

Summary of our response to the Scottish Parliament's Health, social Care and Sport Committee - August 2024

We have responded to the Scottish Parliament's Health, Social Care and Sport committee's call for views on the Assisted Dying for Terminally Ill Adults (Scotland) Bill with a **neutral response, neither supporting nor opposing, but articulated the views of the wide range of older people in Scotland we consulted with on this topic**, whatever they were.

The aim of our response was to offer older people the chance to engage, discuss and explore this topic in more detail, share their views and to provide them with as much practical detail about the Bill as possible. We recognise that older people do not necessarily all share the same views and neither do the specific groups of people with other shared characteristics we engaged with. We aimed to identify the **range of views** which older people might have on this topic to help policymakers making decisions on the Bill to have as rounded a view as possible in their deliberations.

Our Engagement Methods

- **Policy briefing** – we created and distributed a policy briefing explaining the details of the Assisted Dying Bill to people who wished to be part of our engagement. One specifically looked at the potential implications of the Bill for people living with dementia.
- **Online Survey** – we sent a short digital survey to older people who subscribe to Age Scotland's email newsletter receiving **411** responses
- **Focus groups** – we hosted a series of sessions which involved talking through the Bill in an accessible and digestible format before having a space for discussion. These sessions were with:
 - Scottish Ethnic Minority Older People Forum (SEMOPF)
 - About Dementia – People living with dementia
 - About Dementia – Unpaid carers
 - LGBTQ+ Scottish Older People's Network

Key Findings – Statistics

From our survey findings, we found that **81%** of respondents **supported** assisted dying. 65% of these were strongly in support with 16% saying they were somewhat supportive. A further **16%** of respondents were **opposed** to assisted dying - 13% strongly opposed it and 3% somewhat did. Finally, 3% of respondents had a neutral view on assisted dying and 1% said they preferred not to say. This is shown in the graph below (**figure 1**).

It is important to highlight that this survey was completed by a modest sample of older adults in Scotland and we aren't concluding that the high level of support for assisted dying identified is necessarily applicable to all older people. With surveys on topics like

assisted dying, which might be quite divisive, there can often be a case of **‘self-selected bias’**. This is when, because answering this survey was optional, those who chose to answer might have been more likely to already have a strong view (either in support or opposition) on the topic. Those who might not have decided if they support or oppose the assisted dying Bill might have been less likely to answer the survey.

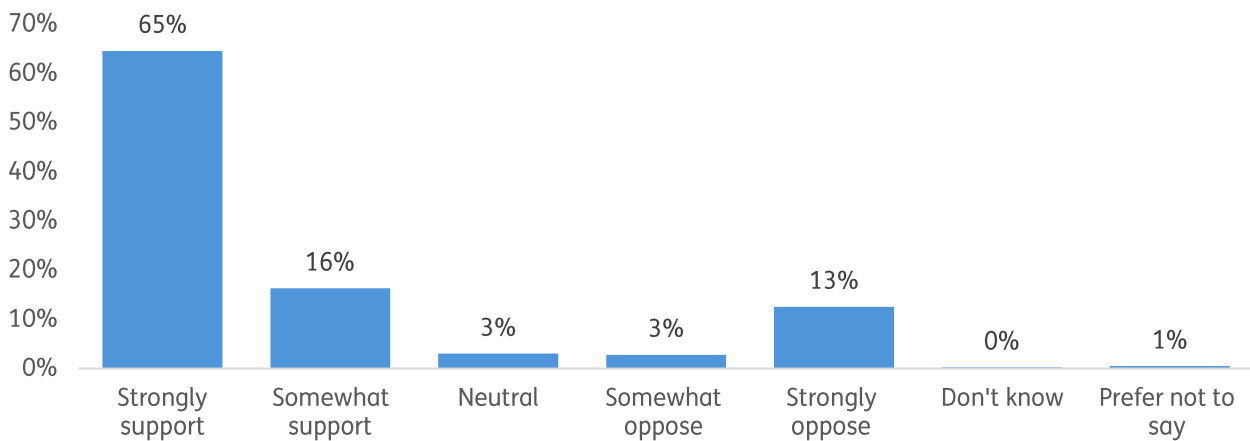


Figure 1 - Views on assisted dying (398 responses)

We were interested to see if views on assisted dying varied across different groups of people, for example, between age groups, genders or ethnicities. We found that regardless of respondent’s age, gender or ethnicity, strong support for assisted dying was always the highest percentage of answers. An example of this is shown in **Figure 2** which shows responses based on age group.

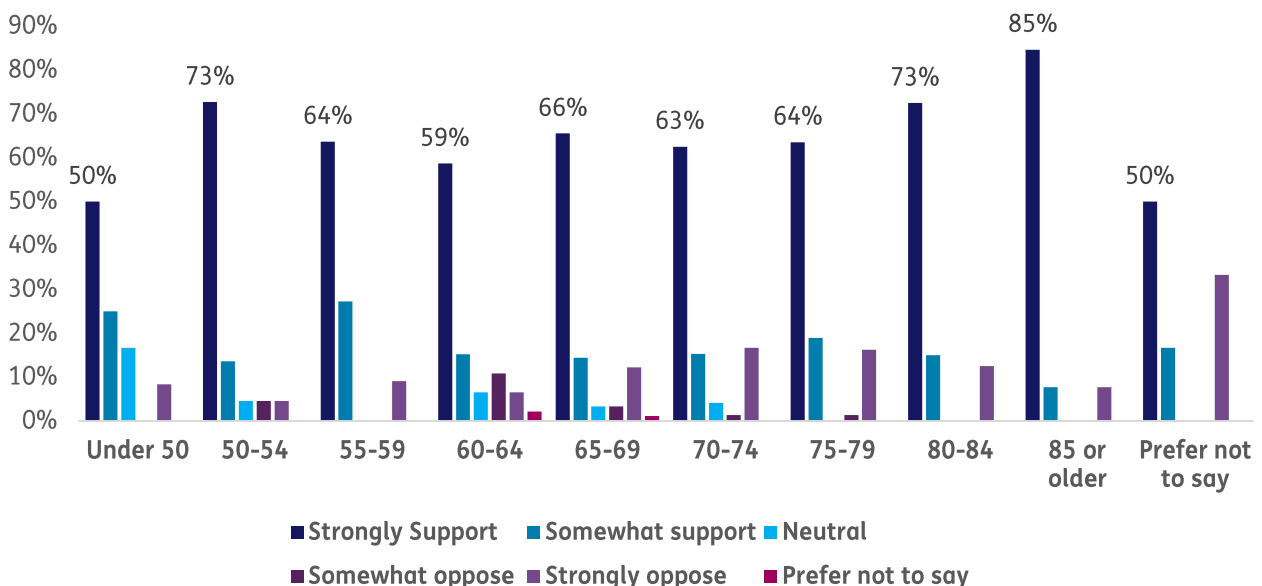


Figure 2 - Age groups and views on assisted dying

As well as the demographic characteristics of those who responded to the survey, we were interested to find out if having experienced either a terminal illness or accessing palliative care might be related to views on assisted dying. Again, similar to age profiles,

experiencing a terminal illness or accessing palliative care did not seem to influence views on assisted dying. For example, for both those living with a terminal illness and those with no experience of a terminal illness, most people who responded to the survey were in strong support of assisted dying. For experience accessing palliative care services, the findings were the same which is shown in the graph below (Figure 3).

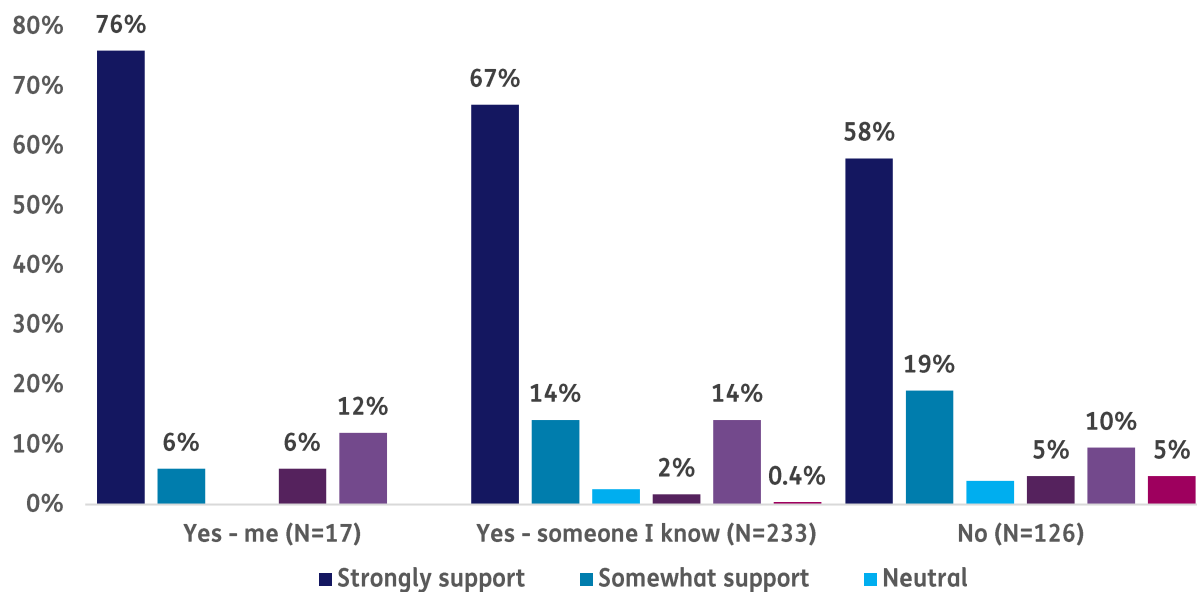


Figure 3 - Experience accessing palliative care and views on assisted dying

Key findings – Reasons for views on assisted dying

The online survey we conducted included the option to explain why you held a particular view on assisted dying. When all responses had been submitted, we were able to identify key ‘themes’ which people used to explain their views.

The three most frequent reasons for supporting assisted dying were:

- Feeling it is a **right** to be able to **choose** to end your life if you wish and that people should be able to have the choice to die with **dignity**
- The view that there should be the option to **reduce suffering** and **pain** if that is what someone wants. Many responses referred to personal experiences where people had seen their loved ones in pain towards the end of their life. Many people also stated how they felt that **quality of life** was more important than quantity
- Several people made the **comparison to how we treat animals**, where we sometimes help to end their lives if they are suffering as it is often seen as the

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

– Survey Respondent

‘kinder’ thing to do. A common reason for supporting assisted dying was that not having the option was ‘inhumane’

The three most frequent explanations for opposing the Assisted Dying Bill from our survey responses were:

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

– Survey Respondent

- The feeling that a Bill like this could be the start of a **‘slippery slope’**. Several people mentioned the journey of assisted dying legislation in Canada which started with strict eligibility criteria, but over several years has made changes to loosen the criteria.
- Some people who opposed assisted dying felt it could be used as a **‘cost-saving exercise’** for health and social care services. Instead of assisted dying, many felt that what Scotland needs is **better palliative** and **end-of-life care**.
- Some respondents felt that having legislation for assisted dying could put **pressure on vulnerable individuals**, those who might feel they are a ‘burden’ to others, to choose this option if it was available. Many who responded in opposition to the Bill felt that a **change in attitudes** in how we view and support the vulnerable people in society is needed instead.

Only a few people who responded to our survey said they had a neutral view of the Bill. Those who said this had a feeling of **uncertainty** about their opinion, as they might not know this until they were in the situation themselves.

Key findings – areas of discussion with older people

As part of our engagement, we spoke with older people from some of Age Scotland’s key networks. Members of these groups represent some of the more **seldom heard voices** in society including those from ethnic minority and LGBTQ+ communities. Again, we are aware that the small number of people we spoke to, do not necessarily represent the views of these important groups as a whole.

Dementia: Similarly to our overall position on assisted dying, we are neither in support nor opposition of people living with dementia being able to access assisted dying. What we are asking, based on our discussions with About Dementia members and our reading of the Bill, is for **greater clarity on the eligibility and capacity criteria** so that, if the Bill passed, it does not rely on medical interpretation if people living with dementia would be able to access assisted dying or not. Some of the points raised during the discussion with About Dementia members included:

- **A clearer definition of terminal illness** is needed to understand if dementia is included. Dementia appears to meet the current definition in the Bill, however, one unpaid carer said how determining when dementia was ‘advanced’ (as is included in the definition), was often open to interpretation.

- **Capacity is not as clear as is suggested in the Bill**
 - people living with dementia and unpaid carers felt that the current criteria for assessing someone’s capacity to make the decision to choose assisted dying is not sufficient. Capacity is not either there or not, it is subjective and time dependent. As the Bill currently stands, it is unclear if someone who has lost capacity in some areas but not others, would be eligible for assisted dying. Therefore, this needs greater clarity.

“People can have capacity for some things but not others [...] capacity is a big wide-open field”

- Person Living with Dementia

LGBTQ+ Community: Discussions with members of the LGBTQ+ community centered around a few key areas. Broadly, the people we spoke with were mostly supportive of the assisted dying Bill. Some of the concerns expressed about the Bill included:

- More **clarity** in the Bill around who is seen to have a ‘mental disorder’, which would make them ineligible for assisted dying if this Bill passed.
 - This was discussed based on the research showing the potential correlation between neurodivergence and identifying as LGBTQ+.¹ There is a general feeling of confusion around if neurodevelopmental conditions, such as ADHD and autism, are included under the definition of a ‘mental disorder’ (based on the Mental Health (Care and Treatment) (Scotland) Act, 2003).
 - Additionally, the term ‘mental disorder’ is currently being reviewed as part of the Scottish Government’s Mental Health and Capacity Reform Programme. If the Bill on assisted dying was to progress, policymakers need to provide more information as to who the definition would impact, especially if any changes are made in years to come.
- More information about how a **history of a ‘mental disorder’** could impact those who are eligible for assisted dying, if the Bill progressed.
 - Members of the LGBTQ+ network we spoke with asked for more clarity, especially as research has shown that LGBTQ+ people are more likely to develop mental health issues than the general population.²
- Members of the LGBTQ+ network we spoke with asked that if the Bill did progress, considerations were made to ensure that support networks, whatever that might look like, including **‘chosen family’** were included.

“If somebody had a couple of episodes of mental health in their life, does that make them unable to make a choice [...]”

- Member of LGBTQ+ Older People Network

¹ Weir, E., Allison, C., & Baron-Cohen, S. (2021). *The sexual health, orientation, and activity of autistic adolescents and adults*. [Link](#)

² Mental Health UK Website. *LGBTQIA+ people’s mental health*. [Link](#)

- People spoke of commonly experiencing health care professionals putting **heteronormative expectations** on patients' support networks, not understanding how this might look different for LGBTQ+ individuals.
- If the Bill did progress, this needs to be addressed so that if people identifying as LGBTQ+ were to receive assistance to end their life, they would be cared for and supported during a potentially challenging time.
- Those we spoke to also asked that **unconscious bias awareness training** for carers is introduced, as this would be important in the context of assisted dying if the Bill passed in the future.

Ethnic Minorities: From the group of individuals we spoke with from the Scottish Ethnic Minority Older People Forum (SEMOPF), views on assisted dying appeared mixed.

- Several people felt that decisions on assistance to end your life are **individual** and **circumstantial**. As one person noted, they supported the right for there to be the choice available, but even if it is there it does not mean it has to be taken, if for example someone's religious beliefs do not agree with it.
- **Language** around assisted dying was seen as a potential challenge for those whose first language is not English. For example, one member of the forum explained how there was no direct translation for 'assisted dying' into their native language, which might create some misunderstanding if the Bill passed. This needs further consideration from policymakers if the Bill does progress.
- Some members of SEMOPF raised concerns that if the Bill passed, similar patterns to what we saw with the use of '**do not attempt resuscitation**' (**DNAR**) orders during the covid pandemic could happen again. During the pandemic, there were stories of DNAR orders being applied without discussions or with pressure experienced to agree to a DNAR. ³ This fear that the same could happen if the Bill on assisted dying passed must be considered by policymakers when scrutinising the Bill. If the Bill did pass, measures to prevent this must be taken, to avoid a repetition similar to what was seen in the pandemic with DNAR orders.

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

Conclusions:

Age Scotland remain **neutral** on **the Assisted Dying Bill** currently in the Scottish Parliament. Based on the insights we have gathered from some older people, we have highlighted to the policymakers who will be scrutinising and making decisions on the Bill, some **key areas** which would need further consideration and clarity if the Bill were to progress.

We feel these areas include:

Which terminal illnesses are eligible – we recommend that the definition of a terminal illness in the Bill should include reference to specific conditions

Inclusion/exclusion of people living with dementia – we do not hold a view on if people living with dementia should be able to access assisted dying or not, but we ask for there to be better **clarification** either way. Contradicting statements between the Bill and the supporting documents about who would be eligible must be addressed.

Capacity Criteria – there must be more consideration about how capacity is not binary and can be subjective and might fluctuate.

History of ‘Mental Disorder’ – there must be greater clarity around the criteria of not having a ‘mental disorder’ and if previous experiences are taken into account or not.

Next Steps

This Bill is currently at **Stage 1** of the scrutiny process in the Scottish Parliament. After the responses to this call for views have been analysed, the Health, Sport and Social Care Committee will write a report. This will explain what they have heard about the Bill and will provide the Committee’s view on the general principles. A Stage 1 debate will then be held in Parliament to decide if the general principles of the Bill are supported or if not, the Bill will be rejected.

Further Information

If you would like any more information on our response, our approach to this piece of work or any of our policy work please contact us at policy@agescotland.org.uk