

Assisted Dying for Terminally Ill Adults Bill (House of Lords)

A briefing from Together for Short Lives

Introduction

- 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.
- If Parliament were to legalise assisted dying for adults aged 18 and over, there would be a number of potential implications for terminally ill children and young people, their families and the professionals and services that provide them with care and support.
- Not only should these implications be recognised and accounted for, but it must also be acknowledged that access to high quality palliative care for children and young people depends on where they live.
- This is a result of severe workforce shortages, significant funding gaps and a lack of accountability among local NHS bodies and councils that the UK's governments must urgently address.
- We cannot allow a scenario in which young adults choose an assisted death because they are unable to access the palliative care they need, when and where they need it.
- When referring to young people and young adults in this briefing, we mean those aged 18-25.
- In this briefing, we have set out what we believe the key considerations are for terminally ill children and young people that parliamentarians need to take account of when debating and scrutinising the Assisted Dying for Terminally Ill Adults Bill (HL).

Key considerations for terminally ill children and young people, their families and the professionals and services that provide them with care and support

Eligibility

Definition of terminal illness

- In the Bill, a person is defined as being terminally ill if that person has been diagnosed as having an inevitably progressive condition which cannot be reversed by treatment and as a consequence of that terminal illness, is reasonably expected to die within six months.
- We are concerned that the requirement for an accurate prognosis to be provided for a person to be considered as 'terminally ill' may 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 in the womb.
- 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 their 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.
- We note that the six month threshold is not consistent with the Ambitions for Palliative and End of Life Care, which states that patients are 'approaching the end of life' when they are likely to die within the next 12 months.²
- The government also extended eligibility to end of life support through the benefits system from six to 12 months from 4 April 2022.³

Minimum age

- 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.⁴
- 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

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 National Palliative and End of Life Care Partnership. (2021). Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. Available at: <https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf>

³ Department for Work and Pensions. (2022). Fast-tracked benefit access extended to more nearing end of life. Available at: <https://www.gov.uk/government/news/fast-tracked-benefit-access-extended-to-more-nearing-end-of-life>.

⁴ 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>

fully appreciate what's involved in their treatment. This is known as being Gillick competent.⁵

- 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 18 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 18 – and on how to hold these conversations with their young people.

Expertise of the attending doctor and the independent doctor

- The Bill states that the qualifications and experience of the attending doctor and the independent doctor would be specified by the Secretary of State in regulations.
- 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.
- We believe that 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.

⁵ 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.>

- 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 attending doctor and the independent doctor to separately examine the person and be satisfied that the person has a clear and settled intention to end their own life which has been reached voluntarily, on an informed basis and without undue influence, coercion or duress, we believe more detail is required about the safeguards that would be put in place to help mitigate against coercion and influence from others.

Outcomes of palliative care or an assisted death

- When deciding whether to countersign a declaration, the Bill would require the attending doctor and the independent doctor to be satisfied that the person making it has been fully informed of the palliative, hospice and other care that is available to them.

- We believe that the Bill needs to make it explicitly clear that both the attending doctor and independent doctor should reiterate the palliative care that is available to them and explain and discuss the impact that palliative care could have. This would help a person who would be considering an assisted death to make a fully informed decision.
- 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.

- 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 attending doctor and independent doctor 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 a prognosis of six months is required to be considered 'terminally ill', 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.

Assistance in dying: Medicines

- The Bill states that in order to assist the death of a terminally ill adult, the attending doctor of a person who has made a valid declaration and obtained the consent of the High Court may prescribe medicines for that person to enable that person to end their own life.
- Whilst we recognise the Bill states that the medicines which may be prescribed would be specified by the Secretary of State in regulations, we are concerned that the Bill does not explicitly account for the fact that young people differ from adults in body size and in the way they metabolise medicines.⁶
- Research indicates that important differences have been found in the paediatric population compared with adults for both phase I enzymes and phase II enzymes.⁷
- The Bill should explicitly account for this difference.
- 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.⁸ If assisted dying were to be legalised, it is crucial that the Bill makes sure patient

⁶ Strolin Benedetti M, Whomsley R & Baltés 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/>.

⁷ Strolin Benedetti M, Whomsley R & Baltés 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/>.

⁸ 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/>.

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 fails. 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.

The impact on professionals and provider organisations in the children's palliative care sector

- 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.⁹ 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 believe the Bill should 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.
- 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.

⁹ 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>.

- 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 England and Wales.
- We are also 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 18 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.
- 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.

Death certification

- From the Bill, we understand that if enacted, the cause of death in cases involving assisted dying would be recorded as an 'assisted death' on the death certificate,

rather than the underlying terminal illness.

- 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.¹⁰
- 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 and interviewing doctors to understand which cases involved an assisted death, vital statistics could be sought directly from certificates and relevant databases.¹¹
- Furthermore, completing the death certificate in this manner could act as a direct tool for the oversight of assisted dying.¹²

Reporting and review requirements

- We believe that the Bill should include a requirement for data to be collected on a series of characteristics of people who:
 - Request an assisted death.
 - Request an assisted death and are eligible.
 - Are refused.
 - Are eligible but do not proceed.
- The characteristics collected could include:
 - Age.
 - Sex & gender.
 - Trans status.

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/>

¹¹ 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/>

¹² 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/>

- Disability.
 - Ethnic group.
 - Religion.
 - Sexual orientation.
 - Socio-economic background.
- This information should be included within the report prepared by the Secretary of State on the review of the operation of the Act.
 - 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.

More information is available

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