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info@togetherforshortlives.org.uk
0117 989 7820

together for short lives

Health, Social Care and Sport Committee's call for evidence on the Assisted Dying for Terminally Ill Adults (Scotland) Bill

A response from Together for Short Lives

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
- Strongly oppose

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
- Personal autonomy
- Personal dignity
- Reducing suffering
- Risk of coercion of vulnerable people
- Risk of devaluing lives of vulnerable groups
- Sanctity of life
- Risk of eligibility being broadened and safeguards reduced over time
- Other, please specify:
    - What the competencies of professionals providing assisted dying would need to be – and whether they would be age and developmentally-appropriate for young people
    - What medicines could be prescribed for assisting the death of a young person – and whether they would be age and developmentally-appropriate for young people

- Impact on providers of palliative care to young people – and whether they will be penalised or receive less statutory funding if they refuse to offer assisted dying.

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 condition from 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 people in some other categories.
- Other – please provide further detail

If you have further comments, please provide these

Together for Short Lives does not have a single agreed view about the ethical or moral philosophical basis for assisted dying or assisted suicide. We represent those who support the general purpose, some who oppose it and some who are uncertain.

We are concerned that the definition of 'terminally ill' that has been adopted in the Bill is extremely broad. This could consequently result in ambiguity when considering the eligibility of young people with life-limiting and life-threatening conditions whose prognosis is uncertain.

Whilst the majority of adults only need palliative care at the end of their lives, many young people with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth or even before.

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During this time, it is common for their conditions to fluctuate meaning many young people may experience relatively long periods of stability. It is therefore much more difficult to provide an accurate prognosis and identify when a young person is moving towards the end of life stage.

The inclusion of terminal illness as a qualifying condition requires clinicians to be able to provide an accurate prognosis. As this can be especially difficult for young people,[1] we believe that greater clarity is needed in the Bill for how 'terminally ill' would be defined in cases involving young people with life-limiting and life-threatening conditions whose prognosis is uncertain.

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
- Other – please provide further detail

If you have further comments, please provide these

Like adults, young people (aged 16 or 17) are presumed to have sufficient capacity to decide on their own medical treatment, unless there is significant evidence to suggest otherwise.[2] The Bill is clear that having capacity to request an assisted death is one of the criteria that a terminally ill adult would need to satisfy to be eligible.

However, children and young under the age of 16 can consent to their own treatment if they are believed to have enough intelligence, competence and understanding to fully appreciate what's involved in their treatment. This is known as being Gillick competent.[3]

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[1] Hain R, McNamara-Goodger K, Carragher P. (2012). Assisted dying in children: a framework for response? Archives of Disease in Childhood, 97. Available at: https://adc.bmj.com/content/97/Suppl_1/A169.1

[2] NHS. (2022). Children and young people: consent to treatment. Available at: https://www.nhs.uk/conditions/consent-to-treatment/children/#:~:text=People%20aged%2016%20or%20over,significant%20evidence%20to%20suggest%20otherwise.

[3] NHS. (2022). Children and young people: consent to treatment. Available at: https://www.nhs.uk/conditions/consent-to-treatment/children/#:~:text=People%20aged%2016%20or%20over,significant%20evidence%20to%20suggest%20otherwise.

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Some children and young people with life-limiting and life-threatening conditions are cognitively able and have the competence to be involved in decisions about their treatment. In some cases, this will include advance care planning decisions about their needs and wishes for their end of life care.

Parents bear a heavy responsibility for personal and nursing care of seriously ill children and young people. They are responsible for agreeing to medical treatment for a child or young person who has neither capacity nor competence to consent themselves.

Children and young people, parents or carers should have a central role in decision-making. If this Bill became law, it would be possible that some young people under the age of 16 who had the competence would wish to include any preferences they may have for requesting an assisted death in these advance care planning discussions.

These would be potentially challenging conversations for young people, their families and the professionals caring for them. It would be vital that young people and their families had access to information and support about the options available to them once a young person reaches the age of 16 – and the support required to hold these conversations with their young people.

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?

- 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
- The procedure strikes an appropriate balance
- The procedure should be simplified to minimise delay and distress to those seeking an assisted death
- Other – please provide further detail

If you have further comments, please provide these

Whilst we recognise the Bill sets out a clear process for accessing an assisted death, we have concerns about the lack of detail in some parts.

Expertise of the coordinating and independent registered medical practitioners

The Bill states that the qualifications and experience of the coordinating registered medical practitioner and the independent registered medical practitioner would be specified by Scottish Ministers.

We believe greater clarity is needed in the Bill on the skills, experience and training that a professional should have to make these preliminary assessments and in turn, assist someone to die. The Bill also needs to explicitly state that clear guidelines would be put in place to ensure that the appropriate level of medical expertise would be involved in the decision-making process.

Nothing currently exists to specify the role or the skillset of a professional who could assist someone to die. The Bill should establish the specific and appropriate competencies which would be needed to assist someone to die, and in particular young people. Without them, there is a risk that young people could inadvertently experience pain or other distressing symptoms during the process of an assisted death.

We believe that the legislation should establish how competencies would be:

- developed
- assessed
- safeguarded
- audited.

Test of capacity and non-coercion

We are also concerned by the lack of detail in the Bill around the test of capacity and the test of non-coercion.

Whilst the Bill does ensure that a person’s capacity would be assessed more than once, a young person’s emotional maturity and understanding of their own death is likely to change over time. We therefore believe that the level of the test for competence and capacity for a young person to request an assisted death would need to be graduated to reflect their emerging emotional maturity, their level of independence and their developmental understanding of their own death.

Young people can also be at a high risk of coercion; they are relatively disempowered because they lack influence in society, are often poor or financially dependent on others, and may be isolated.

As such, some young people may perceive an assisted death as a way of resolving their perceived burden on their families or even their socio-economic difficulties, such as distress

resulting from low income or energy poverty. They may also view assisted dying or suicide as the solution to any pain or distressing symptoms that they may be experiencing.

Some young people may also be influenced through social media and online content. Whilst the Bill would require the coordinating registered medical practitioner and independent registered medical practitioner to assess whether the person was making the declaration voluntarily and free from any coercion or influence from any other person, we believe more detail is required about the safeguards that would be put in place to help mitigate against coercion and influence from others.

Potential outcomes of palliative care or an assisted death

During the assessment, the Bill would require the registered medical practitioner to set out the implications of an assisted death and any further support provision that may be available to them.

Here, the registered medical practitioner would be required to explain and discuss any treatment that would be available and the likely impact this could have on the person's terminal illness. The registered medical practitioner would also be required to explain and discuss any palliative or other care available.

We believe that the Bill needs to make it explicitly clear that the registered medical practitioner should also, in addition to outlining the palliative care available to them, explain and discuss the impact that palliative care could have.

Children and young people's palliative and end of life care includes:

- physical care
- emotional care
- psychological care
- social care
- spiritual care

Palliative care enables young people with life-limiting or life-threatening conditions to live as well as possible until they die. This will mean different things to individual young people, but may include:

- access to leisure activities
- access to education
- the ability to spend time with their family
- the ability to make and maintain friends
- Enabling choice.

For young people, palliative and end of life care may enable them to form and maintain relationships, access further or higher education and access employment.

Palliative and end of life care supports young people and families to have a choice in their:

- place of care
- place of death
- emotional and bereavement support.

In order to help a person who would be considering an assisted death to make a fully informed decision, it would be critical that the registered medical practitioner explained all the options available to them, in addition to the outcomes that these options could lead to. Here, it is especially important that the registered medical practitioner has the experience and knowledge to speak about the outcomes that these options could lead to.

We also believe that when discussing the person's diagnosis and prognosis, the registered medical practitioner should also have a duty to explain the implications of an assisted death. It is critical that the person would be fully informed of and understand what their own death would mean in terms of their permanent erasure from existence.

Where prognosis would be discussed during this assessment, greater clarity would be needed for cases involving young people with life-limiting and life-threatening conditions whose prognosis is uncertain. For many young people, it is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a young person is moving into their end of life phase.

As such, providing and discussing an accurate prognosis can be especially difficult in such cases.

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 opinion 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 – please provide further detail

If you have further comments, please provide these

The Bill states that in order to assist the death of a terminally ill adult, an approved substance could be provided with which the adult may end their own life.

Whilst we recognise the Bill defines an approved substance as a drug or other substance as is specified by the Scottish Ministers by regulations, we are concerned that the Bill does not explicitly account for the fact that children and young people differ from adults in body size and in the way they metabolise medicines.[4]

Research indicates that important differences have been found in the paediatric population compared with adults for both phase I enzymes and phase II enzymes.[5]

The Bill should explicitly account for this difference. We also believe that regulations identifying the approved substances would need to specify the medicines that could be used to assist the death of a young person, as well as the form and manner in which they could be issued.

Here, further challenges may emerge as the efficacy and safety of assisted dying drugs are currently difficult to assess, as clinician reporting is often very low.[6] If assisted dying were to be legalised, it is crucial that the Bill makes sure patient outcomes are monitored and evaluated.

There is also currently no evidence which indicates:

- what means of assisting a death or suicide are preferable over others
- what adverse effects of the medications are intolerable
- whether these are different in young people.

We are also concerned that the Bill does not account for any circumstances in which an assisted death fail. We therefore believe the Bill should state that guidelines would be issued for professionals to follow should their actions or the medicines they had used to assist the death of a young person fail.

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.

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[4] Strolin Benedetti M, Whomsley R & Baltes EL. (2005). Differences in absorption, distribution, metabolism and excretion of xenobiotics between the paediatric and adult populations. Expert Opinion on Drug Metabolism & Toxicology, 1(3). Available at: https://pubmed.ncbi.nlm.nih.gov/16863455/.
[5] Strolin Benedetti M, Whomsley R & Baltes EL. (2005). Differences in absorption, distribution, metabolism and excretion of xenobiotics between the paediatric and adult populations. Expert Opinion on Drug Metabolism & Toxicology, 1(3). Available at: https://pubmed.ncbi.nlm.nih.gov/16863455/.
[6] Worthington A, Finlay I and Regnard, C. (2022). Efficacy and safety of drugs used for ‘assisted dying’. British Medical Bulletin, 142(1). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9270985/.

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, not end it.
- 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 the doctor-patient relationship
- Other – please provide further detail

If you have further comments, please provide these

We are pleased to see that the Bill makes provision for conscientious objection. We agree with the British Medical Association (BMA) that the right of conscientious objection should apply to all health, care, and administrative staff.[7] This would include staff in hospices, who may not wish to offer services that assist death, but which would nevertheless wish to offer support to young people approaching the end of their lives.

We therefore agree with Children’s Hospices Across Scotland (CHAS) in calling for the Bill to explicitly preclude criminal and civil liability for all individuals who decline to provide assisted dying or associated services. Further detail should also be made available on the proposed legislative process by which conscientious objection would be enshrined in law.

We are concerned that, if it becomes law, the Bill could make it more challenging for professionals providing palliative care to young people to hold difficult conversations with them and their families about the fact that they are likely to die – and what their needs and wishes are for the end of their lives.

Some young people with life-limiting and life-threatening conditions are cognitively able and are competent enough to be involved in decisions about their treatment. In some cases, this will include advance care planning decisions about their needs and wishes for their end of life care.

If this Bill becomes law, it is possible that some young people under the age of 16 who are competent would wish to include any preferences they may have for requesting an assisted death in advance care planning discussions. These would be potentially challenging conversations for young people, their families and the professionals caring for them to hold.

[7] British Medical Association. (2021). Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill question one response – NEUTRAL. Available at: https://www.assisteddying.scot/wp-content/uploads/2022/09/Response-14034-British-Medical-Association-BMA-Non-Smart-Survey-Q1-Only.pdf.

It would be vital for professionals and services to have access to education and training to make sure they had the skills and experience to hold these conversations.

A significant proportion of young people with life-limiting and life-threatening conditions have neither the capacity nor competence to be involved in decisions about their treatment, but may do so in future. Their parents bear a heavy responsibility, not only for their personal and nursing care, but also for working with professionals to determine what is in the best interests of the child.

Professionals would need guidance and support to hold challenging conversations with parents about the options available to their young person if and when they attain the capacity to request an assisted death.

Question 6 - Death certification

If a person underwent an 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
- I support this approach because this will help to avoid potential stigma associated with assisted death
- Other – please provide further detail

If you have further comments, please provide these

We believe that both the underlying terminal illness and the substance that assisted a person to end their life should be recorded on the death certificate.

Research conducted by Downie and Oliver (2016) stated that the medical condition that would qualify a person for an assisted death should be recorded as the underlying cause of death whilst the substance that a person could take to end their life should be recorded as the antecedent cause.[8]

According to Downie and Oliver, recording an assisted death in this way will make end of life research much more efficient and reliable. Instead of sampling from all certificates of death

[8] Downie J and Oliver K. (2016). Medical certificates of death: First principles and established practices provide answers to new questions. CMAJ, 188(1). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4695354/

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and interviewing doctors to understand which cases involved an assisted death, vital statistics could be sought directly from certificates and relevant databases.[9] Furthermore, completing the death certificate in this manner could act as a direct tool for the oversight of assisted dying.[10]

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
- The reporting and review requirements seem excessive and would place an undue burden on frontline services
- Other – please provide further detail

If you have further comments, please provide these

We believe that the Bill should specify that Public Health Scotland collects data on a series of characteristics of people who:

- request an assisted death
- request an assisted death and are eligible
- are refused

[9] Downie J and Oliver K. (2016). Medical certificates of death: First principles and established practices provide answers to new questions. CMAJ, 188(1). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4695354/
[10] Downie J and Oliver K. (2016). Medical certificates of death: First principles and established practices provide answers to new questions. CMAJ, 188(1). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4695354/

- are eligible but do not proceed

The characteristics collected should include:

- age
- sex & gender
- trans status
- disability
- ethnic group
- religion
- sexual orientation
- socio-economic background.

We think this information would be important to understand if how the demand for assisted deaths varies among different demographic groups, which could assist future research to determine why any variations have emerged.

We also think that the area in which a person's usual place of residence is in – such as their NHS board or local authority area – should be recorded. This could also help future research, and help politicians and policymakers to assess whether there is any relationship between demand for assisted deaths and access to high quality, sustainable palliative care.

Question 8 – Any other comments on the Bill

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

We are concerned that the Bill does not explicitly state the support that will be in place for families of young people who access an assisted death.

Parents, siblings, and other family members provide care around the clock to seriously ill young people, often over long periods of time. When a young person is diagnosed or recognised as having a life-limiting or life-threatening condition, it is crucial that they are offered appropriate and timely palliative care support. This may include:

- physical care
- emotional care
- psychological care
- social care
- spiritual care.

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Research shows that when provided with emotional and psychological support, parents can prepare for the death of their young person, and in turn are better enabled to be a parent to their seriously ill young person in their final moments.[11]

The Bill should therefore ensure support is in place for families both pre and post bereavement.

We are concerned that the Bill does not set out whether assisted dying would operate as a specialist service, and/or whether it would be offered as part of the NHS. We believe that it should clarify this.

As would be the case for individuals being able to conscientiously object to providing assisted dying, we also believe that provider organisations should also be able to opt out of doing so. If the Bill does not explicitly allow for this, then there could be a risk that services will be compelled to provide an assisted dying service when they are practically not in a position to do so, whether that be due to workforce shortages or financial constraints.

There is also a risk that providing or not providing assisted dying could have an impact on provider organisations' ability to generate charitable income. These organisations should be free to weigh up and make a valued judgement considering these wider organisational factors rather than exposed to a legal obligation.

We also believe that the statutory funding that a provider organisation receives to deliver health and or social care to people with life-limiting or life-threatening conditions should in no way depend on whether or not they decide to offer assisted dying.

This should include voluntary sector providers such as children's hospices, which may wish not to offer assisted dying to young people. We are concerned that, if palliative care services for young people were compelled to provide assisted dying, either as a legal obligation or because their statutory funding depended on it, it could undermine their current service models.

This could also hinder their ability to meet the increasingly complex needs of the growing number of young people with life-limiting or life-threatening conditions in Scotland.

[11] Barrett L, Fraser, L, Noyes J, Taylor, J, Hackett, J. (2023). Understanding parent experiences of end-of-life care for children: A systematic review and qualitative evidence synthesis. Palliative Medicine, 37(2). Available at: https://pubmed.ncbi.nlm.nih.gov/36546591/.