

MODELLING THE IMPACT OF INTERVENTIONS TO DELAY THE ONSET OF DEMENTIA IN AUSTRALIA

**A REPORT FOR
ALZHEIMER'S AUSTRALIA**

PAPER 30

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FURTHER INFORMATION

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FOREWORD

Dementia is one of the major health issues facing Australia in the 21st Century.



We know that without new ways to delay, prevent or even cure dementia, there will be about 900,000 Australians with dementia by 2050. The economic and social impacts will be enormous in terms of costs in the health and aged care systems, and on the quality of life of millions of Australians and their families and friends.

This modelling provides further evidence to support the magnitude of the dementia epidemic. Without treatments and interventions, the analysis in this report suggests more than three million Australians will develop dementia between 2012 and 2050. Almost all of them will be people who are in their 30s, 40s, 50s or 60s today.

There is an opportunity to face the future now and invest in research.

If we can introduce an effective intervention or treatment to delay the onset of dementia by just five years – from an average age of 85 to an average age of 90 – close to one million people would be spared from the personal tragedy of a diagnosis of dementia.

Given that dementia is the condition Australians fear second only to cancer, an extra five years of cognitively healthy life and an increased chance of living into our 80s and 90s without a diagnosis of dementia is something we would all welcome.

In the short term we may be able to reduce our risk of dementia by better protecting our brain through the lifestyle changes that we know may help. In September 2012, Alzheimer's Australia with funding from the Commonwealth Government launched Your Brain Matters, the world's first publicly-funded national dementia risk reduction program, to help people work towards this goal.

In the longer term research offers hope in the development of medical interventions to delay, stop or even reverse the causes of the diseases that lead to dementia.

Progress in the development of medical therapies has been disappointing and slow. In part this reflects the need for a better understanding of the causes of dementia and when in the lifecycle to intervene. This demands a much a greater investment in dementia research.

Alzheimer's Australia commissioned this report to illustrate the potential research has to reduce the numbers of people with dementia. While Australia can claim many world leading scientists, the dementia research sector lacks capacity and has been falling behind other health research areas for over a decade.

Phase two of our Fight Dementia Campaign calls for an increased investment in dementia research of \$40 million per year over five years to bring dementia research up to the same level as other national health priority areas. This report illustrates what such an investment could achieve.

I would like to thank and acknowledge the authors from the Dementia Collaborative Research Centre for their work on this report, and Alzheimer's Australia Research Manager Dr Chris Hatherly for managing the project.

A handwritten signature in black ink, appearing to read 'Ita Buttrose', with a horizontal line underneath.

Ita Buttrose AO, OBE
President, Alzheimer's Australia
November, 2012

SUMMARY

The number of people with dementia throughout the world is increasing. In Australia, there are currently an estimated 311,000 people living with Alzheimer's disease or another form of dementia. Without new treatments or interventions to delay, slow or reverse the diseases that cause dementia, it is estimated that there will be close to 900,000 Australians living with the condition by mid-Century.

This paper reports findings of a dementia prevalence model that, for the first time, estimates the number of people who are likely to develop dementia in Australia between 2012 and 2050, as well as the potential impact of future interventions to delay the onset of the condition.

Specifically it estimates that:

- Without new treatments or interventions, over 3 million Australians will develop dementia in the 38 years between 2012 and 2050.
- An intervention that could delay the onset of dementia by 2 years, introduced in 2020, would reduce the cumulative number of people developing dementia between 2012 and 2050 by 13%, or 398,000 people.
- An intervention capable of delaying onset by 5 years, introduced in 2020 would reduce the cumulative number by almost one third, or 935,000 fewer people living with dementia than would be expected otherwise.

The possibility of enabling a large number of individuals to live dementia free lives has the potential to greatly improve the quality of life of both the individual and their family carer by freeing them from the care, stigma, loss and grief that a diagnosis of dementia brings.

There is the prospect too of avoiding the tens of billions of dollars of costs to the health and care system that would be required for their care.

The reduction in the number of people with dementia is dependent upon interventions that would successfully delay the onset of dementia. This will not come about without research. There is now evidence to support behavioural and lifestyle interventions that promote physical exercise, healthy diet, mentally and socially stimulating activities and management of other medical conditions as a means to reducing dementia risk at a population level. While progress has been slower and more difficult than once hoped in the development of pharmaceutical treatments, new medicines to delay or slow the progress of the major diseases that lead to dementia are currently under trial.

BACKGROUND

The personal, social and financial burden of dementia in Australia is increasing as the population ages. Recent estimates place the current prevalence of dementia at 311,000¹ and in the absence of any intervention or treatment strategy, this number is predicted to rise to almost 900,000 by 2050. Despite the considerable impact dementia is likely to have on future generations efforts to slow or prevent the disease process have been limited or unsuccessful.²

This may be due in part to the focus of clinical trials on participants in the later and symptomatic stages of the disease process when the brain has already been damaged. A number of studies have investigated the effect slowing the progression of dementia might have on the future dementia prevalence³⁻⁸, and have highlighted the positive impact even a small delay in onset could have on the overall numbers, as well as the social, financial and personal costs associated with the disease.

The development of such interventions is dependent on investment in research. For example, as diagnostic methods improve, the ability to detect and intervene in preclinical stages of dementia may facilitate earlier treatment and management, at which point they are more likely to be effective.⁹

The increasing understanding of the pathological and genetic bases of dementia may also allow for specific disease modifying and/or gene therapy approaches to dementia treatment.^{10,11}

Public health initiatives that create a greater awareness of the evidence that factors such as exercise, mental activity and healthy lifestyle and effective management of related conditions such as diabetes and heart disease may protect the brain against dementia.¹²⁻¹⁵

Computer modelling has been used to determine the impact of the slowing of the progression of dementia on future dementia prevalence. Table 1 describes the models that have been reported in the literature, and highlights the projected changes in prevalence under two commonly used onset delay scenarios: 2 and 5 years.

Any modelling exercise necessitates a number of assumptions which often vary from one model to the next. Nonetheless, the modelling undertaken by different analysts over the last ten years in respect of the potential impact of dementia interventions supports a general consensus that a delay of approximately 2-years in onset could result in a significant reduction in disease prevalence of around 20% over the next 30-40 years, and a 5-year delay in onset could achieve a 40-50% reduction in a similar timeframe.

The relevant studies are shown in Table 1.

Table 1: Changes in prevalence associated with delaying onset of dementia by up to 5 years

Study	Study population	Study focus	Base prevalence	Base new cases	Delay onset	Reduction in prevalence relative to no delay	Reduction in new cases
Brookmeyer 1998 ³	U.S.	Alzheimer's	2.32m (1997)	360 000 (1997)	2yrs 5yrs	22.5% @ 2047 46.8% @ 2047	NA NA
Alzheimer's Association 2010 ⁴	U.S.	Alzheimer's	5.1m (2010)	NA	5yrs	43% @ 2050	NA
Brookmeyer 2007 ⁵	Worldwide	Alzheimer's	26.55m (2006)	NA	2yrs	21.4% @ 2050	NA
Jorm 2005 ⁶	Australia	Dementia	172,000 (2000)	NA	2 yrs 5yrs	20.5% @ 2050 43.7% @ 2050	NA NA
Access Economics 2004 ⁷	Australia	Alzheimer's	Na	NA	1.6yrs 4.8yrs	19.2% @ 2050 48.7% @ 2050	20% @ 2050 50% @ 2050
Vickland 2010 ⁸	Australia	Dementia	172,000 (2000) 232,000 (2010)	NA	2yrs 5yrs	16% @ 2040 37% @ 2040	NA

Most of these studies have assessed the impact of delayed onset on overall disease prevalence (i.e., the total number of people with a condition at a given time). What has not been examined is the potential effect of interventions on dementia incidence (i.e., the number of people who develop a condition within a given timeframe, usually 1 year). While useful in determining the overall impact of dementia on the health services, prevalence estimates say little about how the interventions are influencing the rate at which new people are developing disease.

The current study expands upon this literature by examining the cumulative percentage of new dementia cases between 2012 and 2050, as well as how this might be influenced by

interventions capable of delaying onset. To do this, the researchers utilised the Dementia Prevalence Model (DPM), a model based on conservative assumptions that have been used previously to assess overall disease prevalence, as well as the effect of interventions to delay the onset of dementia now and in the future.⁸ The DPM is based on system dynamics modelling, an accurate and easy to understand method where groups of people are represented as 'stocks' and their movement over time as 'flows'. In the current study, the researchers adapted the DPM to assess the likely impact of the delayed onset of dementia on the cumulative new cases of dementia under a scenario in which interventions to delay the onset of dementia between 1-5 years are implemented in 2020.

METHOD

The system dynamics stock-flow approach¹⁶ was used to model and test a hypothetical scenario regarding new cases of dementia in Australia between 2012 and 2050. As per previous studies,³⁻⁸ delays ranging between 1 and 5 years were modelled as reasonable estimates of the impact of future interventions.

DEMENTIA PREVALENCE MODEL FRAMEWORK

The framework of the model was developed in collaboration with experts in health informatics, psychiatry, and psychology. With input from these professionals, as well as through reviews of the dementia literature, key population demographics were identified and extracted. These included:

- Australian population estimates
- Relative risk of death associated with age, dementia, and comorbid health risks
- Incidence and prevalence rates of dementia in Australia and in other similar socioeconomic countries
- Type and severity of dementia in Australia
- Transition rates from mild to moderate, and moderate to severe dementia, defined according to published values^{17, 18}
- Survival times from onset of dementia, based on published values.^{19, 20}

Transition rates from mild to moderate, and moderate to severe dementia, defined according to published values^{17, 18}

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The AnyLogic development platform²¹ was used to build the model. The model consists of two linked modules: a computational logic module that represents populations and transitions, and a user interface module allowing parameter control during virtual experiments. In total seven major populations were defined. These were represented as an array of data associated with various states (e.g. age, gender, diagnosis state). Six of these populations represent people with diagnosed or undiagnosed mild, moderate and severe dementia, while the seventh represents people aged 60+ in the general population who do not have dementia.

A graphical form of this model is shown in Figure 1.

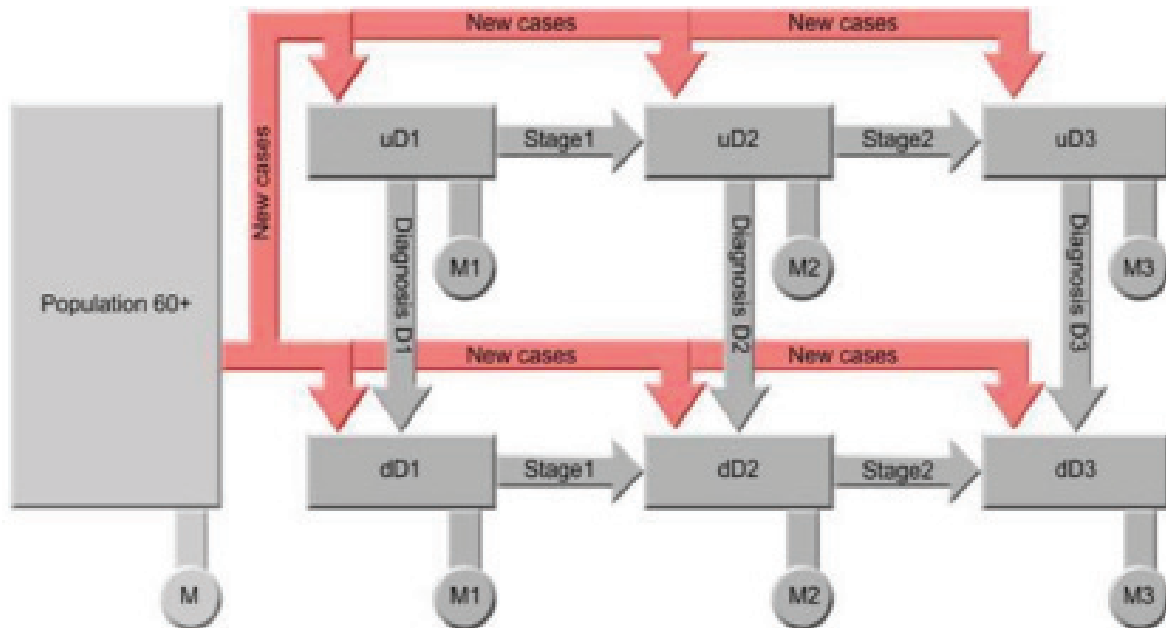


Figure 1: A diagram representing the building blocks of the DPM. uD = Undiagnosed dementia; dD = diagnosed dementia; 1 = mild; 2 = moderate; 3 = severe; M = mortality (diagram adapted from [18]).

COMPUTATIONAL LOGIC

Flows between populations represent rates of transition. These are displayed as the average number of years required for the disease to progress to a more severe stage. The current study altered these transition parameters in order to evaluate an impact of the delayed onset prevalence and cumulative new cases. Net flows of populations were determined from the following inflows and outflows (obtained from published values^{17, 18} unless otherwise stated):

- Ageing
- Births (calculated from fertility rates between 2001 and estimated 2018 values)
- Mortality (from mortality associated with age, diagnosis state and disease severity coupled with a global reduction factor estimated up to 2040)
- Net overseas migration (based on published 2001 values)
- New diagnosed cases based on assumed incidence rates specific to gender and age group (see Figure 2 of [8] and Table 1 of [21] for these values).

The number of people in each population was calculated by iterating calculations over time steps of one week. For each gender (g), each age (a), each diagnosis state (d), and each disease severity (s):

$population[g,a,d,s](0) = \{\text{initial statistics from 2001}\}$

$population[g,a,d,s](t) = population[g,a,d,s](t - 1) + net_flows[g,a,d,s]dt$

Each virtual experiment had explicit assumptions that were implemented during calibration of the virtual model. The same set of assumptions for future general population increases were used for all experiments.

SCENARIO: CUMULATIVE NEW CASES OF DEMENTIA FOLLOWING DELAYED ONSET STARTING IN 2020

An intervention was introduced at the start of 2020, and modelled to 2050. The efficacy of the intervention was assessed after delays in the onset of dementia by 1-5 years. Outcomes were compared to estimates of new cases in the absence of intervention over this time.

ANALYSIS

Virtual experiments were conducted using the DPM described previously. Parameter variation was used to test each hypothesis. Numerical data sets for each combination of parameters were collected after each experiment. New case projections were stored in a spreadsheet for further analysis.

RESULTS

A base model without any intervention, and starting to count new cases from 2012, estimated that there will be 396,000 cumulative new cases of dementia by 2020 and a prevalence (total number of cases in that year) of 356,000 in 2020, and 3,079,000 cumulative new cases of dementia by 2050 and a prevalence of 928,000 in 2050.

The intervention scenario based on an intervention introduced in 2020 estimated that with a delay in onset of 2 years, there would be a reduction of 13% or 398,000 cumulative new cases by 2050. With a delay in onset of 5 years, the cumulative number of new cases by 2050 would be reduced by 30% or 925,000 people. The total prevalence in 2050 under this scenario would be 788,000 with a 2 year delay (a reduction of 15%) and 604,000 with a 5 year delay (a reduction of 35%).

These and other delays are represented in Figure 2.

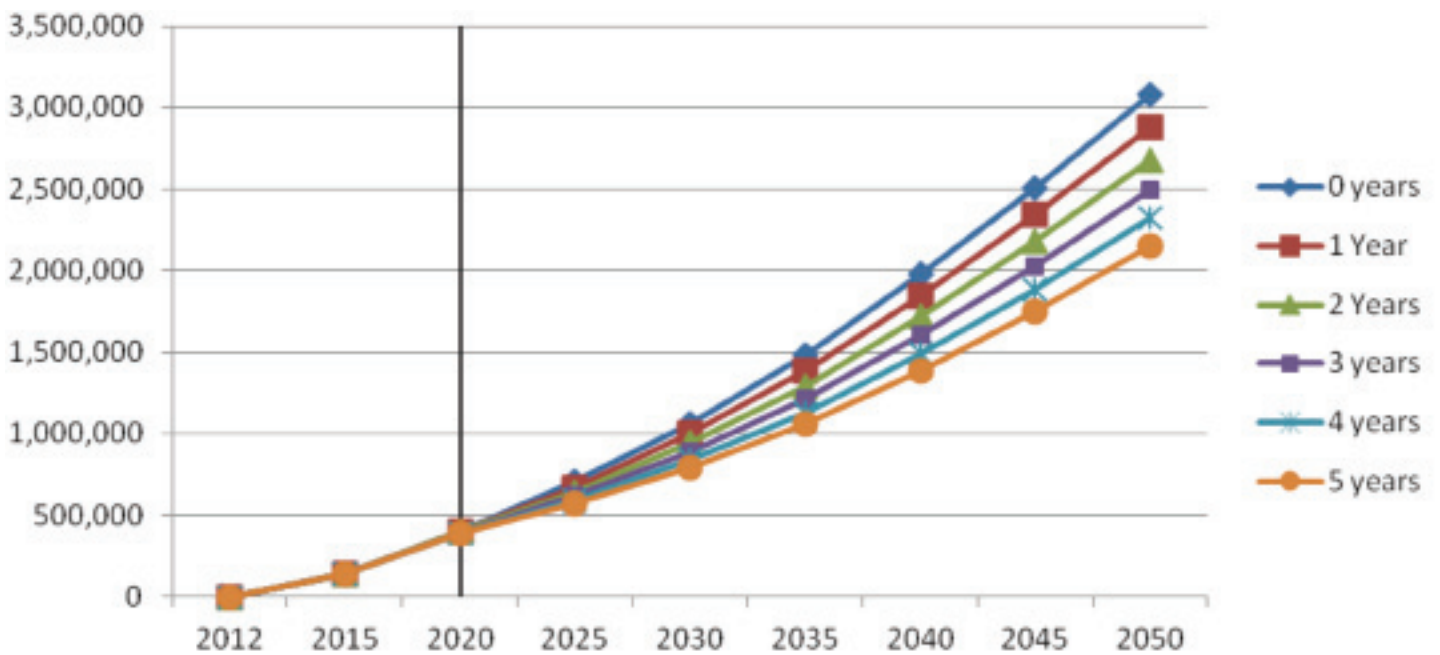


Figure 2: Changes in new cases of dementia due to the implementation of an intervention starting in 2020 resulting in various lengths of onset delay.

DISCUSSION

Dementia prevalence in Australia is rising, primarily because of the ageing of the population. On the basis of conservative assumptions about prevalence, incidence and mortality rates, this study estimates that without interventions to prevent, slow or delay the diseases that cause dementia there would be an estimated 925,000 people with dementia in Australia by 2050, and over 3 million people cumulatively who will develop dementia between 2013 and 2050.

The study also demonstrates the potential impact of possible interventions to delay the onset of dementia on future prevalence of the condition. If introduced in 2020, an intervention that could delay the onset of dementia by 5 years could potentially reduce the number of people with dementia in 2050 by 30%, and decrease the number of new cases of dementia between 2020 and 2050 by approximately 930,000.

Given the social, economic and health system costs associated with dementia,²³ the projected increase in dementia prevalence has serious implications globally. For example, the current cost of dementia to the Australian health and aged care sectors is at least \$4.9 billion per annum¹ and it is the single greatest cause of disability in older Australians (aged 65 years or older)²⁴ and the fourth leading cause of disability burden overall.²⁵ Dementia is projected to become the third greatest source of health and residential aged care spending within two decades, at around 1% of GDP, and by the 2060s, spending on dementia is set to outstrip that of any other health condition at \$83 billion (in 2006-07 dollars), or 11% of health and residential aged care sector spending.²⁵

Increasing numbers of people with dementia will place significant pressure on the aged care system in relation to both workforce and supply. Changes in workforce participation and family structures mean that there will be a likely shortfall of more than 150,000 paid and unpaid carers for people with dementia by 2029,²⁶ while projections of aged care supply suggest that as many as a quarter of a million people could be without a residential aged care place or community aged care package by 2050.²⁷

More specifically, Australia currently has approximately 185,000 operational residential aged care places and 51,000 community care packages.²⁸⁻⁹ By 2050, it is estimated that Australia will need an additional 660,000 places and packages to meet projected demand.²⁷ This is around 17,000 new packages and places each year; substantially more than the current annual increases in supply.

In response, policy makers and advocacy organisations are increasingly focussing on service delivery planning, and on research investment to develop effective interventions. In Australia for example, new funding of \$268 million for a range of new and expanded dementia services was announced as part of the *Living Longer. Living Better* aged care reform package, while an historic decision of Federal and State Health Ministers on 10 August, 2012, saw dementia become one of nine National Health Priority Areas. In America, President Obama signed the

National Alzheimer's Plan in early 2012 with a significant funding boost supporting an ambition to find effective ways to treat and prevent Alzheimer's disease by 2025.³⁰ France³¹ and the UK³² have also recently made significant commitments to increasing investment in dementia research and services.

Is an intervention capable of delaying the onset of dementia likely in the next decade? Research in a number of areas indicates that this may be a possibility.

A variety of new diagnostic technologies and protocols are being developed that will soon allow accurate clinical screening and diagnosis of presymptomatic dementia (prodromal Alzheimer's disease in particular) years or even decades before symptoms first appear.³³ It has now been widely accepted that the failure of numerous clinical trials of dementia medications over the past two decades has likely been compounded by the necessary focus on participants with clinically obvious dementia. These emerging technologies are heralding a new era of clinical trials that can target patients at much earlier stages of the condition, even before symptoms are apparent, when pharmaceutical intervention is much more likely to be effective.

Technologies that allow early diagnosis of conditions such as prodromal Alzheimer's disease will also allow for personalised behavioural and medical interventions targeting a range of risk factors that are known to be related to disease onset and very likely progression. Such interventions include treatment and management of medical conditions such as diabetes, hypertension and cardio-vascular disease, and behavioural changes such as smoking cessation, minimising alcohol consumption, and engaging in a healthy and socially active lifestyle.¹²⁻¹⁵

None of these developments will happen without research, and in competitive research funding environments, it is important that advocates and policy makers looking at ways of increasing research funding have at their disposal rigorous evidence that can inform and support decisions about costs and benefits. This study has added to this evidence base in dementia; providing information for the first time on the cumulative number of new cases of dementia projected over time, and the cumulative number of cases that could be prevented as a result of effective intervention.

This study builds on a number of previous studies in this area, including an earlier study that had estimated prevalence and potential prevalence reductions between 2000 and 2040 using

CONCLUSION

This study has, for the first time, estimated the cumulative number of new cases of dementia in Australia that might be expected in the first half of the 21st Century, and the number of new cases that might be avoided during that period as a result of interventions to delay the onset of dementia. The finding that as many as 30% of incident cases of dementia could be avoided emphasises the importance of prioritising funding for the dementia research that is required to make this happen.

the same computer model.⁸ Despite conservative estimates of prevalence, incidence and mortality rates, the prevalence projections relate closely to other relevant studies such as those by the Australian Institute of Health and Welfare (AIHW)¹ (projected 2050 prevalence: 891,400); Deloitte Access Economics³⁴ (projected 2050 prevalence: 943,000), AIHW¹⁷ (465,000 in 2031) and Vickland²² (742,000 in 2040).

It is also comparable to other studies that have modelled the impact of delaying onset on future prevalence numbers. Specifically, Access Economics⁷ estimated that delaying onset of Alzheimer's disease by 5 years from 2005 would decrease prevalence by 48.5% in 2040; Jorm and colleagues⁶ estimated that delaying onset of dementia by 5 years from 2000 would decrease prevalence by 44% in 2050; and Vickland et al⁸ estimated that delaying onset of dementia by 5 years between 2010 and 2040 would decrease prevalence by 37% in 2040. The study makes a new contribution by estimating the cumulative number of new cases and cases that could be saved over the projection period with an intervention to delay onset.

The study has a number of limitations. First, assumptions about dementia incidence, prevalence and mortality rates are based on limited and dated evidence, primarily from international studies, applied to Australian demographic data and projections. This is a limitation faced by all researchers in this field, and is insurmountable without large epidemiological studies of dementia in Australia. In addition, the models used cannot take into account the possibility of an increasing trend in life expectancy,³⁵ which, by the end of the projection period of 38 years could potentially offset a significant part of the impact of interventions to delay onset. Equally, however, they do not take into account the likelihood that new interventions would be developed, and existing interventions improved during the 38 years of the projection period. Finally, projections about the impact of an intervention to delay onset are limited by assumptions about the nature of such an intervention itself. Clearly, any such intervention would vary in effectiveness (from minimal lifestyle change that might delay onset by a few weeks to a treatment that could halt disease progression altogether), would interact with other factors, and would not be applied equally across the entire at-risk or incident population.

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- 4 Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities. November 2006.
- 5 National Dementia Manifesto: 2007-2010.
- 6 In Our Own Words: Younger Onset Dementia. February 2009.
- 7 National Consumer Summit on Younger Onset Dementia: Communiqué. February 2009.
- 8 Dementia: Facing the Epidemic. A Vision for a World Class Dementia Care System. September 2009.

These documents and others available on our website
www.fightdementia.org.au

**VISIT THE ALZHEIMER'S AUSTRALIA WEBSITE AT
WWW.FIGHTDEMENTIA.ORG.AU**

**FOR COMPREHENSIVE INFORMATION ABOUT
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MEMBER ORGANISATIONS**

**OR FOR INFORMATION AND ADVICE CONTACT
THE NATIONAL DEMENTIA HELPLINE ON**

1800 100 500

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