



Children's Hospices Across Scotland

CHAS response to the proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill

1. About CHAS

Children's Hospices Across Scotland (CHAS) is the single specialist provider of hospice services for babies, children and young people (0-21) and their families across Scotland. We support families through the terrifying heartbreak of knowing their child may die young. With love and compassion, we offer highly personalised care.

CHAS staff and our dedicated volunteer force make a difference by offering integrated palliative and end-of-life care and respite for the whole family through: our two hospices, Rachel House in Kinross and Robin House in Balloch; our CHAS at Home service supporting families in their own homes; and our teams working in every children's hospital across the whole of Scotland.

For nearly thirty years, families across Scotland have been able to turn to CHAS for world-class emotional, practical and medical support. This care begins from the point a child's condition is diagnosed or recognised, and extends right the way through to either bereavement or transition to adult services.

Children's Hospices Across Scotland (known as CHAS) is a Scottish charity, SC019724, regulated by the Scottish Charity Regulator (OSCR).

CHAS is a company limited by guarantee and is registered in Scotland, SC136410. VAT Registration number 214 8303 34.

Registered Office: Head Office, Canal Court, 42 Craiglockhart Avenue, Edinburgh EH14 1LT.

We make things possible so that children have the freedom to be themselves, play outside, laugh, and have treasured moments of joy. We are there when needed most – in really tough days, at the end of life, and then after a child dies.

None of this would be possible without the support we receive from the generosity of the Scottish public, business communities, the Scottish Government, NHS Boards, local authorities and other funders. For every £1 of statutory funding we receive, CHAS is able to generate £6.24 of public value in return.

Our aim is to reach every family in Scotland that needs us - no one should be left to face the death of their child alone.

2. CHAS' position

Responses contained within this document are solely based on CHAS' area of expertise and specialist knowledge. This includes palliative care for people up to the age of 21 years and support for their families and loved ones. As an organisation, CHAS remains neutral on any proposals that fall outside of this age group. However, we have serious reservations about the proposed bill, which we've outlined in the questions below.

It should be noted that there are significant differences between terminal illnesses in children and young people and those in older adults. It is challenging to define terminal prognoses in many of the conditions of the young people who CHAS works with.

It is important that any bill that is introduced is consistent with the obligations of the United Nations Convention on the Rights of the Child in respect of young people aged 16-18.

Many of these young people have varying degrees of cognitive impairment, raising concerns about their ability to consent to and fully comprehend the implications of an assisted death. Furthermore, a teenager or young person diagnosed with, for example, cancer would otherwise expect to have a long life ahead of them. In these circumstances, their feelings and attitudes towards their own death may be very different from those receiving a terminal diagnosis at a later stage in their lives. They

may be more willing to consider a wider range of alternatives, if these options are available, such as trialing experimental therapies.

3. Questions

1. Which of the following best expresses your view of the proposed Bill?

Neutral

We have selected “neutral” merely as we understand ticking one of these boxes is a requirement of this consultation process. We recommend that the points noted below are taken into consideration before any Bill that is introduced. If a Bill is introduced, CHAS anticipates providing more detailed commentary on what is actually proposed.

CHAS has significant concerns about the proposals in relation to young people.

2. Do you think legislation is required, or are there other ways in which the Bill’s aims could be achieved more effectively?

CHAS offers no response to this question.

3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

Neutral

We have selected “neutral” merely as we understand ticking one of these boxes is a requirement of this consultation process. We recommend that the points noted below are taken into consideration before any Bill that is introduced. If a Bill is introduced, CHAS anticipates providing more detailed commentary on what is actually proposed.

CHAS has a number of concerns about the proposed process, which are outlined below:

Step 1

(a)The proposals indicate that anyone 16 years and over could begin the process

outlined in this step. Despite this being the age of majority in Scotland, there are still a number of areas where age-related restrictions remain, for instance, purchasing alcohol and cigarettes (age 18), driving a car (age 17), driving a large goods vehicle (age 21) or being sent to an adult prison (age 21)¹. In all these areas, there is a solid legal and practical basis for varying regulations. Similarly, any legislation that allows assisted dying must take the unique developmental needs of young people into consideration. For example:

- For neurodevelopmental reasons, some young people up to the age of about 25 years old do not fully associate their own death with permanent erasure from existence.² 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.
- Compared with older adults, young people are relatively disempowered as they lack influence in society, are often poor or financially dependent on others, and can feel isolated.
- In the experience of clinical staff at CHAS and other paediatric palliative care specialists across the UK, it is widely recognised that it is challenging to define exact terminal prognoses in many of the conditions of the young, and the more so from 16-21 years. Most of these young people have degrees of cognitive impairment, but for those who are deteriorating with oncological diagnoses they are often willing to trial experimental therapies rather than seek assisted deaths.

Step 3

(a) In the event that the medication administered is 'unsuccessful' it isn't clear what the next action would be. While each person is unique, in some cases young people are relevantly different from older adults in the way they metabolise medications (they

¹ <https://young.scot/get-informed/national/what-can-you-do-at-what-age>

² For example, see *Maturation of the adolescent brain*, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3621648/>

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.

4. Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document?

Neutral

We have selected “neutral” merely as we understand ticking one of these boxes is a requirement of this consultation process. We recommend that the points noted below are taken into consideration before any Bill that is introduced. If a Bill is introduced, CHAS anticipates providing more detailed commentary on what is actually proposed.

In general, the safeguards lack specificity in how they would address the unique needs of young people. CHAS strongly encourages additional consultation directly with young people with life-shortening conditions about the proposals and, specifically, the safeguards within the proposed legislation.

Below is a non-exhaustive selection of issues that CHAS has identified as potential problems in the current list of safeguards:

(a) It isn't clear what degree of independence the 'attending doctor' and 'independent doctor' should have from one another.

(b) The lack of detail on how the capacity of an individual would be assessed is concerning.

(c) 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, while they need to legally obtain 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 death on behalf of such a young person? The dangers of such authority are obvious. Clarity around this is needed.

5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

CHAS offers no response to this question, as it is outside of its field of expertise. However, when collecting data about children and young people, there is an extra layer of sensitivity and awareness that should be taken into consideration.

6. Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.

CHAS strongly recommends that any Bill explicitly precludes criminal and civil liability for individuals and organisations who decline to provide assisted dying or associated services. This must specifically recognise matters of conscience where a healthcare professional does not feel ethically able to participate. Any Bill should also consider the social pressures that clinicians may feel under and ensure their professional judgements and the confidentiality of the patients are respected.

7. Taking into account all those likely to be affected (including public sector bodies, businesses and individuals etc), is the proposed Bill likely to lead to:

CHAS offers no response to this question

8. What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation?

For reasons outlined in previous questions, CHAS believes that the proposals could have a negative impact on young people.

There is a chance that, due to health inequalities, young people from deprived backgrounds may be less likely to access the palliative care options open to them.

In addition, due to the financial implications of caring for a seriously ill child (for example, many parents are unable to work) there is a risk that some young people may feel they are a burden on their families.

All children and young people need positive role models to look up to, and this is just as true if they have a serious illness or disability. There is the potential that this Bill could have the unintended consequence of negatively impacting the perception of people with disabilities in Scotland.

This is a complex and contested area, where there is unlikely to be a uniformity of views. The consultation does not show how the wide range of views that exist has been considered or factored into the proposals.

9. In terms of assessing the proposed Bill's potential impact on sustainable development, you may wish to consider how it relates to the following principles:

- **living within environmental limits**
- **ensuring a strong, healthy and just society**
- **achieving a sustainable economy**
- **promoting effective, participative systems of governance**
- **ensuring policy is developed on the basis of strong scientific evidence.**

With these principles in mind, do you consider that the Bill can be delivered sustainably?

CHAS offers no response to this question

10. Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?

CHAS offers no response to this question

Questions

About you

1. Are you responding as:

On behalf of an organisation

2b. Please select the category which best describes your organisation:

Third sector (charitable, campaigning, social enterprise, voluntary, non-profit)

3. Please choose one of the following:

I am content for this response to be published and attributed to me or my organisation

4. Please provide your name or the name of your organisation.

Name: Children's Hospices Across Scotland (CHAS)

Please provide a way in which we can contact you if there are queries regarding your response.

Contact details:

5. Data protection declaration

X- I confirm that I have read and understood the [Privacy Notice](#) which explains how my personal data will be used.