



Hospice UK response to the proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill

1. About Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end-of-life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

2. Hospice UK's position

Hospice UK welcomes the opportunity to respond to this consultation. Hospice UK is of no collective view on the question of whether the law should be changed to permit any form of assisted dying. However, this doesn't translate to neutrality. The nurses, doctors, social workers, therapists, councillors, and trained volunteers working tirelessly

across Scotland for top-quality palliative care hold varying individual views on this issue. As a result, Hospice UK takes a position of ‘no collective view’ on the issue. But as advocates for high-quality end-of-life care, we believe everyone who is facing the end of their life has the right to the full facts and a clear understanding of all the available options and to access the best quality care and support possible.

As part of this exercise, Hospice UK has engaged extensively with the Scottish public and palliative care professionals as well as carefully studied the proposals. Emerging evidence shows us that conversations about assisted dying cannot exist independently of discussions about broader end-of-life care planning and support.

Global surveys have indicated that the public’s understanding around what constitutes assisted dying is often significantly different than proposed legislation. For instance, a 2017 study from New Zealand¹ found that 66% of respondents believed that assisted dying included ‘turning off life support’ while 52% of people believed that ceasing medical treatment was a form of assisted dying. While the situation in Scotland potentially differs considerably, we know that language around end-of-life decisions varies and often causes confusion. And, while Hospice UK research shows that 65% of people in Scotland agree that hospices should play a role in assisted dying² if made legal, it’s unclear to what extent the public understand what this will actually entail.

There is also emerging evidence that Scots aren’t fully aware of where to obtain end-of-life care. In fact, a December 2021 poll revealed that, when asked ‘If you, or a loved one, needed end-of-life care, do you have a good or bad understanding of how you would go about getting it?’ nearly 6 in 10 Scots had a bad understanding.³

Misperceptions about palliative care options can lead people to make decisions based

¹ <https://blogs.bmj.com/bmj/2021/09/08/assisted-dying-we-must-prioritise-research/>

² Opinion poll, commissioned by Hospice UK, December 2021

³ Opinion poll, commissioned by Hospice UK, December 2021

on information that isn't right for their specific circumstance. In light of this, it is critical that we tackle taboos about death, dying, and bereavement.

In the midst of this conversation, it is important that people are aware of their options and have access to high-quality end-of-life care. Hospice UK urges all decision-makers to help raise the profile of end-of-life issues and to facilitate conversations with one another about choices and availability of care for people as they approach the end of life. We know that around a quarter of people in Scotland aren't getting the palliative care they deserve.⁴ To be effective, this also requires appropriate, sustainable funding and a plan to tackle the inequalities that prevent people from getting the care they deserve.

3. Questions

1. Which of the following best expresses your view of the proposed Bill?

Neutral

Hospice UK is of no collective view on the question of assisted dying. Despite marking neutral in the required question above, our position doesn't translate to neutrality. The nurses, doctors, social workers, therapists, councillors, and trained volunteers working tirelessly across Scotland for top-quality palliative care hold varying individual views on this issue. There are a number of concerns about the substance of the consultation document as it currently stands, which you can find throughout our response. We are happy to liaise with any committee tasked with creating the Bill to discuss the points we've raised.

As mentioned above, Hospice UK is of no collective view on the issue of assisted dying. The answers to the questions below are specifically in relation to the current proposals.

⁴ <https://www.hospiceuk.org/latest-from-hospice-uk/future-hospice-care-scotland>

2. Do you think legislation is required, or are there other ways in which the Bill's aims could be achieved more effectively?

Palliative care needs to be prioritised at a local and national level through a whole system approach. Long-term sustainable funding that meets population need for palliative and end-of-life care across all settings, including the hospice sector, has to underpin this.

3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

Neutral

Despite marking neutral in the required question above, our position doesn't translate to neutrality. The nurses, doctors, social workers, therapists, councillors, and trained volunteers working tirelessly across Scotland for top-quality palliative care hold varying individual views on this issue.

End-of-life decisions cannot be taken lightly. It is critical that people plan for end-of-life care as far in advance as possible and inform their family of their preferences. Hospice UK research shows that, UK-wide, fewer than one in ten people (8%) have put in place medical and/or emotional support for the end of their lives (dropping to 6% among over-55s). Everyone who is approaching death is vulnerable and their wishes should be afforded the utmost care and respect.

The following points should be considered:

Eligibility

The proposals offer a good attempt at explaining eligibility criteria. However, ensuring a robust assessment stage with clear criteria that is applied equally across the country is potentially challenging. It is also critical that the varying nature of capacity is noted throughout the process, along with the acknowledgement that an individual's wishes are not necessarily fixed and, particularly toward the end of life, can change rapidly

Age

Special considerations should be taken into account when dealing with young people. It is recommended that any Assisted Dying Bill takes into consideration the fact that there are significant differences between terminal illnesses in children and young people and those in older adults. It is challenging to define terminal prognoses in many of the conditions affecting young people.

Delivering

In the event that the medication administered is unsuccessful it isn't clear what the next action is. If a dose meant to be lethal fails to act as intended it could lead to distressing and potentially protracted consequences for individuals, loved ones, and staff. An Assisted Dying bill must be transparent about the process in these cases.

4. Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document?

Neutral

Despite marking neutral in the required question above, our position doesn't translate to neutrality. The nurses, doctors, social workers, therapists, councillors, and trained volunteers working tirelessly across Scotland for top-quality palliative care hold varying individual views on this issue.

The right to palliative care is a fundamental missing safeguard. If an Assisted Dying Bill were to become law, a legally recognised right to palliative care is a critical safeguard to have in place.

In terms of the safeguards in the document, an Assisted Dying bill would need to address the lack of specificity with concrete processes and examples where appropriate.

Below is a non-exhaustive selection of proposed safeguards that pose potential problems:

- (a) It isn't clear what degree of independence the 'attending doctor' and 'independent doctor' should have from one another.
- (b) There may be cases where medical professionals should have specific specialisations beyond general medical training. The situations and training should be noted in the legislation.
- (c) The lack of detail on how the capacity of an individual would be assessed is concerning. Clear cases of mental illness are often readily identifiable, but less severe situations must be accurately assessed through an accessible set of criteria. Also, the variable nature of capacity should be taken into consideration.
- (d) There must be clear guidance on coercion, and training available for medical professionals to learn what behaviours might indicate this.
- (e) More detail about how people would be informed about palliative care options is needed. For example, a palliative care assessment that is tailored for the unique needs of each person isn't the same thing as being told about the general options available.

5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

Despite marking neutral in the required question above, our position doesn't translate to neutrality. The nurses, doctors, social workers, therapists, councillors, and trained volunteers working tirelessly across Scotland for top-quality palliative care hold varying individual views on this issue.

The proposals don't offer enough detail to comment fully. Any new body responsible for data should report to Scottish Ministers. An Assisted Dying Bill should fully explain which data should be included, how it will be collected, and for what purposes it is to be used.

6. Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.

An Assisted Dying Bill should contain explicit legal protections for individuals who find themselves unable to morally or practically provide support for assisted death.

7. Taking into account all those likely to be affected (including public sector bodies, businesses and individuals etc), is the proposed Bill likely to lead to:

Don't know

Despite marking neutral in the required question above, our position doesn't translate to neutrality. Please see below for our comments on this section.

There are a number of potential financial consequences for Hospices if the Assisted Dying Bill becomes law. However, significant detail about where and how assisted dying would take place, and who would participate would need to be determined. A non-exhaustive list of potential costs for hospices would be:

- the staff costs of additional palliative care assessments. As mentioned in question 4, such assessments should be a fundamental part any Assisted Dying Bill
- costs of additional staff welfare support
- training for additional specialist staff
- potential rises in/changes to insurance contracts

8. What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation?

Neutral

Despite marking neutral in the required question above, our position doesn't translate to neutrality. Please see below for our comments on this section.

There are concerns about inequalities in accessing high-quality palliative care (or a lack of awareness of it) among some communities, and it is important to address these. As

evidenced above, at the moment nearly 6 in 10 Scots don't know where to obtain end-of-life care and experience tells us that those who have the worst access to information are likely to be those who are most socially disadvantaged.

The proposed bill could have a negative impact on perceptions of older people and those with disabilities, potentially leading to a perception they are a burden on society.

Also, some people have no cognitive impairments, but are physically unable to self-administer medications, leading to potential discrimination in the application of the bill.

9. In terms of assessing the proposed Bill's potential impact on sustainable development, you may wish to consider how it relates to the following principles:

- **living within environmental limits**
- **ensuring a strong, healthy and just society**
- **achieving a sustainable economy**
- **promoting effective, participative systems of governance**
- **ensuring policy is developed on the basis of strong scientific evidence.**

With these principles in mind, do you consider that the Bill can be delivered sustainably?

Hospice UK offers no response to this question

10. Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?

Staff welfare

An Assisted Dying Bill needs to take staff welfare into consideration. People may express some level of distress as a result of participating in an assisted death.

This is potentially quite acute in the case of the staff who are delivering medications

intended to end life and who are present when it happens. Additionally, administrative tasks related to each assisted death could present significant burdens on staff already feeling time pressures. Therefore, the Bill should contain a detailed framework for supporting staff wellbeing.

Isolated communities

Those living in remote parts of Scotland may not have the same access to end-of-life choices as people living in other parts of the country. The Assisted Dying Bill should address such inequalities and detailed plans for funding equitable support regardless of location.

Bereavement care

There is a need for specialist bereavement support for loved ones left behind after an assisted death.

Questions

About you

1. Are you responding as:

On behalf of an organisation

2b. Please select the category which best describes your organisation:

Third sector (charitable, campaigning, social enterprise, voluntary, non-profit)

3. Please choose one of the following:

I am content for this response to be published and attributed to me or my organisation

4. Please provide your name or the name of your organisation.

Name: Hospice UK

Please provide a way in which we can contact you if there are queries regarding your response.

Contact details:

5. Data protection declaration

X- I confirm that I have read and understood the [Privacy Notice](#) which explains how my personal data will be used.