



**dementia
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The new voice of Alzheimer's Australia

2019-20 Pre-budget Submission New South Wales

Dementia Australia

Designing a new future – Diagnosis and Beyond

December 2018

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 436,000 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

Dementia remains one of the largest health and social challenges facing New South Wales, Australia and the world. 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.

In essence, the term describes a disease process that results in progressive cognitive degeneration. It is a terminal condition that affects people's abilities and memories and it has a profound impact on the individual and their loved ones. The condition can lead to discrimination and misunderstanding, it isolates people, their families and carers from social networks, and it continues to carry significant social and economic consequences.

People living with dementia constitute one of the most vulnerable groups in our society. A wide range of evidence comprehensively demonstrates that the care provided to people living with dementia is worse than the care delivered to any other vulnerable group.

It is estimated that there are more than 146,000 people in NSW living with dementia. By 2058 it is estimated there will be almost 1.1 million people living with dementia. These numbers include the more than 27,000 people with younger onset dementia, that is, dementia that develops before the age of 65.²

The cost to our community

The cost of dementia to the New South Wales economy is already significant and growing rapidly.

In 2018, dementia is estimated to have cost New South Wales more than \$4.9 billion. By 2025, the total cost of dementia is predicted to increase to \$5.9 billion in today's dollars, and by 2056, to more than \$11 billion.³

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. Consumer and provider experience tells us that there are further 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 diagnosis, poor access to treatment and lack of choice and quality in residential and community care to name but a few.

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

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

³ The National Centre for Social and Economic Modelling [NATSEM] for Dementia Australia (2016). *Economic Cost of Dementia in Australia 2016-2056*, p.72-74.

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.

Diagnosis and Beyond

Dementia Australia seeks commitment in the forthcoming 2019-2020 NSW 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**;
- **Defining Quality Standards** in dementia care; and
- Reducing **discrimination**.

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.

Each of the three priority areas outlined below embrace a range of initiatives which will ensure that real, system-wide transformation is achieved. A total investment of \$9,919,800 over 5 years will ensure that timely diagnosis, quality care and a life free of discrimination can become a reality.

At a total cost of just under \$10 million, the NSW Government can ensure that people living with dementia are:

- supported by establishing a clear pathway towards diagnosis and beyond which will address timely and appropriate diagnosis support;
- in receipt of quality dementia care by developing specific standards which will build the capacity of the sector to provide care which is truly person-centred and in line with evidence-based best practice; and

- in the position where their diagnoses of dementia will not unduly make them suffer by reducing discrimination through providing education to communities around the complexity of living with dementia.

The breakdown of funding required is as follows:

TOTAL NSW GOVERNMENT FUNDING COMMITMENT

Priority 1	Timely diagnosis and support	\$ 4,656,300
Priority 2	Quality Dementia Standards	\$ 2,904,000
Priority 3	Reducing discrimination	\$ 2,359,500
	TOTAL	\$ 9,919,800

PRIORITY #1: DEVELOP A CLEAR PATHWAY FOR DIAGNOSIS AND SUPPORT

Initiative 1.1	Timely diagnosis of dementia	\$ 415,800
Initiative 1.2	Direct referral model	\$ 825,000
Initiative 1.3	Dementia Care Navigator model	\$ 3,415,500
	TOTAL	\$ 4,656,300

Initiative 1.1: Timely diagnosis of dementia

In partnership with people living with dementia, their families and carers, health, aged care sector, government and vulnerable community groups, Dementia Australia will identify the barriers to seeking a diagnosis.

Implementation cost: \$415,800

Initiative 1.2: Direct referral model

A clear pathway of referral is required across multiple entry points, which includes aged care, disability and health care sectors. A key component of this initiative will be harnessing the experience and established connections of Dementia Australia to ensure that referral pathways to services, including reablement and other services that support independence, are clear and consistent.

Implementation cost: \$825,000

Initiative 1.3: Dementia Care Navigators

Working directly with people living with dementia, their carers and families, Dementia Australia will provide assistance with navigating aged care, disability and health care services, and most importantly navigating the changes as the disease progresses. The dementia care navigator scheme will expand on the 2018-2019 System Navigator Budget measure and will trial an extended sample of this cohort across Australia, including in regional areas to ensure that it is the most effective approach for navigating the complexities of dementia.

Implementation cost: \$3.42 million

PRIORITY #2: DEFINE STANDARDS IN QUALITY DEMENTIA CARE

Initiative 2.1	Quality dementia care is defined, measured and achieved	\$ 775,500
Initiative 2.2	Creation of Dementia Practice Leaders	\$1,320,000
Initiative 2.3	Creation of Dementia Community of Practice	\$ 148,500
Initiative 2.4	Dementia Learning Programs	\$ 165,000
Initiative 2.5	Immersive experiences program	\$ 495,000
	TOTAL	\$2,904,000

Initiative 2.1: Quality in dementia care is achieved

Dementia Australia will collaborate with individuals, families, providers and the government to ensure that aged care quality standards are translated into dementia-specific indicators that build the capacity of people with dementia, their families and carers to make informed choices (based on comparable metrics) as well as informing providers on the components of quality dementia care – with measurable outcomes. In addition to defining foundational standards, Dementia Australia will collaborate with a range of stakeholders, including providers, to establish and test a ‘gold standard’ model of care.

Implementation cost: \$775,000

Initiative 2.2: Dementia Practice Leaders

In recognition of the important role of workforce capacity and education, Dementia Australia will educate NSW aged care workers across three years to successfully complete the Certificate IV in Dementia Practice. A key aspect of this initiative is to provide a platform for certified staff to provide coaching and mentoring to other staff, which will lead to recognition as Dementia Practice Leaders. This role is critical in translating knowledge into practice and recognises that 90 per cent of learning occurs in the workplace.

Implementation cost: \$1.32 million

Initiative 2.3: Dementia Community of Practice

In this capacity building initiative, Dementia Practice Leaders across NSW will be supported in the ongoing practice of bettering the outcomes for people living with dementia in support and care organisations. Technology will support this community of practice to reach out to regional and remote locations to remain current with innovations in dementia care.

Implementation cost: \$148,500

Initiative 2.4: Dementia Learning Programs

Preliminary reviews of dementia education highlight a number of gaps in learning pathways. Dementia Australia will develop and deliver both accredited and non-accredited career pathways for aged care, disability, health staff and professionals wishing to specialise in the dementia care area leading to recognition as a dementia practice leader.

Implementation cost: \$165,000

Initiative 2.5: Immersive experiences program

Immersive educational experiences have proven to be impactful and greatly contribute towards developing deeper insights into the world of living with dementia. Dementia Australia's aim is to incorporate immersive experiences into all of its education. This program will inspire participants to alter their current practice and will influence the practice of others.

Implementation cost: \$495,000

PRIORITY #3: REDUCE DISCRIMINATION

Initiative 3.1	Establish baseline measure of discrimination	\$ 49,500
Initiative 3.2	Establish social movement of inclusiveness	\$ 1,320,000
Initiative 3.3	Expansion of Dementia-Friendly Communities	\$ 990,000
	TOTAL	\$ 2,359,500

Initiative 3.1: Establish baseline measures of discrimination

People living with dementia report that discrimination is a common experience, however the drivers and metrics for measuring change have not been addressed. Research will be undertaken around existing measures of discrimination and stigmatisation experienced by people living with dementia. This research will contribute to the development of a suitable tool for use in the context of dementia.

Implementation cost: \$49,500

Initiative 3.2: Social movement of inclusiveness

An attitudinal shift is required in order to address the misunderstanding and fear which exists around dementia. This initiative aims to create a 'movement of change' that calls the community to action both individually and collectively. A multi-media awareness campaign will be created with the aim to develop the community's knowledge of dementia and to foster an empathetic approach towards the disease.

Implementation cost: \$1.32 million

Initiative 3.3: Dementia-Friendly Communities

The Dementia-Friendly Communities and the Dementia Friends program has achieved great results in increasing the understanding and public awareness of dementia across Australia. It is important that this momentum is sustained and further embedded into society. This initiative will expand the Dementia-Friendly Communities and Dementia Friends program.

Implementation cost: \$990,000

CONCLUSION

The prevalence of dementia in our community is growing exponentially. NSW needs decisive action to ensure that the outcomes for people living with dementia 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 diagnoses, develop quality standards for 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 NSW.