



**dementia
australia™**

The new voice of Alzheimer's Australia

2020-21 Pre-budget Submission Australian Capital Territory

October 2019

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 447,000 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with individuals, families, communities, 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 people who have a lived experience of dementia means that we are an important advocate for those impacted by the condition 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.



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INTRODUCTION

About dementia

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. Symptoms can include memory loss as well as changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. Dementia 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 it is predicted to become the leading cause of death within the next five years.¹ Dementia is not a natural part of ageing. It is more common in older people but it can affect people in their 40s, 50s and even their 30s.

It is estimated that there are more than 447,000 Australians living with dementia and more than 1.5 million people involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.²

It is estimated that there are currently almost 6,000 people living with dementia in the ACT and that by 2058 there will be approximately 19,000 people living with the disease.³

The cost to our community

Dementia has a profound impact on the individual as well as their families, carers and friends. The condition can lead to discrimination and misunderstanding, it isolates people, their families and carers from social networks, and it has significant social and economic consequences.

The cost of dementia to the Australian economy is already enormous and growing rapidly.

In 2019, dementia is estimated to have cost the ACT more than \$2 billion. By 2025, the total cost of dementia is predicted to increase to almost \$3 billion in today's dollars, and by 2056, to almost \$6 billion.⁴

Dementia as core business

Health, aged care and disability services reforms over recent years have been increasingly based on the belief that supporting people impacted by dementia should be part of core business for service providers.

However, despite the pace of reforms in disability and aged care, there is still much to do before this can become a reality. The experiences of people impacted by dementia as well as providers and staff across a range of sectors tell us that there are significant steps that need to be taken for quality dementia care and support to become an intrinsic part of health, aged care and disability services. This is especially so for marginalised or disadvantaged

¹ Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

² Dementia Australia (2019) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

³ Dementia Australia (2019) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

⁴ The National Centre for Social and Economic Modelling [NATSEM] for Dementia Australia (2016) *Economic Cost of Dementia in Australia 2016-2056*

communities where their experience is often characterised by unacceptably long delays in diagnosis, poor access to treatment and lack of choice and quality in residential and community care to name but a few.

DESIGNING A NEW FUTURE - DEMENTIA AUSTRALIA'S STRATEGIC DIRECTION 2018-2023

Dementia Australia's Strategic Direction, *Designing a New Future 2018-2023*, is underpinned by a vision and purpose that speaks to what the organisation represents:

Standing for the rights of people impacted by dementia to receive early supports and high-quality services throughout their lives as well as being respected, valued and included in their communities.

By undertaking rigorous consultations with a wide cross-section of Australia's communities, Dementia Australia found that the biggest issues for people living with dementia are:

1. Access to timely diagnosis and support
2. Quality of dementia care; and
3. Discrimination experienced as a result of living with dementia.

Dementia Australia seeks commitment in the forthcoming 2020-2021 ACT Government Budget to address three integral components. These areas frame Dementia Australia's activities to create an inclusive future where all people impacted by dementia receive the care and support that they need and deserve. They span:

- Developing a clear pathway for diagnosis and support;
- Providing dementia education for hospital and aged care staff; and
- Creating dementia-friendly communities.

It is clear that Dementia Australia cannot achieve these goals in isolation. And it is also clear that the current raft of health, disability and aged care reforms will not, on their own, result in the systemic change that is required to improve the lives of those impacted by dementia.

To put it simply, a generalised approach to reform is not enough. Dementia is not yet core business and requires specific attention to make it so.

The initiatives outline in this pre-budget submission will ensure that real, system-wide transformation is achieved in the ACT. They have been designed to maximise the impact that the ACT Government can make on the lives of Canberrans living with dementia, their families and carers and leverage off the Government's commitment to focusing on hospitals and healthcare, community services and support for families. Like the ACT Government, Dementia Australia is committed to infrastructure, services and improved social outcomes for everyone living in the ACT, including those impacted by dementia.

With a total investment of \$716,000, the ACT Government can ensure that people living with dementia are:

- receiving support from GPs educated in dementia;
- in receipt of quality dementia care in ACT public hospitals and aged care services; and
- living in dementia-friendly communities.

PRIORITY #1: TIMELY DIAGNOSIS

Initiative 1.1 Online GP education

A key component of this initiative will be seeking partnerships with organisations across the primary health space to ensure that dementia education for GPs is embedded into ongoing continuing professional development via existing online platforms.

Implementation cost: \$240,000

PRIORITY #2: QUALITY DEMENTIA CARE

Initiative 2.1 Provide immersive education to hospital staff

Immersive educational experiences have proven to be impactful and greatly contribute to developing deeper insights into what it is like to live with dementia.

Dementia Australia aims to provide a series of immersive education to staff in the three public hospitals in the ACT. This program will inspire participants to alter their current practice to improve the quality of care provided to people living with dementia.

Implementation cost: \$44,000

Initiative 2.2 Support dementia practice development in rural/ regional aged care

Embedding practice improvements in dementia care can be a difficult and long process. Being a part supportive professional community can make a significant difference to helping workers translate insights and knowledge gained through education into 'what we do'.

There are additional challenges for the regional aged care workforce, where access to education and training, mentoring and continuing professional development opportunities are more limited. Dementia Australia aims to establish Dementia Communities of Practice to provide access to ongoing learning and support for workers supporting people living with dementia in rural and regional residential and community aged care in the ACT.

Total Implementation cost: \$288,000

PRIORITY 3: TACKLING DISCRIMINATION

Initiative 3.1 Create a Dementia-Friendly ACT

The Dementia-Friendly Communities and the Dementia Friends program has achieved significant results in increasing the understanding and public awareness of dementia across Australia.

It is important that this momentum is sustained and further embedded into the ACT by expanding the number of dementia-friendly communities here and supporting these communities through targeted grants, resourcing, guidance and advice to ensure their sustainability and impact.

Implementation cost: \$144,000

CONCLUSION

The prevalence of dementia in our community is growing exponentially. Those impacted by dementia in the ACT are seeking decisive action to ensure that the outcomes for people living with dementia, their families and carers are adequately considered in the context of more generalised health, disability and aged care reforms, with targeted, translatable action implemented.

The funding investments outlined in this submission will represent long term savings for the government. Investing in initiatives that define the pathway to diagnosis, develop mechanisms to embed quality dementia care and reduce the daily discrimination faced by people living with dementia will demonstrate that the ACT Government is serious about making dementia core business in Australia.