

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).

Dignity in Dying Scotland is a campaign and membership organisation with almost 60,000 supporters in Scotland. We believe that everybody has the right to a good death, which should include the option of an assisted death for terminally ill, mentally competent adults.

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).

Dignity in Dying 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 supportive

Please explain the reasons for your response.

The choices available to dying people at present are not sufficient. The current law in Scotland, which outlaws assisted dying, prevents terminally ill people exercising their right to choice and control as they approach the end of their lives. It results in dying people suffering against their wishes.

There is an unacceptable degree of inequality built into the status quo. Some dying people who want an assisted death are able to plan, arrange and achieve the peaceful death they want, but whether they can do so is largely dependent on their wealth, knowledge, resources and luck. Dying on your own terms in Scotland is unattainable for many terminally ill people.

Currently, one person every eight days travels from the UK to Switzerland in order to end their life.[1] The law discriminates between those who can afford to access assisted dying overseas and those who cannot. People who die at Dignitas and similar facilities often feel forced to do so prematurely to ensure they are well enough to make the journey. Many doctors shun any attempt to broach the subject while others are complicit in making arrangements for their patients. Family and friends are forced to act in secrecy and left distraught or fearful by police investigations.

"Since my diagnosis with MND four years ago, I have lost the ability to walk, talk and swallow. I have also lost most of the power in my arms. Despite these losses I have tried very hard to remain positive and my palliative care has been outstanding. However, as I enter the final stage of my journey, I don't wish to suffer for much longer so I am seeking an assisted death with Dignitas.

Despite what some people think, Dignitas do not let people simply fly to Zurich, knock on their door and ask to die. I have already had to compose letters, write a life story and obtain medical records that prove that I am terminally ill. This has been stressful, particularly as my GP was advised to refuse my request for an up-to-date medical report.

Having assisted dying available in Switzerland is welcome, but it will cost me about £10,000. I am fortunate that I can afford this, but most people cannot. Having to be able to fly means that I am choosing to die earlier than I would prefer. If an assisted death was possible in Scotland, I would be able to die at a time of my choosing, at home." Richard Selley, Perth, who died at Dignitas in 2019.[2]

Julie, whose sister Sadie had to travel to Dignitas on a private jet during the COVID19 pandemic, said that COVID restrictions meant she had to say goodbye to her sister via Facetime calls. Julie, from Prestwick, said:

"That was the hardest part of it all...the lack of proper closure. My sister shouldn't have had to do that journey with only her two boys. You just wish you could have been there to give her a big cuddle. My sister was very independent and knew her own mind. So from that point of view we were always comfortable in what she was doing.

It's a subject that people will have very strong views on and I understand that. And for those that haven't seen a loved one go through what Sadie did, they maybe won't understand it as much. But having seen it for ourselves, we know just how important it is to have this law changed and allow people in her position to have that choice. At the end of the day, we don't have a choice coming into the world but we should have a choice how we leave."[3]

Many of those who can't afford it, are too unwell to travel or don't want to have to die early while they are still able to make the journey, end their own lives in this country. It is estimated that between 300 and 650 dying people take their own lives every year in the UK.[4] Some people choose not to share their plans and instead die alone in order to protect their loved ones, which can be an incredibly lonely experience. The secrecy of this situation can lead to people choosing violent or distressing ways of ending their own life.

"Now I'm back on chemo and, while it is keeping my cancer at bay, my body isn't tolerating it. I'm scared now that I'm running out of options. When the time comes, if I could, I would go to Dignitas for help but if the only other option is to do it myself then I will. This is the only viable option for me. [...] The sad thing is I have been priced out of being able to choose when I can die." Norma Rivers, Ayr, who has terminal cancer.[5][6]

The current law is unequal, uncompassionate and unsafe. When someone travels to Switzerland for an

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

assisted death only a minority of cases are investigated. Investigations normally take place after the person has died and they can be extremely traumatic for loved ones. Practices that can bring about someone's death under the current law in Scotland – such as the removal of life-sustaining treatment or voluntarily stopping eating and drinking – have fewer safeguards in place than would be present under an assisted dying law.

The ban on assisted dying does not protect people taking action to control the end of their lives but instead drives the practice behind closed doors. This means potentially vulnerable people cannot be, and are not being, protected.

By contrast, a safeguarded assisted dying law would bring choice, compassion and protection to terminally ill people. It would introduce safeguards before a person could access an assisted death, and therefore provide both more protection and more choice than the current law allows. This Bill would also provide an opportunity for robust data collection and regulation, providing a much more accurate picture of the end-of-life choices dying people in Scotland wish to exercise.

"I really want to live. I am a positive person and I laugh a lot. I have never wallowed in doom and gloom and I don't intend to start now. But I don't want cancer to dictate the when and where of my death. I want to be at home and at a time I think is right. It should be my decision and assistance should be there." Tracy McNally, Ayr, who has terminal cancer.[7]

This Bill is something that the Scottish general public overwhelmingly supports. The largest ever poll on the issue shows that 87% of the public back a safeguarded assisted dying law for terminally ill adults.[8] Recent polling has shown that 86% of Scots want the Scottish Parliament to examine the issue and 75% want this done within two years.[9]

Dignity in Dying Scotland supports the name of the Bill as referencing assisted dying as opposed to assisted suicide. People who are terminally ill and approaching the end of their lives simply want to control the way they die. Presenting this as 'suicide' is misleading and does not reflect the academic literature or the views of dying people and their families and leads to a lack of clarity in the assisted dying debate.[10] In a recent poll, 74% of Scots thought that a Bill which would allow terminally ill adults the option of legally seeking assistance to end their lives should be called The Assisted Dying Bill.[11]

This Bill would protect families from making the impossible choice between breaking the law or watching a loved one suffer. It would enable healthcare professionals to offer the full range of options their patients want. It would bring Scotland in line with the growing number of liberal, progressive societies around the world that pride themselves on safe, compassionate assisted dying laws. We are fully supportive of it.

[1] The True Cost: How the UK outsources death to Dignitas, 2017

[2] <https://www.dignityindying.org.uk/news/richard-selley-calls-for-legalisation-of-assisted-dying-on-day-he-is-due-to-die-at-dignitas/>

[3] <https://www.dailyrecord.co.uk/ayrshire/prestwick-family-call-end-blanket-24273746>

[4] Last Resort, Dignity in Dying, 2021

[5] <https://www.sundaypost.com/fp/when-dying-is-a-feminist-issue-report-reveals-why-terminal-illness-their-own-or-loved-ones-hits-women-hardest/>

[6] <https://www.dailyrecord.co.uk/ayrshire/terminally-ill-ayrshire-gran-wants-25666064>

[7] <https://www.dailyrecord.co.uk/news/scottish-news/mum-terminal-cancer-backs-campaign-23377456>

[8] Populus, 2019

[9] Diffley Partnership, 2021

[10] Last Resort, Dignity in Dying, 2021

[11] YouGov, 2021

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 Scotland believes that the Scottish Parliament must legislate to give choice to individuals who are terminally ill and who would like control over their suffering at the end of life. We fully support the proposed Bill.

Legislation ensures there are enshrined, upfront safeguards which will protect everyone. It would make

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.

society safer, replacing the chaos of the status quo with a law that is open and transparent and has meaningful upfront protections, both for those who would want to explore the option of an assisted death and those who would not.

Some organisations and individuals oppose a change in the law on assisted dying based on concerns for the safety of Scottish people. We are concerned that opposing law change on this basis, without acknowledging the absence of safeguards for Scottish people under the status quo is inconsistent. Assisted dying legislation will put dying people's minds at ease. Whether or not someone wants to pursue an assisted death, the right to an assisted death being enshrined in law will offer a great comfort to many people. The number of assisted deaths in Scotland would be relatively small, but the number of people who would take comfort from knowing the option was there if they needed it would be much higher.

"When you're at the end of life, when there's no more treatment that can be given and when it's inevitable that it's going to happen – at that point rather than have people, in this day and age, suffer, they should have a choice. We've made choices all through our lives. We have made choices for our children as parents. And the last choice that we should make is how and in which shape and form that we should pass away." Kay Smith, Kilwinning, who has a complex auto-immune disease.[1]

Some people who oppose a change in the law argue that instead of legislation we should invest more in palliative care. Dignity in Dying Scotland believes that both assisted dying and high quality palliative care should be available to those terminally ill people who want them.

Continuing to improve the quality of palliative care in Scotland through investment, research and improved access should be a priority for the Scottish Parliament but investing in palliative care and legislating for more choice at the end of life are not mutually exclusive. Specialist palliative care has its limits, and while the majority of dying people will have their symptoms managed, a small but significant minority of people will suffer intolerably at the end of their lives.

The Office of Health Economics found that even if every dying person who needed it had access to the level of care currently provided in hospices (i.e. the highest standard of palliative care), 591 people in Scotland a year would still have no relief of their pain in the final three months of their life. This equates to 11 Scots every week.[2]

Physical pain is only one aspect of what can be called 'total pain' which includes social, psychological and spiritual pain, all of which can cause suffering at the end of life. Other symptoms at the end of life can include nausea and vomiting, constipation, faecal incontinence, faecal vomiting, terminal haemorrhages and malignant fungating wounds. These symptoms can be incredibly distressing for the dying person, as well as for their loved ones and their care team.

"There's what we call total pain, where you can't really distinguish the physical from the emotional and spiritual pain, and I think that's the most difficult thing to deal with and the most distressing for everybody concerned. That doesn't happen very often, but it does and it's very, very difficult." Palliative care nurse [3]

"One of the most distressed patients I have ever seen in my life was a man who had had a penile cancer. His penis had been removed and he was left with a big open hole directly into his bladder. He was a very gentle person. He was so ashamed and he would cry. He was begging to have his life ended because he just hated it and he had lived for months in that condition. He was begging to have his life ended because it had absolutely no meaning. He was also in pain, but that was not the main thing; it was the utter degradation. I felt so helpless. We could do nothing about that." Palliative care consultant [4]

Currently, only 6% of Scots think the laws prohibiting assisted dying are working well and just 14% of Scottish healthcare professionals think that without an assisted dying law there are sufficient options available to give dying people meaningful control over their deaths.[5]

Dignity in Dying Scotland recommends that assisted dying is legalised in Scotland to give terminally ill, mentally competent adults a further option of escaping or avoiding a period of unbearable suffering at the end of lives.

[1] <https://www.dignityindyingScotland.org.uk/story/kay-smith/>

[2] The Inescapable Truth about Dying in Scotland, Dignity in Dying Scotland, 2019

[3] The Inescapable Truth about Dying in Scotland, Dignity in Dying Scotland, 2019

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.

[4] The Inescapable Truth about Dying in Scotland, Dignity in Dying Scotland, 2019
[5] Populus, 2019, YouGov 2019

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 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.

We are supportive of the three-step process. It sets out important safeguards to ensure only those who are eligible are able access an assisted death and strikes a good balance between providing protection from abuse and not being overly demanding for a person who is at the end of their life.

We agree that the person should sign a declaration which has been witnessed. This ensures the request is initiated by the person themselves. Initiating the request themselves ensures the requests are voluntary which is vital for a safeguarded assisted dying law. It is also a positive that healthcare professionals would have to explain all the person's options so that the decision to have an assisted death is a fully informed decision. Any verbal requests prior to the written declaration should be recorded in the person's notes. If a healthcare professional has a conscientious objection they should refer the person to another healthcare professional at this stage.

We agree with the need for time for reflection after the declaration. This ensures the person has a clear, settled and enduring intention to die. We are supportive of the reflection period of 14 days which is a similar time frame to that in Oregon and several other US states (15 days). It is also the same period of time that is proposed in legislation in England and Wales, for example the Assisted Dying Bill that was introduced to the House of Lords by Baroness Meacher, which passed its Second Reading unopposed in October 2021. We agree that the time should be lowered if someone is expected to die imminently – this means the reflection period will not act as a barrier to seeking an assisted death for those who are suffering from an extremely aggressive terminal illness.

We agree that the life-ending medication should be delivered by a healthcare professional who should ensure the patient still had capacity and had not revoked their decision.

We also agree that the healthcare professional should be present when the person ingests the medication. This allows the healthcare professional to check that the medication is being ingested properly which limits the potential for any complications in the process. Their presence may also provide comfort and support to the person and the family.

The inclusion of nurses as healthcare professionals who are able to deliver the prescription is positive and will help particularly in rural areas of Scotland or where other healthcare professionals in the locality have conscientiously objected.

These steps have been tried and tested in the USA and Australia, which provides evidence that both the principle and the practicalities of assisted dying can be embedded into existing services.

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

Fully supportive

Please explain the reasons for your response.

We are fully supportive of the safeguards proposed.

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

Dignity in Dying Scotland believes that assisted dying should only be available to terminally ill, mentally competent adults, as proposed in this Bill. When someone is terminally ill and they have assistance to die, they control the manner and timing of a death that would otherwise be unbearable to them. Focusing on those who are already dying strikes the appropriate balance between autonomy and protection.

Most jurisdictions which allow assisted dying require the involvement of two independent doctors. The independence of these assessments will ensure accuracy in assessing eligibility for assisted dying. We welcome the additional safeguard of either doctor being able to refer to a psychologist or other appropriate specialist if there are any doubts about a person's mental capacity.

Dignity in Dying Scotland believes that doctors are well-placed to determine a person's prognosis, assess a person's mental capacity and explore the motivations behind a person's request to exercise control over the end of their lives. These assessments are well-established in medical practice. For example when someone chooses to refuse medical treatment that will result in their death doctors are required to make sure the person has capacity and is not being coerced. We therefore agree that the written declaration must be endorsed by two doctors.

The importance of open and honest conversations between medical practitioners and their patients cannot be overstated. We believe that people making a request must be fully informed of all of their care options as well as having an assisted death – this is an important part of the Oregon process, meaning that many people do not take up the option of an assisted death where their needs may be better served by altering their care or care setting.

As previously stated, we are supportive of the 14 day reflection period as a way of ensuring someone has a settled and clear wish to end their own life.

The requirement that the medication is self-administered is important to ensure that someone is acting voluntarily, and will protect people at risk of abuse, for example by preventing another person administering the drugs. It ensures that the person's decision to end their life is their decision alone and also ensures that only those with decision-making capacity are able to take the life-ending medication.

The safeguards outlined in the proposed Bill have been tried and tested in other jurisdictions and we are confident that they will serve the purpose of allowing genuine choice at the end of life as well as putting in place more stringent protections for potentially vulnerable people.

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

Fully supportive

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.

Reporting and collecting data is vital to monitor any assisted dying law. It gives clear oversight of the safeguards in the law, and ensures that cases of assisted dying are carefully scrutinised for compliance with the law. The reporting can be used to inform Parliament and the public as to how the law is working.

The reporting will inform the improvement of practice. The collection and reporting of data in jurisdictions with an assisted dying law has been instrumental in evidencing that the law is safe, effective and works as intended. It provides insights into how and why people are accessing assisted dying, and their experiences of the process. Reporting this data is also an opportunity for other jurisdictions considering law change to learn from Scotland.

The body responsible should collect information about the patients and healthcare professionals who participate in assisted dying and publish a public annual report.

The data to be collected should include:

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

- The number of prescriptions written that year, how many people who received a prescription ingested the medication and how many people died of other causes
- Patient characteristics including age, gender, location, ethnicity, level of education, marital status, underlying illness and whether they were in receipt of hospice/palliative care
- The patients' end of life concerns which should be recorded qualitatively/as a free text response. In the USA, healthcare professionals retrospectively choose options from a list of pre-selected end of life concerns. This has led to misleading claims that people who choose an assisted death in the USA do so because they are concerned about being a burden. However, being a burden is not in the top three concerns reported. These concerns are recorded by a doctor from a closed list of options and should not be used to make sweeping statements about the complex reasons that inform any medical decision. It's important under a change in the law in Scotland that terminally ill people who meet the eligibility criteria and safeguarding themselves define why they want the choice of assisted dying, rather than their doctors doing so.
- How many people were found to be eligible or ineligible at each assessment
- How many people withdrew from the process
- How many healthcare professionals wrote prescriptions and the drugs that were prescribed
- The time from ingesting the medication until death and details about any complications during the process
- Insights from healthcare professionals, patients and family members including feedback about the process

The body should also review and report on compliance with the law. When the body identifies any issue of non-compliance with the law it should be reported to the appropriate body.

An existing body could take on the role of reporting. Public Health Scotland would be suited to taking on this role. This would be similar to the system in Oregon where the Oregon Health Authority is responsible for data collection, in California it is the California Department of Public Health and in Washington State it is the Washington State Department of Health. Using an existing body makes use of existing resources and infrastructures.

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

It is important that the right of healthcare professionals to conscientiously object to participating in assisted dying is recognised in legislation. A healthcare professional should declare their conscientious objection early in the process, as soon as the person makes a verbal request for an assisted death. Declaring a conscientious objection at this stage means people do not have to go through the process of making a written declaration which then has to be done with another doctor. In Victoria an objecting healthcare professional is required to tell their patient that they are conscientiously objecting within seven days of the patient's request. In Western Australia, this must be done within two days. In New Zealand an objecting healthcare professional must inform the patient that they have a conscientious objection, and tell them of their right to ask the statutory body for assisted dying for the name and contact details of a replacement medical practitioner.

This is already the case in Scotland for conscientious objections to abortion. Guidance from the British Medical Association says that "The BMA believes that a doctor's conscientious objection must be made clear to the patient as soon as possible, and patients must be able to see another doctor as appropriate. Referral in these circumstances need not always be a formal procedure. However, it is not sufficient to simply tell the patient to seek a view elsewhere."^[1]

The General Medical Council provides similar guidance: "You must explain to patients if you have a conscientious objection to a particular procedure. You must tell them about their right to see another doctor and make sure they have enough information to exercise that right. In providing this information you must not imply or express disapproval of the patient's lifestyle, choices or beliefs. If it is not practical for a patient to arrange to see another doctor, you must make sure that arrangements are made for another suitably qualified colleague to take over your role."^[2]

We believe that the objecting healthcare professional should make a referral to another healthcare professional who is willing to be involved in the process to prevent unnecessary stress and harm to the

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

patient.

[1] <https://www.bma.org.uk/media/3307/bma-view-on-the-law-and-ethics-of-abortion-sept-2020.pdf>

[2] <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice>

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:

no overall change 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.

Based on international experience, we believe that there would be no overall change in costs. While there will be some initial spending on training of healthcare professionals and public education this will be small and will be outweighed by the costs saved in areas such as the reduction in police investigations after someone travels to Dignitas.

There is however the opportunity to increase funding for palliative care at the same time as legalising assisted dying. For example, when the Australian States of Victoria, Western Australia and Queensland passed assisted dying legislation, the governments also increased funding towards palliative care services by between \$17m and \$170 million (£9m - £90m), thereby ensuring that every citizen could have the very best, holistic care at the end of life.[1][2] We call upon the Scottish Government to make a similar investment, ensuring that dying Scots have both access to excellent care and more choice at the end of life.

For individuals, an assisted dying law would reduce the financial burden of people funding their own end-of-life choice for example those who pay to have an assisted death at Dignitas, or those who pay to import (potentially dangerous and illegal) life-ending drugs to take at home.

However, Dignity in Dying Scotland believes that cost should not be a factor in deciding whether to legislate for assisted dying. It is a complex issue and one that is very difficult to cost. For example, being able to have open and honest conversations about end of life choice might mean that more people take up other end-of-life options such as specialist palliative care which would increase spending on palliative care, but would reduce the cost of emergency admissions of people at the end of life into inappropriate care settings. This is hard to put a figure on but it is vital that the priority is people being able to choose the end-of-life care and make the end of life decisions that are right for them.

[1] <https://mforum.com.au/palliative-care-a-human-right-vad-voluntary-assisted-dying/>

[2] <https://statements.qld.gov.au/statements/93249>

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?

Positive

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.

The overall impact of the proposed Bill on equality will be positive. Everyone will benefit from having more choice available to them at the end of life. Everyone will benefit from being able to have open and honest conversations with their healthcare professionals about their wishes and fears for the end of their lives. This Bill will provide peace of mind for dying people and their loved ones, no matter how many people make use of the law.

There will be no disproportionate impact on any of the protected characteristic groups outlined in the Equality Act 2010. People who seek an assisted death in places where it is legal are most often aged between 65 and 85, have a 'good education', have medical insurance and have cancer. Similar numbers of men and women have assisted deaths overseas.[1] Potentially vulnerable groups of people do not disproportionately use assisted dying laws.[2]

Systematic reviews have examined the uptake of assisted dying amongst vulnerable people, including people with disabilities. One concluded that the hypothesis that people with disabilities might be disproportionately impacted 'does not seem to be borne out', and that 'in no jurisdiction was there evidence that vulnerable patients have been receiving euthanasia or physician-assisted suicide at rates higher than in the general population... data do not indicate widespread abuses of these practices.'[3] Disability Rights Oregon, an organisation committed to protecting Oregonians living with disabilities, has never received a complaint of abuse or attempted abuse under Oregon's law.[4]

We believe there is an irrefutable moral and ethical case for assisted dying but there's also a logical one – opposing assisted dying because of speculative concerns about how different groups of people might be disproportionately impacted are hypocritical when we look at the lack of protections around current end-of-life choices, which have far more potential for abuse and harm for vulnerable groups (e.g. outsourcing the problem to Dignitas and doctors making decisions without transparency or oversight) compared to the upfront safeguards under the proposed law.

[1] Oregon Death with Dignity Act, Data summary, 2018 and California End of Life Option Act, Data report, 2018.

[2] Medical Assistance in Dying (MAiD): A descriptive study from a Canadian tertiary care hospital, Am J Hosp Palliat Care, Selby D, 2019

[3] Emanuel, E.J. et al. (2016) Attitudes and Practices of Euthanasia and Physician Assisted Suicide in the United States, Canada, and Europe, JAMA 316:79 90.

[4] <https://compassionandchoices.org/letter-from-disability-rights-oregon-dro/>

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?

Yes

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- 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?

Please explain the reasons for your response.

The proposed Bill is based on robust scientific evidence; principles of justice; and is a response to overwhelming public support which reflects Scotland's liberal democracy.

Fears expressed by opponents to choice at the end of life have not been realised in places where assisted dying has been legalised. They are not based in scientific evidence. In fact, law change prompts better end-of-life care, reduces suffering and creates opportunities for more honest and meaningful conversations around death and dying. These are hallmarks of a society that values people regardless of how close to death they are, and prioritises giving people a positive experience at the end of their lives.

The proposed Bill would provide terminally ill people in Scotland with choice and protection and also demonstrates a clear commitment to ongoing monitoring and regulation of practice after law change.

Conversely, the status quo is not sustainable or transparent, it fails to protect people, denies them choice and exacerbates suffering. The options dying people currently have – Dignitas, ending their own lives, stopping eating and drinking, dying in pain – are not an acceptable alternative. Having the option of assisted dying would mean having a fairer and more just society.

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