FIGHT DEMENTIA CAMPAIGN ELECTION 2013

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MESSAGE TO CANDIDATE

Dementia is the public health challenge of the 21st century. More than 320,000 Australians – including many in your electorate – are currently affected by this major health epidemic. Within 20 years, more than half a million of us will have the disease.

Dementia is already the third highest cause of death of Australians and there is no cure. Currently 1700 cases are diagnosed each week – that’s one person every six minutes. This figure is expected to rise to 7400 new cases per week by 2050.

Bipartisan support within the last 10 years has achieved better outcomes for people with dementia and their carers. Last year the Gillard Government committed to tackling dementia in the Living Longer, Living Better, aged care reform package and with the support of the Australian Health Ministers made dementia a National Health Priority.

The Howard Government put the spotlight on dementia in 2005, when it provided essential funding for improved dementia care, dementia training and dementia care research.

We need your support to build on these achievements and to develop an inclusive society, one that values the strengths and contributions of its citizens regardless of age, disease or disability, while also respecting choice and social inclusion rather than institutionalism and isolation.

In order to provide greater choice and better care and support for people with dementia and their family carers we need:

• Access to high quality dementia care and support services
• A health system prepared to confront the issue of timely diagnosis
• Hospitals that meet the needs of people with dementia
• Greater investment in dementia research.

Attached is a manifesto that outlines what Alzheimer’s Australia believes is needed urgently from the Australian Government to support people living with dementia, their families and carers.

On their behalf I ask that you publicly commit yourself to this cause. Help us beat dementia and make a difference to the lives of many of your fellow citizens.

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

KEEPING THE SPOTLIGHT ON DEMENTIA

On 20 April 2012, in response to the Fight Dementia Campaign, Prime Minister Julia Gillard, and the Minister for Mental Health and Ageing, Mark Butler, announced an investment of $268.4 million over five years to tackle dementia as part of the Living Longer, Living Better, aged care reform package. In August 2012, the Commonwealth Government secured the agreement of the State and Territory governments to make dementia a National Health Priority Area.

These initiatives represent a recognition that dementia will be the major health problem of the century.
But nominating dementia as a health priority is not enough. We need continued action and investment to combat this chronic health condition and ensure timely access to appropriate services for Australians who have dementia, including those from diverse backgrounds and individuals with younger onset dementia.

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

- Each week there are 1700 new cases of dementia in Australia. This figure is expected to grow to 7,400 new cases each week by 2050\(^1\)
- There are more than 320,000 Australians living with dementia today\(^2\) and more than one million Australians provide support for them\(^3\)
- In 2009 there were more than 35,000 people with dementia who do not speak English at home. This figure is projected to increase to 120,000 by 2050\(^4\)
- Dementia is the third most common cause of death\(^5\)
- Dementia costs the health system $6 billion per annum and within 20 years will become the third greatest source of health and residential aged care expenditure\(^6\)

Alzheimer’s Australia is seeking a commitment from the next Federal Government to commit to implementing the *Living Longer. Living Better*. aged care reforms and to build on these reforms by:

1. Expanding community care services to ensure all older Australians have a choice about where they receive care
2. Expanding dementia-specific respite
3. Improving the quality of residential aged care by providing appropriate care for those with behavioural and psychological symptoms of dementia
4. Ensuring the National Disabilities Support Scheme (NDIS) is designed to support individuals with younger onset dementia and that there are appropriate services available in both the community and residential care for people with dementia of all ages
5. Establishing a new National Action Framework on dementia that will result in a health system better able to respond to the needs of people with dementia
6. Committing to an investment of $200 million in dementia research over the next five years

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**ACTION 1  EXPANSION OF COMMUNITY CARE**

**What is the issue?**

The majority of older Australians want to live at home for as long as possible. Although successive governments have expanded community care services, Australia still has one of the highest rates of institutionalisation of older adults among developed nations.

**What do we know?**

- Only 54% of older Australians requiring long term care are receiving care in the community. This compares to an OECD average of 64.5%.
- In 2009-2010, 68.5% of individuals who were assessed as eligible for an EACH package waited for more than one month after assessment to receive that package, 12.4% waited more than 9 months.
- Waiting months to receive care is not viable for families and, as a result, many turn to residential care as community care is not available.
- In 2008, the highest level of community care package available (EACH-D) provided an average of 14 hours per week of direct care – this is approximately 2 hours per day.
- For most people who require high level of care, two hours of care a day is not sufficient to enable them to stay in the community. Furthermore, 87% of people on EACH-D packages also receive support from informal carers.
- Community care is not an option for people who live alone or do not have family who can assist with their care.
- **Living Longer. Living Better** includes a significant expansion of community care. By 2020, the number of Home Care packages per 1,000 older people will increase from 27 to 45, yet only 20% of the new packages will be packages for people with high care needs.
- The proposed expansion in **Living Longer. Living Better** does not go far enough to address wait times for community care packages.

**What do we want to achieve?**

To ensure all older people are able to choose where they receive care.

**How can this be done?**

A commitment by all major political parties to achieve the OECD average of 65% of long term care being provided in the community by 2016. This can be done by:

1. Expanding the number of level three and four community care packages
2. Ensuring the additional community care places available will reduce average wait times of receiving packages to less than 2 months
3. Developing a higher level package which provides a minimum of 28 direct hours of care per week in order to assist people who live alone or who have minimal outside support to continue to receive care at home

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8 Productivity Commission (2011). *Caring for Older Australians.*
ACTION 2 EXPANSION OF DEMENTIA SPECIFIC RESPITE

What is the issue?
Respite is an important support for carers and also provides social engagement for individuals with dementia. Respite enables individuals to be supported in the community for longer. Unfortunately, individuals with dementia are often turned away from respite services because their needs are too great or because of behavioural and psychological symptoms of dementia.

What do we know?
- For every three dementia carers who have used respite, there are two dementia carers who need respite but have not used it\(^\text{12}\)
- Dementia carers are 10 times more likely than other carers to say they need respite but had not used it\(^\text{13}\)
- One of the main barriers for carers accessing out of home respite care is the concern that the experience will be negative for the person they are caring for\(^\text{14}\)
- Carers report that once the person with dementia develops behavioural symptoms or becomes incontinent, service providers refuse to continue supporting them\(^\text{15}\)
- Carers also indicate that lack of flexible services impedes their use of respite. Needs for respite – whether emergency or planned – vary so widely in the type of service, the level of care, when it is needed, time of day it is required, that the current system for respite is not meeting these demands\(^\text{16}\)
- The Living Longer, Living Better reforms will expand access to respite but they do not address the need for specialised services that can better meet the needs of individuals with dementia.

What do we want to achieve?
Flexible, high quality respite services that are beneficial to the care recipient as well as the carer by providing appropriate care and support for people with dementia, including those from diverse backgrounds and individuals with younger onset dementia.

How can this be done?
A commitment by all major political parties to ensure all people living with dementia in the community have access to appropriate, flexible respite services. This can be achieved by:
1. Developing 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. All individuals receiving a home care package which includes a dementia supplement to have access to the dementia specific respite services
3. Developing innovative models of planned dementia specific residential respite services 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
4. A 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

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\(^\text{13}\) Alzheimer’s Australia (2009). Respite care for people living with dementia.
\(^\text{15}\) Alzheimer’s Australia (2012). Consumer Engagement in the Aged Care Reform Process.
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.

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
- More than 50% of aged care residents\(^\text{17}\) 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\(^\text{18}\)
- Approximately 25% of individuals in residential aged care are given antipsychotic medication, often as a form of chemical restraint\(^\text{19}\)
- Risks of antipsychotics mean that thousands of people with dementia are dying prematurely each year as a result of this treatment\(^\text{20}\)
- 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\(^\text{21}\)

What do we want to achieve?
High quality residential care that respects the rights and choices of all individuals including people with dementia.

How can this be done?
A commitment by all major political parties to ensure that all older Australians including people living with dementia have access to high quality residential care. This could be achieved through:

1. Implementation of the Living Longer. Living Better proposal to publish quality indicators for all residential care facilities that are meaningful to all consumers
2. Linking dementia supplements in residential care to requirements for staff training, particularly on non-pharmacological approaches to managing behavioural symptoms of dementia
3. A commitment to reducing use of chemical and physical restraint including a target of reducing use of antipsychotic medications so that less than 10% of residents receive these medications by 2016

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\(^{17}\) Australian Institute of Health and Welfare (2011) Dementia among aged care residents: First information from the Ageing Care Funding Instrument. Aged care statistics series no. 32. Cat. no. AGE 63. Canberra


**ACTION 4 NATIONAL DISABILITY INSURANCE SCHEME AND AGED CARE**

**What is the issue?**
There are 24,400 Australians under 65 years of age who have dementia. These are people for whom access to appropriate care and support is extremely limited.

**What do we know?**
- There is a lack of awareness and understanding, even among health professionals that dementia can develop at any age.
- Individuals with younger onset dementia struggle to get access to appropriate services and support.
- Younger people with dementia face many issues that are different from those of older Australians with dementia including employment, dealing with the impact on young families and lack of access to age appropriate services.
- The needs of each younger person with dementia will vary greatly as there are a number of different diseases that can cause younger onset dementia and each is associated with different symptom profiles and progression.
- Individuals who receive a diagnosis of dementia before they turn 65 years of age will receive care and support that is funded through the National Disabilities Insurance Scheme and those over the age of 65 through aged care funding. There are differences between the aged care and disability systems in terms of philosophy, funding and objectives. There is a need to monitor issues around transition and interfaces between the two systems as well as monitoring equity and fairness.
- There is a need to respond to the agenda set by people living with younger onset dementia.

**What do we want to achieve?**
Access to appropriate services and support for all individuals with younger onset dementia and their families.

**How can this be done?**
A commitment by all major political parties to ensure that individuals with younger onset dementia have access to appropriate care and support. This could be achieved by:

1. Implementation of the recommendations from the *Younger Onset Dementia: A New Horizon* report with guidance from the Consumer Dementia Advisory Committee.
2. Continued funding and support for the younger onset dementia key worker program to work with service providers to establish, expand and develop flexible and age appropriate services for all people with dementia.
3. Development of a training program for the disability sector to up-skill workers on the specific needs of people with younger onset dementia.

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ACTION 5 DEMENTIA RESEARCH

What is the issue?
Understanding the causes of dementia and finding cures or ways to delay its progression will remain beyond reach without greater investment in research.

What do we know?

- By 2050 there will be almost 900,000 people with dementia\(^{24}\)
- Dementia will become the third greatest source of health and residential aged care spending within two decades\(^{25}\)
- If the onset of Alzheimer’s disease could be delayed for five years, the number of people with dementia would be halved (between 2000 and 2040)\(^{25}\)
- Dementia research is grossly underfunded in relation to health and care costs, disability burden and prevalence compared to other chronic diseases\(^{26}\)
- In 2012-2013, the National Health and Medical Research Council allocated $21.5 million for dementia research compared with $162.4 million on cancer research, $93.6 million on cardiovascular disease research, $63 million on diabetes research and $55.1 million on mental health research\(^{27}\)
- Australia has some of the best dementia researchers in the world. These scientists have begun to respond to the challenge of dementia by forging ahead with innovation and world-leading breakthroughs in areas such as neuroimaging, stem cell therapies, neurogenesis and biomarkers
- New treatments to cure, prevent or delay dementia can only come from rigorous scientific research. Such research relies both on attracting and retaining the best and brightest scientists to the field, and on long-term investment in research programs from the government
- Australia has the scientific skills and capacity to fight dementia but further investment is urgently needed in order to develop new interventions and treatments

What do we want to achieve?
Reduce the future number of people with dementia.

How can this be done?
An additional $40 million investment per year for dementia research into cause, cure and care is required if we are to advance early intervention and find new treatments. This level of funding would be equivalent to a total research spend of about 1% of the total cost of dementia care.

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26 Alzheimer’s Australia, Paper Number 16, Australian Dementia Research: Current Status, Future Directions?, 2008
27 National Health and Medical Research Council (2013) Research and Funding statistics and data
ACTION 6 NATIONAL ACTION FRAMEWORK

What is the issue?
People with dementia struggle to get a timely diagnosis, receive poor care in hospitals and are often unable to access appropriate palliative care services at the end of their lives. Living Longer. Living Better. provides funding to address some of these issues, but more needs to be done.

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.\(^{28}\)
• Hospitals are often dangerous and confusing places for people with dementia. Many of them have no programs or services to meet the needs of individuals with dementia.\(^{29}\)
• Individuals with dementia generally stay in hospitals for longer and have a higher cost of care.\(^{30}\)
• Recent estimates suggest that approximately half of the individuals with dementia are not recognised as having dementia when they enter hospital. This often leads to inappropriate care and poor outcomes for the person with dementia.\(^{31}\)
• 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.\(^{32}\)

What do we want to achieve?
A health system that responds to the needs of people with dementia including those who come from a diverse background. The health system should ensure access to timely diagnosis, quality health care and appropriate end of life care for all people with dementia.

How can this be done?
The agreement of Health Ministers to a new National Action Framework on Dementia that includes funding for:
• A $5 million campaign to raise awareness of the symptoms of dementia and reduce the time between first noticing symptoms and seeking assistance from a doctor
• Inclusion of cognitive screening for the 75+ health check
• GP training program to assist with recognising the symptoms of dementia
• Cognitive screening for all patients over the age of 75 who are admitted for an overnight stay in hospital
• Identification of individuals in hospital who require additional support due to cognitive impairment and training for all staff on how to care for individuals with cognitive impairment
• Funding for services to avoid unnecessary hospitalisations including dementia specific palliative care services
• Services to ensure smooth transitions for older people between hospital care and returning to the community

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\(^{28}\) Alzheimer’s Australia (2011) Timely Diagnosis of Dementia: Can we do better?
\(^{29}\) AIHW (2013). Dementia Care in Hospitals- Forthcoming
\(^{30}\) Alzheimer’s Australia (2011) Timely Diagnosis of Dementia: Can we do better?
\(^{31}\) Alzheimer’s Australia (2011) Timely Diagnosis of Dementia: Can we do better?
\(^{32}\) Alzheimer’s Australia (2012). Submission to the Senate Community Affairs Committees Inquiry into Palliative Care in Australia.