FIGHT DEMENTIA CAMPAIGN ELECTION 2013
UPDATED JULY 2013

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MESSAGE TO CANDIDATE

Dementia is the public health challenge of the 21st century. More than 321,000 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 leading cause of death of Australians and there is no cure. Currently 1,700 cases are diagnosed each week – that’s one person every six minutes. This figure is expected to rise to 7,400 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 Area.

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 institutionalisation 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.

I am pleased that Carers Australia supports these priorities. Market Research done for Alzheimer’s Australia suggests that 1.2 million Australians provide some level of care for a person with dementia. It is imperative that carers have access to flexible and appropriate respite, as well as counselling and other support.

On behalf of people with dementia and their families, I ask that you publicly commit yourself to this cause by becoming a dementia champion. 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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This document is supported by:
ACTION PLAN

KEEPING THE SPOTLIGHT ON DEMENTIA

On 20 April 2012, in response to the Fight Dementia Campaign, former Prime Minister Julia Gillard, and the former 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 Health Ministers to make dementia a National Health Priority Area.

These initiatives recognise that dementia is the major health problem of this century.

![Projected Dementia Prevalence in Australia 2013-2050](image-url)
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 1,700 new cases of dementia in Australia. This figure is expected to grow to 7,400 new cases each week by 2050¹
- Almost 25,000 Australians have Younger Onset Dementia (onset before 65); some of them in their 30s²
- There are more than 321,000 Australians living with dementia today³ and an estimated 1.2 million Australians who support them⁴
- 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 2050⁵
- Dementia is the third most common cause of death⁶
- Dementia costs at least $4.9 billion each year through the health and aged care systems⁷ and within 20 years will become the third greatest source of health and residential aged care expenditure⁸

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

1. Increasing choice and flexibility in community care to ensure all older Australians have a choice about where they receive care
2. Developing 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. Developing a national network of dementia key workers to support individuals with dementia of all ages
5. Investing $200 million in dementia research over the next five years
6. Establishing a National Action Framework on dementia that will result in a health system better equipped to respond to the needs of people with dementia

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⁴ Alzheimer’s Australia, (2011) Pfizer Health Report Issue #45 – Dementia, Pfizer Australia.
ACTION 1  INCREASE CHOICE & FLEXIBILITY IN 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 a 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.
- 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.

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. 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

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 people to be supported in the community for longer. Unfortunately, people 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.14
- Dementia carers are 10 times more likely than other carers to say they need respite but have not used it.15
- 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.16
- Carers report that once the person with dementia develops behavioural symptoms or becomes incontinent, service providers refuse to continue supporting them.17 These are often the times when family carers are most in need of respite
- 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.18
- 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
- There is some uncertainty about how respite will be provided under DisabilityCare. There is concern that in some cases carers will not have access to this important service

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. Ensuring carers continue to have access to respite services under DisabilityCare
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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**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\(^{19}\) 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\(^{20}\).
- Approximately 25% of individuals in residential aged care are given antipsychotic medication, often as a form of chemical restraint\(^{21}\).
- Risks of antipsychotics mean that thousands of people with dementia are dying prematurely each year as a result of this treatment\(^{22}\).
- Consumers report that aged care facilities often do not have sufficient numbers of trained staff to provide quality care to people with high care needs such as those with behavioural and psychological symptoms of dementia\(^{23}\).

**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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\(^{19}\) 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.


**ACTION 4 NATIONAL DEMENTIA KEY WORKER PROGRAM**

What is the issue?
People living with dementia have difficulty in navigating the service system and getting access to appropriate care and support when it is most needed.

What do we know?
- A recent survey by Alzheimer’s Australia of people with dementia and their carers found that over 50% of families reported not having received any referrals after diagnosis, and only 39% were told of the support services available at Alzheimer’s Australia.
- The Government has recognised a need for a key worker program to support individuals with younger onset dementia and as part of the *Living Longer. Living Better* reforms has funded 40 key workers across Australia to support people with younger onset dementia.
- Consumers have repeatedly called for a national key worker program for all people with dementia to assist in providing support from the point of diagnosis.
- 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.
- The recent House of Representatives 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 key worker approach to dementia care has been successfully implemented in a number of countries including the UK and the Netherlands.
- International research has shown that key worker 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.

What do we want to achieve?
Access to appropriate services and support for all individuals with dementia and their families from the point of diagnosis.

How can this be done?
A commitment by all major political parties to a national key worker program managed by Alzheimer’s Australia which will support individuals with dementia of all ages. The program would be implemented gradually over 5 years, with total investment of $118 over five years. The funding would start at $8 million in the first year increasing to $40 million in year 5.
**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.

Recent initiatives such as the NHMRC Partnership Centre on Cognitive Decline, and additional NHMRC dementia research grants are welcome, but more needs to be done.

**What do we know?**
- By 2050 there will be almost 900,000 people with dementia. 31
- Without new interventions or treatments, over 3 million Australians will develop dementia between 2013 and 2050. More than 2 million of these people will die as a result of the condition during this time. 32
- If new interventions to delay the onset of dementia by five years were developed by 2020, almost 1 million people would be spared from developing dementia by mid-century. 33
- Dementia research is grossly underfunded in relation to health and care costs, disability burden and prevalence compared to other chronic diseases. 34
- 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, and $63 million on diabetes research. 35
- Australia has some of the best dementia researchers in the world who are responding 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?**
An Australian dementia research workforce with the capacity to develop new interventions and treatments, develop better models of care, and reduce the number of Australians with dementia in the future.

**How can this be done?**
An additional $40 million investment per year for dementia research to support new and early career researchers, fund high priority research, and support vital research infrastructure.

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34 Alzheimer’s Australia, Paper Number 16, Australian Dementia Research: Current Status, Future Directions?, 2008
35 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 approximately half of people with dementia are ever diagnosed. For those who are diagnosed, the average time between first symptoms and diagnosis is over three years.\(^{36}\)
- Hospitals are often dangerous and confusing places for people with dementia. Many have no programs or services to meet the needs of individuals with dementia.\(^{37}\)
- Individuals with dementia generally stay in hospitals for longer and have a higher cost of care.\(^{38}\)
- Recent estimates suggest that dementia was not recorded as a diagnosis in almost half of the hospital stays of people with dementia. This often leads to inappropriate care and poor outcomes for the person with dementia.\(^{39}\)
- 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.\(^{40}\)

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
- Programs to improve timely diagnosis including the Inclusion of cognitive screening for the 75+ health check and a GP training program to assist with recognising the symptoms of dementia
- 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
- 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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\(^{36}\) Alzheimer’s Australia (2011) Timely Diagnosis of Dementia: Can we do better?  
\(^{37}\) Australian Institute of Health and Welfare (2013). Dementia Care in Hospitals- Forthcoming  
\(^{38}\) Alzheimer’s Australia (2011) Timely Diagnosis of Dementia: Can we do better?  
\(^{39}\) Alzheimer’s Australia (2011) Timely Diagnosis of Dementia: Can we do better?  
\(^{40}\) Alzheimer’s Australia (2012). Submission to the Senate Community Affairs Committees Inquiry into Palliative Care in Australia.