FIGHT DEMENTIA CAMPAIGN
CREATING A DEMENTIA-FRIENDLY AUSTRALIA

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MESSAGE TO POLITICIANS

Dementia is the public health challenge of the 21st century. The G8 Dementia Summit in the UK in December 2013 recognised dementia as one of the most significant health issues of this century. In Australia, there has been significant progress at the national level in recognising the need for action on dementia through bipartisan support for programs such as the 2005 Dementia Initiative and the passage of the 2012 Aged Care Reform Package.

Most recently, the Coalition committed to investing an additional $200 million in dementia research over the next five years.

But we can’t stop there. We still face a world in which people with dementia experience stigma and social isolation. They struggle to get access to appropriate care and support.

Dementia is both a public health challenge and a social issue. We need a system of support that respects choice and promotes social inclusion for people with dementia rather than institutionalisation and isolation. Therefore to successfully tackle dementia there must be a focus not only on the need for care and support, but also on social engagement.

This social transformation is dependent on action to:

• Achieve timely diagnosis, improve care for people with dementia in hospitals and raise greater awareness of dementia risk reduction.
• Support for people with dementia from the moment of diagnosis in navigating the complex service system.
• Improve access to quality dementia care in community and residential care services that support both the person with dementia and the family carer.
• Improve awareness of dementia and social inclusion through a program aimed at developing dementia-friendly communities and organisations.

Attached is our revised fight dementia document that outlines the action Alzheimer’s Australia believes is necessary over the next three years to ensure people with dementia receive the respect and access to services that all Australians expect.

I am pleased to be able to tell you that COTA and Carers Australia support these priorities. It is imperative that family carers who provide most of the care and support needed in the community have access to respite where and when it is needed.

On behalf of people with dementia and their families, please help us to beat dementia and to make Australia a dementia-friendly country. If you aren’t already a dementia champion visit our website: campaign.fightdementia.org.au and sign up to become one now. Your support would be much appreciated.

Best wishes.

Ita Buttrose AO, OBE
National President
Alzheimer’s Australia
ACTION PLAN

CREATING A DEMENTIA-FRIENDLY COUNTRY

The 2013 G8 Dementia Summit in the UK elevated the issue of dementia onto the global political stage. The commitments outlined in the summit’s Communiqué¹ and Declaration² hold great promise for international collaboration and cooperation in efforts to combat dementia.

In Australia, dementia is now one of the country’s National Health Priority Areas. Through the 2012 Aged Care Reforms, there is significant investment to improve care and services in both the health and aged care system. There is also a renewed focus on moving towards finding a cure and better treatments for dementia with the commitment of the Abbott Government to an additional $200 million over five years for dementia research.

The Government in its aged care Policy for Healthy Life, Better Ageing recognised that the aged care reforms legislated by Parliament are only a first step and that there is a need for careful implementation to build on these reforms to ensure that people with dementia and their families and carers are provided with high quality, dignified care.

The case for sustaining action over the coming years is overwhelming.

- Each week there are 1700 new cases of dementia in Australia. This number is expected to grow to 7,400 new cases each week by 2050³
- There are more than 332,000 Australians living with dementia today⁴ and more than one million Australians involved in the care of a person with dementia⁵
- Many people with dementia and their family and carers experience loneliness and social isolation after their diagnosis
- If diagnosed with dementia, 60% of Australians say that they would experience feelings of shame⁶
- People with dementia from culturally and linguistically diverse backgrounds (CALD), Aboriginal and Torres Strait Islanders (ATSI), those who live in rural areas, the homeless, those living alone, and lesbian, gay, bisexual, transgender, and intersex people and other sexuality and gender diverse (LGBTI) people and communities, face greater difficulty in getting access to appropriate services and supports

Alzheimer’s Australia is seeking a commitment from the Federal Government to tackle the social isolation and stigma associated with dementia and to protect the rights of people with dementia by:

1. Developing a national program of dementia advisors
2. Expanding dementia-specific respite care
3. Improving the quality of residential aged care
4. Developing dementia-friendly communities and organisations to increase awareness and reduce social isolation
5. Taking action on health priorities including a new National Action Framework on Dementia.

¹ G8 UK (2013) G8 Dementia Summit Communiqué
² G8 UK (2013) G8 Dementia Summit Declaration
⁵ Alzheimer’s Australia, (2011) Pfizer Health Report Issue #45 – Dementia, Pfizer Australia.
⁶ Alzheimer’s Australia (2012) Exploring Dementia and Stigma Beliefs
ACTION 1- NATIONAL PROGRAM OF DEMENTIA ADVISORS

What is the issue?

People living with dementia often do not get the support they need after a diagnosis. They 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 difficulty.

Consumer views

‘There needs to be more information and assistance to enable family members to identify signs and know who to turn to for help. There is a lot of confusion about services and how to access them. My whole journey was filling in forms and getting services for the person I care for by stumbling across them.’

What do we know?

- Consumers have repeatedly called for a national program of advisors for all people with dementia to assist in providing support from the point of diagnosis
- A program is now in place to fund 40 key workers to support individuals with younger onset dementia across Australia to access services and assist in service development
- Older people with dementia want face-to-face contact to get support in accessing aged care services. They are reluctant to use national call centres or websites to access information and services
- People from diverse or disadvantaged groups are likely to find the Gateway approach to accessing aged care services difficult and as a result many are likely to miss out on access to services
- The recent House of Representatives’ report *Thinking Ahead: Report on the inquiry into dementia: early diagnosis and intervention* 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”
- The Dementia Services Pathways which was developed for the Department of Health and Ageing in 2011 by KPMG identified limited access to health professionals in the early stage of dementia as one of the common gaps and shortfalls in the care pathway and recommended a national key worker program
- 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 services and reduced likelihood of admission to residential aged care
- People living in rural and remote communities have difficulties accessing the support and care required.

What do we want to achieve?

To build on the Younger Onset Dementia Key Worker Program to ensure that all people with dementia and their families have access to the support they need to navigate the service system and get access to appropriate services and social support from the point of diagnosis.

12 Alzheimer’s Australia NSW (2013), *Living with dementia in regional NSW*. 
How can this be done?

A commitment by the Federal Government to continue the Younger Onset Dementia Key Worker Program beyond the initial three-year funding and to work towards expanding the program to people of all ages with dementia.

Initially this should involve an investment of an additional $4 million each year for the employment of 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, Aboriginal and Torres Strait Islanders, and LGBTI) in order to target people who have the greatest need.

In addition, there should be a roll out of the program in one or two states along with an evaluation to monitor outcomes and ensure it is delivered effectively. If this is done initially in Tasmania, it would require an additional investment of $800,000 per year to employ the eight additional key workers needed given the estimated prevalence of dementia in Tasmania.

The long term goal should be a national program of dementia advisors for all people with dementia.
**ACTION 2- EXPANSION OF DEMENTIA-SPECIFIC RESPITE**

**What is the issue?**

Respite care is a critical issue for family carers and provides social engagement for people with dementia. But access to services is often difficult because they are not resourced and/or their staff are not adequately trained to care for people with the behavioural and psychological symptoms of dementia and because the services are not available where and when they are needed. Lack of support from respite services can lead to earlier entry into residential aged care.

**Consumer views**

‘It is easier to cope as a carer and find respite for someone with low care needs, it becomes more difficult to care for someone as they start to have higher care needs.’

‘If I could receive cash instead of services I would use it to make changes to accessibility in the home to make things easier for my father and less stressful for me in caring for him. Purchasing my own services would give me peace of mind knowing that I do know and can trust the person in my home to care for my vulnerable family member.’

**What do we know?**

- The main unmet need reported by carers of people with dementia was for more respite care, with 48% reporting this need compared to 15% of all primary carers
- Carers of people with dementia are 10 times more likely than other carers to say they need respite but had not used it
- One of the main barriers to accessing out-of-home respite care is the concern that the service experience will be negative for the person they are caring for
- Family carers report that once the person with dementia develops behavioural symptoms or becomes incontinent many service providers refuse to continue to provide services
- Lack of flexible services is a significant barrier to the use of respite. Needs for respite, whether emergency or planned, vary so widely in the type of service, when it is needed, where it is provided and what type of care the recipient requires. The current system for respite is not meeting these demands
- The aged care reforms will expand access to respite. But they do not address the need for services which can better meet the specialised needs of individuals with dementia or the need for more flexible services
- There is some uncertainty about how respite will be provided under the National Disability Insurance Scheme (NDIS). There is concern that in some cases carers will not have access to this important service

**What do we want to achieve?**

Affordable, flexible, high quality, culturally and linguistically appropriate respite services that are beneficial to the person with dementia and their carer and that can provide appropriate care, support and social engagement for people with dementia.

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16 Alzheimer’s Australia (2009). Respite care for people living with dementia.
17 Phillipson, L. and Jones, S.C. (2011) ‘Between the devil and the deep blue sea’: The beliefs that caregivers of people with dementia have regarding the use of in-home respite services. Home Health Care Services Quarterly.
How can this be done?

A commitment by the Federal Government to improve access to appropriate, flexible respite services for people with dementia. This can be achieved by:

1. Investing $15.5 million a year to develop dementia-specific respite services that would receive a 10% dementia supplement in line with the dementia supplement provided for community care packages. This supplement would be linked to a requirement for ongoing dementia training for staff.

2. Ensuring that current respite funding is used flexibly to best support people with dementia and their carers including:
   - Conducting a cost-neutral trial to evaluate the costs and benefits of allowing consumers to cash out the value of respite services to enable them to purchase the services they need
   - Ensuring people with dementia and their carers continue to have access to respite services under the NDIS
   - Developing innovative models of planned dementia-specific residential respite services within the current funding system which would be available for longer term stays in order to support people to continue living in the community for longer periods of time and to assist with transitions to residential care
   - Ensuring that consumers, including those from diverse backgrounds, are aware of the services and supports that are available.
ACTION 3 - IMPROVING QUALITY OF RESIDENTIAL CARE

What is the issue?

There is an urgent need to improve the quality of dementia care within residential aged care facilities to ensure that the basic human rights of people with dementia are protected.

Consumer views

‘There is a willingness to sedate people with Alzheimer’s. There is a link to antipsychotic drugs leading to other illnesses. The nursing home wanted her to be manageable, and therefore sedated her. I believe the longer the resident is in their own home the better. The bullying – there is no other word I can use. The bullying we have come across in nursing homes, from hospitals and doctors.’

‘So many facilities are working so hard to meet the accreditation and they forget the human element. There should be more emphasis placed on the feedback from the residents in the facility. That way the feedback is coming from the residents, not the staff.’

‘I am very pleased with the facility where my wife has been a resident for nearly four years. The staff is very caring and really understand my wife and her moods although she is not able to communicate verbally. I also enjoy a very good relationship with all the staff and management.’

What do we know?

• Consumers find it difficult to evaluate the quality of the care provided in a facility or to compare the services offered by providers

• Over 50% of aged care residents have dementia but the quality of care and access to care is variable for those with complex needs

• The current Residential Aged Care Accreditation Standards offer a process of monitoring care however, they do not have a strong focus on clinical outcomes, and the standards represent a minimal rather than optimal quality of care

• Approximately 25% of people in residential aged care are given antipsychotic medication, often as a form of chemical restraint

• Known risks of antipsychotics mean that thousands of people with dementia may be dying prematurely each year as a result of treatment

• Consumers report that aged care facilities often do not have the staff or the training to provide quality care to individuals with high care needs such as those with behavioural and psychological symptoms of dementia

• The Government in its Policy for Healthy Life, Better Ageing supports the need to develop a more flexible and sustainable system that is focused on the provision of high quality care

20 Alzheimer’s Australia (2013) Quality of residential Aged Care: The consumer perspective.
What do we want to achieve?
High quality residential care that respects the rights, choices and cultural and linguistic preferences of all individuals including people with dementia, and achieves greater transparency in the quality of care and quality of life outcomes.

How can this be done?
A commitment by the Federal Government to provide high quality care and services and protect the rights of all people including those with dementia. This could be achieved through:

1. Investing $2 million to commission an independent cost of care study (by the Aged Care Funding Authority) to ensure that the aged care sector is adequately resourced to provide high quality community and residential care and to lay the basis for greater objectivity about the financial viability of the sector

2. Providing an additional $6 million per annum investment in Dementia Behaviour Management Advisory Service (DBMAS) to provide expanded support to residential care facilities

3. Ensuring that the Aged Care Reform Package is implemented in a way that will best achieve high quality care. This includes:
   - Linking dementia supplements in residential care to requirements for staff training, particularly on non-pharmacological approaches to managing behavioural symptoms of dementia
   - Developing clinical and quality of life indicators for all residential care providers which will be published on the MyAgedCare website. Care needs to be taken to ensure these indicators are meaningful to consumers and assist service providers with continuous improvement
   - Involving consumers in the accreditation and complaints process through an expanded trial of consumer involvement based on the Accreditation Agencies Experts by Experience Program
   - Developing a streamlined process through the Aged Care Complaints Scheme for consumers who report the inappropriate use of medications or physical restraint in residential aged care such that a response is required by the Agency within three working days of a complaint being lodged.
**ACTION 4 - DEMENTIA-FRIENDLY COMMUNITIES AND ORGANISATIONS**

What is the issue?

Many Australians know very little about what dementia is or how it develops. Confusion around the disease can lead to fear and stigma. People in the community as well as retail and service staff often misinterpret symptoms of the disease as being signs of a person being purposefully difficult or uncooperative. Even if they are aware that the symptoms are caused by dementia they often do not know how to best communicate or respond to a person with dementia.

**Consumer views**

‘There needs to be a better understanding of dementia and who we are as people, everyone’s experience with dementia is unique.’

‘My husband found it difficult to admit publicly that he had dementia. It has such a stigma attached to the name and he didn’t want others to feel he was less of a person than beforehand.’

What do we know?

- Many people with dementia experience loneliness and social isolation after they receive their diagnosis
- People with dementia often struggle to engage in their local communities because of limited community understanding of dementia
- Australians associate dementia with loss of memory and difficulties with daily functions, but most are unaware of the effect of dementia on language or mood
- Dementia understanding and perception varies across different CALD communities
- Two out of three Australians are scared of developing dementia – a fear second only to the fear of developing cancer
- 56% of carers report that people with dementia are discriminated against
- Individuals who believe that dementia is associated with stigma are less likely to seek help if they begin to experience memory or other cognitive changes
- In a recent survey about stigma and dementia:
  - 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
  - 60% anticipated that they would experience feelings of shame if diagnosed with dementia.

What do we want to achieve?

Social inclusion for people with dementia and their families by creating a program that will support communities to engage people with dementia in voluntary work, employment, and giving them access to everyday services such as banking and retail.

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26 Pfizer Health Report Issue #45 – Dementia, March 2011
31 Alzheimer’s Australia (2012) Exploring Dementia and Stigma Beliefs.
How can this be done?

A commitment by the Federal Government to ensure their service agencies are dementia-friendly, starting with Centrelink.

A commitment by the Federal Government for funding for a $5 million National Dementia-Friendly Communities Initiative led by Alzheimer’s Australia. This program will take an active approach to improving awareness and reducing stigma associated with the disease. Initially the funding would be used to support a pilot site in each state and territory and would enable communities to engage with people who have dementia to develop strategies to make their community more dementia-friendly. These strategies may include training staff at banks, retail shops and Centrelink to engage people with dementia, create volunteering opportunities for people with dementia and provide supported employment opportunities. The program will aim to achieve 20 dementia-friendly communities by 2016.
**ACTION 5- HEALTH PRIORITIES**

**What is the issue?**
Dementia needs to be addressed within a public health framework that includes action to achieve timely diagnosis and improved dementia care in acute care, access to palliative care services and dementia risk reduction programs.

**Consumer views**
‘Thankfully my diagnosis was very quick and it allowed me and my wife to start planning our future. For others this is unfortunately not the case.’
‘GPs need to have more knowledge of early symptoms and act quickly when presented with symptoms. At the GP I encountered apathy if not denial. It is very important to have a GP who is aware of dementia, and refers you to a specialist as soon as possible for early intervention.’
‘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 told she is not worthy.’

**What do we know?**
- Only one third of people who have dementia receive a diagnosis at any time in their illness. For those who are diagnosed, many do not receive a diagnosis until three years after they first notice symptoms\(^32\)
- Hospitals are dangerous and confusing places for people with dementia and many have no programs or services to meet the needs of individuals with dementia\(^33\)
- Individuals with dementia generally stay in hospitals for longer and have a higher cost of care\(^34\)
- Recent estimates suggest that approximately half of individuals with dementia are not recognised as having dementia when they enter hospital. This can lead to inappropriate care and poor outcomes for the person with dementia\(^35\)
- Individuals with dementia have difficulty accessing appropriate end of life care. As a result many end up in hospital receiving unwanted interventions instead of receiving the palliative care they need and want at home or in a residential aged care facility\(^36\)
- The majority of Australians are not aware that they may be able to reduce their risk of dementia. Up to half the cases of Alzheimer’s disease worldwide are potentially attributable to modifiable risk factors such as physical inactivity, midlife hypertension, midlife obesity, diabetes and cognitive inactivity.\(^37\)

**What do we want to achieve?**
A health system that responds to the needs of people with dementia and ensures access to timely diagnosis, quality health care and appropriate end of life care, as well as promoting the benefits of a brain healthy lifestyle.

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32 Alzheimer’s Australia (2011) *Timely Diagnosis of Dementia: Can we do better?*
33 AIHW (2013). *Dementia Care in Hospitals.*
34 AIHW (2013). *Dementia Care in Hospitals.*
35 AIHW (2013). *Dementia Care in Hospitals.*
36 Alzheimer’s Australia (2012). *Submission to the Senate Community Affairs Committees Inquiry into Palliative Care in Australia.*
How can this be done?

Full implementation of the $268.4 million funding over five years which was committed to tackle dementia in the aged care reforms and delivering on initiatives to improve support for people with dementia across the health system including in relation to timely diagnosis ($41.3 million), dementia care in hospitals ($39.2 million) and dementia risk reduction ($4 million). This funding should be prioritised in consultation with consumers and experts, through the Ministerial Dementia Advisory Group.

Investing an additional $4 million from July 2015 to June 2018 to support the continued implementation of Your Brain Matters, the world’s first nationally-funded dementia risk reduction public awareness program.

The agreement of Health Ministers to a new National Action Framework on Dementia that includes a focus on:

1. Programs to improve timely diagnosis including the option for cognitive screening using culturally and linguistically appropriate tools at the 75+ health check (and younger for Aboriginal and Torres Strait Islanders, due to shorter life expectancy) and a GP, nurse practitioner and practice nurse training program to assist with recognising the symptoms of dementia

2. Initiatives to improve hospital care for people with dementia including cognitive screening for all people over 75 who are admitted to hospital and the implementation of a cognitive impairment symbol and training for staff to assist in the identification and communication with people with dementia

3. Services to avoid unnecessary hospitalisations including dementia and culturally-specific palliative care services

4. Services to ensure smooth transitions for older people between hospital care and returning to the community

5. Initiatives to raise public awareness programs and the connections between dementia and other chronic diseases.