



**dementia  
australia™**

**2020-21 Pre-Budget Submission  
NSW**

**December 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 450,000 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.



## 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.<sup>1</sup> 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 450,000 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.<sup>2</sup>

It is estimated that in 2020 there will be almost 153,000 people living with dementia in NSW and that by 2058 there will be approximately 345,400 people living with the disease.<sup>3</sup>

### 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 NSW more than \$5 billion. By 2025, the total cost of dementia in NSW is predicted to increase to \$5.9 billion in today's dollars, and by 2056, to more than \$11 billion.<sup>4</sup>

### 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 communities, where their experience is often characterised by unacceptably long delays in

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

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

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

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

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 NSW Government Budget to address three integral components. These will contribute to efforts 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.

The specific initiatives outlined in this pre-budget submission will ensure that real, system-wide transformation is achieved in NSW. They have been designed to maximise the impact that the NSW Government can make on the lives of people 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 NSW Government, Dementia Australia is committed to infrastructure, services and improved social outcomes for everyone living in NSW, including those impacted by dementia.

With a total investment of \$1,878,000 the NSW Government can ensure that people living with dementia are:

- provided with timely quality palliative care;
- in receipt of quality dementia care in NSW public hospitals and aged care services; and
- living in dementia-friendly communities.

## **PRIORITY #1: TIMELY DIAGNOSIS AND SUPPORT**

### **Initiative 1.1 Access to early-stage advance care planning and palliative care**

Best practice care for people living with dementia includes a palliative approach from the time of diagnosis. However, a lack of understanding of dementia as a terminal illness contributes to inconsistent and inequitable access to palliative care services for people with dementia.

Dementia Australia's Nightingale Program (currently only available in metropolitan South Australia) is the only nurse-led, dementia specific palliative care program in Australia. The program provides practical advice and emotional support on a one-to-one basis to enable people with dementia and their families to live well via a palliative approach. The Nightingale Program fills a gap in the current models of care and contributes to preventing unnecessary hospital admissions that result from situational crises.

Dementia Australia aims to expand this specialised program to people living with dementia and their families in NSW.

Implementation cost: \$840,000

## **PRIORITY #2: QUALITY DEMENTIA CARE**

### **Initiative 2.1 Provide immersive education to hospital and residential aged staff**

Immersive educational experiences have proven to be impactful to staff providing services to people who have dementia and greatly contribute to staff developing deeper insights into what it is like to live with dementia. Educational Dementia Immersive Experience – EDIE – is an immersive workshop that enables participants to see the world through the eyes of a person living with dementia. Utilising our high quality virtual reality technology, this workshop enhances participants' knowledge of dementia whilst exploring enablement strategies to more effectively support a person with dementia.

Dementia Australia aims to provide a series of EDIE immersive education sessions to staff in all public sector residential aged care services and at least 20% of public hospitals in NSW. This program will inspire participants to alter their current practice to improve the quality of care provided to people living with dementia.

Implementation cost: \$750,000

## **PRIORITY 3: TACKLING DISCRIMINATION**

### **Initiative 3.1 Create a Dementia-Friendly NSW**

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 NSW by expanding the number of dementia-friendly communities or businesses here and supporting these through targeted grants, resourcing, guidance and advice to ensure their sustainability and impact.

Implementation cost: \$288,000

## CONCLUSION

The prevalence of dementia in our community is growing exponentially. Those impacted by dementia in NSW 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 2020-2021 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 NSW Government is serious about making dementia core business in Australia.