

Assisted Suicide (Scotland) Bill

Together for Short Lives

Together for Short Lives is the leading UK charity for all children and young people with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices. Our work helps to ensure that children and young people can get the best possible care, wherever and whenever they need it.

In scrutinising the bill, we ask that the Health and Sport Committee considers the significant impact that it could have on young people with life-limiting or life-threatening conditions. Life-limiting conditions are those for which there is no reasonable hope of cure and from which children are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail.

We ask that the committee takes account of the fact that, compared to older adults, young people will have contrasting perspectives on death and dying. Whereas the majority of adults only need palliative care at the end of their lives, young people with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth. 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. Children with life-threatening and life-limiting conditions often have complex disabilities, while the range of health conditions which result in children being life-threatened or life-limited is more diverse.

Although the number of young people requiring end of life care is small compared to the entire population of those aged 16 or over in this category, it is imperative that the needs of young people are not lost in the debate to come.

Barbara Gelb
Chief Executive
Together for Short Lives

1. Do you agree with the general purpose of the Bill to make it permissible, in the circumstances provided for, to assist another to commit suicide?

We do not have a single agreed view about the ethical or moral philosophical basis for physician-assisted suicide (PAS) itself, but represents the same spread of opinion that is reported among the population as a whole. That is, it encompasses some who support the general purpose, some who oppose it and some who are uncertain.

2. Do you have any views on how the provisions in this Bill compare with those from the previous End of Life Assistance (Scotland) Bill?

We have a clear view that the proposed Bill still does not provide adequate safeguards for young people .

3. The Bill precludes any criminal and civil liability for those providing assistance, providing the processes and requirements set out in the Bill have been adhered to. Do you wish to make any comment on this?

We make no response to this question as it is outside our field of expertise. We do feel strongly, however, that any Bill should explicitly preclude criminal and civil liability for those who decline to provide such assistance.

4. The Bill outlines a three stage declaration and request process that would be required to be followed by an individual seeking assisted suicide. Do you have any comment on the process being proposed?

We recognise that in this new process some attempt has been made to improve the robustness of the safeguards, but we continue to have significant concerns about the process in respect of young people. There is nothing in the background papers to explain the basis on which the current process has been proposed, or how it addresses the distinct issues of assisted suicide among young people. The development of understanding of mortality means that, even in the absence of any psychopathology, young people think differently about their own death from the way that older people do.

For neurodevelopmental reasons, young people up to the age of about 25 do not yet fully associate their own death with permanent erasure from existence. That is extremely important because it means a young person might ask for PAS for reasons that have nothing to do with an actual desire to die in the sense that death is understood by older adults. The distinctness of young people in this important respect is still not acknowledged in the Bill. This is a sufficiently striking omission to cause us to ask respectfully whether the views of any young person had been solicited in the course of preparation of the consultation paper.

5. Do you have any comment on the provisions requiring that the person seeking assisted suicide must have a terminal or life-shortening illness, or a progressive condition which is either terminal or life-shortening?

We are concerned about these provisions, particularly in the context of young people. The definitions are ambiguous:

- The phrase 'life-shortening' is unclear because a young person can have a condition (for example, cystic fibrosis) that will shorten life but could nevertheless allow them to live for several decades more. A condition causing life to be shortened to sixty years of age means that, for an adult aged 58, physician assisted suicide will bring death forward by only two years. But for a young person aged 18, PAS will bring death forward by more than 40 years. This safeguard is therefore inherently much weaker in young people than in older adults.
- The phrase 'prospect ... of improvement' (p5) is unclear because an individual's perception that improvement is impossible is not reliably linked to the actual possibility that their life will improve. Conditions that ultimately shorten life-span are often associated with sadness and a tendency to underestimate the chance of improvement that has nothing to do with reality.
- The word 'prognosis' has two meanings that are quite distinct in a way that is not acknowledged. The first is the sense of the duration of life (the prognosis of Duchenne Muscular Dystrophy is poor because it will inevitably shorten the sufferer's life). The second is the risk of death (the prognosis of metastatic osteosarcoma is poor because the likelihood of cure is small. But if it is cured, the sufferer's life will be of normal duration). This distinction is extremely important in young people, because the implication of the two meanings for their future is quite different. In requesting PAS, a young person with Duchenne Muscular Dystrophy might be choosing death now over inevitable death in five or ten years' time, while a young person with metastatic osteosarcoma might be choosing inevitable death over the possibility of normal life, lasting perhaps fifty or sixty further years. This safeguard is therefore inherently much weaker in young people than in older adults.

6. Are you satisfied with the eligibility requirements as regards age, capacity, and connection with Scotland as set out in the Bill?

We are not satisfied. We have the following concerns about this in young people:

- The assumption here is that capacity and autonomy are the same. That is not true: a person can be subject to coercion even if they have full capacity. That gap between capacity and autonomy is particularly wide in young people. Compared with older adults, young people are relatively disempowered as they lack influence in society, are often poor or financially dependent on others, and are isolated.
- From (5) above, it is clear that the level of the test for capacity that should apply to a young person would need to be greater than that of older adults, since the latter have a more developed and sophisticated sense of

what death means. If this Bill were to become law, there should be a graduated test for capacity that reflects the graduated developmental understanding of death over early adulthood.

- It is not clear what authority the Bill gives to parents of young people who lack capacity. Currently, the parents of such young people in Scotland are given de facto rights to consent on their behalf to medical interventions under the age of 16 years old, they need to legally attain this through the Adults with Incapacity Act 2000 (Scotland) for 'their children' in the age range 16-17.9 years. Would parents therefore be able to request physician-assisted 'suicide' on behalf of such a young person? The dangers of such authority are obvious, but it is not clear how the current Bill would prevent it. The extent and limitations of parental authority over young people who lack capacity need to be made explicit in any Bill.

- At 6.3 it is stated that parents are "given legal consent de facto" - whereas they need to legally attain this through the Adults with Incapacity Act 2007 (Scotland) for 'their children' in the age range 16-17.9 years.

7. Do you have any comment on the roles of medical practitioners and pharmacists as provided for in the Bill?

We had several concerns about this in young people:

- The term 'medical practitioner' seems to include only doctors, but if the Bill were enacted it would involve other clinicians as well, especially nurses. Whom does this term include?

- The term 'core competencies' seems to refer to competencies around mental health, rather than those around young people. Young people are vulnerable to the risk of not being sufficiently well served by professionals whose training and experience are in adults, especially in areas such as end of life care which depend absolutely on a sound understanding of their distinct physical, emotional and psychological needs. If this Bill were enacted, it would be important to ensure that all practitioners involved in facilitating suicide among young people had appropriate competences in young people specifically.

- There are no agreed competencies for facilitating death among patients.

- There is no explicit legal protection for practitioners who would find themselves morally unable to provide support for suicide.

- There is no explicit legal protection for providers of healthcare at the end of life, such as most hospices, whose ethos precludes assisting suicide but which would nevertheless wish to offer support to young people close to death.

8. Do you have any comment on the means by which a person would be

permitted to end his/her life under the Bill?

There is nothing in the proposed Bill to suggest how suicide would be facilitated. It is assumed that practitioners already have the competencies necessary for doing this in an effective and evidence-based manner. That is not true. There is no evidence indicating what means of dying are preferable over others, what adverse effects of the medications used are intolerable, or whether these are different in young people. There are plausible reasons to consider that young people are relevantly different from older adults in the way they metabolise medications (they usually require higher doses for analgesia, for example), and in the way they respond to some anaesthetic agents (for example, children report frightening auditory hallucinations with ketamine when used as an anaesthetic induction agent). There is currently no evidence base that could inform training, nor any competencies that could ensure young people were not inadvertently made to suffer during the process of assisted suicide. This safeguard is inherently weaker in young people than in older adults.

9. Do you have any comment on the role of licensed facilitators as provided for in the Bill?

The proposed Bill does not specify the role or the skillset of such facilitators and is entirely inadequate in this respect. It should define carefully what competencies would be required to be a facilitator, and how these will be developed, assessed, safeguarded and audited.

10. Do you have any comment on the role of the police as provided for in the Bill?

It was not clear to us why the model of legal oversight suggested in the current version of the proposed Bill was selected as the most appropriate over other models (for example, that adopted in the Netherlands).

11. Do you have any comment to make about the Bill not already covered in your answers to the questions above?

Many of our concerns relate to the risk that, in making a judgement between immediate suicide and later death from their condition, a young person is vulnerable to influence or temporary misjudgment in place of an actual desire to die in the sense that older adults understand death. The Bill does not offer sufficient safeguards against that risk.

The risk could be reduced by a much clearer emphasis on the need for all those with a life-limiting condition to have access to first rate palliative care appropriate to their age.

Together for Short Lives welcomes the national strategy for palliative and end of life care (Living and Dying Well, Oct 2008) and the subsequent Framework for the Delivery of Children's Palliative Care in Scotland. The Scottish Government should actively promote excellence in palliative care and

adequately fund palliative and end of life care.

Together for Short Lives believes that all babies, children and young people should have access to choice in their place of care and their place of death and that they should be provided with the support necessary to achieve a “good” life and a “good” death. A good death not only benefits the ill child or young person, but also their loved ones and carers.

Together for Short Lives is concerned that these proposals will bring about differences in treatment for those aged 16-18 between England, Wales, Northern Ireland and Scotland.

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