forms, they are protected under the law; second, there is a 'dual reporting system' because both the prescribing doctor and the dispensing pharmacist are required to report to the ODHS:



*Physicians have a strong incentive for reporting that they have written a prescription... because the pharmacist reports to us once the prescription is filled [too]. Sometimes we do get a report that a pharmacy filled a prescription and we have to contact the doctor and request the initial form. So... there [are] checks and balances there.*<sup>906</sup>

In Switzerland, there is no national body to which assisted suicides must be reported and thus no national reporting data are available. Only the right to die societies, which collect and maintain their own records, have an overview of the cases of assisted suicide.<sup>907</sup> Research has shown that the right to die organisations keep records of every suicide they assist; in the majority of cases these records, alongside the coroner's report and witness statements gathered by the police, succeed in 'communicating the suffering which led to the wish to die'.<sup>908</sup> According to the Swiss Federal Office of Justice, Exit DS and Dignitas are the only two of the five assisted suicide organisations in Switzerland that publish statistics on the assisted suicides they perform.<sup>909</sup> However, Lewis and Black argue in their briefing paper for the Commission that because each suicide must be reported to the police in order to determine if the suicide was in compliance with the law, there exists a level of oversight of all cases of assisted suicide:

*There is no evidence that right to die organisations fail to report deaths to police. Indeed, it has been noted that suicides reported by the right to die organisations match 'the results of an international study on medical end-of-life decisions based on anonymous reports by a large number of physicians attending dying patients'.*<sup>910</sup>

The lack of independent or judicial oversight of assisted suicide has been a subject of concern outside Switzerland<sup>911</sup> and Georg Bosshard expressed frustration during his interview that no centralised statistics are collected on assisted suicides. However, the Swiss Federal Council has recently rejected additional specific criminal law provisions relating to organised assisted suicide.<sup>912</sup>

In the Netherlands, there are five regional review committees (RRCs) to which all assisted deaths must be reported. The place of death determines to which committee the death must be reported. Each RRC has three members: a lawyer, who is also the chair, a physician and an ethicist. Each committee has a secretary, who is also a lawyer, who provides an advisory role at committee meetings.<sup>913</sup> The role of the RRCs is to assess whether the notifying doctor acted in accordance with the statutory due care criteria. If a RRC has any questions following a notification, the doctor in question will be contacted. If the information provided by the doctor is still insufficient, the doctor may then have to provide further information in person, with the opportunity to explain the details of the case in more detail.<sup>914</sup> If the RRCs find that the doctor met the due care criteria, he will not be prosecuted.

The Commission met Gert van Dijk, who sits on one of the RRCs as an ethicist. He explained how the committees commit an opinion on each case: when it's 'careful', which is usually the case, then the case is called 'careful', the physician is notified and the public prosecutor is not notified.<sup>915</sup> Inez de Beaufort, a member of one of the regional review committees, told the Commission how with particularly difficult cases the committees share the case and their draft decision with the four other committees for comments,

before making a final decision. If the RRC detects any inconsistencies with the documentation, indicating that the doctor might not have met the due care criteria, it can invite the doctor in for further questioning. If a problem with compliance is identified, the case is referred to the Board of Procurators General of the Public Prosecution Service and the regional health care inspector. It is then the role of the Public Prosecution Service to determine whether an offence has been committed and to decide to prosecute or not.<sup>916</sup>

Professor Lewis and Isra Black noted in their expert briefing paper that 47 cases were referred by the RRCs to the authorities between 1999 and 2009 — representing 0.2 per cent of reported cases — but no prosecutions have been brought following these referrals.<sup>917</sup> Gert van Dijk said:

*It has never happened that they actually made a case out of it. So, it has been reported to them but usually it's a case that [the doctor] has been careless. There has never been a criminal case against them.*<sup>918</sup>

The RRCs publish their findings in an annual report, containing the number of notifications, the nature of the notified cases and the findings and considerations on which these are based. Specific details of difficult cases are also included.

Bregje Onwuteaka-Philipsen, Associate Professor at the VU University Medical Center, Amsterdam, believes RRCs are effective in reviewing each case:

*They really look at the cases thoroughly I think... But they do have options to ask extra questions and ask for a physician to come to the committee also if they think the criteria were met but we still have some questions, or maybe this was not done perfectly.*<sup>919</sup>

The possible variation between the five committees in their approach to reviewing the cases was identified by Professor Onwuteaka-Philipsen as a potential flaw, and something she and other researchers are hoping to look at in more detail. Professor Inez de Beaufort, also a member of a RRC, argued that the system of retrospective monitoring from the RRCs does provide effective scrutiny and that there is no longer a debate about whether a prospective scrutiny of cases would be more effective: 'We trust the physicians and we have no reason given in the practice as it has developed now to mistrust them or to say things are going wrong'.<sup>920</sup>

The Dutch regulation of euthanasia was heavily criticised before legalisation, not least because of the low rates of reporting by doctors.<sup>921</sup> In 1995, statistics showed that only 41 per cent of cases were reported,<sup>922</sup> but evidence shows that since 1995 and following establishment of the system of control, the rate of reporting has increased. In 2005, the latest year for which data is available, the reporting rate was 80 per cent.<sup>923</sup> Researchers have suggested that the main reason for the failure to report a case is because doctors think their action was not life-terminating, while researchers labelled the act as euthanasia. The unreported cases normally involve the use of non-typical drugs to cause death, such as morphine. Reporting rates of cases involving typical euthanasia drugs, such as barbiturates or muscle relaxants, are 99 per cent. Lewis and Black suggest that 'this inconsistent labelling is now likely to account for most unreported cases',<sup>924</sup> and believe this conclusion is supported by data on doctors' willingness to report euthanasia. Onwuteaka-Philipsen et al agree:

‘Of physicians who stated that they had performed euthanasia since the 2002 act, 97 per cent stated that they had always reported it’.<sup>925</sup>

The self-reporting requirements of the law were identified by Agnes van der Heide as a weakness in the system:

*The main characteristic that makes it a vulnerable system is that it relies on physicians to self-report. I mean, they have to write a report for the review committee and then the committee bases its judgement on the report of the physician.*<sup>926</sup>

She said the safeguards contained in the law, requiring the report of a consultant doctor and that the case must be reported to the coroner, help ensure that the account of the process is objective and increase the likelihood of reporting.

In Belgium, cases of euthanasia are reported to the CFCE, a permanent monitoring committee that oversees the practice of euthanasia. It is composed of 16 members: eight medical doctors, four professors of law or practising lawyers and four members ‘from groups charged with the problem of incurably ill patients’.<sup>927</sup> The purpose of the CFCE is to review the submitted cases in order to determine whether the doctor has complied with the due care criteria set out in the law. If the CFCE is in any doubt, it is able to request further information from the doctor who submitted the report.<sup>928</sup> The Commission on Assisted Dying met representatives of the CFCE during their visit to Belgium, who explained that each report of euthanasia is closely scrutinised and additional information is sought from doctors if the information provided in the original submission is inadequate. This occurs in around 30 per cent of cases. If a two-thirds majority of the CFCE decides that the legal conditions have not been met, the case will be referred to the public prosecutor in the jurisdiction where the patient died. However since 2002, no cases have been reported to the prosecutorial authorities by the CFCE.

The CFCE submits a report every two years, which includes:

- a statistical summary of the information included in the non-confidential part of the completed registration form submitted by doctors
- a description and evaluation of the implementation of the law
- if appropriate, recommendations that could lead to new legislation or changes to the implementation of the law.

The members of the CFCE who the Commission met thought the act is working well and to the benefit of patients and society more widely. However, Professor Bert Broeckert was critical of the CFCE, in much the same way as Dr van der Heide was about the Dutch system:

*This national euthanasia commission, it works because it does not work and it’s the same for the Netherlands. I mean such a control mechanism, of course physicians are quite nervous to report something like that; are quite reluctant to report. They can choose not to do so and nobody would know.*<sup>929</sup>

Professor Herman Nys was also critical of the CFCE, noting that the Commission’s bi-annual reports do not contain nearly as much detail as the equivalent Dutch reports and that the CFCE acts more as a ‘buffer between

the physician and the prosecution system’ rather than a true monitoring system: ‘The commission [CFCE] behaves as much more... as a mechanism to reassure physicians, “Just let it come to us we will, we cannot guarantee but as long as we can we will not send it to the prosecution”.’<sup>930</sup>

As in the Netherlands, the issue of reporting rates is frequently cited as a problem with the Belgian system. A 2007 death certificate study estimated the reporting rate in Belgium at 53 per cent.<sup>931</sup> Professor Lewis and Isra Black note that the reason for the low reporting rate appears to be similar to that in the Netherlands: doctors will only report cases they would classify as euthanasia, and a greater proportion of cases are classified as euthanasia by researchers than those that would be perceived as euthanasia by doctors. This conclusion is supported by a high reporting rate — 93 per cent — for cases that physicians perceived as euthanasia.<sup>932</sup>

Professor Lieve van der Block, who has conducted research into why doctors do not always report cases of euthanasia, confirmed this conclusion. She told to the Commission that the most common reason doctors gave for not reporting a case was that the doctor did not view the case as euthanasia, but as pain treatment or sedation. She said:

*Those cases are not clear-cut euthanasia cases. For physicians it isn’t black or white, but most acts are somewhere on a continuum between pain treatment and euthanasia and it’s not always very clear for the physicians themselves, is this euthanasia or not.*<sup>933</sup>

The geography of the reporting of euthanasia in Belgium is an additional feature that has received attention: a greater proportion of cases of euthanasia are reported from the north of the country than from the south. Professor Bert Broeckaert told the Commission that over 80 per cent of reported cases of euthanasia are from the northern, Dutch-speaking region of the country, with much lower reporting rates in the southern, French-speaking region. Professor Broeckaert suggested that this because the two regions have different medical cultures:

*I think by far the most important explanation is that, in my opinion (there are no hard data on this)... you are dealing with a difference in general culture regarding physician-patient relationships. In the French-speaking part you would have a more paternalistic attitude; that’s the physician decides and takes responsibility. And the second thing is that they want to stick to this talk just between the patient and the physicians; very secretive and not involve society and the legal system.*<sup>934</sup>

A representative from the CFCE told the Commission that this geographical anomaly is the result of cultural differences, with the doctors from the north adopting a similar approach to the Dutch system, and those from the south adhering to traditional medical practices. This is reflected in the fact that doctors from the north, guided by high profile colleagues, had quickly formed educational networks, such as the LEIF organisation, and developed best practice guidelines. Professor Luc Deliens spoke about the differences between reporting in the north and the south, noting that the difference is driven by the low level of reporting and the fact that fewer cases of euthanasia — reported and unreported — occur in the southern regions than the northern ones.



# THE WAY FORWARD





## 9 Reflections on the evidence

In this chapter we reflect on the evidence the Commission has invited, listened to, read and deliberated on as a group during the course of the previous year. The chapter begins with our cultural and social reflections on experiences of death and dying in the UK. We consider why the issue of assisted dying is so emotionally charged and elicits such polarised views and reflect on the shared concerns at the core of the debate. We then consider the current legal status of assisted suicide and reflect on the evidence the Commission received about whether the current law is adequate or appropriate to meet the needs of our society, and the case for change. Finally we consider the main concerns that have been put to the Commission about the legalisation of assisted dying with respect to the adequacy of health and social care and the potential impact of more permissive legislation on vulnerable people.

### **Social and ethical reflections on experiences of death and dying**

As chapter 2 of this report demonstrated, the evidence the Commission received presented a huge range of extremely powerful and nuanced arguments representing the many ethical dimensions encompassed by the assisted dying debate. These ethical principles include the value of individual autonomy, the ‘intrinsic’ or ‘self-determined’ value of human life, the importance of a compassionate response to suffering, the need to protect vulnerable people, the importance of fighting societal discrimination towards disabled people and doctors’ (in some people’s view) conflicting responsibilities to relieve suffering and preserve life. As the evidence presented in chapter 2 demonstrated, we found on inspection of the evidence that every single ethical principle that was put forward has its equally vociferous opposite. For example, while one person argued that supporting a person to end their life could be a compassionate response to unrelieved suffering, another maintained that such an act should be viewed as callous or irresponsible. While one person claimed that a legal prohibition on assisting suicide protects potentially vulnerable disabled people from coming under pressure to end their life, another person viewed the same legislation as an incursion on a disabled person’s right to choose the timing and manner of their own death and to receive the assistance they might need to put them on a level playing field with non-disabled people.

The Commission has not sought to resolve this vibrant, complex and often polarised ethical debate on whether or not assisted dying *should* be legalised; instead we have sought to answer the question: if the UK Parliament did seek to legalise some form of assisted dying, what approach might be most acceptable to our society? In examining the many ethical perspectives on the assisted dying debate, we have sought to understand each of the views put forward and to identify some common concerns shared by all participants in the debate to inform our reflections and recommendations going forward.

The evidence put before the Commission has highlighted the need to explore and re-evaluate how we address the challenges and fears in our society that are associated with suffering, infirmity, dependence and death. It has also demonstrated a shared belief in the principle that our society should have the capacity to offer every person compassion, empathy and support at times when they are especially vulnerable. Where the evidence differed was in people's conclusions about where these principles should lead us.

If as individuals we have a contradictory relationship with death it is hardly surprising our society and the health and social care systems we construct often fail those they are set up to serve at this crucial time in their lives. It is clear from the evidence we have received that we need to raise standards of care and give the person and the patient a voice. The current gaps between theory and practice demonstrate a failure of imagination that limits the depth of compassion that we can communicate as individuals and as a society.

So how do we mind the gap and improve our practice? How might we put humanity back into health and social care? What is the heart and soul of medicine and social work? Is it possible to inspire compassionate care rather than just adequate care? If we are to make the required changes we will need courage to ask questions and to challenge ourselves and others to redraw the map of illness, infirmity, death and dying. If we are to achieve this, there needs to be a different kind of engagement and debate at all levels of society, which is inclusive and seeks to build and communicate shared values, while also recognising the freedom of individuals to arrive at different conclusions and make different choices.

Some of this debate is related to how we view the nature, process and possibilities of human ageing. Our moral choices around death should be enriched with the spiritual wisdom of an engagement with the shape and purpose of living and especially from listening more carefully to the experiences of older people. Contempt for older citizens, the unthinking pushing of them to the edges of our society, is a sure sign of an impoverished view of what it is to be human. Equally, discriminatory attitudes towards impairment have no place in the fair and inclusive society we are striving for, which values all dimensions of human experience equally. Only if we listen to the narratives of people's lives—in living and in dying—can we properly attend to what is 'revealed', 'felt', 'understood' and 'believed'. It is the work of humanity in its openness to life as it is our honesty about our complicated relationship to living and therefore dying that needs to be the starting point for any change in practice.

### **Reflecting on the current legal status of assisted suicide**

As we have set out previously in this report, section 2(1) of the Suicide Act 1961 makes it a criminal offence to assist someone else to commit suicide, with a maximum sentence of 14 years in prison. To help someone travel from England or Wales to Switzerland knowing that the assisted person wishes to commit suicide when they get there, almost certainly involves providing the requisite amount of assistance required by the act. In the Debbie Purdy judgment the Director of Public Prosecutions (DPP) was ordered to publish guidelines setting out the circumstances in which he would exercise his discretion not to prosecute someone who had satisfied the evidential test

for a prosecution under section 2(1). The guidelines—set out fully elsewhere in the report—amount to the DPP saying he will not prosecute in cases where the assistance is provided compassionately to a person who is capable of making a considered and autonomous decision.

These guidelines are exceptional as they prescribe the circumstances in which the public interest test will be used, not with a view to deal with the exceptional or unexpected case, but in order to deal with the most common manifestation of the conduct that is criminalised by section 2(1) of the Suicide Act 1961. There is no doubt that the DPP has a public interest discretion not to bring a prosecution even if he is satisfied that the evidential test is satisfied. But that public interest test is normally used to deal with the exceptional individual case. By contrast, the guidelines provide a reason not to prosecute that applies equally to all. Or, to put it another way, they take a whole identifiable category of case out of the ambit of the criminal justice process.

Currently, the decision about whether the law should be changed, in a contested area (contested in the sense there are strong views for and against law change) is not being made by the law-makers (Parliament), but by the DPP. He has done his best in consulting the public and reflecting what he believes to be society's wishes in relation to prosecutions. However, the effect of being forced to issue guidelines by the judgment of the House of Lords in the Purdy case means the DPP has to decide on the extent of the law, and to whom it applies. The change is therefore piecemeal; it comes after no coherent public debate, and is driven by a response to individual cases rather than by a wider strategic consideration of the aims of the policy that society wishes to adopt.

It is now almost universally accepted that there needed to be some change to the terms of the Suicide Act 1961. This growing consensus is demonstrated by the broad public acceptance of the decisions made by the DPP not to prosecute recent cases of assisted suicide. However, there is a policy question as to whether this is the right way to deal with the balance that needs to be struck between protecting the vulnerable who could be at risk by a change in the law, and allowing those who do wish to commit suicide to obtain assistance which would make their last days easier. There is also a question over whether this is the right way to change the operation of the criminal law.

Some of the evidence that was put to the Commission argued that the DPP policy has brought sufficient resolution to the issue of assisted suicide. The main arguments for defending the current legal approach to assisted suicide were that it:

- balances competing demands between compassion, leniency and a prohibition of intentional killing
- allows for the investigation of individual instances of assisted suicide on a case-by-case basis (after the event)
- protects potentially vulnerable people from abuse.

However, a much larger body of evidence put to the Commission highlighted the many problems with this approach of legal prohibition of assisted suicide combined with a lenient policy on prosecution, as outlined in the DPP policy. First, the question of when cases of assisted suicide should be prosecuted is now being determined by the exercise of a discretion by

a well-meaning official, the DPP, applying general guidelines rather than the letter of the law, subject to a discretion not to prosecute in exceptional cases. Thus the question of whether a category of persons will be prosecuted depends on the view of one official and that view could change when the DPP changes. The essence of the rule of law is that our society is 'ruled by laws not men'. The situation reached with the guidelines is that this basic tenet of the rule of law is broken.

Second, there remains considerable uncertainty about what conduct will attract criminal prosecution. Unlike most other crimes, whether a person is liable to be prosecuted depends, primarily, on the application of non-discretionary requirements in a statute, or requirements established clearly and with precision by the common law. For the offence of assisted suicide there is now the application of the guidelines, which are by their nature only indicative—they cannot cover every factual situation—and then the exercise of a discretion. Some of those who gave evidence argued that a system with upfront safeguards and prospective approval of individual cases would be preferable, as this would remove the uncertainty currently embedded in the system.

Third, the factors for and against prosecution make a special case of health and social care professionals, making it clear they are more likely to be prosecuted for providing assistance with suicide than other members of the public. This has many consequences, including particular insecurities for doctors and other health or social care professionals whose legal position in relation to various forms of minor 'assistance' (such as providing medical records) remains unclear and may come into conflict with their duties of care and patient confidentiality. The particular prohibition on professional assistance also, by implication, favours amateur assistance, thereby putting unreasonable burdens on friends and family members, who could be involved in complex and emotive situations with loved ones who wish to have assistance to die. The option of travelling abroad to obtain assistance is by no means available to all and, as the evidence put to the Commission demonstrated, is also by no means an easy option.

Fourth, people criminalised by the legal prohibition on assisted suicide will be treated as criminal suspects; this attracts certain procedural protections for them, but also brings with it the pain of being investigated and the threat of a criminal prosecution at the end of the investigative process. For some this might mean choosing to die alone to save one's family the disruption and fear of an investigation and potential prosecution. A question arises about the extent to which society wishes to treat as criminal suspects persons the same society does not have the inclination to prosecute. The need to investigate may be unavoidable, but the nature of that investigation, as witnesses described in relation to the Michelle Broad and Daniel James cases, might not need to be as distressing if the law were changed. The current situation also lays a deeply challenging burden on police and prosecutors, which could be eased by a new statutory framework.

### **Reflections on the case for change posed by suffering at the end of life**

In addition to these detailed reflections on the inadequacies of the current law, many evidence submissions simply stated that the current prohibition of assisted suicide and voluntary euthanasia does not meet the needs of terminally ill

people who experience intolerable suffering at the end of life. Many members of the public gave accounts of frightening, painful and undignified deaths, while experts who gave evidence to the Commission have also reported that even in the best palliative care centres in the UK today there is no guarantee that pain and other physical and psychological types of suffering can be successfully managed. In motor neurone disease and some other progressive neurological conditions, the dominant distressing symptoms at the end of life are extreme muscle weakness leading to failure of the respiratory muscles. Patients with these conditions dread the possibility of ‘suffocating’ to death; even with modern technological means of respiratory support such as non-invasive ventilation (NIV), in the final stages there may still be increasing respiratory restriction and when the time comes to reduce or remove the NIV, most patients need extra opioids and sedatives to reduce their distress.

Consequently, one response to this failure of modern palliative medicine to control symptoms is the rise in the use of ‘palliative sedation’, in which patients are sedated with pain killers and other drugs to the point of coma in the hope they may not be experiencing pain or other suffering. However, the lack of regulation or even agreed terminology and definitions of palliative sedation means that little is known about medical practice in this area and it is not clear whether palliative sedation is always carried out with the patient’s consent, or whether palliative sedation can itself lead to the hastening of death—especially if the patient is denied hydration and nutrition during the sedation, which is prevalent in UK practice.<sup>935</sup> It is also unlikely that palliative sedation can provide a panacea to all people experiencing unrelieved suffering at the end of life.

It is true that Britain has some of the best palliative care services in the world<sup>936</sup> and these undoubtedly do relieve the physical, psychological and existential distress of many cancer and some non-cancer patients towards the end of life who are fortunate to receive their cover. However, many people who gave evidence to the Commission supported the view that even with the best end of life care, a comparatively small number of people dying each year experience a degree of suffering towards the end of their lives that leads the patients to believe that it can only be relieved by ending their life.

It was not the purpose or objective of the Commission to decide whether the law should be changed to make assisted dying legally possible. However, based on the evidence, it is the majority view of the Commissioners that there is a strong case for offering the choice of assisted dying for terminally ill people who are suffering unbearably at the end of life. As well as relieving actual suffering, making this choice available could help to relieve the dread of suffering for those who live in fear of a very unpleasant death. It is for Parliament to decide on behalf of the people whether it would be in the interests of society as a whole to implement a safeguarded system that would provide this option, and there is a clear need for a more inclusive public debate to inform this process. In particular, the evidence the Commission received has made it clear that the issue of assisted dying cannot be viewed in isolation from the need for adequate health and social care, or from the considerable concerns from many people that vulnerable people could be put at risk of abuse or indirect social pressure to end their lives, if such an option was to become available. Therefore if an assisted dying framework is to be implemented in the future it must have these concerns at its heart and its purpose must be viewed as providing people with access to high quality end of life care, and protecting

vulnerable people from any kind of social pressure at the same time as providing people with greater choice and control over how and when they die.

### **Concerns about the adequacy of UK health and social care**

During the evidence sessions Commissioners heard much about people's current experiences of health and social care services, its availability and fears about the quality of care they might expect to receive at the end of life. In particular, the Commission heard from experts in the field about the implementation of the Department of Health's End of Life Care Strategy, published in July 2008.<sup>937</sup> Although much progress has been made, implementation is still patchy and not everyone has access to the specialist services they might need at the end of life.

Witnesses from jurisdictions that have experience of assisted dying have emphasised the huge importance of providing a compassionate and effective assisted dying framework that professionals should have the time to discuss sensitively and over time, sometimes over a number of months, the fears and needs of people approaching the end of life who request an assisted death. Developing the skills to have such conversations with compassion and understanding requires professionals to have proper experience and access to the professional support and training they need to carry out this work.

Those implementing the End of Life Care Strategy have also emphasised the importance of these open-ended conversations as a means of exploring people's wishes for their end of life care. However, they acknowledge that while improvements in discussing, planning and delivering end of life care have been made in many areas, much remains to be done to implement the holistic vision set out in the strategy: 'While there is still a long way to go before we can offer all adults their choices and high quality end of life care, the patches of good practice are growing and spreading'.<sup>938</sup> Particular areas for improvement identified by the 2011 annual progress report on the implementation of the strategy were providing better support for the spiritual and emotional needs of individuals and their families. It also acknowledges that the changes to the NHS and social care proposed by the Coalition Government, together with the financial pressures now being experienced across all public services, will prove challenging to the delivery of coherent and sensitive integrated care throughout the health and social care services that provide end of life care.<sup>939</sup>

Some witnesses who gave evidence to the Commission had considerable concerns about the standards of health and social care generally, perceiving it to be of poor quality, particularly in services for older people. The term 'dignity' is increasingly used in health care and end of life care. For many patients, the quiet, person-focused environment and relatively higher nurse to patient ratios of hospices clearly ensure that personal dignity is maintained to a higher level than in busy hospitals. However, government statistics show that the majority of people do not die in hospices, but in hospitals, nursing and care homes, with a minority dying in their own homes. Within the concept of dignity are important notions about how vulnerable people should be fed, assisted with personal hygiene and shown respect at all times. Unfortunately recent evidence has shown that in many English hospitals these basic needs, particularly for older people with chronic illnesses, are far from being met.<sup>940</sup>



During the period of this inquiry the Care Quality Commission (CQC) produced a report on the dignity and nutrition of older people being treated in acute trusts. It discovered that approximately half of the hospitals visited gave the CQC's inspection teams 'cause for concern' and one in five of the hospitals was not meeting legally required standards for care, providing a level of care that 'posed risks to people's health and wellbeing'.<sup>941</sup> Some of the most important issues identified were staff speaking to patients in a dismissive or disrespectful way and patients not being given the help they needed to eat while in hospital. The Secretary of State has requested a further programme of inspections of trusts and care homes; the CQC is also carrying out a programme of inspections to identify the level of health support given to residents of care and nursing homes. The Commission also heard evidence from a number of witnesses highlighting the fact that palliative care services are not always readily accessible for people resident in care homes, and indeed there was evidence that many care home residents currently experience barriers to accessing basic primary care services from a GP.<sup>942</sup> Lack of access to appropriate care or poor quality care leaves people and their families feeling vulnerable and despairing for their future. Witnesses told us in their evidence that these circumstances could result in indirect pressure on vulnerable people and a desire for an assisted death.<sup>943</sup>

As Commissioners learnt during our research visits to jurisdictions that permit assisted dying, it is essential to the effective and safe operation of any assisted dying framework that it is underpinned by responsive, compassionate and personalised end of life care. A good basic health and social care service working in an integrated way that responds to people's physical and emotional needs is critical to ensure that people who request an assisted death do so free from the pressures that an inadequate system can apply. The recommendations put forward in chapters 11 and 12 explore these priorities further.

### **Concerns about the impact of assisted dying on potentially vulnerable people**

As observed above, some of concerns that were frequently voiced to the Commission concerned the position of older people in our society, including how their lives are valued by other members of society and the availability of care and support should they need it if they experience illness or impairment. The types of social pressure to end their lives that those who gave evidence were concerned that older people or other potentially vulnerable people, such as the terminally ill, might experience ranged from very direct pressure or abuse, to indirect or self-imposed pressure. As mentioned previously in chapter 5, Gary Fitzgerald, Chief Executive of Action on Elder Abuse, told us that coercion was a major issue: 'It's about constraint and it's about undue influence'.<sup>944</sup> In some cases people giving evidence expressed concern about very direct coercion and potential financially driven motives that could lead to family putting pressure on a relative to request an assisted death. One specialist palliative care nurse interviewed by Demos in a focus group said, 'You really sometimes get the feeling that their motives aren't completely honourable.' Another nurse referred to the potential role of more indirect or self-imposed social pressure, commenting, 'A lot of our patients will talk about not wanting to be a burden on their family'.<sup>945</sup> A disabled woman who



took part in Demos's focus group in Preston emphasised prejudiced societal views on disability, and how these views can be internalised by people, causing low self-worth.

On the Commission's research visits to jurisdictions that permit assisted dying, Commissioners were particularly careful to explore with the experts we met whether they knew of patients experiencing such social pressures or otherwise being unduly influenced to seek an assisted death. In Oregon, all but one of the interviewees said they had never witnessed any form of pressure on a patient to have an assisted death. One interviewee, Barbara Farmer, the Director of Legacy Hospice, said a member of her staff had picked up on a situation that had the potential to involve an element of pressure or undue influence as the patient 'had swallowing difficulty, and at times his cognition was not always intact'.<sup>946</sup> She said the staff member took steps to ensure that the man had a full psychiatric evaluation to check that he was making a voluntary decision, and had the capacity to self-administer the drug, and she was confident that such cases can be identified effectively. Most of the Oregon interviewees, including Professor Barbara Glidewell and Professor Ganzini, emphasised the particularly stubborn and autonomous characteristics of those who tended to choose assisted dying.

The experts we met from the Netherlands made similar comments on the subject of coercion: Professor Inez de Beaufort, a member of a Dutch Euthanasia Review Committee, said the danger of patients experiencing pressure from others to have an assisted death was minimal in the Netherlands. She suggested that in reality it was more likely that friends and relatives would be reluctant to agree to the patient hastening his or her death. She thought that if the patient was experiencing any pressure it would be picked up during the requesting process, as both doctors are required to see the patient alone and to explore the issue of influence.

The Belgian interviewees also largely rejected the idea that people who chose an assisted death might be acting under the influence of others. Professor Lieve Van den Block, from the End-of-Life Research Group at Vrije University said that the risk of disabled individuals feeling under pressure to have euthanasia has not transpired in Belgium. Research by the End-of-Life Research Group had found that some individuals had given the reason for requesting euthanasia as not wanting to be a burden on their family, but in those cases where the fear of being a burden was a factor, the study found that the request for euthanasia was often rejected or withdrawn.<sup>947</sup>

Although the Commission could not identify any evidence from these jurisdictions of older people, disabled people or other potentially psychologically vulnerable people being abused, or otherwise subjected to subtle social pressure to choose an assisted death, there is strong evidence that many disabled people in the UK are concerned about the impact that a more permissive approach to assisted dying in this country could have on disabled people. As discussed in chapter 5 of this report, Scope conducted a poll in March 2011 to explore disabled people's perspectives on assisted dying. This poll found that 53 per cent of disabled people said they would be 'very' or 'slightly' concerned about a change in the law to legalise assisted suicide and 70 per cent of respondents would be concerned about 'pressure being placed on other disabled people to end their lives prematurely'.<sup>948</sup> Demos's more detailed qualitative research found that most of the disabled people researchers spoke to would be very concerned about the potential implications

of ending the criminalisation of assisted suicide in an unrestricted way, but they might support a safeguarded system that had strictly defined eligibility for assistance.

Commissioners engaged in wide-ranging debate following their detailed examination of all the evidence presented as it might impact on the experiences of disabled people. They were mindful that the DPP's interim policy was amended following consultation with disabled people and organisations representing disabled people among others. As a consequence one of the public interest factors that might be taken into account as a factor against prosecution ('The victim had: a terminal illness; or a severe and incurable physical disability; or a severe degenerative physical condition; from which there was no possibility of recovery'<sup>949</sup>) was removed from the policy. Disabled people and organisations representing them held the view that this amendment of the policy would provide greater legal protection for disabled people who might consider themselves to be a burden on their family and society more generally and thereby seek to access an assisted suicide, or who might come under pressure from others to do so.

The Commission believes strongly that disabled people must have the same rights as all other citizens and be able to exercise those rights through the availability of appropriate social care systems that empower disabled people to develop independent lifestyles by exercising choice and control over how they live their lives. Substantive evidence, referred to earlier, has clearly demonstrated that many disabled people, organisations representing disabled people and professionals working with disabled people share the same concern that society frequently devalues the lives of disabled people through assumptions of limitation and negative quality of life rather than assumptions of opportunity and equality. People giving evidence to the Commission emphasised that it was not an individual disabled person's impairment that resulted in them being marginalised and excluded from contemporary social activities, but the way that society has been organised and designed in a way that limits opportunity. Mobility-impaired people can be limited by steps; visually impaired people can be limited by a lack of access to Braille or text reading software on computers; deaf people can be limited by a lack of subtitles on television or the lack of availability of sign language interpreters at meetings or events. However, the barriers experienced by disabled people are not simply structural in nature.

Commissioners heard compelling evidence suggesting that even with a level 'structural' playing field disabled people face additional barriers daily resulting from the interrelationship of attitudinal and behavioural barriers exhibited by others. Evidence was also presented suggesting that less politicised disabled people, or people who first develop an impairment later in life as a result of illness or accident, might be more prone to adopt negative social perceptions about the status of disabled people in society to such a degree that it may influence their decision-making as it relates to assisted dying.

One witness was worried that 'this opportunity for some people may become an obligation'.<sup>950</sup> In other words, any change in the existing legal framework that resulted in the legalisation of assisted suicide could present a number of disabled people, who perceive themselves as being a burden on others and may also have internalised negative social constructs of disability, with the feeling of being obliged to seek assistance to die in order to alleviate that burden on others alongside their negative perceptions of self.

However, notwithstanding these very realistic concerns there is strong evidence that disabled people are still travelling or planning to travel to Switzerland to take advantage of its permissive legal stance on assisted suicide to end their lives when they are not terminally ill. This clearly demonstrates that although disabled people and organisations representing disabled people were successful in amending the DPP's policy before publication, some disabled people with the support of family and friends are still gaining access to assisted suicide or clearly articulating their plans to do so in the future. To date, the DPP has followed his policy and consistently recommended against prosecution of friends and family members who have been motivated by compassion to assist a loved one to travel to Switzerland to end their own life. This issue of protecting the rights of disabled people is a very real concern for all Commissioners. However, while Switzerland continues to take a permissive approach to so-called 'suicide tourism', there is little that can be done to address the current status quo whereby some disabled people who can afford it are travelling to Switzerland to obtain an assisted suicide. The most important question concerns the potential impact of replicating such a permissive approach to assisted dying in the UK.

The Commission's recommendations will reflect the fact that there is now support among the British public for the idea that people suffering from a terminal illness should be able to pursue the option of an assisted death, as evidenced by recent opinion polls. However, there is much greater concern among the public about the potential impact of extending such an option to people with non-terminal life-limiting conditions or impairments, who might feel that their lives are devalued in the eyes of society by the very fact of such an option being made available. We will present our more detailed recommendations on these matters in the following chapters.





## 10 Core principles

In response to the evidence we received during our enquiry, we have developed a set of core principles, which run throughout the recommendations presented in chapters 11 and 12.

### **Open discussions about death and dying should be promoted**

The Commission has uncovered a great deal of evidence that many people in our society currently feel constrained about discussing their end of life choices. The Commission strongly supports the work of the Dying Matters Coalition in seeking to promote more open discussion about death and dying at individual and societal levels in all possible settings.

The Commission has also received evidence that the legal status of assisted dying, and in particular the DPP policy on assisted suicide, is inhibiting people's ability to speak freely about their wishes at the end of life. The evidence that the Commission received also demonstrated the anxiety that many health and social care professionals experience when patients wish to discuss the desire for a hastened death. These concerns on the part of patients and practitioners are not only affecting people's relationships with healthcare professionals and limiting the conversations they feel able to have, but can also stifle discussions with family and friends. This situation has the potential to hinder the End of Life Care Strategy's aim to promote more open conversations about death and dying. It may also reduce opportunities to tackle misconceptions and/or fears that people may have about dying.

The Commission has also received a number of pieces of evidence demonstrating the continuing belief that illegal medically assisted dying is being carried out in a 'hidden' way. For example, in one of Demos's focus groups a disabled woman commented that she had 'experienced somebody dying of cancer and the doctor did overdose and it did finish the lady. It does happen, it might not come to law but it does happen, it does go on'.<sup>951</sup> The written evidence that Help the Hospices submitted also referred to 'a widely held misunderstanding about the difference between assisted suicide, voluntary euthanasia, and the issues associated with the withholding and withdrawing of life-prolonging treatment'. This anecdotal evidence demonstrates a societal need for much more open and accurate information about dying and end of life care and better regulation and oversight of all end of life decisions.

### **Each person should be entitled to core rights in end of life care**

Every person should be entitled to receive the best end of life care available and appropriate to their needs throughout their illness wherever and whenever they are identified as approaching the end of their life. Demos's focus groups with older people, disabled people and terminally ill people uncovered the fact that some people had a very low awareness of the relevant legal issues affecting end of life care and of their rights, and their loved ones' rights in end of life care.

The Commission has also heard powerful statements from witnesses at our evidence sessions who described a lack of basic supportive care services in the community, which can leave people vulnerable to fear and a sense of decreased self-worth. Suzy Croft, a senior social worker at St John's Hospice, highlighted the recent report by the Health Service Ombudsman that 'criticised NHS staff for treating elderly people without compassion, condemning many to die in "unnecessary pain, indignity and distress"<sup>952</sup>. This evidence demonstrates there is an urgent need for a culture change in health and social care services to ensure that people's core rights in end of life care are openly communicated and are supported at all times.

### **Good quality end of life care should be available in all settings**

Evidence from Professor Sir Mike Richards and other practitioners has demonstrated that there is limited progress in some parts of the country on the implementation of the End of Life Care Strategy. This evidence indicated that much more emphasis must be placed on generalist aspects of end of life care as well as specialist palliative and end of life care. The broader role of health and social care professionals in providing end of life care in all locations (including people's homes, care homes, hospices and hospitals) needs to be recognised and to receive more emphasis as a core component of their roles. All health and social care practitioners who work with dying people need basic training in communication skills to facilitate patient participation in decision-making about end of life care. Such core training could play an important role in facilitating the wider dissemination of established good practice and raising the 'lowest common denominator'. There is also clear evidence of the need for better coordination of end of life care and the pooling of social care and health care resources to meet patients' needs and spread resources more effectively, while knowledge of effective approaches must be communicated more broadly.

### **All forms of discrimination in end of life care should be ended as far as possible, whether these are based on geographical location, physical condition, ethnicity or wealth**

Progress has been made with the End of Life Care Strategy, but there is much to be done in providing better access to, and more uniform availability of, end of life care across the country. This must be borne in mind as further reform is planned for the NHS and financial restraints impact on the NHS and local councils.

Evidence given to the Commission particularly highlighted certain social groups – including older people, adults with learning disabilities, adults with mental health problems including dementia, and adults with life-limiting conditions other than cancer – as being at risk of having poor access to end of life care. The evidence also emphasised the need to ensure that people can die where they wish rather than face an inappropriate emergency transfer to a hospital A&E department because of the lack of knowledge or basic care in their home setting (although the Commission accepts that there will be some occasions when unexpected and/or acute events may make it entirely appropriate for people to be admitted to hospital at the end of life).

All health and social care staff with responsibility for people at the end of life (eg GPs, ward nurses, social workers, staff in care homes) must



be aware of, and confident in, their role in giving people opportunities to discuss their end of life choices, and helping people to access the end of life care they want. As mentioned above, achieving this will require greater access to training and support.

### **There should be more choice in how people die and clear and accessible information must be provided**

This objective of giving people more choice in how they die is closely linked to the principles of improving open discussion and access to high quality end of life care. Choices might include the extent to which patients wish to discuss their illness, the treatments and support they might request or refuse, and their preferences for where they wish to receive care and, ultimately, die. People need to be aware of which choices can be expressed as specific decisions (and recognised in law) and which can only be expressed as preferences. They must also understand how these choices and preferences should be recorded as a paper record or electronically. They should be aware of how decisions might be made on their behalf if they should lose the capacity to make decisions for themselves.

### **There must be effective social support and protection for more vulnerable people**

Having heard a broad range of evidence from professionals and members of the public, the Commission recognises that vulnerability is not a social category. We all experience periods of vulnerability in our lives but some people may have more contextual factors, experiences or characteristics in their lives that make them vulnerable temporarily or over a longer period of time.

Many people who rely on health and social care services can be very vulnerable and experience very poor outcomes, not because of their disability or age, but because of other circumstances in their lives. People can become more vulnerable if their care is poorly coordinated, insufficient for their needs or deficient in quality. People might also be more vulnerable if they are wholly reliant on others for their care and it is delivered in a way that limits choice and control rather than promoting independence. People can also be made more vulnerable through experiences of social isolation.

Sometimes people can be made vulnerable by the attitudes of others who see their inabilities rather than their abilities. If people have ill health or a disability for the most part they do not want their life to be defined by it—even though their life might be dominated by it. If discriminatory attitudes are accepted as ‘the truth’, and are internalised, this can cause vulnerability due to feelings of low self-worth.

The Commission considers that vulnerability is an issue not just in the context of assisted dying but in all end of life decisions that are made, such as ‘do not resuscitate’ decisions and decisions on withholding or withdrawing treatment or administering palliative sedation. If we are to ensure that all people have opportunities to discuss their care and support needs and to receive the care and social support they need, we must be able to offer flexible options for both formal and informal advocacy. At the same time, disabling and discriminatory barriers caused by the way that we organise our society must be dismantled so people can embrace greater choice and control over how they live their lives.



## 11 Principles to underpin a legal framework for assisted dying in the UK

The first chapter of this report observed that while assisted suicide remains illegal in the UK, there have been no prosecutions for the offence of assisting suicide since the DPP's prosecution policy was published in February 2010, although more than 40 cases of assisted suicide have been reported to the Crown Prosecution Service since 2009.<sup>953</sup> There is now a broad public perception that assisted suicides that meet the criteria stipulated in the DPP policy are effectively decriminalised<sup>954</sup> and many of those who gave evidence to the Commission expressed concern that assisting suicide remains an amateur activity, and that no prospective safeguards are in place to protect those who seek such assistance, or who might feel themselves under pressure from others to seek such assistance.

The Commission recognises that — as the evidence summarised in chapter 2 of this report has demonstrated — ethical perspectives on the issue of assisted dying remain polarised and it is extremely unlikely this issue could ever be resolved in a way that was satisfactory to all parties. Ultimately the question of whether a legal framework for assisted dying should be introduced in the UK must be for Parliament to decide on behalf of the people. However, following the Commission's detailed consideration of the evidence we have heard, we have reached a consensus that the current legal status of assisted dying, which appears to accept the principle of compassionate assistance with suicide in some circumstances, but does not allow for open discussion or professional assessment and support for people contemplating assisted suicide, is inadequate, incoherent and should not continue.

The majority of the Commissioners consider that it is possible to devise a legal framework that would set out strictly defined circumstances in which terminally ill people might be assisted to die, supported by health and social care professionals, and which would employ robust upfront safeguards to prevent inappropriate requests from going ahead. The evidence we have received in the Netherlands, Belgium and Oregon suggests that such a framework could be safer than the status quo, while also providing terminally ill people with more choice and control at the end of life.

We have listened very carefully to concerns that poor quality and coordination of health and social care at the end of life could impose hidden pressures on people to request assisted dying when otherwise they might not wish to. Therefore this report will be clear in its recommendations that adequate health and social care services, with well-trained and compassionate staff who would take the time to fully investigate the circumstances and motivations of any person seeking an assisted death and the potential for alternative options for treatment and care, would play an essential role in supporting a safe and effective assisted dying framework in the UK. Therefore, if an assisted dying framework was to be introduced, improvements to health and social care would be required in parallel to ensure that services were adequate to support the core needs of all people approaching the end of life, and could respond in a responsible

and compassionate manner to the small number of requests for assisted dying that would be likely to be made each year.

The Commission also listened very carefully to the concerns of a number of advocacy groups and members of the public that a more permissive legal position on assisted dying could lead to some vulnerable people experiencing direct or indirect social pressure to end their lives. The groups of people particularly mentioned with respect to these concerns included older people, disabled people and terminally ill people. The Commission shares these concerns and considers it is essential that any system to permit assisted dying in the UK should include a series of robust and carefully applied safeguards to ensure that the choice of an assisted death could never become an obligation and that a person could not experience pressure from another person to choose an assisted death without this abuse being detected. We also recognise the importance of ensuring that reduced capacity and impairments caused by undiagnosed or untreated depression could not be allowed to influence a person's decision to choose an assisted death. Therefore any legally defined process to allow an assisted dying framework would need to include measures for assessing the mental capacity and mental health of every person who requests an assisted death to ensure that the individual's choice is genuinely autonomous.

The strong body of evidence that informs this report, and particularly the evidence gathered from jurisdictions that currently permit assisted dying, demonstrates that the potential risks to vulnerable people posed by assisted dying legislation could be minimised effectively by the application of appropriate eligibility criteria and safeguards, in a broader context of adequate health and social care services. We did not identify any academic or anecdotal evidence in these jurisdictions that assisted dying legislation has caused vulnerable people to be put at risk of being assisted to die against their will. The experts we consulted tended to think that the legalisation of assisted dying had played a role in improving people's access to end of life care and facilitating greater openness in the discussion of end of life choices between professionals, patients and their families.

This chapter will outline the broad principles that could underpin a model of support and decision-making, and the choice of eligibility criteria and safeguards that could be included in legislation if an assisted dying framework was to be adopted in the UK. We set out our more detailed thoughts on a safeguarded scheme that policy-makers could potentially adopt in Appendix 2 of this report. Chapter 12 will summarise the changes to law and policy that might be required if a legal framework to permit assisted dying for terminally ill adults was to be introduced in the UK.

## **A model framework for assisted dying**

Before we discuss specific eligibility criteria and safeguards, we will outline the key elements we consider should be included in any future framework for assisted dying, to ensure that all requests were assessed thoroughly and compassionately, appropriate support and care would be provided to all people who requested an assisted death, and potentially vulnerable people would be protected from pressure or abuse. These key elements are summarised in Box 5.

Box 5 **Key elements that should underpin a safeguarded framework for assisted dying**

*These are the key elements that the Commission considers should be included in any future framework for assisted dying:*

- *a good level of care and support services with properly trained health and social care staff*
- *clearly defined eligibility criteria*
- *the person concerned requests an assisted death on his or her own behalf, and has the capacity to make the request*
- *a doctor who, where possible, knows the person well and supports the person and their family through the process*
- *the person who requests an assisted death is fully informed of all the options available to them for treatment, care and support and still wishes to proceed*
- *an assessment to determine if the person meets the eligibility criteria is provided by at least two doctors who are wholly independent of one another*
- *detailed guidance on how lethal medication to be used for an assisted death should be stored, transported and administered in such a way as to ensure, as far as possible, no risk of abuse, constituting a danger to the public, or being stolen*
- *the patient must take the final action that will end their own life*
- *certification of the death expressly records it as an assisted death*
- *correct reporting of the assisted death to a national monitoring commission that reviews all cases and has retrospective powers to investigate whether individual cases complied with the law.*

### **Eligibility criteria**

Following lengthy deliberation, the Commission recommends that the following three eligibility criteria should be met before a person may proceed with requesting an assisted death. The person must:

- be aged 18 or over and have a diagnosis of terminal illness
- be making a voluntary choice that is an expression of his or her own wishes and is not unduly influenced by others
- have the mental capacity to make a voluntary and informed choice, and their decision-making ability must not be impaired as a result of mental health problems such as depression.

We will discuss our reasons for selecting each of these criteria, and for not selecting other criteria, such as ‘unbearable suffering’ or ‘significant impairment’, below. While clear eligibility criteria would be an essential feature of robust legislation, we certainly do not suggest that these criteria should be approached as a tick-box exercise. Instead, it would be essential that each criterion was investigated thoroughly as part of an ongoing discussion and dialogue between the individual and their doctor, and where appropriate including other professionals responsible for that person’s end of life care.

### **Safeguards**

The Commission is clear that any framework to permit assisted dying in the UK would need to include upfront safeguards to help ensure that decisions were made properly at each stage of the process. Having consulted many

experts and members of the public in this country and the jurisdictions that permit assisted dying, the Commission considers that the most important safeguard in any assisted dying regime would lie in the relationship between the patient and their doctor. The Commission envisages that the patient's usual doctor (most likely their GP or a specialist in their condition) would be responsible for exploring the individual's request, understanding whether it was a serious request or a 'cry for help' that could be addressed in another way, and exploring whether access to other types of care and support might remove the patient's wish to die. The doctor would need to give these conversations time and ensure that the patient had enough time to reflect on their decision and discuss it with other people in their life. While safeguards can provide checks and balances and help to structure this process, training, guidance and support for doctors would also clearly play an essential role in helping doctors to carry out this role effectively. As mentioned above, an element of objective decision-making by another independent doctor who was experienced in end of life care would also be essential to check that these decisions were made properly.

We recommend that any future legislation to permit assisted dying should include consideration of the following categories of safeguard:

- 1 a decision-making model involving the assessment, advice, support and independent judgements of two independent doctors, with support from other health and social care professionals where necessary
- 2 a safeguard to ensure the person has been fully informed of all other treatment and end of life care options that are available and still wishes to proceed
- 3 safeguards to ensure that the eligibility criteria are met
- 4 safeguards to ensure that the person has a settled intention to die
- 5 safeguards to ensure the safe storage and transportation of lethal medication
- 6 safeguards to ensure the person has a reliable and supported assisted death
- 7 safeguards to ensure that assisted deaths are reported correctly
- 8 monitoring and regulatory oversight by a national monitoring commission with powers to investigate suspected non-compliance.

This report proposes an approach that could be taken to ensuring that these issues were addressed in assisted dying legislation (with a more detailed process outlined in Appendix 2). However, we do not argue that this is the only possible or appropriate way of ensuring that these safeguards are met and other frameworks could be devised that also address these issues.

### **The type of assisted dying that could be permitted**

As we will discuss in relation to the above safeguard 'the patient has a reliable and supported assisted death', the Commission recommends that if assisted dying was to be legally permitted, this could take the form of a terminally ill patient, who met the legal criteria, taking a dose of medication that will end their life. The Commission is not recommending that any form of euthanasia should be permitted, therefore the patient him or herself would need to be able to take the action that will cause their death, as a clear expression of voluntariness. Appropriate support to take the medication should be provided if it is required by a terminally ill person with an impairment, but this could not take the form of another person administering the medication on their

behalf. This is an important safeguard to ensure that the person who wishes to have an assisted death remains in control of the process throughout, and can change their mind at any point.

## **Eligibility criteria**

### **The condition of the person**

This section will explore the Commission's reasons for recommending an eligibility criterion based on terminal illness and the considerations that led to the Commission deciding to recommend that if an assisted dying framework is introduced in the near future it should not include a criterion based on either 'unbearable suffering' or profound physical impairment.

### **A diagnosis of terminal illness**

As we stated clearly in our core principles above, we view high quality end of life care as an essential feature of a compassionate society and a prerequisite for any assisted dying framework. The Commission supports strongly the continued implementation of the Department of Health's End of Life Care Strategy, which aims to improve access to high quality end of life care throughout England. The evidence put to the Commission has also led us to consider that there is a strong argument for making assisted dying available as an option to terminally ill people. We consider that eligibility should be restricted to people who are terminally ill, for reasons we set out below. As in other jurisdictions that permit assisted dying, we do not envisage that doctors or other health and social care professionals would ever offer assisted dying as an option to their patients; instead it would be available only to those who requested it. The proposed safeguards discussed below will also emphasise the importance that any person who might request an assisted death should not be permitted to proceed with their request until they had been fully informed by their doctor of all other options for treatment and care that were available to them.

As the evidence presented in chapter 3 has shown, there is a small proportion of people with terminal illnesses who believe that palliative care cannot provide the answer to their suffering. Our conversations with the expert witnesses we consulted in Oregon suggested that for some people who are suffering at the end of life, the knowledge that the option of assisted dying is available to them can provide considerable psychological comfort, even if they do not end up making use of this option. We consider that eligibility based on terminal illness would meet the needs of the majority of people who might wish to request assisted dying. As Professor Penney Lewis and Isra Black's expert briefing paper to the Commission has demonstrated, although eligibility for assisted dying in the Netherlands, Belgium and Oregon varies considerably in relation to the person's physical condition or experience of suffering, 'over 80 per cent of all reported cases of euthanasia or PAS in the Netherlands, Belgium and Oregon involve cancer patients'.<sup>955</sup>

We also consider that there is sufficient social consensus on this issue to warrant Parliament considering the decriminalisation of medically assisted suicide for terminally ill people (subject to the further criteria and safeguards set out below). While assisted dying continues to be a controversial subject that generates polarised opinions, large scale surveys suggest that the majority of the British public is in favour of a change in the



law to allow assisted dying for the terminally ill. British Social Attitudes surveys published in 2007 and 2010 found that more than 80 per cent of the public support assisted dying for people dying of incurable illnesses, but only 45 per cent support assisted dying for people with non-terminal conditions.<sup>956</sup> Therefore, we consider that criteria that restrict eligibility to people with terminal illnesses would be in line with the broad thrust of current public opinion.

The Commission has received a number of pieces of evidence that highlight the difficulties with defining ‘terminal illness’ and the problems of diagnosis and prognosis that might be posed by a criterion based on terminal illness. We are fully aware of these challenges, but the Commissioners’ detailed conversations with practitioners in Oregon who have been responsible for implementing the Death with Dignity Act since 1997 suggest that a criterion based on terminal illness is workable and does not present significant problems for either patients or practitioners. Susan King, Executive Director of the Oregon Nurses Association, pointed out that physicians are more likely to overestimate a patient’s prognosis than underestimate; for example, they may predict that a patient will live for another six months when in fact the patient will only live for a further two months. Therefore, in this case there is a far greater risk that a patient will not have sufficient time to progress their request for an assisted death than that the patient’s life might be significantly shortened. Academic research has also found that prognoses are far more frequently over-optimistic about life expectancy than they are overly pessimistic.<sup>957</sup>

To define ‘terminal illness’ for the purpose of this eligibility criterion, we take as our starting point the General Medical Council’s (GMC’s) guidance for doctors, *Treatment and Care Towards the End of Life*, which came into force in July 2010. The guidance states:

*For the purposes of this guidance, patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:*

- a Advanced, progressive, incurable conditions
- b General frailty and co-existing conditions that mean they are expected to die within 12 months
- c Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- d Life-threatening acute conditions caused by sudden catastrophic events.<sup>958</sup>

While the four categories stated in the GMC guidance are appropriate to the broad context of end of life care planning, we consider that only the first category of ‘advanced, progressive, incurable conditions’ is appropriate in the context of assisted dying. This is because we consider that the *risk* of death indicated by categories (b), (c) and (d) is an insufficiently firm basis for proceeding with such a serious decision as ending one’s own life. In scenario (a) we consider that it would be possible for a doctor to ascertain that the patient’s condition was more likely than not to lead to their death within a year. Therefore, we suggest this eligibility criterion should require that the person has *an advanced, progressive, incurable condition that is likely to lead to the patient’s death within the next 12 months*. This definition would be

likely to account for the vast majority of applicants, as Professor Lewis and Isra Black's research cited above indicates.<sup>959</sup>

### **A criterion based on unbearable suffering**

The Commission has not recommended that any criterion based on 'unbearable' or 'unrelievable' suffering should be included in potential assisted dying legislation as we are concerned that a criterion based on suffering would be too unclear and subjective for doctors to assess. Following our discussions with some of the advocacy organisations and disabled people we consulted, we are also persuaded that it would be inappropriate for such a system to rely on one person making a judgement about another person's quality of life. David Congdon, head of policy at Mencap, posed the question: 'How would you actually assess whether someone is suffering unbearably? Because quite often assumptions are made about quality of life that really are quite inappropriate. It's very hard, actually, to judge someone else's quality of life'.<sup>960</sup> We firmly believe it is only for the individual concerned to judge the extent of the suffering caused by their illness. We are also concerned that a person who has a terminal illness should not be required to be already *experiencing* unbearable suffering to request an assisted death; it could be the prospect of anticipated suffering that he or she does not wish to experience that gives rise to the request for assistance.

Eligibility criteria referring to 'unbearable suffering' are used in assisted dying legislation in the Netherlands and Belgium. In the Netherlands, the law on Euthanasia stipulates that the 'attending physician... must have been satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement' and in Belgium, the 'patient [must be] in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident'.<sup>961</sup> However, in Oregon there is no explicit suffering criterion in the Death With Dignity Act; it is only necessary that the patient has 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months'.<sup>962</sup> Lewis and Black's study of the effectiveness of the safeguards in these jurisdictions found that 'unbearable suffering and terminal illness appear to be well adhered to when they are legally binding [but] the evidence does not suggest that one criterion should be preferred over the other'.<sup>963</sup> Therefore, we consider that a terminal illness criterion without a suffering criterion would be sufficient to identify and exclude inappropriate requests.

### **A criterion based on significant physical impairment**

The Commission recommends that any new assisted dying legislation should include measures to extend the right to request an assisted death only to people who are terminally ill. Those with significant physical impairments would therefore only be eligible if they had a coexisting terminal illness.

As discussed in detail previously in this report, the Commission received extremely compelling evidence from Tony Nicklinson who argued that the current law on assisted suicide and euthanasia discriminates between people who can take their own lives without assistance, and physically impaired people who may require help: 'Everybody, whether or not they need assistance, should be able to determine their own future'.<sup>964</sup> Mr Nicklinson argues very passionately that any legislation to permit assisted dying in Britain should not

be restricted to those who are terminally ill, but should be ‘open to everybody over the age of 18 on the grounds that anything else is discrimination’.<sup>965</sup> Some other disabled people who took part in our consultation also argued that the criminalisation of assisted suicide discriminates against disabled people, who might be unable to end their own life without assistance, whereas non-disabled people would be less likely to require such assistance. There is even some precedent in the law for a tolerant approach to non-terminally ill disabled people seeking assistance to end their lives. The Crown Prosecution Service decided not to prosecute Daniel James’s parents for providing him with compassionate assistance to end his life at the Dignitas clinic following the accident that caused him to become tetraplegic. This seems to demonstrate that the Crown Prosecution Service felt sympathetic to the circumstances of both Daniel James and his parents.

However, the research that Demos conducted with disabled people to explore their attitudes to assisted dying demonstrated that—in line with the general public—most people were far more comfortable with the idea of permitting the choice of assisted dying for people who were terminally ill than they were for people like Tony Nicklinson who are not terminally ill but have significant physical impairments. Some of the disabled people we spoke to were very concerned that a disabled person might feel compelled to choose an assisted death as a result of inadequate social support, or because they felt their life was not valued by the rest of society.

In light of these very contradictory viewpoints, we found we were unable to reach a consensus as a Commission on the issue of whether people with significant physical impairments, who have a settled intention to end their life, should be legally permitted to initiate the process of seeking assistance (if they do not have a terminal illness). We consider that our lack of consensus on this issue reflects public debate; as mentioned above, only 45 per cent of the public support the choice of assisted dying being available to people with non-terminal conditions.<sup>966</sup> We have taken on board the strong concerns expressed by many disabled people and do not consider that it would be acceptable to society at this point in time to recommend that a non-terminally ill person with significant physical impairments should be made eligible under any future legislation to request assistance in ending his or her life. The intention of the Commission in recommending that any future legislation should permit assisted suicide exclusively for those who are terminally ill and specifically excluding disabled people (unless they are terminally ill) is to establish a clear delineation between the application of assisted suicide to people who are terminally ill and others with long-term conditions or impairments. This is something that the DPP policy currently fails to achieve. The adoption of this distinction in any future legislation would send a clear message to the British public that disabled people’s lives are equally valued and that if the ‘opportunity’ does not exist the ‘obligation’ cannot follow in the UK.

However, we are concerned that those who might agree to assist a non-terminally ill loved one, who has suffered such a catastrophic life-changing event, to commit suicide for wholly compassionate reasons (for example, the parents of Daniel James) should continue to be treated by the law with compassion and understanding. Therefore, we suggest that the Director of Public Prosecutions’ policy on assisted suicide should continue to be applied to those cases that might fall outside the scope of the legislation that we are proposing for consideration.

Commissioners were also informed by evidence and debate about the need to create equal access to assisted suicide for disabled people with a terminal illness who request such assistance. Further information about reasonable adjustments that might need to be made to an assisted dying process are set out in Appendix 2.

### **Voluntariness and absence of coercion**

As discussed previously, throughout the Commission's process of evidence collection, very real concerns have been voiced to the Commission that some individuals might come under pressure to request an assisted death if this option was to become available. Forms of pressure that have been envisaged include direct pressures from family members or medical professionals; indirect pressures caused by societal discrimination or lack of availability of resources for care and support; and self-imposed pressures that could result from the individual having low self worth or feeling themselves to be a burden on others.

The Commission does not accept that any of these forms of pressure could be a legitimate motivation for a terminally ill individual seeking to end their life. Therefore, it is essential that any future system that might exist in the UK to permit assisted dying for terminally ill adults should provide the space and time for trained professionals to explore each applicant's motivations for seeking an assisted death and to ascertain whether this is a genuinely voluntary and autonomous choice, or whether it might be influenced by another person's wishes, or constrained by social circumstances, such as lack of access to adequate end of life care and support. As we have emphasised throughout section 3 of this report, improvements in health and social care would be needed in parallel with assisted dying legislation to ensure that every person can have their core needs for end of life care met, regardless of their social circumstances.

### **The person has the mental capacity to make a voluntary and informed choice**

The third essential eligibility criterion that should be included in any future assisted dying legislation concerns the person's mental capacity to make such a momentous decision. A large number of submissions of evidence to the Commission identified capacity assessment as an essential cornerstone for any assisted dying framework. We will discuss several key issues here that pertain to mental capacity: the legal definition of mental capacity; permanent or temporary factors that can influence mental capacity; the particular role of depression in impairing capacity in the context of terminal illness; and our thoughts on the eligibility of individuals with dementia for assisted dying.

The legal definition of mental capacity is provided by the Mental Capacity Act 2005:

*A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain... It does not matter whether the impairment or disturbance is permanent or temporary.*<sup>967</sup>

The Mental Capacity Act identifies four dimensions of capacity:

*A person is unable to make a decision for himself if he is unable:*

- a to understand the information relevant to the decision,
- b to retain that information,
- c to use or weigh that information as part of the process of making the decision, or
- d to communicate his decision (whether by talking, using sign language or any other means).<sup>968</sup>

An important premise of the Mental Capacity Act 2005 is that a person ‘must be assumed to have capacity unless it is established that he lacks capacity’.<sup>969</sup> However, in the context of such a serious decision as requesting an assisted death, it would clearly be insufficiently rigorous if the doctors responsible for checking the eligibility criteria were to assume that the patient had capacity, therefore there is clearly the need for a formal assessment. As we explored in chapters 5 and 6, assisted dying legislation in each of the examples of Netherlands, Belgium and Oregon contains explicit eligibility criteria requiring that the person requesting assistance is mentally competent to make such a request.

The evidence given to the Commission made it clear that there are a number of factors that might affect an individual’s mental capacity, including temporary factors caused by physical or mental illness, and more permanent impairments such as a learning disability. Dr Tony Zigmond, a consultant psychiatrist, observed how illness can affect a person’s decision-making capacity, but ‘the decision to die has a clear outcome. Understanding this, and the irreversibility of death, is rather easier than for many decisions we make.’ David Congdon, speaking on behalf of Mencap, pointed out that learning disabilities can affect people’s capacity to a varying extent; some people with learning disabilities might have sufficient capacity to make a decision about assisted dying, while other people with a learning disability might not. Therefore,

*from an equal rights point of view, if there was a law on assisted dying... then yes, one would have to say ‘they [people with learning disabilities] ought to have the same right as anybody else’, and one would fight to defend that, but there’d have to be the safeguards in place.*

Andrew McCulloch from the Mental Health Foundation recognised in his evidence that mental health conditions such as schizophrenia can have a complex interaction with mental capacity, which would need to be taken into account when a request for assisted dying was being explored. However, he highlighted in his oral evidence to the Commission that it was important that assisted dying legislation should not discriminate against people on the basis of mental health problems they might have had in the past:

*If there’s a system that says, ‘because you’ve ever had a diagnosis of say schizophrenia or depression or something, then you can never be eligible for a process of assisted dying’, that would be a major, major problem I think.’<sup>970</sup>*

Many of the discussions Commissioners had with witnesses about capacity in the oral evidence sessions explored the issue of how common mental disorders such as depression might interact with and impair a patient's decision-making capacity. Dr Martin Curtice commented: 'Now major depression in itself, if you apply the Mental Capacity Act, does not automatically mean you lack capacity, but it's highly likely to influence your decision-making'.<sup>971</sup> Christine Kalus pointed out that 'depression can affect one's capacity to make decisions or to behave or emotionally, cognitively, behaviourally, in all sorts of ways'.<sup>972</sup> Dr Annabel Price observed that 'The desire for death is associated with a number of factors, particularly depression and more severe physical symptoms, many of which are potentially remediable with good symptom control and psychological care'.<sup>973</sup> A number of pieces of evidence submitted to the Commission and previous academic research have particularly drawn attention to the greater prevalence of depression among people with terminal illnesses, and the association between depression and a desire for a hastened death in the terminally ill.<sup>974</sup>

While the distinction between 'appropriate sadness' and depression in the context of terminal illness is complex, the Commission does not think that a person with depression, whose judgement might be significantly impaired as a result of this depression, should be permitted to take such a momentous decision as ending their life. Therefore we suggest in Appendix 2 a range of safeguards that might be included in future legislation to screen applicants for depression, and take appropriate action to either treat this depression, or prevent the individual's request for an assisted death from progressing.

Another important issue that was highlighted in evidence to the Commission was the subject of dementia. Some people who have themselves been diagnosed with dementia, or have experienced a close friend or relative having dementia, have described their fear of a loss of dignity associated with the later stages of dementia, and expressed the wish that people who are in the early stages of dementia should be able to either have an assisted death at that point, or to request an assisted death later in their illness once they have lost capacity. Some of the evidence submitted to the Commission suggested that advance decisions could play a more important role in an assisted dying framework, by substituting for the loss of capacity in a person who developed dementia, and allowing the individual to access an assisted death in more advanced stages of the disease. As mentioned previously in chapter 6, a woman named Freda Humble who submitted written evidence to the Commission explained that she was in the early stages of dementia, and argued that if she knew she could request an assisted death using an advance decision, this would give her 'release' from 'a state of constant worry and anxiety'.<sup>975</sup>

This issue of deciding the circumstances in which a person diagnosed with dementia might request an assisted death is currently receiving increasing attention in the Netherlands. During our research visit to the Netherlands, we heard that there is pressure from some quarters of the Dutch public for the 'due care criteria' outlined by the Euthanasia law to be broadened to allow patients with more advanced dementia to access euthanasia.<sup>976</sup> Under the current system in the Netherlands, patients with dementia may only access euthanasia in very early stages of dementia when the individual still has the ability and competency to make the 'voluntary and carefully considered request' that is required by law. As the evidence reviewed in chapter 6 has demonstrated,



none of the four jurisdictions that the Commissioners visited currently legally permits people who have dementia, whose capacity is no longer intact, to either request or receive an assisted death. During our expert interviews in these jurisdictions, the Commission also did not find any professional support for the broadening of legal eligibility criteria to allow access to euthanasia or assisted suicide for patients with dementia who lack capacity.

We are sympathetic as a Commission to people like Freda Humble who are in the early stages of dementia, who might appreciate the security of knowing they could specify in a legal document the circumstances in which they would like to be able to end their life, once they had lost capacity. However, we consider that the requirement of mental capacity is an essential safeguard for assisted dying legislation, and we do not support the legalisation of euthanasia in any form, therefore the Commission does not propose any legislation that might allow non-competent people to receive assistance in ending their lives. Such a situation could clearly put very vulnerable people at great risk of manipulation and abuse. While an advance decision or other record of the patient's consistent wishes over time could play an important role in confirming the settled intention of a mentally competent person to choose an assisted death, we do not consider that such a document could legitimately substitute for a lack of competency at the time of the request or at the moment of death.

## **Principles for framing safeguards that could be included in a framework for assisted dying**

### **1 A decision-making model led by doctors**

In chapter 7 of this report we considered the range of options for how a legal framework for assisted dying might operate in the context of the UK and who might be tasked with assessing requests for assistance and ensuring that the legally defined eligibility criteria and safeguards were adhered to. A wide range of proposed models for decision-making were presented to the Commission, including primarily legal models, primarily medical models and combined approaches. Some medical professionals also insisted very strongly that assisted dying could have no legitimate place in medical care.

However, our assessment of the body of evidence overall has convinced us that it is health and social care professionals who have the knowledge, skills and training structures that would be needed to implement a safeguarded system to permit assisted dying in the UK. Central to such a system would be skilled professionals who can assess those who request an assisted death to confirm their diagnosis, explore their reaction to and understanding of their health condition, the motivation for their request, the voluntariness of their choice and their decision-making capacity. The evidence we have received has made it clear that these are all skills that many health care professionals, and particularly doctors, use daily. As we will discuss below, the professionals assessing the individual's request would also have a key role in informing this person of the available options for treatment, support and care, thereby promoting the uptake of end of life care. However, as mentioned above, we do not envisage that it could ever be appropriate for health or social care professionals to offer assisted dying as an option; only the patients themselves should be able to initiate a conversation about assisted dying.



Three of the four jurisdictions that permit assisted dying that Commissioners visited (the Netherlands, Belgium and Oregon) base their assisted dying framework around a model of medical decision-making and support, and even in Switzerland, where assisted dying is not officially regarded by the Swiss Academy of Medical Sciences to be part of a physician's role, there is a strong element of medical involvement in assisted suicide as the required lethal medication cannot be obtained without a doctor's prescription.<sup>977</sup> There is no precedent in other jurisdictions for the involvement of legal structures such as tribunals in making decisions about whether an individual might be eligible for an assisted death, therefore there is little evidence about the benefits and disadvantages of such an approach. In contrast, there is evidence from jurisdictions such as the Netherlands and Oregon that prospective assessment processes involving medical professionals are functioning well and that the safeguards set out in law to frame their decision-making are well observed.<sup>978</sup>

We are keenly aware that a doctor-led decision-making model for assisted dying would challenge some of the norms that currently prevail in the broader context of health and social care in the UK and we recognise that there are many health and social care professionals who are ethically opposed to any form of assisted dying and would not wish to take any role in assisting people to end their lives. As observed previously, Professor Clive Seale's research with doctors published in 2009 found that 'support for assisted suicide was slightly higher than for euthanasia, and where a terminal illness was present there was more support'.<sup>979</sup> However, the level of support for assisted suicide among doctors was found to be much lower than among the general public, with only 35 per cent of doctors supporting the option of assisted suicide for terminally ill patients.<sup>980</sup>

The experience of Oregon, where it was ordinary citizens rather than doctors who championed the Death with Dignity Act, suggests that this relatively low level of support among doctors should not present an insurmountable barrier to the decriminalisation of physician-assisted suicide. However, given the significant level of professional objections it would be essential that British doctors and other health and social care professionals should not be obliged to take part in assisting patients' deaths. As observed previously, Jane O'Brien, head of standards and ethics at the General Medical Council, gave her personal opinion that if physician-assisted dying were to be decriminalised, the medical profession 'would cope'.<sup>981</sup> It was also clear from the Medical Protection Society's evidence to the Commission that the main concern of many doctors is the lack of clarity over doctors' current responsibilities and liabilities in relation to the law on assisted suicide.<sup>982</sup> If doctors' legal position was made clear through the implementation of a legal framework, they could decide for themselves whether would be willing to participate in assisting a terminally ill patient's death, without the additional uncertainty caused by the fear of prosecution.

Just as UK legislation has previously dealt with conscientious objections to abortion, we consider that new legislation to permit assisted dying must protect doctors and other health and social care professionals who wish to opt out of involvement in assisted dying for ethical reasons. However, as with abortion, we suggest that if a doctor was unwilling to provide the requested assistance, it would be part of his or her duty of care to refer their patient to another doctor who did not conscientiously object

to providing the requested assistance (although he or she might decide that the individual was for some reason ineligible).

We propose that a safeguarded legal framework for assisted dying would require the involvement in assessment and decision-making of a minimum of at least two doctors. It would be critical that these two doctors were wholly independent of one another to ensure the decision-making process was robust and to prevent collusion. Where possible the first doctor would be somebody involved in the care of the patient. The second doctor would need to be an experienced professional who could offer an independent opinion and was prepared to challenge the decisions of the first doctor if necessary. The two doctors would take responsibility for making the decision on whether an individual met the eligibility criteria. They would where necessary and appropriate consult other persons including other healthcare professionals involved in the care of the subject. In addition to satisfying themselves that the eligibility criteria were met, they (or in the case of safeguards 5 and 6 the ‘first’ treating doctor) would also be legally responsible for ensuring that safeguards 2, 4, 5, 6, and 7 were met in each individual case.

### **The role of the first doctor**

We envisage that the first doctor would be one with usual responsibility for the patient’s care, who knows the patient well. This might be a specialist in the patient’s medical condition or the patient’s GP. The first doctor would take responsibility for overseeing the developing conversation with the patient about their medical condition, the treatment and care they wished to receive and, should they request it, their motivation for wanting an assisted death. This doctor would be responsible for the patient’s welfare and should continue to explore throughout the process the issues of whether their request for an assisted death is wholly voluntary and whether they have the capacity to make this request.

It is clear from the conversations we had with practitioners in jurisdictions that permit assisted dying that the first doctor would need to take time to explore the patient’s request for an assisted death in an open and compassionate manner, and where appropriate consult other health and social care professionals responsible for the patient’s care as part of this process. The first doctor would be in a good position to identify whether the patient’s request was a ‘cry for help’ expressing dissatisfaction with the patient’s current care, or anxieties about the dying process, rather than a genuine request for assisted dying.

As we discuss in more detail below (and in Appendix 2), we consider that if an assisted death was to go ahead, the first doctor should be responsible for arranging support for the patient and their family during and after the assisted death. Therefore, we envisage that the first doctor would have a greater level of involvement and responsibility than is currently the case in either Oregon or Switzerland.

### **The role of the second doctor**

We envisage that an assisted dying framework should also include the decisions of a second, independent doctor, who must have no pre-existing professional relationship with either the first doctor or the patient.

While the Dutch euthanasia legislation requires the second doctor to be professionally ‘independent’ of the first, the Oregon Death with Dignity Act does not contain this provision; it merely requires that the second doctor

'is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the patient's disease'.<sup>983</sup> We consider this element of 'independence' would be essential to ensure that the doctor was able objectively and independently to assess whether the conditions required by each of the safeguards had been met, and where necessary to challenge the first doctor's decision-making. We also consider that the second doctor should be someone experienced in providing end of life care, so he or she can provide their expertise and support. This doctor would check that all the safeguards had been met and appropriate records had been kept to document the assessment process.

We do not propose that the second doctor's role should be highly specialised or niche, and consider that a broad range of doctors with expertise in end of life care should be eligible to perform this role. In the Netherlands, the SCEN network has been developed to support doctors to build expertise in this role of providing a robust independent opinion and to ensure that an ethical and skilled approach is taken. The scheme established for the approval of second opinion appointed doctors under the Mental Health Act 1983 could also provide a useful model in this context.

## **2 The person has been fully informed of all available options for treatment and care**

We have proposed this safeguard to respond to the many pieces of evidence that the Commission received that expressed concern that a person might seek an assisted death without full understanding of the nature of his or her medical condition, how it was likely to progress, or the alternative options for treatment, care or practical support such as assistance in daily living that were available.

Demos's research for *The Truth about Suicide*, which explored the relationship between suicide and chronic and terminal illness, found that in a study of prostate cancer patients in the USA published in 2010 the risk of suicide was highest between one and three months following diagnosis. This risk decreased, but remained high for between four and 12 months after diagnosis.<sup>984</sup> These pieces of evidence emphasise the importance that a patient should not be allowed to progress with seeking an assisted death in the immediate aftermath of an upsetting diagnosis, without a full understanding of that diagnosis, and consideration of the many options for treatment and care that may be available. Many patients will require counselling following the diagnosis of a progressive, incurable condition and some patients may need treatment for depression, which research has shown to be associated with the desire for a hastened death in people with cancer and multiple sclerosis.<sup>985</sup>

We hope the existence of a legal framework for assisted dying for terminally ill people might facilitate more open discussions about patients' feelings of depression or despair following the diagnosis of a progressive, incurable illness and potentially avert some suicides through greater opportunities for counselling and treatment. A study conducted in Oregon showed that a significant proportion of people who request and obtain a lethal prescription do not necessarily intend to use it; between 1997 and 2006, 36 per cent of patients who obtained the prescription never used it. The authors of this study suggested that these patients may have derived sufficient peace of mind knowing they had control over their future.<sup>986</sup>

Chapter 3 explored at length the important role that end of life care can play in reducing patients' suffering. Professor Tim Maughan commented, 'My personal experience is that with good holistic care... requests for euthanasia or assisted dying have evaporated.' We do not propose that assisted dying should in any way replace 'good holistic care' or prevent patients from accessing such care. We expect that in most cases a patient who has been diagnosed with 'an advanced, progressive, incurable condition' will already be receiving some form of end of life care. Data collected in Oregon show that the vast majority of patients who have a physician-assisted death are already receiving hospice care<sup>987</sup> and the practitioners we interviewed in Oregon explained that a patient's request for an assisted death will usually initiate a referral to hospice if the person is not already enrolled in a hospice programme. As our core principles and recommendations demonstrate, we do not see assisted dying as an alternative to end of life care, or as something that could ever be offered to people. Instead, we view this as an option that a patient could request an assisted death if they felt they had reached the limits of what end of life care could provide for them and their suffering could not be alleviated in any other way. The briefing paper provided by the European Association for Palliative Care found that in Oregon and the Netherlands 'there is evidence that euthanasia/assisted suicide is related to the higher use of palliative care'.<sup>988</sup> Following our conversations with experts in a number of countries that permit assisted dying, we think the inclusion of this safeguard in an assisted dying framework could in fact increase some patients' access to palliative care by requiring the doctors involved to make sure that all options for end of life care had been fully explored.

The Commission strongly supports continued investment in improving the quality and consistency of end of life care across England and we feel reassured by the expert briefing paper provided by the European Association for Palliative Care, which did not find any evidence from European jurisdictions including Belgium and the Netherlands to suggest that the decriminalisation of assisted dying would be likely to impact negatively on the development of end of life care in England.<sup>989</sup>

However, while we recognise the essential role that end of life care can play in relieving patients' suffering and supporting their families to care for them, we also do not think a patient should feel compelled to accept treatment that he or she may find burdensome or unhelpful, in order to demonstrate that all options had been explored. For this reason, we recommend that people must be informed of all alternative options for treatment and care before they may proceed with assisted dying, but not that they should be required to experience this care.

In addition to these issues about access to treatment, care and support, it is also essential if an individual is to make a properly informed choice about assisted dying that he or she is fully aware of any potentially negative or unexpected consequences that might be associated with the process itself (for example, regurgitation or failure of the medication to end the individual's life).<sup>990</sup> Therefore, to ensure a person who had made a request for an assisted death was 'fully informed of all available options', it would be necessary for the first and second doctors to fully inform the person about the assisted dying process, the medication and procedures that might be used, and any possible problems or side-effects associated with the process.

### 3 The first and second doctors have come to a decision independently about whether the legally required eligibility criteria are met

The Commission has recommended three eligibility criteria that could be included in an assisted dying framework to limit those who might legitimately request assistance to die:

- a diagnosis of terminal illness
- voluntariness and absence of coercion
- the person has the mental capacity to make an informed choice.

Within the physician-led model of decision-making and support that we have proposed, the first and second doctor would both be required to certify independently and document that the safeguards underpinning these eligibility criteria had been met.

The first criterion requiring a diagnosis of terminal illness would need each doctor to certify that the person was terminally ill and had, as derived from the General Medical Council's guidance, an *advanced, progressive, incurable condition that is likely to lead to the patient's death within the next 12 months*.<sup>991</sup> However, as previously discussed, we are not proposing that a patient should be allowed to proceed with requesting an assisted death in the immediate aftermath of an upsetting diagnosis and without careful consideration; the patient must have been fully informed of all other options for treatment and care that are available.

The second criterion, requiring that the person requesting an assisted death made this request voluntarily and without coercion, would particularly rely on the skills of the first doctor, whom we envisage would have an established relationship with the person requesting this assistance, and be familiar with their personal history and family context. The experts and practitioners whom the Commission met in the Netherlands and Belgium particularly emphasised the importance of this relationship. We will discuss in Appendix 2 the types of formal and informal safeguard that might be included in legislation to ensure the individual's motivation for requesting an assisted death has been explored thoroughly, and that there was evidence of this voluntariness. However, above all, it would be essential that only the person who wished to request an assisted death could initiate and progress this request. It would also be extremely important that both the first and second doctors made time to discuss the individual's motivation with them in depth. This would require more than one conversation over a period of time, including at least one conversation with the person on their own. These discussions would be particularly important if the doctor did not have a long-standing relationship with the patient, for example if their usual physician had a conscientious objection to assisted dying and the patient had had to seek a new physician who did not have a principled objection to considering their request. In these circumstances the physician might particularly wish to consult other professionals who know the patient well, such as their family doctor, community nurse or social worker, to explore whether any external factors or relationships might be influencing the person's request.

The third eligibility criterion recommended by the Commission, that the person has the mental capacity to make an informed choice, has been informed by the evidence provided by the many psychiatrists, psychologists,

doctors, mental health experts and other advocates who gave evidence to the Commission including Professor Matthew Hotopf, Dr Annabel Price, Ms Christine Kalus, Dr Andrew McCulloch, Dr Tony Zigmond and David Congdon. Dr Annabel Price observed, 'All registered medical practitioners should be able to assess capacity, but psychiatrists are often asked to provide a second opinion when the decision being made has serious or very significant consequences'.<sup>992</sup> Ms Christine Kalus, lead consultant clinical psychologist and specialist in palliative care, suggested that capacity assessments 'should involve consensus decision making by a multidisciplinary team (where possible), and a robust assessment taking into account the legal, medical and psychosocial aspects of the patient's situation'.<sup>993</sup> Dr Andrew McCulloch also suggested in his evidence that in difficult cases a range of professionals might play a role in assessing whether the individual's capacity was impaired by their mental health condition: 'Well in some cases mental health nurses, occupational therapists and other mental health professionals could help. It would very much depend on what sort of input the person had in the past'.<sup>994</sup>

Ms Kalus also suggested that a healthcare professional would be better able to assess a patient's capacity if he or she knew the patient well, and that gaps in knowledge could potentially be filled through talking to other members of the team responsible for caring for the patient, or members of the patient's family. Ms Kalus suggested that advance decisions could be useful in this context, as 'as one can detect a pattern of consistency or inconsistency with regard to their decisions, which could contribute to the assessment of capacity at the time of requesting assisted dying'.<sup>995</sup> Dr Tony Zigmond observed that 'capacity decisions in relation to assisted dying can be made over a period of time and with as much consultation and investigation as is required'.<sup>996</sup> David Congdon of Mencap suggested that providing the individual with access to an independent advocate 'to try to make sure that what is going on is actually what the individual really, really wants' could also be an important safeguard.<sup>997</sup>

As we discussed in chapter 7 of this report, evidence has emerged from academic studies conducted in Oregon that a small number of people who died under the provisions of the Oregon Death with Dignity Act had clinical depression that might have impaired their decision-making capacity.<sup>998</sup> It would of course be the role of the relevant professional bodies to develop a detailed code of practice for the assessment of mental capacity to safeguard decisions about assisted dying. However, it is clear from the research emerging from Oregon that such a code of practice would need to include specific measures to identify people experiencing depression or other psychological disorders that could potentially impair that person's judgement. Once detected, if a person's depression did not respond to treatment, it is likely that further specialist input would be required, and it might be necessary to exclude that person from obtaining an assisted death. We will discuss particular measures that could be put in place to assess people's mental capacity and detect depression in Appendix 2.

#### **4 The person has a settled intention to die**

The Commission envisages that a person would only initiate the process of requesting an assisted death after considerable discussion with their doctor. In some cases this might have taken place over many months or years, following their diagnosis with a progressive, incurable condition. In other



cases, the period of discussion might have been shorter. We do not envisage that a formal process, such as the framework outlined in Appendix 2, would be initiated until the person had made the decision they would soon be in a position where they were ready to end their life. Given that the person concerned would need to have an advanced, progressive, incurable disease according to the proposed eligibility criteria, the Commission considers that it would be inappropriate to suggest safeguards that would require a very lengthy approval process at this point. However, it is also important that some time should be built into the process to ensure that the patient's decision cannot be made hastily, and that it is a settled decision to die, as opposed to a fluctuating wish. We will discuss particular waiting periods that could be built into the process to prevent hasty decision-making in Appendix 2. This will include the proposal that, as the Belgian legislation requires, if the person requesting an assisted death was 'clearly not expected to die in the near future',<sup>999</sup> the framework could stipulate a longer waiting period between the patient's initial request and the time of the assisted death being carried out. Both doctors would be responsible for ensuring this safeguard was complied with.

## **5 The safe storage and transportation of lethal medication**

In the Netherlands and Belgium, once a patient has requested assisted dying it is very much the doctor's responsibility to remain alongside the patient for the remainder of the process. In the Netherlands and Belgium, euthanasia accounts for the vast majority of assisted deaths, and assisted suicide only a very small proportion. Should a patient opt for an assisted suicide in either of these countries, it is considered part of the doctor's duty of care that he or she should be present at the moment of the patient's death to assist and address any issues that might arise. This means there are very few problems with the storage and transportation of the lethal medication, which remains the responsibility of the physician concerned.

However, in Oregon and Switzerland, where it is assisted suicide as opposed to voluntary euthanasia that is legal, doctors often play a fairly limited role in the assisted death itself and trained volunteers or family members are more likely to be on hand to assist when the actual death takes place. In Switzerland, it is usually a trained volunteer from the suicide organisation (such as Exit DS or Dignitas) who is responsible for collecting the lethal medication from the pharmacy and bringing it to the person who wishes to end his or her life.

In Oregon, any appointed person such as a family member or a volunteer from Compassion and Choices may pick up the lethal medication from the pharmacy and deliver it to the patient's home. The medication could then remain in the patient's home for a year or more; no safeguards are in place to ensure that the medication is stored safely and returned to the pharmacy if unused. During the Commission's research visit to Oregon, Professor Ganzini expressed concerns about the lack of regulation of the lethal prescriptions issued under the Death with Dignity Act. She said: 'What we work on is making sure it's under lock and key, and the key is separate, because you just don't want somebody in a low point to be able to easily access this thing'.<sup>1000</sup> Gary Schnabel, Executive Director of the Oregon State Board of Pharmacy, also identified this element of the Death with Dignity Act as problematic.



We are very concerned to avoid the potentially dangerous ramifications of allowing lethal medication to be kept in an unregulated manner in the community, in a private home, residential care home, hospice or hospital. Therefore, we have suggested a number of safeguards in Appendix 2 that could ensure the lethal medication that would be required to bring about an assisted death was stored and transported safely. Most importantly, the doctor responsible for prescribing the lethal medication, or another suitably qualified healthcare professional, would be expected to deliver the medication to the patient personally and wait until the patient had either taken the medication or declined to take the medication. If the medication was unused we recommend that it should be legally required that it is returned to the pharmacy.

## **6 The person has a reliable and supported assisted death**

### **The type of assisted dying permitted**

As stated above, we recommend that assisted suicide and not voluntary euthanasia should be permitted by any future assisted dying legislation in this country. As interviewees in Oregon argued, assisted suicide, whereby the individual must take the medication that will end their own life, underlines the autonomy of the individual's act and thereby provides an additional safeguard regarding the voluntariness of the individual's choice. It is difficult to see how assisted suicide could in any way lead to a slippery slope towards non-voluntary euthanasia as suggested by some commentators, as doctors or family members would be prohibited from directly administering medication to a patient. Another benefit of assisted suicide, as noted above, is that it has more support among doctors than voluntary euthanasia; therefore it is likely that this would present fewer problems in implementation as more doctors would be willing to take part.

However, the Commissioners who visited Oregon were surprised by the very restrictive nature of the Death with Dignity Act, which only permits one variety of medication to be used and requires the individual to swallow a large quantity of medication in a very short period of time if the medication is to be effective. We are concerned that such an approach could be unnecessarily burdensome for the person taking it. Therefore, the Commission would like to recommend a more personalised process, which would provide the patient with options for taking the medication that could be tailored to the individual's circumstances and provide equal access to assisted suicide for disabled people with a terminal illness who might require reasonable adjustments to the process.

If assisted dying legislation was to be passed in the UK, we recommend that the Department of Health would need to consult palliative medicine and pharmacology experts to develop a clinical protocol or code of practice that would provide guidance on the types and doses of medication that could be used and the ways in which the patient might take the medication. Further details are proposed in Appendix 2.

### **The prescribing doctor's responsibility**

The Commissioners were also surprised during their visits to Oregon and Switzerland that doctors in these jurisdictions might prescribe a patient lethal medication and then have no further involvement in supporting that individual's death. We consider that a doctor who prescribes lethal medication for the purpose of an assisted death should have ongoing responsibility for

the care of that patient and their family during and after their death, as is the case in the Netherlands and Belgium.

Before the first doctor writes the prescription for the lethal medication, we recommend that this doctor and patient should have agreed what support will be in place during the patient's death and how the patient will bring about their own death. The doctor, or another suitably qualified healthcare professional, should be available to provide any support that the patient and their friends or family members might need at the point when the lethal medication is taken.

### **Bereavement support for friends and relatives**

Bereavement support should be available to people who need it in all contexts, regardless of the circumstances of their loved one's death. The Commissioners recognise that the quality of bereavement support available to friends and relatives can vary depending on the location of the loved one's death. Assisted deaths may be more likely to take place at home, which may make it more difficult for the friends and family members left behind to access the supportive infrastructure provided by hospices and hospitals. Therefore we suggest that the first doctor with legal responsibility for assisting the patient's death should have a continuing responsibility for supporting the patient's friends and relatives after his or her death. To facilitate this role, the doctor should ensure he or she has knowledge of the local bereavement support services that are available and, where appropriate, should direct bereaved friends or relatives to these services.

## **7 Correct reporting procedures following the death**

Following the patient's death, the doctor or other suitably qualified healthcare professional overseeing the death should be required to certify the individual's death. This should be recorded on the death certificate in a way that would allow retrospective auditing to identify the cause of death. The doctor should also be required to report the death to a national monitoring commission responsible for regulating the practice of the law (see the policy recommendation to establish such a monitoring commission in chapter 12).



## 12 Changes to law and policy

The Commission on Assisted Dying was set up to explore and provide an evidence-based answer to the question of what a framework for assisted dying might look like, if such a system was to be implemented in the UK. However, the purpose of the Commission was not to recommend whether such a system should pass into law in the UK, or within what timeframe it might be passed into law, as this decision must be made by Parliament on behalf of society as a whole.

This chapter briefly sets out the changes to law and policy that the Commission considers would be required if a legal framework to permit assisted dying for terminally ill adults was to be implemented successfully in the UK. As the previous chapters have discussed in detail, the Commission considers that if a process for requesting an assisted death is to be offered, it should be embedded within the existing framework of care and support that is available through health and social care services to ensure that requests for assisted dying were properly explored, assessed and supported by trained professionals and that inappropriate requests that did not meet the eligibility criteria would be refused. The Commission also recognises that substantial improvements to health and social care services would be needed in parallel with changes to assisted suicide legislation if policy-makers were to ensure that all people approaching the end of life were to have access to high quality end of life care and – for those who wanted it – a robustly safeguarded process for requesting an assisted death. Both of the identified objectives of improving care and support for people at the end of life and correcting the current unsatisfactory legal position on assisted dying should be pursued alongside each other but neither objective should be conditional on the other.

We also recognise that in countries that currently legally permit assisted dying, the legislation is only a small (but important) piece of the picture. Professional training, guidance and support are essential features of these regimes to promote responsible, exemplary practice and adherence to the spirit and letter of the law. Therefore we will consider in the following recommendations what policies and guidance might need to be in place to inform and underpin effective assisted dying legislation. Ongoing monitoring, evaluation and research would be a vitally important aspect of this; we have learnt from our visits to the Netherlands, Belgium, Oregon and Switzerland that transparent and high quality data are essential to allow effective scrutiny of who is making use of assisted dying, and how well professionals are adhering to the law in its implementation. Well-informed public debate is also an important safeguard and if assisted dying was to be legalised in the UK, policy-makers and members of the public would need access to accurate and reliable data to inform their discussions of how well the law was working, and whether any further changes to policy or legislation might be needed. The administrations in Oregon and the Netherlands are

particularly exemplary in the quality of the data they collect and publish on use of assisted dying legislation in their jurisdictions, whereas Switzerland is remarkable for the fact that no centralised data on assisted suicide is collected at all. There are many lessons to be learned from this.

The following points set out below summarise the changes to law and policy that the Commission considers would be needed if assisted dying legislation was to be implemented effectively in the UK.

### **Continuing government investment in improving end of life care**

As we have demonstrated throughout this report, the Commission supports strongly the key aims of the End of Life Care Strategy for England and is convinced that sustained government investment will be required to improve access to high quality generalist and specialist end of life care, to be available to all who need it. It is likely that the level of investment will need to increase in coming years (in both health and social care) to meet the demands of an ageing population, which will increase the rate of people dying each year nationally, while improving the quality of provision. The Government must prioritise taking action to tackle the inequalities in end of life care that have been identified in this report, along with the uncertainty and fragmentation of funding sources that support this area of care. The Commission fully supports the Dying Matters Coalition in its work on promoting the discussion of death and dying at an individual and societal level and we consider that end of life care and the infrastructure needed to support assisted dying would need to be developed in parallel to allow genuine, well-supported choices for patients at the end of life.

The NHS Constitution outlines the values that underpin the NHS (respect and dignity; commitment to quality of care; compassion; improving lives; work together for people; everyone counts). A law to allow assisted dying for terminally ill people would require these values to be demonstrated solidly throughout the NHS for the public to feel confident that their rights under the constitution are a daily reality. Safe implementation will require year on year improvement in health and social care as outlined in the recent progress report on the implementation of the End of Life Care Strategy.<sup>1001</sup> These improvements might include that community services must be sufficiently developed to support those people who wish to die at home (including a care home); appropriate training in working with people at the end of life might be a required element in the training of health and social care professionals developed by the respective bodies concerned with standards; and all health and social care services must meet the minimum requirements for care as outlined in the national standards inspected by the Care Quality Commission.

### **A bill to decriminalise physician-assisted suicide for the terminally ill**

We recognise that the Commission is not able to resolve the polarised ethical debate surrounding assisted dying and it explicitly did not set out to do so. Instead, we have addressed the practical issues surrounding the implementation of a legal process to permit assisted dying in the UK. It is now for Parliament to decide whether the current legal status of assisted suicide meets the needs of our society, and whether it could be appropriate to adopt

a legal framework for assisted dying. There would be a clear need for a more inclusive public debate to inform this process, involving all sectors of society including those often considered ‘hard to reach’ and professionals from all relevant disciplines including palliative care specialists, general practitioners, nurses, social workers and pharmacists.

If Parliament should consider such a statute, the Commission recommends that it could adopt the principles set out in this report: that it will not be a crime if a doctor assists a person to take his or her own life, if the person has an advanced, progressive, incurable condition that is likely to lead to his or her death within the next 12 months, and if the correct safeguards and procedures are observed. Appendix 2 sets out a detailed procedural framework that could inform such a bill.

The Commission recommends that any future bill should include a clause to permit doctors and other health and social care professionals who conscientiously object to the practice of assisted dying to opt out of any involvement. This bill should also include a clause specifying that any insurance policy that has existed for 12 months at the time of the patient’s death will not be invalidated, and that for insurance purposes the death will be treated as a natural death.

We suggest that if such a bill was passed, it could be implemented within a period of two years of the statute being passed. The initial period before the statute came into force would allow time for the appropriate policies, procedures and training to be developed at a national and local level. If such a bill was passed, the Commission recommends that five years after its implementation, a full review should take place, using the data gathered by the monitoring commission, with a Parliamentary debate to determine whether any changes or clarifications in the law might be required.

### **Continuing use of the DPP policy for prosecutors in non-terminal cases**

The Commission was unable to reach a consensus on the issue of whether a person who has had a catastrophically life-changing event that has caused them to be profoundly incapacitated should be able to request an assisted death, and we consider that this lack of consensus reflects the mixed views of society on this issue. Bearing in mind the considerable concerns of many disabled people about such a provision, we have recommended that it would not be appropriate for such a provision to be included in future legislation.

However, the powerful evidence we have received from Tony Nicklinson and the police officers who were responsible for investigating the death of Daniel James has impressed on us the importance that people who agree to assist a non-terminally ill loved one, who has suffered such a catastrophic life-changing event, to commit suicide for wholly compassionate reasons should continue to be treated by the law with compassion and understanding. Therefore, we suggest that the Director of Public Prosecutions’ prosecution policy should continue to be applied to those cases that might fall outside the scope of the legislation we are proposing for consideration (for example assisted suicides involving people with chronic illnesses or significant physical impairments, who are not terminally ill).

## **Codes of practice specifying appropriate professional conduct for health and social care professionals involved in assisted dying**

The relevant professional bodies, including the General Medical Council and the Nursing and Midwifery Council would need to develop codes of practice to guide appropriate professional conduct and specify appropriate training and levels of experience for professionals who take a role in assisted dying. We suggest that the ‘second doctors’ involved in safeguarding the assisted dying process should be required to have at least five years’ experience after higher professional or specialist training and should be experienced in providing end of life care to ensure they have appropriate medical expertise for this role.

The National Institute for Health and Clinical Excellence might provide guidance on the appropriate medication for the patient to use in ending his or her own life and the correct procedures to be followed, in consultation with pharmacologists and other practitioners.

## **Supervision and support for doctors who are involved in cases of assisted dying**

We have received sufficient evidence from historical published data and verbal testimonies in the UK and abroad that doctors who are likely to be involved in the implementation of any future change in the law to allow physician-assisted dying should receive extra training, supervision and support. The areas in which doctors are most in need of these are:

- training in recognising ‘terminal illness’, not just in cancer patients but also in those with other chronic and life-limiting diseases
- training in recognising depression and in using suitable screening tools in the context of an interview to assess the person for depression and documenting the results
- training in being aware of the needs of bereaved friends and relatives and in accessing local resources and services to support these needs
- supervision in the implementation of any future medically assisted dying, especially in writing prescriptions, reporting procedures, record-keeping, and complying with annual reports and audits
- access to support with dealing with the considerable stress that may be associated with witnessing and participating as a medical practitioner in assisted dying, including peer support, regional groups and possibly a national helpline; the SCEN or LEIF networks in the Netherlands and Belgium, as discussed in chapter 8, might provide appropriate models for developing such support networks
- access to support for conscientious objectors, who may be under stress because of a request for assisted dying by a patient whom they might know very well but feel unable to comply with their wishes.



## **Robust procedures for monitoring the uptake of the legislation and for reporting deaths**

We suggest that doctors and other professionals who take part in assisting deaths should be required to give notification to a national monitoring body (outlined in the next section) at a number of different points in the process to provide a check on individual professionals' practice and allow for robust monitoring. We suggest that these points might include:

- when a doctor first approves an individual's request for an assisted death
- when the pharmacist issues the lethal medication
- when the death had occurred.

While we recognise the sensitivities involved, we suggest that the death certificate should make the immediate cause of the individual's death clear to allow for independent auditing and retrospective study.

## **A national monitoring commission**

This national monitoring commission could be an independent statutory body that reports to the Department of Health. We envisage this as a post-hoc review body, as opposed to a court of appeal, which could have powers to investigate problematic cases where there are suspected compliance issues. We do not envisage that the monitoring commission would play a role in giving advice to doctors on difficult cases; this function could fall to peer-support networks or regional advice forums as outlined above.

We envisage that the monitoring commission would be national body with legal, medical and ethical input. It could have four main functions:

- monitoring and reviewing every individual case for compliance with the law, taking further investigatory action in cases of potential non-compliance and referring instances of malpractice to the professional bodies or prosecutorial authorities where appropriate
- encouraging (and potentially funding) prospective independent academic research on the process and the consequences of the introduction of an assisted dying framework
- publishing anonymised information on 'difficult cases' to inform and develop doctors' professional practice in cases of assisted dying that might be regarded as particularly problematic; this role is currently performed in an exemplary manner by the five Dutch regional review committees, which collectively publish a very informative annual report
- collecting and publishing national data on reported cases of assisted dying and publishing an annual report to Parliament each year; findings from these reports could be used to inform ongoing policy development and at the end of the first five years the monitoring commission could assist Parliament in conducting a full review of the law's implementation.



# Appendix 1

## Individuals and organisations that gave evidence to the Commission

The full list of those who provided written evidence, and their written evidence submissions, can be found at: [www.commissiononassisteddying.co.uk/read-evidence](http://www.commissiononassisteddying.co.uk/read-evidence).

Each evidence submission has been assigned a number to enable the individual submissions to be located easily on the website. Where relevant, submission numbers are provided below for ease of reference.

### **Witnesses who gave oral evidence**

Peter Bailey, trustee of the board of Leonard Cheshire Disability  
Evidence submission no 29

Professor Mike Bennett, Professor of Palliative Medicine, International Observatory on End of Life Care, Lancaster University  
Evidence submission no 75

Dr Stephanie Bown, Director of Policy and Communications and Dr Lillian Field, medical legal adviser, Medical Protection Society  
Evidence submission no 70

Chris Broad  
Evidence submission no 342

David Congdon, head of campaigns and policy, Mencap  
Evidence submission no 126

Andrew Copson, Chief Executive, British Humanist Association  
Evidence submission no 127

Suzy Croft, senior social worker, St John's Hospice  
Evidence submission nos 76a (transcript of oral evidence) and 76b (written evidence)

Dr Martin Curtice, consultant in old age psychiatry, Birmingham and Solihull Mental Health NHS Foundation Trust  
Evidence submission no 343

Alan Cutkelvin Rees  
Evidence submission no 129  
Gary Fitzgerald, Chief Executive, Action on Elder Abuse  
Evidence submission no 125

Revd Professor Robin Gill, Professor of Applied Theology, University of Kent  
Evidence submission no 33

Simon Gillespie, Chief Executive, Multiple Sclerosis Society  
Evidence submission no 123

Martin Green, Chief Executive, English Community Care Association  
Evidence submission no 344

Richard Hawkes, Chief Executive and Alice Maynard, Chair, Scope  
Evidence submission no 11

Professor Tony Hazel, Chair, and Roger Thompson, Director of Nursing and  
Midwifery Policy and Standards, Nursing and Midwifery Council  
Evidence submission no 1031

Professor Matthew Hotopf and Dr Annabel Price, Institute of Psychiatry,  
King's College London  
Evidence submission nos 414a (transcript of oral evidence) and 414b  
(written evidence)

Dr Richard Huxtable, Senior Lecturer and Deputy Director of the Centre for  
Ethics in Medicine, University of Bristol  
Evidence submission no 343

Lord Joel Joffe, proponent of the 2004 and 2005 Assisted Dying for the  
Terminally Ill Bills  
Evidence submission nos 340a (transcript of oral evidence), 340b  
(written evidence) and 340c (written evidence)

Christine Kalus, Lead Consultant Clinical Psychologist, Specialist Palliative  
Care, Solent NHS Trust and Dr Rebecca Coles-Gale, Clinical Psychologist,  
Specialist Palliative Care, The Rowans Hospice, representing the British  
Psychological Society  
Evidence submission nos 339a (transcript of oral evidence) and 339b  
(written evidence)

Professor Penney Lewis, Professor of Law, King's College London  
Evidence submission nos 412a (transcript of oral evidence) and 412b  
(written evidence)

Professor Tim Maughan, Consultant Clinical Oncologist and Professor of  
Cancer Studies, Cardiff University  
Evidence submission no 73

Andrew McCulloch, Chief Executive, Mental Health Foundation  
Evidence submission no 128

Dr Ann McPherson, Professor Ray Tallis and Professor Joe Collier,  
Healthcare Professionals for Assisted Dying  
Evidence submission nos 124a (transcript of oral evidence) and 124b  
(written evidence)

Jane Nicklinson and Saimo Chahal, on behalf of Tony Nicklinson  
Evidence submission nos 12 (transcript of oral evidence) and 6 (written  
evidence). Please see evidence submission nos 4, 5 and 19 for further evidence  
from Tony Nicklinson.

Baroness Onora O’Neill, crossbench life peer and Professor of Philosophy,  
University of Cambridge  
Evidence submission no 28

Paul Philip, Deputy Chief Executive and Jane O’Brien, Assistant Director,  
Standards and Ethics, General Medical Council  
Evidence submission no 77

Debbie Purdy  
Evidence submission no 13

Rabbi Danny Rich, Chief Executive, Liberal Judaism  
Evidence submission no 31

Professor Sir Mike Richards, National Clinical Director for Cancer and End  
of Life Care, Department of Health  
Evidence submission no 74

Bridget Robb, Development Manager, BASW – The College of Social Work  
Evidence submission no 71

Joyce Robins, Co-Director, Patient Concern  
Evidence submission no 341

Lucy Scott-Moncrieff and Robert Robinson, Scott-Moncrieff & Associates LLP  
Evidence submission nos 411a (transcript of oral evidence) and 411b  
(written evidence)

Professor Clive Seale, Professor of Medical Sociology, Barts and the London  
School of Medicine and Dentistry, Queen Mary University of London  
Evidence submission nos 9a (transcript of oral evidence) and 9b  
(written evidence)

Pauline Smith, End of Life Care and Dementia Lead, NHS West Midlands  
Evidence submission no 72

Keir Starmer QC, Director of Public Prosecutions  
Evidence submission no 8

Detective Inspector Adrian Todd and Detective Constable Michelle Cook,  
West Mercia Police  
Evidence submission no 413

Dr Adrian Tookman, Consultant Physician in palliative medicine, Royal Free  
Hampstead NHS Trust and Medical Director, Marie Curie Hospice  
Evidence submission no 10

Baroness Mary Warnock, crossbench life peer and moral philosopher  
Evidence submission no 30

Sarah Wootton, Chief Executive, and Davina Hehir, Head of Policy,  
Dignity in Dying  
Evidence submission nos 32a (transcript of oral evidence)  
and 32b (written evidence)

### **Organisations that submitted written evidence**

British Association of Social Work (The College of Social Work)  
Evidence submission no 53

British Geriatrics Society  
Evidence submission no 250

British Humanist Association  
Evidence submission no 277

British Psychological Society  
Evidence submission nos 339a (transcript of oral evidence) and 339b  
(written evidence)

Church of Wales Bio-Ethics Group  
Evidence submission no 47

Dignitas  
Evidence submission no 1012

Dignity in Dying  
Evidence submission nos 32a (transcript of oral evidence) and 32b  
(written evidence)

Exit  
Evidence submission no 51

Friends at the End  
Evidence submission no 37

Healthcare Professionals for Assisted Dying  
Evidence submission nos 124a (transcript of oral evidence)  
and 124b (written evidence)

Help the Hospices  
Evidence submission no 279

The National Centre for Social Research  
Evidence submission nos 972a (written evidence) and 972b (report extract)

Practitioner Alliance Against the Abuse of Vulnerable Adults (PAVA UK)  
Evidence submission no 947

Royal College of General Practitioners  
Evidence submission no 251

Royal College of Surgeons  
Evidence submission no 278

Scott-Moncrieff & Associates  
Evidence submission nos 411a (transcript of oral evidence)  
and 411b (written evidence)

Swiss Federal Office of Justice  
Evidence submission no 1013

World Federation of Right to Die Societies  
Evidence submission no 496

### **Attendees at the AHRC policy seminar**

Professor David Archard, Society for Applied Philosophy  
Professor Hazel Biggs, University of Southampton  
Isra Black, King's College London  
Professor Margaret Brazier, University of Manchester  
Professor Bobbie Farsides, Brighton & Sussex Medical School  
James Harris, Dignity in Dying  
Professor Emily Jackson, London School of Economics  
Martin John, Office of the Public Guardian  
Dr Caroline Jones, University of Southampton  
Professor Penney Lewis, King's College London  
Dr Brendan McCarthy, Church of England Archbishops' Council  
Alex Mullock, University of Manchester  
Professor Richard Norman, British Humanist Society  
Professor Rosamund Scott, King's College London  
Professor Clive Seale, Queen Mary, University of London  
Lord Warner, House of Lords  
Evidence submission no 1030



## **Individuals and organisations the Commission members met and received evidence from during their international visits**

### **Oregon**

Barbara Farmer, Director, Legacy Hospice

Professor Linda Ganzini, Professor of Psychiatry and Medicine, Oregon Health & Science University

Professor Barbara Glidewell, division of Internal Medicine and Geriatrics and Administrative Director for the Interprofessional Ethics Fellowship program, Center for Ethics in Health Care, Oregon Health and Sciences University

Dr Katrina Hedberg, Oregon Health Authority

Anne Jackson, former Director, Oregon Hospice Association

Judge Robert Jones, Senior Judge for the United States District Court for the District of Oregon

Susan King, Executive Director, Julia Gies and Sue Davidson, Oregon Nurses Association

Barbara Coombs Lee, President, Compassion and Choices

Gary Schnabel, Executive Director, Oregon State Board of Pharmacy

Joe Schnabel, Pharmacy Manager, Salem Hospital

Deborah Whiting Jaques, CEO, Oregon Hospice Association

Compassion and Choices of Oregon (volunteers Esther Bell, Susan Smith and Ann Woeste and co-medical directors Dr Peter Lyon and Dr Peter Rasmussen)

### **Belgium**

Professor Bert Broeckert, Director of the Interdisciplinary Centre for Religious Studies, Katholieke Universiteit Leuven

Professor Luc Deliens and Professor Lieve Van den Block, End-of-Life Care Research Group, Vrije University, Brussels

Paul Destrooper and Kris Van de Gaer, Life End Information Forum (LEIF)

Jacqueline Herremans, President, Association pour le Droit de Mourir dans la Dignité (Belgian Right to Die Society or ADMD)

Professor Herman Nys, Director of the Centre for Biomedical Ethics and Law, Katholieke Universiteit Leuven

Dr Marc Englert, Raymond Mathys, Roger de Bondt, Françoise Damas, Jacqueline Herremans, Commission Fédérale de Contrôle et Évaluation (The Federal Control and Evaluation Commission, or CFCE)

### **Switzerland**

Bernhard Sutter, board member, Exit Deutsche Schweiz (DS)

Christian Bretscher, a former congressman who also has personal experience of Exit DS

Professor Christian Kind, President of the Central Ethics Committee, Dr

Marcus Zimmerman-Acklin, Deputy Secretary General and Michelle Salathé, Head of the Ethics Division, Swiss Academy of Medical Sciences

Ludwig Minelli, Founder and General Secretary and Silvan Luley, part-time working member, Dignitas

Andreas Brunner, Chief Public Prosecutor, Zurich Canton

Professor Georg Bosshard, Associate Professor for Clinical Ethics, University of Zurich and Senior Medical Officer, Oberi Nursing Home

## The Netherlands

Professor Inez de Beaufort, Erasmus Medical Centre, Rotterdam, and representative of the regional review committees (the Commission met Professor Beaufort in London)

Dr Gert van Dijk, secretary of the Medical Ethics Committee, Department of Medical Ethics and Philosophy of Medicine, Erasmus Medical Centre, Rotterdam; part-time ethicist, Royal Dutch Medical Association (KNMG) and member of the Review Board on Euthanasia

Dr Agnes van der Heide, senior researcher at Department of Public Health, Erasmus Medical Centre, Rotterdam

Dr Bregje Onwuteaka-Philipsen, Professor of End of Life Research, VU University Medical Centre, Amsterdam

Dr Christiaan Rhodius and Jennifer Straatman, St Jacob's Hospice, Amsterdam

Dr Bernadina Wanrooij, palliative care coordinator and consultant, and Dr Guus Fons, gynaecologist, Academic Medical Centre, Amsterdam

Eric van Wijlick, senior policy adviser, Royal Dutch Medical Association (KNMG)

## Organisations and individuals the Commission invited to give evidence

### Organisations

Academy of Medical Royal Colleges

Age UK

Alert

Alzheimer's UK

Association for Palliative Medicine

Association of British Neurologists

Association of Directors of Adult Social Services

Association of Hospice and Palliative Care Chaplains

BMA Ethics Committee

British Institute of Human Rights

British Medical Association

British Psychological Society

Care Not Killing

Carers UK

Disability Alliance

Disability Awareness in Action

Dying Matters Coalition

Equalities and Human Rights Commission

Exit

Huntingdon Disease Association

Living and Dying Well

Macmillan Cancer Support

Marie Curie Palliative Care Institute

Marie Curie Cancer Care

Mind

Motor Neurone Disease Association

Multiple Sclerosis Trust

Muslim Council of Great Britain

National Council for Palliative Care  
National Pensioner's Convention  
Parkinson's Disease Society  
Patients Association  
Progressive Supranuclear Palsy Association  
Royal College of Anaesthetists  
Royal College of Nursing  
Royal College of Physicians  
Royal College of Psychiatrists  
Royal Society of Medicine  
Sue Ryder Care  
The Stroke Association

### **Individuals**

Dr Idris Baker, Consultant and Lead Clinician in Palliative Medicine, Abertawe Bro Morgannwg University Local Health Board  
Dr Christopher Baxter, Medical Director, North London Hospice  
Professor Nigel Biggar, Regius Professor of Moral and Pastoral Theology, University of Oxford  
Dr Krishnakant Buch, GP, Lower Broughton Health Centre, Salford  
Baroness Jane Campbell, crossbench life peer and Chair, All Party Parliamentary Disability Group  
Rt Revd and Rt Hon Richard Chartres, Bishop of London  
Dr Mark Clayton, GP, Bideford Medical Centre, Devon  
Lord Nigel Crisp, crossbench life peer, House of Lords  
Dr Andrew Davies, Consultant in Palliative Medicine, Royal Surrey County Hospital  
Alison Davis, National Coordinator, No Less Human  
Dr Jennifer Dixon, Director, Nuffield Trust  
Professor Phil Fennell, Professor of Law in Cardiff Law School, University of Wales  
Dr David Feuer, Consultant in Palliative Medicine, St Bartholomew's Hospital, London  
Frank Field MP  
Baroness Ilora Finlay, Professor of Palliative Medicine, Cardiff University School of Medicine  
Dr Rob George, Consultant in Palliative Care, Guy's and Thomas' Foundation Trust  
Baroness Brenda Hale, Justice of the Supreme Court  
Chris Ham, Chief Executive, The King's Fund  
Lord Khalid Hameed, crossbench life peer  
Professor Rt Rev Lord Harries, crossbench life peer and Gresham Professor of Divinity  
Diane Haywood, Macmillan Lead Nurse, Specialist Palliative Care, Barts and the London NHS Trust  
Professor Irene Higginson, Professor of Palliative Care and Policy, King's College London  
Dr Andrew Hoy, Consultant in Palliative Medicine, Princess Alice Hospice, Surrey  
Tessa Ing, Head of End of Life Care, Department of Health  
Dr Jeremy Johnson, Medical Director, Severn Hospice, Shrewsbury  
Professor Allan Kellehear, Director for the Centre for Death & Society, University of Bath

Professor Sir Ian Kennedy, Emeritus Professor of Health Law, Ethics and Policy, University College London  
 Professor John Keown, Professor in Christian Ethics, Georgetown University  
 Lord James Mackay of Clashfern, Chairman of the Select Committee on the Assisted Dying for the Terminally Ill Bill  
 Dr Wendy Makin, Christie Hospice, Manchester  
 Barbara Monroe, Chief Executive, St Christopher's Hospice  
 Rt Revd James Newcome, Bishop of Carlisle  
 Dr Gareth Owen, Honorary Consultant, South London and Maudsley NHS Foundation Trust  
 Rt Rev George Pitcher, Curate, St Bride's Church, Fleet Street  
 Rt Rev Dr Lee Rayfield, Bishop of Swindon  
 Lord Jonathan Sacks, Chief Rabbi of the United Hebrew Congregations of the Commonwealth  
 Dr Peter Saunders, CEO, Christian Medical Fellowship  
 Professor Julian Savulescu, Uehiro Chair in Practical Ethics, University of Oxford  
 Peter Southern, Affiliated Social Worker, Barts Cancer Centre Palliative Care Team, Barts and The London NHS Trust  
 Dr Patrick Stone, Macmillan Reader in Palliative Medicine, St Georges, University of London  
 Judge Philip Sycamore, Department of Law, Lancaster University  
 Aswini Weererante, Barrister, Doughty Street Chambers  
 Michael Wenham, author of *My Donkey Body*  
 Dr Paul Whelan, Consultant in Psychiatry of Old Age, North Westminster Community Mental Health Team  
 Dr Andrew Wilcock, Clinical Reader, Faculty of Medicine & Health Sciences, University of Nottingham  
 The Most Revd and Rt Hon Rowan Williams, Archbishop of Canterbury



## Appendix 2

# A proposed framework to underpin assisted dying legislation in the UK

This report proposes an approach that might be taken to ensure that issues such as clear eligibility for assisted dying, mental competence to make such a choice, freedom from coercion and support to access appropriate end of life care and support were addressed robustly in any future assisted dying legislation that might be adopted in the UK. The Commission's detailed thoughts on a robust procedural approach that could be taken to providing safeguarded access to assisted dying for eligible people are presented below. However, the Commission does not argue that the approach outlined is the only possible or appropriate way of ensuring that these safeguards are met. Indeed, other frameworks that could be devised might address these issues just as effectively. The framework outlined below is presented as one way that these issues might be addressed in law to provide a safeguarded system for assisted dying in the UK.

### **The eligibility criteria proposed by the Commission**

The Commission proposes three eligibility criteria a person must meet before he or she can proceed with requesting an assisted death:

- The person concerned is aged 18 or over and has a diagnosis of terminal illness.
- The person is making a voluntary choice that is an expression of his or her own wishes and is not unduly influenced by others.
- The person has the mental capacity to make a voluntary and informed choice, and the person's decision-making is not significantly impaired as a result of mental health problems such as depression.

### **Proposed safeguards to support a robust framework for assisted dying**

As outlined above, it is proposed that the following categories of safeguard should be included in any future assisted dying legislation:

- 1 a decision-making model involving the assessment, advice, support and independent judgements of two doctors, with support from other health and social care professionals where necessary
- 2 a safeguard to ensure the person has been fully informed of all other treatment and end of life care options that are available and still wishes to proceed
- 3 safeguards to ensure that the eligibility criteria are met
- 4 safeguards to ensure that the person has a settled intention to die
- 5 safeguards to ensure the safe storage and transportation of lethal medication
- 6 safeguards to ensure the person has a reliable and supported assisted death
- 7 safeguards to ensure that assisted deaths are reported correctly
- 8 monitoring and regulatory oversight by a national monitoring commission with powers to investigate suspected non-compliance.

The Commission outlines below a procedural approach that could be taken to ensure that these safeguards were upheld robustly within an assisted dying framework.

## **A decision-making model involving the assessment, advice, support and independent judgements of two doctors**

### **The role of the first doctor**

We envisage that the first doctor, who would have primary responsibility for overseeing the process of the request, the assessment and (if appropriate) prescribing lethal medication and supervising the assisted death, would be a doctor with usual responsibility for that patient's care. This could be a specialist in the patient's medical condition or the patient's general practitioner. As part of the assessment process, the first doctor might also wish to consult other health and social care professionals responsible for the patient's care. In those cases where the person did wish to proceed with seeking an assisted death, we envisage that the first doctor would be responsible for checking whether or not each of the eligibility criteria and safeguards had had been met, and for ensuring that appropriate support was in place throughout the process. If this first doctor ultimately approved the patient's request, we envisage that the doctor's duties would include arranging appropriate support for the patient and their family at the moment of death and in the immediate aftermath.

### **The role of the second doctor**

We recommend that the second doctor should be wholly independent of the first doctor and should not have a pre-existing relationship with the patient or be in any way responsible for that patient's care. We consider that these factors are essential to ensure that the second doctor is able to play the role of objectively and independently assessing whether the conditions required by each of the safeguards have been met. We suggest that the 'second doctors' involved in safeguarding the assisted dying process should be required to have at least five years' experience after higher professional or specialist training and should be experienced in providing end of life care to ensure they have appropriate medical expertise for this role.

## **Safeguards to ensure that the person was fully informed of all available options for treatment and care**

To ensure that this criterion is met, we propose that both the first and second doctor might be required to certify the following:

- The doctor has had a detailed discussion with the patient concerning his or her diagnosis and prognosis, has made any necessary enquiries about locally available services, and can confirm that all appropriate options for treatment and care that are available from health and social care services have been offered to the patient and discussed in detail.
- The doctor has made a written record of the treatments that were offered and the discussion that took place.
- He or she has explained the assisted dying process in full, including how the person might bring about their death by self-administering medication,

the process most likely to be used and any risks of unintended or unpleasant consequences that might be associated with taking this medication.

We propose that the patient's request could only proceed to the next stage of the process if the patient did not wish to try any of the alternative options that were available, or found that having experienced other types of care that were on offer, he or she still wished to proceed with accessing an assisted death.

**Proposed procedural safeguards to check whether the legally required eligibility criteria are met**  
**The individual is diagnosed with a terminal illness**

The Commission proposes that this safeguard might require that the first and second doctor could certify independently that the person has *an advanced, progressive, incurable condition that is likely to lead to the patient's death within the next 12 months*. This definition of terminal illness is derived from is derived from the General Medical Council's guidance in *Treatment and Care Towards the End of Life*.<sup>1002</sup> It is proposed that:

- the first doctor must be able to certify that the person has an advanced, progressive, incurable condition that is likely to lead to the patient's death within the next 12 months
- the second doctor must be able to certify independently that the first doctor's diagnosis is accurate
- the request might only proceed if both the first and second doctors independently came to the judgement that the person was 'terminally ill' according to the legal definition
- both doctors would be required to provide written documentation of the diagnosis and prognosis, and the evidence on which this was based.

The relevant professional bodies, including the General Medical Council and the Nursing and Midwifery Council, would need to develop codes of practice to guide appropriate professional conduct. However, the Commission suggests that each doctor's assessment might be based on a combination of his or her own judgement, the patient's medical notes, and where necessary, informed by the expert input of an appropriate specialist in the patient's medical condition.

**The person is making a voluntary choice, free from coercion**

The Commission proposes that the following procedural safeguards might be included in an assisted dying framework to ensure that the person was making a voluntary choice to end their life, free from coercion or pressure from others:

- The request for an assisted death could only originate from the individual him or herself. No other person, including the patient's doctor or a close family member, would be able to initiate the process of requesting an assisted death.
- Each of the two doctors involved would be required to have in-depth discussions with the individual to explore his or her motivation for requesting an assisted death and to discover any indication that there might be another person influencing the individual's choice. Each doctor should be required to



meet the patient alone at least once so that he or she can speak freely without the influence of friends or relatives.

- If either doctor had any suspicion that there may be an element of coercion at work and wished to seek an independent opinion, he or she could request an independent assessment of the patient. The person providing this assessment should be a professional (such as a community nurse, social worker or care worker) who is familiar with the patient and his or her personal circumstances. This independent professional should interview the patient alone and—where possible—also interview the patient’s relatives to examine whether the individual may be experiencing any form of undue influence. This could provide an additional opportunity for whistle-blowing from the patient’s close family or friends.
- Before the doctor writes a prescription for lethal medication, the patient must have written or signed a statement of his or her wish to have an assisted death. If the individual is unable to sign a statement, his or her oral request could be witnessed by at least two independent observers (these witnesses could not include either the first or second doctor).
- To provide further confirmation of the individual’s autonomous choice, the means of the person’s death should be the self-administration of the lethal medication (assisted suicide) and should not be caused by the direct action of another person (this will be discussed in more detail under the heading ‘the assisted death’). Any form of euthanasia or ‘mercy killing’, whereby another person administered the lethal medication, would fall outside the provisions of the statute and put the assister at risk of prosecution for murder.

**The person has the mental capacity to make a voluntary and informed choice, and the person’s decision-making is not significantly impaired as a result of mental health problems such as depression**

We propose that the following procedural safeguards might be used to ensure that the person has the mental capacity to make a voluntary and informed choice, and that their decision-making is not significantly impaired as a result of mental health problems such as depression:

- *Capacity assessment:* The first and the second doctor should be required to assess the patient’s capacity independently of one another. As several pieces of expert evidence have suggested, in more difficult cases the doctors might wish to consult other members of the multi-agency team responsible for the patient’s care to fill in any gaps in knowledge or increase their understanding of how the patient may have a history of being consistent or inconsistent in his or her decisions over time.
- *Formal documentation:* The first and second doctor should be required to formally document the process of determining the person’s capacity to provide evidence of how they arrived at their decision.
- *Screening for depression:* A capacity assessment safeguard in UK assisted dying legislation should include the need for each doctor to screen the patient for depression using a validated screening tool in the context of an interview. The

Commission does not recommend the use of a particular screening tool, as the appropriate professional bodies should be responsible for recommending a choice of tool, along with the other relevant professional protocols and codes of practice. As above, the results of the screening should be formally documented by both doctors to evidence their decision.

- *Treatment of depression*: If the depression screening identified that a patient had depression, we propose that the depression would need to be successfully treated before the request for an assisted death could proceed. If the individual's depression did not respond to treatment, the individual would need to be referred to a specialist (psychologist or psychiatrist) to assess whether the individual's depression was causing significant impairment of his or her decision-making capacity. If it was decided that the depression was significantly impairing the person's decision-making capacity, the person's request for an assisted death should not be allowed to proceed.
- *Specialist assessment where abnormal psychotic thinking is suspected or the patient has a history of psychosis*: In cases where the first or second doctor suspected abnormal psychotic thinking, or where a person has a history of psychosis, a specialist assessment by a psychiatrist or other mental health professional would be required in addition to the depression screening to determine whether the psychosis was causing significantly impaired judgement.
- *Advance decisions*: People who decide early in their illness that there are particular circumstances in which they would wish to have an assisted death should be able to record this information in an advance decision along with the usual information about treatment the individual would not want to receive. This information could provide important evidence of consistency in the individual's wishes for a future point in time when the individual may wish actively to request an assisted death. However, an advance decision to request an assisted death would not be legally valid if the individual should lose capacity, as under the Mental Capacity Act 2005, an 'advance decision to refuse treatment' can only specify treatment the individual does *not* wish to receive, should he or she lose capacity.
- *Independent advocacy*: Any person who has difficulty communicating their wishes (the fourth dimension of a capacity assessment) might benefit from the help of an independent advocate who can help the individual to articulate his or her decision and explain his or her motivation in requesting an assisted death. The option of an independent advocate, who could be a professional who knows the patient well or a friend or family member, should be available to any person going through the process of requesting an assisted death.

### **Safeguards to ensure that the person has a settled intention to die**

Several of the experts who gave oral evidence expressed concern that a person who had a fluctuating wish to die might act precipitately on such a wish. To reduce the chance of this happening, the Commission proposes that it should be required that a minimum time period of two weeks (14 days) must elapse between the request being made by the subject and the assisted death occurring. This is in addition to the requirement that the

two doctors were satisfied that the subject had made the choice to have an assisted suicide, and that their choice reflected a settled intention to die on the part of the subject.

The Commission is also sympathetic to the fact that some people experience significant suffering towards the end of their lives, therefore the applicant might be 'in extremis', making long waiting periods inappropriate. The Commission considers that where the patient's death was judged by the two doctors to be imminent (eg likely to occur within one month), they could in exceptional circumstances reduce the waiting period to six days, as long as they were satisfied the patient had the requisite settled intention. In such cases we propose that three waiting periods of 48 hours might be built into the process. There should be a 48-hour delay between:

- the patient's first oral request for assistance to his or her doctor and the patient's second request, at which point the doctor may begin assessment of the patient for capacity and voluntariness
- the completion of the first doctor's assessment of the patient and the initiation of the second doctor's assessment of the patient
- the patient confirming his or her request for an assisted death in writing (or a witnessed statement if writing is not possible) and the first doctor approving this request and writing the prescription for lethal medication.

With these built-in waiting periods, the minimum length of time that the process could take would be approximately six days from the initial oral request to the writing of the prescription for lethal medication. In practice it could take longer, as each assessment may require several conversations and the two doctors involved may wish to consult other health and social care professionals who care for the patient and access professional support and guidance.

### **Recommended safeguards on the safe storage and transportation of lethal medication**

Once a person's request for an assisted death had passed each of the safeguards specified above, and had been approved by both the first and second doctors, the person would then be able to choose where and when they wished their death to take place. It is most likely that they would choose to be at home or in a room where they could be in private, as is the case in jurisdictions that permit assisted dying. As mentioned above, careful consideration would need to be given to how the lethal medication required for an assisted death was to be kept securely. We suggest that the following approach to the storage and transport of the prescribed lethal medication could be taken:

- The written prescription would be put in the patient's name and the first doctor would send the prescription directly to the pharmacist, along with the appropriate paperwork demonstrating that the safeguards have been properly implemented. The first doctor would also send copies of the paperwork to the central monitoring commission at this point.
- The pharmacist would retain the written prescription until the time when the patient wanted this fulfilled.

- When the patient wished to access the medication, the first doctor would authorise the pharmacist to order the medication.
- Once the medication had been ordered, it would be held securely at the pharmacy until it was collected. At this point, the pharmacist would notify the central monitoring commission that the medication had been dispensed.
- The medication would need to be collected by either the first doctor or another suitably qualified healthcare professional with sufficient knowledge of the case, who would be responsible for ensuring that the medication was used for the correct purpose.
- The first doctor or a suitably qualified healthcare professional would need to deliver the medication to the patient in person and remain on the premises until the person had taken it or declined to take it. If it was declined, the doctor or other healthcare professional would be legally responsible for returning the lethal medication to the pharmacy for safe keeping.

## **Safeguards to ensure the person has a reliable and supported assisted death**

### **The type of assisted dying permitted**

As we have emphasised, there is an important distinction between assisted suicide and voluntary euthanasia; the Commission considers that only assisted suicide for terminally ill people should be permitted in any future legislation. The members of the Commission with medical expertise have suggested that once the person's request had been approved by the first and second doctors overseeing the process, the following three options for self-administration of lethal medication might be made available, provided they were activated in each case by the patient:

- oral ingestion
- feeding tube
- intravenous administration.

It is most desirable that the person should take the medication orally, as this provides a strong and transparent safeguard against coercion (as has been noted in relation to the Oregon system). However, other options should be made available to tailor the process for people who might have difficulty with this approach, for example if they have problems swallowing.

For those people who feed with the use of a PEG (percutaneous endoscopic gastrostomy) feeding tube or nasogastric tube, this method could be made available for ingesting the lethal medication, although the person would need to be able to administer the medication on their own behalf.

If the options of oral ingestion or ingestion through a feeding tube were not possible because of the individual's impairment or illness, the third option that could be made available might be for the patient to make an action that would activate a mechanism to end his or her life (for example activating a syringe driver). We understand from the evidence we have received that such mechanisms have been used in Switzerland under the understanding that the act is classed as 'suicide' as opposed to 'euthanasia' as long as it is the patient him or herself who makes the final action that ends their own life.

Should this legislation be passed, the Department of Health would need to consult palliative medicine and pharmacology experts and develop a clinical protocol or code of practice that would provide guidance on the types and doses of medication appropriate to each of the three self-administration options. We suggest that this code of practice would need to be reviewed bi-annually or annually to ensure that the recommended medications are kept up to date.

### **The prescribing doctor's responsibility**

As discussed in chapter 11, the Commission considers that a doctor who prescribes lethal medication for the purpose of an assisted death should have ongoing responsibility for the care of that patient and their family during and after their death, as is currently the case in the Netherlands and Belgium. We propose that the guidelines on support that should be provided to the patient at the time of their death could include the following principles, to ensure he or she is making a competent and voluntary choice, and can die in the way he or she would like:

- At the time that the doctor or other suitably qualified professional brings the lethal medication to the patient, he or she should be able to satisfy him or herself that at that moment the patient has capacity to make the decision to end his or her life.
- The doctor or suitably qualified professional must also be satisfied that the patient is capable of self-administering the drug and that whatever practical arrangements and support might be needed to proceed are in place. The doctor or suitably qualified professional should provide whatever practical support is needed, as agreed between the doctor and patient in advance. However, as specified above, this practical support could not include the doctor administering the medication to the patient, as this would constitute voluntary euthanasia, as opposed to assisted suicide, and would therefore fall outside the bounds of the proposed legislation.
- To confirm that the patient had capacity, and that the necessary arrangements were in place to allow the patient to self-administer the medication, the doctor or suitably qualified professional would need to make a written report confirming that the patient had capacity, giving the date and time of the final assessment and the arrangements that had been made for the patient to self-administer the drug (including necessary procedures to accommodate the requirements of significantly disabled people who are terminally ill).
- Support during the patient's death could be provided by the doctor or other suitably qualified professional. However, the doctor or other healthcare professional need not be in the room at the time if the patient would like privacy at this point. It might be that the person would like to spend their final moments alone or with their loved ones.

### **Bereavement support for friends and relatives**

The Commissioners recognise that the quality of bereavement support available to friends and relatives can vary depending on the location of the loved one's death. Assisted deaths may be more likely to take place at home, which may make it more difficult for the friends and family members left

behind to access the supportive infrastructure provided by hospices and hospitals. We therefore suggest that the first doctor with legal responsibility for assisting the patient's death should have a continuing responsibility for supporting the patient's friends and relatives after his or her death. To facilitate this role, the doctor should ensure he or she has knowledge of the local bereavement support services that are available and, where appropriate, should direct bereaved friends or relatives to these services.

## **Safeguards to ensure that assisted deaths were reported correctly**

### **The death certificate**

We recommend that the doctor or other suitably qualified healthcare professional overseeing the death should be required to mark clearly the cause of the patient's death on the death certificate as follows:

- primary cause of death was respiratory failure caused by ingestion of [recommended variety of lethal medication]
- secondary cause of death was [whatever advanced, progressive, incurable illness the person had].

The doctor or other suitably qualified healthcare professional would also report the death to the local coroner.

### **Reporting to the national monitoring commission**

Following confirmation of the patient's death, the first doctor would send all official paperwork relating to the case to the national monitoring commission responsible for regulating the practice of the law.

As specified above, the monitoring commission would already have received notification from the first doctor that the assisted death has been approved and notification from the pharmacy that the lethal medication has been issued. These three notifications, in addition to the means of the death specified on the death certificate, would allow triangulation for research and monitoring purposes.

### **Monitoring and regulatory oversight by a national monitoring commission with powers to investigate suspected non-compliance**

The proposed role and functions of a national monitoring commission are outlined within the recommendation made in chapter 12 that such a monitoring commission would need to be established if assisted dying was legalised.



## Appendix 3

# Statement by the Reverend Canon Dr James Woodward

As set out in the executive summary to this report, I do not feel able to put my name and support to the more specific recommendations that are made in chapters 11 and 12 of this report concerning the majority decision of the Commission that the present law could be changed to allow assisted dying in restricted circumstances. I support the coherence, rigour and quality of this work and hope that it will be read and used as a basis for further research, work and public debate. I regret that some have felt unable to contribute to the process of discussion, engagement and listening that has characterised the process. I wish to continue to work with my fellow Commission members to promote a deeper and wiser dialogue that moves away from polarised and entrenched positions on assisted dying that are incapable of listening to a wide range of issues and experience.

In our work it has become clear that there are significant difficulties with the present law. My visit to Switzerland to learn something of the law and practice there raised many more questions about the way a culture views and values life, death and the freedom to choose. However this complex and contested area of human life cannot be dealt with through the law or medicine alone. We need to engage further with the social and ethical reflections on experiences of death and dying. The ethical debate is not over and it is the responsibility of all 'sides' of the debate to listen more carefully to the questions and concerns of one another.

Further there are important theological questions about suffering, personhood and the value of the vulnerable that need to inform a more open conversation about death and dying in Britain today. I am particularly concerned about the adequacy of UK health and social care where dignity and compassion are values that are universally affirmed but often not part of the day to day practice of those who are tasked to care.

In conclusion I believe that a broader societal debate is required before any attempt is made to move to a change in the law on assisted dying. As a society we need to bring all our collective wisdom to bear on these questions in an open and honest fashion. I understand that my particular view is a minority one and I both respect and admire my fellow Commissioners in their views and recommendations. I hope that the report will be read carefully – it is an important contribution to the debate.





## Appendix 4

# The Demos Secretariat

Demos hosted the Commission on Assisted Dying and provided a research and communications secretariat from October 2010 to December 2011. The functions of the secretariat included providing research support and briefings, organising the Commission's call for evidence and outreach and consultation activities in the UK, coordinating the Commission's research visits to the Netherlands, Belgium, Switzerland and Oregon and managing the Commission's press and communications, including the Commission on Assisted Dying website. The members of the Demos secretariat are as follows.

### **Louise Bazalgette, Secretary and Lead Researcher to the Commission**

Louise managed the Commission's research programme, including the Commission's 'call for evidence', the six evidence hearings, the international research visits, *The Truth about Suicide* research project, commissioning two expert briefing papers and conducting qualitative research to explore attitudes to assisted dying among members of groups frequently considered to be at risk from a change in the law on assisted dying, such as older people and disabled people. Louise also assisted the Commissioners in drafting their final report.

Louise is a Senior Researcher on Demos's Family and Society Programme. In addition to leading on the Commission's research programme, she has also co-authored a number of Demos reports including *Coming of Age* (2011), a study of older people's attitudes to and experiences of ageing; *The Home Front* (2011), a study of the pressures and challenges involved in parenting and the policies and services that are effective in supporting parents; and *In Loco Parentis* (2010), a comprehensive study of the care system.

### **William Bradley, Researcher to the Commission**

William supported the Commission's outreach and consultation activities throughout the course of its inquiry. He particularly led on coordinating the international research visits, managing the Commission on Assisted Dying website and processing and cataloguing more than 1,200 submissions of written and oral evidence. William also assisted the Commissioners in drafting their final report.

William is a Researcher on Demos's Family and Society Programme and in addition to working on the Commission's research secretariat, William has also co-authored a number of Demos reports including *The Truth About Suicide* (2011), *Class of 2010* (2010), *3D Poverty* (2010) and *Wealth of Opportunity* (2009).

### **Phillida Cheetham, Researcher to the Commission**

Phillida co-authored Demos's evidence submission to the Commission on attitudes to assisted dying among members of 'vulnerable' groups and assisted the Commission in drafting their final report.

Phillida is a Junior Associate at Demos, working on the Family and Society Programme and Public Services and Welfare Programme. In addition to her work for the Commission on Assisted Dying, Phillida has co-authored *Experience Required* (2011), a report assessing the impact of long-term volunteering schemes on work-readiness and capabilities and *Coping with the Cuts* (2011), which examines how local authorities' cuts to social care budgets are affecting disabled people.

### **Beatrice Karol Burks, Head of Communications at Demos**

Bea led the communications strategy for the Commission, managing media coverage and the Commission's external profile from the launch of the project through the research phase and up to the publication of the final report.

As Head of Communications, Bea manages Demos's external profile in the media and online, ensuring the successful exchange of Demos's ideas and work. In addition to this, Bea has edited reports on the future of the Labour Party, young women's self-esteem and threats to open societies.

### **Ralph Scott, Head of Publications at Demos**

Ralph managed the publication of a number of briefing papers for the Commission during the course of its evidence gathering and managed the production process for the publication of the Commission's final report. He was responsible for the audio-visual component of the evidence sessions, recording each session and making the videos available via the Commission website.

Ralph is Head of Publications at Demos, and manages the production and dissemination of all published outputs. He also supports Beatrice in maintaining Demos's external profile in the media and through the Demos website.

### **Sarah Kennedy, Head of Partnerships and Events at Demos**

Sarah led on internal communications at the outset of the Commission, liaising with Commissioners and stakeholders and helping to set up the Commission on Assisted Dying website. Additionally, in her role as Demos's Head of Partnerships and Events, she organised public evidence hearings and internal Commission meetings. While working on the Commission Sarah also completed a part-time MA in Legal and Political Theory and was awarded a distinction for her dissertation on the political morality of assisted suicide.

### **Sophie Duder, Events and Operations Officer at Demos**

Sophie organised the Commission's research visits to Belgium, Switzerland and Oregon. In her role as Demos's Events and Operations Officer, Sophie also assisted with organising public evidence hearings and internal Commission meetings.





# Notes

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The Commission on Assisted Dying, launched in November 2010, was set up to consider whether the current legal and policy approach to assisted dying in England and Wales is fit for purpose. In addition to evaluating the strengths and weaknesses of the legal status quo, the Commission also set out to explore the question of what a framework for assisted dying might look like, if such a system were to be implemented in the UK, and what approach might be most acceptable to health and social care professionals and to the general public.

The Commission, chaired by Lord Falconer, includes members with expertise in law, medicine, social care, mental health, palliative care, theology, disability and policing. The Commission engaged in a wide-ranging inquiry into the subject, including a public call for evidence which received over 1,200 responses, public evidence hearings, international research visits, and original and commissioned research on the issues surrounding assisted dying.

In this report, the Commission concludes that the current legal status of assisted suicide is inadequate and incoherent. While the current legal regime can be distressing for the people affected and their families, it is also unclear for health and social care staff, and lays a deeply challenging burden on police and prosecutors, which could be eased by a new statutory framework. A proposed legal framework for assisted dying is laid out in detail in the report, including strict criteria to define who might be eligible to receive assistance and robust safeguards to prevent abuse of any new law.

Based on the evidence received, the Commission considers that substantial improvements to health and social care services would be needed in parallel with changes to the law to permit assisted dying. It proposes that the role of any future assisted dying legislation must be to provide all people with access to high quality end of life care and protect potentially vulnerable people from any form of social pressure to end their lives, at the same time as providing people with greater choice and control regarding how and when they die.

