

Assisted Dying for Terminally Ill Adults (Scotland) Bill – sharing your views

Health, Social Care and Sport Committee,
Scottish Parliament

16th August 2024

Age Scotland is the national charity for older people. We work to improve the lives of people over 50 and promote their rights and interests. We help older people to be as well as they can be, we promote positive views of ageing and later life, and we tackle loneliness and isolation. About Dementia is Age Scotland's Dementia Policy and Practice Forum. We work to ensure that the voices of people living with dementia and unpaid carers are heard at a policy level by building our policy responses with the voice of lived experience at the core

Age Scotland and About Dementia's position

Age Scotland and About Dementia **neither support nor oppose** the Assisted Dying for Terminally Ill Adults (Scotland) Bill, (referred to from now as the Assisted Dying Bill or, the Bill), currently in the Scottish Parliament and take a **neutral stance** on the topic overall.

We have decided to provide a **neutral response** to this call for evidence for several reasons. At the heart of our policy work is listening to and including the voices of older people. We were very conscious of the **sensitivity, complexity** and **emotiveness** of this topic but wanted to ensure that the older people we reach felt they had voice and opportunity to influence policy making in this area in an as accessible way as we could provide.

We specifically asked the older people we consulted on this topic with about whether they supported our approach of taking a neutral stance, but articulating the views of the older people who we engage with on this topic. **60%** of those who responded stated that they supported this approach.

About this call for views

We welcome this opportunity to respond to the Committee's call for evidence on the Bill. We understand that the views gathered through this exercise will help to inform the Committee's scrutiny process, to understand the reasons for support or opposition to the Bill, and to understand how it might need to be amended. We understand that the Committee will not be using this call for evidence to establish if there is more support or opposition for the Bill across Scotland.

Based on our neutral stance, we have decided to not respond directly to the questions within the call for evidence. Instead, our response will present an **analytical overview**, exploring the insights and views articulated by the older people we have engaged with. This response presents findings and considerations that relate to the following question topics from the call for evidence document:

- *Views on the Bill*
- *Eligibility – terminal illness*
- *The Assisted Dying procedure and procedural safeguards*
- *Other comments related to the Bill*

What we have done

Our aim for this response was to give older people a facilitated opportunity to engage and explore this topic, share their views and to provide them with as much practical, neutral, detail about the Bill as possible so they could make informed and considered choices in how they participated. We recognise that older people are **not a homogenous group** and therefore we want to shine a light on the range of views people aged over 50 might have on this topic and the Bill itself. We acknowledge that just because individuals are living with or caring for someone with the same or similar diagnoses, does not mean they will all hold the same opinion on a topic such as assisted dying.

To understand the views and opinions of older people, we carried out the following engagement methods to gather insight to inform our balanced response to the call for evidence:

- **Four ‘policy drop-in’ sessions** with existing groups and networks across Age Scotland. These involved talking attendees through the Bill in an **accessible and digestible format** before discussing the Bill.
 - Scottish Ethnic Minority Older People Forum (SEMOPF)
 - About Dementia – People living with dementia
 - About Dementia – Unpaid carers
 - LGBTQ+ Scottish Older People’s Network
- **Short snap survey [online and paper options]** asking broad questions on views of assisted dying, reasons for views and access to palliative care. The survey also asked for thoughts on Age Scotland’s approach to this call for evidence. A total of **411 responses**¹ were received.

¹ Of the 411 survey participants, 398 expressed a specific view on the topic of assisted dying

- **Two policy briefings** exploring the Bill were also created. One specifically looked at the potential implications of the Bill for people living with dementia.

We hope that our response to the call for evidence offers **extra insight** from older people across a range of groups, including some seldom-heard voices. We hope that this will ensure that policymakers have as rounded a view as possible to inform their decisions.

Limitations of our engagement approach

Whilst we tried to gather a range of views, we are aware that, for example, those who responded to our online survey most likely already had strong views (either in support or opposition) on assisted dying. We acknowledge the potential for this **self-selected answering**, with our data perhaps not representing the individuals who are unsure of their position on this debate.

What do older people think – our findings

From our engagement with older people, we have heard views on all sides of the debate. In the following sections, we will explore both the quantitative and qualitative findings from the online survey sent to Age Scotland supporters and members.

Quantitative findings

This section outlines the quantitative findings of the short online survey sent to Age Scotland supporters and members. A total of **411** responses were received, however, not all these respondents provided an answer to every question.

Views on assisted dying

The opening question of the survey asked, ‘Which of the following best reflects your views on assisted dying?’, with the majority of respondents (**65%**), stating that they strongly supported it, and another **16%** being somewhat supportive. As is seen in **Figure 1** below, **16%** of respondents stated that they opposed assisted dying (3% somewhat oppose, 13% strongly oppose). Just 3% stated a neutral view on the topic.

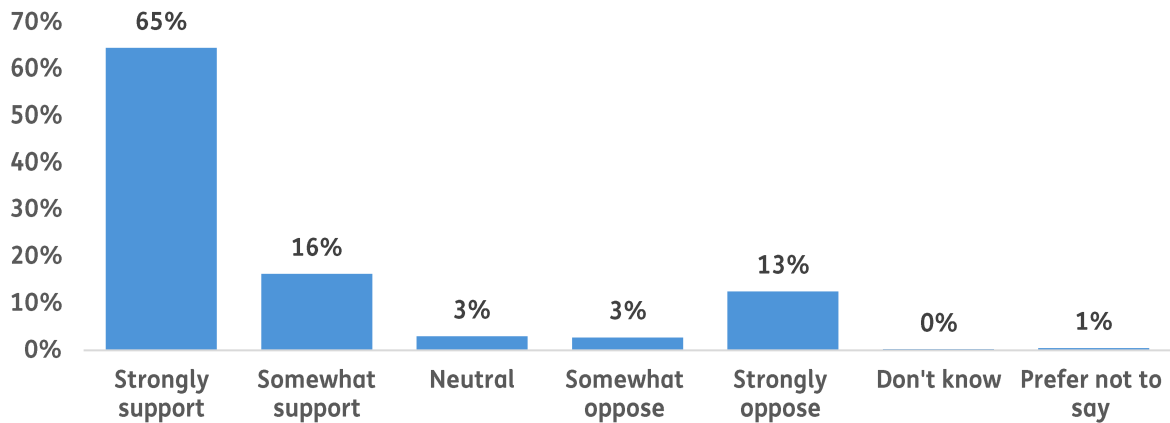


Figure 1- Views on assisted dying (N=398)

Experience of terminal illness

Respondents were asked if they had any experience of living with a terminal illness themselves or if they know or care for someone with a terminal illness. See **Figure 2** below.

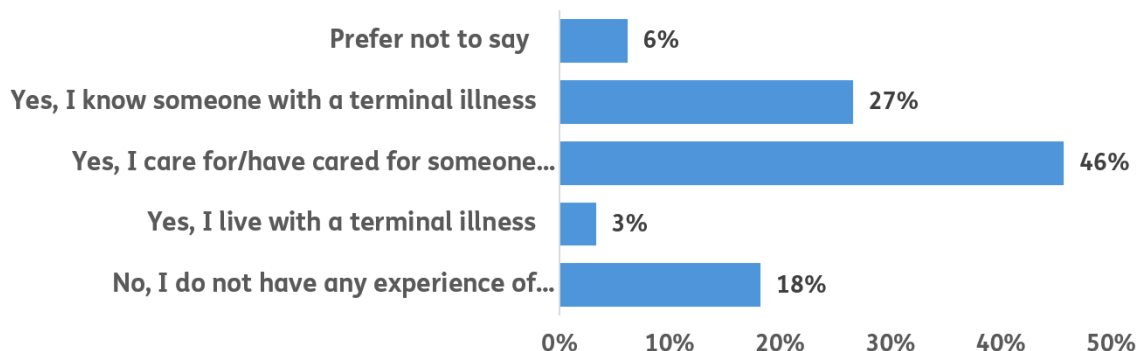


Figure 2 - Experience of terminal illness (N = 455)²

As is seen in Figure 2, just under half of respondents (**46%**), reported that they are either currently, or have previously cared for someone with a terminal illness, with a further **27%** knowing someone with a terminal illness. Just **3%** of respondents stated they currently are living with a terminal illness and **18%** had no experience of having, knowing or caring for someone with a terminal illness.

To find out if having a terminal illness might impact views on assisted dying, we carried out further in-depth analysis. Firstly, of the 3% who reported that they lived with a terminal illness, of which some also know, or care for/have cared for someone with a terminal illness, **71%** of them strongly supported assisted dying

² **Note:** N is higher than total survey responses as respondents could select more than one option.

with a further **7%** somewhat supportive. **21%** of those living with a terminal illness stated they strongly opposed assisted dying. See **Figure 3** below.

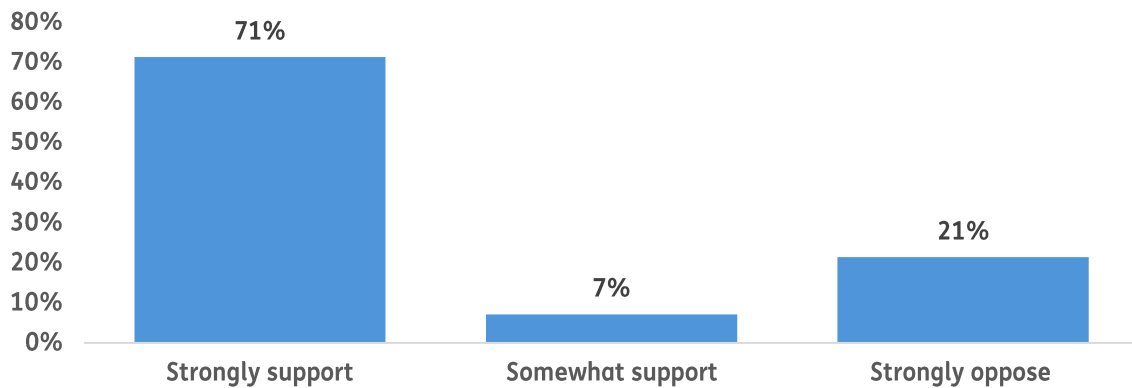


Figure 3 - Views on assisted dying from respondents living with a terminal illness (N=14)

Of the respondents who stated they had no experience of terminal illness, there was a wider spread of responses, although results mirrored overall patterns with the majority (**50%**), strongly supporting assisted dying (see **Figure 4**). An additional **33%** were somewhat supportive, **8%** held a neutral view, and a total of **9%** were opposed (6% strongly; 3% somewhat).

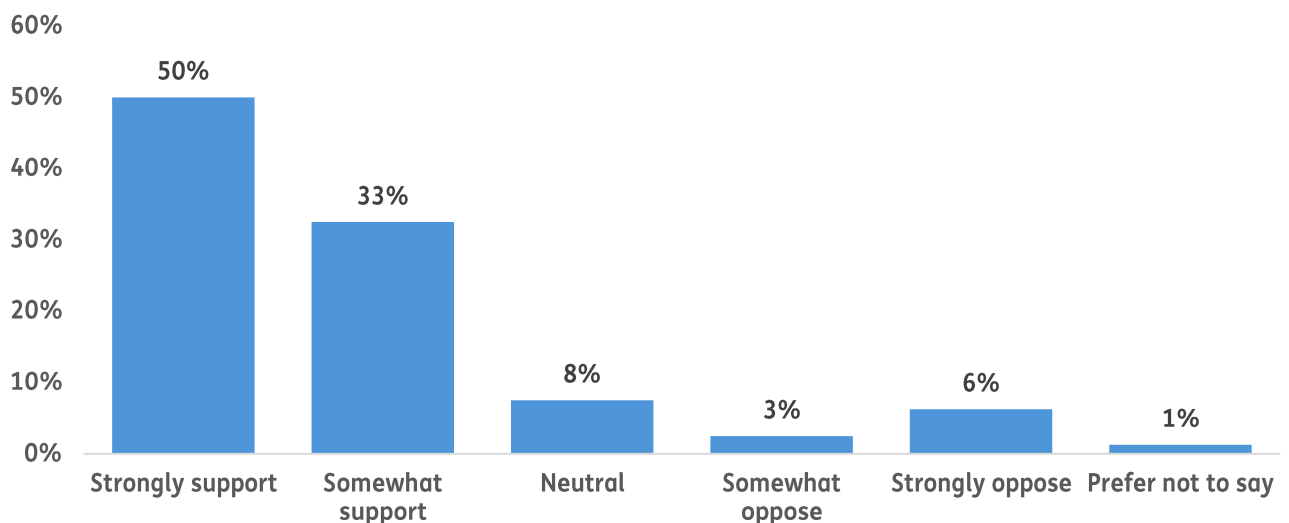


Figure 4 - Views on assisted dying from respondents with no experience of terminal illness (N = 80)

Experience accessing palliative care

As part of the survey, we were interested to see if respondents had experience accessing palliative care in Scotland. As can be seen in **Figure 5** below, the most common response (**58%**), was not having experienced palliative care themselves, but someone they knew having experienced accessing palliative care. Furthermore, just **4%** had experienced palliative care themselves, and **31%** had no experience of palliative care at all.

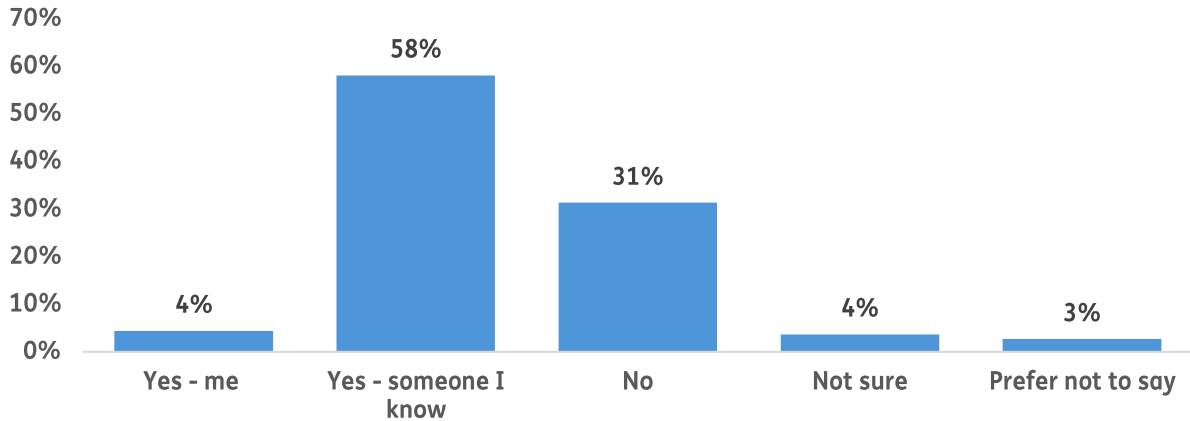


Figure 5 - Experience of accessing palliative care (N=412)

Again, further analysis was carried out to see how respondents viewed assisted dying depending on whether they had either experienced palliative care or not. Of the **4%** who had personally experienced accessing palliative care themselves, again mirroring the general findings, **82%** were supportive, (76% strongly; 6% somewhat) and **18%** opposed assisted dying (6% somewhat; 12% strongly).

Of those who knew someone else who had experienced accessing palliative care, **81%** were supportive (67% strongly; 14% somewhat) and **16%** were opposed (14% strongly; 2% somewhat). Finally, of those with no experience of palliative care, **77%** were in support of assisted dying. Within this, there was a slightly lower strength of support (58% strongly supported; 19% somewhat supported) compared to those who had experienced palliative care themselves or through others. See **Figure 6** below.

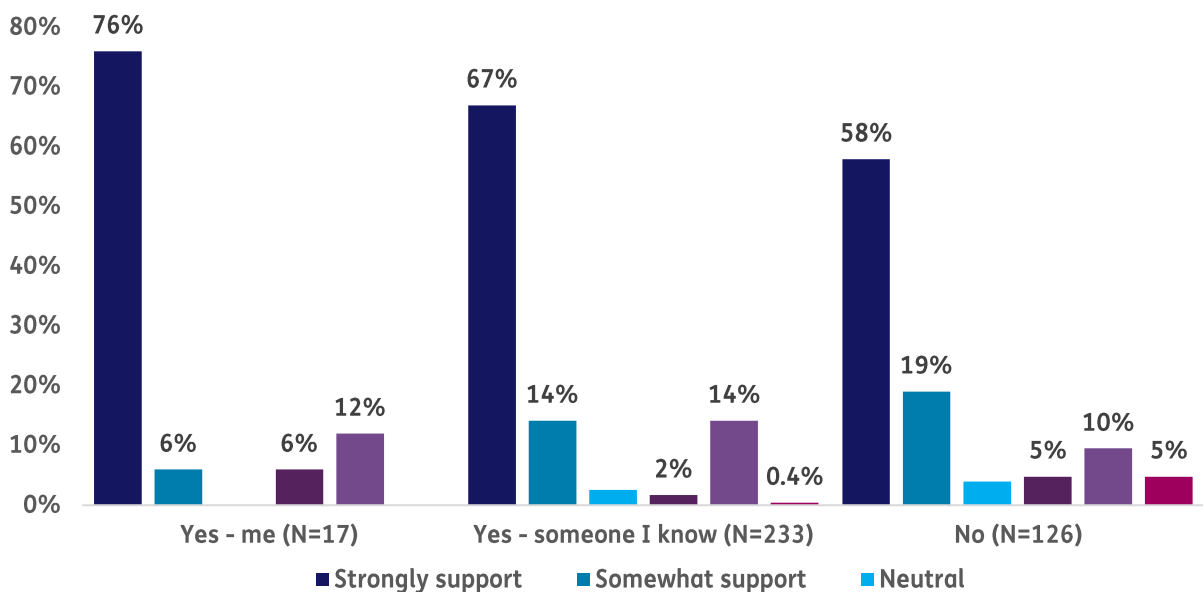


Figure 6 - Experience of accessing palliative care and views on assisted dying

These findings appear to suggest that there is no clear association between having experienced palliative care and views on assisted dying. One explanation for this could be due to the existing lack of consistency in palliative care services in Scotland.³ This might result in some individuals having received high-quality, timely palliative care from the moment of diagnosis, whilst others may not have been as fortunate. Therefore, the lack of high-quality, appropriate and timely palliative care could potentially drive some to support assisted dying, whilst others may view the need for improving access to equitable palliative care to be a reason to oppose it.

Demographics

The following graphs demonstrate the key demographics and their views on assisted dying.

Age

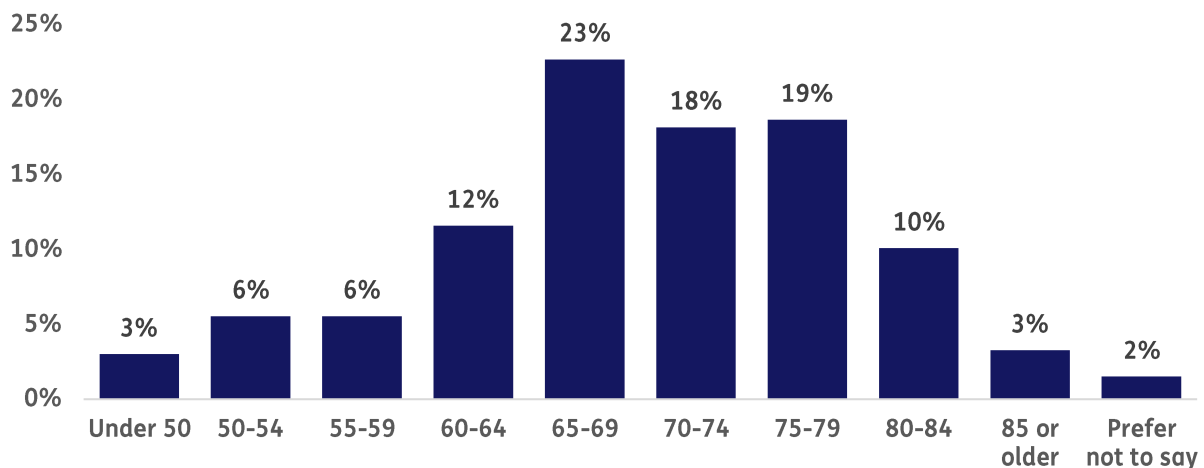


Figure 7 - Age group of respondents

The majority of respondents were in the age group between 65-69 (23%), followed by the 70-74 age group (18%) as is shown in **Figure 7** above. Across all age groups, the most common view for assisted dying was **strongly supportive** as can be seen in **Figure 8** below. Therefore, this suggests that, at least for the older people in Scotland we consulted with, age does not appear to determine views on assisted dying.

³ Health Improvement Scotland (2024). *Gathering view report on palliative care*. [Link](#)

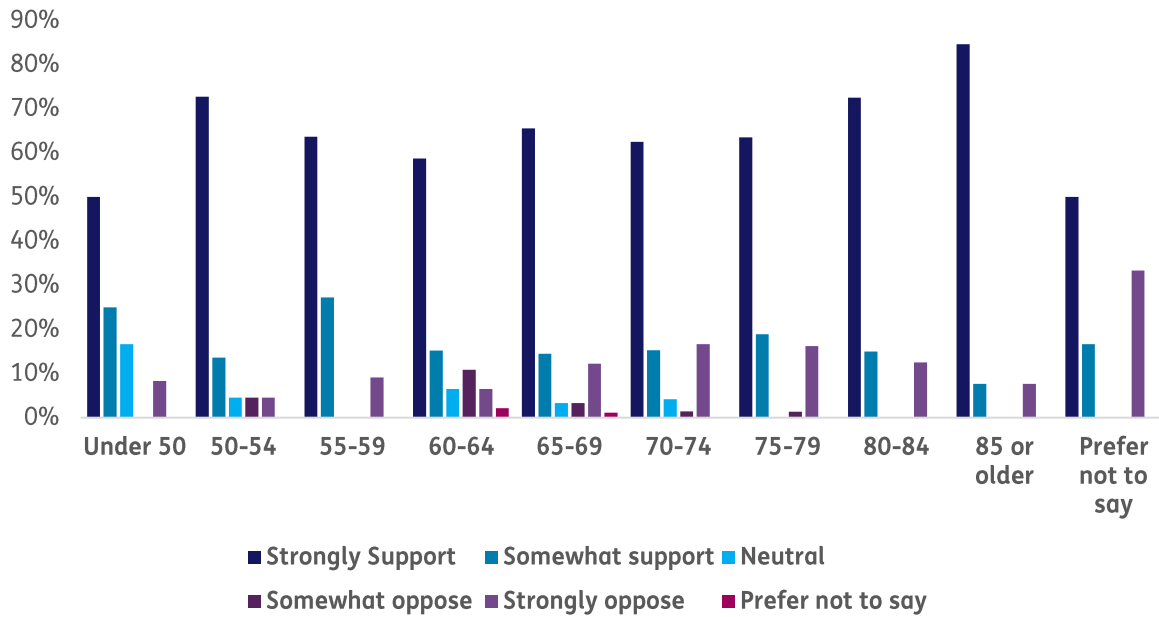


Figure 8 - Age group and views on assisted dying

Gender

Overall, more people identified as female than male (69% compared to 30% respectively) amongst the survey respondents. Similarly to the age of the respondents, views on assisted dying do not seem to differ depending on what gender respondents identified as. For both those individuals identifying as female or male, the most common response was strong support for assisted dying. For respondents identify as female **78%** were in support (62% strongly; 16% somewhat), 4% were neutral, **15%** were opposed (11% strongly; 4% somewhat) and 3% preferred not to say). For those identifying as male, **77%** were in support (63% strongly; 14% somewhat), 2% were neutral, **16%** were opposed (15% strongly; 1% somewhat). One respondent identified as non-binary and was somewhat supportive of assisted dying. See **Figure 9** below

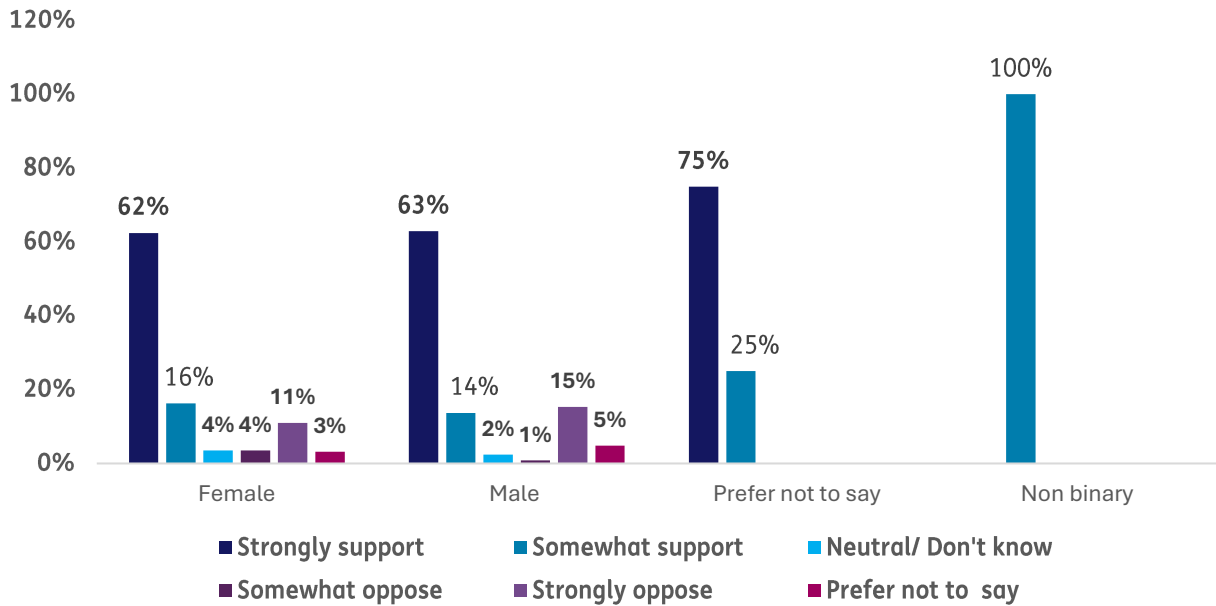


Figure 9 - Gender of respondents and views on assisted dying

Ethnicity

The majority of survey respondents identified as White (94%). This comprised of White Scottish (67%), White Other British (24%) and White other background (3%). The remaining 6% comprised those who preferred not to say (2%) and of ethnic minority groups (4%). See **Figure 10**.

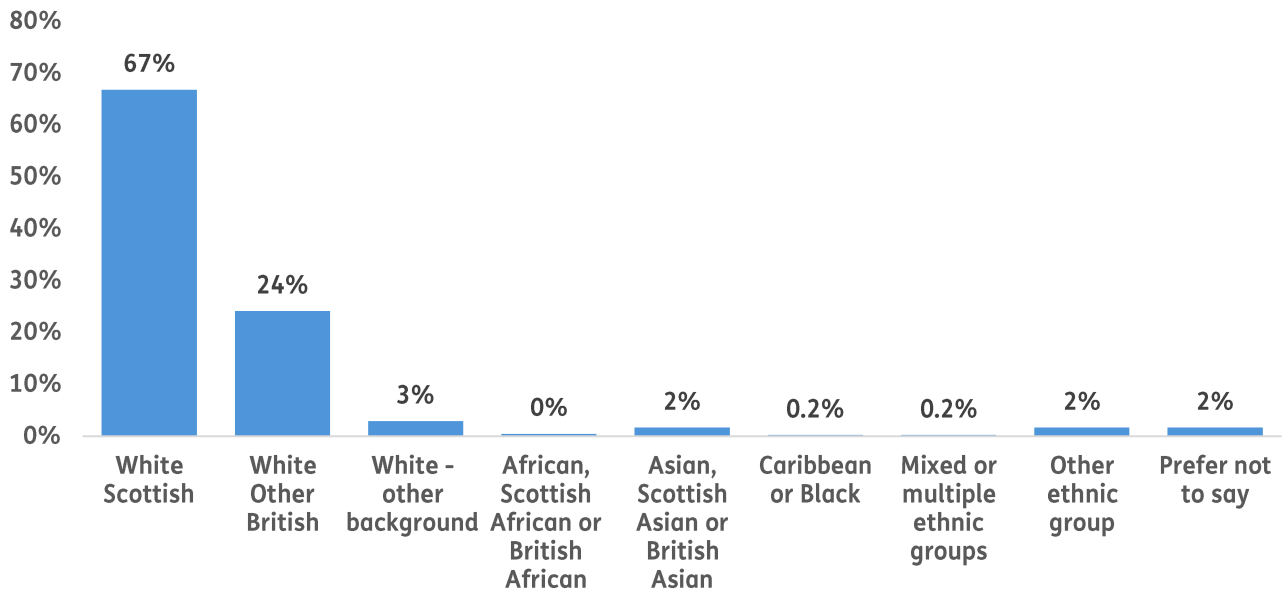


Figure 10 - Ethnicity of respondents

Similarly to the patterns seen with age and gender, ethnicity does not seem to impact views on assisted dying (see **Figure 11**). However, given the much smaller

sample of ethnic minority individuals within the sample (4%), this cannot be concluded with any certainty.

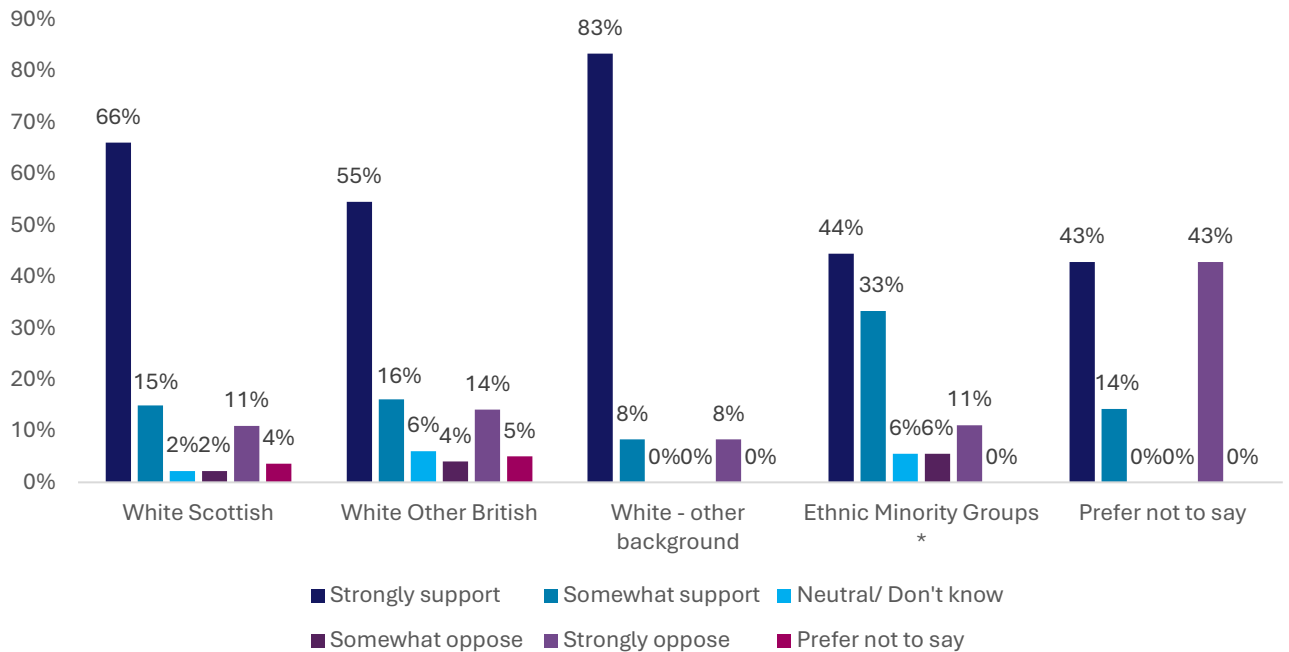


Figure 11 - Views on assisted dying from different ethnic groups

* = African Scottish, African or British African (0.1%); Asian Scottish, Asian or British Asian (2%); Caribbean or Black (0.2%); Mixed or multiple ethnic groups (0.2%); Other ethnic group (2%)

Experience of health conditions

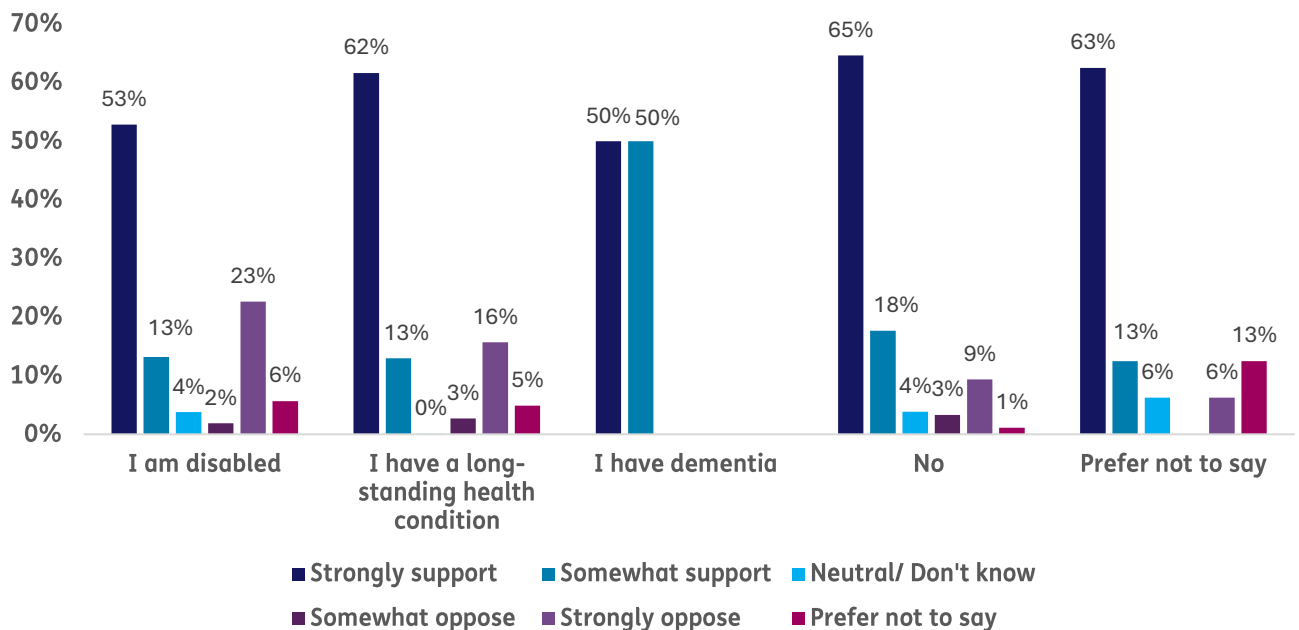


Figure 12 - Health conditions of respondents and views on assisted dying (N = 437)

Finally, respondents were asked to indicate, should they wish, if they have any sort of long-standing health condition, disability or are living with dementia. There was an almost even split between those with a long-standing health condition (42%), and those reporting none of the specified conditions (41%). Again, almost the same level of strong support for assisted dying existed between these two groups. See **Figure 12** above.

Qualitative findings

This section explores some of the qualitative findings of our engagement work around the Assisted Dying Bill, focusing primarily on the open-text responses from the online survey sent to Age Scotland supporters as this provides an overall picture of what a selection of older people think about assisted dying. Findings from our specific engagement sessions will be explored later in our response.

Open text responses to this survey asking for views on assisted dying were collated, grouped into the expressed view of the Bill (support, opposition or neutral), and thematically analysed.

Support for the Assisted Dying Bill – key themes

Three key themes recurred commonly within the open text data from those who either strongly or somewhat supported the Bill. **Figure 13** displays the key themes in a visual form, demonstrating how whilst distinct themes arose from the data, there are common links between these.

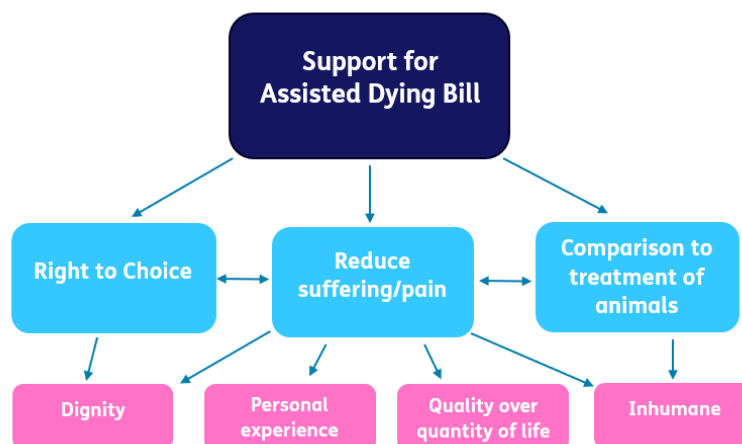


Figure 13 - Support for the Assisted Dying Bill key themes from qualitative survey responses

The most common theme was around the feeling that it was a **fundamental right** to be able to have a **choice** as to when to end your life. As one respondent simply stated, **“my life my choice”**. Several respondents see this as a human right, much like any other decision around our life and health, and it should not be for others to decide if requesting assistance to end our life is the correct choice or not. Within

this theme, there were many views relating this to a right to **maintain dignity** during death. Many felt that dignity is the basis for all our rights, and this includes the right to choose when to end our lives. As one respondent stated:

“I sincerely believe that we are all entitled to a dignified death and as adults we should be allowed to decide when and how”

- Survey Response

The other most common theme arising from the data from those in support of the Bill, was the perception that there should be an option available to **reduce pain and suffering**. Many respondents, often based on **personal experience** of having witnessed loved ones in pain at the end of their lives, felt that the assisted dying bill should be implemented to help reduce this pain in cases where there is no chance of recovery. Several respondents explicitly used the term **“inhumane”** to describe the process of people at the end of their lives being kept alive whilst potentially in severe pain. As one respondent stated:

“I can't imagine anyone living in hellish pain or being in a coma or having a terminal disease, suffering with no chance of recovery and where they are only alive because their heart hasn't stopped beating, that isn't being alive. That's torture.”

- Survey Response

A sub-theme arose around the concept that reducing pain as a reason for supporting assisted dying is about promoting **quality of life** over quantity of time. Some respondents felt that they would rather have the choice to request assistance to end their life if they were in enough pain or distress that they felt they had no quality of life left.

“It is wrong in my opinion to keep people alive if they are suffering and have no quality of life.”

- Survey Response

“The current medical approach of 'preserve life at all costs' takes away someone's choice and quality of life, particularly if their quality of life is already poor and they are suffering.”

- Survey Response

The final theme within responses to the open survey question that demonstrated support for the assisted dying Bill which was mentioned a surprisingly frequent number of times was the comparison to how we **treat animals**. Within explanations, respondents often cited how we treat animals with more dignity and respect when they are suffering and there was a common belief that the same treatment should be available to humans. As one respondent summarised:

“We alleviate animals of their unnecessary suffering, why not humans?!”

- Survey Response

This perception links to the other key themes arising under the responses in support of the Bill. Some respondents believed that it is inhumane to prolong an individual’s life if they are experiencing pain that is unlikely to get better and that if we help end our pet’s lives in this instance, however difficult or upsetting this is, we should offer the same to humans.

Opposition to the Assisted Dying Bill

Whilst overall fewer individuals responding to the survey voiced opposition to the Assisted Dying Bill, those who did offered a series of explanations. Based on a thematic analysis of the open survey responses, three overall key themes were recurring within the data as demonstrated in **Figure 14** below.

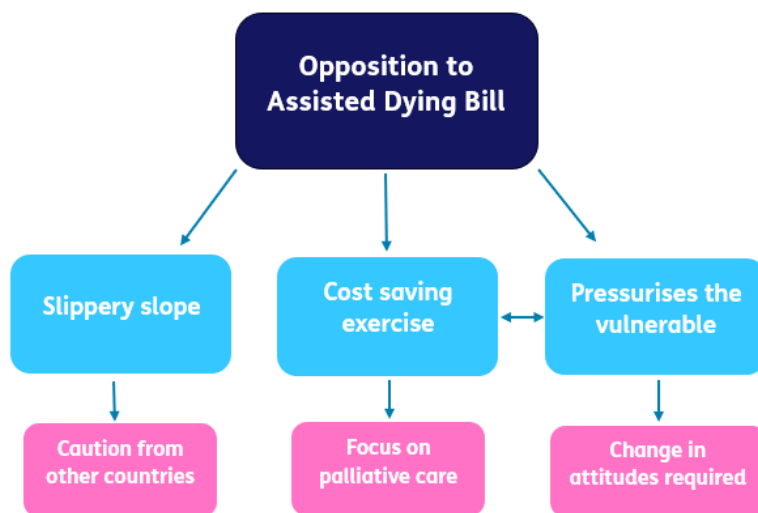


Figure 14 - Opposition to the Assisted Dying Bill key themes from qualitative survey responses

Firstly, commonly expressed as an explanation for opposing the Bill was the notion of this legislation being a **“slippery slope”**, or as the start of a **dangerous road**. The reasoning for this perception amongst many respondents was that passing this Assisted Dying legislation would not be the end of this topic. Many felt that this would just be an initial step and once this legislation passed, it would be easier for secondary legislation and amendments to the Bill potentially being passed.

“It’s too dangerous a route to go down. Where would it end?”

- Survey Response

Within this theme, respondents commonly made direct comparisons to the situation in Canada. Medical Assistance in Dying (MAID), is the legislation in Canada, passed in 2016 which allows eligible adults to request assistance to end

their life. As noted by several respondents, whilst initially, the legislation was only for those with a terminal illness diagnosis, in 2021, changes were made to the eligibility criteria so that the individual does not have to meet the criteria of a “reasonable foreseeability of natural death”.⁴ Furthermore, whilst not yet introduced, there are plans for MAID to be available to those with mental illness from 2027. Respondents who mentioned the situation in Canada appeared to express concern that should the current Bill pass, a similar trajectory to what has happened across the Atlantic would occur in Scotland. Whilst the Bill might have certain eligibility criteria now, there are concerns raised by many that passing future amendments to any Bill passed would enable changes to happen with less scrutiny and objection.

“The introduction of it for terminally ill is the first step then we’ll end up extending the criteria until we are like Canada.”

- Survey Response

“If Canada is anything to go by, unemployed and homeless people may select 'assisted dying' so as not to be a burden to society. That is what happened as the law widened to include people other than those considered 'terminally ill.'”

- Survey Response

Another key theme arising in reasoning for opposing the Bill was the scepticism about this being a **cost-saving exercise** for the NHS and social care services. Whilst this is potentially an extreme explanation, we acknowledge the concerns raised by some respondents that offering the option to end someone’s life potentially prematurely, could be viewed as saving money, with costs of medications and treatments not having to be carried on for as long as perhaps otherwise would be required, or not offered in the first place.

“I believe the NHS might use this to cut costs in their duty of care for the elderly.”

- Survey Response

Within this theme, the concept of where the health and social care budget should be spent was commonly expressed by respondents. In particular, there was a feeling that if there was more investment in **improving palliative and end-of-life care**, then perhaps assisted dying would not be as appealing to some individuals.

“Better provision of palliative care, pain control and more spaces for terminally ill and disabled people to get the adequate nursing and medical care that is badly needed.”

- Survey Response

⁴ Government of Canada. *Canada’s medical assistance in dying (MAID) law*. [Link](#)

This concern around the current provision of palliative and end-of-life care in Scotland will be explored further, later in our response.

The final key theme arising in the open text survey response for those demonstrating opposition to the Bill was the concern around the, potentially subliminal, pressure an Assisted Dying Bill may put on some of the most vulnerable in society, especially older and disabled people. Several respondents specifically felt that the stigma around these vulnerable individuals potentially being seen, in their words, as a “burden” on society would contribute towards these individuals feeling they have a duty to remove this impact supposedly felt by others. As one respondent put it:

“There is too much in our society that allows older people to feel they are a burden on others and, regardless of the good intentions of the proposals, there is a danger that this aspect would play a part in the person's decision to opt for this course of action [...]”.

- Survey Response

It was this change in attitudes towards certain societal groups which was seen as needing to change, instead of offering assisted dying as an option.

“I think that we need a culture change in the attitudes towards those with disabilities and illnesses in this country. The attitude that unless you can contribute economically to the country, that you are disposable, needs to change.”

- Survey Response

Neutrality around the Assisted Dying Bill

For the small number of respondents who stated their view on the Assisted Dying Bill as neutral, the overall sense was that respondents felt **uncertain** about what they thought. Some respondents cited that without having experience in situations where assisted dying may need, or want to be an option, they did not feel they could form a strong opposition or support for the Bill.

“[I] am not in a position to need/want to make this choice for me now but would not wish to prevent others from doing what feels right for them.”

- Survey Response

“[I have] never experienced intense pain or disease so I wouldn't be qualified to show strong support.”

- Survey Response

Another theme within neutral feelings towards the Bill was around the complexity of individual situations and how the uniqueness of each case warranted neither overall support nor opposition to the Assisted Dying Bill.

Key themes of interest

The following section of our response to this detailed call for evidence explores some of the key themes arising within our discussion sessions. These include two policy drop-in meetings with members of About Dementia (people living with dementia and unpaid carers) and discussions with the Scottish Ethnic Minority Older People Forum (SEMOPF) and the LGBTQ+ Scottish Older People's Network.

Dementia

Our experience working with people affected by dementia meant that we felt that this would or could be a prominent issue with regards to the Assisted Dying Bill legislation. Dementia was a common theme arising from the consultation on the proposal for this Bill in 2021, with the consultation summary specifically stating that “*the issue of dementia [...] was raised by a significant number of respondents*” (p. 39).⁵ For example, many of the respondents believed a wider group of people should be eligible, including people living with dementia. As one respondent stated, people living with dementia are a complex group and require further consideration in this area. It is therefore disappointing, given how this was raised in the consultation for the proposed Bill, that dementia is not explicitly mentioned in either the Bill as introduced or the explanatory notes. The only reference is in the policy memorandum, and this is just concerning the 2021 consultation as discussed.

Importantly, as with our response to the Assisted Dying Bill as a whole, About Dementia and Age Scotland is neither calling for people living with dementia to be able to, nor to be excluded, from accessing assistance to end their life should this Bill be introduced. People living with dementia are **not a homogenous group** and we are conscious that individuals will have their unique views on this topic, based on moral, ethical and potentially religious reasons, beyond just their diagnosis. For example, one person living with dementia who we spoke with shared their belief that people living with dementia should be able to access assistance to end their life if they wished to, and that this should be specifically included within the Bill, subject to safeguards being followed. The member reflected on the case of **dementia activist and writer Wendy Mitchell**, who, after 10 years of living with dementia following an early onset diagnosis, died in February 2024 after deciding to stop eating and drinking.⁶ Wendy was in support of people living with dementia having the choice, should they wish, to end their life with assistance. However, we are aware that this is not the view of everyone living with dementia. From our ongoing engagement with About Dementia members in the last 5 years, it has been expressed at times, that following their diagnosis, some have experienced

⁵ Scottish Parliament. *Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill – Liam McArthur MSP. Summary of Consultation Responses.* [Link](#)

⁶ Wendy Mitchell (2024) *My final hug in a mug...* [Link](#)

suicidal thoughts. However, they were glad that the option for assistance to end their life was not available as they learnt that with peer and community support especially, they could live full and fulfilling lives with dementia and may have regretted a choice to end their life, had assistance been available at that early stage. Additionally, the unpaid carers we engaged with had mixed feelings towards the Bill, emphasising that it's a very individual choice and that whilst on paper people might want to make that choice, in practice **“it could be a minefield”**.

Therefore, whilst not taking a stance on whether people living with dementia should be eligible or not, from our concerns and from speaking to our members living with dementia, and some unpaid carers, we ask for more consideration to be made during the scrutiny of this Bill, about some of the ambiguity which might be open a range of interpretations.

Eligibility Criteria

When considering the overall eligibility criteria the Bill outlines for accessing assisted dying, members living with dementia expressed that more clarity is needed. For example, there was the concern that if the person with the terminal illness wanted to decide to receive assistance to end their life, but their carer disagreed with this decision, how this dispute would be resolved.

Members also highlighted that as time progresses, there may be more support available in future for the person as they get older that would improve their quality of life. There was also the recognition that conditions that were previously considered terminal are no longer the case and that allowing people to have access to assistance to end their lives may result in them not being able to see breakthroughs in medicine.

Definition of terminal illness within the Bill

The definition of a terminal illness within the Bill, which a diagnosis of is a key eligibility criterion to access assisted dying, was seen by some people living with dementia as a reasonably clear definition. Based on the definition, whilst no explicit conditions or illnesses are listed in either the Bill or the supporting documents, it could be thought to include dementia as this is a **progressive** condition, which there is no cure for. Additionally, the definition matches closely with the Scottish Government's definition relating to benefit applications. Guidance around this definition specifically states dementia as meeting this criterion for being a terminal illness,⁷ therefore it is possible to argue the same applies to this Bill.

Some members living with dementia felt that this definition was clear as to who would be seen to meet the terminal illness criteria. However, one unpaid carer did note that there is potential ambiguity in the definition as whilst noting there is no

⁷ Social Security Scotland (February 2024). *New guidance on terminal illness to support benefit applications*. [Link](#)

cure, having “advanced” stage dementia was often difficult to describe, or know when someone was at that stage of their journey.

We recognise dementia as a terminal illness; however, we are concerned about the potentially conflicting information contained between the Bill as introduced and the supporting documentation. For example, we found within the depths of the policy memorandum, a sentence stating:

“It is not the intention that people suffering from a progressive disease/illness/condition which is not at an advanced stage but may be expected to cause their death (but which they may live with for many months/years), would be able to access assisted dying” (pg.9) ⁸

Based on our interpretation, this sentence implies that if an individual living with dementia was in the earlier stages of their journey when capacity criteria were still met, they would still not be eligible. Whilst we neither support nor oppose people living with dementia being able to access assisted dying, our concern with this is that there is a lack of clarity. If supporting documents state things which might not be explicitly clear from what is in the official legislation, stating the “intentions” for who might be eligible or not, this could lead to it being open to individual interpretation of who could access assistance to end their life, and be challenging for the clinical/medical professionals once a request is made, or lead to inconsistency of determinations. We ask that if the Bill were to progress, there is more consistency between the Bill and supporting documents and that there is explicit reference to whether certain individuals would either be included or excluded, based on the eligibility criteria, not just what the intention is.

A final comment about the definition of terminal illness within the Bill was from a person living with dementia who noted the exclusion of people who might be experiencing **chronic pain** but with no terminal illness diagnosis. They felt that those who experience severe pain and have their quality of life impacted by this should be able to receive assistance to end their life despite not having a terminal illness, stating:

“I don’t want to spend the rest of my life in pain.”
 - **Person Living with Dementia**

Capacity Criteria

One of the key parts of the Bill which raises potential concerns is around the capacity criteria. From speaking to people living with dementia about this Bill, and from our ongoing work, this criterion is seen as too simplistic. Simply stating that an individual needs to be ‘capable to understand information and advice about the request and make, communicate and understand the decision to request assisted

⁸ Assisted Dying for Terminally Ill Adults (Scotland) Bill (2024). *Policy memorandum*. [Link](#)

dying' as an indication of capacity is not sufficient. Capacity is not a simple black-or-white distinction and can be both subjective and time-dependent. As one member said:

“People can have capacity for some things but not others, they might have capacity to live alone, drive a car but not handle money or not handle their health so capacity is a big wide-open field.”

- **Person Living with Dementia**

Therefore, as the Bill currently stands, it is unclear if someone who has lost the capacity to make certain decisions but not others would be eligible to access assisted dying.

Another potential grey area we foresee in this Bill's capacity criteria is the timing of losing capacity. From an initial reading of the Bill as introduced, on the surface, it appears that as dementia is not currently seen as a 'mental disorder' under the Mental Health (Care and Treatment) Act (2003), and appears to meet the definition of a terminal illness, if someone still meets the other eligibility and capacity criteria, for example, if they are still in the relatively early stages of diagnosis, it could be argued they meet all the criteria to access assisted dying. The key thing here is whether individuals with early stages of dementia, who still maintain capacity and meet all other criteria for assisted dying, including the definition of a terminal illness, can request assistance to end their life before the diagnosis progresses to the stage when they may no longer have the capacity in which to make that decision. As mentioned there is a statement within the policy memorandum document which appears to suggest that this would not be the case.⁹ We do not take a view on if people in the early stages of dementia should be able to access assisted dying. However, we urge that if this not the intention, then this should be explicit within the legislation itself to prevent any potential misunderstanding. Currently, it feels that the decision could be based on the discretion of the medical practitioner(s).

Finally, when discussing the capacity criteria within the Bill, the other key aspect raised by members was around the definition of 'mental disorder'. Members of About Dementia believed that it was unclear if people living with dementia would be included in this Bill as dementia is not considered a 'mental disorder', however, people living with dementia can sometimes be treated under the Mental Health (Care and Treatment) Act 2003. If this Bill were to be passed, this must be explored

⁹ “It is not the intention that people suffering from a progressive disease/illness/condition which is not at an advanced stage but may be expected to cause their death (but which they may live with for many months/years), would be able to access assisted dying” (pg.9)⁹

in more depth to ensure there is clarity and that determining if someone has a ‘mental disorder’, is not down to individual discretion.

Safeguards

Overall, the About Dementia members we spoke with were supportive of the safeguards outlined in the Bill. Regarding the safeguard that two independent medical professionals would assess if terminal illness and capacity criteria are met, they strongly supported that the person’s GP and any consultants who have treated the person should not be involved in the decision-making process. There was also support for the safeguards surrounding the 14-day minimum wait period and the freedom to stop the process after the final declaration.

Palliative and End of Life Care

A key theme raised in several discussions, as well as recurring within the open survey responses (see section [here](#)), was the concept of palliative and end-of-life care.

Whilst this is raised predominantly concerning views opposing a Bill on Assisted Dying being passed in Scotland, we feel that regardless of whether the Bill is passed or not, palliative and end-of-life care services need to be urgently improved. With 95% of all those who die by 2040 potentially requiring palliative care services, ¹⁰ if this is not addressed, more individuals will miss out on the care and support they need to live as well as possible with their diagnosis.

In May 2024, we responded to a consultation on a proposal for a legal right to palliative care to be introduced in Scotland. Our full response can be accessed [here](#). We strongly support the introduction of a legal right to palliative care, to help address the existing inequalities which exist in receiving both palliative and end-of-life care for those living with a terminal illness. We urge that there is work carried out to increase understanding and awareness of what palliative care is, when it is available (e.g., the moment of a terminal illness diagnosis), and who is eligible. We also asked for **minimum service standards** for palliative care to be established, to remove the variation in service quality and availability which currently exists.

All this returns to the current crisis facing health and social care systems in Scotland. For example, a report by Audit Scotland published in July 2024 looking at integration joint board’s (IJBs) performance, noted the “*growing level of unmet and more complex needs [...] deepening challenges in sustaining the workforce, alongside increasing funding pressures*”. ¹¹ Furthermore, with the development of a National Care Service facing significant challenges, delays and criticism from third-sector organisations, ¹² and uncertainty remaining about what this reform could

¹⁰ Marie Curie Scotland (2021). *Future of palliative care need in Scotland*. [Link](#)

¹¹ Audit Scotland (2024). *Integration Joint Boards. Finance and performance 2024*. [Link](#)

¹² Health and Care Scotland (June 2024). ‘*Last ditch attempt*’ to save National Care Service. [Link](#)

look like, the Scottish Government must not pin all promises on this reform and take action to make change where is critically needed now.

Marginalised Voices

Key to our discussions with older people around the Assisted Dying Bill was to consider the views of some of the more seldom-heard voices. Our aim for this neutral response is to raise the voices of older people in Scotland, whatever their view, as this is a group who may be less likely to be able to respond to the consultation themselves. However, there are further groups of individuals we wanted to hear from. This included members of ethnic minority and LGBTQ+ communities through Age Scotland's existing forum and networks.

LGBTQ+

While we cannot assume that the findings from the small number of discussions we had with members of the LGBTQ+ older people network are the views of everyone, with the awareness of potential self-selection bias, where members clearly stated a view, all stated that they supported the Bill for Assisted Dying.

Some questions were raised about specific aspects of the Bill and the potential impact it could have on members of the LGBTQ+ community. For example, one member highlighted the potential correlation between LGBTQ+ individuals and neurodivergence. For example, research has shown that those with autism could be as much as eight times more likely to identify as LGBTQ+ than non-autistic individuals.¹³ The member explored how conditions such as ADHD and autism spectrum disorder are often seen as mental illnesses. As such, there was a question about if these individuals would be eligible to access assistance to end their life. It is clear in the Bill that the definition of a 'mental disorder', which an individual must not have to be eligible for assisted dying, is based on the meaning under section 328 of the Mental Health (Care and Treatment) (Scotland) Act 2003. Under this act, a mental 'disorder' is therefore "any mental illness; personality disorder; or learning disability, however caused or manifested".¹⁴ What seems ambiguous, and could be misunderstood by members of the public, is whether neurodevelopmental conditions such as ADHD and autism are covered by this definition. According to the independent review of Scottish Mental Health Law (2022):¹⁵

"Autism is generally understood to be covered by the definition of mental disorder in the Mental Health Act, although it does not readily fall within any of the three sub-categories of mental illness, learning disability, and personality disorder."

¹³ Weir, E., Allison, C., & Baron-Cohen, S. (2021). *The sexual health, orientation, and activity of autistic adolescents and adults*. [Link](#)

¹⁴ Mental Health (Care and Treatment) (Scotland) Act 2003. *Section 328*. [Link](#)

¹⁵ Scottish Mental Health Law Review (2022). *Final Report*. [Link](#)

However, based on recommendations from this review, the term ‘mental disorder’ is currently under review within the Mental Health and Capacity Reform Programme,¹⁶ with some strong views from individuals and organisations advocating for autism and learning disabilities to specifically not fall under this definition if it remains in law. Therefore, similar to our position on the inclusion or exclusion of people living with dementia within the Assisted Dying Bill, we do not take a position on the inclusion or exclusion of neurodivergent individuals. However, what we do once again ask is for **greater clarity** within the Bill as to who is seen to have a ‘mental disorder’, therefore making them ineligible for assisted dying if the Bill were to pass. This is especially important if the definition or terminology around ‘mental disorder’ is changed during the current mental health law review.

An additional comment made by a member of the LGBTQ+ network, also related to the “not suffering from a mental disorder” eligibility criteria, was around how a history of mental ‘disorder’ might impact this. As the member stated:

“If somebody had a couple of episodes of mental health in their life, does that make them unable to make a choice, or is that choice taken away because they have maybe a short history of mental health issues?”

- **Member of LGBTQ+ Older People Network**

Again, this is another aspect of the Bill that is not clear and if the Bill were to be passed, must be clarified to remove any chance of misinterpretation. This is particularly important to clarify for members of the LGBTQ+ community as it has been widely noted that LGBTQ+ people are more likely to develop mental health issues than the general population,¹⁷ so could be more concerned about what their history of mental health might mean for eligibility for assisted dying should the Bill pass.

The main point raised by the LGBTQ+ members we spoke with concerning specific LGBTQ+ issues and the potential Assisted Dying Bill was around the inclusion of support networks; whatever that might look like. Several members emphasised that if an individual had the opportunity to make that decision to receive assistance to end their life, their ‘chosen family,’ whatever that may look like should be included. Members spoke of the common struggle of members of the LGBTQ+ community of health care professionals placing heteronormative expectations on patients’ support networks, not understanding the concept of a ‘chosen’ family. Members expressed that this needs to be addressed, especially if

¹⁶ Scottish Government (2024). *Mental Health and Capacity Reform Programme. Delivery Plan October 2023-April 2025*. [Link](#)

¹⁷ Mental Health UK Website. *LGBTQIA+ people’s mental health*. [Link](#)

assisted dying were to be legalised, to ensure that those identifying as LGBTQ+ feel cared for, safe and supported through a potentially challenging time.

“To make a space for the chosen family, that a lot of people have, so if they do [go] through with assisted dying, it is done in the way that is sympathetic to [...] the people that they care about and who care about them so that there shouldn’t be a heteronormative expectation.”

- **LGBTQ+ Network Member**

The Bill as introduced makes some indication of the discussions that an individual requesting assisted dying should make in terms of discussions with those close to them. Additionally, the policy memorandum document states that *“If all the required parts of the process have been met successfully, the person decides where and when they wish to die [...]”*.¹⁸ This implies that the individual will be able to decide where they die, and presumably who is there with them. However, given the concerns raised by some LGBTQ+ voices, we urge that should the Bill pass, details of who can be present at this moment should be expressed more clearly to ensure that individuals feel they are in a safe space with those who mean the most to them. Linked to this, one member reiterated a common call of the LGBTQ+ network, about the need for **unconscious bias awareness training** for carers, both those new to the profession and those working for many years.

“It’s an overall subject that encompasses this particular issue of assisted dying. To have training in place to address unconscious bias because people might think oh, I’m not biased when they really have the bias”

- **LGBTQ+ Network Member**

Ethnic Minorities

Individuals from the Scottish Ethnic Minority Older People Forum (SEMOPF) had more mixed views towards the assisted dying Bill. Several members of the forum were conscious to highlight that their views were their **personal, individual views**, and were not reflective of any groups, organisations or religion they may be associated with.

Several respondents felt that this was a very personal, individual matter and that cases should be considered on an individual basis. Those in support of the Bill echoed the feeling that if living was seen as a “burden”, on the individual, community or support networks, then under certain circumstances, to help relieve pain, this should be allowed. One individual noted, they supported the right to have this choice available, but individuals could choose not to take it if, for example, their religious beliefs did not align with this.

¹⁸ Assisted Dying for Terminally Ill Adults (Scotland) Bill. *Policy memorandum*. [Link](#)

For those SEMOPF members who opposed this Bill, this was commonly based on religious beliefs. Furthermore, as one member explained, caring is a key part of their culture, and there is the expectation that people care for those who are ill for as long as needed. For several members who voiced opposition to the Bill, the same point of improving palliative care services was emphasised (see earlier section [here](#)).

As one member stated, the **language** around this topic is potentially challenging for those where English might not be their first language. For example, they explained how there is no easy translation of assisted dying into their native language, and this may lead to potential misunderstanding. We urge this to be considered should the Bill progress further through the scrutiny process.

Another issue raised around language was the term “burden”, which several respondents used to describe how individuals who might want to access assisted dying might feel to those who care for them. We feel this is a very regrettable term and carries many negative connotations, and we feel that if there were more equitable access to high-quality health and social care, including palliative and end-of-life care, then individuals with a terminal illness diagnosis may be less likely to feel this way. Whilst we are not supporting or opposing the assisted dying Bill, we highlight this as an opportunity to address this issue within health and social care in Scotland that individuals, at one of the most potentially vulnerable times, can feel like a “burden” on those who care for them or society in general.

The final area of interest arising from discussions with the SEMOPF, although less explicitly related to the Bill, was around **do not attempt resuscitation (DNAR)** orders. The point raised was how DNAR orders were applied during the recent Covid-19 pandemic, during which there were reports of DNAR orders being applied without discussion, in situations where individuals were not necessarily nearing the end of their lives,¹⁹ or undue pressure was placed to agree to DNAR decision.²⁰ This concerned some members that, should this Bill be passed, similar patterns would emerge in terms of pressure to choose assisted dying, especially during times of crisis. We acknowledge the series of safeguards put in place in the proposed Bill to try and avoid coercion, as perhaps experienced by some individuals during the pandemic. However, we raise this concern of several individuals for policymakers to consider when scrutinising and voting on this Bill.

Conclusions

We have welcomed the opportunity to respond to the Scottish Parliament’s call for views on the Assisted Dying for Terminally Ill Adults (Scotland) Bill currently under

¹⁹ Scottish Covid-19 inquiry: Witness statement. [Link](#)

²⁰ Farrell, A., & Frowde, R., (2022). *Scottish Covid-19 Inquiry. Research Commission: Final Report. Portfolio 3: The Provision of Health and Social Care Services.* [Link](#)

stage 1 of the scrutiny process. The decision to respond from a **neutral position**, neither supporting nor opposing the Bill on assisted dying, was taken on the basis of fairly representing the diversity of views on such an emotive issue, and to ensure that we were able to clearly articulate to MSPs the voices of hundreds of older people who gave their time to express their views.

We hope that this has led to some important insights into the views of older people specifically, which may have previously been missing from national debate, to help those involved in the decision-making process to be as informed as possible when voting on this Bill.

Whilst remaining neutral on the Bill, including which individuals should be eligible or not, we believe that greater clarity is needed on this matter, and further consideration of the nuances of the stated criteria by the committee and parliament is needed.

Throughout our work on the consultation response, and our engagement with older people, several **areas of ambiguity** are apparent which could create confusion or misinterpretation, both from members of the public, policymakers and healthcare professionals. We feel greater clarity is needed in the following areas:

- **Which terminal illnesses could be eligible** – we recommend that should the Bill pass, the definition of terminal illness should include reference to the specific conditions (similar to the one provided by the Scottish Government in relation to benefit applications), to avoid this being determined by the medical practitioner.
- **Inclusion/exclusion of people living with dementia** – we neither support nor oppose people living with dementia being able to access assisted dying, however, we urge for there to be explicit clarification in the Bill either way. Currently, there appear to be contradicting indications between what is stated in the Bill, and what is in the additional supporting documents as to if someone living with a dementia diagnosis, would be eligible.
- **Capacity criteria** – we urge that greater clarification is provided regarding the capacity criteria within the Bill. Should the Bill pass, we ask that there is greater consideration of the subjective and fluctuating nature of capacity and that it is not as simple as is currently suggested within the Bill.

Want to find out more?

As Scotland's national charity supporting people over the age of 50, Age Scotland works to improve older people's lives and promote their rights and interests. We aim to help people love later life, whatever their circumstances. We want Scotland to be the best place in the world to grow older.

Our Policy, Communications and Campaigns team research, analyse and comment on a wide range of public policy issues affecting older people in Scotland. Our work is guided by the views and needs of older people themselves.

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