

Assisted Suicide (Scotland) Bill

Children's Hospice Association

This submission starts by setting out some background information before moving on to address the specific questions posed by the Committee.

About the Children's Hospice Association Scotland (CHAS)

CHAS is the sole provider of children's hospice services in Scotland, caring for children and young people with a wide range of life-shortening conditions, many of which are rare.

CHAS offers care in two children's hospices, Rachel House and Robin House, and through the CHAS at Home service. CHAS estimated that in Scotland there are approximately 800 - 1200 children and young people with palliative care needs in 2013, CHAS is providing care to in excess of 370 of these children, young people and their families across Scotland.

Anyone can refer a child or young person to CHAS, providing the referral has been discussed and agreed by their family. Referral will also be discussed with a child or young person's lead professional and other practitioners who are providing care and advice to the family. CHAS understands that for many families the decision to accept palliative care for their child is very difficult.

CHAS provides children (including babies), young people and their families with the opportunity to be cared for, respected and nurtured as individuals and as a family in an environment which offers rest and recuperation from the demands of caring. The hospices provide a sense of continuity and stability, and encourage trusting relationships to develop between families and staff.

CHAS provides holistic care and support regardless of care setting or geographical location through the delivery of a comprehensive range of services including:

- Short planned breaks for the individual and/or family
- Emergency or unplanned admissions to the hospice
- Symptom management
- End of life care
- Care and support at home, in children's hospitals and in local communities
- 24 hour advice for families and professionals
- Bereavement care and support

CHAS is also involved in the education and training of nursing, medical, social care and allied professionals throughout Scotland and the UK.

Association for Children with Life Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) defines children's palliative care thus; "Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces

physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.” (ACT 2007, RCPCH 2009)

Specialist palliative care focuses on people with complex palliative care needs (e.g. complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (e.g. consultants in palliative medicine and clinical nurse specialists in palliative care). General palliative care forms part of the routine care of patients and support for carers. This may be part of the work of a range of health and social care practitioners including GPs, community children's nurses, care assistants and hospital staff.

Over 40,000 people in Scotland each year could benefit from palliative care. Most people with palliative and end of life care needs are aged over 65 years. However, some babies, children and young people also have palliative and end of life care needs. A study from Leeds in 2011 concluded that there were over 4000 children and young people under 18 years who could benefit from palliative care. With support from the Scottish Government, CHAS has commissioned further research to explore this figure further, and to assess the needs of this patient group and their families.

There is a common misconception that the use of opioid medicines to control pain shortens life in dying patients. In appropriate doses the opioid medicines (e.g. morphine) do not shorten life, and case studies show in children that it can be associated with increased longevity. This also needs to be viewed alongside the fact that there is no robust evidence to support the assertion that medical staff use opioid medicines to shorten deliberately the life of patients.

Society-wide approaches to better death, dying and bereavement whilst death, dying and bereavement are inevitable, it is possible to reduce the harm and trauma associated with these experiences. How people experience death, dying and bereavement is only in part dependent on health and social care services. Other factors include access to adequate legal and financial planning, supportive workplace practices and the extent to which people are able to get support from family, friends and the wider community. There are many ways in which people can exercise choice and control towards the end of their lives. For example, people can make a will, engage a Power of Attorney, and make an Advance Directive, and an Advance Care Plan in discussion with their GP.

However, levels of awareness and uptake of these opportunities are low. This is mainly because Scottish society has not been open to discussions about death, dying and bereavement, and these issues are seldom discussed. This lack of openness makes it more difficult for people to achieve the death that they may have wished for. CHAS has established 'The 100% Project' to promote more openness about these issues in Scotland.

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?**

CHAS does not support the general purpose of the Bill which makes it permissible for a person to assist another to commit suicide. Our response is made in the context of our expertise of working with young people with palliative care needs for whom we further oppose the purpose of the Bill.

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? CHAS is clear that the proposed Bill still does not provide adequate safeguards for young people.**

CHAS offers no response on this question.

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?**

CHAS has no response here as it is outside its field of expertise; however, CHAS recommends strongly 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?**

Assessment

In this new process some attempt has been made to improve the robustness of the safeguards, but CHAS continues 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 years old do not fully associate their own death with permanent erasure from existence. This is extremely important because it means a young person might ask for assisted suicide 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.

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?

CHAS is 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) which 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 years, physician assisted suicide will bring death forward by only two years. But for a young person aged 18 years, assisted suicide 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 under-estimate 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 a 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 potentially fifty or sixty further years. This safeguard is therefore inherently much weaker in young people than in older adults.

The experience of practitioners (particularly those specialists in palliative care) is that it is difficult to predict accurately when a particular person may die. Prognostication is particularly difficult in the case of young people and adolescents with non-malignant disease, meaning that there is a huge uncertainty in determination of what is a life-shortening or terminal condition

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

CHAS is not satisfied. CHAS had two 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, 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.
- 6.3 states 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.

Capacity

A potentially very common combination of factors affecting older requesting persons (mild depression, mild cognitive impairment, multiple morbidities and an internalised perception that they are a burden to relatives or others) may be difficult to identify. The criteria should be clear as to whether such a person is eligible, and it must also be emphasised that there is a considerable staff shortage, and already significant waiting lists for young people to be assessed by specialists in this field.

In young people, the age of legal mental capacity to give consent should not be assumed to be the same as the age at which an individual achieves the cognitive and emotional ability to make a particular decision. The criteria should be clear whether a 16 year old with capacity, pre-existing mental health problems and/or impulsive behaviours and/or self-harm behaviours is eligible.

If persons of the type cited in the previous two paragraphs should not be eligible then any legislation should contain adequate provisions for the identification and exclusion of such individuals.

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

- The term 'medical practitioner' seems to include only doctors, but if the Bill were enacted it would involve other clinicians as well, especially nurses. Who 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 not 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 and no experience of this in young people.
- There is no explicit legal protection for practitioners who would find themselves morally unable to provide support for suicide.

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. 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 is easy to envisage complex scenarios being precipitated by the proximity of death and loss at the scheduled time of suicide e.g. sudden uncertainties, conflicts between family members, belated allegations of undue influence.

Facilitators would need to be equipped to cope with such circumstances. Any legislation should ensure robust vetting, regulation and adequate training for facilitators.

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

CHAS offers no response on this question

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

CHAS offers no response on this question

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