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

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.

- During the bill's House of Commons stages, several amendments were proposed and agreed by MPs that could have further implications for these groups:

    - **Opt-out provision for professionals:** the bill would permit health and care professionals to opt-out of any involvement in assisted dying.

    - **Restriction on raising the subject with those under the age of 18:** the bill would prohibit any professional from raising the subject of assisted dying with a person under the age of 18.

    - **Reporting requirement on palliative care:** the bill would require the Secretary of State to report on the availability, quality and distribution of palliative and end of life care within a year of the Act being passed.

- As the bill progresses to the House of Lords, we urge peers to scrutinise these carefully and raise the issues we highlight during the Second Reading debate.

- This briefing sets out a series of amendments that Together for Short Lives would like peers to make to the bill should it progress to Committee Stage. We believe that these would improve the bill by making it safer for terminally young ill adults

- They would also help to better prepare families of terminally ill young people, young adults and palliative care professionals and services with the skills, knowledge and guidance they will need to hold difficult conversations about the choices available at the end of a young adult's life if an assisted death was available.

- When referring to young adults in this briefing, we mean those aged 18-25. When referring to young people in this briefing, we mean those aged 14-25.

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

Eligibility

Definition of terminal illness

Proposed amendment to Section 2: Duty on the Secretary of State to provide guidance on prognosis

Insert as subsection (5):

(5) The Secretary of State must issue and maintain statutory guidance for healthcare professionals on the assessment and prognosis of life expectancy for individuals, including young adults aged 18-25, whose life-limiting and life-threatening conditions may fluctuate or whose prognosis is uncertain. The guidance must:

(a) Clarify the definition of "terminally ill" as it applies to young adults whose conditions are inevitably progressive but may include periods of stability;

(b) Address the complexities of prognosing for young adults with life-limiting and life-threatening conditions.

(c) Emphasise that a multidisciplinary approach must be taken to ensure a holistic evaluation of the young adult's condition, involving specialists in the young adult's life-limiting or life-threatening condition:

(d) Be subject to regular review and consultation with stakeholders, including healthcare professionals, young adults with life-limiting conditions, and their families, to ensure that it reflects the latest clinical evidence and best practice.

- 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 adults with life-limiting and life-threatening conditions whose prognosis is uncertain.

- While the majority of adults only need palliative care at the end of their lives, many young adults 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 adults 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 adults,[1] we believe that greater clarity is needed in the bill for how 'terminally ill' would be defined in cases involving young adults 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]

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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] 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.

Expertise of the coordinating doctor and the independent doctor

Proposed amendments to Sections 8 and 11: Obligation for regulations to specify expertise of coordinating and independent doctors when assessing young adults

Amendment to Section 8: Insert as subsection (11)

(11) Regulations made under subsection (7) must make provision about the training, qualifications and experience of the coordinating doctor, specifically regarding the assessment of young adults aged 18-25. This provision must:

(a) Specify the competencies required to assess young adults with life-limiting and life-threatening conditions, including the ability to account for the complexities of fluctuating conditions and uncertain prognoses;

(b) Outline the minimum training standards for practitioners responsible for assessing young adults.

(c) Establish mechanisms to ensure practitioners’ qualifications and experience are regularly reviewed and updated in line with evolving clinical guidelines.

Amendment to Section 11: Insert as subsection (14)

(14) Regulations made under subsection (9) must make provision about the training, qualifications and experience of the independent doctor, specifically regarding the assessment of young adults aged 18-25. This provision must:

(a) Specify the competencies required to assess young adults with life-limiting and life-threatening conditions, including the ability to account for the complexities of fluctuating conditions and uncertain prognoses;

(b) Outline the minimum training standards for practitioners responsible for assessing young adults.

(c) Establish mechanisms to ensure practitioners’ qualifications and experience are regularly reviewed and updated in line with evolving clinical guidelines.

- As it stands, the bill provides that the Secretary of State must, by regulation, specify the training, qualifications, and experience required for a registered medical practitioner to act as a coordinating or independent doctor.

- Despite this, there is no recognition of the complex and distinct needs of young adults aged 18-25 with life-limiting and life-threatening conditions, and the specific competencies that would be required when making preliminary assessments.

- We believe that the bill should emphasise that specific competencies would be required when assessing young adults, and ensure that the training, qualifications and experience of practitioners assessing young adults is outlined in regulations issued by the Secretary of State.

- We also believe that the bill should mandate that clear guidelines would be put in place to ensure that the appropriate level of medical expertise is involved in the decision-making process, and that practitioners' qualifications and experience will be regularly reviewed and updated in line with evolving clinical guidelines.

- In the absence of practitioners possessing the specific and appropriate competencies required to assess young adults and assist them to die, there is a risk that young adults could inadvertently experience pain or other distressing symptoms during the process of an assisted death.

Outcomes of palliative care or an assisted death

Proposed amendments to Sections 5 and 12: Requirement to explain the potential impact of palliative care

Amendment to Section 5, addition of subsection (5)(d): Insert the following:

(d) the potential impact of palliative or hospice care on the person's quality of life, wellbeing and ability to manage symptoms, as well as the emotional, social, and psychological outcomes associated with such care.

Amendment to Section 12, subsection (2)(c)(iii): Replace with the following:

(iii) any available palliative, hospice or other care, including symptom management and psychological support, and the potential impact of such care on the person's quality of life, wellbeing and ability to manage symptoms, as well as the emotional, social, and psychological outcomes associated with such care.

- Currently, the bill would require the coordinating doctor and the independent doctor to explain and discuss the palliative and hospice care options available to the person requesting an assisted death, including symptom management and psychological support.

- While Section 39 requires the Secretary of State to issue one or more codes of practice in connection with the information which is made available as mentioned in Sections 5 and 12 on treatment or palliative, hospice or other care available to the person, we believe the bill needs to explicitly set out that both the coordinating doctor and independent doctor should also 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.

- For children and young people, 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 even obtain 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 therefore especially important that the both the coordinating doctor and independent doctor have 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 coordinating doctor and independent doctor should also have a duty to explain the implications of an assisted death.
- Whilst Section 39 notes the Secretary of State may issue one or more codes of practice in relation to this, we believe the bill needs to make an explicit requirement to ensure that the person is fully informed and understands 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 adults with life-limiting and life-threatening conditions whose prognosis is uncertain.
- For many young people and young adults, 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, and to provide an accurate prognosis.

Assistance in dying: approved substances

Proposed amendment to Section 27: Duty to collect evidence about the outcomes experienced by young adults who access an assisted death

Insert as subsection (4):

(4) The Secretary of State must collect and publish evidence on the outcomes experienced by young adults who access an assisted death under this act, with specific regard to the efficacy, safety, and appropriateness of approved substances for this age group. This evidence must be used to inform future decisions about the substances specified under subsection (1).

- The bill states that in order to assist the death of a terminally ill adult, the following needs to occur before any approved substance may be provided:
    - A certificate of eligibility has been granted in respect of a person.
    - The second period for reflection (within the meaning of section 19(2)) has ended.
    - That person has made a second declaration which has not been cancelled.
    - The coordinating doctor has made the statement under section 19(6).
- Once the above has occurred, the coordinating doctor may provide that person with an approved substance with which the person may end their own life.
- While we recognise the bill states that the approved substances 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 younger adults differ from older 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.

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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/.

- 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]
- 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; and
    - whether these are different in young people.
- If assisted dying were to be legalised, it is crucial that the bill makes sure patient outcomes are monitored and evaluated.

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[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/.

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

Proposed amendment to Sections 31, 32 and 33: Conscientious objection and protection for individuals and provider organisations

Amendment to Section 31: Insert as subsection (10)

(10) No provider organisation, including but not limited to hospices, hospitals, and care facilities, shall be under any obligation to offer or facilitate assisted dying services.

(a). A refusal to offer assisted dying services shall not be grounds for any reduction, suspension, or denial of statutory funding that the organisation is otherwise entitled to receive for delivering health or social care services.

(b). The statutory funding that an organisation receives to provide care to individuals with life-limiting or life-threatening conditions shall not in any way be dependent on whether the organisation chooses to offer assisted dying services.

Amendment to Section 32: Insert as subsection (4) and subsection (5):

(4) Any registered medical practitioner or other health professional may conscientiously object to providing, assisting, or facilitating any aspect of assisted dying, without facing criminal liability.

(5) Any provider organisation may decline to provide or facilitate assisted dying without facing criminal liability.

Amendment to Section 33: Insert as subsection (4) and subsection (5):

(4) Any registered medical practitioner or other health professional may conscientiously object to providing, assisting, or facilitating any aspect of assisted dying, without facing civil or professional liability.

(5) Any provider organisation may decline to provide or facilitate assisted dying without facing civil or regulatory liability.

- We are pleased that the bill now make provision for the conscientious objection of individuals. However, we believe that the ability to opt out of involvement in assisted dying services should also extend to provider organisations.

- If the bill does not explicitly allow for this, then there could be a risk that organisations 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.

- 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.

- There is also a risk that providing or not providing assisted dying could have an impact on provider organisations' ability to generate charitable income and the statutory funding that they receive.

- We therefore 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 adults 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 also believe the bill should explicitly protect individuals and organisations from both criminal and civil liability if they choose not to participate in assisted dying or related service.

- Further detail should also be made available on the proposed legislative process by which conscientious objection would be enshrined in law.

Proposed amendment to Section 6: Advance care planning for young people approaching adulthood

Amendment to Section 6: Insert the following as subsections (2), (3), (4) and (5):

(2) The Secretary of State must issue guidance on how advance care planning should be conducted for young people under the age of 18 who raise the subject of seeking an assisted death once they reach the age of 18.

(3) The guidance issued under subsection (2) must include, but is not limited to:

(a) The manner in which conversations about end of life preferences, including assisted dying, should be managed with young people approaching adulthood and their families, ensuring that these discussions are conducted in a sensitive and age-appropriate manner;

(b) The provision of information to young people approaching adulthood about all available care options including palliative care, hospice care, and assisted death, with an emphasis on the emotional, psychological, and social impacts of each option;

(c) The qualifications, experience, training and support required for all practitioners to ensure they are equipped to navigate these difficult conversations with young people and their families.

(3) The guidance issued under subsection (2) must be reviewed and updated regularly to ensure that it reflects current best practices and evolving clinical standards.

(4) Practitioners involved in providing palliative and end of life care to young people must be trained in advance care planning and must follow the guidance issued by the Secretary of State under subsection (2) when conducting advance care planning discussions.

- Despite Section 6 of the bill currently precluding practitioners from raising the subject of assisted dying with a person under the age of 18, we foresee that some competent young people under the age of 18 may raise the subject of seeking an assisted death once they reach adulthood themselves, and as such wish to discuss this as part of advance care planning discussions.

- It is therefore crucial that professionals and services are equipped with the necessary education and training to ensure they have the skills and experience to navigate these sensitive conversations effectively.

- This would enable them to manage potentially challenging discussions with young people and their parents about the available options, particularly as they approach adulthood and the ability to make such a request.

- As it stands, 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 these 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.

Reporting and review requirements

Proposed amendments to Section 35: Reviewing and reporting on the operation of the act and palliative care provision

<u>Amendment to Section 47: Insert as subsection (5)(d):</u>

(d) specific consideration of the needs of children and young people requiring palliative and end of life care, including the availability and quality of children's palliative care and support for families.

<u>Amendment to Section 50: Insert as subsections (3)(f), (3)(g) and (3)(h):</u>

(f) an assessment of the impact of the act on the delivery and funding of palliative and end of life care services across England and Wales.

(g) the collection and analysis of data on the characteristics of individuals who:

  (i) request an assisted death;

  (ii) Request an assisted death and are eligible;

  (iii) Are refused;

  (iv) Are eligible but do not proceed.

(h) the characteristics collected must include, but not be limited to:

  (i) Age;

  (ii) Sex & gender;

  (iii) Trans status;

  (iv) Disability;

  (v) Ethnic group;

  (vi) Religion;

  (vii) Sexual orientation;

  (viii) Socio-economic background.

- We welcome the requirement for the Secretary of State to review the availability, quality and distribution of palliative and end of life care services.

- With significant challenges in children's palliative care, that could influence a young person's decision to seek an assisted death, it is essential that the review required by the bill explicitly includes palliative care for children and young people.

- Without explicit inclusion, there is a risk that the availability, quality and distribution of children's palliative care services could be overlooked in the Secretary of State's review, and any resulting policy responses.

- We also 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.
    - 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 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 integrated health board, local health 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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