

Terminally Ill Adults (End of Life) Bill: Second Reading

Significant Problems regarding Mental Capacity and Adult Safeguarding

Briefing for MPs

British Association of Social Workers

November 2024

Summary

The issues of mental capacity and adult safeguarding are central to the issue of assisted dying. However, there is a significant disconnect between the proposals set out in the Terminally Ill Adults (End of Life) Bill and already existing legislation in England and Wales both in terms of mental capacity (Mental Capacity Act 2005) and adult safeguarding (Care Act 2014 and Social Services and Wellbeing (Wales) Act 2014). This disconnect would create significant legal and practical issues both for those seeking assisted dying, their loved ones, and for professionals involved in the process – risking flawed and irreversible decisions.

Under the mental capacity legislation, significant decisions about mental capacity are undertaken by Best Interests Assessors (BIAs). The vast majority of BIAs are social workers. Social workers also have responsibilities under the adult care legislation for adult safeguarding. Since both legal functions are central to assisted dying it is concerning that the ‘no obligation to provide assistance’ clause only applies to health professionals.

This briefing also addresses constraints on choice in relation to shortfalls in adult care and assisted dying.

The short period between the publication of the Bill and Second Reading, these omissions and inaccuracies raise major concerns about the Bill as it is currently framed.

About BASW

The term social worker is a legally ‘protected title’ reflecting the range of legal duties undertaken by members of the profession.

With just under 22,000 members the British Association of Social Workers (BASW) is the independent professional voice of social work and social workers across the UK. In providing this briefing BASW has drawn on the specialist expertise of its members while also undertaking a consultation with the wider membership.

BASW has not adopted an 'in principle' decision on assisted dying nevertheless it is our responsibility as lead professionals in these areas to point out the legal and practical challenges of the Terminally Ill Adults (End of Life) Bill.

BASW has an Experts by Experience (EBE) Forum. BASW takes the view that listening to the voices of existing and former social work service users is both an ethical imperative and a practical necessity. Along with our members we have consulted the Forum on this Bill.

What is the legislation on mental capacity and how is it applied?

Section 1 of the Bill sets out the option for assisted dying if the person has capacity, has a terminal illness and less than 6 months to live. Section 7 sets out that doctors decide about capacity. Section 30 establishes a Code of Practice, while section 3 states that 'capacity' is to be construed in accordance with the Mental Capacity Act.

Under the Mental Capacity Act (MCA) 2005 (which applies to both England and Wales), the statutory principle of the presumption of capacity means that an assessment should not be undertaken unless there is a reasonable belief that the person does not have capacity. This Bill reverses this assumption, which raises questions about how the two pieces of legislation would work together.

For the purposes of the MCA 2005, capacity is both decision-specific and time-specific. The time-specificity of capacity is an important consideration here for degenerative cognitive conditions such as dementia and fluctuating capacity conditions. The legislation appears to focus on the person's capacity to seek assistance at the point of a formal assessment, without taking into account the person's capacity at a later point when assistance is rendered.

Under the mental capacity legislation significant decisions are referred to Best Interests Assessors (BIAs), for example, Deprivation of Liberty Safeguards. Given the irreversibility of the decision to opt for assisted dying, and the current mental capacity legislation and guidance, not involving BIAs in the assessment of mental capacity would be a significant disconnect.

There is no central register of BIAs and consequently no central record of their professional affiliation, but it is widely recognised that the vast majority of BIAs are social workersⁱ. The Bill does not seem to envisage that social workers who are accredited BIAs undertake capacity assessments on individuals who wish to be considered for assisted dying. Does this mean it is envisaged that doctors delivering assessments of capacity undertake training and accreditation as BIAs? Or is the intention that mental capacity legislation is sidelined, or is it the case that insufficient consideration has been given to existing law in relation to mental capacity?

It is worth noting that there is already a major backlog of significant decisions under the mental capacity legislationⁱⁱ.

What is the legislation on adult safeguarding and how is it applied?

“I am neither strongly for nor against legalising assisted dying but I think the idea that someone could choose to make that decision would require a lot of safeguarding which involves social workers.”

- BASW assisted dying consultation respondent

Although the Bill has been presented as foregrounding issues of safeguarding it remains silent on the legal structures and responsibilities that already exist.

The 2014 Care Act (England) and the Social Services and Well-being (Wales) Act 2014 gives important duties to local authorities in the realm of adult safeguarding. In the statutory guidance this task is allocated to social workers. A safeguarding assessment is only triggered in a case of a specific concern. Where there are safeguarding issues, they can be stopped (e.g. financial abuse), managed (e.g. neglect by a carer) or mitigated (e.g. more restrictive accommodation can be replaced by less restrictive accommodation). Where vulnerable adults have died because organisations have failed to prevent or protect them from abuse or neglect, professionals (including health, social services and police) have come in for the severest criticism.

There is of course a risk that individuals could be unduly influenced or encouraged towards assisted dying. In contrast to ‘small scale’ financial abuse (for example, withdrawing money regularly from an elderly person’s account), death can trigger a substantial transfer of assets, including property. Key questions might be whether the person has made a will, when they have made their will, and who the beneficiary might be. The latest statistics suggest that the number of unpaid carers across the UK is 5.7 million, and there is evidence of safeguarding concerns relating to both the cared for and the carer. Both the potential scale of financial transfer and the fact that assisted dying is not a reversible or modifiable decision means that safeguarding concerns are particularly acute. There are also particular cultural and religious sensitivities and concerns relating to protected characteristics.

Is the assumption of the Bill that adult safeguarding issues are no longer with local authorities despite the relevant legislation, or that each person considering assisted dying has a safeguarding assessment, or it is assumed that there are no safeguarding processes needed other than a broad assurance that all is well (Section (2) (b))?

Adult safeguarding and coercive control

There is a growing realisation of the impact of abuse and coercive control. Individuals may be both coerced and then silenced by individuals with whom a person is in an intimate or family relationship.

It is important to note that coercion in the field of assisted dying could be as much about coercion *not* to take the option of assisted dying as coercion to take the option of assisted dying.

Section 76 of the Serious Crime Act 2015 (SCA 2015) created the offence of controlling or coercive behaviour in an intimate or family relationship (CCB).

Section 76 provides that an offence is committed by a suspect (“A”) against a victim (“B”) if:

- A repeatedly or continuously engages in behaviour towards another person, B, that is controlling or coercive
- at the time of the behaviour, A and B are personally connected
- the behaviour has a serious effect on B, and
- A knows or ought to know that the behaviour will have a serious effect on B

It seems reasonable to assume that a person who is terminally ill, and in the last six months of their life, would be more vulnerable to coercive control.

Safeguards for people with terminal illness must be correspondingly high.

Adult Care and Assisted Dying

Social workers have specific responsibilities for adult care assessments and review (Care Act 2014 and the Social Services and Well-being (Wales) Act 2014).

Only a proportion of people with significant adult care needs will immediately be affected by the Terminally Ill Adults (End of Life) Bill. Nevertheless, many people with significant adult care needs will eventually face terminal illness. The adult care crisis has been worsening for over forty yearsⁱⁱⁱ and successive governments of all persuasions have - as yet - failed to resolve it.

As an illustration, recent figures show that there are some 418,029 waiting for an adult care assessment or care to begin in England^{iv}.

These statistics could well be an underestimate since these are only the cases that are referred to adult social work services. Many of those who can afford private adult care (and many of those who can't afford it) will bypass public sector queues to make their own urgent provision for themselves or loved ones^v.

For those with significant adult care needs there needs to be genuine choice about the option of assisted dying: not a choice constrained by the absence of appropriate, affordable adult care services. This argument can be seen as parallel to the shortfalls in the availability of palliative care and end-of-life care - but one which deserves equal attention. Individuals with a terminal illness without access to appropriate services may well feel the need to ease the burden of those caring for them.

Conversations about ‘dying well’ must be strongly balanced against conversations about ‘living well’, both of which require significant resourcing.

“I can’t be sure my strong view on personal choice is not influenced by the very poorly resourced palliative care. Sadly, even if there was a wish to improve its availability, it’s a long way off being a reasonable prospect for most people. It’s only when that service is able to stand in comparison that the choice of having a calm, dignified passing for everyone can be properly made.”

- BASW Experts by Experience assisted dying consultation respondent

“I would have less anxiety about aspects of what is being proposed if/when the provision of social care including the quality of end-of-life care can be given the attention and resourcing that is so badly needed.”

- BASW assisted dying consultation respondent

Societal Views of Disability

The Bill is clearly targeted at people who are terminally ill with six months to live and not at people with a disability. This rather binary distinction avoids the reality that many people with a disability will at some point face death through a terminal illness. It is therefore worth looking at some aspects of how society treats people with a disability.

Government funding for disabled people has decreased^{vi}, whilst do not resuscitate orders were imposed on Covid patients with learning disabilities during the pandemic^{vii}. This raises questions about the government’s ability to prioritise the rights of disabled people and leads to some concerns that people will be left with no other choice than to consider assisted dying.

Similarly, wider social issues intersect with conversations on the right to die, including cuts to benefits that have been blamed for multiple deaths^{viii}.

The social work workforce and ‘no obligation to provide assistance’

“Professionals in health and social care should be able to confidentially conscientiously object without fear of being intimidated or bullied”

- BASW assisted dying consultation respondent

All professionals that could potentially be involved with assisted dying such as social workers should be able to conscientiously object to participating in assessments or any part of the process that could reasonably be argued would be contributing to an assisted death. As has been shown social workers would have duties in relation both to mental capacity and adult safeguarding. It is concerning that while legal protection

is given to health care professionals in terms of 'no obligation to provide assistance' (Section 23) this protection is not extended to social workers.

Lasting power of attorney

This is not an area of social work responsibility or expertise; however, the issue did come up in our considerations. An increasing number of people appoint spouses, partners, family or close friends to have Lasting Power of Attorney (LPAs) for Health and Welfare and for Property and Affairs to make decisions on that person's behalf in future when they lose capacity. The bill is not clear on whether those who hold LPA are able to request, consent to, or block an assisted death on behalf of the person for whom they hold LPA. Under Deprivation of Liberty Safeguards, an LPA for Health and Welfare can 'refuse' an authorisation of deprivation of liberty.

There is also the question of an Advance Decision, and whether it would be permitted to grant an assisted death in circumstances described in the Advance Decision.

The pace of the legislation.

The Bill was published too close to the Second Reading which has meant limited scrutiny and consideration from interested parties while pre-legislation dialogue has been limited. BASW wrote both to Lord Falconer (23 August) and Kim Leadbeater MP (31st October) raising in detail the issues of both mental capacity and adult safeguarding and offering a detailed briefing. Unfortunately, we received no response to our letters, and we fear that the issues raised have been overlooked. The fact that this Bill still fails to address the legislative issues of mental capacity and adult safeguarding is therefore one of serious concern. The proposed legislation thus appears to frame this significant issue as a predominantly health care decision, without careful consideration of the equally important social care legislative issues and the wider wellbeing agenda.

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Appendix

Key findings from the BASW Social Work Survey

- 75% of respondents agreed that assisted dying would impact their practice, with a further 5% agreeing that although it would not affect their specific role, it would impact wider social work practice.

- When asked what practical considerations need to be made, respondents raised:
 - o Robust safeguards to prevent coercion
 - o Mental capacity assessments and determining best interests
 - o The role of advance directives
 - o Increased resourcing for palliative care and the relationship between assisted dying and palliative care services
 - o Role of the courts
 - o Resourcing for local authority services
 - o Workforce capacity including conscientious objection

- When asked whether social workers should be able to conscientiously object to participating in responsibilities that could lead to an assisted death, 64% of respondents agreed. A further 16% did not know whether social workers should be able to conscientiously object.

ⁱ Although the legislation allows individuals from a range of professional groups to train and register as BIAs it is widely acknowledged that the vast majority of BIAs are social workers. For example, new standards for BIAs and university training providers were recently introduced for *all* BIAs whatever their professional background by the social work regulator - Social Work England – in July 2024.

ⁱⁱ For example, in England in 23/24 there were 332,455 DoLs applications in 23/24 with an estimated 123,790 not completed at year end. In Wales a total of 15, 868 applications were made to Local Health Boards (LHBs, 6126) and local authorities (9742) in the year 2021/22. Of these, 12% (735) of LHB applications and 37% (3564) of local authority applications were still in progress at the end of the year. Both LHBs and local authorities were taking longer than stipulated to process the vast majority of both urgent and standard applications.

ⁱⁱⁱ See for example, The Kings Fund. *The Road to Somewhere: A timeline of Reform of Social Care Funding in England*. <https://www.kingsfund.org.uk/insight-and-analysis/data-and-charts/short-history-social-care-funding>. Accessed 21 November, 2024.

^{iv} ADASS (May 2024) 2024 Spring Survey. <https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf>. Accessed 21 November, 2024.

^v For an estimate on some of the numbers see Baxter K, Heavey E and Birks Y (2020) *Choice and control in social care: experiences of older people in England*. *Social Policy and Administration* 2020 54: 460-474

^{vi} See for example, <https://www.unison.org.uk/about/what-we-do/fairness-equality/disabled-members/key-issues/disabled-people-and-cuts/#:~:text=Reduced%20government%20funding%20means%20local,to%20care%20and%20income%20levels>.

^{vii} See for example, <https://www.theguardian.com/world/2021/feb/13/new-do-not-resuscitate-orders-imposed-on-covid-19-patients-with-learning-difficulties>

^{viii} See for example, <https://www.bbc.co.uk/news/uk-56819727>