



A legal framework for voluntary assisted dying – consultation paper

Queensland Law Reform Commission

27 November 2020

About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Queensland Law Reform Commission's consultation paper on a legal framework for voluntary assisted dying. The Royal Commission into Aged Care Quality and Safety has shone a light on a number of challenges across aged care services, which impact the lives of people living with dementia, their families and carers. These challenges arise from the point of diagnosis, where access to support, and navigating the aged care system proves difficult for many individuals.

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 response is to promote the inclusion of people living with dementia in legislation that enables voluntary assisted dying.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. It is one of the largest health and social challenges facing Australia and the world. It is estimated that there are more than 459,000 Australians living with dementia in 2020¹ and around 1.6 million people² involved in their care. In 2020, there is an estimated 87,700 people living with dementia in Queensland. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³

¹ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

² Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016*, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

³ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

Recommendations

Consultation with people living with dementia, their families and carers have informed the following recommendations for the implementation of voluntary assisted dying legislation in Queensland:

Recommendation 1: That psychological pain be recognised in addition to physical pain

Recommendation 2: That family members are included in assisted dying decision making with the person's consent and with the proper protections for the person

Recommendation 3: That the right of a person with dementia to be fully informed is upheld and that medical practitioners are appropriately trained in dementia care

Recommendation 4: That people with degenerative disorders have the ability to make enduring requests for voluntary assisted dying in an advanced care plan

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

Recommendation 6: The application of a timeframe is neither desirable nor necessary. The Commission should consider alternative eligibility indicators, such as decline in quality of life or function.

Voluntary Assisted Dying

Dementia Australia have consulted with consumers across states and territories, who have mixed views towards voluntary assisted dying. Some are strongly in favour of it in being legislated, while others are opposed. Similarly, it is important to note that although this response suggests support towards assisted dying legislation, this should not be taken as encompassing all of the diverse views and experiences of all people with dementia and carers.

Overall, Dementia Australia is neither for nor against assisted dying. We do advocate, however, that all individuals should have a choice and that any potential legislation regarding voluntary assisted dying does not exclude people living with dementia – who we believe should be entitled to the same end of life options as others. Unlike other terminal conditions, the later stages of dementia often hinder communication and cognition. This means that people with dementia are more likely to be given unwanted life-sustaining treatments, and are often denied the choice in how and when they die. A 2014 survey highlighted that one in four former carers were dissatisfied with the care their loved one received at the end of life.⁴

A dignified death requires planning and support, especially for people with terminal and progressive diagnoses like dementia. Without choice and informed options, people with

⁴ Alzheimer's Australia (2014) *End of life care for people with dementia survey report*

dementia are forced to die in uncomfortable and unwanted conditions – not only does this impact the person living with dementia, but their family and carers.

“As much as I believe in life being a gift of god to be cherished and respected, I believe no human being should be allowed to suffer in pain and total lack of dignity as I have witnessed my loved ones that I have cared for.” Carer of a person living with dementia

As dementia progresses, the need for support with every day activities increases, often to the point where people require support for almost all aspects of their personal care. This gradual loss of independent living often bares a strong psychological impact of people living with dementia. Feelings of frustration, loss of dignity, embarrassment and depression are often experienced by people living with dementia, especially those in the later stages.

For these reasons, the emotional pain and psychological pain associated with terminal diagnoses should be considered within the qualification for voluntary assisted dying.

Recommendation 1: That psychological pain be recognised in addition to physical pain.

Whilst we stress the need for inclusion for people with dementia in to access voluntary assisted dying, it is also imperative that there are strong safeguards to ensure people living with dementia are not directly or indirectly pressured into a decision. The gradual decline in cognitive function can make people with dementia vulnerable to abuse and neglect. This can be a concern for the person with dementia, their families and carers.

Dementia Australia 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 voluntary 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 have formally consented for others to be involved.

Providing there is consent from the individual for others to be involved, we believe that it is important for family members and carers be included in the voluntary assisted dying process and be given equal access to support and information throughout the process.

Recommendation 2: That family members are included in assisted dying decision making with the person’s consent and with the proper protections for the person.

Despite its prevalence, understanding and awareness of dementia still remains low. A lack of dementia specific knowledge is well documented across a number of groups, including aged care workers, community groups and even medical practitioners – who have reported on their lack of confidence in diagnosing dementia.⁵

⁵ Brodaty, H. H (1994) General practice and dementia: a national survey of Australian GP’s. 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.

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

Recommendation 3: That the right of a person with dementia to be fully informed is upheld and that medical practitioners are appropriately trained in dementia care.

Disallowing voluntary assisted dying instructions in advance care plans creates yet another barrier to people with dementia having genuine choice and control in end of life. 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 pain 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.

Allowing people with dementia to provide instruction on voluntary assisted dying in an advance care directive would need to override any legislation that stipulates a prognosis of days or weeks remaining. Legislation in Victoria prohibits people with progressively deteriorating cognitive impairment from accessing voluntary assisted dying. There is an opportunity for Queensland to take this into consideration in the development of voluntary assisted dying legislation.

“Prohibiting the request from being made in an advance care directive and requiring that a medical practitioner must deem that a person is at the end of life when the request is made, would exclude persons with dementia accessing voluntary assisted dying. Those persons who would fall outside the proposed legislative framework will be left to die an excruciatingly painful death.” – Daughter of a person with dementia

Recommendation 4: That people with degenerative disorders have the ability to make enduring requests for voluntary assisted dying in an advanced care plan.

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

As mentioned previously in this response, 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.

Recommendation 6: The application of a timeframe is neither desirable nor necessary. The Commission should consider alternative eligibility indicators, such as decline in quality of life or function.

Conclusion

Dementia is a terminal and incurable condition – which is currently affecting 459,000 people across Australia and 87,700 in Queensland. Dementia Australia believes that people with dementia should have the same rights as others when it comes to end of life choices, both with regards to palliative care and voluntary assisted dying. We ask the Committee to

consider our recommendations made on behalf of those living with dementia, their families and carers.