

FIGHT ALZHEIMER'S
SAVE AUSTRALIA
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2016-17

BUDGET SUBMISSION

**Towards 2020 – a Dementia Response
for Australia**

February 2016

Executive Summary

Dementia is one of the largest health and social challenges facing Australia and is a National Health Priority area. It is estimated that there are now more than 342,800 Australians living with dementia and over a million people involved in their care. By 2050 there will be nearly 900,000 people with dementia¹. Dementia is the second leading cause of death in Australia,² and there is no cure.

The estimated cost of dementia to the health and aged care system is at least \$4.9 billion per annum. Dementia will become the third greatest source of health and residential aged care spending within two decades, with the costs to these sectors alone reaching 1% of GDP.

People living with dementia continue to struggle to get access to the services and supports they require to achieve a high quality of life. People with dementia experience delays in diagnosis, stigma and social isolation³, unpredictable quality of care within residential care and difficulty accessing services and supports to stay connected with their communities. Family carers find it difficult to balance work, life and caring responsibilities, often resulting in reduced workforce participation and adverse physical and mental health outcomes⁴. For people from diverse backgrounds (CALD, people from Aboriginal and Torres Strait Islander backgrounds, LGBTI, Homeless, and those living alone) access to quality care and appropriate services can be even more difficult.

There is both an economic and welfare imperative to ensure that the significant investment in dementia care and support leads to better outcomes for people with dementia and their families.

Alzheimer's Australia welcomes the opportunity to provide a submission to the Federal Treasurer to inform the 2016-17 Federal Budget. Alzheimer's Australia is the peak body providing leadership and advocacy on issues affecting people with dementia and their families and carers in Australia. This submission is informed by our work with consumers, and addresses key priorities that have been identified by consumers across the spectrum of dementia activity.

Alzheimer's Australia is calling for the Government to implement a comprehensive, funded national strategy with measurable outcomes based on the *National Framework for Action on Dementia 2015-2019*. The Framework identifies key areas for action but without leadership from Government to implement a targeted, outcome focused, funded strategy, little progress will be made in developing better supports for people with dementia.

The implementation of a National Dementia Strategy would build on existing areas of success and develop a strategic, collaborative and cost effective response to dementia across Australia.

¹ Australian Institute of Health and Welfare (2015) <http://www.aihw.gov.au/dementia/>. Accessed 4 Nov 2015

² Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013: Cat no. 3303.0*

³ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁴ Brodaty & Green (2002) *Who cares for the carer? The forgotten patient*

In our submission, we propose a number of core priorities to be addressed, including:

1. A community driven collaborative approach to reducing stigma and social isolation associated with dementia through support for dementia-friendly communities.
2. A National Campaign to promote awareness about dementia risk-reduction strategies and to create partnerships with other health promotion campaigns.
3. A timely diagnosis initiative, to promote timely and accurate diagnosis for all Australians with dementia.
4. A coordinated approach to improving post diagnosis care and support focused on a national 'one stop shop' and knowledge centre as well as access to key workers for people with younger onset dementia and to support capacity building within the sector to improve access to care and support for diverse groups.
5. Initiatives to improve the quality of care provided to people with dementia through dementia-specific respite, consumer driven quality programs for home and residential aged care services, workforce education and training and continued investment in support for Behavioural and Psychological symptoms of dementia.
6. An end-of-life care program, to support the choices of people with end-stage dementia, including having access to appropriate palliative care including, bereavement support for carers and those impacted by dementia.
7. Investment in dementia research and support for consumer involvement in dementia research.

This integrated strategy will address the key focus areas of the *National Framework for Action on Dementia 2015-2019*. It would provide comprehensive and flexible support to consumers, in line with the Government's focus on consumer-directed care and choice, with services and supports offered to meet the varied needs of consumers at every stage of dementia. It will leverage support from the community, business and volunteers, as well as capitalising on previous investment in dementia programs and services.

Investment in this integrated approach to dementia has the potential to reduce the costs of dementia to the health and aged care system through delayed placement in residential care and reduced need for crisis intervention, due to a proactive early intervention approach. Most importantly, this investment will improve the wellbeing of the increasing number of people with dementia and their families in Australia. We commend this submission to you.

The priorities for the 2016-2017 Budget in relation to dementia are:

1. DEMENTIA FRIENDLY COMMUNITIES

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|-----|--|-------------------------|
| 1.1 | Establish a national Dementia Friends program in Australia, building on and translating the successful Dementia Friends programs in the UK and Japan to be relevant for the Australian context. It will offer dementia education sessions to interested members of the public, and businesses and other organisations. | \$1 million per annum |
| 1.2 | Develop a National Dementia-Friendly Community Resource Hub, building on the success of pilot sites and leading initiatives, to provide information, resources, best-practice guides as well as opportunities for networking and support for creating local dementia-friendly communities. | \$0.3 million per annum |

2. DEMENTIA RISK REDUCTION

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|-----|---|-----------------------|
| 2.1 | Building on <i>Your Brain Matters</i> , the world's first government-funded dementia risk reduction program, implement a 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. | \$2 million per annum |
|-----|---|-----------------------|

3. TIMELY DIAGNOSIS INITIATIVE

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|-----|---|-------------------------|
| 3.1 | Build capacity within the sector for timely diagnosis of dementia by enabling and supporting practice change initiatives for health professionals and providers. | \$1 million per annum |
| 3.2 | Support the development of social marketing campaign to tackle stigma associated with memory loss and to support people in seeking assistance from their doctors about their memory concerns. | \$0.5 million per annum |

4. POST DIAGNOSTIC DEMENTIA SERVICES AND SUPPORTS

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|-----|--|-------------------------------------|
| 4.1 | Fund the expansion of the National Dementia Helpline and the Alzheimer's Australia website to provide a comprehensive 'one-stop' shop for dementia services, information, policy and supports. | \$2 million per annum |
| 4.2 | Time limited funding for the Younger Onset Dementia key worker program during a transition period as it moves into NDIS. | \$4 million per annum (for 2 years) |
| 4.3 | Fund a National Diversity Officer and eight (8) Key Workers to build capacity in the sector to improve access to dementia services and support for priority target groups. | \$1 million per annum |

5. HIGH QUALITY ONGOING CARE AND SUPPORT

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|-----|--|------------------------|
| 5.1 | Establish a dementia-respite supplement to support the development of dementia-specific respite services. | \$15 million per annum |
| 5.2 | The Government will continue its commitment to improving the care and support for people with BPSD, including through the review of the SBRT and DBMAS, as well as consideration of additional measures such as funding specialised psychogeriatric units or providing grant funding to providers who provide specialist care. Government to continue to fund the ongoing education and training of residential aged care staff and health professionals to ensure appropriate care is available specifically for people with dementia. This should occur under a cohesive, structured and integrated national dementia training and education program that moves the focus from outputs to outcomes and links to clear levels of competency and practice standards. | Cost Neutral |
| 5.3 | Fund the development of a consumer based initiative to increase transparency and support quality care for people with dementia through residential and home based aged care services. | \$1 million per annum |

6. END-OF-LIFE CARE

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| 6.1 | Invest in community awareness and education on end-of-life care issues for people with dementia, including the development of expertise and resources on advance care planning, advance care directives and other end-of-life care matters. | \$1 million per annum |
| 6.2 | Fund an education program to health professionals on advance care planning, advance care directives and end-of-life care for people with dementia is a priority. This would build on work already undertaken on the development of dementia specific advance care planning education and associated resources. Funding to support the delivery of education free of charge by leaders in the field (such as that developed by Alzheimer's Australia and the Respecting Patient Choices program) will increase reach and coverage. | \$1 million per annum |
| 6.3 | Support the development of expertise and resources on loss and grief counselling, and bereavement support for people and carers impacted by dementia, and support for capacity building for service providers, particularly in the aged care sector. | \$0.2 million per annum |

7. RESEARCH

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| 7.1 | A commitment by Government to provide increased investment in dementia research over a 10-year period to achieve a level of \$80 million p.a. by 2025. This would be equivalent to 50% of the current NHMRC funding for cancer research. | \$5 million per annum |
| 7.2 | Continued funding and support for consumer involvement in all aspects of dementia-research in Australia. | \$0.2 million per annum |

ALZHEIMER'S AUSTRALIA BUDGET PROPOSAL

	Additional Funding (\$ millions)			
	2016-17	2017-18	2018-19	Total
Dementia Friendly Communities	1.3	1.3	1.3	3.9
Dementia Risk Reduction	2	2	2	6
Timely Diagnosis Initiative	1.5	1.5	1.5	4.5
Post Diagnosis Support and Care	7	7	3	17
High Quality Ongoing Care and Support	16	16	16	48
End-of-life care	2.2	2.2	2.2	6.6
Research	5.2	5.2	5.2	15.6
Total	35.2	35.2	31.2	101.6

PRIORITY AREA 1 – DEMENTIA FRIENDLY COMMUNITIES

Issue

Dementia has profound social implications for both people with dementia and their family and carers. Often after a diagnosis of dementia, people experience social isolation and discrimination⁵. Friends and even family members may stop visiting or calling because they feel unsure of how to interact with a person who has a cognitive impairment. Many Australians have little understanding of dementia and are unsure of how best to respond to people who are living with the disease⁶.

As a result, people with dementia and their carers often lead increasingly lonely and isolated lives, when with support they can remain actively engaged and connected with the community. This isolation can lead to mental health concerns including anxiety and depression and can exacerbate the symptoms associated with dementia. People with dementia who are isolated often require residential care services earlier. Carers who experience social isolation can have difficulties maintaining their caring role and experience negative impacts on their mental and physical health.

In order to address these concerns, we need local programs that leverage community resources to raise awareness about dementia within the community and to improve access to opportunities for social engagement for people with dementia and their carers. International evidence suggests that dementia-friendly communities are a cost effective and successful solution with some countries including the United Kingdom and Japan adopting a 'Dementia Friends' program as part of the approach. The program aims to educate and train interested community members to recognise the signs and symptoms of dementia and effectively communicate with a person who has dementia.

Alzheimer's Australia has begun piloting dementia-friendly communities across Australia, based on successful overseas models. Experience from these pilots suggests that there is significant community and business goodwill that can be leveraged to better support people with dementia. Very small investments have led to significant achievements within Australian pilot communities.

Action Required

The *National Framework for Action on Dementia 2015-2019* identifies the need to develop dementia-friendly communities in Australia in order to build greater awareness, acceptance and understanding of dementia in the community. As part of the implementation of this framework, Alzheimer's Australia proposes that Government invest in a national dementia-friendly program that leverages community and business interest. There would be two components to the program: A Dementia Friends program and a dementia-friendly community resource hub.

⁵ Alzheimer Society of Ireland (2012). *Report on creating dementia friendly communities*.

⁶ Alzheimer's Australia (2008). *Dementia symbol research project: 'getting dementia out of the closet'*.

First, Alzheimer's Australia will develop a Dementia Friends program, building on and translating the successful programs in the UK and Japan to be relevant for the Australian context. The overseas experience has been that providing public education and awareness raising about dementia has enhanced the community response to dementia, and has addressed the stigma and discrimination that many people with dementia faced. The program will offer online and face-to-face dementia education sessions to interested members of the public and businesses and organisations. The program would initially aim to educate 20,000 Dementia Friends across Australia. These people would be able to better engage with people with dementia in their community, and promote public awareness about the condition.

Second, we propose the development of a national dementia-friendly community resource hub. The international evidence suggests that the most successful examples of dementia-friendly communities are driven locally and have external support. There is already excellent work underway in a number of Australian communities that have leveraged small investments by local, state and federal governments, philanthropic funding, volunteers and local community support. The resource hub would enable communities to network, learn from other initiatives and provide the latest evidence and information on best practice approaches to increasing community awareness and support for people with dementia. It would provide a national clearinghouse of information and resources. This resource hub could be supplemented by seed or grant funding to support community based initiatives, which would leverage volunteers, business and community interest.

These two approaches would be complementary as the Dementia-Friends initiative would raise awareness in the community about dementia and would encourage local businesses and volunteers to take up the challenge of creating dementia-friendly communities. The resource hub would support them taking this interest to the next level and implementing change in their local communities. This combined approach would create a high return on investment due to capitalising on community interest and volunteers.

Recommendations

- 1.1** Establish a national Dementia Friends program in Australia, building on and translating the successful Dementia Friends programs in the UK and Japan to be relevant for the Australian context. It will offer dementia education sessions to interested members of the public, and businesses and other organisations.
- 1.2** Develop a National Dementia-Friendly Community Resource Hub, leveraging the success of the Australian pilot sites and work undertaken in a number of communities across Australia to provide information, resources, best-practice guides as well as opportunities for networking and support for creating local dementia-friendly communities.

PRIORITY AREA 2 – DEMENTIA RISK REDUCTION

Issue

Research over the last decade has shown that addressing behavioural and related clinical risk factors can help to reduce a person's risk of dementia. Up to a third of cases of Alzheimer's disease are potentially attributable to preventable risk factors⁷. It is estimated that a 10-25% reduction in type 2 diabetes, hypertension, obesity, depression, physical inactivity, smoking and cognitive inactivity could prevent as many as 1.1-3.0 million cases of Alzheimer's disease worldwide⁸.

While there is increasing community awareness of the link between health behaviours and physical health status, there is little awareness of the link between these behaviours and the risk of dementia. Alzheimer's Australia's baseline market research indicates that only 51% of Australians believe that dementia risk reduction is possible, 20% believe that nothing can be done to reduce the risk of dementia, and 28% are unsure⁹. Even for those who indicate that risk reduction is possible, the majority are unaware of the role of vascular risk factors in dementia.

Two out of three Australians are afraid of developing dementia – a fear second only to the fear of developing cancer¹⁰. 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 given the level of funding and timeframes.

The key objectives of *Your Brain Matters* was to:

- Raise community awareness about what can be done to improve brain health
- Encourage people to adopt simple practices which are good for their brain health
- Create a partnership model which enables awareness and encourages action
- Achieve demonstrable change that leads to sustainable policy.

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.¹¹

Unfortunately funding for this important program ceased in June 2015.

A comprehensive community awareness campaign building on the success of the *Your Brain Matters Program* with a focus on developing partnerships and links to other chronic disease prevention campaigns is needed to alert people to the links between their health behaviours, their risk of cognitive impairment and dementia.

⁷ Barnes DE, Yaffe K. (2011) *The projected effect of risk factor reduction on Alzheimer's disease prevalence.*

⁸ Barnes DE Yaffe K (2011). *The projected effect of risk factor reduction on Alzheimer's disease prevalence*

⁹ Farrow M (2008), *Dementia Risk Reduction: What do Australians Know?* Alzheimer's Australia; Canberra

¹⁰ Pfizer Health Report (2011) *Dementia's Everybody's Business*

¹¹ Monash University (September 2015, draft) *Your Brain Matters Evaluation 2012-2015, pp 6-7*

Action Required

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 a funded National Dementia strategy, a community awareness campaign is needed based on partnerships with other chronic disease NGOs, which builds on the successes and learnings of *Your Brain Matters*. The partnership approach will lead to an efficient use of funding and will ensure a targeted approach that encompasses not just dementia but broader health promotion. This 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.

The campaign will take into account experience from other successful prevention and risk reduction campaigns, including the “Quit” smoking cessation campaigns, and the “Live Lighter” healthy weight campaign.

Based on the recommendations of the external evaluation report of *Your Brain Matters*¹², 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.
- 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.

This program has the potential to reduce the number of people developing dementia and other chronic diseases, and delay the onset of dementia, resulting in better quality of life for many people, and cost savings to the health and aged care systems.

Recommendation

2.1 Building on *Your Brain Matters*, the world’s first government-funded dementia risk reduction program, implement a 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.

¹²Monash University (September 2015, draft) *Your Brain Matters Evaluation 2012-2015*, pp 7-8.

PRIORITY AREA 3 – TIMELY DIAGNOSIS

Issue

There are clear benefits to timely diagnosis and management of dementia. Unfortunately, as many as two thirds of people with dementia live and die with the condition without ever receiving a diagnosis.¹³ Amongst the minority who do receive a diagnosis, the average time between first symptoms and diagnosis is 3.1 years, and longer for people with Younger Onset Dementia¹⁴. Delays in diagnosis result in missed opportunities for early intervention in the form of treatment, support, advance planning and understanding of their condition¹⁵.

GPs are the first point of contact for people concerned about their memory as well as people with unrecognised signs who present for other health reasons. Consequently, they should be able to provide: identification of dementia symptoms; appropriate assessment; provisional diagnosis where possible; referral to specialist services if uncertain about symptoms and to confirm provisional diagnoses; ongoing medical management of the condition; and referrals to community services.¹⁶

Many GPs (as well as nurses and allied health professionals) have difficulty differentiating normal ageing from early stages of dementia,¹⁷ and lack specific knowledge about dementia assessment, management or appropriate referral pathways.¹⁸ A significant percentage of GPs also consider assessment of cognitive symptoms to be the domain of specialists, or report reluctance to assess for dementia because of concerns about damaging the doctor-patient relationship, or because of incorrect perceptions that there is nothing that can be done and therefore no benefit of a diagnosis to the patient.¹⁹ Rigorous cognitive screening measures and assessment tools, as specified in clinical guidelines²⁰, are not routinely used by GPs²¹.

Delays in diagnosis are also a result of people not seeking assistance when they experience memory concerns. Many people in the community lack knowledge and understanding of dementia. When combined with the stigma surrounding dementia and a general belief that memory loss is a normal part of ageing²², some people delay seeking medical assessment until triggered by a crisis.

¹³ Brodaty, H. (2005). *Six reasons why diagnosis of dementia does not occur, and 10 reasons why it is important*. Dementia Collaborative Research Centres. Available: www.dementia.unsw.edu.au

¹⁴ Speechly, C. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189, 487-9

¹⁵ Phillips, J., Pond, D., & Goode, S., (2011). *Early Diagnosis of Dementia: Can we do Better?* Alzheimer's Australia Paper No 24. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx

¹⁶ Phillips, J., Pond, D., & Shell, A. (2010). *No time like the present: The importance of a early diagnosis of dementia*. Alzheimer's Australia Quality Dementia Care Standards Series, Number 7. Available: www.fightdementia.org.au/research-publications/quality-dementia-care-papers.aspx

¹⁷ Brodaty, H., Howarth, G., Mant, A. & Kurrle, S. (2004). General practice and dementia: A national survey of Australian GPs. *Medical Journal of Australia*, 160(1), 10-14.

¹⁸ Turner, S., Iliffe, S., Downs, M., Wilcock, J., Bryan, M., Levin, E., Keady, J., & O'Carroll, R. (2004). General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age and Ageing*, 33(5), 461-67.

¹⁹ Hansen, E., C., Hughes, C., Routley, G., & Robinson, A. (2008). General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Social Science & Medicine*, 67(11), 1776-83

²⁰ Bridges-Webb, C. (2003). Care of patients with dementia in general practice Guidelines. RACGP.

²¹ Milnea, A., Culverwella, A., Gussa, R., Tuppena, J., & Wheltona, R. (2008). Screening for dementia in primary care: A review of the use, efficacy and quality of measures. *International Psychogeriatrics*, 20(5), 911-26.

²² For example, a recent community survey found that 60% of respondents would feel ashamed if they or someone close to them was diagnosed with dementia. (Publication in preparation, University of Wollongong.)

Delays in receiving a diagnosis are not simply an inconvenience: they can lead to worse outcomes for people with dementia and their carers, and increased costs to the system. A lack of timely access to services and support can lead to earlier admission to residential aged care; higher rates of avoidable hospital admissions; and worse end-of-life care.

Action Required

The *National Framework for Action on Dementia 2015-2019* identifies the need for access to high quality early detection services and access to information and supports. While there has been some government investment in programs to improve timely diagnosis of dementia as part of the 2012 Aged Care Reforms, a cohesive approach is currently lacking.

Evidence from the UK suggests that coordinated local action is very effective in driving improvements to diagnosis rates. In particular, comprehensive, coherent local action plans, which are driven by local leaders, have led to improved diagnosis in local areas. Comprehensive education for health professionals is also effective in supporting improvements in diagnosis.²³

As part of the National Strategy on Dementia, Alzheimer's Australia proposes:

- An integrated and comprehensive approach to education and information for health professionals across general practice and primary healthcare, the acute care sector, and the aged care sector, to support timely diagnosis of dementia. This education program would build on the successful work already undertaken in developing and delivering education to GPs and practice nurses. The goal would be to create a coherent, evidenced-based, long-term sustainable program with wide ranging impact.
- A comprehensive social marketing campaign to tackle the stigma associated with memory loss and support people in talking to their doctors about their memory concerns. This campaign would promote the Alzheimer's Australia Worried about your memory booklet <https://fightdementia.org.au/sites/default/files/WAYM-booklet.pdf>.

Recommendations

- 3.1** Build capacity within sector for timely diagnosis of dementia by enabling and supporting practice change initiatives for health professionals and providers.
- 3.2** Support the development of social marketing campaign to tackle stigma associated with memory loss and to support people in seeking assistance from their doctors about their memory concerns.

²³ Dementia Diagnosis and Care in England (2014) NHS <https://www.england.nhs.uk/wp-content/uploads/2014/04/learn-ccgs-rep.pdf>

PRIORITY AREA 4 – POST DIAGNOSTIC DEMENTIA SERVICES AND SUPPORTS

Issue

After receiving a diagnosis, people with dementia and their families need access to information and support both to assist in their adjustment to the diagnosis as well as planning. Unfortunately, many people do not know what services are available or they feel overwhelmed by the information provided. As a result, often people with dementia and their family members do not access services until they reach a crisis point.

The National Dementia Support Program funds an important suite of services and supports for people with dementia and their carers, but there are some additional supports required to ensure people are linked to the services they need when they need them.

Over the last decade, people with dementia and their families have repeatedly called for a more streamlined coherent approach to service provision and coordination. They indicate that it is difficult to navigate the service system and to understand what services are available at the different stages of dementia. Feedback from consumers suggests that the MyAgedCare service is unable to provide the level of service and support required by people with dementia and their families. Call staff have little understanding of dementia and are unable to provide detailed advice about appropriate local services outside of funded aged care services. Often people find services only through advice from other people who have previously gone through the experience or from being proactive in searching for supports.

The challenge of accessing appropriate services is even greater for people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islander people, people who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI), and those individuals who are living alone, socially isolated, or homeless, as well as people with younger onset dementia, other disabilities or co-morbidities. Evidence suggests that often people from these groups do not access services early in the disease, in part because of a lack of available services and because of a lack of awareness of what is available in the community.

Alzheimer's Australia's pilot work over recent years, has demonstrated that a pro-active support worker approach is beneficial in connecting people from diverse backgrounds to appropriate supports and services as well as in collaborating with providers to create services that are more appropriate.

Action Required

The *National Framework for Action on Dementia 2015-2019* calls for “Accessible, flexible and quality dementia care available to people living with dementia and their carer’s” and “support for planning for the future.”.

Alzheimer's Australia proposes that as part of the National Dementia Strategy the Government continue to fund the National Dementia Support Program and provide additional

support through a coordination of services, support for innovation and a key worker model for younger onset dementia and diverse groups.

Coordinated Dementia Services

In response to calls for a more coordinated and seamless approach to information and services, Alzheimer's Australia proposes the development of a specialised 'one stop-shop' for dementia. This service would essentially be a website and helpline that provided coordinated information about all dementia services, information, local initiatives, policy and supports across Australia. It would build on the current infrastructure of the Alzheimer's Australia website and the National Dementia Helpline. It would be complementary to the MyAgedCare website as it would provide dementia specific information and expertise and would link to the MyAgedCare portal as appropriate.

The helpline could be further developed to provide a point of contact throughout the dementia journey. It would provide linkages to local services, supports and information and consumers could recontact the helpline and speak to someone who was aware of their history and previous use of services. Feedback from consumers indicate that they would welcome this approach indicating that it would be particularly useful for people from regional and rural areas and that it would meet a need for assistance in coordinating services and supports.

The 'one stop shop' website would also be a resource centre and knowledge hub for policy makers and aged care providers in Australia. The website will include information on each of the areas of the National Dementia Framework and provide details about local and national initiatives underway to improve dementia services and supports. This approach would facilitate collaboration, reduce duplication and improve uptake of dementia care services and supports.

Access for priority target groups

The National Younger Onset Dementia Key Worker Program provides one-to-one support from the point of diagnosis throughout the dementia journey. Key workers link clients to early intervention supports and services and build capacity in families and clients to remain independent for as long as possible. The benefits of early intervention are well known and integral in ensuring the person living with dementia remains engaged, independent and maintains a good quality of life for as long as possible following a diagnosis. The Key workers also work within the service sector to develop dementia-specific services and supports. There is a need for continued funding of this program during the transition period into the NDIS.

For diverse groups, there is a need for additional support to access services. This support would be an adapted version of the key worker model focused on capacity building to improve equity of access for people and to support the reform of models of service and delivery modalities to increase reach and efficiency. A national Diversity officer would facilitate collaboration and service development across Australia. There would be one key worker in each state with a focus on facilitating local coordination and working with communities and services to improve linkages, awareness, cultural competency and service delivery to meet the needs of people from diverse groups. This investment will build capacity in existing resources, support consumer-centred innovation and result in improved quality of

life for people with dementia from the specific target groups and their carers; and savings to the aged care and health systems as people from these groups can live well in the community for longer.

Recommendations

- 4.1** Fund the expansion of the Alzheimer's Australia website and helpline to provide a comprehensive one-stop shop for dementia services, information, policy and supports.
- 4.2** Funding for the Younger Onset Dementia key worker program during a transition period as it moves into NDIS
- 4.3** Fund a National Diversity Officer and eight (8) Key Workers to improve access to dementia services and support for diverse groups.

PRIORITY AREA 5 – HIGH QUALITY ONGOING CARE AND SUPPORT

Issue

Dementia is a progressive disease and people with dementia require a range of supports and care. Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.²⁴ Provision of comprehensive home based care, respite, and appropriate, high quality residential care, are therefore critical to meeting the needs of people living with dementia and their families.

For the 70% of people 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. It is essential 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.

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 with dementia²⁵. Often respite is essential to ensuring that family members can continue caring for the person with dementia at home²⁶. Unfortunately, few respite services have services specifically designed to support people with dementia. In fact, as care needs increase, respite providers often turn away people with dementia. Many respite services say that they are not staffed to provide care to people who have behavioural symptoms or who are incontinent.

For the 30% of people with dementia 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. There is evidence that the needs of people with dementia are often not supported through current mainstream aged care services. There are particular concerns regarding residential aged care, where Alzheimer's Australia receives 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.²⁷ People with severe behavioural and psychological symptoms of dementia have even more difficulty in getting access to appropriate support and care.

The Government has implemented a number of measures that aim to improve the quality of residential aged care and to better support people with dementia. It is our view, however, that further work is required if we are to achieve an aged care system that achieves the level of quality and transparency that consumers demand. There is a need to meet the basic physical care requirements and to ensure that social and spiritual needs are being met as well.

²⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

²⁵ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

²⁶ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

²⁷ Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 4.

https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf

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. To achieve this Alzheimer's Australia recommends further work to refine the aged care system including:

Respite

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 who can show they have put in place strategies and training for caring for people with dementia. This supplement would acknowledge the additional costs associated with providing respite to this group and would create an incentive for providers to develop dementia-specific services. A respite supplement would be in line with the Government's focus on increasing choice through implementation of consumer directed care.

Behavioural and Psychological Symptoms of Dementia (BPSD)

People with behavioural and psychological symptoms of dementia often have difficulty accessing appropriate care and support. In some cases, behavioural symptoms are actually a symptom of unmet needs such as boredom, discomfort or pain. The Government has recently invested in the Severe Behaviour Response Teams as a complement to the Dementia Behaviour Management Advisory Service to provide additional specialised support to people with severe behavioural symptoms.

It is essential that Government continue to monitor the care and support that people with BPSD are receiving. There has been a suggestion amongst some experts that there is a need for specialised psycho-geriatric care for people with the most severe BPSD for a limited period of time. These facilities require secure grounds, higher staffing ratios, staff with specialised training and support from specialist mental health services. In Australia, the availability of these specialised care facilities is limited. Similarly, others have called for a specialised grant program to provide additional funding to aged care providers who put in place specialised services and supports for people with BPSD.

Alzheimer's Australia is calling on Government to continue its commitment to improving the care and support for people with BPSD including through the review of the SBRT and DBMAS, as well as consideration of additional measures such as funding specialised psychogeriatric units or providing grant funding to providers who provide specialist care.

Workforce

To ensure quality dementia care, health care professionals and all staff involved in care settings must be educated and trained in key aspects of care, including person-centred care; caring for people with dementia; and areas such as management of behavioural and psychological symptoms of dementia including alternatives to physical and chemical restraints, pain assessment and management, and end-of-life care. There is a need for Government to maintain a commitment to supporting ongoing education and training to develop and sustain a workforce skilled in dementia care.

Further, there is a need to move dementia education and training from an outputs focus to an outcomes focus. Currently, education and training are essentially provided on the presumption that simply undertaking an activity or using a particular resource results in practice change; little import is given to whether this actually occurs. Practice change requires more than simply creating an awareness of knowledge but rather translating that to practice. Within workforce investment, priority needs to be placed on developing a cohesive, structured and integrated national dementia training and education program. Focus should be on practice changes education and training activities that lead to better outcomes for people living with dementia and long-term sustainable change. Dementia training should be linked to clear levels of competency and/or practice standards, so that the learning outcomes of all dementia education and training activities may be aligned with the competencies/practice standards. Ideally, the outcomes of each education and training activity would be assessed using a framework to ensure that they achieve the intended outcomes and lead to practice change.

Quality

It is very difficult for consumers to ascertain quality of dementia care within residential care facilities. This makes the desired move to a more market-driven system challenging, as informed choice is not possible without good information. The development of quality-indicators in aged care is welcome but still limited.

Alzheimer's Australia proposes funding of a consumer-driven Quality in Dementia Care Initiative. This program would engage consumers and carers to develop and implement consumer and carer based initiatives to monitor and promote the delivery of quality care for people with dementia through aged care services, and through hospitals and other healthcare services. This would include developing checklists and guides for consumers as well as a consumer-audit and feedback program.

Recommendations

- 5.1** Establish a dementia-respite supplement to support the development of dementia-specific respite services.
- 5.2** Government to continue its commitment to improving the care and support for people with BPSD including through the review of the SBRT and DBMAS, as well as consideration of additional measures such as funding specialised psychogeriatric units or providing grant funding to providers who provide specialist care.

Government to continue to fund the ongoing education and training of residential aged care staff and health professionals to ensure appropriate care is available specifically for people with dementia. This should occur under a cohesive, structured and integrated national dementia training and education program that moves the focus from outputs to outcomes and links to clear levels of competency and practice standards.

- 5.3** Fund the development of a consumer and carer based initiative to support quality care for people with dementia through residential and home based aged care services.

PRIORITY AREA 6 – BETTER END-OF-LIFE CARE

Issue

Being able to access appropriate care at the end-of-life is a critical factor in a more dignified death. This requires early planning and documentation of wishes, particularly for people who have progressive neurological diseases such as dementia. End-of-life care discussions with clinicians and family members are also important in achieving end-of-life care aligned with the consumer's wishes and goals. Coordination of care amongst various care teams such as health, community, residential and interdisciplinary care teams is needed, and care staff should have training in providing end-of-life care.

A number of factors contribute to poor access to quality end-of-life care for people with dementia including:

- A lack of understanding that dementia is a terminal illness, which leads to delays or inability to access palliative care services.
- Poor understanding of the legal rights of people living in aged care by both health professionals and family members.
- A relatively low rate of advance care planning by people with dementia and their families which means that there may be uncertainty about the person's wishes for end-of-life care.
- Care providers not adhering to end-of-life care wishes due to staffing issues or concerns about legal implications.
- A lack of assessment and appropriate treatment of pain for people who have difficulty communicating their discomfort.

Alzheimer's Australia and Palliative Care Australia have developed a joint position statement on palliative care and dementia. The statement highlights the challenges around access to end-of-life care for people with dementia and makes recommendations to improve access to care.²⁸

There is a need for awareness and education for both consumers and health professionals about dementia end-of-life care. This needs to include education on issues around capacity, legal rights, pain assessment and management in people who have difficulty with communication, and appropriate end-of-life care for people with dementia. There is also a need for better understanding and uptake of advance care planning for people with dementia (a process undertaken by individuals, in consultation with their healthcare providers and significant others, to plan for medical decisions or treatments in advance). Increased use of healthcare directives, relevant education for health professionals, and quality palliative care, can help people with dementia to have better end-of-life care, and reduce grief and trauma for families.

²⁸ Palliative Care Australia and Alzheimer's Australia *Palliative Care and Dementia: Position Statement* Accessed 18 September 2015 at; https://fightdementia.org.au/sites/default/files/18122013_PCA_Alzheimer_position_statement.pdf

Action Required

There is a need to increase uptake of advance care planning, improve the knowledge of health professionals about end-of-life care for people with dementia, and develop knowledge and resources and build capacity on grief and loss for family members. Alzheimer's Australia proposes an end of life care initiative with three areas of focus:

1. Development of consumer resources on advance care planning, advance care directives and other end-of-life care matters for people with dementia.
2. Health professional-focused strategies: Delivery of education and training to health professionals on advance care planning, advance care directives and end-of-life care for people with dementia is a priority. This would build on work already undertaken on the development of dementia specific advance care planning education and associated resources. Funding to support the delivery of education free of charge by leaders in the field (such as that developed by Alzheimer's Australia and the Respecting Patient Choices program) will increase reach and coverage.
3. Development of expertise and resources on grief and loss counselling for loved ones of people with dementia, and support for capacity building for service providers, particularly in the aged care sector.

This program would lead to better end-of-life care for people with dementia, and a reduction in grief and trauma for family members.

Recommendations

- 6.1** Invest in community awareness and education on end-of-life care issues for people with dementia, including the development of expertise and resources on advance care planning, advance care directives and other end-of-life care matters.
- 6.2** Fund an education program to health professionals on advance care planning, advance care directives and end-of-life care for people with dementia. This would build on work already undertaken on the development of dementia specific advance care planning education and associated resources. Funding to support the delivery of education free of charge by leaders in the field (such as that developed by Alzheimer's Australia and the Respecting Patient Choices program) will increase reach and coverage.
- 6.3** Support the development of expertise and resources on loss and grief counselling, and bereavement support for people and carers impacted by dementia, and support for capacity building for service providers, particularly in the aged care sector.

PRIORITY AREA 7 – RESEARCH

Issue

Dementia is a national health priority area, the second leading cause of death overall, and the third leading cause of disability. Yet despite its major impact on health and wellbeing, funding for dementia research has lagged behind other national health priority areas for decades. The commitment to increase funding for dementia research by \$200 million over five years from 2014, and the establishment of the National Institute for Dementia Research is a welcome investment. However, even with an increase of approximately \$40 million p.a., NHMRC funding on dementia research will still be a small fraction of the funding provided to Cancer and Cardiovascular research. The dementia sector is not growing quickly enough to be able to compete in the research funding environment. There is a need to attract new researchers into the field at early and mid-career levels and to establish a cohort of future dementia researchers. In order for this to be achieved there needs to be a sustained increased investment in dementia-research.

There is also a need to support consumer involvement in dementia-research. Alzheimer's Australia, with support from the Dementia Collaborative Research Centres, developed a Consumer Dementia Research Network which facilitates active consumer involvement in a range of research programs and initiatives including the NHMRC Partnership Centre on Cognitive Decline. This Network was independently evaluated and shown to be effective²⁹. There is currently uncertainty regarding future funding for consumer involvement in dementia research due to changes to the structure of the Dementia Collaborative Research Centres.

Action Required

There is a need to ensure that dementia does not continue to lag behind the other National Health Priority Areas in relation to research funding. It is critical that the Government provides sustained investment in dementia research into care, cure and risk reduction. There should be a long-term goal of ensuring reasonable equity in research spending across the health priority areas, given the relative impact on disability burden. The investment in research must also support the translation of research into practice, to ensure that people with dementia and their families benefit through improved care and services.

There is also a need to ensure that people with dementia and their families continue to have a strong voice in how research is prioritised and implemented. There is good evidence that consumer engagement in research improves methodology as well as leads to outcomes that are more relevant for the consumer³⁰. All funding applications for dementia research should be required to include a plan for consumer engagement in research.

Recommendations

7.1 A commitment by Government to provide increased investment in dementia research over a 10-year period to achieve a level of \$80 million p.a. by 2025. This would be equivalent to 50% of the current NHMRC funding for cancer research.

²⁹ CHSD (2012) *Report of the Interim Evaluation of the Consumer Dementia Research Network*

³⁰ Alzheimer's Australia (2010) *Consumer Involvement in Dementia Research: Alzheimer's Australia's Consumer Dementia Research Network*

7.2 Continued funding and support for consumer involvement in all aspects of dementia-research in Australia.

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.

Government needs to implement a comprehensive funded National Strategy to tackle dementia over the next decade with a focus on providing appropriate services and supports and tackling the social isolation and stigma associated with dementia. There is a need for a comprehensive approach to improving quality of care and supporting people in the community and in residential aged care homes.

The suite of initiatives outlined in this proposal represents a comprehensive and integrated national approach to tackling dementia. 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.