

# Delivering on a Roadmap for Quality Dementia Care

Parliamentary Friends of Dementia paper

17 February, 2022

Many of the key priorities laid out in <u>A Roadmap for Quality Dementia</u> <u>Care</u> have been recognised through the current aged care reform process and the 2021 Federal Budget, however, Dementia Australia believes there is much more to be achieved.

Dementia Australia's vision is an inclusive future where all people impacted by dementia receive the care and support they choose.

# An ongoing focus on systemic change

People living with dementia, their families and carers have told us what they need and Dementia Australia is committed to seeing through a transformation that improves the quality of care and support for people impacted by dementia. It is imperative that there is an ongoing focus on a consistent system of timely diagnosis of dementia. This should include clarification on the role of general practice and consideration of the implementation of a national system of memory clinics with direct referrals to Dementia Australia, ensuring early access to dementia management support and education.

Post-diagnostic management for dementia is critical, and often occurs long before mainstream aged care services are needed. Appropriate dementia support requires access to early intervention services including rehabilitative and enabling approaches to ensure that people with dementia can live as well as possible with the condition

# Dementia Australia's pre-budget submission

Dementia Australia acknowledges the Australian Government's 2021 investment in our organisation's capacity to deliver a broader range of services and supports under the National Dementia Support Program.

The initiatives outlined in our pre-budget submission focus on continuing to build the capacity of the sector, to deliver quality dementia care. We have identified some remaining key system gaps that require attention: dementia education; specialist dementia palliative care; and sustainability of the Dementia-Friendly Communities program.

# 1. Improving the dementia capability and capacity of the aged care workforce

Funding was allocated to aged care workforce education as part of the government's response to the recommendations made by the Royal Commission into Aged Care Quality and Safety, however, more substantive funding is required to ensure that all aged care workers are appropriately educated and supported to provide quality dementia care.

Dementia Australia seeks a commitment from government to ensure greater levels of dementia education and capability of the aged care workforce through funding for two initiatives:

## Initiative 1. Dementia Essentials training for all new staff entering the aged care sector

Dementia Essentials is a course which explores strategies to assist with good communication, planning, developing appropriate activities and understanding changed behaviour in people living with dementia. Dementia Australia proposes a tripling of the current Dementia Essentials participants and a requirement that new staff provide evidence of completion of Dementia Essentials to enter the aged care workforce. This initiative would also enable existing aged care staff to complete Dementia Essentials training to consolidate and enhance their dementia knowledge and improve quality care for people living with dementia.

### The key benefits of this initiative are:

- improving the dementia knowledge and skill of the aged care workforce
- ensuring staff are better prepared to provide quality care to people living with dementia and to support their families and carers.

### Initiative 2. Dementia Practice Health Check

Dementia Australia has developed the Dementia Practice Health Check for residential aged care providers, which is aligned with the existing aged care standards and consumer expectations and will be adapted to include home care. The Dementia Practice Health Check will provide a clear assessment of the current workforce dementia capability.

### The key benefits of this initiative are:

- provision of guidance on where current strengths and weaknesses exist in each provider's workforce across the sector
- the ability to inform ongoing workforce planning for each provider as well as informing capacity-building work required
- ensuring that the providers most in need of support have access to the Dementia Practice Health Check
- the ability to inform the work of Dementia Support Australia,
   Dementia Training Australia, the Aged Care Quality and Safety
   Commission and the Aged Care Workforce Industry Council and contribute to broader sector workforce planning.



(Dementia education has) reaffirmed and enhanced my passion at work, and to continue to find alternative ways to provide the quality of care expected.

-aged care worker



It's a no-brainer in residential aged care – not just the understanding of different types of dementia, but the different trajectories – the whole organisation has to have the training.

-person living with dementia



This beautiful training (Dementia Essentials) should be compulsory for all carers. ••

-aged care worker

# 2. National specialist dementia palliative care program

Dementia Australia's Nightingale Program is a unique and innovative nurse-led model of care. It is the only specialist dementia palliative care program in Australia, providing dementia-specific education and clinical support to people living with dementia, their families and carers in South Australia.

The program provides strategies and advice to support people living with dementia, their families and care providers—with a focus on promoting choice and wellbeing during all stages of diagnosis.

Dementia Australia aims to expand delivery of this program nationally to improve the experience of all people living with dementia, their families and carers, and requests funding for an initial three-year period.

### The key benefits of an expanded program will be:

- supporting more individuals around Australia impacted by dementia to stay at home longer and maximise their independence
- encouraging people impacted by dementia to be actively involved in decision-making, including their future care options by planning ahead
- reducing avoidable and unnecessary hospital admissions
- increasing access to clinical advice regarding pain and other symptom management, delirium, incontinence and palliation.



The team at Dementia Australia were a vital support, they provided ongoing assessment, advice and strategies for the changing symptoms of dementia that helped us to be confident with our plans. We even managed a trip to see family interstate just weeks before my husband's death. His final weeks were a collaborative approach. I felt supported and capable to fulfill on his wishes. He died peacefully, with dignity, and surrounded by family.

-family member of Nightingale Program client

# 3. Dementia-Friendly Communities program

Dementia-Friendly Communities is a national community development program. The program team facilitates and supports initiatives across four tiers of dementia-friendly involvement:

Dementia Friends, Dementia Alliances and Dementia-Friendly Organisations, and grant-funded Community Engagement Program demonstration projects.

The program's success is based on the central role that people living with dementia play in all program tiers, from the establishment of Alliances and development of action plans, through to awareness-raising activities and implementation of grassroots dementia-friendly initiatives.

The Dementia-Friendly Communities program has developed an impressive range of diverse, nationwide projects and activities, but support is required to secure the ongoing expansion of the program. Dementia Australia seeks funding for a further three years to ensure the growth, development, and sustainability of current and future Dementia-Friendly Communities initiatives.

### The key benefits of ongoing funding for this program will be:

- ensuring the continuation of local dementia awareness and inclusion initiatives
- supporting new and emerging dementia-friendly communities
- increasing the number of Dementia Friends, Dementia Alliances and Dementia-Friendly Organisations
- building the capacity of the Dementia-Friendly Communities program team to empower people living with dementia and support their involvement in dementia-friendly initiatives.



The Dementia-Friendly Communities program team is committed to continue to work towards an inclusive community, because a community that is dementia-friendly is simply a community that is good for everyone. 

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-Support. Encourage. Empower: Leading the way towards a Dementia-Friendly Community, Dementia Australia Parliamentary Friends of Dementia paper, 2021



# Dementia is the **second leading cause of death of Australians**<sup>1</sup>



In 2022, there are up to 487,500 Australians living with dementia.

Without a medical breakthrough, the number of people with dementia is expected to increase to up to 1.1 million by 2058<sup>2</sup>



In 2021, it is estimated that up to 1.6 million people in Australia are involved in the care of someone living with dementia.<sup>3</sup>

- 1. Australian Bureau of Statistics (2020) Causes of Death, Australia, 2019 (cat. No. 3303.0)
- 2. Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra
- 3. Based on Dementia Australia's analysis of the following publications M.Kostas et al. (2017) National Aged Care Workforce Census and Survey The Aged Care Workforce, 2016, Department of Health; Dementia Australia (2018) Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), Global estimates of informal care, Alzheimer's Disease International; Access Economics (2010) Caring Places: planning for aged care and dementia 2010–2050

### **About Dementia Australia**

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care.

We advocate for positive change and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible.

Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers. We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

No matter how you are impacted by dementia or who you are, we are here for you.

# National Dementia Helpline

### 1800 100 500



For language assistance call **131 450** 

Find us online dementia.org.au









