

Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill

Introduction

A proposal for a Bill to enable competent adults who are terminally ill to be provided at their request with assistance to end their life.

The consultation runs from 23 September 2021 to 22 December 2021.

All those wishing to respond to the consultation are strongly encouraged to enter their responses electronically through this survey. This makes collation of responses much simpler and quicker. However, the option also exists of sending in a separate response (in hard copy or by other electronic means such as e-mail), and details of how to do so are included in the member's consultation document.

Questions marked with an asterisk (*) require an answer.

All responses must include a name and contact details. Names will only be published if you give us permission, and contact details are never published – but we may use them to contact you if there is a query about your response. If you do not include a name and/or contact details, we may have to disregard your response.

Please note that you must complete the survey in order for your response to be accepted. If you don't wish to complete the survey in a single session, you can choose "Save and Continue later" at any point. Whilst you have the option to skip particular questions, you must continue to the end of the survey and press "Submit" to have your response fully recorded.

Please ensure you have read the consultation document before responding to any of the questions that follow. In particular, you should read the information contained in the document about how your response will be handled. The consultation document is available here:

[Consultation Document](#)

[Privacy Notice](#)

I confirm that I have read and understood the Privacy Notice attached to this consultation which explains how my personal data will be used.

On the previous page we asked you if you are UNDER 12 YEARS old, and you responded Yes to this question.

If this is the case, we will have to contact your parent or guardian for consent.

If you are under 12 years of age, please put your contact details into the textbox. This can be your email address or phone number. We will then contact you and your parents to receive consent.

Otherwise please confirm that you are or are not under 12 years old.

No Response

About you

Please choose whether you are responding as an individual or on behalf of an organisation.
Note: If you choose "individual" and consent to have the response published, it will appear under your own name. If you choose "on behalf of an organisation" and consent to have the response published, it will be published under the organisation's name.

on behalf of an organisation

Which of the following best describes you? (If you are a professional or academic, but not in a subject relevant to the consultation, please choose "Member of the public".)

No Response

Please select the category which best describes your organisation

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

Optional: You may wish to explain briefly what the organisation does, its experience and expertise in the subject-matter of the consultation, and how the view expressed in the response was arrived at (e.g. whether it is the view of particular office-holders or has been approved by the membership as a whole).

The Scottish Youth Parliament is the democratically elected voice of young people and works to ensure young people have a say in all issues affecting them.

Our general support for this Bill is informed by a policy stance in support of granting terminally ill individuals the right to die on their own terms. This stance was approved by our members in October 2018 and is still a live policy in line with SYP procedures.

We also carried out additional consultation to ensure members continued to agree with this stance as well as gain their perspectives on the specific provisions of this Bill. This took the form of an online consultation workshop, which took place on 14th December 2021.

This session was co-designed and led by young people and was attended by 16 Members of the Scottish Youth Parliament (MSYPs) aged 15-19 years old. In addition to providing optional reading about the Bill ahead of the session, Alyson Thomson from Dying in Dignity provided a 30-minute input to upskill MSYPs on this topic and the specific provisions within the Bill. A member of Liam McArthur MSP's office also attended to help provide context. After setting the scene, MSYP were given the opportunity to discuss relevant sections of the consultation in smaller groups. Notes from these discussions were used to generate this response along with some additional comments submitted by participants before and after the event.

Please note: this policy stance and response is that of SYP as an organisation. Our affiliated partners, including our National Voluntary Organisations, may have different views on this subject.

Please choose one of the following:

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

Please provide your Full Name or the name of your organisation. (Note: the name will not be published if you have asked for the response to be anonymous or "not for publication". Otherwise this is the name that will be published with your response).

The Scottish Youth Parliament

Please provide details of a way in which we can contact you if there are queries regarding your response. Email is preferred but you can also provide a postal address or phone number.

We will not publish these details.

Aim and Approach - Note: All answers to the questions in this section may be published (unless your response is "not for publication").

Q1. Which of the following best expresses your view of the proposed Bill?

Fully supportive

Please explain the reasons for your response.

As an organisation, we support the proposed Bill. Whilst we do have comments about specific provisions that could be improved or additional elements that the Bill could consider, the MSYPs we consulted were overwhelmingly in agreement with the overall principles behind this proposed legislation.

SYP has been in support of providing people with terminal illnesses with the right to die with dignity for some time. After consultation with over 100 young people and discussions with Dignity in Dying, Neil McCulloch MSYP proposed the following policy to be debated by the SYP membership:

'The Scottish Youth Parliament believes that, as well as the right to life, everyone should have the right to die, and as a result calls on the Scottish Government to legalise assisted suicide* for those with terminal and life-limiting illnesses to relieve patients of terminal suffering and pain.' – Members Motion, passed with 67% agreement at SYP's 67th National Sitting (October 2018)

After extensive consultation with their own constituents (at least 7,450 young people), MSYPs passed the motion with 67% agreement. 18% of our members disagreed and 15% abstained.

In addition this, the vast majority (14 out of 16) of MSYP's who participated in our 'Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill' workshop said they were fully supportive of the proposal.

Reasons for this support include**:

- MSYPs believe that individuals should have personal choice and bodily autonomy
 - o "I fully support bodily autonomy. Everyone (where mentally competent) should have the right to die with dignity, in a humane way."
 - o "It's basic human decency to let people choose the way they die. Just like the right to life, we should have the right to choose not to suffer."
 - o "Dying is a part of life. You shouldn't be limited in how you do that."
 - o "I believe that because of the pain and depression some people feel when terminally ill, that forcing them to live is in its own way cruel and inhumane."
 - o "Why force people to live when they may have no chance of recovery?"
- The system proposed by the Bill would provide all those with terminal illnesses the chance to die with comfort, dignity and equality, without resorting to extreme or expensive options (e.g. starvation or Dignitas).
 - o "People will end their suffering one way or another. We should allow them to do it so it's peaceful rather than painful."
 - o "It allows people to do it at home and more relaxed and also removes financial barrier making it fairer."
 - o "It allows people dignity and their own terms for what otherwise be a horrible experience."
 - o "I think that, especially when implemented carefully, it is more humane to allow [assisted dying] compared to other options".
- Assisted dying could prevent people ending their own lives in dangerous ways, along with the pain and suffering it comes with for the individual and their loved ones.
 - o "...those who are in this situation feel great suffering and the anticipation of knowing your dying but not being able to change it. It can be overwhelming enough for someone to commit suicide alone and no one

Q1. Which of the following best expresses your view of the proposed Bill?

should have to die alone and unsupported".

- The Bill took into account quality of life, something which MSYPs felt was important and not reflected enough in current options available for terminally ill individuals.
 - o "I believe that every individual should have control over their own life and the quality of someone's life should be taken into account."
 - o "It's important that quality of life is mentioned. There's a difference to being alive and having the [capabilities] you need to [truly live]".

- The Bill presents a well thought out and measured approach which took away the majority of doubts and concerns MSYPs had about assisted dying as a process.
 - o Several members had concerns about elements of this process such as doctor bias, whether doctors would have to go against their own personal morals and how mental competency is defined. However, after learning more about the Bill they felt that it took account of these potential issues and took steps to overcome the majority of them.

One member referenced how their own personal experience of a terminally ill loved one having a lack of options with their death had changed their perspective on the issue:
"I was originally not sure but having had first-hand experience of it, I really understood the importance of [having the option].

Other MSYPs made the point that, in a society that provides the option to assist animals in the process of dying, it feels wrong not to allow people the dignity of the same option.

Two workshop participants noted that they were partially supportive of the Bill. One said they were almost in full support but would like to see the final draft of the Bill before committing. Another said they would like the Bill to be extended to detail support offered to family members. No MSYPs at the workshop stood against the Bill.

*We recognise that this policy uses the phrase 'assisted suicide' as opposed to 'assisted dying', as used within the Bill and by the campaigning organisations working on this issue. This language was written by an MSYP and was deemed appropriate at that time. However, as an organisation we now endorse assisted dying as the correct term of this process and know from previous discussions this process is the intent behind the motion and our wider policy work on this issue.

**All quotes are directly from MSYPs who attended our Assisted Dying Bill Workshop

Q2. Do you think legislation is required, or are there other ways in which the Bill's aims could be achieved more effectively? Please explain the reasons for your response.

As seen in our policy on this issue, young people do believe that a legal change is required for the Bill's aims to be realised. As an organisation, we see no other way a change of this magnitude could be achieved.

Q3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 in the consultation document (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

Partially supportive

Please explain the reasons for your response, including if you think there should be any additional measures, or if any of the existing proposed measures should be removed. In particular, we are keen to hear views on Step 2 - Reflection period, and the length of time that is most appropriate.

Step 1 – Declaration

The majority of MSYPs who attended the workshop were fully supportive of this step.

They felt it was important to have the level of checks detailed in this step to ensure safety and protect all

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individuals involved in the process. They also felt that many of the provisions within this step helped to overcome concerns they had about assisted dying as a process. For example, one MSYP noted that they felt it was important for this to be presented along with other options so that people didn't feel pushed toward this. Another felt it was essential to have two doctors, with one being independent, to keep the processes fair and safe.

"Coming into tonight my biggest question was about being of sound mind, however the layers of both it being an independent decision and level of assurance by doctors etc have answered that." – an MSYP

There were a some concerns and queries raised about this section, including:

- How fair an mental competency assessment can be when a person is in constant pain?
- Outstanding concerns about unconscious bias in doctors
- How secure the process of signing and processing declarations is (e.g. could it be forged?)

However, we believe that the Bill will deal with many of these concerns. Training for medical staff specifically on this issue would also overcome any outstanding worries MSYPs have.

Step 2 - Reflection period

After in-depth discussion with MSYPs, we partially agree on the provisions detailed with in this step.

Members agreed that, in order to give people the chance to reflect on a decision of this magnitude, a mandatory reflection period is "vital".

"It's necessary with such a big decision like this. It would be pretty strange if we didn't give people the time to realise the choice they are making." – an MSYP

However, they had mixed feelings about the length of time that the Bill should stipulate.

Some members noted their belief that the 14-day mandatory period, coupled with the other stages of the process, offered a well-balanced approach. They felt it would give people the chance to reflect whilst still appreciating that they will have been processing their prognosis for some time.

"With that time period plus additional reflection post-prescription, and last checks before it is administered, [I think] it should be suitable enough" – an MSYP

However, others commented that this period was unnecessarily long. They believe that people choosing to go down this route will have already given the decision detailed consideration, and adding two weeks onto the process was unnecessary or unfair. Others felt that this length of reflection period could lead to people taking matters into their own hands out of desperation when suffering and in pain.

"14 days feels a bit long for someone to be waiting. Not the kind of thing you do out the blue, you'll have thought about it before." –an MSYP

In response to this, some members felt a week would be a more appropriate length of time. Another group felt that this should be judged on a case by case basis by those making the medical and mental assessments.

A final group felt that there should be an increased reflection period, with one member suggesting up to a month. They felt this was more appropriate for a such a large decision and that it may also help family member process their loved ones decision.

Therefore, we believe the length of reflection period requires additional consideration.

Members did unanimously support the provision for a shorter reflection period for those who are deemed likely to die within 30 days. They felt this was particularly important in cases of terminal illness where people have slow declines.

Members also noted that the Bill and subsequent guidance would benefit from clarity over the difference between required and recommended reflection time. They also believed it was important for individuals to know they can take longer if required to make a final decision. Members also wanted clarity over how far in advance a person could make this decision and be assessed (i.e. can someone seek declaration to be used further down the line for their illness?).

Step 3 - Prescribing/delivering

We are partially supportive of the provisions in step 3.

Q3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 in the consultation document (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

Whilst some members had concerns around individuals self-administering the drugs, noting that still a medical process, the majority agreed that this element was essential to keeping everyone involved safe and allowing the individual autonomy. MSYPs also appreciated that giving the HCP a more hands on role in this step would take the process away from the assisted dying model and into a different issue beyond the scope of this Bill's aim.

"I agree with that it is fully self-administrated and independently done, free from pressure. Also the last checks, I believe would be adequate to ensure that it is the right thing." – an MSYP
"Self-administration is important, reaffirms that it's their choice and gives them independence." an MSYP

They also agreed that it was important to have a HPC there to support and keep everyone involved safe. They felt the final check on a person's decision was vital to ensure this process protects everyone involved.

"[This is a]nother layer to the protection that goes into the Bill [to ensure] that it isn't being abused." - an MSYP

"I think having the HCP there is important as it means that someone is there to make sure everything is being done properly and safely." - an MSYP

Members did have questions about whether the involvement of HPCs would prevent people being able to choose to carry out the procedure at home. We suspect that the proposal does aim to give people this option and is, therefore, something that needs to be clarified on the face of the Bill rather than making any a change to the process.

MSYPs were also concerned for the mental wellbeing of others involved at this stage of the process (HPCs and family members) and noted that they would like to see support offered to them (this may be more appropriate for subsequent policy and guidance rather than the Bill itself).

There was an equalities concern raised about this step in relation to individuals with disabilities. MSYPs noted that some people may be mentally capable of making the decision to access assisted dying, but physically unable to self-administer the medication due to a physical disability. We believe the Bill needs to account for this possibility and ensure that people of all physical abilities can access the rights granted to them under this proposal.

Q4. Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document?

Partially supportive

Please explain the reasons for your response.

Whilst we do agree with the majority of safeguards proposed, MSYPs had some questions around a few of the processes (as noted earlier in our response) including:

- Mixed feelings around the length of the mandatory reflection period.
- The equalities implications of self-administering for individuals with certain physical disabilities.
- Support provided to keep others involved in the process (e.g. HPCs and family members) mentally safe.

In addition to this, some MSYPs suggested additional measures they believe could further ensure those involved are safe:

- A couple of members noted they would prefer for a psychologist to present at one or more of the assessment appointment to ensure proper assessment of mental competency.
- Regular, mandatory training for all HCPs and medical professionals involved in these processes that is reviewed at regular intervals.
- Having a more specialist individual, such as a pharmacist, present to oversee stage 3 (from prescription to self-administration) to ensure that there is no opportunity for abuse during step 3.

Q5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

Unsure

Please explain the reasons for your response, including whether you think this should be a new or existing body (and if so, which body) and what data you think should be collected.

This is not a question we discussed with our members at our workshop.

Q6. Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.

No comment

Financial Implications

Q7. 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:

don't know

Equalities

Q8. 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?

Unsure

Please explain the reasons for your response. Where any negative impacts are identified, you may also wish to suggest ways in which these could be minimised or avoided.

Whilst we are not in a position to make a general assessment on the impact this proposal would have on equality, MSYPs have raised the following comments in relation to this question:

Young people – members were concerned that there may be conscious or unconscious bias to keep terminally ill young people away from accessing this process due to their young age. However, they did note that they were reassured to hear that this issue has not emerged in the 20 years assisted dying has been legal in Oregon. There was also concern about young people being vulnerable to the influence of their parents/guardians and noted that steps would need to be taken to ensure their views are kept at the heart of any decision made

Older people – there was concern that older generations may worry about this legislative change being a stepping-stone to euthanasia in the future. We believe that this is more of a communications issue can tackled through implementation as opposed to the Bill itself.

Disabled people – MSYPs noted that those with certain disabilities may be unable to access assisted dying if they didn't have the physical ability to self-administer. Whilst we do not have a proposed solution for this issue, we believe it should be explored in advance of the final Bill being published. This concern also extends to the signing of the declaration, which would need to have accessible alternatives for those

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who cannot physically sign.

Income inequality – one young person noted their concern that the Bill could negatively affect those in poverty. They noted that if those with terminal illnesses cannot access sufficient financial support, they may choose to use this option to remove the financial burden of their care from family rather than because it is their preferred option. However, this alludes to a separate issue in relation to benefits for those with terminal illnesses, rather than an issue with the Bill itself.

Additional Support Needs/Learning Difficulties – how will those with different needs and mental capabilities be assessed? Members were concerned that those who have the mental capabilities to make this decision may be denied the opportunity due to any additional support needs and the biases doctors could hold.

Sustainability

Q9. 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?

Unsure

Please explain the reasons for your response.

We did not discuss this question with our members.

General

Q10. 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)?

No Response