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Dying Well

**Improving Palliative
and End of Life care
for people with
dementia**

Dementia Australia

Victoria

October 2019

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Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people living with dementia, their families and carers. We represent the more than 447,000 Australians living with dementia (including more than 27,000 people under the age of 65 years with younger onset dementia)¹ and the estimated 1.5 million Australians involved in their care.²

Dementia Australia works with people impacted by dementia, all levels of government 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.

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

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 – Kostas, M. et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce*; 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*; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*.

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Executive Summary

Good palliative care is an essential element of quality care and end of life care for people with a terminal illness. Dementia is a terminal illness, with a trajectory of steady and gradual decline over a number of years.

Palliative care has a well-developed conceptual framework and evidence base when it comes to chronic disease but the notion of palliative care for people with dementia has traditionally received less attention. Consequently, in Australia, palliative care services for dementia are inconsistent in the way they are delivered, they lack equitable service provision, and services lack unified standards and accepted definitions. Improving palliative care for people with dementia therefore must be a policy priority, Australia-wide, across the different states and territories.

Currently more than 50% of people in Australia die in hospitals, around 32% die in residential aged care and only a small percentage of people die in their own homes. A large number of people who die in hospitals do not receive tailored palliative care at all, and this includes a sizeable proportion of people with advanced stage dementia.

Once in their 'end of life' stage, people with dementia face frequent hospitalisations and may be given unnecessary procedures and treatment. They can be unsuitably admitted into acute beds in unfamiliar and stressful settings where staff do not have the capacity or the specialised training and skills to recognise and provide individually tailored palliative care for people with dementia. As a result of this, people with dementia end up being caught in a cycle of transfers from home to hospital to residential aged care and back to hospital.

The lack of clear, streamlined care pathways is detrimental for people with dementia, their families and carers. Furthermore, families and carers frequently report feeling stressed and confused as to how and where to access end of life care services, and feel guilt and pressure to make immediate decisions for their loved ones.

Streamlined access to palliative care and more effective home and community palliative care service provision needs to be driven through a concerted and coordinated effort of all levels of government. State and Territory governments are in the strongest position to ensure acute and subacute care staff have a better understanding of palliative and end of life care as well as recognise the symptoms of dementia and provide quality care for people in the advance stages of the disease.

Current funding arrangements and service structures, as well as a wide range of cultural approaches to death, have resulted in substandard end of life care for many people with dementia. Rather than being approached as being an inevitable and a natural process of life, death remains a sensitive topic that many of us find difficult to discuss openly, let alone plan for. This is certainly reflected in the poor and inconsistent practices of advance care planning across states and territories.

Advance care planning is paramount for people diagnosed with dementia and needs to occur early, considering the cognitive decline nature of the disease. The general public and – in the context of moving the healthcare sector forward, healthcare staff – should have the capacity to facilitate more open conversations. State/Territory governments need to demonstrate the willingness to work collaboratively and with the Commonwealth government to standardise approaches to advance care planning in order to ensure consistency of care for people with dementia, no matter where they live.

Dementia Australia is calling on the Victorian State government (in collaboration with the Commonwealth government) to systematise and customise palliative care for people with dementia, acknowledging the contextual complexities of dementia care within the different health care and community settings.

Recommendations

Workforce

- Increase workforce training about the unique palliation needs of people with dementia to the aged care workforce, GPs, and acute care staff.
- State and Territory Governments continue to work closely with the Commonwealth government to provide dedicated services of specialist palliative care specific to dementia in acute care settings, where staff are appropriately trained in dementia specific palliative care.
- Provide dementia-specific palliative care training to State and Territory run residential aged care staff and allocate Health department funding for clinical nurse consultants who specialise in dementia palliative care.

Advanced Care Planning

- Build care pathways that ensure healthcare professionals initiate timely discussions (and ideally at the point of diagnosis) about advance care planning with a person with dementia and their family.
- Promote advance care planning across all care settings.
- Start the dialogue about consistent advance care planning legislation to reduce jurisdictional confusion, provide protection to health professionals and community members, and allow care recipients to transition across borders to be closer to family and their community.

Flexible and responsive funding models

- Enable and enhance palliative care support services in community based settings beyond the common sub-acute hospital setting, through funding models that help people with dementia to die in their own home where they have identified a wish to do so, supported by family and carers.

Improved access and service coordination

- State and Territory Governments improve options for appropriate palliative care for people with dementia across all settings – community or home based care, residential care, hospice care and acute care. This also needs to factor in specific considerations for special needs groups and vulnerable populations, through collaboration with community health organisations, primary and acute care providers.
- Provide State and Territory funding for the expansion of the Nightingale program model (successfully implemented in South Australia).

Better community awareness of dementia and palliative care

- State and Territory health departments recognise and respond to the needs of people with dementia as outlined in the *National Palliative Care Strategy and Victoria's end of life and palliative care framework*.
- Collaborate with community based service providers to ensure carers of people living with dementia have appropriate support networks around them.

Introduction

Dementia is currently the second leading cause of death in Australia. Despite this, many people, even within the health profession, don't understand the terminal nature of dementia. Consequently, people living with dementia face barriers in accessing appropriate palliative care services and having their end of life needs met.

This discussion paper examines the current state of end of life and palliative care for people with dementia and their families. The important role that State and Territory Governments have to play is examined, and recommendations are provided to improve the provision of quality end of life and palliative care to people with dementia and their families.

The Impact of dementia

Dementia is the term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning, including thinking, behaviour and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, and frontotemporal dementia. There are currently more than 447,000 Australians living with dementia. Without a significant medical breakthrough, that number is expected to increase to more than one million by 2058.³

Dementia has a profound impact on the individual and those around them. People with dementia commonly experience social isolation, which can lead to a decline in mental and physical health and they are more than three times as likely not to have a friend to confide in, compared to the general public.⁴ Some of this social isolation can be as a result of discrimination from those around them — not necessarily deliberate neglect, but because people may not know how to engage, include or maintain relationships with people with dementia.

Dementia is a progressive neurological condition and is the leading cause of disability burden for people over the age of 65 years in Australia.⁵ Although the majority of people diagnosed with dementia are 65 years or older, dementia is not a natural part of ageing. In fact, it is one of the largest health and social challenges facing Australia and the world. It is a terminal condition and there is currently no cure.⁶ Dementia is the leading cause of death of women, the second leading cause of death for all Australians, and is predicted to become the overall leading cause of death within the next five years.⁷

In Victoria alone, prevalence estimates data show that there are 114,779 people with dementia in 2019. These figures are projected to increase to 300,867 by 2058, a growth rate of 162%.⁸

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

4 Dementia Australia (2016) *Dementia and Loneliness report*.

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

6 Australian Bureau of Statistics (2019) *Australia's leading causes of death*, accessed online.

7 Australian Bureau of Statistics (2019) *Australia's leading causes of death*, accessed online.

8 Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra.

Dementia prognosis and progression

On average, people with dementia survive for three to ten years from the point of diagnosis.⁹ Age, gender, type of dementia, the person's comorbidities, and the severity of the illness at the time of diagnosis can impact this trajectory.

As a progressive disease, dementia can be broadly categorised into three phases: mild, moderate, and severe. People in severe or late stage dementia can experience, not only severe memory loss, but physical symptoms of pain, substantial difficulties with eating and swallowing, limited or no speech, immobility and inability

to control bodily functions. People in the later stages typically require assistance with nearly all aspects of personal care.

A person with advanced stage dementia is said to be approaching their 'end-of-life' when they are likely to die within the next 12 months. However, due to other co-morbidities, people with dementia may qualify for palliative care at any stage of their journey, such that people with mild to moderate dementia may be in the end stage of other terminal comorbidities, such as organ failure or cancer.

Palliative care for people with dementia

Although palliative care has traditionally been an approach associated with other chronic diseases, dementia is becoming better recognised as a terminal condition for which palliative care is appropriate and necessary.

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life. Dying is a normal process, with palliative care offering a support system to help people to live their life as fully and as comfortably as possible until death and to help families cope during this illness and in their bereavement.¹⁰ 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.¹¹

“Appropriate palliative care is recognising end of life stages – someone who has dementia cannot say what they need – they need clinical staff, up skilled nurses to provide palliative care.” – Carer

Recent data from Australian Institute of Health and Welfare (AIHW) through Aged Care Funding Instrument

(ACFI) assessment showed that around 41.6% of residential aged care residents assessed as requiring palliative care in 2017–18 were living with dementia.¹² This demonstrates the important role aged care services play in the provision of palliative and end-of-life care for older Australians, especially those living with dementia. However, quality of palliative care for people with dementia provided in residential aged care varies.

“Aged care has become a business, not a service. It's a business in which the people to be served are not considered. Despite flashy amenities, the personhood of the residents is not attended to. At best, there is nothing in place to nurture their spirit, to prepare them for a peaceful end. At worst, they are neglected, antagonised and frightened until they die. The residents move on silently and no more is heard of them.”

– Former carer

People with dementia have twice the rate of hospital admissions as people within the same age group who do not have dementia.¹³ They have higher than average hospital mortality rates, readmission rates and longer lengths of hospital stay.¹⁴ Moreover, evidence shows that there is a lack of adequate staff training in dementia and poor service design in acute settings to address and

9 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 Psychogeriatric*, 24 (7), 1034–1045.

10 Palliative Care Australia and Dementia Australia (2018) Joint policy statement – Palliative Care and Dementia.

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

12 Australian Institute of Health and Welfare (AIHW) (2019) Palliative care in residential aged care, available from: www.aihw.gov.au/getmedia/7fef3743-2905-4f6f-bc7c-81c1e067e7bc/Palliative-care-in-residential-aged-care.pdf.aspx.

13 Alzheimer's Australia (2014) *Dementia Care in the Acute Hospital Setting: Issues and Strategies*, Paper 40.

14 Australian Commission on Quality and Safety in Health Care (2013) *Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review*.

cater to the needs of people with dementia. An example of such is the failure to recognise a dementia diagnosis, with as many as 50% of people with dementia being found to not have their diagnosis documented on admission into acute care settings.¹⁵

Access to quality palliative care, whether that be in an individual's home or in a residential aged care setting, is critical to ensuring people with dementia die well. Hence, it is imperative that health care staff are appropriately skilled to deliver palliative care to people with dementia in the various care settings. Service redesign, aimed at better coordination, integration and individually tailored care is required to ensure people with dementia are able to access quality palliative care services and support during the end of life across the different care settings.

Under the *National Health Reform Agreement*, the Australian Government is responsible for funding palliative care through general practice and residential aged care; the Australian Government and State and Territory Governments jointly fund palliative care through public hospital funding; while State and Territory Governments are responsible for the delivery of specialist public palliative care services, including community palliative care, inpatient and outpatient services, and providing support to primary health care providers. Additionally, all Australian governments have committed to the *National Palliative Care Strategy* to ensure that evidence-based, quality palliative care is available to everyone who requires it.¹⁶ To ensure the best possible outcomes for people with dementia and their families, all levels of Government and service providers must have focus on delivering person-centred models of care that overcome this policy and funding complexity.

Specifically, in the context of Victoria, Dementia Australia supports *Victoria's end of life and palliative care framework*. There is a need for healthcare, human services, social and community sectors to collaborate to develop innovative strategies to guide providers across all sectors to take responsibility for delivering high-quality end of life care.¹⁷ This framework needs to be applied to people living with dementia whereby it forms a core component of person centred care across the different care settings and throughout the journey of the disease until end of life. Incorporating the views and wishes of people living with dementia, through ongoing engagement with the relevant public and advocacy groups, will be integral to the development of appropriate palliative care options for people with dementia.

Recommendation: State and Territory health departments recognise and respond to the needs of people with dementia as outlined in the *National Palliative Care Strategy* and *Victoria's end of life and palliative care framework*.

Recommendation: State and Territory Governments improve options for appropriate palliative care for people with dementia across all settings – community or home based care, residential care, hospice care and acute care. This also needs to factor in specific considerations for special needs groups and vulnerable populations, through collaboration with community health organisations, primary and acute care providers.

Recommendation: Increase workforce training about the unique palliation needs of people with dementia to the aged care workforce, GPs, and acute care staff.

Recommendation: State and Territory governments continue to work closely with the Commonwealth government to provide dedicated services of specialist palliative care specific to dementia in acute care settings, where staff are appropriately trained in dementia specific palliative care.

Recommendation: Provide dementia-specific palliative care training to State and Territory run residential aged care staff and allocate Health department funding for clinical nurse consultants who specialise in dementia palliative care.

Recommendation: Enable and enhance palliative care support services in community based settings beyond the common sub-acute hospital setting, through funding models that help people with dementia to die in their own home where they have identified a wish to do so, supported by family and carers.

15 Alzheimer's Australia (2014) *Dementia Care in the Acute Hospital Setting: Issues and Strategies*.

16 Department of Health (2018) *National Palliative Care Strategy*.

17 Victorian Government (2016) *Victoria's end of life and palliative care framework – A guide for high-quality end of life care for all Victorians*.

End of life care

The goal of care changes in the terminal phase of dementia and becomes about maintaining comfort and dignity for the person, and to provide support for family and staff.

People in the later stages of dementia are often at 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, making it difficult for them to communicate if they have pain. Evidence suggests that the neuropathological nature of dementia, and increased attention to painful stimuli, can result in increased levels and duration of pain among people with dementia.^{18 19} Pain and depression are also linked, with evidence that depression is 2.6 times more likely in people with dementia (than those not living with dementia) reporting pain in a residential aged care facility.²⁰ Moreover, pain can result in interrupted sleep patterns, further exacerbating behavioural and psychological symptoms of dementia. People with dementia may not be able to verbalise their symptoms, but they often express pain

through body language, emotional responses, behaviours and physiological changes. Understanding the range of pain responses in people with dementia enables a more accurate and comprehensive assessment.

The symptoms of late stage dementia – immobility, swallowing difficulties, and incontinence – make people highly susceptible to recurring chronic infections and ulcers. 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 cancer.²¹ Care in the end of life phase includes regular mouth care and eye care as well as pressure care, of regular turning and using pressure relieving mattresses, where possible to relieve pain. Pharmacological management in the terminal phase often involve “as required” medications to manage pain, breathlessness and agitation.²²

Recommendation: Collaborate with community based service providers to ensure carers of people living with dementia have appropriate support networks around them.

18 Cole L.K., Farrell M., Duff E., Barber J., Egan G., Gibson S. (2006) 'Pain and sensitivity and fMRI pain-related brain activity in Alzheimer's disease', *Brain*, 129 (11), 2957–2965.

19 Achterberg W.P. et al. (2013) 'Pain management in patients with dementia', *Clinical Interventions in Aging* (8), 1471–1482.

20 Achterberg W.P. et al. (2013) 'Pain management in patients with dementia', *Clinical Interventions in Aging* (8), 1471–1482.

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

22 Achterberg W.P. et al. (2013) 'Pain management in patients with dementia', *Clinical Interventions in Aging* (8), 1471–1482.

The importance of advance care planning

As the condition progresses, people living with dementia, their family and carers can experience tremendous levels of stress, especially around making decisions for the person's care.

“The person loses ability to speak for themselves with dementia, unlike any other condition or disease – they are reliant on how good the carer is in ascertaining what they require.” – Carer

Ultimately, families and carers of people living with dementia find themselves in a position where they need to inform, or directly make, decisions on behalf of the person with dementia. This can be incredibly difficult when they don't have access to clear information on what to expect with dementia to allow them to make informed decisions.²³ They can also experience substantial feelings of loss, guilt and pain, especially when needing to make decisions to place their loved ones into residential care²⁴ and on end-of-life care.²⁵ Advance care planning can play an important role in reducing such pressures on people with dementia, their family and carers.

“Everyone has to have their own personalised care and Advance Care Plans, and involve their dedicated carers. Family involved, team involved, facility involved.” – Former Carer

Advance care planning allows the person with a terminal condition like dementia to express their choices for future health and personal care ahead of a time when they no longer can make or communicate their decisions. This can be in the form of an advance care plan, or an advance care directive or appointing a substitute decision-maker. The requirements for writing advance care directives and appointing substitute decision-makers vary between and states and territories.

Dementia Australia recommends that advance care planning begins at diagnosis so people impacted by dementia can have supports and services in place in accordance with their wishes before the disease progresses.²⁶ This is known as supported decision-making, whereby people are enabled to make decisions about their own life and can be involved in decisions that affect their care. The plan should also be reviewed on a regular basis, particularly when the person's health condition or circumstances change.²⁷ People living with dementia should be involved in discussions and decision making as much as possible, and their competence and ability to participate in discussions should be assumed, unless it is clear this is not possible.

“There is a need to learn about the illness in order to live better with it as well as be a better carer, but of course also about later stages and the need to plan for palliative care and end of life, possibility of donating brain to research and similar.” – Carer

Recommendation: Build care pathways that ensure healthcare professionals initiate timely discussions (and ideally at the point of diagnosis) about advance care planning with a person with dementia and their family.

Recommendation: Promote advance care planning across all care settings.

Recommendation: Start the dialogue about consistent advance care planning legislation to reduce jurisdictional confusion, provide protection to health professionals and community members, and allow care recipients to transition across borders to be closer to family and their community.

23 Caron C.D., Griffith J., Arcand M. (2005) 'Decision making at the end of life in dementia: how family caregivers perceive their interactions with health care providers in long-term-care settings', *Journal of Applied Gerontology* (22), 1–17.

24 Alzheimer's Australia NSW (2012) *The Most Difficult Decision: Dementia and the move into residential aged care*, Discussion Paper 5.

25 Cees M.P., Hertogh, M. (2006) 'Advance care planning and the relevance of a palliative care approach in dementia', *Age and Ageing* (35), 553–555.

26 Cognitive Decline Partnership Centre (2016) *Future planning and advance care planning. Why it needs to be different for people with dementia and other forms of cognitive decline*.

27 Guideline Adaptation Committee (2016) *Clinical Practice Guidelines and Principles of Care for People with Dementia*.

Voluntary assisted dying

Dementia Australia is neither for nor against Voluntary Assisted Dying (VAD). 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.

Several Australian States and Territories are currently, or have recently, examined voluntary assisted dying schemes.

Victoria

Victoria has introduced VAD. The scheme has strict eligibility criteria; only people with decision-making capacity, who are suffering with an incurable, advanced and progressive illness that is likely to cause death within six months (or 12 months for people with neurodegenerative conditions) are eligible for VAD. Advance care directives do not have legal standing for VAD. The scheme therefore effectively excludes people with dementia from accessing VAD even through an ACD.

Western Australia

In September 2019, the *Voluntary Assisted Dying Bill* passed through the lower house of Western Australian Parliament without any amendments.

Queensland

The Queensland Parliament is currently conducting an *Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying*. The committee is due to report by March 31 2020.

ACT

The ACT Government recently responded to an End of Life Choices report, tabled in March, which examined options currently available to dying residents and considered options for a potential voluntary assisted dying scheme. The report did not make any recommendations as to the implementation of a scheme, as territories do not have the power to enact such legislation under the Australian Government's *Euthanasia Laws Act 1997*).

South Australia

A voluntary assisted dying bill was defeated in 2016. The South Australian Government has recently undertaken an inquiry into end-of-life choices.

NSW

In November 2017, the NSW Voluntary Assisted Dying Bill 2017 failed to pass in the NSW Upper House by one vote.

Case Study: The Nightingale Program

The Nightingale Program, established in 2016, is a unique and innovative palliative model of care for people with dementia, their families and carers. It is a nurse led model, with nurses who specialise in both dementia and palliative care. The Nightingale Program is the only specialist palliative dementia program of its kind in Australia. Working in partnership with a geriatrician and other stakeholders, the program successfully provides person-centred care from the point of diagnosis to end of life. The program is funded by The Rosemary Foundation for Memory Support and is operated by Dementia Australia in South Australia. It is currently only available to people living in metropolitan South Australia.

The program provides strategies and advice to support people living with dementia, their families and care providers with a focus on promoting choice and well-being during all stages of diagnosis. Using a person-centred approach, Nightingale Program staff can develop care strategies to enable people living with dementia to:

- Stay at home longer and maximise their independence;
- Promote quality of life and positive relationships;
- Have a voice in their future care options and decision making by planning ahead;
- Avoid unnecessary presentations to acute hospital settings; and
- Be in receipt of clinical advice including: pain management, delirium, incontinence, and palliation.

The benefits of the Nightingale Program include:

- Comprehensive and holistic nursing assessment which identifies current issues, anticipates changing needs, and refers to other service providers;
- Continuity of care, offering a single point of contact for advice;
- Advice provided in home, residential aged care, community and hospital settings;
- Consultation in the development of advance care directives for future health care needs; and
- Education and emotional support to support family and carers.

“Pre dementia, my mother was an incredibly independent person with lots of energy and drive. Always kind and thoughtful of others. Karma has repaid my mother with the Nightingale Program’s involvement.

The Nightingale nurse has been the constant/ steady/calming support through the tumultuous, often confusing and stressful journey. She has made a significant difference to our family, supporting us as we experienced all of humanities emotions to their extremes.

When she visited my mother and the family she showed compassion and care. She interacted with my mother with respect and dignity. She has provided us with options for consideration, valuable advice and much needed support. Her involvement has not only helped my mother but helped her family maintain our own mental health, which has given us the confidence to care for my mother at home.”

Recommendation: Provide State and Territory funding for the expansion of the Nightingale program model (successfully implemented in South Australia).

Conclusion

State and Territory Governments play an integral role in the provision of quality end of life and palliative care for people living with dementia. Comprehensive palliative care for people living with dementia should be available when and where it is needed, including community or home based care, residential aged care, hospice care,

and acute care settings. There is a need to improve the provision of palliative care services for people living with dementia in each of these settings, and to increase the ability of health professionals, staff, families and the community to meet the specific palliative care needs of people living with dementia.

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