



**dementia
australia™**

2020-21 Federal Pre-Budget Submission

November 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.



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.²

It is estimated that there will be more than 452,000 Australians living with dementia in 2020 and around 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 2058.³

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 was estimated to have cost Australia more than \$15 billion. By 2025, the total cost of dementia is predicted to increase to \$18.7 billion in today's dollars, and by 2056, to more than \$36.8 billion.⁴

Dementia as core business

Health, aged care and disability sector 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. Findings from the Royal Commission into Aged Care Quality and Safety, coupled with the experiences of people impacted by dementia as well as

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

² There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

³ Dementia Australia (2018) *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*

providers and staff across a range of sectors, all 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 diagnosis, poor access to treatment and lack of choice and quality in residential and community care to name but a few challenges.

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 Federal 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 sector navigation and support;
- Implementing quality 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 are not and 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 outlined in this pre-budget submission will ensure that real, system-wide transformation is achieved. They have been designed to maximise the impact that the Federal Government can make on the lives of people living with dementia, their families and carers, and will assist the Government in responding to the challenges identified by the Royal Commission into Aged Care Quality and Safety, particularly with regard to system navigation and workforce capacity.

FEDERAL FUNDING COMMITMENT

With a total investment of just over \$20.8 million the Federal Government can ensure that people living with dementia are:

- Able to receive a timely diagnosis and supported to navigate the complex aged care, health and disability sectors;
- In receipt of quality dementia care; and
- In the position where their diagnoses of dementia will not unduly make them suffer by reducing discrimination through providing education to communities.

The breakdown of funding sought for 2020-2021 is as follows:

Priority 1	Timely diagnosis and early intervention	\$ 10,240,000
Priority 2	Quality dementia care	\$ 9,608,000
Priority 3	Reduce discrimination	\$ 1,000,000
	TOTAL IN 2020-21	\$ 20,848,000

PRIORITY #1: TIMELY DIAGNOSIS AND EARLY INTERVENTION

Initiative 1.1 Dementia Care Navigators

Working directly with people living with dementia, their carers and families, Dementia Australia will provide assistance to navigate the aged care, disability and health care services, and, most importantly, to navigate the changes as the disease progresses.

The dementia care navigator will expand on the pilot scheme already in operation and will trial an extended model across other parts of Australia, including in regional areas, to ensure that it is the most effective approach for navigating the complexities of dementia.

Implementation cost: \$10 million per annum for 3 years

Initiative 1.2 Online GP education

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

In the first instance, Dementia Australia will create service offerings for existing online platforms.

Implementation cost: \$240,000 in year 1 and \$150,000 per annum for years 2 and 3

PRIORITY #2: QUALITY DEMENTIA CARE

Initiative 2.1 Quality Dementia Care in practice

In 2019, Dementia Australia sought to find out what quality dementia care meant to people with a lived experience of dementia, particularly in the context of the new Aged Care Quality Standards. We asked people: What does quality dementia look like? Feel like?

The culmination of this work was a Consumer Summit to discuss consultation findings and ratify a communique – Our Solution: Quality Care for people living with dementia.⁵ The result was an unequivocal vision of holistic and person-centred care that is underpinned by strong leadership and a positive culture within and across the sector.

A subsequent roundtable with key government, provider and regulatory stakeholders confirmed that the industry shares this vision but requires tools to a) understand where they are at; and b) inform their approach to embedding quality dementia care more consistently through their services.

In this initiative, Dementia Australia will offer two inter-related audits that will deliver a 'health check' and 'environmental audit' to every service provider in Australia over a three-year

⁵ Available at www.dementia.org.au/files/documents/DA-Consumer-Summit-Communique.pdf.

period; that is, 1,531 residential aged care and home care providers.⁶ Both tools align with the recommendations of people impacted by dementia and facilitate the ability of providers to identify gaps, inform continuous improvement activities and, ultimately, the data collected through these audits may help to inform any future targeted funding allocations by the Government.

Implementation cost: \$4.3 million per annum over 3 years

Initiative 2.2 Foundational Dementia Education

Dementia Australia is committed to improving the dementia knowledge of the aged care workforce through foundational dementia education workshops.

In this initiative, Dementia Australia will complement the range of national accredited dementia education available with two 3-hour non-accredited courses that address two of the fundamental issues highlighted by staff, providers and people with a lived experience of dementia: 'Understanding dementia' and 'Applying a problem solving approach to behaviour'.

This investment will expand the capacity of the aged care workforce to both understand and respond to dementia within their services which can include the inappropriate use of restraints and antipsychotics.

Implementation cost: \$858,000 per annum for 3 years

Initiative 2.3 Dementia Practice Leaders

In recognition of the important role of workforce capacity, career pathways and ongoing education, Dementia Australia will educate 1,000 aged care workers across three years to successfully complete the Certificate IV in Dementia Practice. This is an accredited course that elevates the individual leadership capacity of participants and provides tools to successfully embed systemic culture change and apply contemporary, evidence-based dementia practice.

A key aspect of this initiative is the expectation that staff certified in the Certificate IV in Dementia Practice will provide coaching and mentoring to other staff in their service or organisation, which could lead in turn to their recognition as Dementia Practice Leaders. The role of these leaders is critical in ensuring that knowledge is translated into practice on an ongoing basis, and recognises that 90 percent of learning occurs in the workplace.

Implementation cost: \$4 million per annum for 3 years

⁶ Department of Health (2019) Total Number of Providers with Operational Aged Care Places by Service Type by State/Territory as at 30 June 2019 available at www.gen-agedcaredata.gov.au/Resources/Access-data/2019/August/Stocktake-data-30-June-2019.

Initiative 2.4 Dementia Community of Practice

In this capacity building initiative, Dementia Practice Leaders from aged care organisations across the country will be supported to create and participate within a dementia community of practice, aimed at bettering outcomes for people living with dementia, their families and carers through professional networking that increases the capacity of leaders to tackle systemic and service-level change management and implement contemporary evidence-based practices.

Technology is a vital component in supporting this community of practice to span metropolitan as well as regional and remote locations. This approach to establishing communities of practice means that ideas and innovations in dementia care are able to be universally accessed by Dementia Practice Leaders, no matter what their geographical location.

Implementation cost: \$450,000 per annum for 3 years

PRIORITY #3: REDUCE DISCRIMINATION

Initiative 3.1 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 build on initial findings gathered through a nationwide survey on dementia and discrimination in 2019 to create a social 'movement of change' that calls the community to action both individually and collectively. Given that many forms of discrimination are perceived by people both with and without dementia as all too common, 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 people impacted by the disease.

Implementation cost: \$1 million per annum for 2 years

CONCLUSION

The prevalence of dementia in our community is growing exponentially. Those impacted by dementia across Australia 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.

The funding investments outlined in this submission will represent long term savings for the government, not least through more effective use of health, disability and ageing services, fewer emergency interventions and a focus on continuous improvement. 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 Federal Government is serious about making dementia core business in Australia.