

**FIGHT ALZHEIMER'S**  
**SAVE AUSTRALIA**  
**FIGHTDEMENTIA.ORG.AU**

**2017-18**

# **BUDGET SUBMISSION**

**Stage 1 of a comprehensive  
National Dementia Strategy for  
Australia**

**February 2017**

## EXECUTIVE SUMMARY

As the peak advocacy body supporting and representing people living with dementia, their families and carers across Australia, Alzheimer's Australia welcomes the opportunity to provide a submission to inform the 2017-18 Federal Budget.

Our submission is put forward in the international context of the imminent release of the World Health Organisation (WHO) *Global Action Plan on the Public Health Response to Dementia*. The vision for this plan is to achieve “a world in which people can live well with or without dementia, and receive the supports they need to fulfil their potential with dignity, respect and equality”.<sup>1</sup> Alzheimer's Australia shares this aspiration.

The Australian context for our submission is the *National Framework for Action on Dementia 2015-2019*,<sup>2</sup> signed off by all Australian Governments, which strongly aligns with the draft WHO plan and shares with it a vision to improve the quality of life of people living with dementia and their support networks.

Our submission proposes a staged approach to implementing a funded National Dementia Strategy across Australia, based on the priorities identified in this *National Framework for Action* and with the first stage funded through the 2017-18 Federal Budget.

Importantly, our submission – and the proposed staging therein – is reflective of advice received from consumers – people living with dementia, their families and carers – who are the backbone and driving force of our organisation. Consumers have told us very clearly the most urgent areas for action and if we are to make progress in tackling dementia in this country it is these priority areas that we recommend to you for action in 2017-18.

Successive stages of a National Dementia Strategy must rely on contemporary evidence and consumer perspectives, and of course align with the comprehensive range of key areas for action outlined in *The National Framework for Action*. Alzheimer's Australia therefore calls on the Australian government to make a firm commitment to fund a long-term National Dementia Strategy on a progressive basis as fiscal circumstances allow, and in order of priority as identified by consumers.

Alzheimer's Australia acknowledges that some headway has been made through existing programs as well as recent Federal funding announcements, but it is vital that specific priority areas are addressed more systematically and systemically through the 2017-18 Federal Budget.

Consumers have identified the following top priorities among the strategies identified in the *National Framework for Action on Dementia*, and Alzheimer's Australia strongly recommends them for Federal Budget inclusion:

- Do more to reduce people's risk of dementia so that onset of dementia in individuals is avoided or delayed, resulting in fewer people in the community having dementia.
- Ensure that people with dementia have access to quality aged care services.

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<sup>1</sup> [http://www.who.int/mental\\_health/neurology/dementia/action\\_plan\\_consultation/en/](http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/).

<sup>2</sup> [https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/09\\_2015/national-framework-for-action-on-dementia-2015-2019.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/09_2015/national-framework-for-action-on-dementia-2015-2019.pdf).

- Improve access to quality respite care to support people with dementia living in the community, and their families and carers.

The funding sought for these priority areas is \$19 million per annum for each of the three years from 1 July 2017, a total of \$57 million over three years. We urge the Federal Government to make these funds available through the forthcoming Budget.

## SUMMARY OF FUNDING PROPOSAL

### 1. DEMENTIA RISK REDUCTION

Implement a *Healthy Life, Healthy Brain* campaign to inform and educate Australians about brain health and alert people to the links between lifestyle and health factors, their risk of cognitive impairment and dementia, and their risk of developing other chronic conditions. \$3 million per annum

### 2. QUALITY AGED CARE SERVICES FOR PEOPLE WITH DEMENTIA

Fund the development of a consumer and carer based *Quality in Dementia Care* program to increase transparency and support quality care for people with dementia, through residential and home based aged care services. \$1 million per annum

### 3. BETTER RESPITE CARE TO SUPPORT PEOPLE WITH DEMENTIA AND THEIR CARERS

Establish a dementia respite supplement to support the development of dementia-specific respite services. \$15 million per annum

	Additional Funding (\$ million)			
	2017-18	2018-19	2019-20	Total
1. Dementia Risk Reduction	3	3	3	9
2. Quality Aged Care Services	1	1	1	3
3. Better Respite Care	15	15	15	45
<b>Total</b>	<b>19</b>	<b>19</b>	<b>19</b>	<b>57</b>

## BACKGROUND

Dementia is one of the largest health and social challenges facing Australia. Forthcoming estimates by the National Centre for Social and Economic Modelling (NATSEM) put the number of Australians living with probable dementia in 2016 at 400,833. More than 25,000 people have younger onset dementia (a diagnosis of dementia under the age of 65). NATSEM further estimates that the total number of Australians with dementia will double over the next 20 years, and nearly triple over the next 40 years, to reach over 1.1 million in 2056.<sup>3</sup> The contribution of vascular risk factors compounds dementia rates.<sup>4</sup> The societal impact is even greater than these figures suggest, as many more people are involved in the care of a person with dementia or impacted by their condition.

The cost of dementia to the Australian economy is already enormous and growing rapidly. NATSEM has estimated that the total direct cost of dementia in 2016 was \$8.8 billion, with hospitalisation and care costs being the largest components. The total direct costs of dementia are projected to increase nearly threefold to \$24.1 billion by 2056. Indirect costs arising from the potential loss of income of people with dementia and carers were calculated to have been an additional \$5.5 billion in 2016, and this figure is set to more than double to \$12.8 billion by 2056.<sup>5</sup>

Australia is yet to implement a funded National Dementia Strategy that would comprehensively tackle the devastating impact this group of diseases continues to have on our community and our economy.

However, it is clear that we know what needs to be done. In late 2015, all Australian Governments agreed to the *National Framework for Action on Dementia 2015-2019*, which utilises current evidence along with expert opinion and lived experience drawn from consultations, to put forward seven priority areas for action:

1. Increasing awareness and reducing risk
2. The need for timely diagnosis
3. Accessing care and support post diagnosis
4. Accessing ongoing care and support
5. Accessing care and support during and after hospital care
6. Accessing end of life and palliative care
7. Promoting and supporting research.<sup>6</sup>

These priority areas align with the action areas identified in the draft WHO *Global Action Plan*, which identifies a need to focus on:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment and care

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<sup>3</sup> Brown M, Hansnata E, La HA for Alzheimer's Australia (forthcoming); NATSEM. *Economic cost of dementia in Australia, 2016-2056*: Executive Summary, p. 8.

<sup>4</sup> Australian Institute of Health and Welfare (2016). *Contribution of vascular diseases and risk factors to the burden of dementia in Australia: Australian Burden of Disease Study 2011*. Australian Burden of Disease Study series no. 9. Cat. no. BOD 10.

<sup>5</sup> Brown M, Hansnata E, La HA for Alzheimer's Australia (forthcoming); NATSEM. *Economic cost of dementia in Australia, 2016-2056*: Executive Summary.

<sup>6</sup> [https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/09\\_2015/national-framework-for-action-on-dementia-2015-2019.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/09_2015/national-framework-for-action-on-dementia-2015-2019.pdf).

5. Support for dementia carers and families
6. Information systems for dementia
7. Dementia research and innovation.<sup>7</sup>

Alzheimer's Australia proposes that the Federal Government, in partnership with State/Territory Governments, agrees to implement a staged National Dementia Strategy based on the *National Framework for Action on Dementia 2015-2019*. This would represent for the first time a strategic, collaborative and cost-effective response to dementia across Australia.

Action is already underway in several areas. For example, the Federal Government's 2016 announcement of further funding for Dementia Friendly Communities will help to advance community awareness. Several initiatives have also been implemented that focus on improving timely diagnosis of dementia and support for people with younger onset dementia. In addition, the National Dementia Support Program, due for renewal in 2017, provides a range of critical care and support services for people living with dementia, their families and carers at diagnosis and beyond. Moreover, the establishment of the NHMRC National Institute for Dementia Research has provided the impetus to draw together diverse approaches to dementia research and develop a more strategic approach.

Yet there is still much to be done. Few Australians know that they can reduce their risk for dementia, let alone understand how to do so.<sup>8</sup> People living with dementia continue to struggle to get access to the services and supports they require both in the community and in residential aged care and this struggle is even more challenging for those living with younger onset dementia or those with special needs. Family carers find it difficult to balance work, life and caring responsibilities, often resulting in reduced workforce participation and adverse physical and mental health outcomes.<sup>9</sup>

The staged implementation of an integrated National Dementia Strategy will address the key focus areas of the *National Framework for Action*. It will offer comprehensive and flexible support to consumers, building on previous investment in dementia programs and services.

Investment in this integrated approach to dementia has the potential to reduce the short-term and long-term costs of dementia to the health and aged care system by delaying the onset of dementia; providing better community supports and thus delaying placement in residential care; and ensuring better quality aged care services – all of which will reduce the need for crisis intervention. Most importantly, this investment will improve the wellbeing of the increasing number of people impacted by dementia in Australia.<sup>10</sup>

Alzheimer's Australia is aware of the fiscal constraints facing the Federal Government and therefore proposes a staged approach to the full implementation of the National Dementia Strategy.

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<sup>7</sup> [http://www.who.int/mental\\_health/neurology/dementia/action\\_plan\\_consultation/en/](http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/).

<sup>8</sup> Australian Institute of Health and Welfare (2016). *Contribution of vascular diseases and risk factors to the burden of dementia in Australia: Australian Burden of Disease Study 2011*. Australian Burden of Disease Study series no. 9. Cat. no. BOD 10.

<sup>9</sup> Brodaty, H, Green, A (2002). 'Who cares for the carer? The forgotten patient', *Australian Family Physician*, 31(9): pp. 833-36.

<sup>10</sup> Alzheimer's Australia notes, however, that ongoing investment into younger onset dementia services is also required, given this cohort are not able to access aged care services and access to National Disability Insurance Scheme services can be problematic.

Based on input to date from consumers, Alzheimer's Australia proposes that the following elements of an integrated National Dementia Strategy are funded through the Federal Budget from 2017-18:

- Action to reduce people's risk of dementia so that onset of dementia is avoided or delayed and fewer people in the community have dementia.
- Action to ensure that people with dementia have access to quality home-based and residential aged care services.
- Action to improve access to quality respite care to support people with dementia living in the community, their families and carers.

Further information is set out below on each of these priorities, including a summary of the underlying issues and an outline of what needs to happen to make a difference.

## PRIORITY AREA 1 – DEMENTIA RISK REDUCTION

### Issue

Research over the last decade has shown that addressing behavioural and clinical risk factors can significantly reduce a person's risk of dementia. Up to a third of cases of Alzheimer's disease are potentially attributable to preventable risk factors<sup>11</sup>. It is estimated that reducing risk factor prevalence could result in a 14% reduction in dementia burden attributable in 2020, particularly in the context of diabetes (48% reduction in dementia burden due to diabetes), obesity in mid-life (26%) and physical inactivity (15%).<sup>12</sup> Even more significantly, a reduction in risk factors would result in a total savings of some \$26.8 billion in the costs of dementia over the next twenty years (comprising savings in direct costs of \$17.6bn and indirect costs of \$7.2bn) and a massive \$120.4 billion by 2056 (savings in direct costs of \$76.6bn and indirect costs of \$43.8bn).<sup>13</sup>

In just one major randomised controlled trial undertaken in Finland (the FINGER study), researchers have shown that older adults who follow a healthy eating plan and undertake regular exercise and brain-training activities have enhanced memory performance.<sup>14</sup>

While there is increasing community awareness of the link between health behaviours and physical health, there is little awareness of the link between these behaviours and the risk of dementia. Market research commissioned by Alzheimer's Australia in 2015 indicates that only six in ten Australians understand that dementia is *not* a normal part of ageing. One in five people surveyed believed there is nothing anyone can do to reduce the risk of dementia, and a further one in five did not know whether this notion was true.<sup>15</sup> Previous research has shown that, even for those who believe risk reduction is possible, the majority are unaware of the role of vascular risk factors in dementia.<sup>16</sup>

At the same time, the research indicates a real interest in the community to know more about how to reduce risk for dementia, with more than eight in ten people surveyed keen to have more information about how to reduce their risk. The figure is even higher for women and for people aged over 50.<sup>17</sup>

Two out of three Australians are afraid of developing dementia – a fear second only to the fear of developing cancer<sup>18</sup>. There is an opportunity to translate this fear into a motivation to make positive behavioural changes in an effort to avoid dementia.

Australia was the first country in the world to fund a national dementia risk reduction program, *Your Brain Matters*. This program was in place from September 2012 to June 2015 and was successful in the context of the funding levels and timeframes. The program aimed

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<sup>11</sup> Barnes DE, Yaffe K (2011). 'The projected effect of risk factor reduction on Alzheimer's disease prevalence', *Lancet Neurology*, 10(9): pp. 819-28.

<sup>12</sup> Australian Institute of Health and Welfare (2016). *Contribution of vascular diseases and risk factors to the burden of dementia in Australia: Australian Burden of Disease Study 2011*. Australian Burden of Disease Study series no. 9. Cat. no. BOD 10: p. vii.

<sup>13</sup> Brown M, Hansnata E, La HA for Alzheimer's Australia (forthcoming); NATSEM. *Economic cost of dementia in Australia, 2016-2056*: chapter 8.

<sup>14</sup> <http://www.dementiaresearchfoundation.org.au/blog/dementia-risk-reduction-strategies-prove-beneficial-enhancing-memory-performance-older-people>.

<sup>15</sup> Ipsos (November 2015). *Perceptions and understandings of dementia: Report of findings*. Unpublished.

<sup>16</sup> Farrow M (2008). *Dementia Risk Reduction: What do Australians Know?* Alzheimer's Australia Paper 14.

<sup>17</sup> Ipsos (November 2015). *Perceptions and understandings of dementia: Report of findings*. Unpublished.

<sup>18</sup> Pfizer Health Report (2011). *Dementia's Everybody's Business*: p. 4.

to raise community awareness about how to improve brain health and encourage people to adopt simple practices that are good for brain health. The *Your Brain Matters* campaign had a measurable impact on the community, with a 2014 survey indicating that up to 15% of those polled could recall at least one campaign message and that these people had strong intentions to take action to reduce their risk of dementia.<sup>19</sup> Unfortunately, funding for this important program ceased in June 2015.

### **Action Required**

A new *Healthy Life, Healthy Brain* program has the potential to reduce the number of people developing dementia and other chronic diseases, and delay the onset of dementia. A delay of five years in onset of dementia has the potential to reduce the number of people with dementia in the community by 30%,<sup>20</sup> resulting in better quality of life for many people and cost savings of more than \$26 billion to the health and aged care systems over the next twenty years.

The *National Framework for Action on Dementia 2015-2019* identifies the need to: “Provide accurate and evidence-based information on risk factors and risk reduction strategies for dementia that are readily available to the community ensuring that it is easy for individuals to seek further information and adopt risk reduction behaviours”.

As part of the initial phase of a funded National Dementia Strategy, the *Healthy Life, Healthy Brain* community awareness campaign should be implemented to inform and educate Australians about brain health and alert people to the links between lifestyle and health factors, their risk of cognitive impairment and dementia, and their risk of developing other chronic conditions, especially vascular conditions. The campaign will build on the successes and learnings of *Your Brain Matters* and other relevant initiatives including the Finnish research and experience from successful risk reduction campaigns such as the “Quit” smoking cessation campaign. In addition, the program will leverage existing partnerships with like-minded public health organisations and not-for-profit organisations with whom Alzheimer’s Australia already collaborates through such initiatives as Prevention 1st.

The approach will integrate dementia prevention with broader health promotion. The campaign will rely heavily on free and low-cost messaging, through public relations efforts involving broadcast and print media, delivery of information and messaging through social media and online channels and Community Service Announcements.

As recommended by the external evaluation of *Your Brain Matters*<sup>21</sup>, the campaign will:

- Collaborate with other NGOs involved in the promotion of vascular health to facilitate the broader reach of the brain health message.
- Engage and equip clinicians, researchers, and public figures as spokespeople to facilitate ongoing media coverage of the brain health message.
- Develop a co-ordinated State and Territory action plan for brain health promotion.

<sup>19</sup> Monash University (September 2015, draft). *Your Brain Matters Evaluation 2012-2015*: pp. 6-7.

<sup>20</sup> Moore, B, Miskovski, K, Stupar, M, Ng, H (2015). *Reducing the Prevalence of Alzheimer’s Disease: modifiable risk factors or social determinants of health?* Alzheimer’s Australia NSW: p. 5; Australian Institute of Health and Welfare (2016). *Contribution of vascular diseases and risk factors to the burden of dementia in Australia: Australian Burden of Disease Study 2011*. Australian Burden of Disease Study series no. 9. Cat. no. BOD 10: p. vii.

<sup>21</sup> Monash University (September 2015, draft). *Your Brain Matters Evaluation 2012-2015*: pp. 7-8.

- Prioritise the engagement of primary healthcare providers as receptive and influential partners in brain health promotion.
- Develop strategies for workplace education which link with other workplace health concerns, such as sedentariness and fatigue.

### **Recommendation**

Implement a *Healthy Life, Healthy Brain* campaign to inform and educate Australians about brain health and alert people to the links between lifestyle and health factors, their risk of cognitive impairment and dementia, and their risk of developing other chronic conditions.

## PRIORITY AREA 2 – QUALITY AGED CARE SERVICES FOR PEOPLE WITH DEMENTIA

### Issue

Dementia is a progressive disease and people with dementia require a range of supports and care. It is estimated that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.<sup>22</sup> Provision of comprehensive home based care and appropriate high quality residential care are therefore fundamental to meeting the needs of people living with dementia, their families and carers.

For the 70% of people with dementia living in the community, access to high quality, flexible home care services is essential. Recent expansion of home care packages and the addition of the dementia supplement in all levels of packages has been a welcome support for people with dementia living in the community.<sup>23</sup> It is important that Government continue to monitor the implementation of Consumer Directed Care and the mix of package levels to ensure that consumers are able to access appropriate care and services in a timely manner.

For the 30% of people with dementia living in residential care, it is critical that all aged care services are well equipped and motivated to provide high quality care for people with dementia, as part of their core business. More than half of all people in Commonwealth-funded residential aged care settings have dementia,<sup>24</sup> yet there is abundant evidence that the needs of these people are often unmet. Alzheimer's Australia receives multiple reports from consumers about physical, psychological and sexual abuse, inappropriate use of restraints, unreported assaults, and people in extreme pain at end-of-life not having access to palliative care.<sup>25</sup>

People with severe behavioural and psychological symptoms of dementia have even more difficulty in getting access to appropriate support and care, even with the implementation of Severe Behaviour Response Teams. Consumers have also expressed major concerns about aged care workforce changes involving a substantial decrease in the proportion of qualified nursing staff and an increase in the proportion of unlicensed and unregulated personal carers<sup>26</sup> and the impact this has on quality of care.

It is very concerning that only *one in four* people surveyed in 2016 through market research commissioned by Alzheimer's Australia were confident that if they had to find an aged care facility for themselves or a family member with dementia, high quality services would be available where they were needed. A major challenge for people living with dementia, their families and carers is the difficulty that consumers experience in judging the quality of a residential care service. The vast majority of Australians in the 2016 survey – more than four

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<sup>22</sup> Australian Institute of Health and Welfare (2012). *Dementia in Australia*. Cat. no. AGE 70.

<sup>23</sup> Although it must be noted that these developments do not contribute to the care and support for people living with younger onset dementia, who are not eligible for aged care supports and instead are required to access services through the National Disability Insurance Scheme.

<sup>24</sup> Department of Health (2015). *2014–15 Report on the Operation of the Aged Care Act 1997*: p. 13.

<sup>25</sup> Alzheimer's Australia (2013). *Quality of residential aged care: The consumer perspective*. Alzheimer's Australia Paper 37: p. 4. [https://fightdementia.org.au/sites/default/files/20131112\\_Paper\\_37\\_Quality\\_of\\_Residential\\_Aged\\_Care.pdf](https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf).

<sup>26</sup> King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, Moskos M, Smith L (2013); National Institute of Labour Studies, Flinders University. *The aged care workforce 2012: Final report*.

in five people – want to see better information provided by Governments about the quality of life of residents in residential care facilities – information such as ratings.<sup>27</sup>

The Government has implemented a number of measures that aim to improve the quality of aged care and to better support people with dementia. However, further work is required if we are to construct an aged care system that achieves the level of quality and transparency that consumers demand. These principles must also be apparent in dementia-specific services offered under the National Disability Insurance Scheme to people with younger onset dementia.

Currently the funding model and accreditation standards for residential aged care focus on clinical inputs, processes and documentation, which has created a medical model of care without a focus on quality of life for residents. There is a need for a cultural shift within aged care to move from “looking after residents” to providing “support for residents to achieve quality of life”.

There is also a need for publicly reported quality indicators for aged care in Australia. A voluntary quality-indicator program has commenced as part of the aged care reforms but data is not yet being made publicly available. In addition, the initial indicators included as part of this program have a clinical focus and do not capture consumer experience or quality of life within aged care services. This lack of quality measures within residential aged care is in stark contrast to the hospital and health care systems, which have successfully implemented a range of quality measures as part of their accreditation programs.

### **Action required**

The *National Framework for Action on Dementia 2015-2019* identifies the need for access to quality care and support for all people with dementia.

It is very difficult for consumers to ascertain quality of dementia care through home-based or residential aged care, and to navigate the aged care service system, including in rural and remote areas. This makes the desired move to a more market-driven system challenging, as informed choice is not possible without good information. Much the same can be said for people living with younger onset dementia accessing services under the National Disability Insurance Scheme, where both access and choice can be hugely challenging.

Access to quality care should be a basic human right. The key to improving the consumer experience of care is a shift from minimum standards through the accreditation process to establishing quality measures that empower consumer choice through better information. Transparent measurement and reporting of quality and consumer experience in aged care are the cornerstone of changing the culture and improving quality in aged care.

Alzheimer’s Australia proposes as a first step funding of a consumer-driven *Quality in Dementia Care* program. In the first instance, this program will engage consumers and carers to develop and implement initiatives to monitor and promote quality aged care for people living with dementia, potentially by including a Dementia Champions capacity-building program for residential aged care. The *Dementia Care* program will provide the

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<sup>27</sup> Roy Morgan Research (2016). *Dementia and Services Research*. Unpublished.

basis for the development, implementation and reporting of measures of quality of life for people with dementia, within home-based and residential aged care, supporting real consumer directed care.

**Recommendation**

Fund the development of a consumer and carer based *Quality in Dementia Care* program to support quality care for people with dementia through residential and home based aged care services.

## PRIORITY AREA 3 – BETTER RESPITE CARE TO SUPPORT PEOPLE WITH DEMENTIA AND THEIR CARERS

### Issue

Informal, unpaid carers, usually family or close friends, play a critical part in enabling people with dementia to live well in the community for longer. In 2016, there were an estimated 190,500 carers of people living with dementia in the community, the majority of whom were informal carers. The projection over the next 20 years suggests that 536,150 paid and unpaid carers will be needed to provide assistance to people living with dementia, and by 2056 the number increases to 775,940.<sup>28</sup> Despite this demand, it has been estimated that there is already an unmet need for hundreds of thousands of residential and community based support packages, and access to appropriate services is even more problematic for those living with younger onset dementia.<sup>29</sup>

With the increasing reliance on home care, it is essential to ensure that there is adequate support for family carers. Respite plays a critical role in providing a break for carers as well as an important opportunity for social engagement for the person living with dementia.<sup>30</sup> Often respite is essential to ensuring that family members can continue caring for the person with dementia at home.<sup>31</sup>

Unfortunately, few respite services are designed specifically to support people living with dementia, let alone those who are under the age of 65. In fact, as care needs increase, respite providers often turn away people who have dementia. Many respite services say that they are not staffed to provide care to people who have behavioural symptoms or who are incontinent.

Over half of co-resident primary carers of people living with dementia have indicated they need more support, and the greatest single unmet area of demand is for respite care. Use of respite care by carers of people living with dementia is lower than would be expected, but those who do use respite care report high levels of satisfaction, in terms of allowing them time for self-care and providing relief from the caring role. Some negative experiences have also been reported, relating to poor quality and/or inflexibility of some services.<sup>32</sup>

Carers repeatedly identify good respite care as an important support for a sustainable caring relationship. In a recent Alzheimer's Australia consumer survey, respite care was ranked second only to peer support amongst programs identified by carers as having been most useful to them. In the same survey, limited respite care was identified as the top area of support that consumers felt needed to be addressed.

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<sup>28</sup> Brown M, Hansnata E, La HA for Alzheimer's Australia (forthcoming); NATSEM. *Economic cost of dementia in Australia, 2016-2056: Executive Summary*.

<sup>29</sup> Access Economics for Alzheimer's Australia (2010). *Caring Places: Planning for aged care and dementia 2010-2050, Volume 1: p. ii*.

<sup>30</sup> Bruen W, Howe A for Alzheimer's Australia (2009). *Respite Care for People Living with Dementia "It's more than just a short break"*. Alzheimer's Australia Discussion Paper 17.

<sup>31</sup> Bruen W, Howe A for Alzheimer's Australia (2009). *Respite Care for People Living with Dementia "It's more than just a short break"*. Alzheimer's Australia Discussion Paper 17.

<sup>32</sup> Brooks D, Ross C, Beattie D for Alzheimer's Australia (2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia Numbered Publication 42: pp. 15-16.

Current residential respite options are very limited and not assisted by the fact that people waiting for permanent care are often utilising this temporary form of respite, meaning these services are less able to assist people to remain in their home.

In addition, people living with dementia have great difficulty accessing any in-home, day centre, or overnight/residential respite options if there are behaviours of concern, even though carers in this situation are at high risk and have greater need. This is especially true of people living with younger onset dementia. There is significant unmet demand for community-based respite care, including the cottage respite model, which while still relatively uncommon, has been a very successful model that is highly valued by the community.

There is an economic as well as a human dimension to this issue. Recent modelling has identified that the per capita direct costs of dementia ranged from \$15,911 for a person aged under 70 years living in the community with mild dementia, to \$137,926 for a male aged 75-79 years living in residential aged care with severe dementia.<sup>33</sup> Access to quality respite care is therefore economically beneficial, supports people living with dementia to live well and constitutes a fundamental element in enabling carers to support a person with dementia to live successfully in the community.

### **Action Required**

A comprehensive recent review of respite care in Australia, undertaken by Alzheimer's Australia for the Australian Government, put forward a series of evidence-based recommendations. These include the introduction of a dementia supplement for all forms of respite care; greater flexibility in the provision of respite care; measures to reduce direct and indirect cost barriers to accessing respite care; and a more coordinated approach that links respite with timely access to counselling and support services for carers.<sup>34</sup>

There is a need for a dementia supplement for respite providers, similar to the supplement provided within community care. This supplement should only be available to services that can show they have put in place strategies and training for caring for people living with dementia. This supplement should acknowledge the additional costs associated with providing respite to this group, and create an incentive for providers to develop dementia-specific services. This respite supplement would align with the Government's focus on increasing choice through the implementation of consumer directed care.

The supplement should also be designed in order to facilitate greater investment in flexible respite options, including centre-based day respite and in-home day respite.

The ability to 'cash out' or access informal respite through friends and neighbours is important, particularly for rural and regional carers (for example, when a carer needs to arrange someone to be at home with the person with dementia while they attend an appointment in a metropolitan area) or for people with younger onset dementia (for whom more mainstream respite services may not be appropriate).

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<sup>33</sup>Brown M, Hansnata E, La HA for Alzheimer's Australia (forthcoming); NATSEM. *Economic cost of dementia in Australia, 2016-2056*. Executive Summary.

<sup>34</sup> Howe, A for Alzheimer's Australia (2013). *Respite review policy paper. Report prepared for the Department of Health and Ageing*. Alzheimer's Australia Numbered Publication 33.

**Recommendation**

Establish a dementia respite supplement to support the development of dementia-specific respite services, in recognition of the higher costs of caring for a person with dementia. The design of this funding should achieve greater flexibility in the provision of respite care and make respite care more responsive to consumer needs and preferences, including the high demand for centre-based day respite and in-home day respite.

## 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, and on 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 in partnership with States and Territories needs to implement a comprehensive and phased funded National Dementia Strategy to tackle dementia over the next decade. The first phase of the strategy should focus on reducing the community's risk of dementia and providing appropriate services and supports for people living with dementia, their families and carers by improving quality of care and better supporting people in the community and in residential aged care.

This proposal has identified three top priority initiatives, which together constitute the first stages of a comprehensive and integrated approach to tackling dementia through a funded National Dementia Strategy: risk reduction; better quality aged care services; and better access to quality respite 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.