

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

**2014-2015
BUDGET SUBMISSION**

JANUARY 2014

ALZHEIMER'S AUSTRALIA

INTRODUCTION

Dementia has been recognised by the Australian State and Territory Health Ministers as a National Health Priority Area. There are over 330,000 Australians with dementia in 2014 and this is expected to increase to nearly 900,000 by 2050.¹ Dementia will become the third greatest demand on health and residential aged care spending within two decades. These costs alone will be around 1% of GDP.² There is both a welfare and economic imperative to provide quality care and support to people with dementia.

Alzheimer's Australia welcomes the commitment made by the Government to:

- Provide an additional \$200m over 5 years for dementia research
- Implement and build on the 2012 Aged Care Reforms
- Implement the National Disabilities Insurance Scheme.

Alzheimer's Australia recognises the difficult economic circumstances within which the 2014-2015 Federal Budget is being developed. The need for fiscal constraint provides an imperative to ensure that every dollar spent in relation to dementia is being used effectively and leading to better outcomes for consumers and that red-tape is minimised.

Investment in health promotion, early intervention, workforce and targeted community services and supports within both the health and aged care sector can lead to a significant reduction in health care costs and improved quality of life for older Australians.

Alzheimer's Australia has set out in ***Creating a Dementia Friendly Australia*** (Attachment 1) the action necessary over the next three years to ensure people with dementia receive the respect and access to services that all Australians expect.

This submission makes recommendations to respond to the commitments made by Government and the priorities as set out in *Creating a Dementia Friendly Australia*. Alzheimer's Australia is pleased that the Government has already committed to additional investment in research and we have provided a separate submission to the Minister for Health which gives recommendations on how this funding could be best targeted.

Recommendations

DEMENTIA FRIENDLY COMMUNITIES

- | | | |
|-----|--|--------------------------|
| 1.1 | Support a program to tackle the stigma and social isolation associated with dementia. Building on Australian and overseas experience the funding would be used to support projects (eg voluntary work, employment, social activities, promoting access to every day services such as banking and retail) in each state and territory that would support communities to engage with people who have dementia to develop strategies to make their community more dementia-friendly. The program will achieve 20 dementia-friendly communities by 2016. | \$5 million over 3 years |
|-----|--|--------------------------|

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

² Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and prevalence 2009-2050*. Report for Alzheimer's Australia.

- 1.2 A commitment by Government to make Centrelink dementia friendly through training staff to communicate with clients with cognitive impairment and working with people with dementia to ensure that the services provided by Centrelink staff are appropriate for people with dementia.

BUILD ON THE 2012 AGED CARE REFORMS

- | | | |
|-----|---|-----------------------|
| 2.1 | Commit in full to the implementation of the 2012 Aged Care Reforms including initiatives to achieve timely diagnosis (\$41.5m over 5 years) and improved dementia care in hospitals (\$39.2m over 5 years) and to existing contractual arrangements with Alzheimer's Australia for dementia services. | COST-
NEUTRAL |
| 2.2 | The \$1.2 billion workforce supplement funding is used to support improvements in the quality of the aged care system through measures to support the workforce. Priorities for action within the original workforce objectives are improving the parity of wages across the aged care and health sector, the expansion of the Dementia Behaviour Management Advisory Services and development of nationally consistent training and education programs, particularly around psychosocial approaches to managing behavioural and psychological symptoms and monitoring the use of anti-psychotic medications. From a consumer perspective consideration should also be given to expanding packages and respite care in building on the 2012 Aged Care reforms | COST-
NEUTRAL |
| 2.3 | The Federal Government to build on the Younger Onset Dementia Key Worker Program by progressively expanding the program to people of all ages with dementia. The first step of this proposed expansion is the employment of an additional 40 dementia advisors for older people with dementia who are living alone, those in rural or remote communities, the homeless and those from diverse backgrounds (CALD, LGBTI, and Aboriginal and Torres Strait Islanders) commencing in 2014-2015. | \$10m over 3
years |
| 2.4 | The Federal Government should set a benchmark with regards to waiting times for access to both community and residential care. The rationing formula should be readjusted regularly in response to performance against this benchmark to ensure that older Australians have timely access to the care they need where they want it delivered. | COST
NEUTRAL |
| 2.5 | The Federal Government to conduct a cost-neutral trial to evaluate the risks and benefits of allowing consumers to cash out the value of respite services to enable them to purchase the services they need | COST
NEUTRAL |

NATIONAL DISABILITY INSURANCE SCHEME

- 3.1 The Government should provide some clear directions to the disabilities and aged care sectors to address access to assessment and services for people with younger onset dementia.

ALZHEIMER'S AUSTRALIA BUDGET PROPOSAL

Additional Funding (millions)				
	2014-15	2015-16	2016-17	Total
Dementia Friendly Communities	1	2	2	5
Building on aged care reform	2	4	4	10
Total	3	6	6	15

1. DEMENTIA-FRIENDLY COMMUNITIES

The onset and progression of dementia has considerable implications for the person's daily life and engagement with society. As well as a decline in cognitive capabilities, people with dementia also experience changes in their personality and emotional state that can negatively affect their social interaction result in a profound sense of social isolation. In addition to changes which are directly related to dementia, some people also experience a profound sense of social isolation and lack of purpose due to social stigma.

A 2012 study about stigma and dementia found³:

- 22% of those surveyed said they would feel uncomfortable spending time with someone who had dementia
- 34% of respondents found people with dementia to be irritating
- 11% said they would avoid spending time with people who had dementia; and
- If diagnosed with dementia, 60% anticipated that they would feel shame.

People with dementia have identified social isolation as a key concern and members of the Alzheimer's Australia Dementia Advisory Committee have provided the following comments:

- "We want to have a real part in the decision making that affects us"
- "Stop looking past us (to our carer) and talk to me, I am here"
- "It is my right to speak for myself, no matter how much time it takes me, or how much of a struggle it is"

Alzheimer's Australia has published reports on dementia friendly communities and organisations which outline international approaches as well as describing how initiatives could be implemented in Australia.⁴ The goal of developing this approach in Australia is to raise community awareness while also supporting people with dementia to remain involved in and to contribute to their local community. Projects will include voluntary work, supported employment opportunities, social activities, and training for front-line services and retail staff to improve access to every day services such as retail, transport and banking. A key service for family carers and people with dementia is Centrelink. Centrelink staff need to be trained to communicate and advise people with cognitive impairment.

Recommendation 1.1

Support a program to tackle the stigma and social isolation associated with dementia. Building Australian and overseas experience the funding would be used to support projects (e.g. voluntary work, employment, social activities, access to every day services such as banking and retail) in each state and territory that would support communities to engage with people who have dementia to develop strategies to make their community more dementia-friendly. The program will achieve 20 dementia-friendly communities by 2016.

Recommendation 1.2

A commitment by Government to make Centrelink dementia friendly through training staff to communicate with clients with cognitive impairment and working with people with dementia to ensure that the services provided by Centrelink staff are appropriate for people with dementia.

³ Alzheimer's Australia (2012) *Exploring Dementia and Stigma Beliefs*.

⁴ Alzheimer's Australia (2013). *Dementia-Friendly Communities: A Way Forward*.

2. BUILDING ON THE 2012 AGED CARE REFORMS

Background

The 2012 Aged Care Reforms set the framework for a world class aged care system which will be flexible and responsive to the increasing demands of an ageing population. These reforms represent a fundamental shift in the philosophy of care and support for older people in Australia and a landmark change in how providers will work with consumers in identifying the best use of services to support them to meet their individual goals.

But as the Government has recognised, there is a need to build on these reforms if we are to realise the promise of a system of high quality care that is sustainable. It is critical to ensure that the reforms continue to evolve to respond to the needs of older Australians and that in areas where the reforms are not working well they are revised to ensure that the system continues to improve.

Based on consumer feedback, Alzheimer's Australia believes there are five main priorities for building on reform:

- Commit fully to the 2012 Aged Care Reforms
- Improved Quality of Care
- Dementia Advisors
- Improved Access to Home Care
- Flexible Respite Care

2012 Aged Care Reforms

As part of the reform package \$269 million was committed over 5 years to tackling dementia. A number of elements of this package including the dementia supplements, dementia risk reduction and younger onset dementia key workers have already been implemented. The outstanding action relates to the implementation of initiatives:

- To support people with dementia across the health system including to achieve timely diagnosis and expand the scope of DBMAS (\$41.5m over 5 years)
- To pilot new programs to improve dementia care in acute care (\$39.2m over 5 years)

These initiatives are the first in Australian public health policy and a recognition that dementia is not only a priority for aged care but also the health system. It is imperative that these initiatives are delivered on and appropriately targeted to lead to better care and support for people with dementia in both the primary and acute care settings.

Alzheimer's Australia, through funding from the Australian Government provides important support and services to people with dementia, their families, and workforce in the sector. The programs delivered by Alzheimer's Australia have been extensively evaluated and been found to lead to positive outcomes for people with dementia and their families. The funding

of core dementia services under the National Dementia Support Program provided by Alzheimer's Australia has not kept up with growth of numbers of people with dementia. Funding has only increased minimally, for example, by a 1.47 indexation in recent years, compared to the average growth in number of people with dementia of 3.4 percent each year. Existing contracts are in place until 2015-16 and at a minimum this funding should be continued for the next two years at contracted levels.

Quality of Care

Over the past several years, consumers have shared experiences of poor quality care and the frustrations navigating a highly complex system. Concerns include mismanagement of behavioural and psychological symptoms of dementia (BPSD), chemical and physical restraint, care recipients treated with a lack of dignity and respect, and psychological, physical and sexual abuse. Alzheimer's Australia has outlined these concerns in a recent publication: *Quality of Residential Aged Care: The Consumer Perspective*⁵, and similar stories have been documented in a series of investigative reports by ABC1's Lateline during 2012 and 2013. The disturbing picture is parts of an aged care system under strain and in some cases failing to meet the basic human rights of our most vulnerable citizens.

The 2012 Aged Care Reforms address quality of care issues through a range of measures, including dementia and veteran supplements, the gradual introduction of quality indicators and the new Australian Aged Care Quality Agency. These initiatives represent an important focus on quality but they are unlikely to achieve a zero tolerance for poor quality care across both the residential and community care settings. Consumers will rightly be concerned about a regime of increased user charges without significant improvements to the quality of care.

The Government has suspended applications for the \$1.2 billion workforce supplement, which was a key component of the Aged Care Reform Package, and is considering how this funding will be utilised to support the aged care workforce. Within the original objectives set for the use of this funding measures are needed which will improve quality of care including initiatives which are targeted at ensuring equitable wages, reducing the inappropriate use of antipsychotic medications through the expansion of Dementia Behaviour Management Advisory Services (DBMAS), staff training, and monitoring the use of medications. If the Government is prepared to consider a whole of aged care sector distribution then an expansion of community packages (especially at levels 3 and 4) and respite care would be priorities from a consumer perspective

Recommendation 2.1

Commit in full to the implementation of the 2012 Aged Care Reforms including initiatives to achieve timely diagnosis (\$41.5m over 5 years) and improved dementia care in hospitals (\$39.2m over 5 years) and to existing contractual arrangements with Alzheimer's Australia for dementia services.

Recommendation 2.2

The \$1.2 billion workforce supplement funding is used to support improvements in the quality of the aged care system through measures to support the workforce. Priorities for action within the original workforce objectives are improving the parity of wages across the aged

⁵http://www.fightdementia.org.au/common/files/NAT/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf

care and health sector, the expansion of the Dementia Behaviour Management Advisory Services and development of nationally consistent training and education programs, particularly around psychosocial approaches to managing behavioural and psychological symptoms and monitoring the use of anti-psychotic medications. From a consumer perspective consideration should also be given to expanding packages and respite care in building on the 2012 Aged Care reforms

Dementia Advisors

After diagnosis people living with dementia often have difficulty in navigating the service system and gaining access to appropriate care, support and opportunities for social engagement. People from diverse backgrounds including CALD, LGBTI, Aboriginal and Torres Strait Islanders, those who live in rural areas, the homeless, people living with disabilities and those living alone face even greater difficulty⁶.

The 2012 Aged Care Reforms include the development of a National Aged Care Gateway, which is essentially a website and national call-centre to assist people in navigating the care sector. For people with dementia including those from diverse backgrounds or disadvantaged groups, this approach is problematic and may lead to them missing out on important services and supports. People with dementia want face to face individualised support in navigating the service sector.

Consumers have repeatedly called for a national program of advisors for all people with dementia to assist in providing support and advice from the point of diagnosis and throughout the dementia journey. As part of the 2012 Aged Care Reforms, a new national program of 40 key workers for people with younger onset dementia has been implemented by Alzheimer's Australia.

There is a need to extend this program to provide services and supports to all people with dementia who require support, regardless of their age. A dementia advisor approach to dementia care has been successfully implemented in a number of countries and international research has shown that dementia advisor programs for people with dementia are cost effective and lead to reduced care giver burden, reduced cost of formal care services⁷ and reduced likelihood of admission to residential aged care.⁸ Within Australia, the importance of this approach has been recognised in the recent House of Representatives report *Thinking Ahead: Report on the inquiry into dementia: early diagnosis and intervention* which recommended that: "The Australian Government Department of Health and Ageing examine the case for establishing a Dementia Link Worker program to assist in the ongoing case management of people with dementia and their carers".

Initially, the new funding should focus on those with the greatest need for face to face support. Longer term there should be a staged roll out of the program nationally to achieve a long term goal of 340 dementia advisors across Australia.

⁷ Alzheimer's Society of Canada (2013). *Rising tide: The impact of dementia on Canadian Society*.

⁸ Challis et al. (2002). *Care Management, dementia care, and specialist mental health services: an evaluation*. International Journal of Geriatric Psychiatry, 17, 315-325.

Recommendation 2.3

The Federal Government to build on the Younger Onset Dementia Key Worker Program by progressively expanding the program to people of all ages with dementia. The first step of this proposed expansion is the employment of an additional 40 dementia advisors for older people with dementia who are living alone, those in rural or remote communities, the homeless and those from diverse backgrounds (CALD, LGBTI, and Aboriginal and Torres Strait Islanders) commencing in 2014-2015.

Access to Home Care

The central tenet of aged care is to enable older people to stay at home longer while recognising that for many entry into residential care will be necessary – often because the family carer even with support cannot continue to provide care, the older person has no family carer or the care needs of those with dementia are too great for the support network. The 2012 Aged Care reforms provide an important expansion of home care packages from 64,800 in 2012 to 144,469 in 2022.

Some in the sector have been critical of the reforms for not moving more quickly to an entitlement approach which would eliminate rationing and enable consumers to have access to the care they need where they want to receive it. We share the concern about rationing of services highlighted by other stakeholders and the interest in entitlement. We agree that in the long term a more contestable marketplace will lead to greater choice and higher quality of care for older Australians. At the same time we are cautious about moving too quickly to an entitlement approach because we know that Government will need to control expenditure in some way such as increasing user charges, being prescriptive about services that are funded or raising the level of need required to be eligible for services. Such approaches are not guaranteed to produce greater equity as we have seen in other entitlement approaches such as Medicare. Moreover the current allocation formula with all its weaknesses and distortions of the market has the advantage of certainty of funding.

The preferred approach of Alzheimer's Australia is to be more pragmatic. We are pleased with the rapid expansion of community care over the next 10 years and believe that this is the first step towards creating a system that is more responsive to consumer demand. There will need to be a regular review of how well the allocations of community care and residential care are meeting demand. A benchmark should be set with regards to waiting times (e.g. 90% of people assessed as eligible for community care should have access to a package within 6 weeks). There needs to be a specific review of the mix of level 1–4 packages to ensure that there is sufficient support for people at all levels of care needs. The regular review should be used to readjust the formula as required to ensure that older Australians have timely access to the care they need where they want it delivered. Consideration should also be given to a higher level package to provide support for people with the highest care needs or to assist those who are living alone.

Recommendation 2.4

The Federal Government should set a benchmark with regards to waiting times for access to both community and residential care. The rationing formula should be readjusted regularly in response to performance against this benchmark to ensure that older Australians have timely access to the care they need where they want it delivered.

Respite Care

Respite care whether home based, community based or residential care based is a critical support for family carers and provides important social engagement for people with dementia. But access to services is often difficult because respite services are not resourced and/or staff do not have adequate training to care for people with high care needs such as behavioural and psychological symptoms of dementia and because the services are not available where and when they are needed.⁹ Family carers report that once the person with dementia develops behavioural symptoms or becomes incontinent many service providers refuse to continue to provide services.¹⁰ Lack of support from respite services and the subsequent lack of support for carers can lead to earlier entry into residential aged care.

The current system for respite is not meeting the needs of people with dementia and their carers, as is evident from the gap between reported need for respite and uptake of existing residential respite services. The main unmet need reported by carers of people with dementia is for respite¹¹. At the same time carers of people with dementia are 10 times more likely than other carers to say they need respite but not have used it.¹²

There are a range of barriers to respite use including services not being available when and where they are needed, issues around quality of care, concern over whether the service will benefit the person with dementia, transport issues and lack of information.¹³ For people from diverse backgrounds or those in regional or rural areas, access can be even more difficult.

Although the 2012 Aged Care Reforms aim to improve access to respite, they do not sufficiently address the barriers that people with dementia experience. Given the range of needs and the difficulty in accessing appropriate services, extending the entitlement of respite beyond 'approved providers' to include family members (other than the primary carer), friends and others would be an important step in enabling individuals to get access to the care they need, when and where they want it.

International evidence suggests that there are a number of benefits of programs that provide care recipients with cash which can be used to access services from a range of providers. These include a greater sense of choice and control, psychological benefits, assistance that better fits needs delivered when and where it is required and greater satisfaction with care.¹⁴ This approach also has the advantage of reducing red tape by enabling consumers to directly access the services they need. There is a need for a trial to identify the benefits and risks of this model of respite provision.

Recommendation 2.5

The Federal Government to conduct a cost-neutral trial to evaluate the risks and benefits of allowing consumers to cash out the value of respite services to enable them to purchase the services they need.

⁹ Alzheimer's Australia (2013), *Respite Review Policy Paper*.

¹⁰ Alzheimer's Australia (2012). *Consumer Engagement in the Aged Care Reform Process*.

¹¹ ABS(2009). *Survey of disabilities, ageing and carers*.

¹² Alzheimer's Australia (2013), *Respite Review Policy Paper*.

¹³ Alzheimer's Australia (2013), *Respite Review Policy Paper*.

¹⁴ see Arksey & Kemp, 2008 or Ottman, Allen & Feldman, 2009 for a review of international evidence on cash-for-service

3. NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

There are approximately 24,400 people in Australia with younger onset dementia (that is, a diagnosis of dementia under the age of 65) with most 'falling through the cracks' because they do not fit neatly into the aged care system or the disability sector. The NDIS holds promise for providing people with younger onset dementia with access to individualised support and care.

Alzheimer's Australia supports the principles of the NDIS which include a focus on:

1. Supporting the independence and social and economic participation of people with a disability;
2. Providing reasonable and necessary supports, including early intervention mechanisms;
3. Enabling people to exercise choice and control; and
4. Promoting the provision of high quality, innovative supports.¹⁵

These principles are crucial in supporting people with younger onset dementia because their dementia appears at an earlier stage in their life when they are likely to be more physically and socially active and maybe the primary wage earner in a family. The current trials have been useful in highlighting important issues and barriers to accessing appropriate support and care including:

- The difficulties people with younger onset dementia experience in navigating the disability and aged care sector particularly in access in some states to aged care assessment teams
- Difficulty for people with cognitive impairment to complete the application process, explain their condition and needs, manage their plan, and contact and consult with NDIS staff and service providers and the importance of advocates (family carers, younger onset dementia key workers etc) throughout the application process and beyond.
- Subjectivity of what supports may be considered 'reasonable and necessary'.
- Lack of awareness that people with younger onset dementia are eligible to receive support through the NDIS.
- Concerns about the adequacy of support options available to people who are not successful in becoming an NDIS participant.
- Uncertainty about how carers can receive support if needed.

It is essential that people with younger onset dementia are not caught between two different schemes, neither of which is willing to take responsibility for their care and support. It is essential to learn lessons from the trials and refine the NDIS to ensure that it provides adequate support for people with younger onset dementia.

Recommendation 3.1

The Government should provide some clear directions to the disabilities and aged care sectors to address access to assessment and services for people with younger onset dementia.

¹⁵ National Disability Insurance Scheme Bill 2012 (2012), Chapter 1, Part 2, sub-section 3.