



**dementia
australia™**

The new voice of Alzheimer's Australia

2018-19 Pre-budget Submission

Embedding empathy, understanding and
quality in the provision of dementia care.

December 2017

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 413,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care.

Dementia Australia works with consumers, 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 consumers means that we are an important 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 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.

About Dementia Australia



INTRODUCTION

A twenty-first century challenge

Dementia is one of the largest health and social challenges facing 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 is predicted to become the leading cause of death within the next five years¹. Dementia is not a natural part of ageing. It is a disease of the brain and affects a person's ability to function and ultimately to care for themselves. It is a terminal condition that affects people's abilities and memories and has a profound impact on the individual and their loved ones. It is surrounded by stigma and misunderstanding, isolates people, their families and carers from social networks, and carries 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 those living with dementia is worse than the care delivered to any other vulnerable group.

It is estimated that there are more than 413,000 Australians living with dementia and 1.2 million people involved in their care; by 2056 there will be over one million people living with dementia. To put it another way, by 2056 more than 650 people will be diagnosed with dementia every day. These numbers include more than 25,000 people with younger onset dementia, that is, dementia that develops before the age of 65, in people aged from their thirties-to-sixties and more rarely in a person's twenties. One in 13 people living with dementia today lives with younger onset dementia².

Dementia is an ever changing and progressive condition, often with complex physical comorbidities and potentially psychological and behavioural symptoms which require expert assessment by appropriately trained professionals, and care and management by well trained staff. At present there are insufficient measures to ensure that these critical elements are in place.

The cost to our community

The cost of dementia to the Australian economy is already enormous and growing rapidly.

In 2017, dementia is estimated to have cost Australia \$14.67 billion. By 2025, the total cost of dementia is predicted to increase to \$18.7 billion in today's dollars, and by 2056, to over \$36.8 billion.³ Of this, \$5.6 billion is attributable to the estimated loss of income of people with dementia and carers, a figure set to more than double to \$12.8 billion by 2056. Cumulatively, that equates to a staggering total cost of more than \$1 trillion over the next 40 years.

Without the right supports at the right time in the appropriate care settings, dementia can also present a significant cost to our already stretched health systems. People with dementia are high users of acute care services with about one in four people with dementia being admitted to hospital every year, which is twice the rate of people of the same age who do not have dementia⁴. The cost associated with hospitalisation for people with dementia is also high. In NSW alone, the average

1 Australian Bureau of Statistics (2016) *Dementia: Australia's leading cause of death?* Accessed online.

2 The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017) *Economic Cost of Dementia in Australia 2016-2056*.

3 The National Centre for Social and Economic Modelling NATSEM (2016) *Economic Cost of Dementia in Australia 2016-2056*

4 Professor Diane Gibson (2014) Understanding what is different for patients with dementia in acute care hospitals, presentation at *Dementia Care in Hospitals Symposium*, Sydney, 2014.

cost of hospital care for people with dementia was generally higher than for people without dementia (\$7,720 compared with \$5,010 per episode). The total cost of hospital care for these patients was estimated to be \$462.9 million, of which around \$162.5 million may be associated with dementia.⁵ People with dementia also stay in hospital almost twice as long as those without dementia, averaging 16.4 days of care compared with 8.9 days for other patients.⁶

Upskilling the aged care workforce

Care for people with dementia is a core responsibility of all aged care service providers, and there must be clear criteria and expectations to support this. To ensure quality, the workforce must have the appropriate education and training, skills, and attributes to provide the care that is needed. This includes the capacity to provide quality care to people with dementia, who are often frail and vulnerable, and may have complex care needs.

In 2016–17, over 1.3 million people received some form of aged care, delivered through an aged care workforce that numbers over 366,000 and includes nurses, personal care workers, support staff and allied health professionals. Of this workforce, 240,000 are direct care roles.⁷ There are an estimated 197,046 older people currently being supported in residential aged care nationally, and more than half of this group has dementia. Approximately 3 in every 10 people living with dementia live in residential aged care whilst 7 in every 10 live in the community⁸.

Clearly then, the imperative in ensuring quality dementia care can only be achieved when health care professionals and all care staff are educated and trained in key aspects of dementia care to an appropriate standard including:

- person-centred care,
- the fundamentals of caring for people with dementia,
- psychosocial approaches to addressing unmet needs,
- pain assessment and management (particularly as people with dementia may be unable to verbalise their needs), and
- appropriate end-of-life care.

The 2012 Aged Care Workforce Survey found that direct care workers in the aged care sector identified “Dementia” and “Palliative Care” as the top two areas where they require further education and training.⁹ This indicates an unmet need for education and training to improve knowledge, skills and confidence in caring for people with dementia.

The same survey found that working with “aggressive service users” (this is likely to include people with behavioural and psychological symptoms of dementia) was a normal expectation in 33 per cent of facilities, with another 47 per cent indicating that workers were required to do this in exceptional circumstances. Behavioural and psychological symptoms often reflect unmet needs of the person with dementia and as dementia advances is a more complex symptom of the disease. Similarly, a recent review of Commonwealth-funded dementia programs identified a need for better

5 Australian Institute of Health and Welfare (2013) *Dementia care in hospitals: costs and strategies*.

6 Draper B, Karmel R, Gibson D, Peut A & Anderson P. (2011) The Hospital Dementia Services Project: age differences in hospital stays for older people with and without dementia. *International Psychogeriatrics*, 23:1649–58.

7 Department of Health (2017) *2016–17 Report on the Operation of the Aged Care Act 1997* [Accessed](#) online.

8 Australian Institute of Health and Welfare (2012) *Dementia in Australia*. Access Online.

9 King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, Moskos M, Smith L; National Institute of Labour Studies, Flinders University (2013) *The aged care workforce 2012: Final report*.

co-ordination and promotion of education and training programs, and improved consistency and quality across these services.¹⁰

A recent stocktake of Commonwealth-funded aged care workforce activities confirmed that the quality and quantity of aged and community care training varies significantly, with workplace placements for Certificate III students ranging from under 60 hours for some providers to up to two years for other providers. The stocktake recommended that greater targeting of workforce training and education is needed to ensure responsiveness to identified workforce or skill gaps in the industry.¹¹

Therefore, learning pathways are needed across the country for care staff to develop knowledge, skills and emotional intelligence, from basic level to advanced practice level across dementia. Government and aged care service providers have a shared responsibility to develop and fund education and career pathways for the aged care workforce. To this end, Dementia Australia urges the federal government to support better ongoing education and training to develop and sustain a workforce skilled in dementia care especially for the aged care workforce.

With 413,000 Australians living with dementia today and the anticipated increase in prevalence in coming years, dementia-specific quality care standards must be set and met. Dementia Australia's education and training programs respond to the evolving characteristics of the workforce, including targeted education and training for the increasing proportion of the workforce which comes from culturally and linguistically diverse backgrounds.

The solution: Dementia specialist education

The overwhelming response to Dementia Australia's Virtual Dementia Experience™ (VDE) has highlighted the success of experiential and immersive learning experiences in stimulating meaningful practice change in health and ageing services. The Educational Dementia Immersive Experience (EDIE) is the portable version of VDE and an innovative educational program that uses virtual reality technology to enable participants to see the world through the eyes of a person with dementia.

The EDIE program, which operates within a fee-for-service model in NSW and Victoria, provides health care workers and those caring for people living with dementia with an increased understanding of the experiences and needs of individuals with dementia. EDIE aims to improve outcomes for people with dementia by training workers to take a consumer perspective of dementia, increasing knowledge of dementia, and improving understanding of how to identify support needs in partnership with clients and carers.

The workshops explore what it feels like to experience dementia and care for someone living with dementia, and to work in partnership with the person living with dementia and their carer in identifying support needs and developing a support plan that enables them to live more confidently with Dementia. Evaluation by Swinburne University has shown that immersive technology can increase empathy and understanding twofold compared to a standard workshop experience. The introduction of the Educational Dementia Immersive Experience (EDIE) brings a portable version of this kind of learning to the workplace by providing on-site education that generates empathy and better understanding of dementia as well as working in partnership with people living with dementia, their families and carers to identify support needs and stronger paths of engagement.

¹⁰ KPMG (2015) *Analysis of dementia programmes funded by the Department of Social Services*.

¹¹ Health Outcomes International for Department of Social Services (2015) *Stocktake and analysis of Commonwealth funded aged care workforce activities: Final report*.

Research shows that the experience of the Enabling EDIE workshop provides deep insight into the experience of dementia for people from all walks of life and, importantly, anecdotal evidence suggests that it is changing clinical practice, improving the treatment of people with dementia and reducing the inappropriate use of antipsychotic medications and aggressive incidents.

Dementia Australia is thus committed to ensuring that EDIE plays a pivotal role in improving dementia care across the spectrum of residential and community based care in Australia, and has designed a three-hour educational program called Enabling EDIE, to expand our educational reach. This strategy would ensure that the aged care workforce is at the forefront of culture and practice change in dementia care.

Under our proposed national model, all residential aged care staff and community aged care workers will undertake the Enabling EDIE workshop to help them develop genuine insight into what it is like to live with dementia.

This three hour workshop is delivered to groups of 15 staff and enables participants to develop a greater understanding of:

- Dementia across various stages
- A consumer perspective of dementia
- Dementia support considerations including individual and diverse needs
- How to identify support needs in partnership with the client and their carer
- How to develop a dementia support plan that focuses on enabling a person to live more confidently with dementia

It is anticipated that the program will be able to provide Enabling EDIE to the following direct staff across the workforce.¹²

Care Setting	Number of Workers ¹³	Enabling EDIE
Residential Aged Care	153,854	\$10,300,000
Home care and home support outlets	86,463	\$5,800,000
Total		\$15,100,000

At a total cost of \$15.1 million, the Federal Government can ensure that our aged care workforce will have an increased understanding of dementia across various stages, the needs of people living with dementia and their carers, and how to develop a dementia support plan that focuses on enabling a person to live more confidently with dementia. Upskilling the 240,317 direct care aged care workforce outlined above will also have a positive flow on impact on the nearly 1.3 million aged care consumers accessing these services.

¹² Department of Health 2017. *2016–17 Report on the Operation of the Aged Care Act 1997* [Accessed](#) online.

¹³ Department of Health (2017). *2016 National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016*. [Access](#) here.

CONCLUSION

The prevalence of dementia in our community is growing exponentially. Australia needs decisive action to prevent, delay, and manage dementia. Without such action, the disease will take an enormous toll on large numbers of individuals, on our community, on our health and aged care systems, our taxation base and our economy.

We have robust evidence and expert consensus regarding the actions needed to address the challenges dementia presents, with the international context provided by the WHO draft *Global Action Plan* and the Australian context provided by the *National Framework for Action on Dementia*. The Federal Government itself has acknowledged the significance of the current and future impact of dementia by making it a national health priority.

Building on these foundations, the Federal Government can enhance our vital aged care workforce, by embedding empathy, understanding and, importantly, quality across the provision of dementia care. Building our capacity to address dementia now will save billions in lost productivity for years to come as well as improving the welfare of the millions of Australians who are in some way impacted by dementia.