



Western Australia

Authorised Version No. 005
Voluntary Assisted Dying Act
No. 61 of 2017
Authorised Version incorporating amendments
19 June 2021

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Voluntary Assisted Dying Act 2019

House of Assembly—No 107
As laid on the table and read a first time, 2 December 2020

South Australia

Voluntary Assisted Dying Bill 2020

A BILL FOR
An Act to provide for and regulate access to voluntary assisted dying, to establish the Voluntary Assisted Dying Review Board, to make related amendments to other Acts, and for other purposes.

TASMANIA

VOLUNTARY ASSISTED DYING BILL 2020

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HA GP 704-B: Dr Susan Close MP

THE QUALITY OF DEATH? SENIOR AUSTRALIANS' VIEWS ON VOLUNTARY ASSISTED DYING

August 2021

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National Seniors ABN: 81 101 126 587
ISBN 978-0-6450109-3-0

Suggested citation: Orthia L., Hosking D., Ee N., McCallum J. (2021) *The Quality of Death? Senior Australians' Views on Voluntary Assisted Dying*. Canberra, ACT: National Seniors Australia.

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Executive Summary

- In a 2021 survey of 5430 Australian seniors, over 3500 people answered questions about their attitudes towards Voluntary Assisted Dying (VAD).
- Survey participants were asked whether they agreed or disagreed with making VAD provisions available to people who meet the eligibility criteria currently legislated in Victoria, including having a terminal illness. Of the 3514 who answered this question, the majority, 85.71%, strongly agreed or agreed with this proposition. Almost two-thirds of respondents strongly agreed.
- Survey participants were also asked whether they agreed or disagreed with making VAD provisions available to people with *non-terminal* illness who met the other current eligibility criteria in Victoria. Of the 3512 who answered this question, 67.11% strongly agreed or agreed. The remainder were split almost evenly between people who disagreed or strongly disagreed and people who were undecided.
- Older respondents (70 years and older) were more likely to oppose VAD in both scenarios than seniors in younger age brackets (50-69 years).
- Respondents who had prepared a written advance care plan were more likely to support VAD than those who did not have one. The difference was particularly striking for the non-terminal illness question.
- Survey participants were also offered the opportunity to make a comment about VAD, and 662 respondents did so. The proportions of those who supported or opposed non-terminal VAD were about the same for those who commented and those who did not, but commenters held stronger views in either direction, and were much less likely to be undecided than non-commenters.
- Pro-VAD commenters emphasised the importance of “quality of life” and “dying with dignity”. They frequently supported extending VAD provisions to people suffering with a range of conditions beyond terminal illness and even beyond non-terminal illness. Such conditions included the loss of independence and control associated with neurodegenerative conditions, and emotional suffering associated with feelings of loneliness and meaninglessness. Some wanted VAD to be made accessible to all seniors over a certain age whether ill or not.
- Pro-VAD commenters commonly sought resolution on how to accommodate the VAD wishes of people with diminished decision-making capacity, such as those with advanced dementia. Many of these commenters sought recognition of VAD decisions made prior to a person losing cognitive capacity, such as directives expressed in an advance care plan.
- Other commonly expressed pro-VAD arguments included principles of individual choice and personal decision-making; a comparison to the merciful act of euthanising suffering animals; and the fact that suffering people sometimes end their lives by suicide and VAD could make their deaths less distressing.

- Pro-VAD commenters disagreed on the appropriate roles for governments, health practitioners and family members in making VAD decisions.
- A common anti-VAD argument was that services such as palliative care, aged care and mental health supports should be improved to ensure there are viable alternatives to VAD for suffering people.
- Anti-VAD commenters often based their arguments on religious views, such as the belief that humans do not have the right to end life.
- Commenters who were against VAD for non-terminal illness but undecided about terminal illness, and those undecided on both, were often torn between religious beliefs or fears of a “slippery slope” on VAD ethics, and the desire to alleviate suffering for dying people.
- Many commenters agreed on the need for better solutions to relieve the suffering of people in pain, even though they held different views on whether VAD was an appropriate solution.
- Many commenters, irrespective of being pro-VAD, anti-VAD or undecided, sought clarification and further discussion on a range of issues related to the practical implementation of VAD legislation, including the need for safeguards to prevent a suffering person from being coerced into a VAD decision by family members, care services or society at large.
- A large portion of commenters shared their experiences of witnessing suffering and death in their personal or professional lives to illustrate the reasons for their views on VAD. Many of them, but not all, were pro-VAD.
- Some commenters sought further clarification or information before forming their views on VAD. There is thus a need for clear and accessible communication about the specifics of current VAD legislation.
- Given the different kinds of arguments people used to form their views about VAD, and the different views people expressed on a number of VAD-related questions, there is also a clear need for respectful debate and discussion at the national level about whether and how current VAD provisions should be extended to who are not terminally ill.

Background

The title for this report was provided by a respondent in their text comment:

“Quality of death should be given the same attention as the quality of birth. There seems to be a reluctance to discuss the process of dying in detail. Planning for a dignified end of life should receive the same weighting as any other important milestone in your life.”

Voluntary Assisted Dying, or VAD, is a means by which a person seeks and gains assistance from a health practitioner to end their life. The word “voluntary” indicates that it is the person’s choice to end their own life, not a coerced or forced decision. In the past, other terms such as “voluntary euthanasia” or “physician-assisted suicide” were used in Australia when discussing medically assisted dying, but the term “voluntary assisted dying” is now used most commonly by relevant professions and sectors of the community [1].

The ethics and legalities of allowing people to access VAD provisions have been debated in Australia and internationally for decades. The subject is a sensitive and ethically difficult one, and debates have often been heated. Nonetheless, community support for legalising VAD for terminally ill people has consistently increased since the 1960s. One polling agency reported support within the Australian population has steadily increased from 47% in 1962, to 67% in 1978, 74% in 1996 and 85% in 2017 [2].

There have been many unsuccessful attempts to pass VAD laws in Australian jurisdictions in the past. It is only in recent years that VAD provisions have been legalised in some Australian states. Aside from short-lived legislation introduced in the Northern Territory in 1996 that was subsequently overturned by the Federal Government, the first jurisdiction to legalise VAD was Victoria, with its *Voluntary Assisted Dying Act 2017* coming into effect in 2019. Since then, three other Australian states have legalised VAD: Western Australia (in effect from July 2021), Tasmania (expected to come into effect October 2022) and South Australia (expected to come into effect late 2022).¹ At the time of writing, the Queensland Parliament is also considering its *Voluntary Assisted Dying Bill 2021*, which, if passed, is likely to come into effect in early 2023. Should Queensland pass the bill, New South Wales will be the only state not to have legalised VAD despite state-wide support for it [3]. The Northern Territory and Australian Capital Territory have been prohibited from legislating on VAD by the Federal Government since 1997, despite political will in both territories to do so [4,5].

A small number of other countries have legalised versions of VAD provisions, each with different conditions and regulatory frameworks. In practice, VAD is most commonly made

¹ The relevant laws are the *Voluntary Assisted Dying Act 2019* (WA), the *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) and the *Voluntary Assisted Dying Bill 2020* (SA).

available to people with a terminal illness, but exceptions to this occur in some countries, such as the Netherlands [6]. Some countries including Austria have overturned laws that prohibited assisting a person to end their lives by suicide, but they have not yet introduced regulatory legislation to govern the practice [7]. In the global context, the current Australian laws are relatively conservative, with VAD provisions restricted to terminally ill people who meet strict conditions, and many safeguards incorporated into legislation [8].

Previous National Seniors surveys about VAD

Given this context, National Seniors Australia felt it was timely to include questions about VAD in our annual survey of older Australians. This report is the result of that action.

In past years, National Seniors has been involved in two surveys related to VAD, against which the current report's results make an interesting comparison.

In 2017, National Seniors sought to craft policy positions that reflected, as best as possible, the views, values and beliefs of older Australians, so included a VAD question in the organisation's advocacy survey that year. The survey asked respondents: "Do you support legislating to allow medically assisted dying?" Nationally, 5,619 people responded to it, with 66.5% answering "Yes", 17.2% answering "No", and 16.3% answering "Unsure" [9].

In 2019, the ACT Policy Advisory Group of National Seniors Australia, a member-driven group, conducted an in-depth survey of 93 registered members of National Seniors ACT branches to gauge their attitudes to numerous aspects of VAD [10]. Overall, the survey found strong support for making VAD provisions available to people in three categories:

(a) adults who are in extremis - those having a terminal illness and only a short time left to live;

(b) adults who do not have a terminal illness or a short time to live, but do have an intolerable serious condition; and

(c) adults of an advanced age who do not have a terminal illness or a serious condition, but whose quality of life is intolerable, especially if they are aged over 90 and possibly where they are aged 81 to 90. [10, p. 3]

It was in response to these findings and members' interest in VAD that the National Seniors research team decided to ask not one but two questions about VAD in its 9th annual survey (NSSS-9). The survey was open in early 2021, prior to Tasmania and South Australia passing their VAD laws and prior to the Western Australian VAD law coming into force. While legislation around the country was rapidly moving to allow VAD for people with a terminal illness, it was apparent that many older Australians also supported VAD provisions for people in other situations. We therefore wanted to find out how many survey participants

supported legalising VAD for people with a terminal illness, and also how many participants supported VAD access for people with a non-terminal illness that caused them unacceptable suffering. In addition, to investigate why people held their views and to hear other thoughts they had about VAD, we invited participants to write further comments on this topic.

Survey and analysis methods

National Seniors Australia is a not-for-profit, non-government advocacy organisation for Australians aged 50 years and over. Every year, National Seniors conducts an online survey of members' behaviours and views across a range of topics relevant to older peoples' lifestyle, health and wellbeing and a range of demographic questions. The survey is open to members and non-members aged 50 plus from all states and territories. The survey is made available on the National Seniors website and circulated via a member online newsletter and in the quarterly magazine. The 9th National Seniors Social Survey (NSSS-9), on which this report is based, was approved by the NHMRC accredited Human Research Ethics Committee of Bellberry Limited (APP 2020-12-1319). The survey was open from 15 February 2021 to 1 March 2021. Anonymous and non-identifiable responses were collected online via the survey tool Survey Monkey.

NSSS-9 included one section about Voluntary Assisted Dying. To formulate the section, the National Seniors research team engaged in a focus group discussion with members of the National Seniors ACT Policy Advisory Group who had conducted the 2019 survey of ACT members on this topic, together arriving at the questioning route for NSSS-9. While survey participants were able to skip any of the survey questions, we included an additional foreword for this section because of its sensitivity. Prior to accessing the VAD section, survey participants were forewarned of it with a statement on a separate page: "These next questions ask your views on Voluntary Assisted Dying (VAD). VAD may be a sensitive topic and we appreciate not everyone is willing to think about it or express their views." Participants were then given the option to skip the entire section if they wanted to, without looking at the questions.

Within the VAD section there were two questions and a comment box. The questions were worded as follows:

For the purpose of this survey, voluntary assisted dying (VAD) refers to a person voluntarily ending their life with the assistance of a doctor. People need to meet strict eligibility criteria to access VAD.

Currently, in Australia the eligibility criteria are:

- *Being an adult (18 years or over)*
- *Having an incurable terminal illness that is expected to cause death within 6-months or within 12-months for a neurodegenerative condition.*
- *Experiencing suffering that can not be relieved in a way that is acceptable to the person with the illness.*
- *Having decision-making capacity*

- *The person requests VAD voluntarily, they are not influenced by coercion and they make the request repeatedly.*

In Australia, VAD is legal in Victoria and will be legal in Western Australia from mid-2021. VAD is not legal in other States and Territories.

Please indicate how much you agree or disagree with each of the following statements about VAD.

Q1. VAD should be legally accessible to adult Australians who meet the eligibility criteria listed above.

[Options: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree]

Q2. VAD also should be legally accessible to adult Australians with decision making capacity who have a non-terminal illness causing them unacceptable suffering, provided they meet all other eligibility criteria listed above.

[Options: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree]

This was immediately followed by a sentence detailing Lifeline support services for any survey participants who may have been distressed by the questions. Following that, we placed a free comment box with the statement *“Please use the box below to tell us more about your views on VAD if you would like to.”*

Of the 5430 people who commenced the survey, 960 had already discontinued their participation prior to the VAD section. An additional 1001 selected the option to skip the VAD questions, though around 50 of them went back and answered VAD questions anyway. This meant 3519 people answered one or both VAD questions and/or made a comment in the VAD comment box. There were some statistically significant differences between those who chose the option to skip the VAD section and those who elected to view the VAD questions, in terms of demographic traits. Those who elected not to skip the VAD section were proportionately more likely to be women, partnered and younger than those who selected the “skip” option, and on average had more formal education, more money in savings or investments, and a greater likelihood of having written an advance care plan. Graphs and statistics showing the demographic makeup of the sample who answered VAD questions can be found in the Appendix.

All statistical calculations were performed in Stata (version 15.1). A pre-defined data cleaning protocol was used to remove duplicate responses prior to analysis. All reported statistics beyond descriptive statistics are from chi-squared analyses for which p-values <0.05 were considered statistically significant. For the purposes of chi-squared tests,

“strongly agree” and “agree” responses were combined into an “agree” measure, and “strongly disagree” and “disagree” responses were combined into a “disagree” measure.

Part of this report is based on text comments that respondents submitted to the optional comment box. We analysed text comments using the thematic analysis framework described by Braun and Clarke [11]. One National Seniors Research Officer analysed all the comments and produced an initial thematic map. A second analysed half the comments independently, producing their own thematic map. To ensure our themes were comprehensive and consistent, we discussed any discrepancies and agreed on a consensus thematic approach. Themes were identified through inductive analysis, i.e. data were coded without reference to an explicit pre-existing theoretical framework, aside from associating some themes with pro-VAD and anti-VAD stances. The analysis was guided by a critical realist approach which aimed to summarise and reflect participants' views as accurately and objectively as possible, without reading other layers of meaning into them. Emphasis was placed both on highlighting common ideas expressed by tens or hundreds of participants and on describing the diversity of ideas present, some of which were expressed by fewer people. The researchers acknowledge the influence of their pre-existing theoretical knowledge and understandings on the themes identified from the data.

Quotes from survey participants were selected to illustrate the variety of ideas expressed by the cohort and commonly articulated ideas. Sometimes this entailed reproducing only part of a person's comment if the rest was not relevant to the theme. We endeavoured to reproduce each selected quote verbatim whenever possible. In a small number of cases we omitted or altered part of a quote for clarity and indicated this with square brackets []. In additional cases, minor typos and obvious spelling errors were corrected for readability. Quotes were only corrected in this way if there was no ambiguity about the participant's intended meaning in the part of the quote that was corrected. All other phrasing idiosyncrasies were retained in the quotes.

Quantitative trends in survey participants' views on VAD

The two VAD questions revealed strong support for making VAD provisions available to people who are ill and suffering.

Of those who answered the question about terminally ill people, 85.71% strongly agreed or agreed with making VAD available, while only 8.17% disagreed or strongly disagreed. Almost two-thirds of the sample agreed strongly with the proposition (Figure 1).

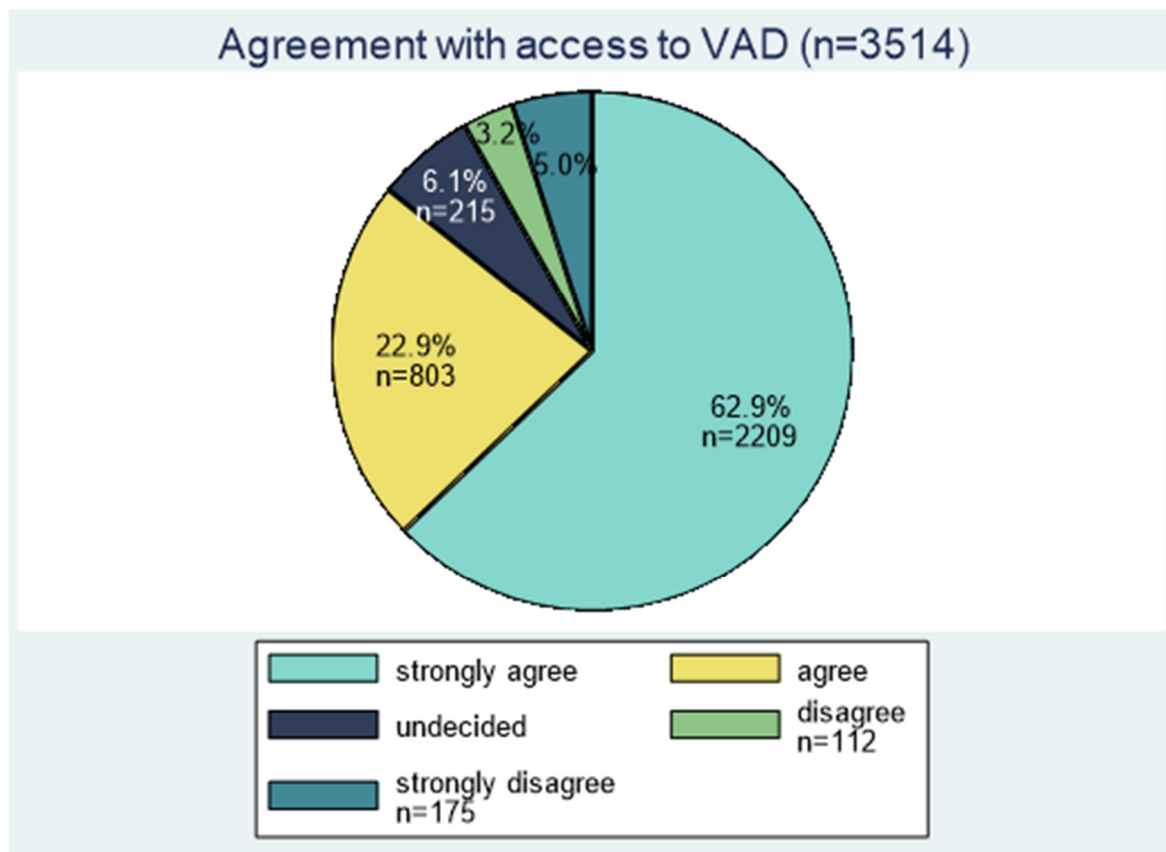


Figure 1 Distribution of responses to VAD Q1, pertaining to making VAD available to people with a terminal illness.

Of those who answered the question about people whose condition or illness was not terminal, 67.11% strongly agreed or agreed with making VAD available, while 14.86% disagreed or strongly disagreed. There were almost three times as many people who were undecided for this question than for the terminal illness question (Figure 2).

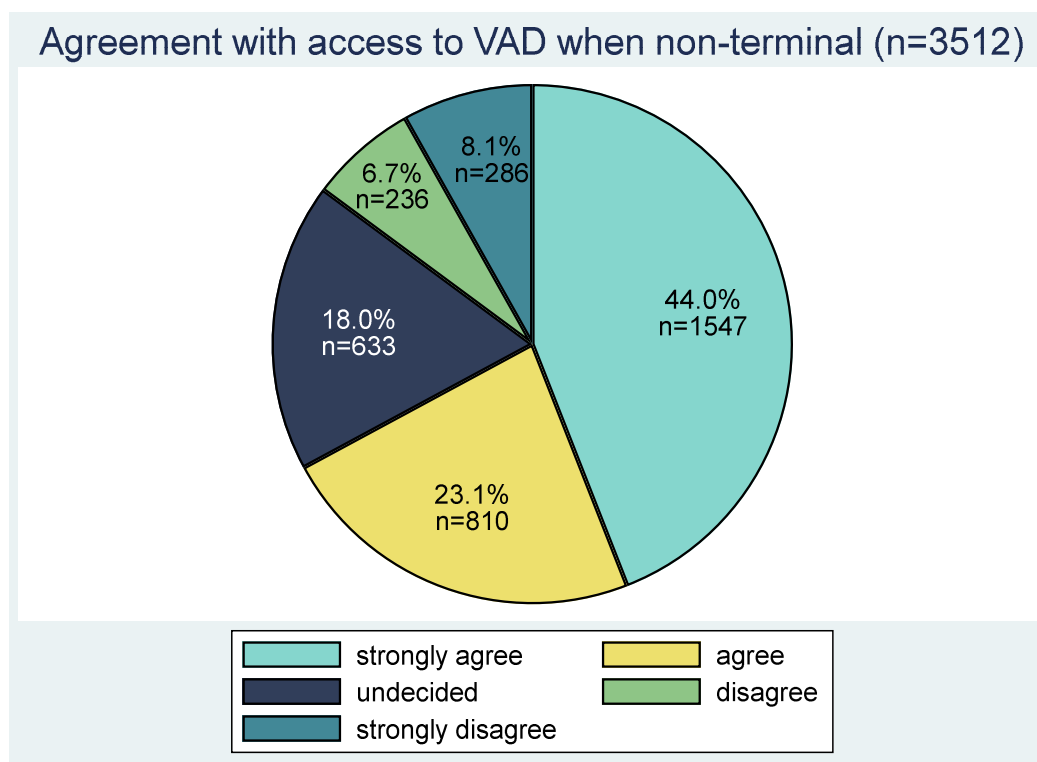


Figure 2 Distribution of responses to VAD Q2, pertaining to making VAD available to people with a non-terminal illness.

We analysed the agree versus disagree responses to both questions in terms of a range of the demographic questions we had asked survey participants, to see if any demographic traits were significantly associated with support for VAD or with opposition to VAD. Most demographic traits we tested were not significantly associated with responses to the VAD questions, including gender, formal education level, partnered status, health status, disability status, and state or territory of residence. The only demographic traits for which there were statistically significant differences in attitude to VAD were age group and whether a survey participant had a written advance care plan.

A greater proportion of younger seniors than older seniors supported VAD provisions in both terminal and non-terminal illness situations. People aged 60 to 69 expressed higher support for VAD than other age groups (50-59, 70-79, 80+), and older age groups expressed greater opposition to VAD (Figure 3).

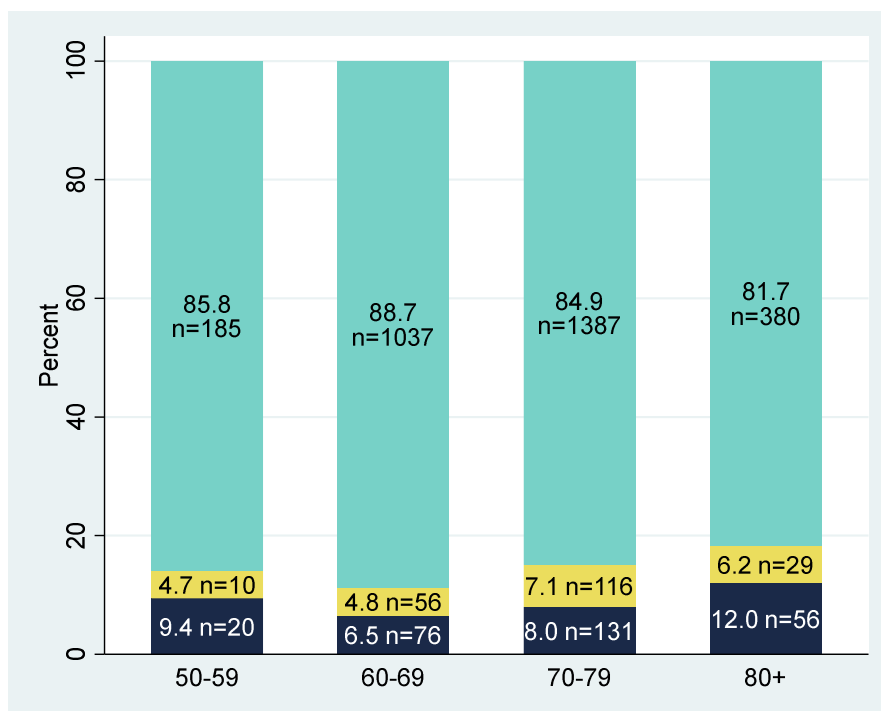
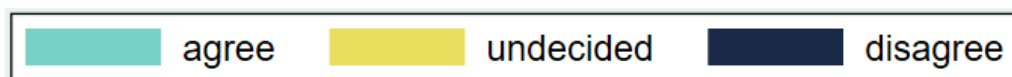


Figure 3 Distribution of responses to VAD questions by age group. In both, strongly agree and agree responses are combined into the “agree” measure, while strongly disagree and disagree responses are combined into the “disagree” measure. The top graph shows responses to VAD Q1, pertaining to making VAD available to people with a terminal illness, and the bottom graph shows responses to VAD Q2, pertaining to non-terminal illness. In both cases the 60-69 years age group had proportionately more people agreeing with making VAD available while the two oldest age groups showed the highest proportions of disagreement with VAD.

Proportionately more people with written advance care plans supported VAD than those without a written advance care plan. This pattern was especially marked for the non-terminal illness question (Figure 4).

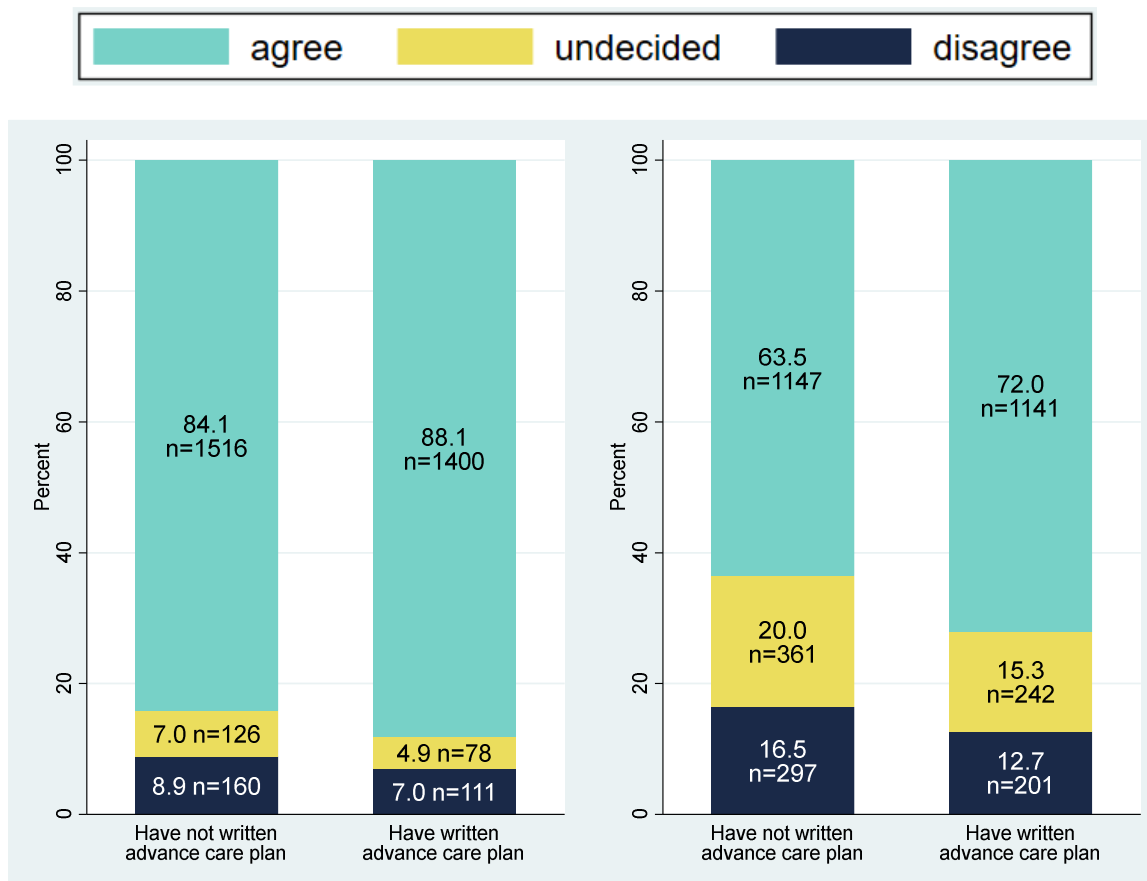


Figure 4 Distribution of responses to VAD questions by whether or not the survey participant had a written advance care plan. In both, strongly agree and agree responses are combined into the “agree” measure, while strongly disagree and disagree responses are combined into the “disagree” measure. The graph on the left shows responses to VAD Q1, pertaining to making VAD available to people with a terminal illness, and the graph on the right shows responses to VAD Q2, pertaining to non-terminal illness. In both cases the proportion in support of VAD was greater among those who had a written advance care plan than among those who didn’t.

Survey participants' comments on VAD

Overview

Of the 3519 people who did not skip the VAD section of the NSSS-9 survey, 662 (18.81%) wrote a comment in the optional comment box.

The subset of participants who made comments was broadly representative of the set who answered the non-terminal VAD question, in terms of the balance of pro- and anti- views (Figure 5).

However, commenters tended to possess more strongly held views on VAD for people who have a non-terminal illness, and they were significantly less likely to be undecided, than non-commenters (Figure 6). This is unsurprising, given it seems inherently more likely that people with strongly held views will want to articulate them in a comment.

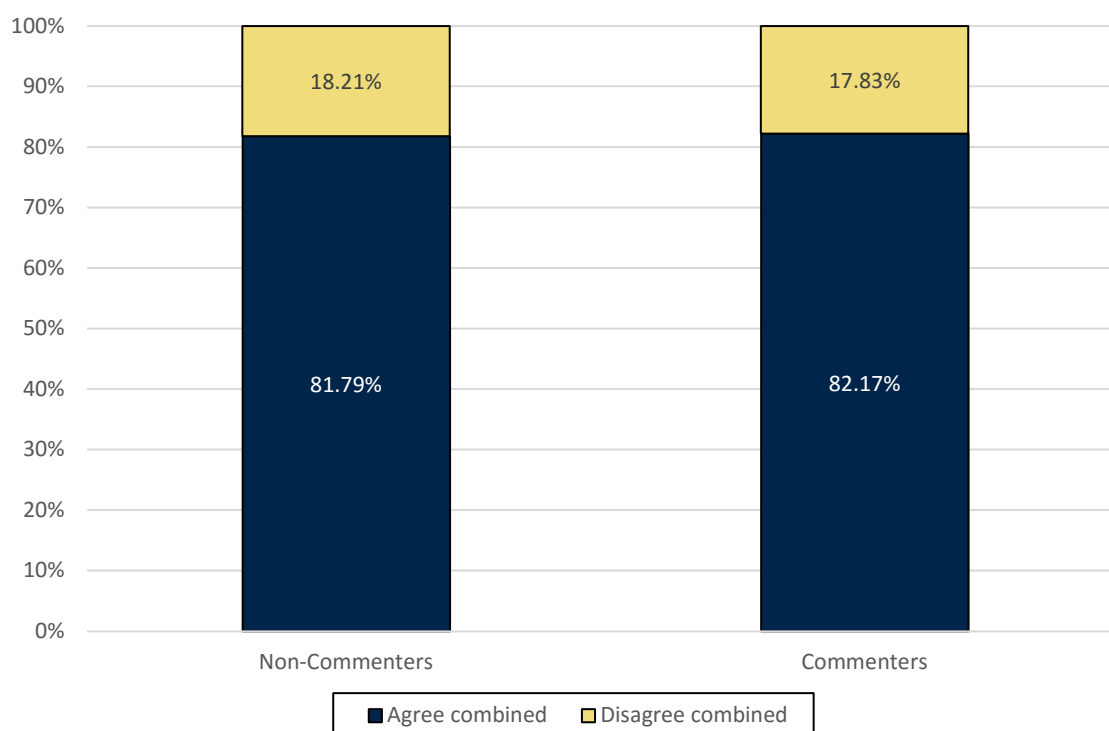


Figure 5 Comparison of proportions of pro- and anti- sentiments on the non-terminal VAD question, for the subset who wrote comments versus those who did not write comments. "Combined" measures include strongly agree plus agree responses or strongly disagree plus disagree responses. Undecided responses were removed prior to making the calculations to ensure the comparison was only between combined agree and combined disagree measures.

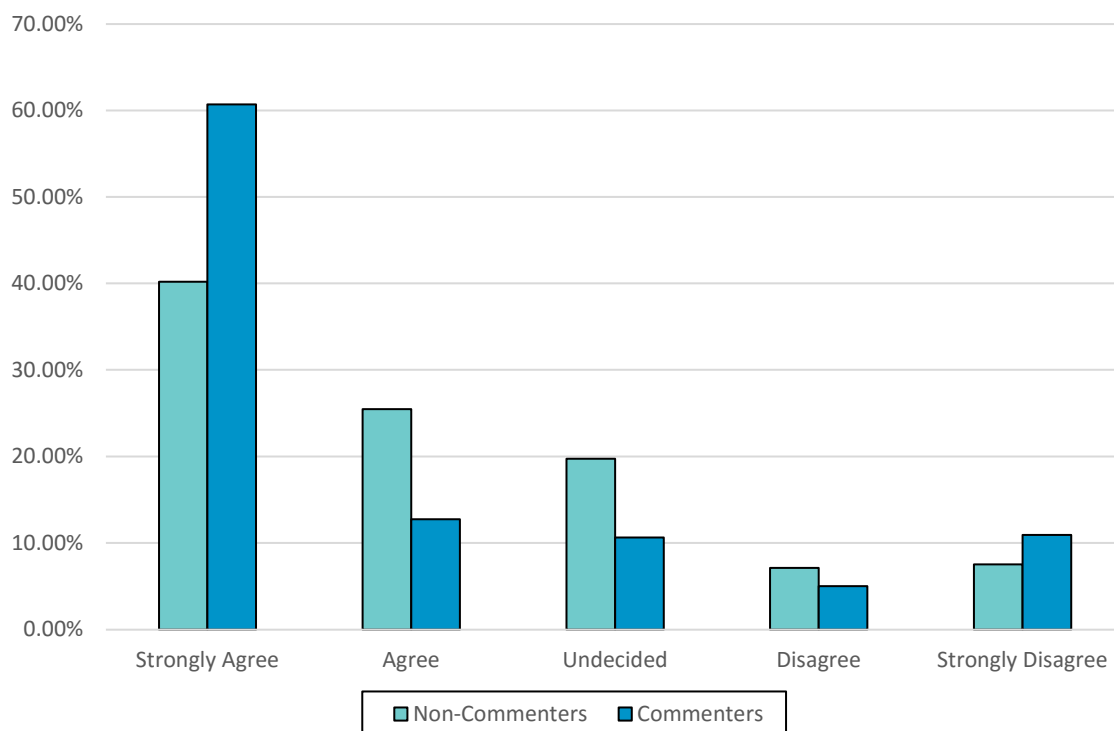


Figure 6 Comparison of the distribution of responses to the non-terminal VAD question for the subsample who wrote comments versus those who did not write comments. Commenters overall had more strongly held views and less indecision than non-commenters.

In addition, a significantly higher proportion of commenters disagreed with terminal VAD compared to non-commenters. It may be the case that opponents of any VAD were more motivated to express their views than supporters, in an era in which VAD provisions for people with terminal illness are being legalised in many Australian states.

Seventy-seven commenters (11.63%) opposed VAD being available to people with either terminal or non-terminal illnesses, while 477 commenters (72.05%) supported availability in both circumstances. Only 18 commenters (2.72%) who supported VAD provisions for terminal illnesses did not also support VAD provisions for non-terminal illnesses.² However, 57 commenters (8.61%) were undecided about one of the VAD questions while indicating a firmer view on the other.³ Twenty-four (3.63%) were undecided about both.⁴

This distribution of views should be borne in mind when reading the following analysis. Aside from specific questions people raised about who should be able to access VAD and in

² Unusually, four commenters selected responses indicating they supported VAD provisions for people with non-terminal illnesses but opposed VAD provisions for people with terminal illnesses. However, based on their comments, it is likely these commenters made a mistake in selecting their answer to one of the VAD questions.

³ The balance of pro/anti views represented in these response pairs was about proportionate to the whole.

⁴ Five commenters did not answer one or both VAD questions.

what circumstances, the majority of comments will potentially be applicable to both terminal and non-terminal VAD scenarios. Indeed, as we will discuss in the analysis, some commenters specifically expressed the viewpoint that a person should not have to be ill at all to access VAD. Many of the commenters expressed aspirations for VAD to become available well beyond current scenarios being considered by Australian governments. Their views suggest there is substantial interest within the community of older Australians to broaden the terms of debate in the public conversation about VAD.

When analysing the comments, we identified two ways of grouping them, and present both here. The first is the most straightforward: we group comments in terms of pro-, anti- or undecided stances, and identify major trends within each cohort. This gives an at-a-glance view of what people on each side are saying and the more prominent factors influencing them.

The second approach to grouping the comments cuts across these stances, instead showing people articulate their views using quite different kinds of argument. We characterise four such arguments in the following discussion. The four argument types we identified are:

- “caring” arguments: appropriate strategies for alleviating suffering,
- “normative” arguments: aligning VAD decision-making with value systems and philosophical principles,
- “logical” arguments: appeals to consistency, comparing VAD to other social practices to inform decisions about it, and
- “regulatory” arguments: questions about the practical implementation of VAD provisions with respect to governance and technical issues.

Both pro- and anti- stances are represented in all four, demonstrating that people may be talking at cross purposes during VAD debates if they are defending their views using different types of argument. The four argument types also show there may be more common ground than we think between some pro- and anti- camps.

Major trends in comments characterising pro-VAD, anti-VAD and undecided stances

Pro-VAD

Most of the major pro-VAD, anti-VAD or undecided perspectives we list here fit into one of the four argument types we discuss in the following pages, so quotes illustrating these perspectives can be found in those sections. However, two commonly expressed pro-VAD viewpoints that cut across argument types were the importance of “quality of life” or living and dying with “dignity” as the deciding factor for their VAD views:

“VAD should be available to all people of sound mind who want it. Why should people have to suffer with an unacceptable quality of life.”

“Should there be NO quality of life, and NO definite medical solution, I strongly believe to medically assist in a humanly and peaceful manner the end of a person’s life.”

“I think in circumstances where the person is suffering severe pain and no hope of survival they should be able to make their own decision and die with dignity. Gives the person time to have everything in order beforehand.”

“We should all have the right to die with dignity, surrounded by love.”

Pro-VAD commenters expressed these perspectives whether in relation to physical pain, mental and emotional suffering, dependency on others, the feeling that one has simply had enough of life and resources could be better used elsewhere, or something else. This idea that VAD should be extended to a range of situations beyond terminal illness and even beyond non-terminal illness was relatively widespread in the sample.

Approximately one in six commenters shared their personal experiences of witnessing suffering and death, and most of these people were pro-VAD, linking those experiences to their views. Alleviation of suffering was the most frequently mentioned reason for supporting VAD. The principles of individual choice and personal decision-making over one’s own body, life and death were also frequently invoked by supporters, with many commenters asserting that these are human rights. Such commenters often made the point that allowing some people to access VAD does not impact on those who do not want it, and that no one (governments, religious bodies, or anyone else) should be allowed to override what individuals want.

Some pro-VAD commenters appealed to consistency with how we treat suffering animals or noted that suffering people sometimes end their lives suicide and VAD would allow that to be less messy, more dignified, and less painful for all concerned. A few commenters noted that making VAD available in Australia was long overdue, with campaigns for it stretching

back decades and effective systems in place in other countries such as Switzerland. A few also mentioned they were members of pro-VAD organisations such as Dying with Dignity or Exit International.

Pro-VAD commenters identified several technical and governance issues that felt needed to be addressed if VAD provisions were to be legalised. The two issues mentioned most frequently were the need for safeguards to prevent coerced VAD decisions, and the need for VAD provisions to be extended to include conditions such as dementia with accompanying measures enabling people to state their VAD wishes before losing cognitive capacity. Pro-VAD commenters disagreed on how much legal oversight governments should have over VAD and the extent to which a health practitioner's consent should be required for people to access VAD provisions.

Anti-VAD

A large proportion of anti-VAD commenters stated that their views were determined by their religious beliefs, with all those who mentioned a specific religion specifying Christianity. Many such people believe only God can decide when a person dies, so VAD is the equivalent of suicide or murder. VAD opponents also frequently argued that services to the living – including palliative care, mental health support and aged care services – needed to be improved so that they are genuine, attractive alternatives to VAD. Opponents expressed the view that there are often solutions for the problems causing people to want to die, including new treatments and social supports. Some commenters drew on negative impressions of existing systems in other countries such as the Netherlands as reasons for greater caution in Australia. Opponents, like supporters, were also frequently concerned about the potential for families, care services and governments to coerce VAD decisions.

Undecided

More than half the commenters undecided about VAD for non-terminal illness supported VAD being available to people with terminal illness, so a key issue for many of them was the nature of the suffering the person experienced and their treatment histories and options. Those against VAD for non-terminal illness but undecided re terminal illness, and those undecided on both, were often torn between religious beliefs or fears of a “slippery slope” on VAD ethics, and the desire to alleviate suffering for dying people. Some undecided on both simply wanted more information before making a decision, or clearer definitions of key terms of debate. Questions of coercion and lack of trust in governments to do the right thing were also present. One commenter undecided about VAD for non-terminal cases was concerned that moves in that direction would jeopardise VAD provisions for terminal illness.

“Caring” arguments: Appropriate strategies for alleviating suffering

For many commenters the key question in the VAD debate seemed to be whether VAD is an appropriate solution to human suffering or not. Just over 300 comments, or just under half of all comments, contained remarks we considered relevant to this theme. The proportion of people supporting VAD provisions in non-terminal cases was slightly higher for this theme than for the whole sample.

Most commonly, commenters asserted that VAD provisions should be an option for alleviating unbearable suffering. They recognised that many people (including, often, themselves) do not want to continue living if they are experiencing serious physical pain, especially if it is prolonged:

“I think it’s great. I would not like to suffer unnecessarily and I would not like others to suffer unnecessarily. I am all for it.”

“It’s totally inhumane to deny relief to those with confirmed proof of impending mortality and suffering gross pain or degradation of life.”

“Loathe how people think suffering of others is somehow socially beneficial”

“No one should be forced to suffer just to satisfy doctors or family.”

“Personally I think good health is essential to ability to enjoy life. If a person is in continual pain & suffering that cannot be called a good life.”

Numerous commenters extended the concept of suffering to psychological, emotional, and even existential realms. Thirty-three people stated that they or others may not want to go on living if they were experiencing the lack of dignity and lack of control that comes with degenerative illnesses and conditions such as Alzheimer’s disease, motor neurone disease, multiple sclerosis, Parkinson’s disease and various forms of dementia:

“I don’t believe seeking to end your life when palliative care is available on moral grounds, however I understand the slow death of a person with Motor neuron disease may be a justifiable exception.”

“I feel that living your last days in extreme pain or in a vegetive state, or with severe dementia and not knowing your children, family and friends is so unfair and causes unnecessary stress on family.”

“Dementia is completely ignored by the criteria as, once diagnosed, the person is not considered to have decision making capacity, which is not necessarily true. A person with dementia is unlikely to die from the disease within 12 months but they and their families will suffer years of mental anguish. It is beyond cruel to oblige a person to live through the ravages of this disease until the inevitable end.”

“Some chronic diseases, such as Parkinson's Disease are not terminal but may cause terrible pain and suffering and should be considered as applicable in some circumstances. Many sufferers of chronic pain take their own lives in desperation.”

“If I get to the point in my life where someone else has to feed and bathe me and see to my personal bodily functions then I want to have the right to choose VAD to preserve my dignity.”

“When the time comes that the loss of dignity and independence and the reliance on others to perform basic tasks becomes too much, an adult should be able to decide when enough is enough.”

On top of this, 36 people said they would like VAD as an option for people subject to unrelieved feelings of pointlessness, meaninglessness, loneliness or feeling they are a burden to others:

“I feel strongly that people should have the right to decide whether they want to end their lives if they feel that their lives are no longer meaningful to them.”

“My husband and I have been lifelong partners and were not able to have children. Our lives totally revolve around each other. Life in old age will become difficult, lonely and without purpose without family (children) to support and look out for the surviving partner consequently VAD is something I would consider in my old age if I survive my partner.”

“Sometimes the pain, depression, feeling useless and not able to do things anymore is more than a person should bear. Should have the right and ability to end one's misery. This decision can only be made when you have tried all the possible answers been given to you. When it's time it's time. No one should have to suffer when their life becomes unbearable.”

“VAD also should be legally accessible to adult Australians with decision making capacity who MAY NOT have a terminal or non-terminal illness. Unacceptable psychological mild suffering (measured over a reasonable period of time), or feeling that there is no sense of meaning or purpose (other than waiting for the slippery slope to deliver a terminal illness) should be enough to 'die with dignity' Having no sense of purpose, achievement or meaning - DOES NOT NECESSARILY mean Depression - just that one has had enough & feels that their time should be allowed to end with dignity rather than suicide.”

“I very strongly agree that VAD should be legally available in Australia for everyone who would like to make use of this service. If I ever felt I was going to become a burden on my Family and Friends and was eligible, I would not hesitate in a heartbeat to make the decision to end my life with dignity.”

“There are far too many people being cared for in nursing homes who have no purpose in life left and their wishes should be granted to end their life as they feel they are a burden to society.”

"It should be available to anyone over 80, who have lost all their family/ friends and no longer see any point in living."

Several people wrote about VAD being a better option than the alternatives if they should become ill or infirm, including poor quality residential aged care and palliative care, and treatments with serious side effects or inadequate pain relief:

"For those who have experienced severe long term pain that the medical profession thinks is being relieved by narcotics and/or other so called pain relief know VAD is the only answer."

"I just want to exit this mortal world at a time of my choosing. I detest palliative care and want to avoid it."

"I will NEVER EVER go into a nursing home. So dehumanising. Suicide if necessary"

"It is my wish that I never have to go into a nursing home. When I am no longer able to look after myself I wish to die as I feel that I will no longer be any use to society or myself."

"My views are influenced by me identifying as a transgendered woman who does not really see herself as being part of the glbti community. I fear being in an aged care home, and would rather end my life at the point of entry."

"If pain /symptoms are unable to be managed or side effects are intolerable then the choice should be available for VAD."

A few commenters noted people vary in their ability to tolerate any or all of the above situations, making VAD a positive choice over anticipated suffering for them:

"I do not believe that the current medical models in place are completely supportive of the rights of individuals for a dignified death. There appears to be this idea that people should be kept alive despite their immeasurable suffering and angst. An individual's response or lack of it to pain relief is also very unique and complex. There is also no 'one size fits all' approach to the administration of pain medication."

"Should be up to the individual without being on a whim. If meds aren't assisting or if an individual cannot cope with a physical problem. Not all people can cope with life after constant health problems over a long period of time or amputation etc."

"When severe / terminal illness arrives individuals have differing ability to cope. I don't believe others have the right to impose their beliefs on others in that situation. I know if I suffered a severe stroke that greatly impaired me I wouldn't wish to go on surviving or being a burden on others."

Others commented that the very existence of VAD as an option can relieve despair and foster hope for suffering people:

"I think the choice should be available. Often when people feel they have a choice they elect not to use it but it reduces fear and gives peace of mind."

"In Oregon USA and other places, the 'product' is held by the client and used when necessary. Statistics show that these people live longer knowing that the future is not wrought with uncertainty, pain and distress."

In contrast to these pro-VAD arguments, other commenters argued that society should improve existing services to alleviate suffering rather than using VAD as a solution to poor service provision. Such services included, most commonly, palliative care (26 comments), but also quality aged care, better and more accessible mental health services, and better pain control:

"I would like to see more research, effort and funding invested in improving palliative care options."

"I believe we should greatly expand palliative care and deal with terminal and painful illness in this context. For me this is an ethical issue to do with the sanctity of life. My views are based on a humanist rather than religious foundation."

"Capable of setting dangerous precedents in changing social expectations about end of life care and VAD becoming the norm and palliative care viewed as an indulgence. Palliative care options need addressing as a priority before throwing valuable resources at Voluntary Assisted Dying."

"VAD - to me is a result of poor terminal care and disgraceful age care! VAD can be affected by feeling useless, no longer wanted and being a general "pain" for everybody. I get told to sell my collectibles, downsize, put the money in the bank and leave it for the next generation - not this boy - I want to live among my memories to the day I die of natural causes - and just hope they will develop some better painkillers that will give you quality of life to the last breath!"

"Support for chronic non terminal illness should be funded by our government. no one should be left to feel hopeless. Depression is treatable and reversible. Easier access to mental health services which are funded through Medicare means cheaper Specialist appointments where there is a co payment. How many Psychiatrists are there?"

A few people felt VAD was an inappropriate solution to what might be temporary suffering or suffering imposed by societal expectations:

"I strongly oppose VAD, principally because in this day and age science and medicine are making so many advances so quickly there is always the probability of a treatment that will manage the malady"

"I agree but am undecided in cases of mental illness especially in the young. I doubt this would ever be considered. It can be a permanent solution for a short time problem"

"I strongly disagree with VAD on Religious and personal grounds. A person can be depressed, feel worthless and decide they would be better off agreeing to VAD. This could change with a new friend and appropriate support."

"VAD is morally wrong. End of life situations require care, support and improved palliative care facilities - not "easy way out". VAD sends the wrong message to older and infirm people - "You're not wanted, you're in the way, you've outlived your usefulness, you're a burden on us"."

"I believe the aged or disabled may feel obliged to end their life because they are a burden on others. The emphasis should be on better palliative care so that VAD is not necessary."

"I think this is an extreme form of elder abuse"

It was quite common for people to support their arguments about suffering by sharing stories of how a particular person or people suffered and/or died (109 comments). Eighty-four people shared their past experiences witnessing the prolonged suffering and/or death of family members and close friends, and/or reflected on their own experiences of illness and pain relevant to their VAD opinions. Eight others alluded to personal experiences of witnessing suffering and death without specifying detail, and four people shared stories of this kind passed on to them by friends.

These comments included stories about people with a terminal illness:

"I have watched my mother, daughter and husband die slowly from a terminal illness in the last 5 years, so I believe strongly in VAD"

"My husband wanted to die at home. He did. He had cancer and he was in so much pain. I hated having to watch him die like that. He never gave up - he wanted to live but I don't want to go like that. I try to remember the good times we had but all I can see is an incontinent old man in tremendous pain."

"I watched my darling wife LGBTI endure a lingering 7 days in palliative care. If we had known she had a right to making a decision it would have been an assisted VAD. I was her primary legal health and welfare chosen person but it didn't make a difference."

"It may appear to be easy to make comment by agreeing or dis-agreeing, but if and when it effects a family or me personally then it comes home. I had this dilemma 26yr ago when my then wife was dying of Pancreatic Cancer. She had been diagnosed on Melbourne cup day in Nov 1994 and from Xmas '94 till early Feb 1995 she was in palliative care. I was concerned about the pain she was in and this went on for most of Jan 95 and I asked the nurses if there was any way

we could hurry along her death but was assured she is not feeling any pain due to the medication the Dr's prescribed. In the last week she did not open her eyes, it was not long after that that my wife gave up the ghost on Feb 2 1995. I'm not sure what I would have felt if they heeded my request to assist termination, I don't know how I would have felt the guilt of that. I know we euthanise our pets when they are in pain and we don't want them to suffer needlessly, but it's different when it's your wife or your Mum."

"I knew someone whose elderly relative had terminal cancer. She was in extreme pain and the hospital gave her a machine so she could dispense her own pain killer, by pushing a button on it when the pain was too much, so she could control the dosage. They warned her very carefully that she needed to be very careful when dispensing it not to have too much at one time as it could be fatal. She took the advice at face value and was very careful not to have too much, but kept saying she just wanted it all to be over and to die. It was sometime before she worked out what that meant....or until someone told her. Very sad."

"The most sensible, kind, compassionate and humane solution. This allows us to pass with dignity, being able to have all our affairs in place, and allows family and friends to see us pass in a better way and shorten their grieving etc., not to mention massive cost savings. My mother had a do not resuscitate order in her will, but when she had a massive aneurysm some 23 years ago the hospital insisted on putting her on life support system. Horrible watching your mother appear to be alive and then gradually falsely hoping something may change. VAD should be expanded to the many souls who simply do not cope with modern life and after genuine discussion and search for options but still wish to end their suffering to do so with some dignity instead of doing so by their own hands as my son did."

"I saw way too much suffering when my mother passed away from lung cancer at age 77. I wish VAD could have been an option then, albeit a very difficult option to use."

Some were stories about people with degenerative conditions and chronic pain:

"I have watched younger relatives suffer from Motor Neurone Disease & Brain Tumours. They are both cruel diseases for the patient to have to suffer & hard for those close to the patient to watch the deterioration of a previously young vital person."

"Over the last few years, I have been watching my 95 year old Mother's distress with the dreadful pain, that she suffers day and night. Along with the pain through-out her body, her kidneys have failed and she no longer hears. She doesn't have a terminal illness but she desperately wants to die. As she says, it is so cruel to keep her alive this way. She has NO quality of life whatsoever. I understand how she feels and it is heart-breaking to see her struggle daily. Prior to this however, it was always my belief VAD should be available to those who are

terminally ill and those who now have no quality of life at all, and never will have."

"No one should live a life of suffering. I watched my mother in-law suffer slowly and painfully from Parkinson's Disease. Many times, she said she was envious of her friends who went before her. The only thing that kept her alive was her strong heart. She lived many years longer than she would have liked. It was so horrible and sad."

"I watched my father go through the world of dementia. I do not want to put my family through the on going agony of watching me deteriorate and will consciously commit suicide to save them from the turmoil of watching my deterioration. I would like to be able to consciously be able to access an appropriate VAD method when I feel the necessity i.e. prior to becoming a burden on my family"

"My mother lived with constant pain for many years and constantly wished that she had access to VAD. As I was brought up a Catholic I do have reservations about this, but do wonder if in some circumstances..... I believe that someone would need to be extremely desperate to even consider this option. With advances in medical treatment hopefully less people will feel such desperation."

Some commenters shared stories about loved ones dying by suicide unassisted to avoid suffering:

"Both my parents died (1999, 2010) by taking overdoses of prescription medication for their terminal medical conditions. They were both determined but had no medical support in their actions. I believe we should listen and help those who are suffering and have decided to die."

"My dad had inoperable cancer at the junction to his lungs. For a number of reasons he took himself off one morning to a quiet spot in the bush and opened a vein in his arm, he had left his second wife a note, my brothers went looking for him and his body was found after his passing. He was only 70 and if it had been legal in 1994 his family could have been with him and he could have felt/saw the love we had for him. I would not deny anyone the opportunity to be with their loved ones if they choose to end their pain and suffering."

People also wrote at length about their own struggles with pain, illness and the prospect of suffering in their own futures:

"Time is a factor here. I am familiar with real pain. A decision made in one set of circumstances may well not apply in another set. There have been times when I haven't been able to move, not so much as a little finger, which is lucky, because I would have cheerfully topped myself to get away from the pain, but then life returns as it recedes, hearing comes back and you hear the birds, and you are able to get up from lying down for the past five days (and nights! Don't forget the nights) and feel the breeze on your face, and you think 'maybe next time'."

"There have been three occasions in my life where it seemed as if all was over, but through a miracle drug and some very good medical helpers well as prayer, I am still able to answer this survey. There is always hope and all human beings are valuable, even when they are terminally ill."

"I am in constant pain from operations on my spine and have been for the past 10+ years. I have absolutely no family and dread the idea of going into a nursing home which is all that is left for me as my mobility becomes less and less. I was a very active and busy person and although I have good friends, living with poor food and teddy bears decorating the rooms where activities are held does not fill me with delight. The poor food in nursing homes frightens me and as I am of no further use to society I would like to be able to take a magic pill and quietly go to sleep. Apart from my very poor mobility my general health is excellent and at 75 I could go on for another 15 to 20 years easily - but that would not be in my own home."

"I am undecided about non-terminal illnesses as I don't know what sort of suffering would be unacceptable. I live with pain daily and I would not want to end my life but maybe there are others who are much worse than me. Medical break throughs are happening all the time and I would like to hope there is some way these people could be made more comfortable and find some enjoyment."

"I have an incurable disease and have a Do Not Resuscitate clause in my end of life plan. Should my pain become unmanageable and my quality of life non-existent I would, with input of my doctors who would advise my family, accept VAD."

"Dementia is hereditary in my family & once I start to get it if I do I want VAD asap so I go with dignity, not linger for years & deteriorate I am passionate about this for my self"

"As I have had breast cancer and my niece died in agony from it I would like to have the right to VAD."

In addition to stories about loved ones, 13 people shared experiences of witnessing suffering and death during their professional lives:

"People who don't want to end their lives need not do so, but I don't believe they should prevent others from doing so. As a police officer I witnessed some horrific suicides by people who had no other option to achieve their demise. What their children and other loved ones saw, nobody should have to see."

"During a career in residential aged care I have seen so many examples of intervention in the dying process and the inability to provide a peaceful and dignified death that I have developed strong views on the inappropriateness of our death denying culture. However, my first choice is that everyone is confident that they will die naturally, peacefully in the presence of other people"

"I am a chaplain in a public hospital and know palliative care can accomplish miracles in persons and in families. Death can be such a positive completion to a life."

"I look at this from the point of view of a nurse. I worked in a Hospice for many years, and shed many a tear when asked to "please give me something to end it all"."

"As a retired Supervisor in Palliative Care, and having been able to provide the best palliative care possible, I witnessed on countless occasions, where PC was not able to control horrendous side effects of some terminal illnesses, leaving people to suffer the most inhumane death, their family shattered at having to sit by and watch their loved one suffer, and care staff traumatised by their inability to alleviate the suffering. I placed submissions before the Qld Government, WA Government, Tasmanian Gov and also the Dying With Dignity Association in New Zealand in their successful efforts to have VAD accepted."

“Normative” arguments: Aligning VAD with value systems and philosophical principles

Over 200 comments articulated support or opposition to VAD in terms of higher-level values, principles, and beliefs that they felt should be adhered to. Some of these connections were made rather briefly along with other arguments for or against VAD, but for other commenters the value, principle or belief system was the most important factor determining their views. The proportion of comments in this theme that were against VAD was slightly higher than for the whole sample of text comments.

One of the most frequently mentioned belief systems was religion, with Christianity the only organised religion that was specifically named (in general or via specific denominations such as Catholicism). Seventy commenters explicitly mentioned religion in their comments. Of these, 27 were opposed to any application of VAD, primarily or entirely because of their religious convictions. About the same number (28) explicitly opposed any role for religion in policy decisions about VAD provisions, all of whom were pro-VAD at least for people with terminal illness. Fourteen people who mentioned religion were undecided on one or both VAD questions, with internal conflict related to the commenter's religious views or upbringing often playing a role in that:

“Nobody should play God.”

“Life is sacred. We belong to the creator God who alone has the right of life and death.”

“God created life and when your time is up all believers are called to his heavenly Kingdom. Otherwise it is called suicide or murder which God does not approve of”

“This is against my Christian upbringing”

“As a practising Christian the idea of VAD is abhorrent to me”

“As a Christian, I do not believe that VAD is permitted however other non Christians may require this control”

“I am a Christian and while I do lean to acceptance of voluntarily assisted death in certain circumstances, I have not yet really come to terms with it.”

“Difficult because as a committed Christian I see & know life is very valuable & precious to my Creator & those around me but I can understand some situations are dire & I can't decide for other people unless they are no longer conscious & the end is inevitable & I know what they would want!”

“I have the conflict of my religious belief with this subject.”

“VAD should be available to anyone over the age of 18 as no one person, government, medical organisation or religion should determine if a person has the right to exit their life.”

“It is an individual's choice, provided the decision is made with all the appropriate supports in place. I strongly object to the so-called Christian lobby's opposition to euthanasia or VAD.”

“I believe that eventually - in 20 - 30 + years time - Voluntary Assisted Dying will be a reality. I have some sympathy for those whose religious beliefs lead them to oppose this, but don't think they should be able to impose their views on everyone else. We live in a secular society and the majority of our society are not regular church goers. It should be possible to build safeguards into assisted dying legislation to prevent coercion by others.”

However, the principle most frequently mentioned re VAD views was personal choice: the notion that a person should be able to make decisions for themselves about their body, their life and their death. Altogether, 123 commenters articulated this principle in one form or another, opposing others such as religious bodies, politicians, doctors, family or young people impeding it. Some linked personal choice to human rights principles: the right to make decisions, the right to die, with no one else having a “right to determine how others choose to live or die” as one person put it. The vast majority of these 123 people supported VAD provisions, with a few unsure about one or both VAD questions. Nine opponents of VAD also expressed their comments in “rights” language, albeit emphasising different rights or asserting that other values, beliefs or principles take precedence over human rights:

“My life my choice.”

“It is a human right. One should choose the time and way to die without interference from Govt or religious institutions”

“I strongly believe each individual has the right to choose how they die, have seen too much suffering in the elderly because of someone else's beliefs. It is a big decision and the individual should have this right”

“It is obviously a very difficult situation and I guess relatives are not always willing to let the person decide, but ultimately I strongly believe it is oneself highest right to decide something like this”

“A very important human right is autonomy”

“What other people want to do about VAD is their business alone and nothing to do with me. I believe it's all nonsense. If you want to end your life, just do it, and don't bother others with your whining. I have a plan to end my life if and when it suits me and it's no-one's business but mine.”

“It's my life so why shouldn't I have the last word.”

"It violates my sense of humanity that we do not have VAD as a choice for those who want it. Surely we judge ourselves as a nation on how we treat the vulnerable in our society?"

"Life is about choice. You choose what you need and not let others decide for you!"

"I agree with VAD for other people who choose to, but I would not choose it for myself."

"No one has a right to take his or her life."

"Assisted suicide or voluntary assisted dying is MURDER, no matter what you call it. Personally, I do value human rights, and an individual's choice, however I will never assist anyone in regards to this matter. To allow VAD is the optimal level of lunacy, as it directly contradicts the ethos of every primary mainstream Christian religion, and the Hippocratic Oath."

Several commenters shared broadly pitched views governed by philosophical perspectives concerning the nature and meaning of life:

"Life is a gift given to us by God our creator, we do not have the right to end it."

"Life should be a gift, not something inflicted on someone by others."

"Personally I do not wish to hasten death - I believe life is a gift that has to be accepted in good times or bad. Yet I do not want to impose my views on a wider community - including those who sincerely believe they need to control their way of dying."

"I find the whole VAD "debate" somewhat hypocritical. it is my view that we as a community value life, with all its pitfalls, and life is not something that can be thrown away, just with the same level of decision making as for commodities eg putting petrol in our car."

"Really! If people break a nail today they need counseling. Harden up life is not and never has been a bowl of roses."

Finally, some commenters endorsed the provision of VAD for reasons related to money and other resources, or opposed it because of the prospect of policies being made on the basis of such arguments:

"Too many Doctors and Businesses are making too much money by extending the suffering of people."

"There are too many people on our poor planet. The advances in medical technology seem directed at keeping old people alive - the baby boomers are moving into the aged category and that is a massive bulge and therefore drain on resources."

“As over population continues and natural resources dwindle, VAD will become more common. As the cost of healthcare continues to rise VAD will become more welcome. No person on the dole (or part disability pension like us) can afford to spend their half their yearly income on private healthcare. The older you get the more you need private healthcare and the less you can afford it. Also I would like to see the government less burdened with healthcare costs that keep people alive and in pain when that money could be going to education etc. A greater proportion of elderly citizens also creates a major logistical and statistical expense. Money needs to go to providing services to, and supporting the people who are making it. It is an unfair expectation to spend all their taxes on non productive elderly people who don't want to live or have that money wasted on them.”

“I think that despite all of the proposed safeguards VAD could be the ‘thin edge of the wedge’ for future abuse or expansion of the system, eg involuntary assisted dying by nursing homes for financial purposes, coercion by family or others to gain access to inheritance. There have also been worrying debates in the past, initiated by people who believe that public funds should not be used on certain older people, because the funds could be better used in other areas. I think there is a misunderstanding in the community in terms of what is euthanasia and what is already legal and moral eg, withdrawing life support when prolonging life would be futile, giving pain killers / morphine to ease a person's pain when they are already close to death, even though the administration of morphine might hasten their death.”

“It is only a short step from here to Unvoluntary Assisted Dying, because the Homes are full and more space is needed, The cost of keeping someone alive is not "Economically" viable, or any other seemingly. In other words it could become state sanctioned murder.”

“Logical” arguments: Appeals to consistency between VAD and similar issues

About 100 commenters expressed their views on VAD in the form of a comparison between it and other social practices connected to ending life, seeking logical consistency between them in policy decisions about VAD. The relative proportions of pro- and anti-VAD views mirrored the proportions for the overall sample. Only one commenter who said they were undecided about a VAD question made a comparison of the kinds included in this theme.

The most common comparison people made was a straightforward one, comparing VAD to euthanising pets and other non-human animals when they were suffering. Of the 46 comparisons of this type, only one was from a person who was undecided about VAD, and none from strict opponents of it. This comparison was expressed quite consistently:

“We euthanise animals when they are suffering, why don't we treat people with the same respect????”

“If we can allow pets the dignity of peace at the end of life, we should allow humans the same right.”

“We are fined if we allow animals to suffer yet have to stand by and watch our parents/partner/child to suffer and have no quality of life”

“I watched a dear friend who was a supporter of VAD struggle with severe pain till she died. I would not have let a dog die like that.”

The second most common comparison was to unassisted suicide (35 comments), with just over a quarter of those comparisons coming from people opposed to VAD for people with non-terminal illnesses, most of whom also opposed VAD for people with terminal illnesses. Comments from those in support of VAD provisions pointed out that people who do not want to live may die by suicide, but that such suicides can be “messy”, creating trauma for witnesses and loved ones. Some noted that, unlike for VAD, people committing suicide unassisted cannot have the comfort of support from family and friends at the time of death, as loved ones may risk legal proceedings if they are thought to have assisted. One person said that the fear of being physically unable to die by suicide later in life may cause them to suicide earlier, in the absence of a VAD option. Another felt that VAD removed the stigma of a person's death being named a suicide. One person mentioned that unassisted suicides can sometimes fail, leaving people suffering further, though another person expressed the parallel concern that VAD might fail sometimes, hence their hesitancy about it. Those opposed to VAD used the comparison to suicide as an argument for why VAD is wrong, because they felt suicide itself is wrong and also preventable. One person addressed the question of stigma about suicide, suggesting it was not a valid concern, and they opposed

VAD because unassisted suicide is a readily available option for those wanting to end their lives:

My experience with older people and very ill people tells me that pain can now be managed so that, where VAD is legal, very few people use the option. If the option is not there, I am afraid more people will get around the law by suicide. Not a good option for their families to cope with."

"I personally at this time do not need access to these services. I would never deny anyone wishing to access them their right to do so. I think it is a better system than forcing someone to commit suicide alone and desperate and if assisted that person facing police investigation."

"There are people who also suffer from severe mental issues who try or succeed in taking their own lives in the most terrible ways and do this alone. After suitable criteria and evaluations, people should be able to access VAD rather than taking their own lives by shooting, jumping, hanging, gassing, overdoses etc. We are surely a democratic country, sufficiently skilled and resourced so that people don't need to do these terrible things to themselves and sometimes not succeed and then become a burden on others or the public purse using precious human and fiscal resources. Some because of their unsuccessful attempt, are mere 'vegetables' with no possibility of change but if capable, will try to end their lives again. Simply tragic."

"VAD definitely not be legally accessible to adult Australians with decision making capacity who have a non-terminal illness causing them unacceptable suffering, provided they meet all other eligibility criteria listed. This is tantamount to facilitating suicide which, as we all know, is often a rash decision made as a result of anger or depression. Better Mental Health support is what is critically needed in this country, not the provision of legalised opportunities to end the lives of individuals who are otherwise healthy."

A few people discussed VAD provisions in other countries (Switzerland, Netherlands, Belgium), or in one case historical cultures in which suicide was "seen as an 'honourable' exit". While some used this comparison as an appeal to make VAD access consistent between Australia and elsewhere, others were opposed to VAD in Australia because of what they perceived as poor practices elsewhere:

"This is way overdue. Get on board Australia and save me a trip to Switzerland when the time comes."

"Please look at the Swiss, Dutch etc. systems and criteria. Light years ahead of Australia."

"I would only support VAD if palliative care was not sufficient to relieve suffering or restore some quality of life. If the rules are relaxed too much people could seek euthanasia for more trivial reasons. There were cases overseas where people accessed VAD overseas because they suffered from alcoholism and rehabilitation

failed or there was a case of a women with two teenage children who opted for euthanasia because she suffered from tinnitus.”

“The VA the legislation is flawed. The so-called safeguards are not workable in actual clinical medical situations because the doctor is not obliged to confirm diagnosis or to refer to a palliative care specialist or to a psychiatrist. Experience overseas in the Netherlands and Belgium is that once the issue of "Doctors helping to take people's lives" is breached, the criteria inevitably expand to include psychiatric illness, people with dementia, people with disability. It is flawed legislation which as time passes people will see the major problems with. It will eventually result in the abuse of older people for financial or social reasons.”

A small number of people made a comparison between VAD and existing medical practices of allowing people to die by withdrawing life support, food, or medication:

“Their life their decision. I have been at the bedside of many loved ones over the years and feel the traditional way of starving and dehydration is so inhumane. Oh nearly forgot filling them up with high amounts of morphine to add more to the barbaric practices of the past, going out on a high has some advantages but starving and dehydration is totally unacceptable.”

“I disagree strongly with VAD, it is in God's hands not humans. Yes medically doctors can make dying more easy with the person's own ideas such as not using antibiotics and giving pain relief but actively taking a person's life in my opinion, not matter what the reason, is against my beliefs.”

Finally, a few people compared VAD to abortion or capital punishment, with views expressed on both sides:

“We heartlessly kill babies so let's not kill the elderly too. Better palliative care should be our aim.”

“In South Australia, just last week abortion was taken from the Crimes Act. How long a struggle! Same with VAD, not in force after 30+ years campaigning. Who are the mysterious forces that influence parliamentarians on what the public is clear about!!!”

“We don't execute violent criminals but are happy to end the lives of vulnerable people.”

“Everybody dies, the fortunate ones die without suffering after, hopefully, saying their goodbyes. I don't see why people should be forced to hang around waiting for the inevitable just because some people have a belief system that prevents them from consenting to a change in the law. Perversely, many of those same people would happily reintroduce Capital Punishment or send people off to pointless wars in far away places.”

“Regulatory” arguments: Questions about the practical implementation of VAD provisions

For about 200 commenters, the technical conditions placed on VAD, and governance structures set up to oversee these, are key factors they want to see addressed in any VAD discussions. This final area of consideration moves the debate from loftier questions of principle and consistency to the nitty gritty of how VAD should be implemented given political realities. The proportion of commenters supporting non-terminal VAD was slightly higher for this theme than for the whole sample.

Some of the issues relevant to this theme have already been raised in the preceding sections of this report, most pertinently questions about who should have access to VAD and under what conditions. As has been noted, while commenters supporting VAD generally agreed that people with a terminal illness should be able to access it, other situations were up for debate. In particular, as noted, commenters had different opinions about whether people should be able to access VAD provisions to alleviate suffering associated with degenerative conditions, disability, mental ill health and socially oriented states of mind such as meaninglessness and loneliness.

People also disagreed about whether a person's level of suffering should have to be validated by an external authority such as a doctor, or if a person should be allowed make a VAD decision by themselves:

“It should be a decision made by me based on my own choice, not a doctor's permission!”

“It should be your own personal choice, but having a reasonable amount of support and guidance to confirm it is the right choice”

“I believe that too much power sits with medical professionals. I have no problem with Medical opinion being part of mix but arbiter needs to be a panel of legal/psychiatric experts.”

“The criteria is too rigid and inflexible. There aren't too many doctors who will commit to telling you you have only a certain number of months before death. A friend was told he had 6 months and lasted 4 years. There certainly should be checks and balances ensuring a person isn't being coerced but if doctors won't commit to a timeframe and the patient is in a sound state of mind, the decision is theirs to make and not a bunch of bureaucrats covering their backside.”

“I believe in the right of a person who is of sound mind and not influenced by others, to make such decisions if they feel they are experiencing unacceptable suffering, whether terminal or not. What's considered 'unacceptable suffering' may be debatable, so the opinion of medical professionals would still be mandatory.”

"I believe that every individual person should have the choice of their choosing as long as it is supported by the medical profession."

"I do agree with VAD but only if it is under strict guidelines and with more than 1 person to make the decision."

In general, views varied on whether strict legislative oversight of VAD was desirable. Some commenters felt it was not appropriate for governments to obstruct individuals' choices with red tape, while others sought carefully administered protocols:

"VAD - too much red tape. Too many rules. We will all die. I would like to access VAD when it suits me and not when it complies with rules that suit the government."

"This a vexed area. While I think an individual should be able to make decisions about their existence I am not sure I believe it is something the state should be involved in.....if you legislate then it is open to abuse and manipulation"

"I have picked strongly agree because that is the most aligned with my position, however I do not agree that legislating Voluntary Assisted Dying is the appropriate pathway. I acknowledge that those who offer assistance need protection under the current legislation however, the right to terminate one's life should not be legislated by politicians whose personal and political views impact on the legislation. I would prefer to see a system where negotiations between those included in the informed consent process (medical provider, family, friends etc) that facilitate the process. The right to die with dignity has been progressively been legislated away. End of life choices are personal and not for State intervention, which, from my observation always leads to unforeseen complications."

"It is a very difficult question, so any legislation has to be exceptionally clear-cut and well-defined."

"It is an extremely sensitive issue and the eligibility criteria must be seriously and carefully considered regarding legislation, the medical profession and the definitions of 'adult Australians', 'decision making capacity', 'terminal and non-terminal illness', 'unacceptable suffering', 'doctor' and 'meet all other eligibility criteria'. Also what provisions will be provided to meet with any 'fall out' after the VAD decision has been acted upon?"

Many people raised issues regarding cognitive impairment, especially associated with dementia but also with mental ill health. The issue is how (or indeed whether) to grant VAD to a person who can no longer express their wishes clearly and who may be unable to make decisions. Some asserted people must be of sound mind to make such decisions and some questioned how that is to be determined. Twenty-five commenters specifically sought recognition for decisions made prior to diminished capacity, many proposing practical measures such as advance care plans to effect that for themselves and others:

"I recognise it is a tricky area but I would like to see VAD extended to people who have lost decision-making capacity but who expressed their views before they lost decision-making capacity"

"I see one of my brothers in a nursing home, in an almost vegetative state, with many health issues. On discussion with my sister in law, we would be OK with his death, just by ceasing to live. He has a request to his executors not to prolong life by intervention. This is harrowing for his children though. I think that the ultimate decision about VAD is with the person. But just how compos mentis does one need to be really?"

"I would like to have the option of VAD if I fit any of the relevant criteria and if my life has lost dignity or the capacity to contribute to life around me. My family is aware of this, and I do not want them to have to make the decision of whether or not to end my life. My wishes will be recorded in an Advanced Care Directive with the guidance of my doctor and the understanding of my family, and in a health Power of Attorney."

"The frustration is that those with dementia cannot choose VAD. I've made it very clear in my ACP [advance care plan] that I would prefer VAD to living an incapacitated life. I don't want to die with dementia as my poor little mum did. It's a dreadful, undignified disease."

"If you were diagnosed with a form of dementia you should be able to determine at what stage you would wish to be assisted in dying"

"I believe that living recorded Wills should be an acceptable form to express your wishes in this regard."

"A carefully worded paragraph in a will should be executed and be the definitive trigger for VAD"

"You should be able to sign a document in advance so that if you lose decision making capacity your request for VAD is followed, just as you can for organ donation."

Another prominent concern expressed by many commenters was a desire for safeguards to prevent coercion, to ensure a person's decision to terminate their life through VAD is genuinely voluntary. Some questioned whether effective safeguards against coercion were possible. Concerns were raised about the prospect of coercion by family members who were set to inherit wealth or were tired of caring duties; social pressure put on vulnerable people by care facilities, governments and the community at large to use VAD when they don't want to; and even the possibility of involuntary euthanasia decisions:

"Complex issue. The main concern is the potential for external influencers (including family members and care providers) to move to the process before the individual is ready to make such a choice. I am not convinced as yet that there is sufficient protection for people for whom such legislation may be applicable."

“There may be problems if an heir is felt to pressure a frail person so maybe a lawyer or medical practitioner should have a 1/2 to one hour interview to ensure it is the person’s own (uninfluenced) decision.”

“I’ve seen houses sold out from under seniors by descendants. There’s too much to go wrong with VAD. It could be misused.”

“very suspicious of the motives of those pushing this option. It seems many of our elders are mistreated already and I think many would be pressured especially if they leave a legacy that greedy youngster feel is their right.”

“The problem here for older people and particularly those with dementia, is that much of their suffering is caused by providers and others... and this can add to a difficult condition to develop a case for VAD that even the person goes along with. While I support VAD, it’s very dangerous while ageism is so prevalent and aged care is so bad... and the safeguards don’t really work in these areas.”

“My concerns are more about how the safeguards can really be made robust. How can infirm people be protected from feeling guilty that they have become a burden on their family and on the health care system in general? How can avaricious family members be effectively kept out of the equation as they eye the inheritance, or simply the release from responsibility? Balancing such concerns against the inherent kindness of permitting someone to escape their suffering is the conundrum that has kept most jurisdictions from legislating VAD, and understandably so.”

“We have no children and are concerned people will make a decision to end our lives without our consent because they think they know better.”

“Worry it could be the start of the slippery slope when “the State” may well be the decider”

“with the sort of political parties (Lationals/Nibberals) that we have in power, I would not put it past them, over time, to introduce compulsory VAD legislation, and that the VAD is just the thin edge of the wedge. Morally I am all for it, as per my answers above, but politically, I would not trust the current parties to lie straight in bed, let alone decide what is best for me.”

Connected to this were questions about the appropriate role for family members and close friends in VAD decisions:

“If the person meets all the criteria then they should be eligible after all it is their life and they know their own feelings. I think also family members should be involved in decision making but they must respect the person who wants VAD to have the final say.”

“it would be a great burden for the relations to have to follow such desires to be fulfilled [if] the person in question cannot make that decision themselves. A very complex and emotional aspect of life.”

“Any person of sound mind should be allowed to seek voluntary assisted dying, provided they have given due consideration to the pain that this may cause family and friends. People will suicide anyway and the option to seek VAD may avail the opportunity of a counsellor to help”

“I strongly agree with a person requesting VAD. The problem for me is who is making the decision and how the request is made. If the patient is making the decision, is of sound mind and the request is discussed between the patient and a panel who are in agreement with the patient then yes allow the VAD. My reason for this is that often nursing staff listen to the more charismatic family member of a family instead of reading the legal instructions and talking to the enduring power of attorneys.”

“I think for lack of mental competency you should be able to empower a family member (or close friend) in advance to make the VAD decision on your behalf based on their knowledge of your general principles in the matter (ideally you would write down your general principles). Having seen dementia in my own family, I would certainly like to give a VAD-power-of-attorney to my husband to activate when I cease to recognise my family and friends any more.”

“I feel that all people have a right to make decisions while they can in their own life VAD is a personal decision and must become legal to not be challenged by family or health professionals. I have seen this with a family member and I was so happy with the choices made”

Several commenters raised questions of timing regarding VAD availability. Current Australian state-based legislation specifies that a person must have a terminal illness expected to cause death within 6 or 12 months to access VAD provisions, but for some this condition of timing is too strict. Other commenters raised the prospect of waiting times or the need to undergo counselling first, or queried the current legal requirement for a person to request VAD repeatedly, asking what “repeatedly” means:

[re VAD question detailing current Australian legislation] “I believe that the second condition should read: “Having an incurable terminal illness causing intolerable pain and/or distress to the Patient.” I believe no term should be put on the suffering.”

“Individual choice and should be more widely available with less intrusion from government and fewer hurdles and much quicker timelines”

“I believe VAD should be available to those that meet criteria. Though I would strongly like counselling to be pushed beforehand to ensure that it is not just depression making the decision. And please don't make them wait for counselling for months on end!”

“I personally believe that there needs to be clear pathways which involve hurdles to create delays that allow for reflection and consideration, and are led by counsellors, not with the intention of changing someone's mind, but to ensure

that person has thought about the grief to friends and family or so as to develop a plan of support for the individual to assist friends and family understand and accept the decision, and the process. As VAD currently appears in the media, it is as simple as talk to the Dr, you are of sound mind, here's the drugs, you end your life when you are ready, unsupervised and unsupported. I interpret this as suicide. I would like to see a more humane and respectful face given to VAD with a wholistic family-and-friends-orientated focus so the individual is supported throughout the journey."

"When making a request 'repeatedly' - do we have to beg? If I can make a decision to apply initially, how often would I need to repeat - hourly, daily, weekly, monthly? Very broad, subjective criteria in my opinion."

A few people raised questions about the age at which VAD should be made available. There were two issues here: first, whether young people should be able to access it at all or with more stringent constraints than for older people, and second, whether the VAD option should simply be made available to all people above a certain age whether ill or not:

"Death should be a personal choice and available to every adult. The only stipulation should be a waiting time to assure it isn't a knee jerk reaction. The time limits should be longer for younger people and increasingly shorter for older people, and be very short for people with terminal illness."

"I've followed this discussion for many years & still believe that VAD should be available to everyone, of any age."

"I strongly agree that I should have the right to make this decision when I'm over 90 years of age if I am tired of making myself carry on. To what purpose. While I have a loving family I'm not looking forward to those I cherish watching me disintegrate as I must. Add any illness or disability and the decision is even easier to go peacefully, medically assisted, with no fear of friends or family facing the farcical prospects of criminal sanctions. The slippery slope hypotheses has to be acknowledged but as a scare campaign it is a distraction to sound policy making."

"For some time now, I have been saying to my friends of similar ages, how I would prefer to 'go to my own wake', so to speak. Choose the time when I am ready to leave this world, invite family and friends for farewell drinks, then go to bed with a nice strong cup of 'poppy' tea, and die peacefully in my sleep. This has created much discussion, and we all agree on the basics. Obviously we all have several more years yet. 1 of these friends Mother's, who died in her 90's, was in the nursing home, had dementia, kept asking 'Why am I still here?' Another friend is a having similar experience with her Uncle in his 90's. I feel anyone over the age of 85 should have the choice."

"It should be available to anyone over 80, who have lost all their family/ friends and no longer see any point in living."

"I STRONGLY believe that VAD should be available to anyone over 70yrs who wishes it for any reason what so ever!!"

From a technical perspective, a small number of people commented on how they would like to see the circumstances of the assisted death itself arranged:

"I have concerns about medical persons actually administering euthanasia. There is an obvious need for medical involvement in assessment of eligibility, But administration should be from an automatic system activated by the patient."

"I have watched on YouTube programs on assisted dying and most of the facilities seem to be located in or close to Industrial areas. If I did take up the option I would like to be able to lie outside in a beautiful garden or bush or isolated beach setting. The approach to assisting the dying has been far too clinical and quite distressing for the individual and any family member involved. A beautiful glass of wine laced with tasteless chemical would be the way to go. I DO NOT have any desire to end up in any form of aged care (having had considerable contact due to the work I did). This would be a far worse death than euthanasia to me"

On a governance note, numerous people discussed the appropriate jurisdictions for VAD policy, with many arguing it should be applied Australia-wide not by individual states and territories:

"This issue should be decided by the people and not by political party organisations or the individual preference/belief of elected politicians. A national referendum with options regarding the level of access to be provided (similar to the above options [in the VAD questions' wording]) should also be considered at the same time."

"ALL states in Australia must allow it."

"The situation is undemocratic in NT and ACT where Commonwealth legislation overrides the clear views of both populations."

"We should have euthanasia and Dying with dignity, uniform and legal Australia wide."

"Should be an Australian decision to agree to VAD not made per State."

Finally, some commenters wrote of the need for more open discussion about VAD:

"We desperately need a bipartisan conversation Australia wide about this topic and hopefully there will be better outcomes established for those who are suffering and their families."

"Lots of information and debate is needed"

"I understand the many views about this topic. However, much more public discussion needs to be had to progress the issue. I think it seems like an old person's problem but there are many ages that are affected by pain and terminal"

illness etc. Therefore, the more the public understands, the more encompassing the legislation can be.”

“More info should be supplied to citizens re brochures in medical centres. All kept quiet in case someone gets upset. WELL GROW UP. FACE IT.”

“There is still a need for all people to have a better understanding of [VAD], and for all opinions to be respected”

“Every one should have all the information available to them so they can make their own decision without anyone else influencing them.”

This desire for further open communication goes hand in hand with the many VAD questions on which seniors do not yet agree.

Discussion

Prevalence of views for and against VAD

The survey showed the majority of senior Australians overwhelming support legalising VAD under the conditions currently legislated in Victoria and Western Australia. Our results also suggest over two-thirds of senior Australians support expanding eligibility for VAD to people who have a non-terminal illness that is causing them unacceptable suffering, with the remainder slightly more likely to be uncertain than opposed.

The percentage of our respondents who support VAD for terminally ill people (85.71%) is very close to the percentage of Australians who support it (85% in one 2017 national poll [2]). It is substantially higher than the level of support expressed in a 2017 survey of over 5600 National Seniors members, though the VAD question in that survey was broad and did not specify conditions or contexts [9].

VAD appears to be a great leveller as a social issue. We found very few demographic traits were significantly associated with a pro-VAD or anti-VAD stance. The two that were statistically significantly associated with VAD attitudes were age and whether a participant had written an advance care plan or not. The former might be explained as a generational difference, since older survey participants were proportionately more likely to oppose VAD, and Australian attitudes to VAD have changed over time, becoming more supportive since the 1960s [2]. In addition, the greater exposure to death and end of life experiences may shape older seniors' views in different ways that have not yet affected younger seniors. There is also a logic to our finding that respondents who had written an advance care plan expressed much greater rates of support for VAD, especially for people with non-terminal illness. Numerous commenters expressed the view that VAD eligibility should be expanded for people with degenerative conditions such as dementia, and many specifically sought a mechanism for capturing people's VAD wishes prior to losing the capacity to make medical decisions. Some specifically mentioned advance care plans in this regard and wanted wishes expressed within them to be respected. While of course not everyone with an advance care plan supports VAD, it seems clear how the two could be connected, for example for people who want more choice and control over all aspects of their ageing process, including their deaths.

Themes of VAD comments

We conducted our thematic analysis of the survey comments without reference to published studies on attitudes to VAD, formulating our themes based on the comments themselves. The result was a more independent analysis than might otherwise have resulted, had we based our themes on existing VAD attitudes research. However, despite

this, there was considerable overlap between our themes and the themes other researchers have identified and defined, as well as some differences.

A 2012 systematic review of VAD attitude studies from around the world [12] similarly identified that concerns about poor quality of life in terms of physical pain, loss of function, cognitive impairment, dependency, meaninglessness, loneliness and more are a major determinant of VAD attitudes. While our commenters expressed different opinions about whether VAD should be made available in all these circumstances, a large proportion were certainly in favour of it. Given the strict restriction of current Australian VAD legislation to situations of terminal illness, it is important to highlight that others in the world are thinking about much broader eligibility criteria, in concert with many of our survey participants.

Other themes from the systematic review that overlapped with our themes included a desire for choice, autonomy and control over one's death; a need for safeguards against potential abuse of VAD; questions about the desirable roles of doctors and of family and friends in VAD decisions; and the prominence of drivers such as religious views and personal experience of death in shaping VAD attitudes. Themes present in the review that were slightly different in our survey included concerns that vulnerable groups (e.g. people with disabilities) would be discriminated against in what treatments were offered, and made to feel they were a financial burden, if VAD was on the table. Our survey commenters did discuss the notion of palliative care being seen as a luxury if VAD was an alternative, and of people feeling socially pressured to use VAD provisions to take their life because of their high care needs, so the issues were raised but in a slightly different way.

A 2020 discourse analysis of public reasoning about VAD also identified many themes that overlapped with ours [13]. That study was based on comments submitted to the Queensland Government's 2018 parliamentary inquiry into VAD, aged care, end-of-life and palliative care, so it is not greatly surprising that there was overlap given the location and timing of their dataset. The researchers, Kirchhoffer and Lui, identified five themes that also appeared in our survey comments: narrative accounts of witnessing or experiencing pain and suffering; respect for choice; palliative care as effective alternative; suicide as morally wrong; and a desire to ensure that any VAD choices outlined in a person's advance health directive are respected. The other five themes they identified appeared in slightly different forms in our survey. Their theme C was dying with dignity, which was frequently associated with comparisons to euthanising suffering animals. "Dying with dignity" as a phrase also appeared frequently in our survey, as did comparisons to animal euthanasia, but the two did not directly overlap often. Kirchhoffer and Lui's theme E was the notion of VAD being incompatible with medical practice, and while this was seen in some of our commenters' points about the Hippocratic Oath, it was not common. Kirchhoffer and Lui's theme G grouped together numerous kinds of concern about state-sanctioned killing, e.g. abortion and the prospect of involuntary euthanasia. However, our thematic approach separated out

these different kinds of issues into different themes, in part because they were not consistently framed as about state power, merging into individual, institutional and societal morals and choices too. Kirchhoffer and Lui's theme H was about protecting vulnerable groups such as elderly people, people with disabilities, and children from the implied message that their lives are not worth living. While, as noted above, some of our commenters were equally concerned about this and about the coercion that may result from such messaging, there was also discourse among our commenters about VAD being a kindness for the vulnerable rather than a threat. Finally, Kirchhoffer and Lui identified a "sanctity of life" theme, which, while present in our comments too, was by no means the only kind of comment our survey participants made about the meaning of life. For example, a few of our commenters used the phrase "life is a gift" in different ways, in both pro- and anti-VAD arguments.

Themes we identified that neither of these studies mentioned included:

- Concerns that suffering or elderly people will be coerced and pressured into seeking VAD by family members or others set to inherit their wealth.
- The argument that making VAD provisions available can itself alleviate a person's suffering even if they do not use them.
- The fact that the perceived quality of palliative care, aged care, pain relief and mental health support can influence VAD attitudes, with some people seeking VAD provisions to avoid poor care of these types, and others seeking to improve care of these types so that they become a viable, attractive alternative to VAD.
- The argument that suffering people choose to die by suicide, and legalising VAD will make their deaths less messy, lonely, desperate events.
- The argument that withdrawal of treatment, food and water already occurs legally in medical settings to hasten death, but actively hastening death through VAD is an option that entails less suffering than that.
- Technical and governance questions about the appropriate role for governments in regulating VAD and the jurisdictions in which it is available; the appropriate timing of VAD provision; and the notion of making VAD available to anyone over a certain age irrespective of their health status.

Kirchhoffer and Lui also found that religion was not a prominent factor in the data they analysed, in contrast to previous studies (including the 2012 systematic review), but it was a reasonably prominent theme in our survey comments.

Overall, many of our survey participants are engaged with similar kinds of reasoning and grounds of debate as others in the world who are thinking about VAD. But there are also differences, some of which may be related to Australia-specific or age-group-specific concerns. One is likely to be heightened awareness of the suffering and abuses that have

occurred in the Australian aged care sector, thanks to the Royal Commission into Aged Care Quality and Safety whose final report was tabled in early 2021, during the period when our survey was open [14,15]. Another is knowledge of the history of VAD debates in Australia, including the Federal Government prohibiting the territories from legislating on VAD after the Northern Territory did so in 1996, and the state-based nature of VAD debates in recent years. Our commentors who were concerned about social pressure placed on vulnerable people to access VAD mentioned ageism as well as ableism, probably because all survey respondents were seniors themselves and because our survey was explicitly about seniors' experiences. The way questions are phrased and framed in VAD surveys can affect the results to an extent [16], however there is no obvious link between the phrasing of our VAD questions and our commentors' more distinctive comments aside from the discussions about state and territory versus federal legislative instruments.

The argument made by many of our commentors that suffering people frequently die by suicide unassisted in lieu of VAD access is worthy of further discussion, particularly when we are considering VAD provisions for seniors. The Australian Bureau of Statistics data on cause of death in 2018 showed that the 85+ age group had the highest age-specific suicide rate for men in Australia [17]. The same is true in the US, and in many countries suicide rates increase during the life course [18,19]. Risk factors for suicide among older people overlap with reasons people seek VAD provisions in advance, including loss of independence, neurocognitive impairment, chronic pain and illness [17, 19]. Given these links, it isn't clear why this argument that VAD is a more desirable alternative to unassisted suicide was not mentioned in the other studies we reviewed here. It may be because they did not have the same focus on seniors' views that we have in our research program. Seniors are likely to be more acutely aware of general suicide risk for older people than are other segments of the population. The argument has been mentioned by some pro-VAD campaigners, such as the Go Gentle Australia campaign [20].

Where to next?

In concert with other surveys on VAD questions, our survey results indicate that a majority of Australian seniors would like to see VAD legislation passed in their jurisdiction. And a similar, although slightly smaller majority, would like to see VAD eligibility extended to members of the community suffering in different kinds of situation, not just terminally ill people.

The support for the extension of VAD provisions to some people who are suffering but not terminally ill is coloured by comments about the potential risks of extending VAD beyond the current strict criteria, such as coercion. Survey participants also sought technical clarity on some matters of VAD implementation, such as how to manage a person's reduced decision-making capacity if they have a condition such as dementia. In addition, they did not

hold uniform views about who should become eligible to access VAD. For these reasons, there is an urgent need for a national dialogue about VAD to work through such issues, prior to expanding VAD provisions beyond the limits set by current Australian legislation.

We can take some inspiration from the Canadian situation, in which the VAD legislation passed in 2016 was slated for parliamentary review five years later. The Canadian review's purpose is threefold: to review how the legislation is working in general, to consider legally recognising advance requests for VAD by people with degenerative conditions such as dementia, and to consider extending VAD provisions to people suffering intolerably because of mental illness [21]. This seems a very reasonable response to both needs and concerns and to the increasing engagement of members of the public in ethical deliberation about VAD. Australia would do well to follow suit.

Some of our participants specifically sought more information on VAD before making up their minds about it, and other participants sought greater, more open discussion about it within society at large. National Seniors endorses these calls for more informed communication about VAD within Australia to serve these and other purposes.

Clear and accessible communication about the specifics of current legislation is critical to answer the questions people have such as how coercion risks are to be managed or what constitutes a repeated request to access VAD. The piecemeal (state-based) approach to VAD policy inevitably means it is more difficult for people to gain clarity on the provisions than would be the case if there was Commonwealth VAD legislation. Careful communication of key information is therefore required now and into the future.

Open, respectful debate and discussion on extending VAD is also essential if we are to craft legislation that meets people's needs without impinging on people's rights, health, safety, freedom and choices about their own lives. In this spirit, we hope our report will contribute to fostering dialogue and mutual understanding between opposing camps rather than polarising them.

It was inevitable that, as populations aged and the prevalence of dementia and other debilitating conditions increased, VAD would become a major social issue to be confronted. As an Australian philosopher wrote from Melbourne earlier this year [21]:

The right to assistance in dying continues to gain ground. [In] the end only the patient can judge how unbearable the suffering is, and therefore, how much weight should be given to the possibility that it will end, either with further treatment or on its own.

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Appendix: Characteristics of the sample

Personal traits

Disclosed demographic traits of the subset of NSSS-9 3469 survey participants who answered at least one VAD question and did not elect to skip the VAD section:

- Highest formal education level: year 10 15.9%, year 12 or diploma 40.7%, bachelor's degree or higher 43.4%
- Age: 50-59 years 6.1%, 60-69 years 33.9%, 70-79 years 46.8%, 80+ years 13.0%
- Gender: woman 57.5%, man 42.3%, non-binary 0.06%, other identity 0.03%
- Partnered 60.3%, not partnered 39.7%
- Retired 77.7%, not retired 23.3%
- Health: excellent/good 76.3%, fair 19.5%, poor/very poor 4.1%
- Savings/investments: \$200K or less 38.1%, \$200K-\$500K 23.1%, \$500K-\$750K 11.7%
- Have written an advance care plan 46.7%, have not 53.3%.

State or territory

Disclosed state or territory of residence of respondents who answered VAD question 1:

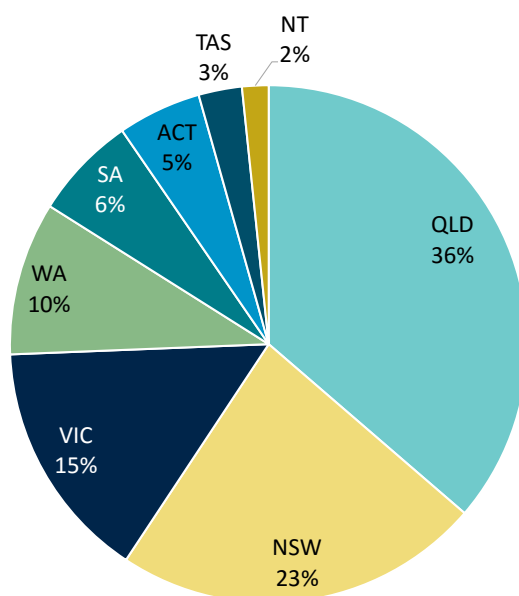


Figure A1 Distribution of survey participants who answered VAD Q1 by state and territory. The percentages are not proportionate to national populations of Australian seniors, in particular oversampling Queenslanders compared to national populations, so caution should be exercised in drawing any conclusions related to state or territory. A small number of survey participants did not answer the state/territory question.

Distribution of VAD views by state and territory (differences not statistically significant):

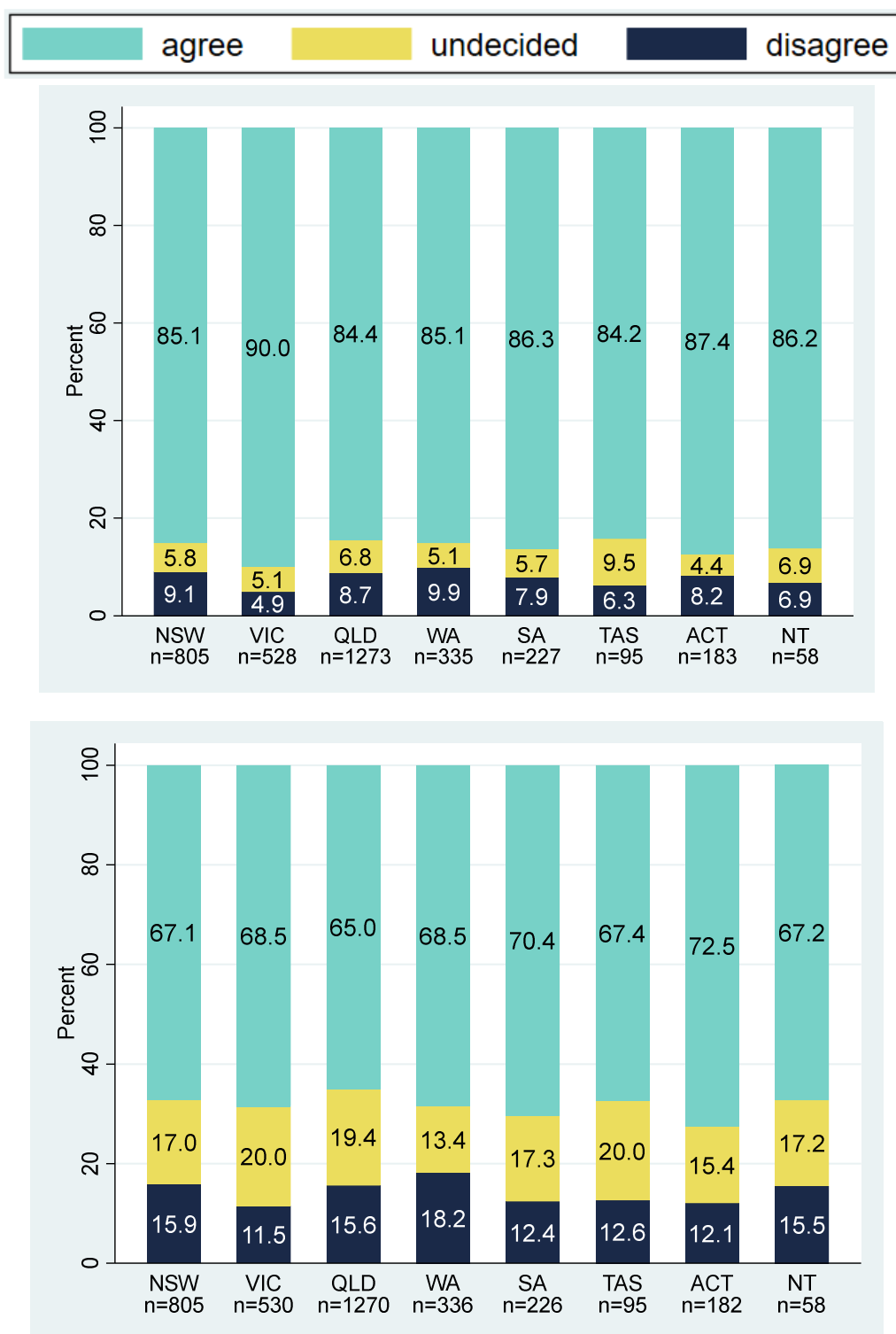


Figure A2 Distribution of combined agreement, combined disagreement, and undecided status on VAD questions by state and territory. The top graph is for VAD Q1 pertaining to terminal illness, and the bottom graph is for VAD Q2 pertaining to non-terminal illness. Statistical tests showed there was no statistically significant difference between the states and territories, with any apparent differences able to be explained as chance events. We included this figure for the interest of survey participants, not to imply significant differences between jurisdictions, especially given our survey's disproportionate representation of the states and territories (illustrated in Figure A1).

Support if you are feeling distressed

If reading this report or thinking about Voluntary Assisted Dying has raised issues of grief, stress or personal crisis for you, support and counselling are available from these services, or find others at <https://www.healthdirect.gov.au/mental-health-helplines>.

Lifeline – 24/7 crisis support and counselling

Telephone support and counselling 24 hours a day, 7 days a week 13 11 14
Crisis text service 12pm to 2am (Sydney time) 0477 13 11 14
Online chat service 7pm to 2am (Sydney time) <https://www.lifeline.org.au/crisis-chat/>

Suicide Call Back Service – 24/7 crisis counselling if you are feeling suicidal

Telephone counselling 24 hours a day, 7 days a week 1300 659 467
Online chat 24 hours a day, 7 days a week <https://www.suicidecallbackservice.org.au/>
Video chat by appointment, details at website

Friendline – 24/7 non-crisis service for anyone feeling lonely or who just wants to chat

Telephone chat 10am-8pm, 7 days a week 1800 424 287
Online chat 1pm-5pm Tue/Wed/Thu (at the page, select region) <https://friendline.org.au/>

Beyond Blue – short-term counselling, info and referrals about depression and anxiety

Telephone advice 24 hours a day, 7 days a week 1300 22 4636
Website, including access to online chat <https://www.beyondblue.org.au/>

QLife – support and information for LGBTI people of all ages

Telephone support 3pm-12am (local time, Australia wide) 1800 184 527
Webchat service 3pm-12am (local time, Australia wide) <https://qlife.org.au/resources/chat>

More information about VAD

You can find out more about Australian end of life laws including VAD legislation at these non-government websites:

Queensland University of Technology (QUT) End of Life Law in Australia website

End of life legal overview: <https://end-of-life.qut.edu.au/legal-overview>

VAD: <https://end-of-life.qut.edu.au/euthanasia>

End of Life Directions for Aged Care (ELDAC) website and toolkits

End of Life Law Toolkit: <https://www.eldac.com.au/tabid/4902/Default.aspx>

VAD: <https://www.eldac.com.au/tabid/5755/Default.aspx>

These state government websites have state-specific information about VAD:

Health.vic

<https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying>

WA Health

<https://www2.health.wa.gov.au/voluntaryassisteddying>

Tasmanian Department of Health

<https://www.health.tas.gov.au/vad>

SA Health

<https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/services/primary+and+specialised+services/voluntary+assisted+dying/voluntary+assisted+dying+in+south+australia>

Queensland Health

<https://www.health.qld.gov.au/system-governance/legislation/voluntary-assisted-dying-bill>

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