

FIGHT DEMENTIA CAMPAIGN

**FIGHT ALZHEIMER'S
SAVE AUSTRALIA**
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CAMPAIGN BRIEF: WHY DO WE NEED ACTION ON DEMENTIA?

Changes in Government Policy

The Government has terminated the Dementia Initiative and risks squandering 6 years of investment.

The Dementia Initiative - Making Dementia a National Health Priority was implemented in the 2005 Federal Budget with \$320 million in funding over 5 years. **At the end of 5 years both major parties supported continuing the Initiative.**

The Dementia Initiative was a landmark for people living with dementia because it recognised the scale of the problem and its impact on the quality of life of Australians.

The main elements of the Initiative included:

- High care dementia community packages;
- Dementia Care Essentials Training at the Certificate Level 3;
- Dementia Behaviour Management Advisory Service (services that provide advice to those in the community and residential care staff);
- The National Dementia Support Program managed by Alzheimer's Australia which provides information, counselling and support;
- Funding for the Dementia Collaborative Research Centres;
- Community support grants (grants of up to \$50,000 to community groups); and
- Funding initiatives such dementia research grants and consultancies on issues such as dementia pathways, primary care and a communications strategy.

Has the Initiative been effective?

The Government has no evidence to justify terminating the Dementia Initiative.

The Dementia Initiative has been independently evaluated and was found to have made a substantial contribution to support people living with dementia and their carers. The Dementia Initiative lifted the profile of dementia by making it a National Health Priority and developing a coordinated policy response. Australia was the first country in the world to make dementia a health priority and gave Australia a chance to be a leader in this field.

The investment in the Dementia Initiative should be built upon to further improve the quality of dementia care through training, Dementia Behaviour Management Advisory services and getting research into practice. Moreover there are important issues that have been neglected and require urgent attention - issues such as timely diagnosis of dementia, making hospitals safer places for people with dementia, dementia risk reduction and cutting edge research into the cause of dementia.

Has the Productivity Commission on Care for Older Australians recognised the impact of dementia on the care system?

The Commission has ignored dementia as the core business of aged care. There is not a single recommendation that addresses dementia or acknowledges the additional costs of caring for individuals with dementia at home or in residential care. Alzheimer's Australia supports the strategic direction of the aged care reforms as they are based on increased choice and options for receiving care at home. However, the Commission has made no recommendations to promote awareness of dementia; to assist those with severe Behavioural and Psychological Symptoms of Dementia (BPSD); to greatly expand access to respite care that meets the needs of people with dementia as well as those of carers; or to recognise the importance of dementia training and education for formal and informal carers if the quality of dementia care is to improve. There is no vision for investment in dementia research or risk reduction.

FIGHT DEMENTIA ACTION PLAN

DEMENTIA IS A HEALTH PRIORITY

Dementia will be the major health problem of this century.

Over one million Australians are already affected by the disease themselves or are caring for a person with dementia.¹ Too many Australians do not understand that dementia is a chronic disease and not a natural consequence of old age. Australia can beat dementia if we tackle it the same way as we have heart disease and cancer.

The case for action to combat dementia over the next 10 years is overwhelming.

- Each week, there are 1,600 new cases of dementia in Australia. That is expected to grow to 7,400 new cases each week by 2050.²
- There are almost 280,000³ Australians living with dementia today and over one million Australians provide support for them.¹
- Dementia is the third most common cause of death.⁴
- Dementia costs the health system \$6 billion per annum and will become the third greatest source of health and residential aged care expenditure within 20 years.⁵

Dementia will affect everybody's lives in one way or another. There will be nearly one million people with dementia by 2050 – the equivalent of a city three times the size of Canberra. That is the world we will face in 2050.

We need Government to restore dementia as a health priority now and to invest in action to combat the dementia epidemic.

Alzheimer's Australia wants the 2012/13 Federal Budget to allocate an extra \$500 million over the next 5 years to:

- 1. Promote awareness of dementia**
- 2. Achieve timely diagnosis of dementia**
- 3. Provide quality dementia care in community, residential and acute care settings**
- 4. Reduce the future numbers of people with dementia**
- 5. Make Australians aware they may be able to reduce their risk of dementia**

¹ Pfizer Health Report Issue #45 – Dementia, March 2011

² Keeping Dementia Front of Mind: Incidence and prevalence 2009 – 2050, Access Economics, August 2009

³ Dementia Across Australia: 2011-2050, Deloitte Access Economics, September 2011

⁴ Causes of Death, Australia, 2009, Australian Bureau of Statistics, May 2011

⁵ The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, Access Economics 2003

RESTORE DEMENTIA AS A HEALTH PRIORITY THROUGH THESE ACTIONS:

Awareness Reduce the stigma and social isolation that result from dementia

Fund a two year, \$15 million information campaign to tackle community ignorance of dementia.

Diagnosis Reduce the time between the first signs of memory loss to diagnosis

Invest \$53 million over five years to address barriers to timely diagnosis by employing specialist dementia nurses and providing training and education programs for doctors and nurses.

Care Improve access to quality dementia care and support services

Invest \$228 million over five years to:

- Support service staff and family carers through expanded training and Dementia Behaviour Management Advisory Services.
- Fund an integrated suite of services to assist people with dementia and family carers with information, support, education, counselling and access to services.
- Develop systems to make hospitals safer places for people with dementia by increasing recognition of those with dementia and improving coordination and support systems.
- Improve access to services for individuals with younger onset dementia.
- Ensure access to support and services for individuals who have severe behavioural and psychological symptoms of dementia.

Research Reduce the future number of people with dementia

An additional \$40 million investment per year into dementia research is required if we are to find new treatments and better ways to manage the disease. This would be equivalent to a total research spend of about 1% of the total cost of dementia care.

Risk Reduction Reduce the risk of dementia for Australians

Fund a \$4 million public education campaign to make Australians aware that they may be able to reduce their risk of dementia both by management of other chronic diseases which increase the risk of dementia (e.g. stroke, diabetes, hypertension, obesity) and by changes in lifestyle including social and mental activity, nutrition and physical exercise.

We can fight dementia and improve the present and future quality of life of all Australians.

ACTION 1 – AWARENESS

What is the Problem?

Many Australians know very little about what dementia is or how it develops. This lack of awareness means that some people may not seek help when they experience symptoms of dementia. There is confusion around the disease which can lead to fear and stigma.

What do we know already?

- 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.⁶
- Dementia is the third leading cause of death in Australia, yet most Australians are not aware that it is a terminal illness.⁶
- Two out of three Australians are scared of developing dementia - a fear second only to the fear of developing cancer.⁶
- 56% of carers report that people with dementia are discriminated against.⁶
- Almost a third of Australians say that they would feel uncomfortable spending time with someone with dementia.⁶
- 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.⁷
- In a recent pilot survey about stigma and dementia:⁷
 - 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 experience feelings of shame.

What do we want to achieve?

Reduce the stigma and social isolation that result from dementia

This would mean that:

- Australians would not avoid spending time with people who had dementia and would not anticipate feeling shame if diagnosed with dementia.
- All Australians would know the symptoms of dementia, including symptoms other than memory problems and where to seek assistance if they experience symptoms.
- The community would be aware of the Government's comprehensive strategy to address dementia.

How can this be done?

Fund a two year, \$15 million information campaign to tackle community ignorance of dementia. This campaign would include social marketing, national advertising, community engagement, and education activities to raise awareness about dementia.

⁶ Pfizer Health Report Issue #45 – Dementia, March 2011

⁷ Unpublished report. University of Wollongong

ACTION 2 – DIAGNOSIS

What is the Problem?

Only a 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. Timely diagnosis is important as it enables better management of the disease and allows families to access support and plan for the future.

What do we know already?

- 94% of Australians say that if they were worried about their memories they would see their GP.⁸
- GPs often do not complete a full assessment as suggested in the guidelines.⁹
- Early symptoms of younger onset dementia are often misdiagnosed as depression or anxiety.
- There are a number of barriers to early diagnosis in primary care and these include:¹⁰
 - A belief that there is no benefit to timely diagnosis;
 - Difficulties in differentiating normal ageing from dementia;
 - GPs lack of confidence or knowledge and risk of misdiagnosis;
 - A lack of appropriate specialist diagnostic services, especially in rural areas;
 - Limited time and lack of an effective time-efficient screening tool;
 - Perception that the patient cannot comprehend/cope with the diagnosis; and
 - Fear of damaging the doctor-patient relationship.

What do we want to achieve?

Reduce the time between the first signs of memory loss and diagnosis

We want to achieve a reduction in average time between the first appearance of symptoms and the diagnosis of dementia from 3.1 years to 12 months. We also need to ensure that individuals with dementia are provided with appropriate referrals and support.

How can this be done?

Invest \$53 million over five years to address barriers to timely diagnosis by employing specialist dementia nurses and providing training and education programs for doctors and practice nurses. This should be supported by two additional actions:

1. Bring the Department of Health and Ageing together with medical and consumer stakeholders to determine strategies to achieve timely diagnosis.
2. Link diagnosis and management of dementia into the current health reform process by acting on the strategies identified through the reform of Primary Care and mandating that Medicare Locals include diagnosis and management of dementia as part of their reporting framework and needs assessment.

⁸ Market research conducted for Alzheimer's Australia by Newspoll September 2004

⁹ Williams J., Byrne J., Pond, D (2006). DCRC Summary: Dementia Identification, Assessment and Management in Community- Based Primary Health Care: A review of the international literature 1995-2006.

¹⁰ Brodaty (2005). DCRC: Six Reasons Why Early Diagnosis of Dementia Does Not Occur and Ten Reasons Why It Is Important

ACTION 3 – DEMENTIA CARE

What is the Problem?

There is an urgent need to improve the quality of dementia care and ensure sustainable support and care services for all individuals with dementia.

What do we know already?

- Alzheimer's Australia struggles to meet the increasing demand for information, counselling and support services.
- Individuals with dementia and their families are often unable to find appropriate aged care services that are flexible and respond to their needs.
- Aged care staff need support to provide quality dementia care through training programs and services such as the Dementia Behaviour Management Advisory Service (DBMAS).
- DBMAS combines expertise in dementia care and the translation of knowledge to service providers in both the management of individual cases and through training.
- With the number of people with dementia set to increase by almost 50% over the next 10 years, there will be a greater demand on support services for individuals with dementia and training programs for care staff.
- 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.
- Funding for the Dementia Initiative, which provides essential counselling and support programs, training and the DBMAS will be terminated as of 2013.
- After 2013 there will be no coordinated Government approach to address the care needs of people with dementia.
- The final report of the Productivity Commission failed to acknowledge in the recommendations that dementia is core business of aged care.

What do we want to achieve?

Improve access to quality dementia care and support services

How can this be done?

Invest \$228 million over five years to:

- Support service staff and family carers through expanded training and Dementia Behaviour Management Advisory Services.
- Fund Alzheimer's Australia to provide an integrated suite of services to assist people with dementia and family carers with information, support, education, counselling and access to services.
- Develop systems to make hospitals safer places for people with dementia by increasing recognition of those with dementia and improving coordination and support systems.
- Develop appropriate services for those with younger onset dementia and for those with severe behavioural and psychological symptoms of dementia.

ACTION 4 – RESEARCH

What is the problem?

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

What do we know already?

- By 2030 there will be 553,000 people with dementia.¹¹
- Dementia will become the third greatest source of health and residential aged care spending within two decades.
- If the onset of Alzheimer's disease could be delayed by five years, the numbers of people with dementia would be halved (between 2000 and 2040).¹²
- Dementia research is grossly underfunded in relation to health and care costs, disability burden and prevalence compared to other chronic diseases.¹³
- In the 2010-11 financial year, National Health and Medical Research Council research funding for chronic diseases was \$144 million for cancer, \$97.4 million for research on cardiovascular disease, \$63.1 million for diabetes. Alzheimer's disease and other types of dementias received only \$19.3 million.¹⁴
- 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 innovative 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 we just need the Federal Government to invest.

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 into dementia research is required if we are to find new treatments. This would be equivalent to a total research spend of about 1% of the total cost of dementia care.

¹¹ Dementia Across Australia: 2011-2050, Deloitte Access Economics, September 2011

¹² Access Economics (2004) Delaying the Onset of Alzheimer's Disease: Projections and issues, Report for Alzheimer's Australia, Canberra, September.

¹³ Alzheimer's Australia, Paper Number 16 – Australian Dementia Research: Current Status, Future Directions?, 2008

¹⁴ NHMRC: Research funding statistics and data: Accessed 1 June 2011: <http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data>

ACTION 5 – DEMENTIA RISK REDUCTION

What is the Problem?

There are ways of reducing the risk of dementia through lifestyle changes and vascular risk factor management but most Australians are unaware of these factors.

What do we know already?

- There is now good evidence that we can reduce our risk of dementia by taking control of alcohol use, blood pressure, body weight, cholesterol, depression, diabetes, diet, head injury, mental activity, physical activity, smoking and social activity.
- Only 50% of Australians believe that it is possible to reduce the risk of developing Alzheimer's disease and other forms of dementia.¹⁵
- Even among those who are aware there is something they can do to reduce risk, most are only aware of the benefits of staying mentally active.¹⁵
- There is very little understanding of the links between physical and mental health. For example, approximately 80% of Australians are not aware of the potential benefits of reducing high blood pressure, cholesterol and avoiding head injuries.¹⁵
- It has been estimated that half of all cases of Alzheimer's disease (the most common form of dementia) could be attributed to modifiable risk factors.¹⁶
- It is also estimated that significant numbers of dementia cases could be prevented by addressing risk factors. For example, around 100,000 fewer Australians would have dementia in 2050 if physical inactivity rates were reduced by 5% every 5 years.¹⁷
- The modifiable risk factors for dementia overlap with many other chronic diseases such as heart disease and diabetes.
- Some chronic diseases such as diabetes are themselves risk factors for dementia.
- Alzheimer's Australia has developed and successfully implemented the first stage of the Mind Your Mind® public education program which provides information on ways to reduce risk for dementia.

What do we want to achieve?

Reduce the risk of dementia for Australians

How can this be done?

Fund a \$4 million public education campaign to make Australians aware that they may be able to reduce their risk of dementia both by management of other chronic diseases which increase the risk of dementia (e.g. stroke, diabetes, obesity) and by changes in lifestyle including social and mental activity, nutrition and physical exercise.

¹⁵ Pfizer Health Report Issue #45 – Dementia, March 2011

¹⁶ Barnes & Yaffe (2011). The projected effect of risk factor reduction on Alzheimer's disease.

¹⁷ Binod, Brown & Ranmuthugala. (2010). Modelling the impact of modifying lifestyle risk factors on dementia prevalence in Australian population aged 45 year and over, 2006-2051