



**dementia
australia™**

The new voice of Alzheimer's Australia

Ministerial Expert Panel on Voluntary Assisted Dying

A response from Dementia Australia

May 2019

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 447,115 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.



Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Ministerial Expert panel on Voluntary Assisted Dying. Dementia Australia consulted with Dementia Australia advocates across Western Australia – including people living with dementia, families and current or former carers – in developing this submission.

People with dementia will differ in the rate at which their abilities deteriorate. However, it is inevitable that a dementia diagnosis will lead to progressive cognitive and functional decline. Most people in the later stages of dementia need significant care and support across almost every aspect of their life. In the later stages of dementia people will often experience more complex personal and clinical care needs, in addition to experiencing psychological pain and distress. Access to high quality palliative care and end-of-life support is therefore of peak importance to people living with dementia, their families and carers. Dementia Australia believes people with dementia should be able to exercise choice over how they die, be able to die with dignity and without pain – and for those who may choose to do so – access voluntary assisted dying.

Dementia Australia is neither for nor against voluntary assisted dying. However, we support the right of people with dementia to have choice in their end of life care, including their right to access voluntary assisted dying measures where they are available. Therefore, Dementia Australia's key position throughout this paper is to promote the inclusion of people living with dementia in legislation that enables voluntary assisted dying.

Background

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning including loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, and frontotemporal dementia. Dementia is a progressive neurological disability and is the leading cause of disability burden for people over the age of 65 years in Australia.¹

Dementia is one of the largest health and social challenges facing Australia and the world. Dementia is not a natural part of ageing. It is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country, and is predicted to become the leading cause of death within the next five years.²

There are 447,115 Australians living with dementia and without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056.

In Western Australia, there is an estimated 41,630 people living with dementia in 2019. Without a medical breakthrough, the number of people living with dementia is expected to increase to an estimated 56,886 people by 2028 and 107,664 people by 2058. Dementia affects people's abilities and memories and has a profound impact on the individual and their

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

² Australian Bureau of Statistics (2016) *Dementia: Australia's leading cause of death?* Accessed online

loved ones. It is cloaked in stigma and misunderstanding, isolates people with dementia and their carers from social networks, and carries significant social and economic consequences. People living with dementia constitute one of the most vulnerable groups in our society.

Response to discussion paper questions

1. The Decision

This section responds to the following questions:

- a) *Should health practitioners be able to discuss voluntary assisted dying with their patients in the same way they raise and discuss other health or medical decisions and care options?*
- b) *What initiatives should be considered to ensure people are properly informed about voluntary assisted dying and supported in the decision making process?*
- c) *How should capacity be determined and should a medical practitioner be able to refer to other health practitioners?*
- d) *Should there be consideration to people who lose their capacity?*

Informed decision making

A gradual decline in cognitive function is a typical symptom of dementia. Some individuals may experience this decline much sooner than others, and generally the rate of cognitive decline is hard to predict. Declining cognitive function often leaves people with dementia vulnerable to multiple forms of abuse, including physical, psychological and financial. Therefore, it is important that appropriate safeguards are in place to ensure people with dementia are not being pressured into a decision.

One safeguard that is often adopted, is enabling a family member, carer or friend to act on behalf of the person living with dementia, from a point in time where their own decision making becomes impaired. By enabling a family member or carer to act on their behalf, the individual has assurance that a representative will ensure their wishes are being upheld, beyond a point where they are able to do so themselves.

Recommendation 1: That family members and trusted carers be included in decision making, where the individual with dementia has given consent to do so.

Both within and outside the context of voluntary assisted dying, Dementia Australia advocates for the inclusion of trusted family members and carers in decision making.

Our advocates – which includes people living with dementia, family and carers – support the recommendation that family members and carers should have the opportunity to be included in the decision making process for assisted dying, providing the following conditions are met. First, the person living with dementia must have capacity at the point of making the initial request for voluntary assisted dying. Second, the person with dementia must formally consented for others to be involved.

“We make arrangements for their financial security, we do the forms to ensure guardianship is organised, we get family members to do an advanced health directive early, but do insufficient to ensure that good palliation for end-of-life is provided.”

Carer of a person living with dementia

Recommendation 2: That medical and care professionals use supported decision making practices to support people with dementia to make independent decisions regarding their care

Whilst cognitive decline is inevitable for people living with dementia, it is important to note that many people with dementia – especially those in the early stages – maintain the capacity to make decisions on their own behalf. Given the unpredictability of cognitive decline, it is unjust to assume that anyone with dementia at any specific stage does not have capacity to make decisions on their own behalf. Until the individual living with dementia reaches the point where their decision-making becomes inconsistent, medical and care practitioners need to support people with dementia to make an informed decision.

Supported decision making describes a set of techniques that support people with cognitive impairment, such as people with dementia, to make informed and independent decisions. Techniques include; getting to know the individual, understanding what their preferences are and simplifying jargon so complex information, such as health and finance can be understood. These techniques have proven to help individuals make informed decisions on a range of everyday activities, from shopping to decisions regarding finances or their health care.

As a basic safeguard against coercion or being pressured into decision making, supported decision making techniques enables people with dementia to comprehend information and make independent and informed decisions about their own care.

Dementia Australia has long advocated for the inclusion of supported decision making practices both within and outside the context of voluntary assisted dying.

Recommendation 3: Western Australia Health should ensure that all staff, including medical practitioners and decision makers receive specific dementia training

A lack of dementia-specific knowledge is well documented across a number of professional groups, including aged care workers, community groups and even medical practitioners – who have reported on their lack of confidence in diagnosing dementia.³ Without a working understanding of dementia, the symptoms associated and the progressive nature of the condition, we cannot expect accurate and informed decisions to be made by medical or care staff with regards to their care. Therefore, mandatory dementia education for all care and medical staff should be seen as a critical priority across all states and territories.

³ Brodaty, H. H (1994) General practice and dementia: a national survey of Australian GPs. Medical Journal of Australia, 10-14

In order to appropriately support an individual's end of life decision, medical professional must have the appropriate skills and training. Dementia Australia supports a collaborative approach, whereby medical professionals in addition to receiving dementia training, utilise the expertise of neuropsychologists, geriatricians, palliative care professionals and dementia experts to ensure the best possible advice is being given to the people with dementia.

Recommendation 4: That medical practitioners and decision makers include the topic of voluntary assisted dying in early end-of-life conversations

Preparing an advanced health directive enables people with terminal and degenerative conditions, like dementia, to state their wishes for their care, whilst they are still able to. Preparing an advanced health directive in the earlier stages of dementia, is generally seen as good practice.

Our advocates, which includes people with dementia, their family and carers, believe that a conversation on end-of-life plans should include the topic of voluntary assisted dying, within the wider context of end-of-life and palliative care options. Informing people with dementia of all the options for end of life care is critical to enabling individuals to make an informed decision.

However, when asked about medical professionals proactively raising the topic of voluntary assisted dying, people with dementia and their families had mixed views. Broadly, individuals with whom Dementia Australia consulted preferred that the topic of voluntary assisted dying be incorporated within the wider options for palliative and end-of-life care for people with dementia. Alternatively, they suggested that information on assisted dying be provided for anyone who asks.

“Early discussions on lifestyle and needs, including this topic (voluntary assisted dying) should be part of the Advanced health directive.”

Carer of a person living with dementia

Capacity for decision making

Recommendation 5: People living with dementia, whose capacity for decision making remains intact, should be eligible for voluntary assisted dying

It is often assumed that people with dementia lack the capacity to make decisions, due to the experience of cognitive decline. Whilst it is true that people with dementia will experience cognitive decline at some point in their journey, the rate of cognitive decline is difficult to predict. Some people living with dementia will maintain their cognitive capacity for a long time following a diagnosis, others will experience decline much quicker.

Dementia Australia supports the view that, if a person living with dementia wishes to access voluntary assisted dying, whilst their cognitive function is unimpaired, they should maintain the same rights as others to do so. We do not believe that the eventual experience of cognitive decline should, in itself, disallow all individuals with dementia from accessing assisted dying.

“My wife is seven years into her journey (with dementia) but still has the ability to make decisions and she has always stated that she wants to end it all when the quality of life has gone.”

Partner of someone living with dementia

Recommendation 6: Western Australian legislation on voluntary assisted dying should consider allowing people with dementia to make enduring requests for voluntary assisted dying in advanced care directives

Given the progressive nature of dementia and other neurocognitive diseases, legislation on voluntary assisted dying should give consideration to people who may lose capacity throughout their diagnosis. Provisions should be considered to ensure that people who anticipate a loss in capacity have the opportunity to express their wishes for end-of-life care and have assurance of those wishes being upheld.

For individuals who anticipate a loss in cognitive capacity, preparation is key. Advanced health directives are a means of ensuring that an individual’s wishes for their end-of-life care are upheld at a point in time where they are unable to communicate those wishes themselves. An advanced health directive should incorporate the individual’s end-of-life wishes, which for some may include accessing voluntary assisted dying if their quality of life decreases beyond a point that is not acceptable to the person.

“I support assisted death for terminally ill people who have expressed that wish at an earlier point in their illness when they are able to do so. I don’t want to creep endlessly into the night over weeks, or months or even years.”

Person living with dementia

Many of Dementia Australia’s advocates argue that disallowing voluntary assisted dying instructions in advance care plans would create yet another barrier to people with dementia having genuine choice and control in end of life.

They argue that people with incurable, degenerative diseases should, if they wish, be able to participate in voluntary assisted dying by working with their medical team, Medical Enduring Power of Attorney and other family members to identify a quality of life or level of suffering which would be unacceptable to them and record this in their advance care plan (or other binding document). The person with dementia could then, if that is their choice, recommend that voluntary assisted dying be administered at a time when their medical team and family agree that their quality of life has declined in a way that meets their stated wishes.

Enabling people living with dementia to apply for voluntary assisted dying through an advanced care directive, would allow people with dementia, their families and carers peace of mind, that when they reached a significant level of pain their end-of-life plans would come into action. Preventing them from dying in an unwanted and undignified way.

“As dementia will often take away the person’s ability to speak, to communicate pain and suffering, the legislative framework should allow for identification of what the person would consider as enduring and unbearable suffering, at a point in time when they have capacity to express themselves.”

Daughter of a person with dementia

“Long term planning needs to be offered to people with dementia and families as early as possible to ensure no coercion is possible.”

Carer of a person living with dementia

2. Eligible conditions

This section responds to the question:

- a) If voluntary assisted dying only applies to an illness or disease that is terminal, is specification of a timeframe either desirable or necessary?

Recommendation 7: The application of a timeframe is neither desirable nor necessary. The Exert Panel should consider alternative eligibility indicators, such as decline in quality of life or function.

As mentioned previously in this paper, the prognosis for someone with dementia is difficult to predict. Whilst we know that symptoms of dementia will progressively worsen as the disease progresses, the speed of progression differs amongst individuals.

People in the severe or later stages of dementia not only experience more severe cognitive symptoms, but physical symptoms, such as being unable to eat or swallow, limited communication and speech, and reduced ability to control bodily functions. Many people in the later stages require assistance with almost every aspect of their daily living, and left inadequately supported, can experience a significant decrease in quality of life.

The unpredictability of dementia’s progression means that some individuals will experience pain and discomfort much sooner than others, and people can become palliative at any stage of their journey. Therefore implementing a timeframe would likely exclude people with degenerative diseases from accessing voluntary assisted dying.

People with dementia, their families and carers feel that implementing a timeframe would unjustly prohibit people with dementia from having choice and control over their death.

“Timeframes are too difficult, people who are at end of life can have a turn for the better, but this is not possible with dementia.”

Carer of a person living with dementia

Rather than opting to implement a timeframe, a number of individuals suggested that the severity of symptoms that individuals are experiencing and the individuals overall quality of life is a better indicator for eligibility.

3. The process

This section responds to the question:

- b) What other ways are there to appropriately enable access to voluntary assisted dying?

Dementia Australia welcomes the Joint Select Committee's recommendations to develop a telephone access line, community education and resources that would help to facilitate access to assisted dying.

As with any new legislation, communicating the process of voluntary assisted dying, the eligibility requirements and what it entails is incredibly important to ensuring people are making a fully informed decision. People with dementia often highlight the issue of information not being 'user-friendly' and difficult to engage with. Simple techniques, such as writing in plain language and using visual aids can easily remedy written documents – therefore making it usable for people with dementia.

Dementia Australia have developed a set of resources through our Dementia-Friendly Communities program. [Here](#) you will be able to find resources and guidelines to producing dementia-friendly resources, which will aid access for people living with dementia.

As mentioned earlier in this paper, engaging in early conversations about end-of-life decisions is encouraged for people diagnosed with dementia. Early conversations allow people with dementia to consider the full spectrum of options carefully, whilst they are still able to.

Conclusion

Dementia is a terminal and incurable condition – which is currently affecting 447,115 people across Australia and 41,630 in Western Australia. Dementia Australia believes that people with dementia should have the same rights as others when it comes to end of life choices, which includes access to voluntary assisted dying. On behalf of those living with dementia, their families and carers we ask the Expert Panel to consider our recommendations.