

Health, Social Care and Sport Committee - 7.01.2025

Informal engagement with the Scottish Assembly: Assisted Dying for Terminally Ill Adults (Scotland) Bill

TABLE 1

- Participants were asked: What do you think about adults being able to choose to end their life if they are very sick and expected to die?
- Participants expressed a view that; “It’s our lives, so we should have the right to choose”.
- Participants also raised questions about what “terminally ill” means – that is, how ill would someone need to be to be eligible?
- It was accepted that diagnosis is an inexact science. However, some participants expressed a view that there should be a time limit on life expectancy of six months to be able to qualify.
- Participants also had questions as to whether it would always be the case that someone eligible for assisted dying would be at the point of receiving palliative care.
- They raised questions about individuals making decisions to request assisted dying at a point where they could no longer speak – and, if that were the case, whether they would be denied the option of requesting assisted dying.
- Participants also had questions about self-administration and the circumstances of an individual who wishes to access assisted dying but is physically unable to swallow a substance. They suggested these individuals may feel they were being discriminated against by being denied access to assisted dying because a physical disability means they are unable to self-administer.
- Participants also raised concerns around the scenario where medical professionals decide to opt out of involvement in assisted dying en masse. This led them to question whether it would be preferable to have a dedicated service providing assisted dying.
- The discussion then turned to the situation of individuals living with Motor Neurone Disease where a life expectancy threshold of 6 months might be considered too short and could potentially exclude cases of individuals with MND who would wish to access assisted dying more than 6 months out from their anticipated life expectancy.
- One participant had questions about locations where it would be permissible for individuals to access assisted dying – i.e. whether it would be limited to hospitals or hospices, whether individuals would be able to access assisted dying at home, but also whether individuals might choose to access assisted dying in a favourite location which might be a public place. For example, if

they had a particular attachment to Arthur's Seat and decided they wished to die there, would this be permissible under the terms of the Bill? A participant suggested this could have implications for other aspects of existing law that prohibit people from committing suicide in a public place.

- Participants had questions as to whether an individual accessing assisted dying would have the freedom to keep the substance at home and then to administer it at a time of their own choosing. It was clarified that, under the terms of the Bill, this would not be possible since a medical professional would need to be in attendance throughout the process and would be assumed to bring the substance with them at the point where the individual had chosen to proceed.
- One participant suggested that having the option of being able to access assisted dying could be a positive thing for the mental health of someone living with a terminal illness, even if they ultimately did not follow it through.
- Discussion returned to whether assisted dying services should be provided by a dedicated team in a dedicated building. One participant raised the prospect of patients in a hospital objecting to assisted dying services being provided in that same premises.
- Participants were asked: Do you think other people should also have this choice (of accessing assisted dying)? If so, who?
- Some participants felt that the provisions of the Bill on self-administration were not fair – and would result in some individuals still having to access assisted dying by travelling to Dignitas in Switzerland because they did not meet the criteria as a result of a physical disability.
- There followed some discussion about the definition of self-administration and whether this could include individuals having the option of pushing a button that would then allow the substance to be administered intravenously.
- The risk was also discussed of the Bill being subject to legal challenge by individuals who felt they were being discriminated against by being denied access to assisted dying due to the eligibility criteria.
- Discussion then turned to whether the eligibility criteria should therefore be widened to include individuals who feel that their quality of life is so poor that they would wish to access assisted dying – even in the absence of a terminal illness.
- This prompted participants to question how to define a good quality of life and where the line should be drawn if the eligibility criteria were to be widened.
- They pointed to the example of people with Down's Syndrome who some people may judge as having a poor quality of life – whereas their own experience showed that individuals with Down's Syndrome can enjoy an excellent quality of life.

- There was some agreement that, aside from people with a terminal illness, the eligibility criteria should be widened to allow people with progressive illnesses that are not necessarily terminal to be included.
- In this context, participants also pointed out that the same illness or disease can progress in different ways for different individuals.
- One participant advised that the Church of Scotland is currently still deciding its position on the Bill but indicated that, as currently drafted, it looks as though the Church may decide to support it. The General Assembly is due to consider this in mid-May this year.
- The discussion then turned to the age-related eligibility criterion. Participants questioned why an age of 16 had been chosen as the threshold.
- Giving the example of a child living with terminal cancer, one participant argued that the age threshold should be lower. However, another participant took a different view and argued that the threshold should be raised to age 18.
- In the case of children living with a terminal illness, one participant suggested that access to assisted dying should be made possible by a collective decision being taken on behalf of the child, possibly also with the involvement of the courts.
- One participant reiterated that purely having the option of potentially accessing assisted dying could relieve pressure on many individuals. They pointed to the example of one individual with a terminal illness who experienced many highs and lows and a lot of anger about their situation. This participant suggested that, in this case, knowing the option of assisted dying was available could have been a significant relief that would have resulted in a change of mindset.
- Participants argued that the mental health of individuals needed to be taken into account.
- One participant argued that assisted dying should not become a viable option for people purely because they are suicidal.
- It was acknowledged that, in itself, a terminal diagnosis is likely to result in a mental health crisis for individuals.
- Participants argued that it is important not to confuse mental health conditions with people who have a learning disability.
- Participants were asked: Do you think the way capacity is assessed in the Bill is fair?
- One participant highlighted the situation of someone with a terminal illness who is unable to speak and asked how they would be able to request assisted dying in those circumstances. They then wondered whether, in such cases,

guardians or advocates should have role to play in representing that individual.

- Another participant pointed out there would be a need to create safeguards against coercion by guardians in those circumstances – for instance in cases where a guardian has a financial interest in encouraging an individual to request assisted dying.
- At the same time, participants argued in favour of a role for guardians to support individuals who may have communication difficulties to help them communicate their request for assisted dying.
- Participants argued that there would be a need for safeguards not only for individuals requesting assisted dying but also for medical professions involved in providing assisted dying services.
- Participants raised questions and concerns about security related to the storage of substances used in assisted dying.
- Returning to the issue of the age threshold for access to assisted dying, participants highlighted the significant challenges faced by people with learning difficulties in making the transition to adulthood – and having to make the shift from a situation where they have no decision-making capacity to having to make decisions for themselves as an adult. It was suggested this can be a traumatic process for many as their previous system of support is removed. They argued that the process of transition should start earlier than is currently the case to enable people to get used to making decisions for themselves.
- Participants were asked whether individuals accessing assisted dying with a condition that prevents them self-administering the substance should be permitted to receive assistance.
- Participants were generally of the view that they should.
- It was acknowledged that, without such a widening of access criteria, there was a strong risk of the Bill being subject to legal challenge in the future. Participants also pointed out that maintaining a requirement to self-administer would result in many individuals being forced to continue to access assisted dying by travelling to Dignitas in Switzerland.
- One participant reiterated concerns that, if GPs or other medical professions were to opt out of involvement in assisted dying en masse, this would leave individuals seeking access to assisted dying in a position of being unable to do so. They questioned whether, if GPs were to opt out, it would be left to palliative care nurses to take on that responsibility.
- Discussion returned to the question of whether there should be a dedicated service providing assisted dying outside other NHS services. It was acknowledged that there was unlikely to be capacity to offer this as a separate service across Scotland's 32 local authority areas.

- One participant again highlighted the risk of patients in hospitals objecting to individuals accessing assisted dying in that same hospital.
- Participants were asked: Are there any parts of the Bill that worry you?
- Participants responded that issues around the requirement to self-administer the substance need to be addressed.
- They also argued that the possibility of advanced directives should also be considered.
- It was acknowledged that there is a need to strike an appropriate balance between safeguarding against coercion and ensuring people's wishes are taken seriously.
- One participant reiterated that, in certain circumstances, it should be a collective group that takes a decision rather than just the individual. They asked what would happen if an individual seeking assisted dying does not get on with their GP.
- Participants pointed out that GPs are currently receiving additional training on supporting people with learning disabilities and that many of these people currently experience issues with not being listened to, believed or taken seriously – or being judged as not having the capacity to make decisions. They pointed out that this creates additional obstacles which individuals with learning disabilities would have to overcome if requesting access to assisted dying.
- One participant argued that it is important to give individuals the freedom to decide when and if to go through with their initial request for access to assisted dying – given that circumstances can change and people with a terminal diagnosis can live for a long time – and much longer than initially expected.
- One participant raised a question about a situation where a pharmacist might object to storing substances used for assisted dying – or might refuse to do so. They also reiterated concerns about a potential mass opt-out of assisted dying by medical professionals.

TABLE 2

- Participants were first asked what they thought about adults being able to choose to end their life if they are very sick and expected to die.
- Participants were in favour of the principal of assisted dying but highlighted numerous areas of concern or where they felt the Bill was currently lacking.
- One participant, who has a condition called Rett Syndrome and uses eye gaze technology to communicate, stated that people who are eligible should be able to access assisted dying but was worried people with similar conditions would be excluded given the current wording in the Bill. This was in specific reference to self-administration – as many conditions make it physically impossible for a person to self-administer.
- Other participants were in agreement that self-administration should be available where possible, but more targeted support for people with complex physical needs should be taken into account and legislated for in the Bill.
- It was also highlighted that people with complex communication needs would require additional support and there are fears that the Bill in its current form may be discriminatory to people with complex communication needs – “often assumed not to have capacity, but they do.”
- Some discussion was also given to the age of capacity, which in the Scottish Bill is 16 years old while the UK Bill has the age of capacity at 18. Participants were concerned that, at the age of 16, individuals with lifelong conditions may feel more pressured into choosing Assisted Dying due to limited life experience.
- It was stated that the majority of the Scottish Assembly feel the age of 16 to be too young to have capacity to make such a decision. One participant stated that they would be in favour of the Bill including 16–18-year-olds “in special circumstances”.
- Participants raised the matter of inadequate palliative care services – which one participant described as being a “postcode lottery” when it comes to the level of service provided. There were fears that if people are unable to secure adequate hospice or palliative care, then they may choose assisted dying as an alternative or be at risk of being pressured into assisted dying, rather than their preferred option.
- The group also discussed the process as set out in the Bill for assisted dying. One participant was concerned that the Doctor/Patient relationship (i.e. whether it is positive or negative) may influence the patient or assessing doctor’s verdict. It was floated that perhaps a team of specialists with experience of dealing with patients with complex needs would be better suited to make such an assessment and provide assistance throughout the process.
- One participant raised the matter of life insurance and whether the cause of death being listed as “assisted dying” or not would have an effect on

insurance companies paying out. This is a live issue which is not covered in either the UK or Scottish Bills.

- Participants also stated they would not be opposed to a referendum on the matter (similar to how decisions on contentious issues are taken in Ireland).
- Participants from the assembly also noted that they were not made fully aware of the Bill's consultation timeframe and would have missed their chance to respond had it not been for PACT highlighting the consultation.
- Participants were also unsure of where the substance would be administered (i.e at a hospital or another location) and sought further clarity regarding this.
- Finally, one participant also highlighted that their own views on the matter differed from their Church – but that it was assumed they held the same view as the Church. Should not be assumed that all faith groups are in consensus on this matter.

TABLE 3

- Participants were of the view that the most important thing is protection from coercion, as there are very vulnerable groups which means we need to be extra careful. One participant thought that assisted dying decisions for people with learning disabilities should be approved by a judge because they need additional protection.
- Given that many people will be physically disabled, participants thought there needs to be different means of administration. If not, they highlighted there will be human rights implications of this.
- Participants would like more information on whether people with learning disabilities will be included in the Bill, stating it's not clear and they would like an answer on this before the Bill goes ahead.
- One participant pointed out that if someone is non-verbal, this does not mean they don't understand what they are doing.
- One participant did not agree with the Bill being extended to those who don't have a terminal illness. They felt that for conditions like quadriplegia, there is still some hope and people can be supported to adjust to a new lifestyle. For terminal illness however, participants argued you are hastening the inevitable so it's different.
- Another participant thought that it should be extended to people with broader suffering and that the level of suffering that qualifies should be left to the individual to decide.
- The inequality of some people being able to go to Switzerland who can afford it was raised. It was felt that, in a civilised society, your access to assisted dying should not be based on whether you can afford it or not.
- Participants thought there should be more support for families during the process, e.g. counselling.
- Questions were raised about the prospect of including a prognosis within the definition of terminal illness. Participants were sceptical about how accurate this could be.
- Participants had questions about what happens if doctors disagree. There were concerns that doctors may be penalised for denying someone assisted dying. Participants questioned whether there would be a dispute resolution procedure or arbitration process.
- Participants had mixed opinions on age – one participant thought that 16 was too young and the age limit should be at least 18, because 16-year-olds aren't mature enough to make such a big decision and they might not know what they are doing. Another participant thought there should be no age limits as the end of life does not discriminate.

- There was also some discussion about the type of service model that would deliver assisted dying. There was a strong feeling that this should be a service provided by the NHS and not the private sector. There were concerns about equal access to assisted dying and it was felt that the introduction of money could make that access more unequal. There was also a lack of trust in a private service and participants felt there could be greater potential for abuse.
- Participants stated doctors should make the decision separately from each other and not 'collude'.
- Participants stated that any decision should be made at a time when someone is not in pain as this could cloud their judgement. Therefore, a decision should be made significantly in advance so that it is a more considered opinion.
- Some participants wanted to know how it would work with guardianship orders. Specifically, would there be any role for a guardian? Or would it still be a decision for the individual? One participant felt strongly that it should always be the decision of the individual alone and they should be protected. Another participant was more open to the idea of greater involvement of the guardian as they know the person better than anyone.
- Some participants had strong opinions that junior doctors should not be allowed to be involved in assisted dying. They thought that the doctors should be at least 5 years post-qualification. They also argued that they should have specialist training in assisted dying.
- Some participants suggested that the decision should be made by a Committee or panel, with a wider membership than just doctors – including, for example, counsellors, family members, other professionals that know the person and people with lived experience.
- Some participants also wanted to know whether the person's family could challenge their decision in court, for example, if they didn't think they had the capacity to make the decision.
- Participants questioned how assisted dying was any different from being able to refuse treatment. Some also thought it should be included in the options for advanced decision making. They thought there should be a process to respect advance decision making even if the individual has subsequently lost physical or mental capacity.
- Broadly, participants felt that the wider context is important. Specifically, getting access to good palliative care is important and the decision should be made prior to the point of needing palliative care.