

Assisted Dying for Terminally Ill Adults (Scotland) Bill SOCIAL WORK SCOTLAND RESPONSE TO CALL FOR VIEWS HEALTH, SOCIAL CARE AND SPORTS COMMITTEE

August 2024

Social Work Scotland is the professional body for social work leaders, working closely with our partners to shape policy and practice, and improve the quality and experience of social services. As an organisation and across our members we are committed to service improvement and ongoing development based on evidence and research on how as a society, we can best meet the needs of our citizens and particularly those who experience the greatest challenges and barriers to their wellbeing and lives.

Social Work Scotland represents social work leaders across Scotland. The profession is based on the principles of human rights, reflecting the value of all individuals and upholding their rights^{1,2} is expressed in the SSSC Codes of Practice³ and in the BASW code of ethics³. These underline the inherent worth and dignity of all people, demonstrated in practice through relationships, and promotion of self-determination, participation and wellbeing.

This also means that social justice and advocating for the wellbeing and rights of citizens, is part of the context within which we operate, balancing often-complex issues of competing rights and a challenging legislative and social environment. Rights rarely sit in isolation, but impact on wider society and those who make up that society.

Thus, understanding the impact of loss and trauma on individuals is important, including how that affects decision making, and how views can change over time.

¹ <https://www.ifsw.org/what-is-social-work/global-definition-of-social-work/>

² [SSSC Codes of Practice - Scottish Social Services Council](#)

³ [Code of Ethics | BASW](#)

Social work spans the spectrum of need in the children, adult and justice arenas. The profession works with some of the most vulnerable in society, and often at times of trauma distress and crisis, assessing risk and providing a holistic context for decision making. Palliative care, disability, mental health and substance use, and a societal context of poverty and discrimination are features which impact on much of our work. An overarching focus is working in a relational manner.

The area of assisted dying is complex and emotive. Our membership as individuals and practitioners hold a range of views, all of which are respected and legitimate. Our response seeks to highlight learning from other spheres where we work and to underline the criticality of viewing assisted dying as more than a medical matter linking this to the wider legislative and practice context, which it is hoped will assist the Health, Social Care and Sports Committee in their deliberations.

The reflections within this response are drawn from consultation with our membership which covers senior leaders in social work, including Chief Social Work Officers, service and team managers from across the country in both local authorities and third sector involved in delivery of services to children and adults.

Consultation Questions:

Question 1 – Overarching Question

The purpose of the Assisted Dying for Terminally Ill Adults (Scotland) Bill is to introduce a lawful form of assisted dying for people over the age of 16 with a terminal illness

Which of the following best reflects your views on the Bill

- Fully support
- Partially support
- Neutral/don't know
- Partially oppose x
- Strongly oppose

Further comment on your answer

Social Work Scotland has a range of members with varying views on this topic. Our partial oppose response however is based on the age range used in the Bill, and specifically the importance of consistency of definition of child, alongside applying understanding of brain development and the impact of vulnerabilities. These matters are explored further in our responses to other questions in the consultation.

Which of the following factors are most important to you when considering the issue of assisted dying?

- Impact on healthcare professionals and the doctor/patient relationship x
- Personal autonomy x
- Personal dignity x
- Reducing suffering
- Risk of coercion of vulnerable people x
- Risk of devaluing lives of vulnerable groups x
- Sanctity of life
- Risk of eligibility being broadened, and safeguard reduced over time x
- Other

Further comment on your answer:

Our value base would also ensure that personal autonomy, dignity and the risk of eligibility are important factors.

Question 2 – Eligibility

The Bill proposes that assisted dying would be available only to terminally ill adults

The Bill defines someone as terminally ill if they ‘have an advanced and progressive disease, illness or conditions for which they are unable to recover and that can reasonably be expected to cause their premature death’

An adult is defined as someone aged 16 or over. To be eligible a person would also need to have been resident in Scotland for at least 12 months and be registered with a GP practice.

Eligibility – Terminal illness

Which of the following most closely matches your opinion on the terminal illness criterion for determining eligibility for assisted dying?

- *No-one should be eligible for assisted dying*
- *Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness should be narrower than in the Bill*
- *Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness in the Bill is about right*
- *Assisted dying should be available only to people who are terminally ill, but the definition of terminal illness should be broader than in the Bill*
- *Assisted dying should be available to people who are terminally ill, and to other people in some categories*
- *Other – please provide further detail* x

If you have further comments, please provide these.

Assessment of eligibility is complex, but also central to the intent of the Bill. Given the seriousness and irreversible nature of the actions involved, the inclusion of safeguards for both individuals seeking to end their lives and those asked to assist is considered essential and must be strong and not open to interpretation. This is particularly important given the definition encompasses a number of individuals who may be described as particularly vulnerable, including some children with disabilities and others with life limiting conditions where there are additional factors which may consciously or unconsciously influence an individual's 'voluntary choice to end their life'.

While eligibility will be determined by two medical practitioners, those factors are much broader than the medical context. The critical factor requiring consideration is the holistic environmental experience of the individual wishing to end their life earlier than medical expertise would suggest will occur in the usual course of illness. This requires understanding and assessment of the social and relationship influences and context, including how close relationships and influence/power dynamics impact on individual decision making. Social Work Scotland suggest that a wider multi-agency assessment of eligibility is therefore indicated.

We also note that the term 'premature death' is also open to definition and that further attention to clarity of definition would be useful. In its current form the term could be interpreted as either the average lifespan of individuals with similar age or cultural characteristics -which may exclude some elderly individuals - or any terminal illness or condition which may result in dying from something other than 'natural' causes.

Eligibility – minimum age

Which of the following most closely matches your opinion on the minimum age at which people should be eligible for assisted dying?

- *No-one should be eligible for assisted dying*
- *The minimum age should be lower than 16*
- *The minimum age should be 16*
- *The minimum age should be 18*
- *The minimum age should be higher than 18 x*
- *Other – please provide further detail*

If you have further comments, please provide these

Social Work Scotland members have concerns about the age criteria in the Bill, thus the 'partially oppose' response to Q1.

Our work highlights that the circumstances of individuals and their family context are important features, and a range of individual and external factors can make people more susceptible to influence. In a context where the consequences of influence could result in death, robust safeguards are critical. This is especially significant for children with disabilities, many of whose life limiting conditions meet the Bill's definition of terminal illness.

Children are acknowledged as amongst societies' most vulnerable individuals. They are dependent on others for their wellbeing, and developmentally, have not yet gained optimal cognitive and social skills. Their circumstances are recognised across the board in the legal rights and duties vested with parents to act on behalf of their children. Adverse

circumstances through illness, disability or family/societal factors such as poverty or discrimination further enhance that vulnerability in terms of cognitive functioning. Article 1 of The United Nations Convention on the Rights of the Child (UNCRC) ⁴ which Scotland has introduced into domestic law ⁵ defines a child as someone under the age of 18 years. There are extra protections for children with a disability in Article 23 and UN Convention of the Rights of People with a Disability.⁶ Other legislation mirrors this with the Children and Young People (Scotland) Act 2014), recognising research indicating that young people's brains and related social and cognitive skills are still in development until the age of 26⁷. For groups such as looked after young people, this has led to extra protection through the provision of continuing care until the age of 21, and aftercare until the age of 26.

Social Work Scotland strongly suggests that the UNCRC definition of a child is adopted to align with other legislation in Scotland, thus ensuring international consistency and avoiding children's rights challenge. Given the significance of an assisted dying decision and the complexities where guardianship is involved, we also encourage consideration what brain development research means for decision making to inform whether the age criteria should be set at 26 years or over.

Question 3 – The Assisted Dying procedure and procedural safeguards

The Bill describes the procedure which would be in place for those wishing to have an assisted death.

It sets out various procedural safeguards, including:

- *Examination by two doctors*
- *Test of capacity*
- *Test of non-coercion*
- *Two stage process with period for reflection*

Which of the following most closely matches your opinion on the assisted Dying procedure and the procedural safeguards set out in the Bill?

⁴ <https://www.unicef.org.uk/wp-content/uploads/2016/08/unicef-convention-rights-child-uncrc.pdf>

⁵ <https://www.legislation.gov.uk/asp/2024/1/contents>

⁶ https://www.equalityhumanrights.com/sites/default/files/uncrpdguide_0.pdf

⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3621648/#:~:text=In%20fact%2C%20>

- *I do not agree with the procedure and procedural safeguards because I oppose assisted dying in principle*
- *The procedure should be strengthened to protect against abuse x*
- *The procedure strikes an appropriate balance*
- *The procedure should be simplified to minimize delay and distress to those seeking an assisted death*
- *Other – please provide further detail*

If you have further comments, please provide these

Please see the comments on children in the eligibility section. Additionally, many adults live with factors that may make them vulnerable to abuse, and independent robust safeguards are required to protect against coercion and pressure to agree. The opinion of two clinicians on the medical context is insufficient to determine if coercion or persuasion is involved and we suggest a more detailed multi-disciplinary assessment is indicated. The significance of the ultimate decision is such that the necessary time required to make a comprehensive assessment should be allowed.

Question 4- Method of dying

The Bill authorises a medical practitioner or authorised health professional to provide an eligible adult who meets certain conditions with a substance with which the adult can end their own life.

Which of the following most closely matches your opinions on this aspect of the Bill?

- *It should remain unlawful to supply people with a substance for the purpose of ending their own life*
- *It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill*
- *It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill, and it should also be possible for someone else to administer the substance to the adult, where the adult is unable to self-administer*
- *Other – lease provide further detail. X*

If you have further comments, please provide these

Social Work Scotland members are acutely conscious of the impact of difficult decisions and traumatic events on individuals. Assisting someone to die will always be traumatic, and the impact of those decisions and involvement in an act - even where there is agreement with the ending of suffering - should be undertaken with extreme caution and taking cognisance of the impact on the individual providing the substance as well as those who administer it.

As an organisation, Social Work Scotland cautions against legislating for allowing people to not only provide a substance with which an individual can end their life but to also administer that substance. This steps into a wider area which involves additional risk and therefore requires careful additional consideration and consultation. We suggest that extending the Bill in this way feeds into concerns expressed about the danger of the scope of the current Bill gradually creeping beyond parameters with which people are comfortable. This has been voiced by some of our members who work with people with a disability, life limiting or terminal conditions.

Question 5- Health professionals

The Bill requires the direct involvement of medical practitioners and authorised health professionals in the assisted dying process. It includes a provision allowing individuals to opt out as a matter of conscience.

Which of the following most closely matches your opinion on how the Bill may affect the medical profession? Tick all that apply.

- *Medical professionals should not be involved in assisted dying, as their duty is to preserve life*
- *The Bill strikes an appropriate balance by requiring that there are medical practitioners involved, but also allowing those with a conscientious objection to opt out*
- *Assisting people to have a ;'good death' should be recognised as a legitimate role for medical professionals*

- *Legalising assisted dying risks undermining doctor-patient relationship*
- *Other – please provide further detail*

If you have further comments, please provide these

Social Work Scotland is not a medical professional organisation and we would not therefore comment specifically on the potential impact of the involvement of medical practitioners. We would however note that opting out creates its own challenges and an alternative could be an ‘opt in’ position, which would mitigate the pressure on medical professionals, and others who may be involved in the decision about eligibility, to either conform to a view they may be uncomfortable with, or to be forced to justify their opting out position.

Question 6 – Death certificate:

If a person underwent assisted death, the Bill would require their underlying terminal illness to be recorded as the cause of death on their death certificate, rather than the substance that they took to end their life

Which of the following most closely matches your opinion on recording the cause of death?

- I do not support this approach because it is important that the cause of death information is recorded accurately x
- I support this approach because this will help to avoid potential stigma associate with assisted death
- Other - please provide further detail

Social Work Scotland appreciates the stigma aspect that may accompany assisted dying should the Bill become law. This is a feature in other situations such as suicide or death which results from a drug overdose. We understand that a death certificate usually notes, for example, an overdose as cause of death but with opportunity for the pathologist to provide context and notes. This may be that the cause of death was the result of suicide or self-harm.⁸

⁸ <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths/deaths-background-information/death-certificates-and-coding-the-causes-of-death>.

This approach feels appropriate and consistent should the assisted dying Bill become law. Inclusion of the underlying illness as cause of death would we feel create an unusual – and concerning - anomaly by legally supporting recording an inaccurate cause of death. This also creates a precedent which may have more far-reaching consequences. Providing wrong information in other situations would be a criminal offence⁹.

Stigma is however something which social workers deal with on a daily basis and consideration of how this aspect of what is a complex and emotive topic might be mitigated for both assisted dying and other forms of death which attract stigma would be welcomed. Form a social justice perspective, this is a cultural matter which is not resolved or aided by the proposed means of recording death.

Question 7 – Reporting and review requirements

The Bill proposes that data on first and second declarations, and cancellations, will be recorded and form part of the person’s medical record.

It also proposes that Public Health Scotland should collect data on: requests for assisted dying, how many people requesting assisted dying were eligible, how many were refused and why, how many did not proceed and why, and how many assisted deaths took place.

Public Health Scotland would have to report on this anonymised data annually and a report would be laid before the Scottish Parliament.

The Scottish Government must review the operation of the legislation within five years and lay a report before the Scottish Parliament within six months of the end of the review period.

Which of the following most closely matches your opinion on the reporting and review requirements set out in the Bill?

- The reporting and review requirements should be extended to increase transparency
- The reporting and review requirements set out in the bill are broadly appropriate x
- The reporting and review requirements seem excessive and would place an undue burden on frontline services

⁹ <https://www.nrscotland.gov.uk/registration/penalty-for-giving-false-information>

- Other

If you have further comments, please provide these

No further comments

Question 8 – Any other comments on the Bill

Do you have any other comments in relation to the Bill?

No

For further information, please contact:

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