



# SYP's response to the Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill

December 2021

## SYP's Approach

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 14<sup>th</sup> 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.

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

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 67<sup>th</sup> 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
  - “I fully support bodily autonomy. Everyone (where mentally competent) should have the right to die with dignity, in a humane way.”
  - “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.”
  - “Dying is a part of life. You shouldn’t be limited in how you do that.”
  - “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.”
  - “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).
  - “People will end their suffering one way or another. We should allow them to do it so it's peaceful rather than painful.”
  - “It allows people to do it at home and more relaxed and also removes financial barrier making it fairer.”
  - “It allows people dignity and their own terms for what otherwise be a horrible experience.”
  - “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.
  - “..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 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.
  - “I believe that every individual should have control over their own life and the quality of someone’s life should be taken into account.”
  - “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.
  - 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.

The two 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

**2. Do you think legislation is required, or are there are 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.

**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)?**

**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 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 a 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.

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.

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

**SYP is supportive of the safeguards detailed within the consultation document.**

However, 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.

**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?**

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 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.

For more information about this response, please contact:

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