BASW UK Briefing: Assisted dying

September 2024

Purpose

Assisted dying continues to be discussed both in the media and by legislatures. In Scotland, there is a Members Bill which, if successful, would legalise assisted dying. A change of government in Westminster could mean that an assisted dying Bill for England and Wales is debated and passed. This briefing is to ensure that we are prepared to respond to any government consultations or legislation. The purpose is also to establish how an assisted dying law would impact social work, not about our views on the issue more generally.

Terminology

Assisted dying, also known as doctor-assisted suicide, is when a person chooses to end their own life with the assistance of a physician to administer the drugs required to do so. When assisted dying happens in other countries, it is often because the person has a terminal physical illness, but this is not always the case.

A person is terminally ill if they have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death. Conditions that are lifelong but not fatal are considered chronic, not terminal, meaning mental health conditions or other disabilities would not be included under this legislation.

Extent

While assisted dying is an issue relating to the health and life of individuals, it is a criminal justice matter. This means that it is a devolved matter and is in the jurisdiction of the Northern Ireland Assembly, the Scottish Parliament, and the UK Parliament for England and Wales.

Although this issue is devolved, this is a UK-wide position paper and will act as a resource to all four nations.

Current situation -

In England and Wales, assisted dying is illegal. Assisting or encouraging another person's suicide is prohibited by s.2 of the Suicide Act 1961.

In Northern Ireland, assisting or encouraging another person's suicide is illegal under s.13 of the Criminal Justice (Northern Ireland) Act 1966, which extends the Suicide Act 1961 to Northern Ireland.

In Scotland, there is no specific offence of assisting or encouraging suicide. Any suspected offence would be dealt with under homicide law. In March 2024, a member of the Scottish

Parliament introduced a Members Bill to allow assisted dying for terminally ill adults that request this,

Across the UK, there is advanced care planning in which individuals can plan future health care and support, including for end of life. A person must have the capacity to make the decision to create an advanced care plan and what goes into it. Part of an advanced care plan can be an advance decision to refuse treatment (ADRT). These plans are not fixed and can be changed by the person at any time.

An ADRT can mean refusing cardiopulmonary resuscitation (CPR), or any other treatment that might be used to treat your illness or condition or save your life such as antibiotics.

Guidance and terminology for advanced decisions differ across the four nations, but the principles are consistent. For detailed information about advance decisions where you live, we recommend searching online for registered charities focused on older people and/or end of life care.

Countries that permit assisted dying

There are a small number of countries that permit assisted dying including Canada, Switzerland, and Australia. Some US states allow for an assisted death. The protocol, accessibility, and eligibility varies from country to country. For example, Canada is pursuing mental health as a permissible reason to seek an assisted death, whereas other countries allow only terminal illness as the criterion.

Some countries such as Canada provide <u>guidance for social workers</u> on the social work role within the assisted dying framework, including what social workers can and cannot do. This can vary between jurisdictions depending on legislation and regulation.

Rights

Changes in laws around the right to die would primarily affect those who have been diagnosed with a terminal condition, defined in the proposed Scottish bill¹ around assisted dying as a person with "a disease, illness or condition which they will not recover from, is worsening and at a late stage, and which is expected to cause their premature death."

Although subject to change, current proposals would not include people with non-terminal long-term health conditions or disabilities or those who have long-term mental health issues, though wider debates around assisted dying also touch on these groups.

Debates in this area often focus on the rights of disabled people and the potential negative consequences of legalising assisted dying. However, there is no one position taken by disabled people on the right to die. Subsequently, though many disabled people and disabled-led organisations actively support assisted dying, others acknowledge the complexity and divisiveness of the debate (and its then theoretical nature) and take a more neutral stance. A recent survey of 140 disability rights organisations in the UK indicated that 4% explicitly

¹ https://www.parliament.scot/-/media/files/legislation/bills/s6-bills/assisted-dying-for-terminally-ill-adults-scotland-bill/introduction/explanatory-notes-accessible.pdf

oppose assisted dying laws, explicitly endorse neutrality (4%) or remain silent on the issue (84%)².

Similarly, there are mixed opinions on the right to die from those with terminal illnesses. Campaigning organisation Dignity in Dying frequently share personal stories from terminally ill people and their families who are keen to see laws changed³. Yet others are against changes in law and campaign for better safeguards⁴.

There are also concerns about the rights of people with disabilities as they interact with the actions of the state. Government funding for disabled people has decreased⁵, while do not resuscitate orders were imposed on Covid patients with learning disabilities during the pandemic⁶. This raises questions about the government's ability to prioritise the rights of disabled people.

Social context

End of life care can be provided at home, in a care home, in hospital, or in a hospice. Per the NHS resource on end of life care⁷, this can involve doctors, nurses, GPs, hospice staff, counsellors, social care staff, chaplains, and other professionals. Where someone receives end of life care, and who is involved, is decided by the person receiving the care.

Although many people choose to die in a hospice (4.7% in 2022)⁸, hospices have faced a real-terms cut of £47m in Government funding in the past two years⁹. This could have a significant impact on decision-making around end of life care and the decision to die. Similarly, there have been significant cuts to social care services that may impact how people feel able to cope with their illness and their decisions around their care.

Similarly, wider social issues intersect with conversations on the right to die, including cuts to benefits that have been blamed for multiple deaths¹⁰.

Personal context

Current proposals around legalising assisted dying do not include those with long-term mental health issues. However, mental health remains a key facet of the discussion.

² Box, G. & Chambaere, K. (2021) Views of disability rights organisations on assisted dying legislation in England, Wales and Scotland: an analysis of position statements. Journal of Medical Ethics. Published online first 5 January 2021. doi: 10.1136/medethics-2020-107021.

³ https://www.dignityindying.org.uk/why-we-need-change/personal-stories/

⁴ https://notdeadyetuk.org/

⁵ https://www.unison.org.uk/about/what-we-do/fairness-equality/disabled-members/key-issues/disabled-people-and-

 $[\]underline{\text{cuts/\#:}} \sim \underline{\text{text}} = \underline{\text{Reduced\%20government\%20funding\%20means\%20local,}} \\ \underline{\text{to\%20levels}}.$

⁶ https://www.theguardian.com/world/2021/feb/13/new-do-not-resuscitate-orders-imposed-on-covid-19-patients-with-learning-difficulties

⁷ https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts

⁸ https://www.gov.uk/government/statistics/palliative-and-end-of-life-care-profiles-december-2023-data-update/palliative-and-end-of-life-care-profile-december-2023-update-statistical-commentary

https://www.hospiceuk.org/latest-from-hospice-uk/hospice-funding-falls-short-ps47m

¹⁰ https://www.bbc.co.uk/news/uk-56819727

Isolation and Ioneliness, for example, are key factors in where people can die. According to Marie Curie¹¹, having a carer is the single most important factor associated with home deaths, and those who are unmarried or living alone are more likely to have a death in hospital. Loss of someone's "self-image, their sense of control, their relationships or their independence" can also increase loneliness and isolation at end of life.

Loneliness can have a devastating impact on the mental and physical wellbeing of someone with a terminal illness¹² and can be a trigger for serious mental ill health, which some staff in end of life care find difficult to manage¹³.

Another Marie Curie paper, developed through conversations with people with terminal illness in Northern Ireland, also found that in some cases loneliness and isolation was "driving dying people to the conclusion that they've nothing more to live for, causing them to give up on the time they have left". Such factors are central to discussions on assisted dying.

What is being proposed?

There have been multiple attempts in the UK Parliament to legalise assisted dying, but these have never had the support of the House of Commons when they have been put to a vote. Despite this, there are likely to be further attempts to change the law and a UK Parliament in the future may proceed with legalisation for England and Wales.

In Northern Ireland, there are political parties that say they would consider the contents of any proposed bill on assisted dying carefully, whereas other parties are firmly opposed.

In Scotland, a <u>Members Bill was introduced in March 2024 to legalise assisted dying</u> for those with a terminal illness who wish to end their life through assisted dying. The Bill says:

- Assisted-dying would only be available to people aged over 16
- Two doctors would have to be satisfied the patient's condition was terminal
- It would only be open to people who have lived in Scotland for at least a year
- There would be a 14-day "reflection" period between making a request and being given the necessary medication
- There is no duty on any medical or health practitioner to be part of the assisted dying process
- Any person who has a mental illness, personality disorder, or learning disability is not eligible for an assisted death

This is likely to be very similar to any assisted dying legislation laid in the UK Parliament or the Northern Ireland Assembly.

¹¹ <u>https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-</u>consultations/scotland-briefings/marie-curie-briefing-inequities-isolation-loneliness.pdf

¹² https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/experiences-of-loneliness-among-people-at-the-end-of-life-and-their-carers-in-northern-ireland.pdf

¹³ https://evidence.nihr.ac.uk/alert/how-to-improve-end-of-life-care-for-people-with-severe-mental-illness/

Role of Social Workers

It is clear that assisted dying involves medical professionals such as doctors, it is less clear about the role of other professionals such as social workers. The day to day work of social workers includes assessing the needs and wishes of individuals and families, and if a person has requested an assisted death it is likely that their social worker (if they have one) would be made aware.

Social workers could also be a named professional tasked with carrying out mental capacity assessments on individuals who wish to have an assisted death. Although social workers will not be administering any drugs, it is possible that they would still have a role within the process and for that reason should be aware of procedure and the ethics, and how they interact with social work standards of practice and code of ethics.

The <u>Nova Scotia College of Social Workers produced some guidance for social workers</u>, and any change in the UK could result in similar guidance.

Practicalities

Legalising assisted suicide is more complicated than just changing the law to prevent it from being illegal anymore. It could have a large impact on an already-strained health and care service, and there are significant decisions that need to be made about the process someone would have to go through to have an assisted death.

There are different ways that assisted dying could happen. For example, the necessary drugs could be physician-administered or self-administered. Individuals could be required to be in a medical or hospital setting, or are able to die at home. Mental capacity may require to be determined by two doctors, or it could be through an assessment of other professionals such as social workers. Assisted death in the UK could look a variety of ways, and each aspect will need to be carefully considered.

Another practicality to consider is how assisted dying would fit with mental capacity legislation. Mental capacity is decision and time specific, and a person would need to have capacity to make that particular decision at that particular moment in time. If they can't, it would need to be considered as to whether they are able to make the decision at a different moment in time e.g. if capacity returns following an episode of hospitalisation/treatment.

Which professions are able to assess mental capacity would also need to be a practical consideration and whether further training or qualification would be required, and whether there are enough suitable professionals to meet demand. As proposals were developed along with further guidance, more practical considerations would arise and the Government of the day must address these before any law is passed.

Safeguarding

Social workers are skilled at dealing with cases of abuse and neglect, and there needs to be rigorous checks to ensure that people who wish to have an assisted death are not being abused or neglected. There is a risk that victims could be pushed or encouraged towards assisted dying, and this needs to be safeguarded against.

There is also a risk of an individual feeling like assisted dying would help them escape any abuse or neglect. This makes the role of social workers in safeguarding adults even more important and should be a consideration of every social worker if they engage with someone who is contemplating an assisted death.

Where do other organisations stand on assisted dying?

Prior to September 2021, the British Medical Association (BMA) were opposed to assisted dying but have since adopted a position of neutrality. Alongside this, the BMA has adopted views including that:

- There should be an opt-in model for doctors provide assisted dying
- There should be a right to opt-out of any action or activity that may be related to an assisted death
- There should be a separate service for assisted dying with an official body and adequate funding

<u>Healthcare Professionals for Assisted Dying (HPAD) submitted evidence</u> to the Health and Social Care Select Committee inquiry into assisted dying, and we recommended reading this alongside the BMA submission.

Further learning

There is a significant amount of literature on assisted dying that can be used to develop knowledge and further understand the pros and cons.

Papers and reports

Twycross, R. Assisted dying: principles, possibilities, and practicalities. An English physician's perspective <u>Assisted dying: principles, possibilities, and practicalities. An English physician's perspective | BMC Palliative Care</u>

House of Commons Health and Social Care Committee. Assisted Dying/Assisted Suicide Report.2024.

https://publications.parliament.uk/pa/cm5804/cmselect/cmhealth/321/report.html
All-Party Parliamentary Group on Choice at End of Life
https://committees.parliament.uk/writtenevidence/117124/pdf/

Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3998063/

Assisted dying / assisted suicide – concrete British realities

https://www.mentalcapacitylawandpolicy.org.uk/assisted-dying-assisted-suicide-concrete-british-realities/

Television and other visual media

A Time to Die: An ITV documentary: https://www.itv.com/watch/a-time-to-die/10a3960

How to Die: Simon's Choice: A BBC documentary: https://www.bbc.co.uk/programmes/b070jm26

Better off Dead?: https://www.bbc.co.uk/programmes/m001z8wc

Media coverage

Better Off Dead?: The Guardian https://www.theguardian.com/society/article/2024/may/18/once-you-take-choice-away-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-adio/article/2024/may/18/once-you-take-

theres-nothing-left-assisted-dying-edges-closer-in-jersey-but-can-they-protect-against-aduty-to-die

Campaigning organisations

Dignity in dying: https://www.dignityindying.org.uk/

My death, my decision: https://www.mydeath-mydecision.org.uk/

Care, not killing: https://www.carenotkilling.org.uk/about/