



**Dementia
Australia™**

Provisions of the Voluntary Assisted Dying Bill 2021

A submission to the NSW Standing Committee on Law and
Justice

22 November 2021

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 NSW Standing Committee on Law and Justice in response to the Provisions of the Voluntary Assisted Dying Bill 2021. Given the complexity of this issue for people living with dementia and the need to provide a nuanced response to the Bill, rather than complete the online questionnaire, we have prepared a submission.

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 estimated that there are up to 472,000 Australians living with dementia in 2021¹ and around 1.6 million people² involved in their care. In 2021, there is an estimated 157,000 people living with dementia in NSW.³ Without a significant medical breakthrough, there will be 375,000 people in NSW and almost 1.1 million people in Australia living with dementia by 2058.⁴

Dementia as a life-limiting condition

Every individual diagnosed with dementia will experience the condition differently, but dementia is life-limiting and progressive and leads to increasing cognitive and functional decline. In the advanced stages, a person living with dementia will often have complex personal and clinical care needs, and may experience psychological pain and distress.

Dementia Australia believes in universal access to all medical services for every Australian regardless of their socioeconomic and other circumstances. Consistent with this, we believe that people living with dementia have the right to high quality palliative and end-of-life support care, delivered in a timely manner commensurate with other health care service consumers.

Unlike other terminal conditions, the later stages of dementia are often characterised by declining cognition and increasing difficulties with verbal communication. People in the later stages of dementia not only experience more severe cognitive symptoms, but physical symptoms including swallowing difficulties, limited communication and

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

⁴ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

speech, and reduced ability to control bodily functions. Assistance is often required with almost every aspect of daily living and if not cared for and supported appropriately, people living with dementia can experience a significant decrease in quality of life.

In these later stages, people with dementia may be less able to articulate their treatment and care preferences and are less likely to be offered choices in relation to end of life care wishes. People with late-stage dementia are also more likely to be given unwanted life-sustaining treatments. In addition to physical symptoms, a person with dementia in the advanced stages can experience increasing emotional, psychological and existential distress. A 2014 survey highlighted that one in four former carers were dissatisfied with the care their family member received at the end of life.⁵

A well-managed death requires careful planning and support, especially for people with progressive conditions associated with cognitive decline, including dementia. Given the variable illness trajectory for dementia, planning for end of life can often present challenges for people with dementia, their families and carers and can result in poor end of life outcomes. Supported decision-making, involving the person with dementia for as long as possible, is an important part of addressing challenges associated with end-of-life care planning.

Voluntary Assisted Dying

Australian States have progressively introduced voluntary assisted dying legislation over the last five years. Dementia Australia has consulted widely on this issue with people living with dementia, their families and carers. As with the broader Australian population, the people we represent have diverse views on voluntary assisted dying. As the peak advocacy body for people impacted by dementia, Dementia Australia reflects this diversity of opinion in neither supporting nor rejecting the concept of voluntary assisted dying as an organisation.

Dementia Australia believes that as with every other Australian citizen, a person living with dementia should be able to exercise choice over where and how they die - and this includes the right to access voluntary assisted dying measures. Dementia Australia notes that people living with dementia have been excluded from existing voluntary assisted dying legislation. We also note that the proposed NSW Voluntary Assisted Dying Bill 2021 stipulates that only people whose terminal disease will cause death within six months, or 12 months for neurodegenerative conditions, qualify. Multiple assessments of decision-making capacity are also required. Both these criteria would effectively prevent people living with dementia from accessing the proposed voluntary assisted dying measures.

⁵ Alzheimer's Australia (2014) *End of life care for people with dementia survey report*

Dementia Australia believes that people diagnosed with dementia should be able to access high quality palliative and end of life care support and services. Equally, we believe that people with dementia have the right to bodily and cognitive autonomy and should therefore have the right to access voluntary assisted dying measures.

Dementia Australia offers partial support for the proposed NSW Voluntary Assisted Dying Bill 2021. This partial support is accompanied by a recommendation to review the current criteria in relation to people with neurodegenerative conditions and a 12-month prognosis. Dementia Australia believes further consultation in relation to what is included in the neurodegenerative category and the current time frame of 12-months is warranted to understand how people with these conditions currently access voluntary assisted dying and to consider how that access might re-evaluated in the future.

Safeguards to protect vulnerable people

Dementia Australia supports the right of people with dementia to access voluntary assisted dying measures but equally understands the importance of strong safeguards to ensure decision-making is not subject to direct or indirect influence. Declining cognitive function can make people with dementia vulnerable to abuse and neglect.

Despite its prevalence, understanding and awareness of dementia in the broader community remains poor. The lack of dementia specific knowledge is well documented within the health care sector including aged care and acute care settings. Medical practitioners have self-reported their lack of confidence in diagnosing dementia.⁶

Medical professionals must have the appropriate skills and training in understanding dementia to provide effective and competent support for end of life decision-making. Dementia Australia supports a multidisciplinary, collaborative approach, where medical professionals liaise with neuropsychologists, geriatricians, palliative care professionals and dementia experts to ensure the best possible advice is being given to the person with dementia and their support decision-maker.

A supported decision-making approach mitigates against the possibility of coercion or influence and ensures people living with dementia are supported to make independent and informed decisions about their own care. People living with incurable, neurodegenerative diseases including dementia should be supported to access voluntary assisted dying measures by working with their medical team, Enduring Power of Attorney/Guardian 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 another binding document). A person with dementia could specify their desire for voluntary assisted dying measures in an advance care plan, and this could subsequently be enacted at a time when their medical team and family agree that their quality of life has declined to a point that conforms with their

⁶ Brodaty, H. (1994) General practice and dementia: a national survey of Australian GPs, *Medical Journal of Australia*, 10-14

stated wishes. Disallowing voluntary assisted dying instructions in advance care plans for people with dementia works against their autonomy and the right to make decisions about their own health care.

Allowing people with dementia to provide instructions 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 NSW to take this into consideration in the development of voluntary assisted dying legislation.

Dementia and decision-making capacity

It is often assumed that people with dementia, and associated cognitive decline, lack the capacity to make decisions. A person with dementia will experience cognitive decline but this depends on the type of dementia and a range of other variables and will be different for every individual. Some people living with dementia will maintain a degree of cognitive capacity for a significant time post-diagnosis, others will experience a more rapid deterioration.

Decision-making capacity encompasses a person's ability to understand information that may be relevant to the decision including the consequences, to retain this information (even if only for a short time), to use the information for decision-making purposes and to communicate those decisions. Dementia Australia supports the view that if a person living with dementia has a degree of intact cognitive function and wishes to access voluntary assisted dying, they have the same right as any other Australian citizen to do so. We do not believe that the eventual experience of cognitive decline should disqualify all individuals with dementia from accessing voluntary assisted dying measures.

Furthermore, given the variable dementia trajectory, the 12-month time frame in the proposed legislation would potentially exclude many people with neurodegenerative conditions including dementia, from qualifying. Dementia Australia believes that an alternative framework that could be considered would evaluate the severity of symptoms and reduction in overall quality of life. This would arguably constitute a more accurate and realistic criteria for eligibility, noting the challenges associated in determining this.

Conclusion

Dementia is a progressive, life-limiting and incurable condition. Dementia Australia believes that people living with dementia should have the same rights as other Australian citizens in relation to end of life care choices including access to high quality palliative care and voluntary assisted dying measures. Dementia Australia offers partial support for the proposed NSW Voluntary Assisted Dying Bill 2021 with the accompanying recommendation to review the current criteria as outlined above. We respectfully ask the Committee to consider the issues raised in our submission and would welcome the opportunity for further consultation.