SPICe The Information Centre An t-Ionad Fiosrachaidh

Health, Social Care, and Sport Committee
Assisted Dying for Terminally III Adults
(Scotland) Bill – Summary of responses to the short call for views

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Introduction

The Health, Social Care and Sport Committee ("the Committee") ran a call for views on the <u>Assisted Dying for Terminally III Adults (Scotland) Bill</u> ("the Bill") between 7 June and 16 August 2024. The public were able to respond to two surveys: (1) a short survey on the high-level principles of the Bill; and (2) a more detailed survey assessing respondents' views on specific provisions of the Bill. This report presents the findings of the short survey.

Understanding the context of this call for views

The data gathered from the call for views is not intended to reflect a representative sample of the population, but rather to offer a snapshot of the experiences, opinions, and concerns expressed by those who responded, so that the broadest span of views can be heard by Members. Respondents to the Parliament's calls for views are self-selecting, and though the submissions received offer a helpful insight into the key issues surrounding the topic in question, they do not necessarily represent the majority opinion of the general public, and should not be interpreted as such.

Respondent characteristics

The short call for views received 13,821 responses, eight of which were submitted using British Sign Language (BSL). Of these responses, 13,791 were submitted by individuals, and the remaining 30 were submitted on behalf of organisations.

Respondents were asked whether they lived in Scotland. 9,225 respondents lived in Scotland, and 4,567 did not. The 29 respondents who did not answer the question reflect responses submitted from organisations, rather than individuals.

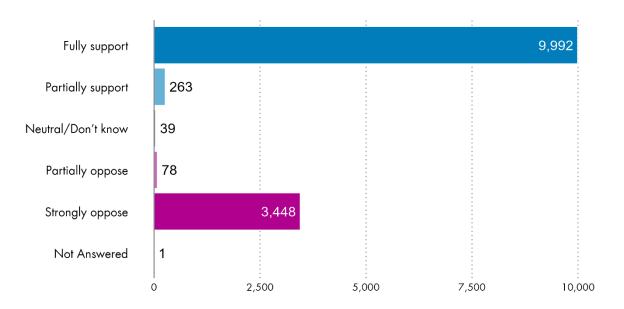
Summary of responses

The responses to the short call for views were not individually published on the Scottish Parliament website, in keeping with the Committee's <u>statement on the handling of information and evidence</u>. Instead, this report offers a high-level summary of the views shared by respondents to the short call for views. The summary reflects only the views of those who chose to respond and should not be viewed as representative of the broader opinion of the general public.

Which of the following best reflects your views on the Bill?

Respondents were asked to share their views on the Bill on a scale from "fully support" to "strongly oppose". The majority of those who responded (9,992 respondents) expressed their full support for the Bill and 263 stated partial support. 3,448 respondents strongly opposed the Bill and 78 expresse partial opposition. The remaining 39 were neutral or unsure. One respondent did not answer this question.

Figure 1: Responses to the question 'Which of the following best reflects your views on the Bill?'



Source: Scottish Parliament

Which of the following factors are most important to you when considering the issue of assisted dying? Please rank up to three options.

Respondents to the short survey were asked to rank the 3 factors which were most important to them in relation to the topic of assisted dying. The respondents were offered the same list of pre-determined options whatever their stated views on the Bill:

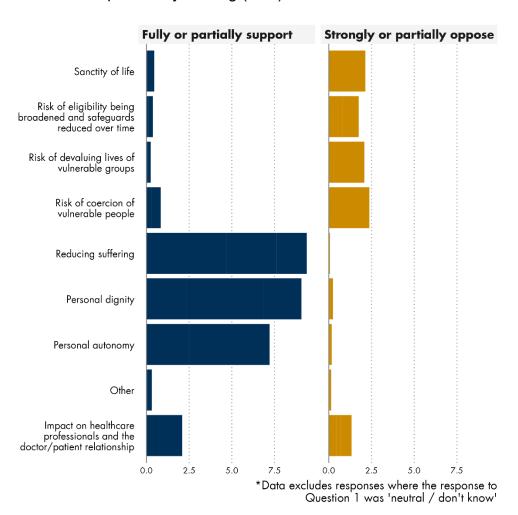
- Reducing suffering
- Personal dignity
- Personal autonomy
- Risk of coercion of vulnerable people
- Sanctity of life

- Impact on healthcare professionals and the doctor/patient relationship
- Risk of devaluing lives of vulnerable groups
- Risk of eligibility being broadened and safeguards reduced over time
- Other please provide further details in the text box

As summarised in the chart below, the key factors for those in support of the Bill were reducing suffering, personal dignity, and personal autonomy. Those who opposed the Bill were concerned about the sanctity of life, and the risk of eligibility broadening and safeguards reducing over time, referred to by some respondents as a "slippery slope". Respondents opposed to the Bill also identified the potential impact on vulnerable people as a factor in their consideration of assisted dying.

Figure 2: Which of the following factors are most important to you when considering the issue of assisted dying?

Number of responses by ranking ('000)



Source: Scottish Parliament

Respondents were also invited to share other factors influencing their view on assisted dying. Most respondents used this option to expand on their reasons for selecting the pre-determined options, with many opposed to the Bill sharing their objections on the grounds of religion. Some respondents also stated that they would prefer to see greater investment in palliative care, rather than a focus on assisted dying. Many respondents supportive of the Bill shared personal experiences of losing a loved one, and their belief that assisted dying provision would have alleviated their loved one's suffering. Respondents also highlighted the wider effect of a person's end of life suffering on their loved ones, with some sharing stories of family members dying by suicide after witnessing a loved one suffering at the end of life. Some respondents also expressed that they would wish to see the criteria for access to assisted dying broadened, with conditions like dementia and Parkinson's disease considered eligible.

Do you have any other comments on the Bill?

Respondents were invited to share any additional comments on the Bill. A random sample of these responses was analysed using thematic analysis, and the themes identified are summarised below.

Support for the Bill

Alleviating suffering

Many of the respondents who expressed support for the Bill used the "other comments" question to share personal experiences of witnessing suffering at the end of life. One person said:

"As someone who saw so many family members die a long and agonising death at the hands of cancer, as I probably will too – this is about safety and compassion towards those who have no hope or dignity left."

Some respondents also drew on their experience in the healthcare profession to justify their support for the Bill. One respondent said:

"I have worked in healthcare in Scotland for 30 years. Of those, 12 years were spent caring for adults toward the end of their lives. I have witnessed first hand the suffering many had to endure and listen to their pleas to help them die painfree and with dignity. The law has to change to allow people the choice to end their lives if they are enduring or facing a painful, protracted and undignified death."

The alleviation or avoidance of suffering was a key concern among respondents supportive of the Bill. In particular, respondents highlighted the disparity between the

treatment of animals and people at the end of life as justification for the introduction of assisted dying:

"This Bill needs to be introduced as soon as possible. It is a terrifying prospect to know that at this time terminally ill people are being allowed to suffer. We would not allow an animal to suffer unduly and yet we allow people to die in agony. People should have the right to choose to end their life with dignity."

Comparison with other countries

The perceived success of assisted dying legislation in other countries was referenced by multiple respondents who expressed support for the Bill, including one person who said:

"Look at the number of civilised countries that have already made provision for this and ask how many, if any, have revoked it because of abuse of the persons individual decision."

Autonomy and dignity

The importance of autonomy over end-of-life decision-making was also highlighted by respondents:

"I strongly believe we should have the right to determine how we exit this life at a time of our choosing when faced with a terminal and intolerable disease/illness."

Similarly, respondents felt that assisted dying could afford dignity in death to people with terminal illnesses:

"With stringent procedures in place this bill could reduce end of life suffering and give a person some dignity in allowing them to pass in peace."

The scope of the Bill

Some respondents who supported the Bill expressed that they would wish to see its scope expanded to include non-terminal but life-altering conditions such as chronic pain, and questioned whether the Bill could be amended to include advance care planning for conditions involving loss of mental capacity, such as dementia:

"My own view is that the Bill does not adequately cover one of the worst possible ends to life as it requires Mental Capacity at the time of making the request. Hence dementia, of which I have first hand exposure, appears to be excluded. In reading the Bill it is not clear whether a request to terminate made while still mentally capable but facing a death with dementia (in the years hence) would be accepted."

Current end-of-life care provision

Some respondents in support of the Bill felt that the current end-of-life care provision was not adequate, and that palliative care could not always alleviate a person's suffering:

"The right and humane approach for Scotland is to support and fund excellent palliative care which is not the case currently; but also to give people who face a bad death greater choice at the end of life. The current situation for dying people isn't good enough. When suffering goes beyond the reach of palliative care, the current options aren't acceptable to dying people. Your life belongs to you, and you should have the option of choosing how to die in dignity and at your time of choosing if the alternative is painful (physically or mentally). The choice of an assisted death should be one of the options."

A number of respondents shared personal stories of loved ones who had attempted or died by suicide due to their terminal illness. They expressed that had assisted dying been in place, their loved one may not have considered this action to be necessary:

"My niece committed suicide because she did not want to die from MS causes. She was only 40 and in the early stages of her MS, but she had worked with people with MS who could not function, talk or swallow and saw how cruel this condition was at their death. If she had had a choice of assisted dying, I believe she would have lived a longer life knowing that she had a plan for her death when she felt scared of her cruel death."

Safeguarding

Even among those who supported the Bill, there was acknowledgement of the potential for coercion to take place, and calls for robust safeguarding:

"I accept that this Bill may allow coercion to take place, safeguards have to be very considered to keep this to the absolute minimum. No system can guarantee to be 100% perfect and to prevent this Bill going forward because of this argument will cause more pain and suffering."

Opposition to the Bill

Sanctity of life, and religious objection

A belief in the sanctity of life was one of the most commonly-cited concerns from people opposed to the Bill. One respondent said:

"I strongly believe that our society should uphold as one of its chief principles, the sanctity of life. Once this is eroded then many other values will follow suit. We must prioritise assisted living – especially helping those who are most

vulnerable, to live well until a natural death. Palliative care should be seen as the means for supporting people to die well – with pain relief as required and a loving and caring environment provided until a natural death."

These concerns regarding the sanctity of life were sometimes informed by religious or moral objections to assisted dying:

"I fear this Bill changes the relationship between patients and healthcare providers and will lead to the devaluing of life and the ending of life before time. Ultimately God gives and takes away life and when He commanded "do not murder" I believe suicide and assisted suicide are thus forbidden."

Safeguarding and coercion

Respondents opposed to the Bill expressed worries that adequate safeguards against broadening the scope of the Bill would not be in place, and that other countries in which assisted dying is legal had gradually broadened the scope of their legislation over time:

"My primary concern is for the safety of vulnerable people across the nation, including those who are disabled, frail, elderly, or incapacitated. It's clear from the evidence in other countries that safeguards are slowly but surely removed after the initiation legalisation of assisted dying – one only needs to look at the situation in Canada where the need for a "reasonably foreseeable" death was removed only 5 years after the initial law was passed."

Similarly, some respondents were concerned that the legislation could be open to abuse, and that terminally ill people may be coerced into choosing assisted dying to avoid becoming a "burden":

"Having worked for years in the NHS, I have seen the extreme stress and strain on the healthcare system and how this affects patients and their families. I have no doubt whatsoever that making assisted dying legal will lead to an inevitable pressure on the elderly and disabled to be euthanised because of the feeling of being a burden."

Others expressed that the introduction of assisted dying may harm the doctor-patient relationship, and lead to a lack of trust in healthcare professionals:

"As an eighty year old if I became seriously ill it would undermine my confidence and trust in the medical care I might receive and more vulnerable people with no family support could be easily pressured to commit suicide."

Some healthcare professionals also shared that they would feel uncomfortable participating in assisted dying, should the Bill be introduced:

"As a district nurse, I don't want to be involved or complicit in the inevitable direct or indirect pressures that would ensue on vulnerable people if this Bill was passed. Pressure either they would will feel from others, or project onto themselves, to end their life prematurely."

Some respondents also questioned whether financial motivations could be used to pressure a patient into choosing assisted dying:

"We know that finances are limited. The fear is that as Assisted Living costs more than Assisted Dying, the latter could start to be promoted as 'the responsible choice'."

Current end-of-life care provision

Some respondents felt that improvements to healthcare and end-of-life care would be more appropriate than introducing assisted dying. One respondent, a GP, said:

"We need better treatment for those who are suffering. Our health service inadequately provides this, and if, instead of making improvements, we simply put on the table the option of death, which will vulnerable, suffering patients choose? If you have to wait months to see a pain specialist, for example, why bother waiting when your suffering could be ended now?"

SPICe Research

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