

# 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).**

Inclusion Scotland is a 'Disabled People's Organisation' (DPO) – led by disabled people ourselves. Inclusion Scotland works to achieve positive changes to policy and practice, so that we disabled people are fully included throughout all Scottish society as equal citizens.

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).

Inclusion Scotland

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 opposed

**Please explain the reasons for your response.**

We are in the midst of a pandemic which has put the lives of those most at risk of complications in huge danger. As well as putting enormous pressure on health services, the pandemic has 'supercharged' inequalities including:

- Lack of value ascribed to disabled people's lives (e.g. unrequested DNACPRs) and therefore a right to life
- Lack of access to suitable social care support (many people lost vital social care support literally overnight during the first lockdown);
- Access to routine health treatments including preventative treatments were removed and some are still not back in place.

As a result of these, and more, we believe that this is can be viewed as the worst time in history to propose legislation to enable assisted suicide. The Bill proposed is not safe and is being introduced at a precarious uncertain and dangerous time for disabled people.

When we ran our first survey on disabled people's experiences during the pandemic, one of the most difficult aspects of analysing it was that a number of respondents expressed suicidal ideation. This was not a question we asked, but when we published the report we were extremely concerned about the mental health impacts of the removal of services and drastic changes to others, as well as isolation and the loss of independent living. Official statistics support our understanding that suicide rose during this period. Meanwhile we are aware that the Scottish Government has published details of a suicide prevention fund as part of wider suicide prevention efforts.

To be acknowledging the huge need to take action to prevent suicide, whilst allowing choice of suicide at the same time devalues and undermines these efforts. As Care Not Killing states, "to say in law that some suicides are to be prevented, and others assisted, necessarily devalues people's lives". We are aware of a colossal amount of evidence from other countries that shows:

- When legislation such as this proposal is brought in, it is always widened to include others beyond those diagnosed with 'a progressive disease, which can reasonably be expected to cause their death' .
- There is little to no safeguard that could keep some disabled people from becoming victims of its abuse
- It becomes the cheapest option when other treatments and care support are considered
- It gives people 'the distress of choice' to end their life when they are at their most vulnerable
- Disabled people are already marginalised throughout society and feel at risk from our health and social care support systems as they currently are. Some disabled people will receive or already be diagnosed with life limiting conditions. We need support to live and not support to die.

We are living through a pandemic that has spotlighted and deepened inequality. We are also going to live with the consequences of the pandemic, on our NHS, services, society and economy, for a long time. This proposed legislation to end lives is out of step with the time we are living through, and the measures that need to be put in place now to allow people to live their lives and die good deaths with the support and care all Scottish citizens deserve.

Our research further shows that once the provision is in legislation, it has been the subject of 'legislative creep' - this is where groups of people not included in the Bill want equal eligibility, taking their case to court with rulings widening the law. Also, it has been regulated for widening in parliament following advocacy from other groups. The reasoning in every instance has moved from the ending of unbearable suffering in the last months of life, to other reasons, such as fear of care dependence, loneliness and meaninglessness. The legislation has also been widened in some places to include children, even though advances in medical treatment and care are made every day.

In Oregon, which originally brought similar legislation to that proposed into law, the law was expanded to include medical conditions that are not 'terminal'; between 1999 and 2020, there has been an 807% increase per annum of people choosing Physician Assisted Suicide (PAS) (Care, 2021 ).

In Canada, people with no terminal illness demanded the 'right' to assisted dying following its legalisation. A Quebec court agreed that if someone was suffering severely, even if they had no terminal diagnosis, that this would be acceptable.

Unpacking this for a moment, without a terminal illness, how is "unbearable suffering" defined? Does it apply to someone with a life limiting impairment, or to someone with complex mental illness, like the case of 29 year old Arelia Brouwers in the Netherlands? Young people with mental health support needs are now taking getting assistance to die rather than support to live. In the Netherlands, 'unbearable suffering' is now open to interpretation from the patient. Even without the stigma and discrimination they face and with medication and therapy, they are likely to spend a lot of time suffering unbearably. However, social and systematic stigma and discrimination makes suffering much more extreme; different treatments and good social care support may also allow that person to survive and live well with their condition.

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

Now there are moves to allow children under 12, couples where one is dependent on the terminally ill person and when someone feels they have completed their lives, to decide to end their life with the support of medical professionals. In the Netherlands, the law was expanded to euthanise babies born with impairments, and nowadays only 3% of assisted suicides are carried out with the assistance of a physician. The Dutch euthanasia regime has now been criticised twice by the United Nations Human Rights Committee, in 2001 and in 2009 .

In Canada, initial Medical Assistance in Dying (MAiD) legislation was brought in in 2016 for 'those whose natural death was reasonably foreseeable'. In 2021 this legislation has been amended to allow MAiD for people with chronic disease, impairment, and as of March 2023, will be extended to mental illness as a sole diagnosis. Some of the basic safeguards originally included in the legislation have been removed, for example the reflection period and having two witnesses. There has been a 6.41% increase in MAiD deaths in the five years since it was brought in.

It is this kind of slippage that many disabled people feel extremely anxious about.

SHRC, in its response, also state how the law could, during consideration during a first reading of a bill, be immediately widened out to people who could not administer the fatal prescription themselves.

When the legislation is available to more people, the reasons for opting for choosing PAS (and euthanasia in other countries) becomes associated more with people's experiences of oppression and discrimination in society rather than the terminal diagnosis, for which pain can often be well-managed with good quality palliative care. For example, in the Netherlands in 2019, conditions ranged away from Cancer diagnoses, to dementia and psychiatry. People were no longer afraid of a bad death but were afraid of living. As palliative care in that country has improved, pain was no longer the primary reason. Fear of being cared for and being a burden (in Washington State 51% chose AS due to fear of being a burden on family); associated depression on diagnosis are all reasons that have been given for choosing AS. In Canada, reasons given are fear of becoming a burden, loss of ability to enjoy life, desire for control and fear of pain (but not due to uncontrolled physical symptoms such as pain).

As Scottish Human Rights Commission say in their own response:

"We wish to highlight the importance of ensuring that adequate support for the full range of human rights for disabled people is a fundamental component to reducing risks to their right to life, without which the risk that they may be placed in a position where they feel they are a burden on society or loved ones may persist" [emphasis added].

Currently disabled people do not experience the full range of human rights, and indeed some have been breached, as is evident in our most recent Shadow report list of issues to the UN Committee on the Rights of Disabled People (forthcoming) and in the decision of the Committee on the Rights of Disabled People to uphold the optional protocol complaints about systemic breaches. We also cite the experience of disabled people during the pandemic, when not only were services to keep us safe, healthy and living independently removed, but many were asked by their GP if they would mind dying at home if they got COVID and to sign DNA CPR. This in particular has given disabled people the impression that our lives are of less value than others.

As the delivery of legislation to assist people to commit suicide continues, people's justification for choosing it changes, from unbearable suffering to feeling like a burden. For example, the Oregon Death with Dignity Act 2020 Data Summary shows that 53% of people seeking AS reported feeling like "a burden on families, friends and care givers". The current attitudinal barriers and an inaccessible society, lack of sufficient good quality social care support, financial support or access to good health care and treatment, all conspire to make disabled people feel burdensome, on both family and on society. It is no wonder, then, that when people receive a terminal diagnosis as defined in this consultation, they feel fear of neglect and burdensome, when they view others who have impairments in everyday society as living intolerable lives.

We are concerned that the proposed Bill, should it become law, would mark a substantive turning point against the Right to Life (article 10 of the UN CRDP and article 2 of the Human Rights Act 1998), which has been under particularly threat over the last two years due to the pandemic and the responses to it. They also represent a wholesale move away from prevention of suicide which is also part of the Scottish Government's agenda – an action plan with part of its vision to "minimise the risk of suicide by delivering better services and building stronger, more connected communities." We cannot see how two such policies can be compatible.

We take issue with the inherent bias in the statistic citing that 4/5 of disabled people support such a change to legislation as we believe that the audience for the poll already held this view as supporters of the organisation Dignity In Dying, and is therefore not truly indicative of the wider feeling. Nor is there been any meaningful consultation in a reasonable time frame with the full range of Scottish DPOs. We are aware that the views of disabled people in Scotland are not homogenous. However, we think that this may be because the evidence that shows assisted dying does not guarantee dignity and may put disabled people's lives at further risk is not as readily available as the research funded and promoted by such well-resourced organisations as Dignity in Dying.

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

For instance, the Bill proposal argues that where assisted dying laws are in place, the provision of palliative care improves. This is not evidentially true. In Canada, where they have a Medical Assistance in Dying (MAiD) legislation, while the law says that not every care provider has to provide MAiD, the reality is that at least one hospice had its funding removed because it refused to provide it even though MAiD was offered in the hospital nearby. This is the case in other countries too – research published in the journal Palliative Medicine shows that palliative care development has stalled in European countries where PAS and euthanasia are legal.

Care Not Killing conducted a poll in 2014 that asked about support for a bill proposal similar to this one. Over 80% supported it initially, but when CNK asked questions that included the arguments against legalising Assisted dying, support for such a bill significantly dropped:

"Polls consistently show between 70% and 80% in support of AS. However, the issue is clearly far more complex than a simple 'support'/oppose' question can do justice to. This polling strongly suggests that when offered evidence about the nature or source of opposition to AS, and some of the key arguments against it, this high level of support rapidly dwindles.

"The most powerful argument in swaying the public was that changing the law would place pressure on vulnerable people to end their lives for fear of being a burden on friends, family or caregivers, as has been the experience in the US states of Washington and Oregon."

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.

Dignity in Dying warn that under current conditions, '17 people will suffer when they die'. This is a meaningless statistic as it lacks any value without relation or contextualisation. But it is also not true that assisted dying will necessarily result in reduced suffering during death. In countries and states with 'permissive regulation' (and those with legislation similar to the one proposed) cited in the bill proposal, there is evidence that assisted death using an overdose of barbiturates can cause people to have painful, undignified deaths. Examples include evidence from the Netherlands where 'complications included muscle spasms, extreme gasping, and vomiting in 7% of all cases'. It is also reported that this can be distressing to patients. It's hard to see, therefore, how legislating for assisted dying is a necessary step to improve the human experience of death.

Clinician assisted dying is also not always successful. A lung cancer patient who opted for assisted suicide in the American state of Oregon 'ingested dozens of capsules of a powerful barbiturate, only to wake up 65 hours later'.

Cases like these are not described in the bill proposal, nor are they common public knowledge.

Regarding the claim that '17 people a day suffer as they die', this headline does not describe the level of suffering, but we do know that around 1900 people a day die in the UK, so they are stating around 0.8% of people suffer while they die. While no one likes the idea of people suffering as they die, this data only strengthens the argument for improvements to be made to palliative care and pain management during the process of a patient dying – which for the majority of people, works well and is subject to their own wishes.

The focus should be on ensuring people have the right amount of support they need to live well in their communities. We agree with the statement that 'as a country we must do better for our dying citizens'. Investment in good quality palliative care and research on pain management as well as protecting our NHS would help this endeavour. We support the recommendation from Scottish Partnership for Palliative Care for "the explicit inclusion of a human right to palliative care within the forthcoming Scottish Human Rights Act". Additionally, doctors and health care professionals need expert training in conversations about existing end of life choices with patients diagnosed with terminal illness, including on active listening, supporting them with difficult decisions and making clear the range of support that's available to them.

Additionally, people with terminal illness need to be supported well financially so that this is not a risk to their lives. Although this bill is supported by people who are generally well off, when someone becomes disabled, loss of earnings and payment of social care charges can have a detrimental impact on income. Additionally, being refused benefits in the final weeks of life is a horror that must not be repeated – a recent article on the BBC website highlighted that 100 people died challenging a decision to deny them fast-tracked disability benefits for terminal illness.

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)?

Fully opposed

**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.**

As SHRC note in its consultation response, the Adults with Capacity (Scotland) Act (2000) is currently under scrutiny. This is another reason why this is not an appropriate time to consider the legalisation of Assisted Dying. There is currently very little provision for supported decision making in Scotland which puts a person who lacks mental capacity (they have a right to legal capacity under article 12 of the UN CRPD) at increased risk if they change their minds between the second and third stages."

Our concerns about the availability of doctors who will prescribe lethal medication to end a patients' life are set out in answer to question 6, but area also relevant here.

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

Fully opposed

**Please explain the reasons for your response.**

Independent confirmation of terminal illness – life expectancy - is notoriously unreliable, and doctors should not be encouraged to psychologically restrict patients to however many months when they do not actually know.

We repeat the warning of relying on mental capacity to assess decision making capacity – although this is a safeguard that is deemed to protect people from abuse – it would not be compatible with the human right to legal capacity which says that people who do not have capacity to make decisions should have support to make them. Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity. Assessment of mental capacity, as a basis for denial of legal capacity, is discriminatory. And yet supported decision making is not compatible with safeguarding a person against abuse.

There is also an inherent risk of this safeguard being removed to widen eligibility as it has been in other countries, for example, for people with late-stage dementia who may argue for advance directives to be allowed as competent decision making. Again, this draws attention to nature of unbearable suffering at the end of life. A Canadian court decision acquitted a physician who assisted someone to die under an advance directive even though the patient resisted death when the assisted death was being carried out – the legal precedent from this decision means that no matter what the person feels at the time, if an advanced decision is made to choose assisted dying, this will be allowed to go ahead. Many disabled people still require use of the Adults with Incapacity (Scotland) Act (2000) to access suitable support to live their lives fully and safely. There is a concern that the capacity afforded them will be refocussed on people requesting AS.

"Though assisted suicide requests from people with terminal illness, like most suicide attempts, are based on fear and depression, Oregon's statistics show that, for example, in 2017, only 3.5% of those who reportedly died under the Oregon Law were referred by the prescribing doctor for a psychological evaluation before a prescription for lethal drugs was written. In 2018 it was 1.8%."

The bill proposal is vague on how mental capacity will be assessed and in particular, on how assessment will be made for pressure or coercion from someone else. Whereas the Scottish Government are working on rising hate crime, and the phenomena known as "mate crime", which people with learning difficulties are usually but not exclusively victims of. In this example, disabled people are skilfully manipulated until they feel valueless – this could be considered "unbearable suffering" and the reason for it has not always been uncovered. Inclusion Scotland has highlighted to the parliament previously the danger that disabled women may live in in their own households from their experience of domestic abuse from either partners or carers – they are less likely to tell someone they are being abused if it is at the hands of a carer they rely on.

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

Fully opposed

**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.**

Opposition to a bill proposal that sets out how legislation would allow assisted dying means that we oppose any means to support it. The proposal would require that deaths by assisted suicide be listed on death certificates as in fact caused by the underlying illness. This would not be in the interests of transparency and would not be accurate. It would skew the numbers in the data provided about people opting for AS.

If the legislation were to be passed, it would of course be absolutely crucial to collect accurate data. There are examples of other countries where data collection, reliant on physicians filling in the necessary forms, has not been completed successfully, or in some cases at all. The inherent risk is that the doctor has not followed the protocol – how would the body collecting data know?

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

It also brings into question the deep ethical concerns around how those deemed under present legislation to have diminished capacity might be treated – it is not unreasonable to foresee a scenario where an individual or organisation shops around to make the decision for someone, without any meaningful proof or need to even secure clear guidance from the individual whom they are suggesting would benefit from Assisted Dying. This is even more problematic where so much of our institutional care services are provided by the private sector. This is giving the private sector the power of life and death over individuals in their care – something that should be seen as ethically abhorrent, especially given the substantive proof around the use of unagreed DNACPRs during the early stages of the pandemic (which predominately targeted learning-disabled people, ie. those frequently classified by the system to have diminished capacity).

## 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:

a significant reduction in costs

**Please indicate where you would expect the impact identified to fall (including public sector bodies, businesses and individuals etc). You may also wish to suggest ways in which the aims of the Bill could be delivered more cost-effectively.**

The cost of palliative, health and social care support will all be reduced as time goes on if people are assisted with their suicide. In many places the cost of assisting death is much cheaper than other treatment options, which may in some cases have led to people opting for it (feeling like a burden). In countries that rely on private health insurance (an option that is increasingly realistic in this country as our NHS services are divested and become less reliable), this is sometimes prompted as the only option that is viable due to the high cost of other treatments. And in Canada, calculations have been made that assure legislators that expansion of assistance in dying will make multi-million-dollar financial savings.

## 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?

Negative

**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.**

This legislation would impact on disabled people, at times disabled women in situations of abuse, and any further widening of the legislation could impact on disabled children and young people. These risks have been well outlined in this response as legislation in other countries has widened out. It would impact on their equal access to support and treatment. As Care Not Killing state in their response, "if assisted suicide is legal, lives will be lost due to mistakes, abuse, lack of information, or a lack of better options; no current or proposed safeguards can change that".

## 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?

No

**Please explain the reasons for your response.**

Until all disabled people, including disabled people living with life limiting or terminal illness, have enough to live on and enough support, equal access to healthcare and therapies, fully funded and high-quality palliative care, and have all of their rights met, this bill will not lead to a just society. Injustices will go unchallenged and inevitably there will be mistakes. Until disabled people's bodies and lives (DNACPR forms sent out during the pandemic) are valued equally, this bill cannot be brought in. The bill does not have a requirement for all treatments or supports to be exhausted and death could be offered as a first line treatment as it has been in other countries.

## 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*