



**dementia
australia™**

**2020-21 Federal Pre-Budget
Submission**

June 2020

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, 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.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia 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 of all ages 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.



SUPPORTING PEOPLE IMPACTED BY DEMENTIA THROUGH THE CHALLENGE OF COVID-19 AND BEYOND

Dementia has a profound impact on individuals as well as their families, carers and friends.¹ Services that support people living with dementia, their families and carers are a social imperative, particularly in a COVID-19 environment in which meaningful social engagement may become more challenging. There are more than 459,000 Australians living with dementia in 2020² and around 1.6 million people involved in their care³. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.⁴

Dementia is a terminal condition and there is still no cure. It continues to be the leading cause of death of women in Australia, the second leading cause of death in this country overall and it is predicted to become the leading cause of death within the next five years.⁵

Although 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, we know from what individuals impacted by dementia tell us that there is still much to do before this becomes a reality. As the Royal Commission into Aged Care Quality and Safety has demonstrated, substantial and sustained transformation is required for quality dementia care and support to become an intrinsic part of service delivery.

In 2020, the unprecedented social distancing measures and restrictions put in place as a result of COVID-19 have affected people living with dementia, their families and carers significantly. People living with dementia are already one of the most vulnerable groups in our community and it is important that COVID-19 and its longer-term impacts do not inadvertently add to the challenge that the symptoms of dementia already pose to many people.

Although the disruption to service delivery is gradually lifting, and services are looking to recalibrate their delivery to suit a post-COVID-19 environment, the pandemic has placed a spotlight on some significant service gaps for people impacted by dementia.

Dementia Australia is experiencing an increase in demand for support as a result of the unintended consequences of social distancing. The mental health of people living with dementia is being impacted, along with a decline in cognitive functioning for many, as a

¹ 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.

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

³ Based on Dementia Australia's analysis of the following publications – M.Kostas et al., *National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016*, Department of Health, 2017; Dementia Australia, *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra, 2018; Alzheimer's Disease International and Karolinska Institute, *Global estimates of informal care*, Alzheimer's Disease International, 2018; Access Economics, *Caring Places: planning for aged care and dementia 2010–2050*, 2010

⁴ Dementia Australia, *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra, 2018

⁵ Australian Bureau of Statistics, *Causes of Death, Australia, 2017* (cat. no. 3303.0), 2018

result of changes to routine, lack of mental stimulation, and social isolation. This has subsequent flow-on mental health impacts for carers of people living with dementia.

For people living with dementia, their families and carers, the extent and impact of social distancing and other COVID-19 measures is likely to be significant and potentially far-reaching. It is therefore imperative that now, more than ever, we are more proactive in building social connection, even as the ability to connect in-person is hampered.

Dementia Australia seeks commitment in the forthcoming 2020-2021 Federal Budget to ensure that people living with dementia, their families and carers receive the support they need as Australian's continue to live with the impact of COVID-19 and navigate the subsequent 'new normal'.

Based on the experiences being reported by people impacted by dementia and service providers, Dementia Australia is certain that a package of supports designed for people with dementia, their families and carers will:

- address the mental health challenges that informal carers of people with dementia are experiencing (including carer stress, burnout and reports of violence or abuse)
- potentially address the trajectory of cognitive decline that people with dementia are experiencing as a result of service changes and social isolation;
- support aged care providers to build the capacity of their staff to deliver quality dementia care in an environment that has fundamentally changed.

FEDERAL FUNDING COMMITMENT

With an investment of just over \$7.4 million in 2020-21 the Federal Government can ensure that people impacted by dementia receive:

- Outreach and early intervention through the National Dementia Helpline
- Online social support
- Quality care in residential aged care facilities.

The initiatives outlined in this submission have been designed to maximise the impact that the 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 presented by the COVID-19 pandemic and its aftermath.

PRIORITY 1 – TIMELY DIAGNOSIS AND EARLY INTERVENTION

Initiative 1.1 National Dementia Helpline outreach

The National Dementia Helpline is currently only funded to provide information and counselling to people who call (in bound) and there is limited capacity to provide follow up or outreach. Dementia Australia would like to expand our capacity to make outbound calls in order to mitigate the risk that people who may need support after their first contact with us are not left isolated and are enabled to access the early intervention services and supports that would help them avoid crisis situations.

This investment will expand the capacity of the National Dementia Helpline to provide an outreach model of support to people living with dementia, their families and carers. This will enhance our ability to ensure people living with dementia, their families and carers receive the timely support they need.

Implementation cost: \$900,000 per annum for at least one year

Initiative 1.2 Dementia Connect - online social support

The social/physical distancing measures and restrictions implemented to combat the COVID-19 pandemic have impacted significantly on people living with dementia, their families and carers. Social isolation, loneliness and poor mental health outcomes are being experienced by many impacted by dementia. At a time when social and peer support is so desperately needed, people with dementia and carers have been faced with the cancellation and disruption of their usual activities and services.

Dementia Australia will develop 20 time-limited national social support groups for people with dementia and carers. These groups will be structured, supported groups that are coordinated by a trained facilitator and designed to address the mental health concerns people impacted by dementia are experiencing. This investment will also enable us to purchase tablets available on loan to clients who do not have access to the required technology and to provide support to use the tablets.

Implementation cost: \$1.2 million per annum for three years (TOTAL \$3,600,000)

PRIORITY 2 – QUALITY DEMENTIA CARE

Initiative 2.1 Foundational Dementia Education

Dementia Australia is committed to improving the dementia knowledge of the aged care workforce through foundational dementia education workshops. This initiative is particularly important for the ‘surge’ aged care workforce required as a result of the COVID-19 pandemic.

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 (TOTAL \$2,574,000)

Initiative 2.2 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. Leadership in dementia care is particularly important in the current context of the COVID-19 pandemic as the aged care sector faces increased pressure day-to-day and at a systemic level.

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 (TOTAL \$12,000,000)

Initiative 2.3 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 an online 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.

The Centre for Dementia Learning at Dementia Australia piloted online communities of practice to support the sector to respond to challenges presented during the COVID-19 pandemic. These sessions were very well received and oversubscribed – there is clear demand for this type of support and professional development.

Implementation cost: \$450,000 per annum for 3 years (TOTAL \$1,350,000)