



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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The new voice of Alzheimer's Australia

ACT Legislative Assembly Select Committee Inquiry on End of Life Choices in the ACT

Submission from Dementia Australia

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About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people of all ages, living with all forms of dementia, their families and carers. We represent the more than 425,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care.

Dementia Australia works with consumers, all levels of government, and other key stakeholders to ensure that people with 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 consumers 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 ACT Legislative Assembly Select Committee *Inquiry on End of Life Choices in the ACT*.

Dementia Australia consulted with our consumers (including people living with dementia and current and former carers) in developing this submission.

Access to quality palliative care, whether that be in an individual's home or in a residential aged care facility, is critical to ensuring people with dementia die well. It is imperative that aged care staff are appropriately skilled to deliver palliative care to people with dementia.

Dementia Australia is neither for nor against voluntary assisted dying. 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.

Background Information

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 In 2016 alone, there were 163 deaths attributed to dementia in the ACT.³

There are more than 425,000 Australians living with dementia in 2018 (including 25,000 people under the age of 65 years with younger onset dementia) and, without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056.

There were an estimated 5,369 people with dementia living in the ACT in 2017. This number is expected to increase to 7,353 in 2025 and 16,313 by 2056 without a significant medical breakthrough. The rates of growth in the number of persons predicted to have dementia are higher than the national average in the ACT. Dementia is estimated to cost the ACT \$211 million in 2017, an amount which is expected to soar to \$282 million in eight years, by 2025, and to \$586 million by 2056.⁴

Dementia affects people's abilities and memories and has a profound impact on the individual and their loved ones⁵. It is cloaked in stigma and misunderstanding⁶, isolates

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

³ Australian Bureau of Statistics (2017) *Causes of Death, Australia, 2016* Accessed online

⁴ The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017) *Economic Cost of Dementia in Australia 2016-2056*

⁵ Mitchell, S. *et al.* (2009) The clinical course of advanced dementia, *The New England Journal of Medicine*, 361: 1529-38

⁶ George, D. (2010) Overcoming the 'Social Death' of Dementia through Language, *The Lancet*, 376: 586-87

people with dementia and their carers from social networks⁷, and carries significant social and economic consequences⁸. People living with dementia constitute one of the most vulnerable groups in our society.

Response to Inquiry Terms of Reference

(a) current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;

Palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. It is an approach that improves the quality of life of patients and their families facing a terminal condition. Quality of life is improved through prevention and relief of suffering by means of early identification and assessment and treatment of pain, as well as addressing physical, psychosocial and spiritual concerns.⁹

Although palliative care has traditionally been an approach associated with people with cancer, dementia is now recognised as a terminal condition for which palliative care is appropriate and necessary.

On average, people with dementia survive for three to ten years from the point of diagnosis¹⁰. However, survival prognosis is very difficult in dementia and is influenced by various factors including age, gender, type of dementia, the person's comorbidities, and the severity of the illness at the time of diagnosis.

Dementia, especially Alzheimer's disease, can be broadly categorised into three phases: mild, moderate, and severe. People in severe or late stage dementia experience not only severe memory loss but physical symptoms such as being unable eat or swallow, limited or no speech, and inability to control bodily functions. People in these later stages require assistance with nearly all aspects of personal care. However, people with dementia may become palliative at any stage of their journey. People with mild to moderate dementia may be in the end stage of other terminal comorbidities, such as organ failure or cancer.

Currently, there is no single tool for accurately predicting the need for palliative or end-of-life care in people with dementia. Further, there are no dedicated programs for specialist palliative care specific to dementia available.¹¹

My late husband had an advanced care directive; we had a package of care for 6 months, then he was in residential care for 4 months but he moved back home for the last two months of his life and he died at home. I employed carers to assist with his needs each day. We had the services of palliative nursing for the last few days of his life. (Former carer of a person with dementia)

⁷ Blay, S. & Peluso, E. (2010) Public Stigma: The community's tolerance of Alzheimer's disease, *American Journal of Geriatric Psychiatry*, 18(2): 163-7

⁸ Access Economics (2003) *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia, Available at: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

⁹ Parker, D., Lewis, J. and K. Gourlay (2017) *Palliative Care and Dementia*, Paper No. 43 for Dementia Australia (yet to be released)

¹⁰ Brodaty, H. S. (2012) Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia, *International Psychogeriatrics*, 1034-1045.

¹¹ Parker, D., Lewis, J. and K. Gourlay (2017) *Palliative Care and Dementia*, Paper No. 43 for Dementia Australia (yet to be released)

People with dementia being cared for at home or in a residential aged care facility may receive specialist community palliative care services. However, in comparison to patients with cancer, the proportion of people with a diagnosis of dementia using specialist palliative care services is low (75.4% versus 2.4%)¹². Many people with dementia die in hospitals and receive palliation there.

Until quite recently, it was widely believed that people with dementia could not feel pain. This lack of understanding has had devastating consequences for people with dementia, particularly at the end of life. Pain is often exhibited in changed behaviour resulting in unnecessary use of antipsychotic medications.

We know from what our consumers tell us that people with dementia still struggle to access palliative care or receive care in a timely fashion; they are given inappropriate life-sustaining or invasive procedures; and they receive inadequate pain management. Encouraging improvements in the quality and appropriateness of care keep us hopeful, yet there is still much work to be done to improve the quality of care provided to people with dementia at the end of their lives¹³.

End of life care can be done a lot better. Palliative care being more active in the end of life. Staff being well educated making people comfortable especially people living in care. Educating people earlier in life to have their advance plan in place. (Current carer of a person with dementia)

People in the later stages of dementia have an increased risk of experiencing unrecognised or poorly managed pain. They are vulnerable to accidents, injuries and falls and will often experience cognitive and speech difficulties that mean that they cannot communicate their pain. The symptoms of late stage dementia – immobility, swallowing difficulties, and incontinence – make people highly susceptible to recurring chronic infections and ulcers. In the United Kingdom, two thirds of people with dementia ultimately die from pneumonia¹⁴. People with dementia are three times more likely to receive emergency interventions and invasive procedures than people of comparable age with a different terminal illness, such as cancer¹⁵.

Dementia is different from other terminal illnesses in that in the later stages of the disease symptoms hinder communication and cognition. Unfortunately, this means that people with dementia are at increased risk of receiving not only unwanted life-sustaining treatments, but being denied a choice in how and when they die. In a survey commissioned by Alzheimer's Australia, one in four former carers were dissatisfied with the care their loved one received at the end of life¹⁶.

A good death for people with dementia is unlikely to happen as a matter of course. A dignified death requires proper planning and support to ensure that the person's wishes are respected. An advance care plan and the nomination of a guardian in the ACT enable a person with dementia to ensure that their preferences are known should a medical or end of life decision need to be made after they have lost capacity.

¹² Palliative Care Outcomes Collaboration (2017) Patient outcomes in Palliative Care: National results for July – December 2016 Detailed report. Wollongong: University of Wollongong cited in Parker, D., Lewis, J. and K. Gourlay (2017) *Palliative Care and Dementia*, Paper No. 43 for Dementia Australia

¹³ Alzheimer's Australia Victoria (2016) *A Good Death is My Right – Response of people with dementia and carers to the Voluntary Assisted Dying Bill Discussion Paper*

¹⁴ Alzheimer's Society (2012) *My Life Until the End: Dying Well with Dementia*, London

¹⁵ Mitchell, S. L. (2006) *Advanced Dementia Research in the Nursing Home: The CASCADE Study*, Alzheimer's Disease Association Disorders, 166-175

¹⁶ Alzheimer's Australia (2014) *End of Life Care for People with Dementia Survey Report*

Despite the high prevalence of dementia in our community, medical understanding of the condition remains low. In a survey of health professionals conducted by Dementia Australia, 41 percent said they had inadequate training in identifying pain in people with dementia and 90 percent felt that they would benefit from additional palliative care training¹⁷.

Medical professionals should have access to appropriate training and resources to support end of life choices for people with dementia. A collaborative approach, drawing on expertise of neuropsychologists, geriatricians, palliative care professionals, and dementia experts, will ensure people have a greater understanding of their illness and available treatment options¹⁸.

Both the hospital and RACF staff were very honest and caring/considerate with the family about my stepfather's condition and expected progress, they also gave us time to think about and discuss his condition before his death. Dying at home was unfortunately not possible. (Carer of multiple family members)

[I would like end of life care in the ACT to be] as peaceful and dignified as possible and preferably at home. (Former carer of a person with dementia)

Palliative care to support people with dementia to die at home if that is their wish is required. Many people with dementia, especially in their end of life, will need to enter residential aged care. It is therefore imperative that residential aged care staff are appropriately skilled and trained to deliver palliative care to people with dementia.

(b) ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;

Dementia Australia consulted with consumers in the ACT and their views on voluntary assisted dying varied. Some are strongly in favour of it in being legislated in the ACT, while others are opposed.

It should be legalised and also be available for people with dementia based on wishes expressed prior to loss of capacity. (Former carer of a person with dementia)

I believe in euthanasia, but so hard to know how to apply it. Some patients/clients will have the capacity to make that choice towards the end of their life or as life gets too hard, but what about the people who have lost their cognitive abilities? (Current carer of a person with dementia)

I do not believe I have the right to take anyone's life - not my own or anyone else's. (Current carer of a person with dementia)

When there is no longer any quality of life and when the patient has already made their wishes known, then it should be an option. (Former carer of a person with dementia)

I think voluntary assisted dying should be legalised in the ACT with the proviso that all avenues of medication and research have been explored and that family members are in accord with the individuals' wishes. (Person living with dementia)

¹⁷ Alzheimer's Australia (2014) *End of Life Care for People with Dementia Survey Report*

¹⁸ Alzheimer's Australia Victoria (2016) *A Good Death is My Right – Response of people with dementia and carers to the Voluntary Assisted Dying Bill Discussion Paper*

I have researched everything available with regard to my diagnosis and would be open to a discussion on assisted dying when I believe my 'willpower' and emotional state has deteriorated to the nth degree, however I would be guided by my son who has my Enduring Power of Attorney. (Person living with dementia)

As an organisation, Dementia Australia is neither for nor against voluntary assisted dying. We acknowledge the inherent challenges of any potential voluntary assisted dying legislation, particularly in its application to people living with dementia and other cognitive impairments. For example, who would decide when it was time for a person with dementia to end their life if it was deemed that they had lost legal capacity or the decision-making ability to do so. Consumers in Victoria felt very strongly that this should be decided by the person with dementia and noted in a quality of life statement made in the earlier stages of the illness, with clinical indicators that could be used by medical professionals in partnership with families¹⁹.

Dementia Australia supports and advocates for the right of people with dementia to exercise choice in their end of life including with regard to any future voluntary assisted dying legislation in the ACT.

(c) risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;

There are potential risks to individual and the community associated with voluntary assisted dying, including voluntary assisted dying being poorly understood and, the potential abuse or misuse of the terms of any potential legislation (for example, the possibility for coercion).

Our consumers identified several ways in which the potential risks associated with voluntary assisted dying to individuals and the community could be managed.

Decision should be made in consultation with at least 2 medical professionals and a person with enduring power of attorney or equivalent. (Former carer of a person with dementia)

Lots of counselling for the person involved and their family or significant others. Maybe psych testing, no possibility of pressure from any source to force a decision in that direction from any person. Opportunities for the person to change their mind or reconsider. (Carer of a person with dementia)

Making the wishes of the patient clear through e.g. an advanced care directive. Consultation between the family and medical practitioners. (Former carer of a person with dementia)

People who are opposed to voluntary assisted dying cited the risk of things going wrong or being 'messed up' as reason not to proceed with voluntary assisted dying legislation.

I cannot even begin to think about the risks and man (or woman)'s ability to mess things up. (Carer of a person with dementia)

¹⁹ Alzheimer's Australia Victoria (2016) *A Good Death is My Right – Response of people with dementia and carers to the Voluntary Assisted Dying Bill Discussion Paper*

(d) the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;

Dementia Australia (as then Alzheimer's Australia Victoria) consumers expressed concerns that some of the key clauses in the proposed Victorian legislation effectively, and from the outset, exclude people with dementia from accessing voluntary assisted dying, thereby limiting their end of life choices²⁰. The final version of the legislation all but stipulates that cognitive impairment excludes people from voluntary assisted dying in Victoria.

(e) the impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change;

(f) any other relevant matter;

Dementia Australia is a strong supporter of advance care planning and believes it should be more widely accessible for people living with dementia and their families and carers. Dementia is a progressive disease with symptoms often including issues with memory, understanding and reasoning that generally interfere with cognitive functioning and behaviour. As the disease progresses, there will be a time when the person with dementia loses the capacity to make decisions for themselves. This is why advance care planning can be such a vital support for our consumers to ensure that their end of life wishes are respected and enacted.

²⁰ Alzheimer's Australia Victoria (2016) *A Good Death is My Right – Response of people with dementia and carers to the Voluntary Assisted Dying Bill Discussion Paper*