

FIGHT ALZHEIMER'S
SAVE AUSTRALIA
FIGHTDEMENTIA.ORG.AU

2015-16

BUDGET SUBMISSION

6 February 2015

Executive Summary

Alzheimer's Australia is the national peak body representing people with dementia and their families and carers. Our vision is for a society committed to the prevention of dementia, while valuing and supporting people living with dementia. Alzheimer's Australia welcomes the opportunity to provide a submission to the Federal Treasurer to inform the 2015-16 Federal Budget, particularly at a time when we are in the midst of major reform of the aged care and disability sectors in Australia and when we are facing an ageing population with increasing numbers of people experiencing chronic diseases such as dementia.

The care and support of people with dementia is one of the largest health care challenges facing Australia. It is estimated that there are now more than 340,000 Australians living with dementia¹ and over a million people involved in their care². By 2050 there will be nearly 900,000 people with dementia³. Each week there are 1,800 new cases of dementia in Australia and this is expected to increase to 7,400 new cases each week by 2050⁴.

Dementia has a large impact on the health and aged care system with the cost of dementia to the health and aged care sectors estimated to be at least \$4.9 billion per annum⁵. Dementia also has a profound social impact, with people with dementia experiencing stigma and social isolation⁶, and family carers often finding it difficult to balance work, life and caring responsibilities⁷.

The increasing prevalence of dementia means that there is both an economic and welfare imperative for Government to develop initiatives to address dementia and ensure that people with dementia have access to appropriate care and support from the moment of diagnosis.

There is overwhelming evidence to suggest that the complex needs of people with dementia cannot be supported through mainstream health and care services. Instead there is a need to fund dementia-specific services which can provide the care, support and social engagement that people with dementia and their families so desperately need.

There is an urgent need for Government to build on the important initiatives set out in the 2012 Aged Care Reforms, to ensure a continued targeted and responsive policy to address both the health and social implications of dementia. The recent decision to develop severe behaviour response teams for residential care is welcome first step. The goal should be both to ensure that investment leads to better outcomes for people with dementia and their families and is an effective use of public money.

The recommendations set out in this submission focus on improving social inclusion, and access to specialist early interventions and supports. Investment in these priorities has the potential for savings in the overall health budget as it can reduce or delay the need for costly formal services or hospitalisation.

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

³ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁴ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁶ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁷ Brodaty & Green (2002) *Who cares for the carer? The forgotten patient*

The priorities for the 2015-2016 Budget in respect of dementia include:

DEMENTIA RISK REDUCTION

- | | | |
|-----|---|----------------------------|
| 1.1 | Government to continue to invest in the Your Brain Matters to ensure Australians are educated and aware of the risks of dementia and how to reduce the modifiable risk factors associated with dementia. Currently funding for this program is due to end in June 2015. | \$6.2 million over 3 years |
|-----|---|----------------------------|

SPECIALISED DEMENTIA SERVICES

- | | | |
|-----|--|-----------------------------------|
| 2.1 | The Government continue the block-funding of the Younger Onset Dementia Key Worker program outside of the NDIS which is ill-equipped to deal with the needs of people with dementia. This will ensure that people with younger onset dementia have access to this essential support service. | \$4 million p.a. starting in 2016 |
| 2.2 | A dementia-respite supplement is established to support the development of dementia-specific respite services. | \$45 million over 3 years |
| 2.3 | The review of services provided through the Commonwealth Home Support Program consider the value of dementia-specific services and ensure that these important supports are not discontinued. | COST
NEUTRAL |

DEMENTIA FRIENDLY COMMUNITIES

- | | | |
|-----|---|--------------------------|
| 3.1 | Invest in a national program to tackle the stigma and social isolation associated with dementia. Building on Australian and overseas experience the funding would be used to support the development of dementia-friendly communities in each state and territory. The program will achieve 20 dementia-friendly communities by 2016. These communities would support projects to both raise awareness about dementia and also engage people with dementia in the community through volunteer opportunities, social activities and improved access to every day services such as banking and retail. | \$5 million over 3 years |
| 3.2 | Support the establishment of a national 'Dementia Mates' program in Australia. The program will build on and translate the successful Dementia Friends programs in the UK and Japan to be relevant for the Australian context. It will offer online and face to face dementia education sessions to interested members of the public and businesses and organisations. The program is scalable dependent on funding, but would initially aim to educate 300,000 Dementia Mates across Australia. These people would be able to assist people with dementia in their community and promote public awareness about the condition. | \$3 million over 3 years |

DEMENTIA RESEARCH

- 4.1 A commitment by Government to provide increased investment in dementia research over a 3 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. \$25 million over 3 years
- 4.2 Continued funding for the Alzheimer's Australia Consumer Dementia Research Network which supports consumer involvement in all aspects of dementia-research in Australia. \$0.3 million over 3 years

ALZHEIMER'S AUSTRALIA BUDGET PROPOSAL

Additional Funding (millions)				
	2015-16	2016-17	2017-18	Total
Dementia Risk Reduction	2	2	2.2	6.2
Specialised Dementia Services	15	19	19	53
Dementia Friendly Communities	2	3	3	8
Dementia Research	0.1	5.1	20.1	25.3
Total	19.1	29.1	44.3	92.5

PRIORITY AREA 1 – DEMENTIA RISK REDUCTION

Issue

Research over the last decade has shown that a number of lifestyle and health factors may help to reduce one's risk of dementia. Researchers estimate that up to a third of the cases of Alzheimer's disease are potentially attributable to preventable risk factors⁸. 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 worldwide⁹. Many of these risk factors are common to other chronic conditions. Some chronic diseases such as diabetes are risk factors for dementia themselves.

Preliminary research internationally indicates that the incidence of dementia may be declining in high income countries. The reasons for this are currently being explored, however, education, more stimulating environments and better control of vascular risk factors may have contributed to this decrease¹⁰.

Australia has been a world leader in combatting dementia through risk reduction. In 2012, the Government funded **Your Brain Matters**, the world's first publicly funded dementia prevention program. It has had strong success since the program began in September 2012. Funding for this program ends in June 2015.

Two key population surveys of Australians aged 20-75 years, conducted in 2012 and 2014, reveal that since the launch of Your Brain Matters, changes are beginning to take place in public perceptions of dementia risk reduction. However, there is still much work to be done with only a little over one-third of people expressing a firm belief that it is possible to reduce the risk of dementia in later life. Although there is increasing understanding of the importance of staying mentally active, surveys reveal a low level of understanding of the association between dementia and cardiovascular factors, such as exercise and diet.

"The Australian Government should ensure that messages on brain health and dementia prevention are included in all relevant national initiatives and public health awareness campaigns which promote healthy lifestyle choices through diet, exercise, smoking cessation and responsible consumption of alcohol. Key messages to be included in any future campaigns with relevance to brain health should also promote the importance of mental activity and social engagement".¹¹

"An area where Australia may well take a championship type leadership role in this global environment... [is].. Prevention and Risk reduction...identifying risk factors, promoting those and saying we need a reduction of those risk factors to cause more prevention I feel could be a championing role that Australia can take."¹²

- Dr Dennis Gillings, World Dementia Envoy

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

⁹ Barnes DE Yaffe K (2011). *The projected effect of risk factor reduction on Alzheimer's disease prevalence*

¹⁰ Alzheimer's Australia (2014) *Is the Incidence of Dementia Declining?*

¹¹ House of Representatives (2013) *Thinking ahead: Report on the Inquiry into Dementia; Early Diagnosis and Intervention*

¹² McDonald I(Producer) (2014) Dr Dennis Gillings *World Dementia Envoy - a cure for dementia by 2025?*

Action Required

There is a need to continue to inform Australians about brain health and create awareness about the links between cardiovascular disease, cerebrovascular disease and cognitive impairment.

Alzheimer's Australia's Your Brain Matter's program has developed a comprehensive, holistic platform for changing public attitudes and has developed important partnerships with other health organisations such as the Australian Heart Foundation. The initial stages of this program has been shown to be effective through changes in public awareness, but further work is required to improve public awareness.

A multi-pronged, multi-sectoral approach across services and settings is needed to facilitate the integration of dementia risk with those for other chronic diseases. The sharing of resources across these settings will ensure a cost-effective national preventive health strategy. It may also provide increased incentive for individuals to not only look after their physical health but their brain health as well. Further resources are needed to support these partnerships as well as local education initiatives.

The Australian Government should build on the success to date of the Your Brian Matters Program through continued support for this important program.

Recommendation

- 1.1** Government to continue to invest in the Your Brain Matters program to ensure Australians are educated and aware of the risks of dementia and how to reduce the modifiable risk factors associated with dementia. Currently funding for this program is due to end in June 2015.

PRIORITY AREA 2 – SPECIALISED DEMENTIA SERVICES AND SUPPORTS

Issue

People with dementia often have difficulty accessing appropriate services and supports within the health and aged care system. Consumers indicate that the system is complex, often they do not know where to turn, and are unsure of what is available to them¹³. After receiving a diagnosis of dementia, people are often not given information about early intervention services and supports. This means that many people with dementia and their families do not seek services until they reach a crisis point.

Even once that crisis point is reached, often main-stream services are ill equipped to meet the specialised care needs of people with dementia due to lack of staff-training, staffing levels, or other issues¹⁴. As a result people with dementia are often turned away from main-stream services due to high care needs such as behavioural symptoms or incontinence.

This invariably results in worse outcomes for the person with dementia, their family members and carers as they cope with the substantial strain and distress that accompanies a diagnosis while fulfilling caring roles and meeting other responsibilities.

Changes to the Commonwealth Home Support Program and the impending transition of the Younger Onset Dementia Key Worker Program into the National Disability Insurance Scheme raise significant concerns about the future of essential dementia-specific support services and programs.

“My pathway into the services was fragmented and chaotic; serendipitous. I learnt everything by accident.”¹⁵

“I care for my mother, who has younger onset dementia. Respite took her for one day, and now they refuse to take her; too much hard work...all she did was wander.”¹⁶

I’ve been told that if my mother does not die fast enough in a palliative care setting she will be sent away. I am fighting for my mother to die in a palliative facility because I am told¹⁷she is not worthy”.

Action Required

There is a need for continued investment in a range of dementia-specific services and supports within the community to enable people with dementia to continue to live at home for as long as possible. This includes continuing existing dementia-services and supports such as the National Dementia Support Program, Dementia Behaviour Management Advisory Services and the Dementia Training Study Centres.

¹³ Alzheimer’s Australia (2011) *Effective Consumer Engagement in the Aged Care Reform Process*

¹⁴ Productivity Commission (2011) *Caring for Older Australians*

¹⁵ Alzheimer’s Australia (2011) *Effective Consumer Engagement in the Aged Care Reform Process*

¹⁶ Alzheimer’s Australia (2011) *Effective Consumer Engagement in the Aged Care Reform Process*

¹⁷ Alzheimer’s Australia (2011) *Effective Consumer Engagement in the Aged Care Reform Process*

In addition there is a need to ensure that the aged care and disability reforms do not lead to the dismantling of important dementia-specific programmes.

- **National Younger Onset Dementia (YOD) Key Worker Program.** This 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 every indication that this program will be subsumed under the NDIS. This is an ill-informed approach that is not reflective of the desires of consumers, carers or experts in this area and is essentially relying on a mainstream solution to meet the complex needs of people with dementia. . Without continued block funding, people with younger onset dementia would again be without support until they had reached a point in their diagnosis where they were deemed eligible for NDIS. The advocacy, early intervention and capacity building components of the program would be lost.

- **Dementia Specific Respite**
Respite plays a critical role in providing a break for carers as well as an important opportunity for social engagement for the person with dementia¹⁸. Often respite is essential to ensuring that family members can continue caring for the person with dementia at home¹⁹. Unfortunately there are few respite services that have services specifically designed to support people with dementia. In fact as care needs increase, people with dementia are often turned away from respite. Many respite services say that they are not staffed to provide care to people who have behavioural symptoms or who are incontinent.

There is a need for a dementia-supplement for respite providers, similar to the supplement which is 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.

- **Commonwealth Home Support Program (CHSP)**
As part of the aged care reform process, the Commonwealth Home Support Program will be rolled out in July 2015. CHSP brings together four existing programs and focuses on reducing red-tape and creating national consistency across the program. Alzheimer's Australia supports the direction of these changes but is concerned about the possible loss of specialised programs and services.

¹⁸ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

¹⁹ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

It is essential that the dementia-specific services which are funded under counselling, information, and advocacy continue to provide support to people with dementia. There is concern that in the process of streamlining the program, these specialised services will be lost and replaced by mainstream services which are ill-equipped to support people with dementia.

Recommendations:

- 2.1** The Government continue the block-funding of the Younger Onset Dementia Key Worker program outside of the NDIS which is ill-equipped to deal with the needs of people with dementia. This will ensure that people with younger onset dementia have access to this essential support service.
- 2.2** A dementia-respite supplement is established to support the development of dementia-specific respite services.
- 2.3** The review of services provided through the Commonwealth Home Support Program consider the value of dementia-specific services and ensure that these important supports are not discontinued.

PRIORITY AREA 3 – DEMENTIA FRIENDLY COMMUNITIES

Issue

Dementia has profound social implications for both people with dementia and their family carers. Often after a diagnosis of dementia, people experience social isolation and discrimination²⁰. 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 disease²¹.

As a result, people with dementia often lead increasingly lonely and isolated lives when with support they could 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. As a result often people with dementia who are isolated end up requiring formal care services earlier

Recent research reveals the extent of the stigma and discrimination associated with dementia:

- Two out of three Australians are scared of developing dementia – a fear second only to the fear of developing cancer²²
- 56% of carers report that people with dementia are discriminated against²³
- Individuals who believe that dementia is associated with stigma are less likely to seek help if they begin to experience memory or other cognitive changes²⁴
- In a recent survey of people living with dementia²⁵:
 - 41% wished they had more social contact with people in the community
 - 48% said they had difficulty communicating with staff in stores
 - 25% said people seemed to feel uneasy because of their diagnosis
 - 42% said that people avoided them because of their diagnosis

“No one wants to spend time with me now that I have a diagnosis. It is like they think I no longer count and I am not a person anymore. It makes me so sad and I end up sitting at home wishing life was different.”²⁶

Action Required

The social impact of dementia needs to be addressed through supporting communities to be more aware of dementia and to provide opportunities for social engagement. Alzheimer’s Australia has begun this process through piloting dementia-friendly communities across Australia.

²⁰ Alzheimer Society of Ireland (2012). *Report on creating dementia friendly communities.*

²¹ Alzheimer’s Australia (2008). *Dementia symbol research project: ‘getting dementia out of the closet’.*

²² Pfizer Health Report (2011) *Dementia’s Everybody’s Business*

²³ Pfizer Health Report (2011) *Dementia’s Everybody’s Business*

²⁴ Alzheimer’s Australia (2012) *Exploring Dementia and Stigma and Beliefs*

²⁵ Alzheimer’s Australia (2014) *Living With Dementia in the Community: Challenges & Opportunities*

²⁶ Alzheimer’s Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value. Each dementia-friendly community will look different, but may include:

- Businesses that provide accessible services to people with dementia including having staff who understand dementia and know how to communicate effectively with people who have dementia
- Employers that provide support for people living with the disabilities of dementia to continue with paid employment
- Volunteering opportunities for people with dementia
- Memory cafes for people with dementia and their families
- Choirs, walking groups, sporting clubs and social groups that are welcoming and inclusive of members with dementia

The dementia-friendly communities approach has a high return on investment because it builds on community interest and volunteers. With a relatively small investment, Dementia Friendly Communities have been implemented internationally with some countries including the United Kingdom and Japan adopting a 'Dementia 'Friends' program. 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.

Recommendations

3.1 Invest in a national program to tackle the stigma and social isolation associated with dementia. Building on Australian and overseas experience the funding would be used to support the development of dementia-friendly communities in each state and territory. The program will achieve 20 dementia-friendly communities by 2016. These communities would be support projects to both raise awareness about dementia and also engage people with dementia in the community through volunteer opportunities, social activities and improved access to every day services such as banking and retail.

3.2 Support the establishment of a national 'Dementia Mates' program in Australia. The program will build on and translate the successful Dementia Friends programs in the UK and Japan to be relevant for the Australian context. It will offer online and face to face dementia education sessions to interested members of the public and businesses and organisations. The program is scalable dependent on funding, but would initially aim to educate 300,000 Dementia Mates across Australia. These people would be able to assist people with dementia in their community and promote public awareness about the condition.

PRIORITY AREA 4 – RESEARCH

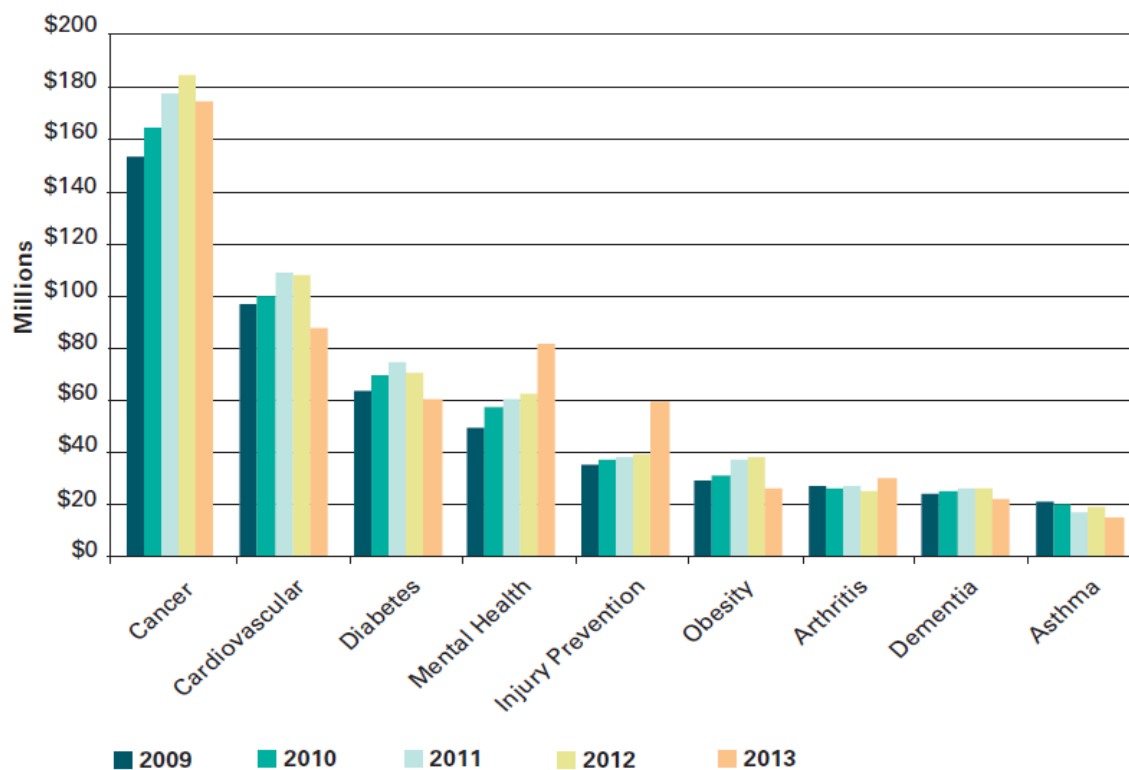
Issue

Dementia is a national health priority area, the third leading cause of death overall, the second leading cause of death for woman 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 recent commitment to increase funding for dementia research by \$200 million over five years from 2014 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 (Figure 1).

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 which goes beyond the initial \$200 million commitment.

Figure 1.

NHMRC Research Expenditure for National Health Priority Areas – 2009 to 2013



There is also a need to continue to support consumer involvement in dementia-research. Alzheimer's Australia, with support from the Dementia Collaborative Research Centres, has developed a Consumer Dementia Research Network which facilitates active consumer

involvement in a range of research programs and initiatives. This Network has been independently evaluated and shown to be effective as well as an international exemplar in consumer engagement in dementia research²⁷. There is currently uncertainty regarding future funding for this network due to changes to the future structure of the Dementia Collaborative Research Centres as part of the establishment of the National Dementia Institute.

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. 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 which are more relevant for the consumer²⁸.

Recommendations

- 4.1** 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.
- 4.2** Continued funding for the Alzheimer's Australia Consumer Dementia Research Network which supports consumer involvement in all aspects of dementia-research in Australia.

²⁷ CHSD (2012) *Report of the Interim Evaluation of the Consumer Dementia Research Network*

²⁸ Alzheimer's Australia (2010) *Consumer Involvement in Dementia Research: Alzheimer's Australia's Consumer Dementia Research Network*

CONCLUSION

Dementia is one of the major chronic diseases of this century. There are more than 340,000 Australians living with dementia and this is expected to increase to nearly 900,000 by 2050. It is estimated that over a million Australians are involved in the care and support of people with dementia. The significance of the economic and social impact of dementia has been recognised with the 2012 decision to make dementia a National Health Priority Area. Unfortunately, people with dementia and their families are still struggling to get access to the care and support they require.

With the current Government focus on streamlining services, there is a danger that much needed specialist dementia services will be lost. There are a range of essential dementia programs which are currently at risk of being defunded including:

- World's first Government funded risk reduction program- Your Brain Matters- which provides information and awareness on the links between physical and brain health. Funding for this program ends in 2015.
- The Younger Onset Dementia Key Worker Program- which provides much needed one on one support to people with younger onset dementia and assists in linking them to services and supports. Government has indicated this program will be dismantled and rolled into NDIS.
- Dementia-specific programs funded through the Commonwealth Home Support Program including dementia advisors and rural and remote outreach.

The loss of these programs would be devastating to consumers and the sector. It would leave significant gaps in service provision that main-stream services are simply not capable of filling.

Government needs to implement a holistic plan 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. The recent announcement of the reinstatement of funding to address the needs of people with dementia who have severe behavioural and psychological symptoms in residential care was a welcome first step. But there is a need for a comprehensive approach to improving quality of care and supporting people in the community. In addition, there is a need for a sustainable and long-term investment in dementia research which better reflects the disability burden associated with the condition.

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.