



# **ECONOMIC COST OF DEMENTIA IN AUSTRALIA**

## **2016-2056**

Report Prepared for Alzheimer's Australia  
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# ABOUT NATSEM AT THE INSTITUTE FOR GOVERNANCE AND POLICY ANALYSIS

The National Centre for Social and Economic Modelling (NATSEM) was established on 1 January 1993, and supports its activities through research grants, commissioned research and longer term contracts for policy analysis and model development and maintenance. In January 2014, the Institute for Governance and Policy Analysis (IGPA) at the University of Canberra was established to harness the research strengths of NATSEM and the ANZSOG Institute for Governance (ANZSIG). The aim of this Institute is *to create and sustain an international class research institution for the study and practice of governance and public policy*. The Institute has a strong social mission committed to the production of leading edge research and research driven education programs with genuine public value and, by implication, policy impact. The integration of ANZSIG and NATSEM has created exciting opportunities for the development of cutting edge research in public policy analysis through combining expertise in qualitative and quantitative methods, micro-simulation and policy modelling and evaluation.

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# FOREWORD

In the absence of a significant medical breakthrough, more than 6.4 million Australians will be diagnosed with dementia in the next 40 years, at a cost of more than \$1 trillion.

We cannot ignore the significant impact of this insidious disease on the people who are living with dementia, their carers and families, the Health and Aged Care systems and the Australian economy as a whole.

*The Economic Cost of Dementia in Australia 2016-2056*, commissioned by Alzheimer's Australia and developed by NATSEM, provides a comprehensive overview of dementia in Australia to inform future dementia policy, treatment, care and research.

In 2015, all Australian Governments signed the National Framework for Action on Dementia 2015-2019. The Framework outlines comprehensive key action areas, which must now be progressed in order to achieve a meaningful reduction in dementia over the coming decades and improve treatment and care options for the more than 400,000 Australians currently living with dementia, to continue to live engaging, meaningful, pre-diagnosis lives.

In recent years, there has also been a real and concentrated effort on bolstering dementia research at home and abroad in a bid to improve diagnosis, treatment, prevention and ultimately find a cure for dementia.

The impact of dementia is tremendous and will only endure should we choose to ignore what the staggering numbers in this report are telling us. Serious and urgent collective action is needed now, to combat or mitigate the impacts of dementia not only within Australia, but globally.

A whole of community approach and commitment to the implementation of a fully funded National Dementia Strategy is a vital next-step in a plan for dementia that:

- Promotes greater awareness and risk reduction
- Tackles the stigma and discrimination associated with dementia and supports social inclusion and participation
- Improves access to timely diagnosis and high-quality health care
- Provides care and support in the community that fosters independence, social engagement and effective support for informal carers
- Ensures access to high-quality residential care and publicly available information about consumer experience and quality of care
- Improves end-of-life care and support for people with dementia
- Commits to increased investment in dementia research

The National Dementia Strategy would take positive steps toward a 5% reduction in the number of people with dementia over the age of 65 that could lead to savings of \$5.7 billion from 2016-2025, and a staggering \$120.4 billion by 2056 and contribute to a global commitment to work toward a world without dementia.



**Professor Graeme Samuel AC**  
**Alzheimer's Australia National President**

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A range of data sources were used to generate the epidemiological and economic estimates and projections presented in this report, including national survey data from the Australian Bureau of Statistics, health datasets held by the Australian Institute for Health and Welfare and unit record data from the Household, Income and Labour Dynamics in Australia (HILDA) survey. The findings and views reported here are those of the authors and should not be attributed to the custodians or owners of the data that was used.

# ABBREVIATIONS

<b>ABS</b>	Australian Bureau of Statistics
<b>ACAP</b>	Aged Care Assessment Program
<b>ACAS</b>	Aged Care Assessment Service
<b>ACAT</b>	Aged Care Assessment Team
<b>ACFI</b>	Aged Care Funding Instrument
<b>ADI</b>	Alzheimer's Disease International
<b>ADL</b>	activity of daily living
<b>AIHW</b>	Australian Institute of Health and Welfare
<b>ALOS</b>	average length of stay
<b>BEACH</b>	Bettering the Evaluation and Care of Health
<b>CACP</b>	Community Aged Care Package
<b>CCC</b>	Community Care Census
<b>CDR</b>	Clinical Dementia Rating
<b>CURF</b>	confidentialised unit record file
<b>DAE</b>	Deloitte Access Economics
<b>DALY</b>	disability-adjusted life year
<b>DBMAS</b>	Dementia Behaviour Management Advisory Service
<b>DRG</b>	Diagnosis Related Group
<b>DYNOPTA</b>	Dynamic Analyses to Optimise Ageing
<b>EACH</b>	Extended Aged Care at Home
<b>EACHD</b>	Extended Aged Care at Home Dementia
<b>GP</b>	general practitioner
<b>HACC</b>	Home and Community Care
<b>HDS</b>	Hospital Dementia Services
<b>ICD-10-AM</b>	International Statistical Classification of Diseases and Related Health, 10th revision, Australian Modification
<b>MBS</b>	Medicare Benefits Schedule
<b>MMSE</b>	Mini-Mental State Examination
<b>NHCDC</b>	National Hospital Cost Data Collection
<b>NHMD</b>	National Hospital Morbidity Database
<b>NHPA</b>	National Health Priority Area
<b>NMD</b>	National Mortality Database
<b>PBS</b>	Pharmaceutical Benefits Scheme
<b>RACF</b>	Residential aged care facility
<b>RPBS</b>	Repatriation Pharmaceutical Benefits Scheme
<b>SDAC</b>	ABS Survey of Disability, Ageing and Carers
<b>YLD</b>	years lost due to disability
<b>YLL</b>	years of life lost



# EXECUTIVE SUMMARY

Alzheimer's Australia commissioned NATSEM at the Institute for Governance and Policy Analysis at the University of Canberra to estimate the cost of dementia in Australia. The economic impact of dementia is a major concern nationally and internationally as the number of individuals with dementia continues to rise. Access Economics (2003) estimated the total cost of dementia to be \$6.6 billion in 2002. **This report now shows that the cost of dementia in Australia in 2016 is \$14.25 billion, which equates to an average cost of \$35,550 per person with dementia.**

Not only does this report update the Access Economics 2002 estimate to 2016, it also projects likely future costs of dementia over the next 40 years. In doing so, it provides an overview of dementia in Australia, including increases in the prevalence and incidence of dementia over the next 40 years, describes some of the social and economic characteristics of people with dementia, and identifies the impact of dementia on mortality and burden of disease. The need for care and provision of care services is also reported on, including estimating the future need for both informal and formal carers in both the community and residential aged care sectors. The report models direct and indirect costs of dementia in 2016 out to 2056. The impact on costs of a 'hypothetical' intervention program that reduces the annual incidence of dementia by 5% is modelled. A second scenario simulates the impact of 'hypothetical' technological change in hospital care and its impact on costs.

## Methods

There is no consensus on how best to calculate all costs related to people with dementia with studies in the last 20 years applying various methods and techniques to estimate costs of dementia. A cost of illness (COI) approach is adopted in this report. The COI has been defined as the value of the resources that are expended or foregone as a result of a health problem. A COI includes:

- **direct costs** which can be regarded as the cost of 'resources' expended on the person with dementia. Direct costs can be either health and aged care related or non-medical expenses: typically out-of-pocket costs borne by individuals with dementia, their family or carers e.g. cost of transport;
- **indirect costs** which are usually seen in terms of the value of lost productivity by the person with dementia or their carer e.g. the foregone earnings of a person with younger onset dementia when they retire early from the workforce or those of a carer who reduces the number of hours worked in order to care for a person with dementia; and
- **intangible costs** which are non-material costs e.g. the cost of pain and suffering, emotional toll, stress, sadness, fear, exhaustion, social exclusion, impact on personal relationships and family including activities and use of time etc. These are typically excluded from economic analyses because intangible costs are better expressed in qualitative terms and do not lend themselves to be monetised. In this study, intangible costs have been captured by the 'burden of disease' concept which broadly divides impacts into non-fatal (living with dementia) and fatal (dying from dementia) effects.

The study uses a 'bottom up' approach where a per capita cost is estimated for different groups of people with dementia e.g. by first year of dementia and subsequent years, by disease severity and by care setting. These per capita costs are scaled up to the projected future population with dementia. The cost estimation uses econometric modelling of the latest available cost data and costing procedures and strategies found in the literature. All costs are expressed in 2016 dollars i.e. in constant dollar terms.

The methodology to estimate and project dementia prevalence in Australia was a standard demographic modelling approach in which age-sex dementia prevalence rates are applied to age-sex population projection estimates. The prevalence rates for older cases i.e. those aged 65+ years were derived from the pooled, harmonised, dataset from DYNOPTA reported by Anstey and colleagues (2010). The prevalence rates for the younger onset dementia age group were those used by AIHW in their 2012 report.

Projections of the general population over the 40 year period 2016-2056 were obtained from the ABS online services for the Population Projections by Region, 2012-2061, dataset using medium assumptions for fertility, mortality, and net migration. Annual age-sex rates of incidence of dementia were calculated from incidence-prevalence ratios used by AIHW (2012).

Data used in the report was drawn from a wide range of sources. This included the 2009 and 2012 ABS Survey of Disability, Ageing and Carers (SDAC); ABS statistics on cause of death 2015 and 2016; AIHW data from the National Aged Care Data Clearinghouse for information on residential aged care; the carers workforce census; and the Australian Burden of Disease study (AIHW, 2016). Data on the use and cost of prescribed medications used in the treatment of dementia was obtained from the Pharmaceutical Benefits Scheme online item reports. Information on rates, duration and costs of hospitalisation were obtained from AIHW's National hospital morbidity database and the Hospital Dementia Services Project, with the pricing of diagnostic related groups (DRGs) following the national pricing model specification of the National Weighted Activity Units (NWAU), provided by the Independent Hospital Pricing Authority (IHPA). Data from the Australian Government Welfare payments system for home care and aged care homes was used to estimate costs of care. With respect to calculating indirect costs, data from the latest wave (2014) of the Household, Income and Labour Dynamics in Australia (HILDA) survey was used to calculate average earnings from wages and salaries by gender and age groups.

## Dementia in Australia

- It was estimated that 400,833 persons with dementia were living in Australia in 2016 – 178,169 (44.4%) males and 222,664 (55.6%) females. With an annual growth rate of 3.8% in the prevalence of dementia for males and 2.5% for females, these numbers are expected to increase to 184,868 males (44.8%) and 228,238 females (55.2%) in 2017, giving the total number of persons with dementia in 2017 at 413,106 persons. The prevalence of dementia is projected to increase by 90% to 760,672 individuals over the next 20 years and 2.75 fold to 1,100,890 by 2056.
- Some 25,938 persons are estimated to be living with younger onset dementia in Australia in 2017. This number is expected to rise to 32,450 persons by 2036 and 42,252 persons by 2056.
- The number of persons with dementia in 2017 by jurisdiction is estimated to range from 1,663 individuals living in the Northern Territory to 138,721 persons living in New South Wales. The greatest percentage increase in the number of persons with dementia over the next 40 years is expected to occur in the Northern Territory followed by Western Australia.
- One in five individuals with dementia is from a cultural and linguistically diverse background. Aboriginal and Torres Strait Islanders have 3-5 times the risk of developing dementia than non-Indigenous persons. In 2016, there may be as many as 118,000 individuals with dementia living alone in the community.
- Currently around 244 persons are joining the population with dementia each day. The number of new cases of dementia is projected to increase to 451 people per day by 2036 and over 650 people per day by 2056.
- Dementia – as listed on death certificates – is now the second leading cause of death of Australians: contributing to 5.4% of all deaths in males and 10.6% of all deaths in females each year. However, deaths with dementia identified as the underlying cause of death on death certificates represent only 15% of all deaths in males with dementia and around 22% of all deaths in females with dementia.

## Caring for People with Dementia

- Around 83% of all males with dementia (148,224) and 71% of females with dementia (157,699) live in the community.
- Approximately 46% of those living in the community receive informal assistance only, 29% receive both informal and formal care, 16% receive formal assistance only and 9% no assistance at all.
- In 2016, some 29,945 males and 64,965 females with dementia lived in cared accommodation – 94% in residential aged care facilities. People with dementia represent just over half of all residents in RACFs and they tend to have much higher care needs than residents who do not have dementia.
- In 2017, there are an estimated 94,672 paid carers looking after people with dementia in the residential aged care setting, and 196,491 carers of people with dementia in the community, the majority of whom are informal carers.
- The projections suggest that by 2036 some 362,930 carers will be needed in the community and 173,225 carers working in the paid cared accommodation sector. The need for carers for people with dementia is expected to double by 2056 to around 525,540 carers in the community and 250,420 paid carers in residential aged care if current levels of care are to be maintained.

## Direct Costs of Dementia

- The total annual direct cost of dementia was estimated to be \$8.8 billion in 2016, which is expected to rise to \$9.1 billion in 2017. These costs consist of direct medical expenses (hospitalisation, GPs and specialists, pharmaceuticals) and direct non-medical expense of aged care (home care or nursing homes), transportation and other costs.
- Costs of hospitalisation and care costs are the largest components of direct costs of dementia, representing 52.6% and 37% of total direct costs respectively. The cost of hospitalisation of people with dementia was estimated to be \$4.6 billion and the cost of care \$3.3 billion in 2016, and \$4.8 billion and \$3.4 billion respectively in 2017.

- The direct costs of dementia are expected to rise to \$16.7 billion by 2036 and by 2.7 fold to \$24.1 billion by 2056 (in 2016 dollars). Costs of hospitalisation and the cost of care are projected to rise to \$8.8 billion and \$6.2 billion by 2036 and to \$12.6 billion and \$8.9 billion respectively by 2056.
- Costs at the person level differ by age and gender, the first versus subsequent years of dementia, severity of dementia and care setting. In 2016, per capita costs ranged from \$15,911 for a person aged <70 years who lives in the community with mild dementia to \$137,926 for a male aged 75-79 years living in residential aged care with severe dementia.
- In 2016, the average direct cost of dementia in the community was estimated to be \$45,393 per person within the first year of dementia compared with \$55,904 for a person with dementia living in residential aged care. The cost for subsequent years of dementia is estimated to be \$12,835 and \$23,810 per person respectively.

## Indirect Costs of Dementia

- Total indirect costs of dementia from the potential loss of income from lost productivity of people with dementia and their carers was estimated to be \$5.5 billion in 2016, and \$5.6 billion for 2017.
- In 2016, this comprised \$3.2 billion (59%) from the forgone earnings by carers and \$2.3 billion (41%) from the potential loss of income from people with dementia withdrawing from the workforce. In 2017, these costs are expected to increase by \$103 million and \$44 million respectively.
- The total indirect costs of dementia are expected to increase to \$9.1 billion by 2036 and more than double to \$12.8 billion by 2056.

## Burden of Disease

- Dementia is the second leading cause of burden of disease in men aged 85+ years and the leading cause of disease burden in women aged 85+ years.
- The disability associated with living with dementia (years lived with disability) and the premature mortality caused by the condition (years of life lost) now contribute equally to the total burden of disease from dementia.

## Total Costs of Dementia

- In 2016, the cost of dementia to Australia was \$14.25 billion which equated to an average cost of \$35,550 per person with dementia. In 2017, the total cost of dementia is expected to increase by 2.9% to \$14.67 billion in 2016 dollars.
- Direct costs such as the cost of hospitalisation, visits to GPs and medical specialists, care, pharmaceuticals, transport and other direct costs, contribute to 62% of the total costs of dementia, and indirect costs through the lost productivity of both persons with dementia and carers to 38% of total costs.
- By 2036, the total cost of dementia is predicted to increase by 81% to \$25.8 billion in today's dollars, and by 2056, to \$36.8 billion which represents a 2.6 fold increase in costs from 2016.

## Impact of Reduced Incidence of Dementia on Costs

The lifestyle risk and protective factors for dementia offer very real opportunities for prevention programs that reduce the number of Australians developing dementia each year. In this scenario, it is assumed that the annual age-sex incidence rates of dementia are reduced by 5% in people aged 65 years and above.

- This reduction in the incidence of dementia would lead to a 13% reduction in the number of persons with dementia in the population by 2036 and a 24% reduction by 2056 i.e. there would be 98,529 fewer people with dementia in 2036 and almost 261,000 fewer people by 2056 compared with the current projections of the prevalence of dementia over the next 40 years.
- Such an intervention would result in a total savings of \$26.8 billion in the costs of dementia over the next twenty years (comprising savings in direct costs of \$17.6 billion and indirect costs of \$7.2 billion) and a massive \$120.4 billion by 2056 (savings in direct costs of \$76.6 billion and indirect costs of \$43.8 billion).

## Impact of Reduced Hospital Costs from Technological Change

In this scenario it is assumed that the funding of future research will result in technological changes in the treatment of dementia which lead to reductions in the cost of hospitalisation of people with dementia. An impact is observed every five years and results in a 10% reduction in hospital costs.

- In the first two decades, under this scenario, the total direct costs of dementia increase from \$8.8 billion in 2016 to \$13.7 billion in 2036, compared with \$16.7 billion under the base case projection, giving a cumulative total savings of \$23.4 billion.
- With research funding bringing continuous technological improvements over the 40 years to 2056, the annual direct costs increase to \$16.9 billion by 2056, compared with \$24.1 billion for the base case projection. This generates a cumulative savings of \$122.2 billion over the 40 year period 2016-2056.

## Conclusions

Dementia is one of the major chronic diseases of this century. The health, social and economic costs of the disorder are enormous, as shown in this cost of illness (COI) study and these will only grow in the future as the population with dementia rises sharply over coming decades. There is a significant economic burden from dementia for persons with dementia and their families, the health and aged care systems and on the economy as a whole. The increasing prevalence of dementia means that there is both an economic and social imperative for governments to develop initiatives to address dementia and ensure that people with dementia have access to appropriate care and support from the moment of diagnosis.

In keeping with the recommendations by Schaller and colleagues (2015) in their systematic review of COI studies of dementia, the significant variation of cost estimates for different care settings, duration of dementia and disease severity underlines the need to understand and address the financial burden of dementia from all perspectives.

Initiatives that focus on prevention and early intervention and timely diagnosis, and on supporting people with dementia to live in the community, are particularly important given the long-term benefits they deliver. Building capacity to address dementia now will save billions in direct costs and lost productivity for years to come, as well as improving the quality of life of the millions of Australians who are in some way impacted by dementia.

The policy implications of the latest data highlights the urgent need for the government to implement a funded, holistic national plan to tackle dementia over the next decade and more, with a focus on providing appropriate services and supports including addressing the social isolation and stigma associated with dementia. This plan must include a comprehensive approach to improving quality of care and supporting people in the community, as well as better care through our health and aged care systems.

Current ongoing changes to the aged care system have a significant impact on how consumers access and receive services. Alzheimer's Australia supports the Government's commitment to aged care reform and the broader intent and ongoing implementation of Consumer Directed Care (CDC) across the aged care system. CDC aims to provide consumers with greater control over their own health and wellbeing by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when.

Concern remains about the current inability of mainstream services to deliver appropriate care and support for people with dementia. Specialist services such as dementia specific advocacy, information and support are critical. Evidence suggests that the complex needs of people with dementia cannot be supported through mainstream health and aged care services alone.<sup>1</sup> There is a need to also fund dementia-specific specialist services that can provide the care, support and social engagement that people with dementia and their families need. Targeted programs and services can lessen the burden and reduce dementia-related costs across the broader health and aged care sector.

The core business of both residential and home-based aged care services increasingly includes providing care to people with dementia. The demand for carers will rise over the coming decades as the number of people with dementia in the population increases. As the prevalence of dementia increases in the community, it is critical that all aged care services are well-equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business. The aged care sector workforce is a critical element in the provision of quality services, and this workforce must be available in the future in sufficient numbers, and at a high quality.

To ensure quality care, management in aged care services must be committed to person-centred high quality care, and services must have adequate numbers of skilled, qualified staff. The workforce must have the appropriate education and training, skills, and attributes to provide quality care for older people, including people with dementia, who frequently have complex care needs.

Backed by the evidence provided in this report, Alzheimer's Australia strongly urges the government to develop and implement a National Dementia Strategy to ensure a comprehensive and co-ordinated approach to addressing dementia in Australia. A comprehensive approach has the potential to produce significant social and economic benefits.

While dementia is not curable, effective risk reduction and preventative health measures can delay the onset of dementia for up to five years. Effective early intervention and psychosocial support for people with dementia and their carers can increase quality of life, reduce stress and sometimes delay admission to residential care. Effective programs in the community and residential care can reduce unnecessary admissions to hospital; and dementia-focused programs in acute care can reduce length of hospital stays and associated expenditure.

A holistic approach to dementia care begins with raising awareness amongst the general population, and spans the provision of services to people with dementia and their families from point of diagnosis, through to appropriate end of life care. An individualised approach to care involves understanding not only the unique characteristics of the disease but also what it means for that person to live well with dementia and how they can be supported to do so. This involves focusing on the social, emotional, physical, and health needs of the person with dementia as well as their carers and family members.

1. Report for the Department of Health and Ageing commissioned from Alzheimer's Australia, December 2011

To achieve any real change a national strategy for dementia is urgently needed that will prepare Australia for the challenges of the coming decades as portrayed in this report. For effective policy planning, this strategy needs to encompass:

- Greater effort to promote awareness of the risk factors for dementia and risk reduction, so that fewer people develop dementia;
- Timely diagnosis and post-diagnostic support, including early intervention, so that people can live successfully in the community for longer, and admissions to aged and acute care facilities are delayed or avoided;
- Effective education and training for health professionals and others working in the field;
- Improved carer support and respite, so that the experience of carers is improved, and carers can continue to participate socially and economically;
- Better access to ongoing support and treatment services, so that the journey for people with dementia, and their carers, is improved;
- Better access to end-of-life palliative care; and
- Increased investment in dementia research, with emphasis on translational research and consumer involvement in all aspects of dementia research in Australia.

# 1. INTRODUCTION

On 10 August 2012, the Australian Health Ministers recognised dementia as the ninth National Health Priority Area (NHPA). This was in recognition of the increasing number of Australians developing dementia and its significant burden of disease. Very few studies have examined the costs associated with dementia in Australia and the economic burden placed on families, support services and government. Alzheimer's Australia has commissioned this report to explore the economic cost of dementia broadly in line with the study *"The Dementia Epidemic: Economic Impact and Positive Solutions for Australia"* undertaken in 2003 by Access Economics. The primary aims of this new report are to provide an updated estimate of the cost of dementia in 2016 and to project likely future costs of dementia over the next 40 years.

As AIHW (2012) states, dementia is not a single specific disease but an umbrella term describing a syndrome associated with more than 100 different diseases that are characterised by the impairment of brain functions; including language, memory, perception, personality and cognitive skills. Although the type and severity of symptoms and their pattern of development varies with the type of dementia, it is usually of gradual onset, progressive in nature and irreversible. The most common types of dementia are Alzheimer disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Thus, people usually experience a gradual deterioration in brain functioning that impacts on thinking skills – memory, reasoning, planning and the ability to perform everyday tasks. It also impacts on mental health including mood and emotions, and often leads to depression. Changes in people's behaviour are often problematic, especially as individuals lose their independence and self-control.

The economic impact of dementia is a major concern nationally and internationally as the number of individuals with dementia continues to increase. The World Alzheimer Report 2015 states

that the global costs of dementia have increased 35% in the last five years from US\$604 billion in 2010 to US\$818 billion in 2015. On average, the economic impact represents around 1% of global GDP. The report also shows that based on the World Bank country classification, 82% of the costs or \$670 billion comes from high income countries such as Australia. The large proportion of high income countries is related to their better data collections and the existence of studies that estimate the costs of dementia such as in European countries, US, and Canada (Rapp et al, 2004; Herrmann et al, 2006; Masterton et al, 2010; Hurd et al, 2013). The figures from the latest World Alzheimer Report reflect the inadequate estimation of dementia costs and the ability to capture all cost components. Although many studies have contributed to a diverse cost component and different care settings, detailed analyses are still limited (Schaller et al, 2014).

Increasing life expectancy and population ageing during recent decades have impacted on the prevalence of dementia. The growing number of individuals developing dementia in the late 1990s raised concerns about future costs of care and whether the support from government would be able to cope with the increasing number of elderly people (Wimo et al, 1997). However, there is no general consensus on how to calculate all costs related to people with dementia. Studies in the last 20 years have applied various methods and techniques to estimate the costs of dementia.

This report provides an overview of dementia in Australia, including the prevalence and incidence of dementia over the next 40 years, some of the social and economic characteristics of people with dementia and its impact in terms of mortality. A brief review of the need for care and provision of care services is also provided. The report then provides the results of the modelling of the direct and indirect costs of dementia in 2016 and out to 2056.

# 2. METHODS

## 2.1 PREVALENCE AND INCIDENCE RATES

The methodology to estimate and project dementia prevalence in Australia is a standard demographic modelling approach in which age-sex dementia prevalence rates are applied to age-sex population projection estimates. Similar to the approach used by AIHW (2012), the estimates of the number of Australians who may develop dementia in the future are due solely to the projected population growth and continued ageing of the population i.e. the same age-sex prevalence rates have been applied across time. This assumes that the dementia prevalence rates have been stable and will continue to be so until 2036. This assumption is commonly made since there is a lack of evidence to suggest changes in age-specific prevalence rates over time (AIHW, 2012). Any future changes in the risk factor profile of Australians and in the prevention, management and treatment of dementia will affect the accuracy of the estimates produced. For example, work by Nepal, Brown and Anstey (2014) suggests that if the rising trend in midlife obesity and declining trend in midlife normal weight in Australia are taken into account in projecting future numbers of Australians with dementia then the number of people aged 65 years and above with dementia, by 2050, would be 14% higher than that expected from demographic ageing only.

The prevalence of dementia was estimated for 5-year age groups starting from age 30 with top coding at 85 years and over (while prevalence rates are available for older age groups, the population projections used were top-coded by ABS at 85+ years). Younger onset dementia is typically taken to be the onset of dementia before the age of 65 years. In keeping with the approach used by AIHW, dementia rates were not estimated for children or young adults. The results presented for younger onset dementia therefore represent those aged 30-64 years.

Two data sources were used to determine the age-sex prevalence rates. First, the estimates of the older cases, i.e. those aged 65+ years were derived from the pooled, harmonised, dataset from DYNOPTA reported by Anstey and colleagues (2010). Four of the nine longitudinal studies of ageing contributing to the DYNOPTA project had cognitive decline or dementia as a key focus of the investigators (Anstey et al, 2010). These four studies provided Mini-Mental State Examination (MMSE) scores for about 3,908 Australians

aged 65 years and over. A MMSE score of less than 24 was used in the DYNOPTA study to identify individuals in the DYNOPTA dataset as having 'probable' dementia – the cutoff of 23/24 for probable dementia being widely recommended and validated in studies of the sensitivity and specificity of the MMSE (Anstey et al, 2010; Creavin et al, 2016). Rates for 'probable' dementia were preferred in this costing analysis as these rates are more inclusive in estimating the likely burden being placed on the Australian health and aged care systems and on families who have members with noticeable cognitive decline. Probable dementia may include a small proportion of people with cognitive impairment who would not meet stricter clinical diagnostic criteria for dementia. However, these individuals on the 'borderline' are likely to have similar needs to those with mild dementia and incur costs associated with their symptoms. In the 2012 Dementia in Australia report, for people aged 60 years and over, AIHW used the dementia prevalence rates released by Alzheimer's Disease International in the World Alzheimer Report (ADI, 2009).

Second, for those with younger onset dementia, the prevalence rates for this age group were those used by AIHW in their 2012 report on Dementia in Australia. To derive estimated prevalence rates for people under 60 years of age, AIHW used the same rates that were included in the first Dementia in Australia report (AIHW 2007). These were modelled rates,<sup>2</sup> based on rates published in the Harvey et al. (2003) UK study. Information on the prevalence of younger onset dementia is scarce. Harvey and colleagues (2003) estimated that the prevalence of younger onset dementia, in two London boroughs, was 54 per 100,000 persons in the 30-64 year age group. A recent Australian study undertaken in southeast Sydney estimated a similar prevalence of 68.2 per 100,000 persons in the 30-64 age group (Withall et al, 2012).

A comparison of the age-sex prevalence rates used by AIHW and in this current research and the resulting number of persons expected to have dementia is given in Table 1. NATSEM estimates that around 401,000 persons have probable dementia in Australia in 2016 (based on the AIHW rates for those under 60 years of age and the DYNOPTA rates for the 65+ age group). This is 17% higher compared with an estimate generated using the AIHW (ADI and Harvey) rates. As can be seen, the prevalence rates using the Australian-dedicated DYNOPTA dataset are typically higher than the rates used by AIHW. The major difference is for males. The DYNOPTA prevalence rates for males are

2. the modelling methods are available in Box 4.3 on page 65 in Dementia in Australia: national data analysis and development <http://www.aihw.gov.au/publication-detail?id=6442467941>

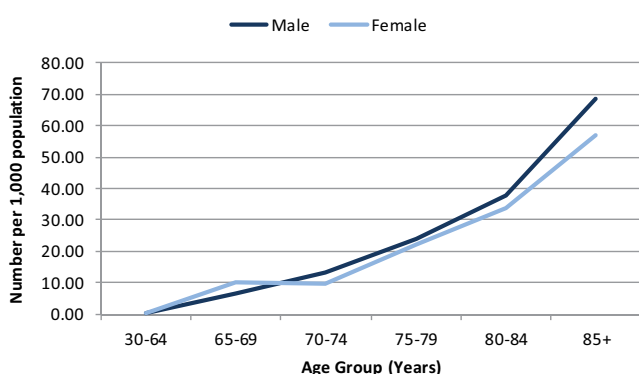


significantly higher than the AIHW (ADI) rates. The expected number of males with probable dementia used in this report is nearly 35% higher than if the AIHW rates had been used, compared with only 7% for females. Indeed the DYNOPTA rates actually lead to fewer females being counted with dementia in the 85+ age group and in the 70-74 year age group, although to a lesser degree.

Where prevalence refers to the number of people with dementia in the population at a particular point in time, incidence measures the number of people developing dementia, i.e. the number of new cases of dementia in a specified time period, usually in a year. There are major methodological difficulties in estimating the incidence of dementia. There are very few empirical studies that follow individuals over time and record the onset of dementia: the diagnosis is problematic with screening instruments not necessarily being specific to dementia (as opposed to other cognitive conditions), and usually symptoms are initially mild and therefore not recognised as being due to dementia until the condition progresses (AIHW, 2002; Access Economics, 2009).

In calculating incident cases, rather than trying to find appropriate age-sex incidence rates, AIHW (2007) calculated the ratio of the number of incident cases to prevalence numbers. AIHW applied the same ratios in their 2011 estimates. These ratios are given in the Technical Notes and the resulting incidence rates in Figure 1 below. These incidence rates are in keeping with those reported in the 2015 World Alzheimer Report.

**Figure 1 Annual age-sex incidence rates of dementia (number of new case per 1,000 population)**



Source: NATSEM calculations from AIHW data (AIHW 2007 and 2012)

## 2.2 POPULATION PROJECTIONS

The projections of the general population over the 40 year period 2016-2056 were obtained from the ABS online services for the Population Projections by Region, 2012-2061, dataset. The data was extracted for each State and Territory by age and sex group, and by capital city and balance of the State. The assumptions were in keeping with the ABS Series B population projections:

- Fertility Assumption – Medium fertility
- Mortality Assumption – Medium life expectancy
- Net overseas migration – Medium NOM
- Net interstate migration – Medium interstate flows

## 2.3 A COST OF ILLNESS APPROACH

Wimo et al. (1997, 2011) identify that many studies analysing dementia costs draw on a cost classification. First, the approach taken by many researchers is calculating all relevant costs or as Lindgren (1982) terms undertake a cost of illness (COI) study. Second, costs can be identified based on different caring strategies, such as costs for home care by family members and costs from institutionalised aged (nursing) care. A third approach analyses the trade-off between the cost of care and the different aspects of care related to a non-monetary outcome measurement. Studies applying the last approach are usually designed as a cost-effectiveness or cost-benefit analysis of dementia.

The calculation of dementia costs may also investigate costs by the degree of dementia severity. Leicht et al. (2011) in a cross-sectional study in Germany, found that the annual costs of dementia by severity stage were around \$AUD27,900 for patients with mild dementia, \$AUD59,500 for moderately affected patients, and \$AUD78,100 for those with severe symptoms. Jonsson et al. (2006) utilised a different approach by identifying the severity according to the Mini-Mental State Examination (MMSE) score. This Swedish study found that the least severe cases by MMSE score were associated with a lower dementia cost (around \$AUD8,855) compared with the highest state of MMSE with a total cost of about \$AUD25,100. A combination approach using both the degree of severity (mild, moderate, severe) and MMSE levels was

Table 1 Comparison of age-sex prevalence rates AIHW (2012) and DYNOPTA (2010)

Age	AIHW (ADI) Rates		DYNOPTA Rates		AIHW (2011) Number of Persons			AIHW (2016)* Number of Persons			NATSEM (2016) Number of Persons			RATIO of NATSEM 2016 ESTIMATES to AIHW 2016		
	Males	Females	Males	Females	Males	Females	Total	Males	Females	Total	Males	Females	Total	Males	Females	Total
30-34	0.005	0.001	-	-	36	6	43	46	9	55	46	9	55	1.00	1.00	1.00
35-39	0.010	0.002	-	-	78	17	95	82	16	99	82	16	99	1.00	1.00	1.00
40-44	0.022	0.005	-	-	172	42	214	181	42	222	181	42	222	1.00	1.00	1.00
45-49	0.050	0.015	-	-	386	116	502	404	123	527	404	123	527	1.00	1.00	1.00
50-54	0.114	0.042	-	-	845	322	1,167	877	330	1,208	877	330	1,208	1.00	1.00	1.00
55-59	0.257	0.118	-	-	1,713	803	2,515	1,886	892	2,778	1,886	892	2,778	1.00	1.00	1.00
60-64	1.517	1.596	-	-	9,383	10,027	19,410	9,836	10,679	20,515	9,836	10,679	20,515	1.00	1.00	1.00
65-69	2.395	2.581	3.02	4.47	11,310	12,403	23,712	14,015	15,514	29,529	17,670	26,867	44,536	1.26	1.73	1.51
70-74	3.928	4.367	6.22	4.30	13,906	16,461	30,367	17,254	20,074	37,328	27,320	19,765	47,085	1.58	0.98	1.26
75-79	6.780	7.723	10.74	10.55	17,692	23,077	40,769	21,216	26,382	47,598	33,605	36,038	69,643	1.58	1.37	1.46
80-84	11.499	13.679	16.92	15.97	22,144	34,442	56,586	23,314	35,145	58,459	34,304	41,030	75,334	1.47	1.17	1.29
85+	24.363	32.329	28.90	28.31	35,643	86,976	122,616	43,810	99,196	143,006	51,960	86,874	138,834	1.19	0.88	0.97
65+/ <b>Total</b>	7.06	10.34	9.92	10.97	113,307	184,689	297,997	132,921	208,402	341,323	178,169	222,664	400,833	1.34	1.07	1.17

Source: AIHW (2012) 'Dementia in Australia', Anstey et al (2010), and NATSEM estimates. \* The rates used by AIHW to estimate dementia in 2011 were applied to the ABS estimated resident population figures for 2016.

also applied in the case of European and North-American countries. A review study by Quentin et al. (2010) showed that the ascending stages of these two measurements were consistent with the increasing dementia costs.

However, the costs of dementia are not only related to direct medical costs but also to indirect costs. A review study of the economic impact of dementia in Europe in 2008, (Wimo, 2011) shows that the costs of care for people with dementia was larger than the direct costs related to medical and hospital expenses. In 2008, in 27 Euro countries the total annual cost of dementia was \$AUD31,450 per person where \$AUD14,060 was for direct medical costs and \$AUD17,390 was for costs of care. In aggregate for all European countries in 2008, the total cost of dementia was approximately \$AUD251.1 billion, where \$AUD114.2 billion were for direct medical costs and \$AUD136.9 billion as costs of care.

Several studies conducted their analyses of dementia costs based on care setting, which can be divided into two main categories; institutionalised care and community-based care (Beeri et al, 2002; Masterton et al, 2010; Kraft et al, 2010; and Allegri et al, 2007). Two studies (Allegri et al, 2007 and Masterton et al, 2010) examined a most comprehensive cost of illness (COI) estimation with a stratification based on disease severity as well as care setting and varying cost instruments (direct medical costs and non-direct medical costs).

In estimating the costs of dementia in Australia, a COI approach is adopted in this report. The COI has been defined as the value of the resources that are expended or foregone as a result of a health problem. A COI includes:

- **direct costs** which can be regarded as the cost of 'resources' expended on the person with dementia. Direct costs can be either health and aged care related e.g. costs of medical practitioner or allied health professional visits, hospital care, treatments, medications, specialised aids and equipment, diagnostic testing, residential and community aged care and respite etc.; or non-medical expenses typically out-of-pocket costs borne by individuals with dementia, their family or carers e.g. cost of transport, personnel care, household expenses e.g. food, utilities, house and garden maintenance, home modifications etc. Direct costs also include government income and welfare support payments provided through pensions and allowances to the person with dementia, their family or carers;

- **indirect costs** which are usually seen in terms of the value of lost productivity by the person with dementia or their carer. For example, a person with dementia, especially those with early onset or a caregiver may no longer be able to work or are only able to participate in paid work on a restricted basis, and thus have to forego earnings. This impacts on superannuation accumulation, the running down of savings and sale of personal or family assets as well as a reduction in income tax revenue for government.
- **intangible costs** which are non-material costs e.g. the cost of pain and suffering, emotional toll, stress, sadness, fear, exhaustion, social exclusion, impact on personal relationships and family including activities and use of time etc. These are typically excluded from economic analyses because intangible costs are better expressed in qualitative terms and do not lend themselves to be monetised. However, intangible costs can in part be captured by the 'burden of disease' concept which broadly divides impacts into non-fatal (living with dementia) and fatal (dying from dementia) effects. These effects are combined in the summary measure of disability adjusted life years (DALYs) which adds estimates of years of life lost due to premature death (YLL) to years lived in ill-health or with disability (YLD). Burden of disease, thus, can capture both the quantity and quality of life lost as an outcome of dementia.

The estimation approach used in this study is based on the literature relating to the cost of dementia and the costing procedures and strategies used by AIHW to calculate the direct health and aged care system expenditure on people with dementia in 2009–10 (AIHW, 2012). The methods were also informed by those used by Access Economics in their 2003 report *'The Dementia Epidemic: Economic Impact and Positive Solutions for Australia'*. Access Economics used a top-down approach to estimate direct health system costs. This attributes a share of total health expenditures to a disease based on available information on the mix of diseases treated and the costs of treatment. A 'bottom up' approach itemises actual or imputed costs incurred by a representative sample of patients and weights these to get an estimate for the entire population. This is the approach used in this report where a per capita cost is estimated for different groups of people with dementia (e.g. by disease severity and care setting) with costs then applied to the future population with dementia.

The costs of illness can represent expenditure on people with a health problem or those directly *attributable* to the disorder. In general, the costs presented in this report represent expenditure on people with dementia. While many of the costs can be attributed to dementia, it is often difficult to assign causation entirely to dementia as an individual may have incurred a similar expense in the absence of dementia. For example, the majority of persons with dementia require a carer but many older Australians who do not have dementia have carers because of frailty, disability or other morbidities.

All costs are expressed in 2016 dollars i.e. in constant dollar terms. This means that the projected future costs are neither inflated for future price rises nor discounted for the impact of time on how future costs are valued in today's dollars.

# 3. DEMENTIA IN AUSTRALIA 2016-2056

## KEY POINTS

- Over the next 40 years, the number of Australians with probable dementia is projected to increase 2.75 fold from 413,106 adults living with dementia in Australia in 2017 to 1,100,890 persons by 2056.
- There are an estimated 25,938 individuals currently living in Australia with younger onset dementia (aged less than 65 years). This is expected to rise to around 42,250 persons by 2056.
- The number of persons with dementia in 2017 by jurisdiction ranged from 1,663 individuals living in the Northern Territory to 138,721 persons living in New South Wales. The greatest percentage increase in the number of persons with dementia over the next 40 years is expected to occur in the Northern Territory followed by Western Australia.
- Two of every five persons with dementia live in regional cities and towns and rural and remote communities and areas of Australia. One in five individuals with dementia, is from a cultural and linguistically diverse background. Aboriginal and Torres Strait Islanders have 3-5 times the risk of developing dementia than non-Indigenous persons. In 2016, there may be as many as 118,000 individuals with dementia living alone in the community.
- Around 244 individuals are developing dementia each day in Australia. By 2056, each day over 650 people will be joining the dementia population.
- Dementia is now the second leading cause of death of Australians contributing as an underlying cause of death to 7.9% of all deaths each year. However, the current rate of identification of dementia as the underlying cause of death on death certificates represents only 15% of all deaths in males with dementia and around 22% of all deaths of females with dementia.

## 3.1 PREVALENCE OF DEMENTIA

Using the Australian-based prevalence rates for probable dementia (Anstey et al, 2010), it is estimated that in 2016 there were some 400,800 adults living with dementia in Australia – 178,200 males (44%) and 222,600 females (56%) (Table 2). In 2017, these numbers are expected to rise to over 413,000 (184,868 males and 228,238 females). Dementia is now a highly prevalent health condition within the population with one in 10 Australians aged 65 years or above having dementia and three of every 10 persons aged 85 years and above. Currently, just over 70% of people with dementia are aged 75 years and over. However, there are 25,400 persons living with younger onset dementia (i.e. are less than 65 years of age). These individuals represent just over 6% of all persons with dementia (Table 2).

Over the next 20 years, the number of Australians with dementia will almost double to an estimated 760,700 individuals by 2036 (349,500 males and 411,200 females) and by 2056 numbers of people with dementia will be 2.75 fold higher (508,147 males and 592,743 females) (Table 2 and Figure 2). The rate of growth in the number of Australians with

dementia is highest over the next 16 years – over the period 2016-2032, each year, on average there will be 3.35<sup>3</sup> more Australians with dementia than in the previous year. Although the number of Australians with dementia continues to rise in absolute terms, the rate of growth slows to 2.06% in the period 2033-2049 and to 1.30% in 2050-2056. The projected population with dementia by age and gender from 2016-2056 by year is given in Appendix 1.

Although the number of persons with younger onset dementia will continue to increase over the next 40 years (by nearly 30% by 2036 and 66% by 2056), it is in the older age groups where the highest growth in numbers of persons with dementia will occur. For example, the number of males aged 80-84 years who will have dementia in 2036 will be 2.2 fold higher than now, and for those aged 85+ years 2.4 fold higher. By 2056 there will be three times the number of males aged 80-84 years with dementia and four times the number for those aged 85+ years. This means that by 2036 nearly 78% of people with dementia will be 75 years of age or over, and by 2056 80%. In 40 years' time, 45 of every 100 persons with dementia will be aged 85 years and over. This growth in numbers and ageing of the population has major ramifications in terms of the need for, provision and costs of care.

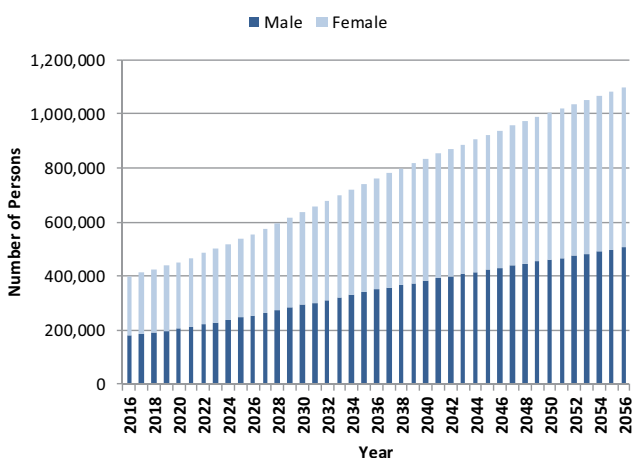
3. 3.35% is the compound growth rate in the number of persons with dementia 2016-2032.

In addition, such changes in the prevalence of the population with dementia are not evenly shared among the States and Territories. The estimated age-sex prevalence of persons with dementia in 2016, 2017, 2036 and 2056 by State and Territory, and by capital city and the rest (balance) of the State, is given in Table 3, while the relative growth in numbers over the 40 years is provided in Table 4. These numbers reflect differences in the size of the State and Territory populations, their age-sex distributions, expected population growth and geographical distribution (and not other factors, such as risk factor profiles, that may influence the prevalence of dementia).

The estimated number of persons with dementia in 2016 by jurisdiction ranged from 1,576 individuals living in the Northern Territory to 135,093 persons living in New South Wales. In 2016, nearly 80% of people with dementia live in New South Wales (34%), Victoria (25%) or Queensland (19%).

The increase in the number of people expected to have probable dementia in 20 and 40 years' time varies considerably across the States and Territories and between capital cities and the balance of the States. While the majority of the population with dementia will still live in New South Wales, Victoria and Queensland (Table 3), the greatest percentage increase is expected to occur in the Northern Territory. Darwin recorded the highest estimated annual growth rate in the number of people with dementia over the past year (Table 4). For the period 2016-2036, the number of people with dementia living in Darwin is expected to grow by

**Figure 2 Estimated number of Australians with dementia, 2016-2056**



Source: NATSEM calculations using ABS population projections

**Table 2 Estimated number of Australians with dementia by age and gender, 2016, 2017, 2036 and 2056**

	2016			2017			2036			2056			Growth 2016-36			Growth 2016-56					
	Male No.	Female No.	Total %	Male No.	Female No.	Total %	Male No.	Female No.	Total %	Male No.	Female No.	Total %	Male %	Female %	Total %	Male %	Female %	Total %			
<b>30-64</b>	13,310	12,090	25,400	13,567	12,371	25,938	6.3	16,983	15,466	32,450	4.3	22,167	20,085	42,252	3.8	276	279	278	66.5	66.1	66.3
<b>65-69</b>	17,670	26,867	44,536	17,617	26,935	44,552	10.8	23,378	36,515	59,893	7.9	31,738	48,414	80,152	7.3	32.3	35.9	34.5	79.6	80.2	80.0
<b>70-74</b>	27,320	19,765	47,085	29,358	21,256	50,614	12.3	43,121	32,203	75,324	9.9	58,536	42,366	100,902	9.2	57.8	62.9	60.0	114.3	114.3	114.3
<b>75-79</b>	33,605	36,038	69,643	35,017	37,497	72,514	17.6	64,754	71,270	136,024	17.9	80,277	85,657	165,934	15.1	92.7	97.8	95.3	138.9	137.7	138.3
<b>80-84</b>	34,304	41,030	75,334	35,686	41,946	77,632	18.8	75,744	85,034	160,778	21.1	102,457	112,333	214,790	19.5	120.8	107.2	113.4	198.7	173.8	185.1
<b>85+</b>	51,960	86,874	138,834	53,623	88,233	141,856	34.3	125,528	170,675	296,204	38.9	212,972	283,888	496,860	45.1	141.6	96.5	113.4	309.9	226.8	257.9
<b>Total</b>	<b>178,169</b>	<b>222,664</b>	<b>400,833</b>	<b>184,868</b>	<b>228,238</b>	<b>413,106</b>	<b>100.0</b>	<b>349,509</b>	<b>411,163</b>	<b>760,672</b>	<b>100.0</b>	<b>508,147</b>	<b>592,743</b>	<b>1,100,890</b>	<b>100.0</b>	<b>96.2</b>	<b>84.7</b>	<b>89.8</b>	<b>185.2</b>	<b>166.2</b>	<b>174.7</b>

Source: NATSEM calculations using ABS population projections

140% and in the rest of the Northern Territory by 130% (Table 4). Numbers of people with dementia in the Northern Territory will continue to grow over the next 20 period 2036-2056. By 2056, the Northern Territory will have 3.5 times the number of people with dementia than it currently has. Western Australia shows a similar pattern with large increases in the prevalence of dementia in both the population of Perth and remainder of the State, and in both periods 2016-2036 and 2036-2056.

The rates of growth in the number of persons predicted to have dementia are also higher than the national average in both the Australian Capital Territory and Queensland, although not as marked as for the Northern Territory or Western Australia. Growth rates in the number of people with dementia are lower than the national average for both capital cities and balance of the State for New South Wales but particularly South Australia and Tasmania. Also much of the expected growth in the dementia population in South Australia, Tasmania and regional-rural New South Wales also occurs in the next 20 years rather than in 30-40 years' time. These patterns reflect different rates of population ageing between the States and Territories and particularly between their capital cities and balance of the States.

This is shown by the different rates of increase in dementia across the jurisdictions by age group. In absolute terms, the number of persons with younger onset dementia will increase the greatest in Melbourne, Sydney and Perth. In relative terms, Perth will experience almost a 60% increase over the next 20 years in people with younger onset dementia and will increase by 2.5 fold by 2056. Numbers of people with younger onset dementia in Melbourne, Brisbane and the balance of the Northern Territory will increase by 40% between 2016 and 2036 and will double by 2056. Rates of increase in younger onset dementia were also higher than the national average for the regional, rural and remote areas of Western Australia and Queensland. However, in sharp contrast, the increase in persons with younger onset dementia is expected to be quite low in the balance of New South Wales and Victoria, and the number of people with younger onset dementia is actually estimated to fall in regional and rural South Australia and Tasmania over the next 20 years, although the numbers are small. The increase in the numbers of people with dementia expected in the Northern Territory reflects a particularly high growth rate in the number of older persons with dementia although rates across all age groups are above the national average. The same pattern is observed for Western Australia.

As shown in Table 3, three of every five persons with dementia live in Australia's capital cities, including the

Australian Capital Territory. Still, nearly 155,000 persons with dementia currently live in regional and rural cities, towns and country areas. Data from the 2012 SDAC indicates that less than 1% of people with dementia live in remote parts of Australia and 7% in outer regional areas. Compared with the State and Territory average, Tasmania, Queensland and New South Wales all have greater proportions of their residents with dementia living outside their capital cities – 59, 56 and 43% in 2016. In contrast, in Western Australia, South Australia and Victoria, the vast majority of people with dementia live and will continue to live in Perth, Adelaide and Melbourne – 80, 75 and 70% in 2016 respectively. This geographical distribution between capital cities versus the remainder of the State is not expected to change significantly over the next 20 years with the proportion of people with dementia living in the capital cities rising slightly from 61.4% in 2016 to 62.6% in 2036. However, by 2056 two-thirds of people with dementia will live in the capital cities. This reflects the ongoing dominance of Sydney and Melbourne as major centres of population growth. However, it is important to recognise the significant number of Australians who currently have dementia, or who will develop dementia in coming years, and who 'live in the bush' and may face major issues with access to appropriate services.

## **3.2 CHARACTERISTICS OF PEOPLE WITH DEMENTIA – SPECIAL NEEDS GROUPS**

The prevalence of dementia is likely to vary among groups from different cultural and socio-economic backgrounds, but there is a paucity of epidemiological data to quantify these differences. However, there is an increasing awareness of the needs of different groups, including their risk and understanding of dementia and access to dementia services. Special needs groups include Aboriginal and Torres Strait Islander people; people from Culturally and Linguistically Diverse backgrounds (CALD); Gay, Lesbian, Bi-Sexual, Transgender and Intersex people (GLBTI); people with younger onset dementia; people in rural and remote locations, those from economically or socially disadvantaged backgrounds and those who live alone (Stevens et al, 2011).

According to the 2012 SDAC, 64% of people with dementia are born in Australia, 11% in main English speaking countries (e.g. Canada, Republic of Ireland, New Zealand, South Africa, United Kingdom, United States of America), and 25% in 'other' countries. In 2003, only 15% of persons with dementia were born in 'other' countries. There is no major difference

**Table 3 Estimated number of Australians with dementia by age and gender, State and Territory, 2016, 2036 and 2056**

	2016					2017					2036					2056					
	30-64	65-74	75-84	85+	Total	30-64	65-74	75-84	85+	Total	30-64	65-74	75-84	85+	Total	30-64	65-74	75-84	85+	Total	
<b>NSW</b>																					
Sydney	4,840	16,871	27,063	27,511	76,285	4,952	17,505	27,855	27,970	78,283	6,325	24,911	54,217	55,214	140,668	8,286	33,983	71,919	93,177	207,365	
Balance of NSW	3,331	13,176	21,898	20,403	58,808	3,385	13,610	22,561	20,882	60,438	3,400	16,668	39,917	39,519	99,504	3,586	17,759	41,007	56,391	118,743	
<b>Total</b>	<b>8,171</b>	<b>30,047</b>	<b>48,961</b>	<b>47,914</b>	<b>135,093</b>	<b>8,338</b>	<b>31,115</b>	<b>50,417</b>	<b>48,852</b>	<b>138,721</b>	<b>9,725</b>	<b>41,579</b>	<b>94,134</b>	<b>94,733</b>	<b>240,171</b>	<b>11,872</b>	<b>51,742</b>	<b>112,926</b>	<b>149,568</b>	<b>326,108</b>	
<b>Vic</b>																					
Melbourne	4,417	15,488	25,795	25,360	71,060	4,528	16,074	26,622	25,904	73,127	6,183	24,492	52,200	53,036	135,911	8,477	35,455	73,180	94,826	211,938	
Balance of Vic	1,796	6,947	11,199	10,680	30,622	1,824	7,206	11,615	10,850	31,495	1,900	9,257	22,019	21,544	54,720	2,046	10,240	23,663	32,354	68,303	
<b>Total</b>	<b>6,213</b>	<b>22,435</b>	<b>36,994</b>	<b>36,040</b>	<b>101,682</b>	<b>6,351</b>	<b>23,280</b>	<b>38,238</b>	<b>36,753</b>	<b>104,622</b>	<b>8,083</b>	<b>33,749</b>	<b>74,220</b>	<b>74,580</b>	<b>190,632</b>	<b>10,523</b>	<b>45,695</b>	<b>96,844</b>	<b>127,180</b>	<b>280,241</b>	
<b>Qld</b>																					
Brisbane	2,266	7,877	11,438	11,039	32,621	2,308	8,217	11,955	11,298	33,778	3,199	12,366	26,042	26,413	68,019	4,456	17,935	36,910	47,328	106,630	
Balance of Qld	2,819	10,508	15,528	13,395	42,250	2,887	10,903	16,262	13,802	43,855	3,734	16,050	33,811	32,726	86,320	4,767	21,085	44,314	56,502	126,668	
<b>Total</b>	<b>5,085</b>	<b>18,385</b>	<b>26,965</b>	<b>24,435</b>	<b>74,871</b>	<b>5,196</b>	<b>19,120</b>	<b>28,216</b>	<b>25,100</b>	<b>77,633</b>	<b>6,932</b>	<b>28,416</b>	<b>59,853</b>	<b>59,138</b>	<b>154,339</b>	<b>9,223</b>	<b>39,020</b>	<b>81,225</b>	<b>103,830</b>	<b>233,298</b>	
<b>WA</b>																					
Perth	2,081	7,098	11,009	10,165	30,353	2,134	7,434	11,481	10,488	31,536	3,277	12,374	25,810	25,288	66,749	5,289	21,361	40,553	49,748	116,952	
Balance of WA	644	1,998	2,767	2,304	7,712	667	2,097	2,904	2,397	8,064	898	3,575	6,901	6,038	17,412	1,152	4,921	9,328	11,604	27,005	
<b>Total</b>	<b>2,725</b>	<b>9,096</b>	<b>13,776</b>	<b>12,468</b>	<b>38,065</b>	<b>2,801</b>	<b>9,531</b>	<b>14,384</b>	<b>12,885</b>	<b>39,600</b>	<b>4,174</b>	<b>15,950</b>	<b>32,711</b>	<b>31,326</b>	<b>84,161</b>	<b>6,441</b>	<b>26,282</b>	<b>49,882</b>	<b>61,352</b>	<b>143,957</b>	
<b>SA</b>																					
Adelaide	1,447	5,334	8,953	9,722	25,456	1,471	5,543	9,182	9,813	26,009	1,630	7,213	17,021	17,884	43,748	1,967	8,747	19,422	27,330	57,466	
Balance of SA	502	2,022	3,181	2,943	8,649	507	2,091	3,301	3,009	8,907	467	2,413	5,824	6,106	14,810	477	2,386	5,496	8,266	16,625	
<b>Total</b>	<b>1,949</b>	<b>7,357</b>	<b>12,134</b>	<b>12,665</b>	<b>34,105</b>	<b>1,978</b>	<b>7,634</b>	<b>12,483</b>	<b>12,821</b>	<b>34,916</b>	<b>2,098</b>	<b>9,626</b>	<b>22,845</b>	<b>23,989</b>	<b>58,559</b>	<b>2,445</b>	<b>11,133</b>	<b>24,918</b>	<b>35,595</b>	<b>74,091</b>	
<b>Tas</b>																					
Hobart	264	945	1,528	1,456	4,193	268	990	1,572	1,481	4,310	269	1,244	3,064	2,944	7,520	298	1,398	3,182	4,331	9,208	
Balance of Tas	392	1,536	2,281	1,877	6,086	397	1,587	2,373	1,915	6,272	372	1,870	4,388	4,082	10,712	370	1,804	4,184	5,654	12,012	
<b>Total</b>	<b>656</b>	<b>2,481</b>	<b>3,809</b>	<b>3,333</b>	<b>10,279</b>	<b>664</b>	<b>2,577</b>	<b>3,944</b>	<b>3,396</b>	<b>10,582</b>	<b>640</b>	<b>3,114</b>	<b>7,453</b>	<b>7,026</b>	<b>18,232</b>	<b>667</b>	<b>3,203</b>	<b>7,366</b>	<b>9,985</b>	<b>21,220</b>	
<b>ACT</b>																					
Total	378	1,272	1,823	1,689	5,162	383	1,329	1,914	1,743	5,369	505	1,861	4,111	4,373	10,849	680	2,665	5,551	7,416	16,313	
<b>NT</b>																					
Darwin	131	355	338	189	1,013	133	374	364	202	1,073	164	557	965	747	2,434	213	754	1,261	1,343	3,572	
Balance of NT	91	194	177	101	563	94	206	186	103	590	128	365	510	291	1,295	187	561	753	590	2,090	
<b>Total</b>	<b>223</b>	<b>549</b>	<b>515</b>	<b>290</b>	<b>1,576</b>	<b>227</b>	<b>580</b>	<b>550</b>	<b>306</b>	<b>1,663</b>	<b>292</b>	<b>923</b>	<b>1,475</b>	<b>1,038</b>	<b>3,729</b>	<b>401</b>	<b>1,315</b>	<b>2,013</b>	<b>1,933</b>	<b>5,662</b>	
<b>Aust</b>																					
Capital Cities	15,825	55,240	87,947	87,130	246,142	16,176	57,466	90,945	88,898	253,486	21,552	85,018	183,430	185,898	475,898	29,667	122,299	251,979	325,499	729,444	
Balance of State	9,575	36,381	57,031	51,704	154,691	9,762	37,700	59,201	52,958	159,621	10,897	50,200	113,371	110,305	284,774	12,585	58,756	128,745	171,361	371,446	
<b>Total</b>	<b>25,400</b>	<b>91,621</b>	<b>144,978</b>	<b>138,834</b>	<b>400,833</b>	<b>25,938</b>	<b>95,166</b>	<b>150,146</b>	<b>141,856</b>	<b>413,106</b>	<b>32,450</b>	<b>135,217</b>	<b>296,802</b>	<b>296,204</b>	<b>760,672</b>	<b>42,252</b>	<b>181,055</b>	<b>380,724</b>	<b>496,860</b>	<b>1,100,890</b>	

Source: NATSEM calculations using ABS population projections. Capital cities includes the ACT

**Table 4 %age increase in the number of persons with dementia by age and gender, State and Territory, 2016-2056**

	2016-2017 (%)					2016-2036 (%)					2016-2056 (%)				
	30-64	65-74	75-84	85+	Total	30-64	65-74	75-84	85+	Total	30-64	65-74	75-84	85+	Total
<b>NSW</b>															
Sydney	2.3	3.8	2.9	1.7	2.6	30.7	47.7	100.3	100.7	84.4	71.2	101.4	165.7	238.7	171.8
Balance of NSW	1.6	3.3	3.0	2.3	2.8	2.1	26.5	82.3	93.7	69.2	7.7	34.8	87.3	176.4	101.9
<b>Total</b>	<b>2.0</b>	<b>3.6</b>	<b>3.0</b>	<b>2.0</b>	<b>2.7</b>	<b>19.0</b>	<b>38.4</b>	<b>92.3</b>	<b>97.7</b>	<b>77.8</b>	<b>45.3</b>	<b>72.2</b>	<b>130.6</b>	<b>212.2</b>	<b>141.4</b>
<b>Vic</b>															
Melbourne	2.5	3.8	3.2	2.1	2.9	40.0	58.1	102.4	109.1	91.3	91.9	128.9	183.7	273.9	198.3
Balance of Vic	1.6	3.7	3.7	1.6	2.8	5.8	33.2	96.6	101.7	78.7	13.9	47.4	111.3	202.9	123.0
<b>Total</b>	<b>2.2</b>	<b>3.8</b>	<b>3.4</b>	<b>2.0</b>	<b>2.9</b>	<b>30.1</b>	<b>50.4</b>	<b>100.6</b>	<b>106.9</b>	<b>87.5</b>	<b>69.4</b>	<b>103.7</b>	<b>161.8</b>	<b>252.9</b>	<b>175.6</b>
<b>Qld</b>															
Brisbane	1.9	4.3	4.5	2.3	3.5	41.1	57.0	127.7	139.3	108.5	96.6	127.7	222.7	328.7	226.9
Balance of QLD	2.4	3.8	4.7	3.0	3.8	32.4	52.7	117.7	144.3	104.3	69.1	100.7	185.4	321.8	199.8
<b>Total</b>	<b>2.2</b>	<b>4.0</b>	<b>4.6</b>	<b>2.7</b>	<b>3.7</b>	<b>36.3</b>	<b>54.6</b>	<b>122.0</b>	<b>142.0</b>	<b>106.1</b>	<b>81.4</b>	<b>112.2</b>	<b>201.2</b>	<b>324.9</b>	<b>211.6</b>
<b>WA</b>															
Perth	2.5	4.7	4.3	3.2	3.9	57.5	74.3	134.4	148.8	119.9	154.2	200.9	268.4	389.4	285.3
Balance of WA	3.6	4.9	4.9	4.0	4.6	39.4	79.0	149.4	162.1	125.8	78.9	146.3	237.1	403.8	250.2
<b>Total</b>	<b>2.8</b>	<b>4.8</b>	<b>4.4</b>	<b>3.3</b>	<b>4.0</b>	<b>53.2</b>	<b>75.4</b>	<b>137.4</b>	<b>151.2</b>	<b>121.1</b>	<b>136.4</b>	<b>188.9</b>	<b>262.1</b>	<b>392.1</b>	<b>278.2</b>
<b>SA</b>															
Adelaide	1.7	3.9	2.6	0.9	2.2	12.7	35.2	90.1	84.0	71.9	36.0	64.0	116.9	181.1	125.7
Balance of SA	1.0	3.4	3.8	2.2	3.0	-7.0	19.3	83.1	107.4	71.2	-5.0	18.0	72.8	180.8	92.2
<b>Total</b>	<b>1.5</b>	<b>3.8</b>	<b>2.9</b>	<b>1.2</b>	<b>2.4</b>	<b>7.6</b>	<b>30.9</b>	<b>88.3</b>	<b>89.4</b>	<b>71.7</b>	<b>25.4</b>	<b>51.3</b>	<b>105.4</b>	<b>181.0</b>	<b>117.2</b>
<b>Tas</b>															
Hobart	1.3	4.7	2.8	1.7	2.8	1.6	31.6	100.5	102.2	79.4	12.6	47.9	108.2	197.5	119.6
Balance of Tas	1.2	3.3	4.0	2.0	3.1	-5.2	21.8	92.4	117.5	76.0	-5.7	17.5	83.4	201.2	97.4
<b>Total</b>	<b>1.3</b>	<b>3.9</b>	<b>3.6</b>	<b>1.9</b>	<b>2.9</b>	<b>-2.5</b>	<b>25.5</b>	<b>95.7</b>	<b>110.8</b>	<b>77.4</b>	<b>1.7</b>	<b>29.1</b>	<b>93.4</b>	<b>199.6</b>	<b>106.4</b>
<b>ACT</b>															
<b>Total</b>	<b>1.2</b>	<b>4.5</b>	<b>5.0</b>	<b>3.2</b>	<b>4.0</b>	<b>33.8</b>	<b>46.3</b>	<b>125.5</b>	<b>158.8</b>	<b>110.2</b>	<b>80.2</b>	<b>109.6</b>	<b>204.5</b>	<b>339.0</b>	<b>216.0</b>
<b>NT</b>															
Darwin	1.7	5.3	7.7	7.0	6.0	25.2	57.1	185.3	296.1	140.3	62.4	112.6	272.7	612.5	252.6
Balance of NT	3.5	6.4	5.1	2.3	4.8	40.1	88.5	188.5	187.4	129.9	105.2	189.3	325.5	482.2	271.1
<b>Total</b>	<b>2.0</b>	<b>5.7</b>	<b>6.8</b>	<b>5.4</b>	<b>5.5</b>	<b>31.4</b>	<b>68.2</b>	<b>186.4</b>	<b>258.1</b>	<b>136.6</b>	<b>79.9</b>	<b>139.7</b>	<b>290.9</b>	<b>567.0</b>	<b>259.2</b>
<b>Aust</b>															
Capital Cities	2.2	4.0	3.4	2.0	3.0	36.2	53.9	108.6	113.4	93.3	87.5	121.4	186.5	273.6	196.4
Balance of State	2.0	3.6	3.8	2.4	3.2	13.8	38.0	98.8	113.3	84.1	31.4	61.5	125.7	231.4	140.1
<b>Total</b>	<b>2.1</b>	<b>3.9</b>	<b>3.6</b>	<b>2.2</b>	<b>3.1</b>	<b>27.8</b>	<b>47.6</b>	<b>104.7</b>	<b>113.4</b>	<b>89.8</b>	<b>66.3</b>	<b>97.6</b>	<b>162.6</b>	<b>257.9</b>	<b>174.7</b>

Source: NATSEM calculations using ABS population projections. \* Capital cities includes the ACT



in the country of birth by broad grouping between men and women with dementia. The 2012 SDAC indicates that around 18% of people with dementia are from a CALD background defined as speaking a language other than English at home. If the same approach to that used by Access Economics (2009)<sup>4</sup> to estimating the number of persons from a CALD background is applied to the 2016 data used in this report then around 67,600 people who speak a language other than English at home will have dementia (representing 17% of all persons with dementia in Australia).

Ethnic elders in Australia are a heterogeneous group with variable cultural, educational, and socioeconomic backgrounds and diversity in their life experiences. Over the last 30 years, the number of persons born in Australia aged 65 years or over has increased by around 70%. In sharp contrast, the number of older persons (i.e. aged 65+ years) born in countries from North West, Southern and Eastern Europe has increased by 140%; from North Africa, Middle East and Sub-Saharan Africa by 440%; and South East, North East, Southern and Central Asia by 830%.<sup>5</sup> Ageing of Australia's CALD population has major implications for the need for ethnic-specific dementia services including cultural specific information about dementia (see Parveen et al, 2016 for British experience in the perceptions of dementia and use of services in minority ethnic communities).

There is a lack of national data on the prevalence of dementia in Aboriginal and Torres Strait Islander people. However, a number of recent epidemiological studies suggest rates of dementia may be up to 3-5 times more common in Indigenous communities across remote, regional and urban Australia when compared to non-Indigenous rates and that dementia often occurs at younger ages in these communities (AIHW, 2012; de Souza-Talarico et al, 2016). For example, a study by Smith et al. (2008) of remote communities in the Kimberley region of Western Australia found a prevalence of dementia in the 65+ year age group of 26.8%. A second study by LoGiudice and colleagues (2015) reported 21% of Indigenous persons aged 65 years and above had dementia, and Radford et al (2015) 21% of those aged 60 years and above. LoGiudice et al also report a dementia prevalence rate of 7.3% in Aboriginal and Torres Strait Islander people aged 45 years and above. Two other studies of Indigenous people aged 45 years or above reported prevalence rates of 6.3% and 6.5% respectively (Cotter et al, 2012; Li et al, 2014). Arkles and colleagues (2010) in their review of the literature report that dementia affects Indigenous Australians at an earlier age than the general population, with a relatively larger proportion of Indigenous Australians in the 45

to 69 year age group of people with dementia. Averaging these prevalence rates suggest that there are currently around 10,200 Aboriginal and Torres Strait Islander people aged 45 years and above with dementia and 7,400 aged 65+ years. The Indigenous population is ageing and over the next 10 years, the number of older individuals (aged 65+ years) with dementia may double.

Information on the socio-economic status of individuals with dementia and their families is lacking. In terms of reporting person or household income for people with dementia, the 2012 SDAC either suppresses data because of sparse numbers or classifies the data as being unavailable for the majority of cases. However, the ABS has several indexes that summarise a range of information about the economic and social conditions of people and households living within areas.

The Index of Relative Socio-economic Disadvantage (IRSD) which includes only measures of relative disadvantage, suggests people with dementia are over-represented in the lowest quintile of the IRSD (26% of individuals vs an expected 20%) and under-represented in the highest quintile (13%). The Index of Economic Resources (IER) focuses on the financial aspects of relative socio-economic advantage and disadvantage, by summarising variables related to income and wealth (ABS, 2013). This also shows that around 26% of people with dementia live in the most disadvantaged communities in terms of a relative lack of access to economic resources such as income, home ownership and employment rates. Only 15% live in areas in the top IER quintile. A third index is the Index of Education and Occupation (IEO) which is designed to reflect the educational and occupational level of communities. The education variables in this index show either the level of qualification achieved or whether further education is being undertaken. The occupation variables classify the workforce into the major groups and skill levels of the Australian and New Zealand Standard Classification of Occupations (ANZSCO) and the unemployed (ABS, 2013). Persons with dementia are slightly over-represented in the lowest two quintiles of the IEO (44% vs. an expected 40%) and under-represented in the highest two quintiles (35% vs. an expected 40%).

Another special needs group are those people with dementia but who live alone in the community (Eichler et al, 2016). It is difficult to estimate the number of such individuals, as most studies and surveys tend not to identify this special needs group or have insufficient cases to accurately report on their prevalence in the population. Data from 2008-2009 on Aged Care Assessment Program (ACAP) clients with dementia

4. Access Economics (2009) assumed the same age-sex prevalence rates of dementia in the general population also applied to those from a CALD background

5. Based on data from the 1981 and 2011 population census.

living in the community showed that 34% lived alone, with women with dementia being more likely to live alone than men (41% and 22% respectively) (AIHW, 2012). Modelling undertaken in this report to estimate this special needs group uses the proportion of the general population living alone by age and sex, the DYNOPTA dementia age-sex prevalence rates used above and the proportion of men and women with dementia who are likely to be living in the community. The results suggest that in 2016 there may be as many as 118,000 individuals with dementia living alone in the community. These individuals represent about 39% of all persons with dementia in the community, and like the earlier ACAP data, more women with dementia (58%) were thought to be living alone than men (18%).

### 3.3 INCIDENCE OF DEMENTIA

The AIHW (2012) estimated that around 63,300 Australian adults would develop dementia in 2011, and Access Economics (2009) estimated approximately 79,100 cases. Based on the incidence rates calculated from the AIHW ratios of incident cases to prevalence, the number of persons developing dementia in 2016 is estimated to be in excess of 86,400 persons, nearly 5,500 developing younger onset dementia (Table 5). This is equivalent to 237 new cases of dementia in Australia each day. These numbers increase in 2017 by 3.8% for males and 2.5% for females. The number of males expected to develop dementia in 2017 rises to over 41,000 individuals and with nearly 48,000 females likely to develop dementia during the year. This represents 244 people developing dementia each day in Australia.

However, in 40 years' time the incidence will be in the order of 240,000 new cases per year, which is equivalent to over 650 cases per day. The patterns of increase in the number of incident cases follow those for prevalence.

The projected number of new cases of dementia each year by age and gender for the period 2016-2056 is provided in Appendix 2.

### 3.4 RISK AND PROTECTIVE FACTORS FOR DEMENTIA

The prevalence and incidence of dementia not only related to age and gender but also reflect the joint or interactive effects of a range of 'lifestyle' and other factors. There are many risk and protective factors known to be associated with either an increased or decreased risk of developing dementia in late life. These are discussed in detail elsewhere (see for example Woodward, M et al, 2007; Barnes et al, 2009; AIHW, 2012; Anstey et al, 2013) and therefore will only be briefly commented upon here. Being overweight or obese in mid-life; having diabetes or depression; raised serum cholesterol; having at risk alcohol consumption; being a current or ex-smoker; having been exposed to pesticides; having a traumatic brain injury; or having low levels of social participation all increase the increase of dementia in late life. For example, being overweight in mid-life imposes a relative risk of 1.26 compared with those who are normal weight and being obese an increased risk of 1.64 (Anstey et al, 2011).

However, having more years of schooling i.e. higher levels of educational attainment, being more physically active as well as cognitively active, and having higher levels of fish and vegetable intakes confer some protection against dementia. For example, early school leavers i.e. those who left high school before year 8 have a 2.2 fold increase in their risk of dementia and those leaving between years 8 and 11 a relative risk of 1.5 compared with individuals completing high school (year 12) (Anstey et al, 2013).

Other factors such as a family history of dementia also increase one's risk of developing dementia while one gene (Apolipoprotein E) has been associated with an increased risk of late onset Alzheimer's disease. Three additional genes (Amyloid Precursor Protein, Presenilin 1 and Presenilin 2) have been found to be associated with younger onset Alzheimer's disease (<https://www.fightdementia.org.au/about-dementia-and-memory-loss/am-i-at-risk/risk-factors>).

### 3.5 MORTALITY

People with dementia have an increased risk of dying compared with persons of a similar age and gender but who do not have dementia (Rait et al, 2010; Brodaty et al, 2012; Garcia-Ptaceka et al, 2014; Park, 2015). Deaths with the underlying cause being dementia have been increasing in number for many years. In Australia, as elsewhere, this information is sourced from death certificates which are problematic for identifying people with dementia and the role dementia may have played in the death. As pointed out by AIHW (2012) disentangling the cause of death for older individuals who had multiple comorbidities can lead to the under-reporting of dementia, medical practitioners' views about attributing dementia as the cause of death are thought to influence the recording of dementia as the underlying cause of death, and changes over time in the recognition, diagnosis and classification of dementia are likely to have affected the frequency with which this condition is recorded as a cause of death.

ABS statistics on cause of death (ABS 2015, 2016) show that by 2013 dementia<sup>6</sup> had outranked cerebrovascular diseases as the second leading cause of death of Australians (ABS, 2015). By 2015, the number of deaths per year caused by dementia had reached 12,625 which accounted for 8% of all deaths (Table 6). In 2015, the standardised death rate for dementia as the underlying cause for males was 35.4 and females 43.1 deaths per 100,000 of the estimated mid-year population. These figures represent a significant increase over the previous 10 years when in 2005 dementia was recorded as the underlying cause in only 4,653 deaths and contributed to only 4% of total deaths. Over the five year period 2010-2015 the number of deaths due to dementia in males increased on average by 7.8% per year and for females by 7%.

In 2015, deaths with dementia as the underlying cause contributed to 5.4% of total deaths for men and 10.6% for women (Table 6). If the annual growth rates in the number of deaths recorded over the period 2010-2015 extend to 2016 then there would be around 4,717 deaths in males from dementia and 8,832 in females. The number of women dying from dementia is 1.9 fold higher than for men. These figures suggest that 37 Australians are now dying each day from dementia. However, the number of deaths of persons with dementia (rather than those caused by dementia) is

**Table 5 Estimated number of new (incident) cases of dementia by age and gender in 2016, 2017, 2036 and 2056**

	2016			2017			2036			2056			Growth 2016-36			Growth 2016-56		
	Male		Female	Male		Female	Male		Female	Male		Female	Male		Female	Male		Female
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
<b>30-64</b>	2,662	6.3	2,790	6.3	2,713	5.68	2,855	6.2	3,397	6.966	4.2	4,433	9.068	3.8	276	279	66.5	66.1
<b>65-69</b>	3,748	11.2	5,946	11.2	3,737	9.698	5,961	10.9	4,959	13,040	7.9	6,732	17,447	7.3	32.3	35.9	79.6	80.2
<b>70-74</b>	5,795	11.8	4,374	10.169	6,227	10.932	4,704	12.3	9,147	16,274	9.9	12,417	21,793	9.1	578	62.9	114.3	114.4
<b>75-79</b>	7,508	17.4	7,567	15,075	7,823	15,697	7,874	17.6	14,466	29,432	17.9	17,934	35,920	15.1	92.7	97.8	138.9	137.7
<b>80-84</b>	7,664	18.8	8,616	16,279	7,972	16,780	8,808	18.8	16,922	34,777	21.1	22,889	46,477	19.5	120.8	107.2	198.7	173.8
<b>85+</b>	12,324	34.4	17,445	29,769	12,718	30,436	17,718	34.2	29,773	64,046	38.9	50,512	107,520	45.1	141.6	96.5	309.9	226.8
<b>Total</b>	39,700	100.0	46,738	86,438	41,191	89,111	47,920	100.0	78,663	164,534	100.0	114,919	238,226	100.0	98.1	83.7	189.5	163.8

Source: NATSEM calculations using ABS population projections and AIHW incidence to prevalence ratios

6. Dementia coded in ICD-10 principally includes dementia in Alzheimer's disease (ICD-10 code F00), vascular dementia (F01), unspecified dementia (F03) and Alzheimer's disease (G30).

substantially higher. This number can be calculated from the difference in the number of prevalent cases of dementia in 2016 and 2017 taking into account the number of expected incident cases. Using this approach, approximately 33,000 males with dementia are expected to die in 2016 and 41,164 females or around 18% of the population with dementia. Thus, the current rate of identification of dementia as the underlying cause of death on death certificates represents only 15% of all deaths in males with dementia and around 22% of females. This supports studies that have found significant under-reporting of dementia on death certificates and that rates of mortality based on death certificate data will under-estimate the impact of dementia (Romeroa et al, 2014; Perera et al, 2016).

The average survival time for people with dementia from the onset of symptoms to death appears to be between seven and nine years (AIHW, 2012) but a review of the evidence by Brodaty and colleagues (2012) and Staekenborg et al (2016) show that survival times vary considerably from one study to another (ranging from three to 13 years).

**Table 6 Deaths with an underlying cause of dementia, by sex, 2015**

	2005			2010			2015		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
<b>Number of deaths</b>	1,434	3,219	4,653	2,920	6,083	9,003	4,374	8,251	12,625
<b>Percent of all deaths</b>	2.13	5.07	3.56	3.97	8.69	6.28	5.40	10.60	7.90

Source: ABS (2016)

# 4. CARING FOR PERSONS WITH DEMENTIA 2016-2056

## KEY POINTS

- In 2016, approximately 94,910 persons with dementia were living in cared accommodation, 94% of whom were residents of residential aged care facilities. People with dementia represent just over half of all residents in RACFs and they tend to have much higher care needs than residents who do not have dementia.
- Around 83% of all males with dementia and 71% of females with dementia live in the community.
- Approximately 46% of those living in the community receive informal assistance only, 29% receive both informal and formal care, 16% receive formal assistance only and 9% no assistance at all.
- The main carers of a person with dementia living in the community is the individual's spouse or partner (around 35% of carers), a daughter or son (41%) with other family members such as daughters-in-law, sons-in-law, grandchildren, sisters and brothers being the primary carer for another 15% of persons with dementia.
- In 2017, an estimated 94,672 paid carers will be looking after people with dementia in the residential aged care setting, and 196,491 carers in the community, the majority of whom are informal carers.
- By 2056, the need for carers for people with dementia is expected to increase to 250,400 paid workers in cared accommodation and 525,540 carers in the community if current levels of care are to be maintained.

The increasing number of people with dementia is placing stress on care and support services provided through both informal care arrangements in the community and formal home care packages and residential aged care facilities. The AIHW (2012) estimated that in 2011, 77.3% of males and 65.2% of females with dementia lived in the community. The AIHW calculated the number of people with dementia living in the community by subtraction, using information on the overall number estimated to have dementia minus the estimated number of people living in cared accommodation. The number of permanent residents in residential aged care facilities (RACFs) (identified through the ACFI data) was scaled up by 5.7% as the 2009 SDAC indicated that this proportion of people with dementia were living in types of cared accommodation other than RACFs.

Applying a similar approach to the updated 2016 data indicates that around 148,200 males with dementia and 157,700 females with dementia would be living in the community. These individuals represent 83.2% of all males with dementia and 70.8% of females. The relative increase in community dwelling individuals with dementia in part reflects that the growth in number of persons with dementia is outstripping the growth in RACF operational places but also recent policy agendas emphasising 'ageing in place' with increasing support for and programs directed at older Australians to stay at home longer. The use of different data sources and prevalence rates may also account for some of this difference.

In 2015, 88,572 individuals with dementia were living in RACFs (Table 7). This number is expected to have increased to around 89,500 persons for 2016. People with dementia account for 52% of all residents in RACFs. The majority of RACF residents with dementia are women – females with dementia outnumber males five to two. Over the past five years, the number of persons with dementia living in cared accommodation – principally RACFs – only increased by just over 1% per year (1.03%). In 2015, 1,888 residents of RACFs had younger onset dementia or 2% of all residents with dementia, indicating that the majority of persons with younger onset dementia are cared for at home.

Residents of cared accommodation who have dementia tend to have high care needs. For example, over three quarters of people with dementia (78.4%) living in RACFs have high-care needs with respect to behaviour (cognitive skills, wandering, verbal behaviour, physical behaviour and depression); 59.2% with activities of daily living (care needs covering nutrition, mobility, personal hygiene, toileting and continence); and 52.1% with complex health needs (e.g. use of medications, and the residents' need for the management of complex health care procedures) (AIHW, 2012; AIHW National Aged Care Data Clearinghouse). The proportion of persons with dementia having high care needs is significantly more than the percentage of residents without dementia (38.4%, 42.4% and 50.6% respectively).

**Table 7 Persons with dementia in permanent residential aged care, 2015**

	Male		Female	
	Number	Proportion of all Residents (%)	Number	Proportion of all Residents (%)
<b>0–49</b>	57	19.7	32	12.4
<b>50–64</b>	979	32.2	820	31.9
<b>65–69</b>	1,234	28.1	1,115	37.9
<b>70–74</b>	2,202	34.0	2,467	46.8
<b>75–79</b>	3,901	37.4	5,481	54.2
<b>80–84</b>	6,031	45.0	11,264	56.7
<b>85–89</b>	7,275	54.0	18,032	55.2
<b>90–94</b>	4,416	58.3	15,818	52.3
<b>95+</b>	1,165	41.5	6,283	49.0
<b>Total</b>	<b>27,260</b>	<b>50.6</b>	<b>61,312</b>	<b>52.5</b>

Source: AIHW National Aged Care Data Clearinghouse

It is difficult to identify the need for assistance by persons with dementia living in the community and whether this is being adequately met through formal care, informal means or a combination of both. Information on the source of assistance for people with dementia living in the community is available in the 2012 SDAC. This is summarised in Table 8, noting that the SDAC significantly under-reports the number of people with dementia and is heavily biased to those with severe and profound limitations in activities of daily living. The majority of both men and women relied solely on informal carers to provide assistance. Around three in 10 used a combination of informal and formal care, with less than 20% using formal assistance only. Around 9% received no assistance, because they either were able to live independently or were not able to access support. Overall, nine in every 10 people with dementia living in the community were receiving care from one or more carers.

**Table 8 Source of assistance for people with dementia living in the community**

	Males (%)	Females (%)	Persons* (%)
<b>Informal assistance only</b>	57.5	46.1	45.8
<b>Informal and formal assistance</b>	26.0	30.7	29.0
<b>Formal assistance only</b>	6.4	19.3	16.1
<b>No assistance</b>	10.1	3.9	9.0

Source: 2012 SDAC. Because of small cell sizes the estimates in the SDAC have high relative standard errors.

Main carers of a person with dementia living in the community are the individual's spouse or partner (around 35% of carers), or a daughter or son (41%). Other family members such as daughters in-law, sons in-law, grandchildren, sisters and brothers are the primary carer for another 15% of persons with dementia.

The same approach used by AIHW is applied in this report to estimate the current and future number of carers of people with dementia living either in the community or in cared accommodation. The average number of carers per person by disability level is multiplied by the estimated number of people with dementia in the community and in residential care by dementia severity level. AIHW (2012) based on data from the 2009 SDAC suggested that people with milder forms of

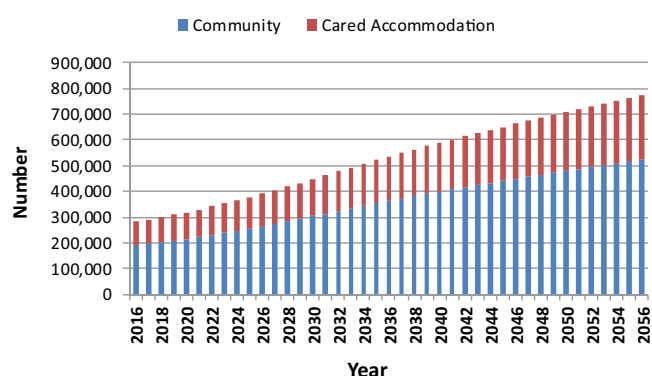
dementia have an average of 0.5 carers, those with moderate severity 0.7 carers while those with more severe forms of dementia have an average of 1.6 carers each. Around 69.1% of males with dementia living in the community have milder forms of the disorder and 81.4% of females, while only 7 and 5.8% respectively in cared accommodation, the majority of who have dementia of a moderate severity (Table 9).

Using this approach, AIHW (2012) initially estimated that there were around 240,300 carers of people with dementia in the community in 2011. However, since the SDAC under-represents those in the earlier or milder stages of dementia, AIHW indicated that the derived average number of carers of people with milder forms of dementia (0.7 per person) may be too high, and that the estimate of 240,300 carers was more likely to be an upper bound on the number of carers of people with dementia in the community. If the average was actually 0.5, the estimate would be 216,300 carers of people with dementia, and if it was 0.3, the estimate would be 195,300 carers (AIHW, 2012).

Around 83% of males and 71% of females with dementia currently live in the community. In 2016, approximately 29,945 males with dementia and 64,965 females with dementia were living in cared accommodation. Given their level of dementia severity, it was estimated that in 2016 that there would be around 92,000 carers looking after people with dementia in the residential care setting, and in 2017 94,672 carers. These appear to be realistic estimates. The Carers Workforce Census indicated that there were a total of 147,086 direct care workers employed in residential aged care in 2012 (King et al, 2012). If increases in this workforce observed between 2007 and 2012 continued over the next four years then in 2016 the total number of paid carers working in the residential setting would be around 159,600. Just over half of RACF residents have dementia but they have much higher care needs than those residents without dementia. Therefore, it seems reasonable that around 57-58% of these workers (91,000-92,500) may care for residents with dementia.

Based on the number of persons with dementia expected to be living in the community and their likely disease severity, the estimate of the number of carers of people with dementia in the community in 2016 was modelled at 190,500 carers and in 2017 196,491 carers. The majority of these carers are family members or friends. These figures are in keeping with the lower estimate calculated by AIHW for 2011.

**Figure 3 Projection of the future need for carers by setting, 2016-2056**



Source: NATSEM calculations

**Table 9 Proportion of people with dementia by residency, severity and gender**

Severity	In the Community		In Cared Accommodation	
	Males	Females	Males	Females
Mild	69.1	81.4	7.0	5.8
Moderate	20.7	12.5	61.9	62.8
Severe	10.2	6.2	31.1	31.4

Source: AIHW (2012)

Projections over the next 40 years can be interpreted as the future demand for carers. If patterns of care remain unchanged over the next 20 years, then by 2036, some 536,150 carers will be needed to provide assistance to persons with dementia – 173,220 carers working in the cared accommodation sector and 362,930 carers in the community (Figure 3). This represents a 90% increase in the number of carers in keeping with the growth in the number of persons with dementia. By 2056, the number of carers that are likely to be needed for assisting people with dementia is 250,400 in cared accommodation and 525,540 in the community. The question remains whether or not this growth in demand can be met by an increased paid carer workforce and through the provision of unpaid informal care in the community. The annual projection of carers over the period 2016 to 2056 is provided in Appendix 3.

# 5. DIRECT COSTS OF DEMENTIA 2016-2036

## KEY POINTS

- The total annual direct cost of dementia was estimated to be \$8.8 billion in 2016, which is expected to rise to \$9.1 billion in 2017. These costs consist of direct medical expenses (hospitalisation, GPs and specialists and pharmaceuticals) and direct non-medical expenses of aged care (home care or nursing homes), transportation and other costs.
- Costs at the person level differ by age and gender, severity of dementia and care setting. In 2016 the per capita costs ranged from \$15,911 for a person aged <70 years living in the community with mild dementia to \$137,926 for a male aged 75-79 years living in residential aged care with severe dementia.
- At the individual level, the per capita cost in 2016 for a new incident case of dementia is estimated to be \$47,811 per annum and for the subsequent years of dementia the cost is estimated to be \$14,842 per annum.
- Costs of hospitalisation and care costs are the largest components of the direct costs of dementia, representing 52.6% and 37% of total direct costs respectively. The cost of hospitalisation of people with dementia was estimated to be \$4.6 billion and the cost of care \$3.3 billion in 2016, and \$4.8 billion and \$3.4 billion respectively in 2017.
- The direct costs of dementia are expected to rise to \$16.7 billion by 2036 and by 2.7 fold to \$24.1 billion by 2056 (in 2016 dollars). Costs of hospitalisation and the cost of care are projected to rise to \$8.8 billion and \$6.2 billion by 2036 and to \$12.6 billion and \$8.9 billion respectively by 2056.

## 5.1 OVERVIEW

The direct costs of dementia are estimated in this section of the report. These are divided into direct medical costs (e.g. hospital, medical services and medications) as well as direct non-medical costs that are derived from outside of the health care system, such as aged care services and transportation. A recent study by Schaller et al, (2014) summarises the average annual total costs per person with dementia from studies in the last two decades in many countries. Table 10 shows that on average, total costs of dementia (direct medical costs, non-direct medical costs and costs of care) in mixed settings are the lowest compared with community-based or institutional settings.

Recent studies applied a combination of methodologies to estimate dementia costs in a comprehensive manner based on longitudinal survey data (Dixon et al, 2014; Hurd et al, 2013; Knapp et al, 2012). From the survey, the studies were able to identify the initial cost when people were first diagnosed

with dementia and the annual costs related to medication and costs of care thereafter. Cost-benefit or cost-effectiveness analytical methods were then applied over the average life expectancy with different care settings and degree of severity of dementia. Thus, the annual total costs of dementia per person in these studies reflected a lifetime average, depending on different care settings and assumptions.

Studies over the last two decades to estimate dementia costs in Australia are relatively limited. The report on the economic impact of dementia in 2003 by Access Economics attempted to estimate the total annual total costs by applying a top-down approach based on methodology developed by the AIHW (Access Economics, 2003). The data were based on direct health system costs estimated by AIHW in 1993-1994. The costs consisted of nine components, which include all direct medical costs such as hospitalisation and direct non-medical cost (Table 11).



**Table 10 Annual total costs (direct medical costs and direct non-medical costs) per person with dementia based on care settings and countries (\$AUD 2013).**

<b>Community-Based Setting</b>	<b>Direct costs components including medical and non-medical costs</b>		<b>Total Costs</b>
<b>Studies</b>	<b>Year of study</b>	<b>Country</b>	<b>\$AUD (2013 price)</b>
Lopez-Bastida et al.2006	2001	Spain	58,285
Allegri et al. 2007	2001	Argentina	8,219
Beeri et al. 2002	1999	Israel	25,502
Kraft et al. 2010	2007	Switzerland	41,882
Mesterton et al. 2010	2007	Sweden	20,107
Rapp et al. 2012	2004	France	49,312
Rigaud et al. 2003	1996	France	36,097
Schwarzkopf et al. 2011	2008	Germany	67,210
Wang et al. 2008	2006	China	7,084
Zhu et al. 2008	2004	USA	32,024
Herrmann et al. 2006	2000	Canada	16,754
<b>AVERAGE</b>			<b>32,952</b>

<b>Institutionalised Setting</b>	<b>Direct costs components including medical and non-medical costs</b>		<b>Total Costs</b>
<b>Studies</b>	<b>Year of study</b>	<b>Country</b>	<b>\$AUD (2013 price)</b>
Allegri et al. 2007	2001	Argentina	14,996
Beeri et al. 2002	1999	Israel	24,444
Kraft et al. 2010	2007	Switzerland	52,174
Mesterton et al. 2010	2007	Sweden	73,260
<b>AVERAGE</b>			<b>41,219</b>

<b>Mixed Setting</b>	<b>Direct costs components including medical and non-medical costs</b>		<b>Total Costs</b>
<b>Studies</b>	<b>Year of study</b>	<b>Country</b>	<b>\$AUD (2013 price)</b>
Suh et al. 2006	2002	Korea	21,673
Coduras et al. 2010	2006	Spain	30,116
Allegri et al. 2007	2001	Argentina	7,803
Jonsson et al. 2006	2003	Scandinavia	23,061
Leicht et al. 2010	2008	Germany	43,502
Mesterton et al. 2010	2007	Sweden	40,639
Murman et al. 2007	2001	USA	43,973
Livingston et al. 2004	2003	UK	31,476
Wimo et al. 2003	2000	Sweden	34,782
<b>AVERAGE</b>			<b>30,781</b>

Source: Schaller et al. (2014)

The total costs are adjusted with the average index currency in 2013 as the study presented all the costs in USD 2013

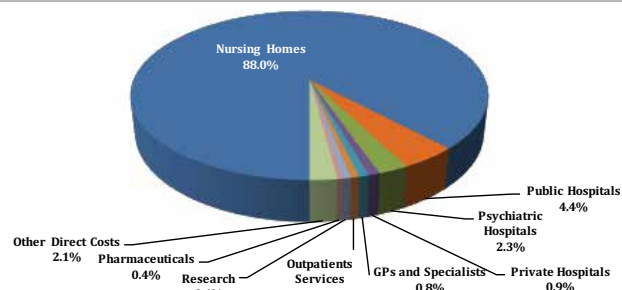
With the approximate prevalence number of 162,000 people with dementia in Australia (Access Economics, 2003) and aggregate total costs of \$3,236 million, the annual average total cost per person with dementia in 2002 was \$19,975. The breakdown of cost components (Figure 4) indicates that the cost of nursing home care was the largest portion of total costs (88%), while costs related to direct medical costs were below 5% on average e.g. public hospitals cost (4.4%), psychiatric hospitals (2.3%), private hospitals (0.9%), GPs and specialists (0.8%), and pharmaceuticals (0.4%). The report also projected that the total costs of dementia would grow by 82% by 2011 or from \$3.4 billion in 2002 to \$5.96 billion in 2011.

**Table 11 Component of direct costs for dementia in 2002 – Access Economics (\$AUD 2002)**

Cost Components	\$AUD (million)	\$AUD/person
<b>Nursing Homes</b>	2847.1	17575
<b>Public Hospitals</b>	141.2	872
<b>Psychiatric Hospitals</b>	74.7	461
<b>Private Hospitals</b>	28.0	173
<b>GPs and Specialists</b>	24.5	151
<b>Outpatients' Services</b>	20.6	127
<b>Research</b>	19.2	119
<b>Pharmaceuticals</b>	13.8	85
<b>Other Direct Costs</b>	66.8	412
<b>Total Costs</b>	3236	19975

Source: Access Economics (2003)

**Figure 4 The Proportion of Dementia Costs in 2002**



Source: Access Economics Report (2003)

In the report of Dementia in Australia (AIHW, 2012), the expenditure on hospitalisation was estimated in 2009-2010 by using data from the National Hospital Cost Data Collection. In general, the increasing of hospitalisation costs for patients with dementia as the principal diagnosis<sup>7</sup> corresponds with age groups (Table 12). Moreover, the average cost per patient/ per day for females was slightly higher than males. The cost for females was \$724 per day while the cost for males was \$612 per day. The daily cost per patient was \$664 for males and females while the average length of stay (LOS) was 17.7 days.

The AIHW 2012 report stated that the amount of hospitalisation expenditure increased by \$34.9 million from 2005-2006 to 2009-2010, or from \$109.6 million to \$144.5 million. These figures are far below the projection from Access Economics of the total direct cost of dementia between 2002 and 2011 where costs were projected to grow by 82%.

The most recent data available online from the AIHW National Hospital Morbidity Database on hospital separations by principal diagnosis is for 2013-14. By 2013-14, the number of hospital separations with dementia as the principal diagnosis<sup>8</sup> had increased to 7,008 separations for males and 7,234 for females. However, total patient days spent in hospital by males for dementia decreased (114,306 patient days) and increased only slightly for females (101,869 patient days). This suggests that the ALOS for hospitalisations for dementia in 2013-14 was two days shorter than that recorded in 2009-10. Whether the 2013-14 ALOS of 15.2 days is unusually low or indicative of a trend for reduced length of hospital stay for dementia requires further investigation.

A recent report from AIHW (2013) attempted to identify the cost of dementia care in hospital by applying the Hospitals Dementia Service (HDS) data in 2006-2007 in New South Wales. The data in this study related to people aged 50 years and over by 1 July 2006. The HDS population included 252,313 patients, where 20,748 or 8.2% were identified as having dementia and 231,565 without dementia. The estimation found that the total cost of care for people with dementia in New South Wales' public hospitals was \$462.9 million. The annual average cost for people with dementia was approximately \$22,313 and \$14,573 for people without dementia, or \$7,740 more in care costs for people with

7. The principal diagnosis is defined as the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital. <http://www.aihw.gov.au/hospitals-data/principal-diagnosis-data-cubes/>

8. These numbers were extracted using the same ICD codes used by AIHW for the data presented in Table 12 - ICD-10-AM 8th edition F00, F01, F02, F03, F05.1, G30 and G31.3.

**Table 12 Hospitalisation costs with dementia as the principal diagnosis by gender and age (\$AUD 2009-2010)**

Gender/ Age	Hospitalisations (number)	Patient days	Average length of stay (days)	Expenditure (\$ million)	Cost per hospitalisation (\$)	Cost per patient/ per day (\$)
<b>Males</b>						
< 70	596	18,648	31.3	6.9	11,511	367.89
70–74	751	12,599	16.8	8.8	11,766	701.37
75–79	1,089	27,093	24.9	12.8	11,790	473.89
80–84	1,701	27,688	16.3	19.9	11,723	720.17
85–89	1,396	21,414	15.3	16.5	11,825	770.90
90–94	425	7,313	17.2	5.0	11,854	688.93
95+	74	1,022	13.8	0.9	11,808	855.00
<b>Total</b>	<b>6,032</b>	<b>115,777</b>	<b>19.2</b>	<b>70.9</b>	<b>11,753</b>	<b>612.35</b>
<b>Females</b>						
< 70	583	12,797	22.0	6.6	11,358	517.45
70–74	616	11,291	18.3	7.3	11,788	643.11
75–79	1002	16,480	16.5	11.9	11,842	719.99
80–84	1,574	25,093	15.9	18.5	11,781	738.99
85–89	1,622	23,731	14.6	19.2	11,827	808.36
90–94	687	10,032	14.6	8.1	11,812	808.91
95+	170	2,267	13.3	2.0	11,810	885.64
<b>Total</b>	<b>6,254</b>	<b>101,691</b>	<b>16.3</b>	<b>73.6</b>	<b>11,768</b>	<b>723.74</b>
<b>Persons</b>						
<b>Total</b>	<b>12,286</b>	<b>217,468</b>	<b>17.7</b>	<b>144.5</b>	<b>11,761</b>	<b>664.44</b>

Source: AIHW Report (2012): Dementia in Australia

dementia. These figures only calculated hospital costs, which are categorized as one of the direct medical costs when compared with the Access Economics report in 2003.

The methodology to estimate dementia costs utilised the Australian Refined Diagnosis Related Group (AR-DRG), which links the characteristics of patients to match resource funding, budgeting and related policy development (AIHW 2013). The linked data recorded the number of hospital episodes and hospital stay. In terms of patients with dementia, the average number of episodes per patient was 2.9 episodes and the average length of hospital stay per patient was 2.4 days. As seen in Table 13, the average costs per episode of care was \$7,720 (\$7,740 for patients aged 70 years or over), while the average cost per hospital stay was \$9,395 (\$9,431 for patients aged 70 and over).

The AIHW argued that the advantage of using the HDS data was the ability to link hospital episodes for a robust and accurate estimation. The limitation of the HDS data as it stated in the report is the data is restricted to patients in public hospitals in New South Wales and there is no classification in order to link to the National Weighted Activity Unit (NWAU) calculation. The major limitation is that the report excluded the cost component incurred outside the hospital.

The most recent studies focusing on dementia costs in Australia were conducted by Bail et al. (2015) and Annear et al. (2016). These studies apply AIHW public hospitals' data in 2006-2007 and a database of 4,332 separations from a large regional hospital in Tasmania in 2013-2014. The estimation follows the AIHW method by utilising Diagnostic Related Group (DRG) codes on diagnosis and treatment. The study found that the average cost for patients with dementia in 2013

**Table 13 Cost of Hospital Stays and Episodes (\$AUD 2006-2007)**

Total Hospital Cost	Per-Episode of Care		Per-Hospital Stay	
	All (\$)	Age ≥70 (\$)	All (\$)	Age ≥70 (\$)
<b>Total Costs Annual (\$)</b>				
<b>With Dementia</b>	22,313	22,397	7,720	7,749
<b>Without Dementia</b>	14,573	15,475	5,010	5,320
<b>GAP</b>	7,740	6,922	2,710	2,429

Source: AIHW Report (2013): Dementia care in hospitals: costs and strategies

and 2014 was \$10,322 and \$10,827 respectively, compared with patients without dementia with costs of \$8,119 in 2013 and \$8,299 in 2014. In terms of hospital stays, the mean LOS for patients with dementia was around seven days in 2013-2014 compared with five days for patients without dementia.

As noted in the Technical Notes, the cost of pharmaceuticals is considered as a treatment cost incurred outside of hospitals. The cost of prescribed medicines used in the treatment of the cognitive symptoms of dementia provided under the Pharmaceutical Benefit Scheme (PBS) (and Repatriation PBS) are not estimated directly from the PBS benefits paid by government and consumer out-of-pocket co-payments. Rather, these costs are included in the estimation of the component costs.

However, the main drugs used in the treatment of dementia and which are subsidised through the PBS are the cholinesterase inhibitor drugs of donepezil, galantamine and rivastigmine. A fourth drug memantine became available under the PBS in 2008-09. This targets the neurotransmitter glutamate which is present in high levels in people with Alzheimer's disease.<sup>9</sup> In 2015-16, some 323,991 scripts for donepezil were dispensed at a cost to government of \$8.76 million and \$1.84 million in patient co-payments; 86,878 scripts for galantamine with \$3.42 million in PBS/RPBS benefits and \$0.65 million in patient co-payments; 63,158 scripts for rivastigmine with a cost to government of \$5.62 million and patient contribution of \$0.47 million; and 38,948 scripts for memantine at a cost of \$2.04 million in benefits and \$0.30 million in patient co-payments.<sup>10</sup> Thus, total cost of these four drugs in 2015-16 alone was \$23.1 million.

## 5.2 METHODOLOGY FOR DIRECT COST ESTIMATION

This study develops a methodology to estimate the costs of dementia by combining methods chiefly based on those used by the AIHW in terms of hospitalisation costs. The calculation also follows studies that calculate the total dementia costs based on direct medical costs and direct non-medical costs (Schaller et al, 2014). The calculation is an actual out-of-pocket cost, which excludes subsidies and support from government. The sub-classification also includes age groups, degree of dementia severity, and care settings.

Per capita costs by first year of dementia and subsequent years, dementia severity and care setting are derived first. Aggregate estimation costs are then calculated based on the prevalence number of people with dementia provided earlier in the report. Total costs are classified by age groups, gender, and States/Territories.

The assumptions and methods for the estimation are outlined in the Technical Notes.

**Table 14 The cost components and total direct cost for people diagnosed with dementia in Australia (in \$AUD 2016)**

Cost Components	Male (\$AUD)	Female (\$AUD)	Average Person (\$AUD)
Hospitalisation	34,125	28,970	31,459
GPs and Specialists	4,736	4,021	4,366
Pharmaceuticals	2,036	1,729	1,877
Transportation and Other Costs	984	835	907
Care costs	8,551	9,855	9,202
<b>Total Direct Cost</b>	<b>50,432</b>	<b>45,410</b>	<b>47,811</b>

Source: NATSEM calculation

9. <https://www.fightdementia.org.au/national/about-dementia/how-is-dementia-treated/drugs-used-to-relieve-behavioural-and-psychological-symptoms-of-dementia>

10. Data on PBS/RPBS script volumes and benefits was provided by Medicines Australia through PBS online statistics portal.

## 5.3 TOTAL DIRECT COSTS OF DEMENTIA

### 5.3.1 Total direct costs in general

The models to estimate total direct costs of dementia are developed based on the assumptions in the Technical Notes and are described in detail in the Technical Notes. First, the estimation is calculated on average, applying in terms of hospitalisation the LOS based on an average of 17.7 days for people diagnosed with dementia in the initial year (AIHW, 2012) and 2.4 days in the next episode or in subsequent years (AIHW, 2013). The proportion of cost components such as hospitalisation, GPs and specialists, pharmaceuticals, and other costs follows previous studies (AIHW, 2013; AIHW, 2012; Access Economics, 2003). The calculation for direct non-medical (care cost) follows AIHW (2012) where on average 77% of people with dementia stay in community home care while 23% are in aged care.

On average, the total direct costs (medical and non-medical) of dementia in 2016 are estimated to be \$47,811 per person when people are first diagnosed with dementia (Table 14). Almost 66% of the cost goes to hospitalisation expenditures (\$31,459), while 19% are for care expenses (\$9,202). By gender, the estimated total direct cost for males (\$50,432) is higher than females (\$45,410) due to a longer average length of stay in hospital. The cost for subsequent years is estimated to be \$14,842 per annum for a person with dementia. In the following year most of the expenditure goes to the cost of care (65%), while hospitalisation is about 29% of the total cost. By gender, the average cost for males in the subsequent years is estimated to be \$14,202, while for females the cost is \$15,483 per annum.

### 5.3.2 Total direct costs per person by gender, age groups and degree of severity

The total cost of dementia in 2016 is also estimated for two different settings. The calculation also includes classification by degree of severity, gender and age groups. First, for the non-institutionalised community setting or home care, the average initial total costs when a person is diagnosed with dementia is \$45,393 in 2016 prices (Table 15a). The expenditure component includes hospitalisation costs with the average LOS and home care costs for the rest of the year. However, the gap between the total costs of severe dementia and moderate or mild dementia is relatively large (\$65,164 and \$66,254 respectively). The reason is the component of the price weight for a severe condition is five times larger than for moderate or mild dementia. The average initial total costs of dementia for males (\$48,585) are 15% higher than for female (\$41,609). This is due to a longer average LOS for males (19.2 days) than females (16.3 days). The pattern is also similar in terms of the degree of severity of dementia.

Meanwhile, in an institutionalized setting or in aged care or nursing homes, the average initial costs when a person is diagnosed with dementia is \$55,904 or 23% higher than the home care setting (Table 15b). The average costs of dementia for males (\$59,051) is 11% higher than females (\$52,968) and the degree of severity consistently show a large gap between those with severe symptoms versus moderate or mild condition.

The total costs of dementia in following years after the diagnosis, as stated in the assumption of direct medical costs, follows the average LOS of multiple episodes of 2.4 days (AIHW, 2013). The average total costs of dementia in general is \$12,835 in the home care setting, while total costs in residential aged care/nursing home setting is \$23,810 or 86% more than the community home care setting. A significant gap in total costs can also be seen in terms of the degree of severity. The average gap between residential age care/nursing homes and home care in all degrees of severity is \$10,975. The large gap between these two settings is due to the difference in the basic daily fee between home care and aged care services.

**Table 15 Total Direct Costs of Dementia in 2016 by care setting, gender, and age groups**

**a. Home Care Setting (in \$AUD 2016)**

<b>Males</b>	<b>Average</b>	<b>Severe</b>	<b>Moderate</b>	<b>Mild</b>
<b>Under 70</b>	\$30,923	\$60,216	\$16,641	\$15,911
<b>70-74</b>	\$43,478	\$88,627	\$21,465	\$20,341
<b>75-79</b>	\$60,714	\$127,632	\$28,088	\$26,422
<b>80-84</b>	\$42,414	\$86,220	\$21,056	\$19,966
<b>85+</b>	\$42,573	\$86,581	\$21,117	\$20,022
<b>85-89</b>	\$40,286	\$81,404	\$20,238	\$19,215
<b>90-94</b>	\$44,329	\$90,554	\$21,792	\$20,641
<b>95+</b>	\$37,094	\$74,181	\$19,012	\$18,089
<b>Ave. Males</b>	<b>\$48,585</b>	<b>\$100,184</b>	<b>\$23,427</b>	<b>\$22,143</b>
<b>Females</b>	<b>Average</b>	<b>Severe</b>	<b>Moderate</b>	<b>Mild</b>
<b>Under 70</b>	\$30,923	\$60,216	\$16,641	\$15,911
<b>70-74</b>	\$46,670	\$95,851	\$22,691	\$21,467
<b>75-79</b>	\$42,839	\$87,183	\$21,220	\$20,116
<b>80-84</b>	\$41,563	\$84,293	\$20,729	\$19,665
<b>85+</b>	\$39,009	\$78,515	\$19,748	\$18,764
<b>85-89</b>	\$38,796	\$78,033	\$19,666	\$18,689
<b>90-94</b>	\$38,796	\$78,033	\$19,666	\$18,689
<b>95+</b>	\$36,030	\$71,773	\$18,603	\$17,713
<b>Ave. Female</b>	<b>\$42,414</b>	<b>\$86,220</b>	<b>\$21,056</b>	<b>\$19,966</b>
<b>Ave. Person</b>	<b>\$45,393</b>	<b>\$92,961</b>	<b>\$22,201</b>	<b>\$21,017</b>

**b. Residential Aged Care/Nursing Home Setting (in \$AUD 2016)**

<b>Males</b>	<b>Average</b>	<b>Severe</b>	<b>Moderate</b>	<b>Mild</b>
<b>Under 70</b>	\$41,640	\$70,934	\$27,358	\$25,078
<b>70-74</b>	\$54,016	\$99,166	\$32,004	\$29,082
<b>75-79</b>	\$71,008	\$137,926	\$38,382	\$34,578
<b>80-84</b>	\$52,968	\$96,773	\$31,610	\$28,742
<b>85+</b>	\$53,125	\$97,132	\$31,669	\$28,793
<b>85-89</b>	\$50,870	\$91,988	\$30,822	\$28,064
<b>90-94</b>	\$54,856	\$101,080	\$32,319	\$29,353
<b>95+</b>	\$47,723	\$84,811	\$29,641	\$27,046
<b>Ave. Male</b>	<b>\$59,051</b>	<b>\$110,650</b>	<b>\$33,893</b>	<b>\$30,710</b>
<b>Females</b>	<b>Average</b>	<b>Severe</b>	<b>Moderate</b>	<b>Mild</b>
<b>Under 70</b>	\$41,640	\$70,934	\$27,358	\$25,078
<b>70-74</b>	\$57,163	\$106,344	\$33,185	\$30,100
<b>75-79</b>	\$53,387	\$97,731	\$31,767	\$28,878
<b>80-84</b>	\$52,129	\$94,859	\$31,295	\$28,471
<b>85+</b>	\$49,611	\$89,117	\$30,350	\$27,657
<b>85-89</b>	\$49,402	\$88,639	\$30,271	\$27,589
<b>90-94</b>	\$49,402	\$88,639	\$30,271	\$27,589
<b>95+</b>	\$46,675	\$82,418	\$29,248	\$26,707
<b>Ave. Female</b>	<b>\$52,968</b>	<b>\$96,773</b>	<b>\$31,610</b>	<b>\$28,742</b>
<b>Ave. Person</b>	<b>\$55,904</b>	<b>\$103,473</b>	<b>\$32,712</b>	<b>\$29,692</b>

Source: NATSEM Calculation

**Table 16 The average total direct cost in the subsequent year by care setting and degree of severity (in \$AUD 2016)**

Subsequent (following year) Total Cost	Average	Severe	Moderate	Mild
Home Care Setting	\$12,835	\$19,285	\$9,690	\$9,530
Aged Care Setting	\$23,810	\$30,260	\$20,665	\$20,504

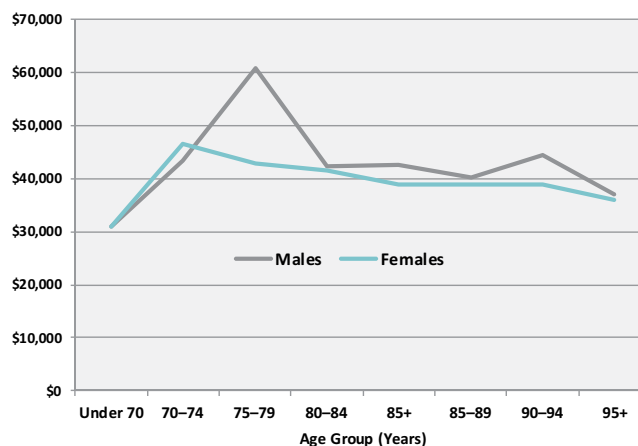
Source: NATSEM calculation

In terms of age group classifications, the total initial cost for people diagnosed with dementia under 70 years is \$30,923 for both males and females in the home care setting, while in the aged care/nursing home setting the total costs are \$41,640 or 35% higher. The average LOS based on Bail et al, (2015) estimation is 10.9 days for people under 70 years. The average total costs increase with age (Table 15a and 15b). For males, total costs peak in the 75-79 year age group. On average, the total costs are \$60,714 (home care setting) and \$71,008 (aged care setting).

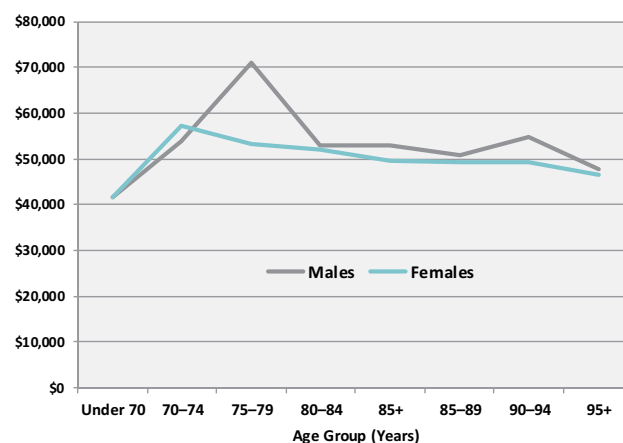
Severe dementia in males in this age group has high total costs for both care settings (\$127,632 and \$137,926 respectively). Meanwhile, for females the age group between 70 and 74 years incurs peak total costs. Total costs for females with dementia in this group are \$46,670 (home care setting) and \$57,163 (age care setting). The gap in total costs between males and females is due to the higher length of stay (LOS) for males than females (AIHW, 2012). The pattern of direct total costs at the individual level for males and females by care setting can be seen in Figure 6a and 6b. The degree of severity also suggests a significant gap in total costs between people with severe dementia and people diagnosed with moderate or mild dementia. The gap increases with the groups (Table 15a and 15b).

**Figure 5 The average total direct costs by age groups and care settings (in \$AUD 2016)**

**a. Home Care Setting**



**b. Aged Care/Nursing Home Setting**



Source: NATSEM calculation

## 5.4 THE PROJECTION OF TOTAL DIRECT COSTS OF DEMENTIA (2016-2056)

Total direct costs of dementia in Australia have been projected in the Access Economics report (2003). The projection was based on demographic ageing growth and GDP inflator of costs of health and community service (Access Economics, 2003 p.90). The average growth was 3.8% per annum and the projection result was an increase from \$3.24 billion in 2002 to \$5.96 billion in 2011 (82% growth). Meanwhile, the AIHW report (2012) based on health system data estimated total direct cost on people with dementia to be at least \$4.9 billion in 2009-2010.

In this report, the projection also applies demographic ageing growth and the projected number of people with dementia as stated previously. The calculation utilises cost components from the national efficient price for direct medical costs and basic maximum daily fee for home care packages and

residential aged care/nursing home. The projection is based on 2016 prices and is projected over four decades or until 2056 (Table 17).

### 5.4.1 The projection of total direct costs of dementia at national level

The aggregate cost of dementia in 2016 is estimated to be \$8.8 billion with 53% of the total costs going to hospitalisation expenditures or around \$4.6 billion, followed by the cost of care (\$3.3 billion), GPs and specialist (\$564 million), pharmaceuticals (\$242 million), and transportation/other costs (\$117 million). In the projection (Table 17), the aggregate cost of dementia is estimated to grow by 29% every ten years. The highest rate is between 2016 and 2026 with a growth rate of 38% or from \$8.8 billion in 2016 to \$12.2 billion in 2026. The last decade from the projection will be the lowest with a growth rate of 17% or from \$20.6 billion in 2046 to \$24.1 billion in 2056. The projected annual costs for each year over the period 2016-2056 are given in Appendix 4.

**Table 17 Aggregate total costs of dementia by cost components 2016-2056 (\$AUD 2016 million)**

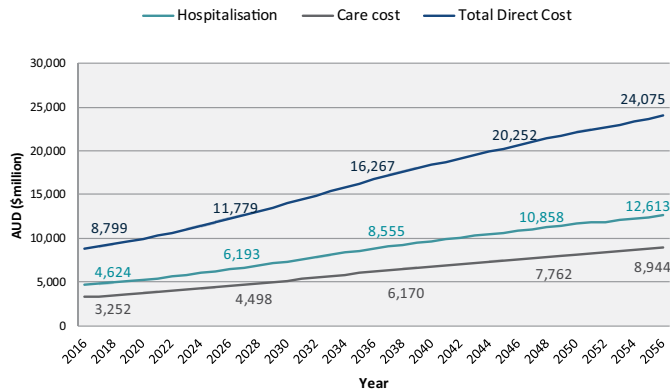
Year	Hospitalisation	GPs and Specialists	Pharmaceuticals	Transportation and Other Costs	Care cost	Total Direct Cost
2016	4,624	564	242	117	3,252	8,799
2017	4,766	581	250	121	3,352	9,069
2018	4,909	598	257	124	3,452	9,340
2019	5,062	617	265	128	3,558	9,630
2020	5,223	637	274	132	3,671	9,937
2021	5,396	658	283	137	3,792	10,265
2022	5,593	682	293	142	3,930	10,639
2023	5,786	705	303	146	4,064	11,005
2024	5,986	730	314	152	4,205	11,386
2025	6,193	755	324	157	4,349	11,779
2026	6,406	781	336	162	4,498	12,183
2031	7,577	923	397	192	5,319	14,407
2036	8,790	1,071	461	222	6,170	16,715
2041	9,857	1,201	516	249	6,919	18,744
2046	10,858	1,323	569	275	7,622	20,647
2051	11,792	1,437	618	298	8,277	22,423
2056	12,613	1,537	661	319	8,944	24,075

Source: NATSEM calculation. All estimation based on 2016 price



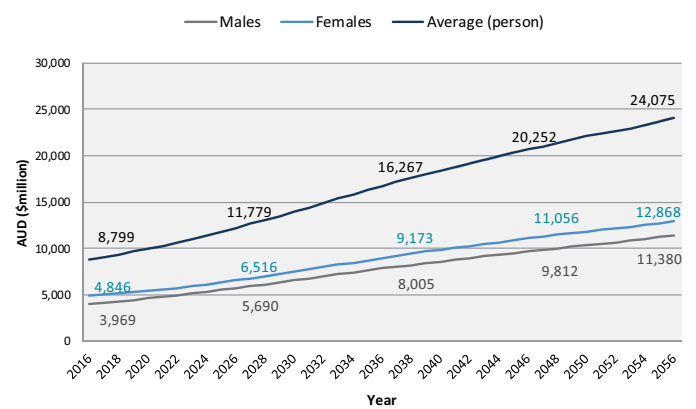
**Figure 6 Projection patterns of aggregate direct costs of dementia 2016-2056 (\$AUD 2016 million)**

**a. By cost components**



Source: NATSEM calculation

**b. By gender**



**Table 18 The projection of total costs of dementia by State and Territory 2016-2056 (\$AUD 2016 million)**

Year	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	Australia
2016	2,969	2,234	1,645	748	835	224	32	111	8,799
2017	3,049	2,299	1,705	766	869	231	34	116	9,069
2018	3,129	2,365	1,766	784	903	237	36	120	9,340
2019	3,214	2,435	1,831	803	939	245	38	125	9,630
2020	3,305	2,509	1,901	824	976	252	40	130	9,937
2021	3,402	2,589	1,974	845	1,016	260	43	135	10,265
2022	3,513	2,680	2,057	872	1,062	269	45	142	10,639
2023	3,621	2,769	2,138	897	1,107	278	47	148	11,005
2024	3,733	2,861	2,223	924	1,155	287	50	154	11,386
2025	3,849	2,956	2,311	951	1,203	296	52	160	11,779
2026	3,967	3,056	2,401	979	1,252	306	55	166	12,183
2031	4,619	3,607	2,890	1,134	1,535	354	67	201	14,407
2036	5,281	4,191	3,393	1,286	1,849	399	80	236	16,715
2041	5,842	4,715	3,844	1,401	2,156	429	91	266	18,744
2046	6,337	5,216	4,283	1,495	2,472	448	101	296	20,647
2051	6,764	5,689	4,706	1,566	2,804	458	111	325	22,423
2056	7,156	6,147	5,114	1,612	3,149	449	107	341	24,075

Source: NATSEM calculation. All estimation based on 2016 price

In terms of gender, the aggregate total cost for females is higher than for males. In 2016, the total cost for females with dementia at the national level is \$4.8 billion while for males with dementia it's \$4 billion. In two decades, the cost will almost double for both males and females. The projection indicates that the aggregate cost in 2036 is \$8.9 billion for females and \$7.8 billion for males with dementia. In 2056, the projection cost is \$12.8 billion for females and \$11.3 billion for males. Figures 6a and 6b show the patterns of expenditure by the main cost components and by gender.

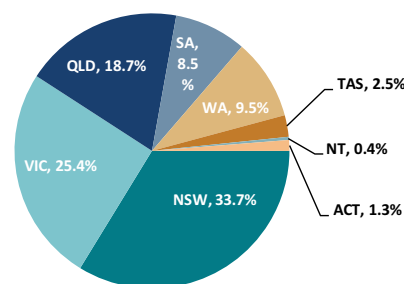
### 5.4.2 The projection of total direct costs of dementia at State/Territory

Corresponding with the projection of the prevalent number of people with dementia, the projection also estimates total costs in aggregate by State/Territory as well as at the national level. Table 18 shows the total costs of all persons with dementia in 2016-2056 for selected years by the States and Territories. Costs for the individual years 2016-2056 are given in Appendix 5.

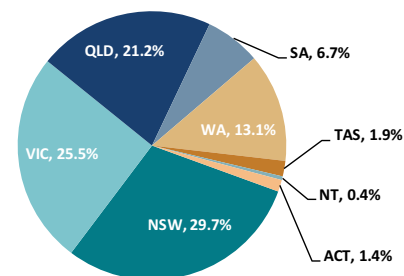
At the State/Territory level (Figure 7), in 2016 New South Wales has the largest proportion of the total costs of dementia (33.7%) or almost \$3 billion, followed by Victoria (25.4%; \$2.2 billion), Queensland (18.7%; \$1.6 billion), Western Australia (9.5%; \$835 million), South Australia (8.5%; \$748 million), Tasmania (2.5%; \$224 million), the Australian Capital Territory (1.3%; \$111 million), and the Northern Territory (0.4%; \$32 million). The composition is projected to change by 2056, where the expenditure for dementia in New South Wales decreases to 29.7% (\$7.2 billion) as well as South Australia to 6.7% (\$1.6 billion) and Tasmania to 1.9% (\$449 million), while Queensland increases to 21.2% (\$5.1 billion) as well as Victoria to 25.5% (\$6.1 billion) and the Australian Capital Territory to 1.4% (\$341 million).

**Figure 7 The proportion from the aggregate direct costs of dementia by State and Territory between 2016 and 2056**

The proportion of aggregate direct cost of dementia by state/territory in 2016



The proportion of aggregate direct cost of dementia by state/territory in 2056



Source: NATSEM calculation

# 6. INDIRECT COSTS OF DEMENTIA 2016-2036

## KEY POINTS

- Total indirect cost of dementia from the potential loss of income of people with dementia and carers was estimated to be \$5.5 billion in 2016, and \$5.6 billion for 2017.
- In 2016, this comprised \$3.2 billion (59%) from the forgone earnings by carers and \$2.3 billion (41%) from the potential loss of income from people with dementia withdrawing from the workforce. In 2017, these costs are expected to increase by \$103 million and \$44 million respectively.
- The potential loss of income in 2016 from people with dementia by gender shows that the total forgone earnings from males was \$1.5 billion and females \$754 million.
- The total indirect costs of dementia are expected to increase to \$9.1 billion by 2036 and more than double to \$12.8 billion by 2056.

## 6.1 OVERVIEW

Dementia costs not only consist of direct medical and non-medical costs, but also the forgone earnings or the potential loss of income from people with dementia and carers. The World Alzheimer Report (2015) has included informal care costs as part of dementia costs. The report (ADI 2015, p62) shows that on average the global proportion of informal costs to total dementia cost in 2015 was 40%. The report also highlights that in some regions such in Central Europe, Sub-Saharan, East Asian, and South Asia this proportion was above 60% of the total costs.

In Australia, the AIHW report in 2012 stated that 92% of people with dementia living in the community were receiving care from one or more carers, and the results presented earlier in this report show only 9% of people living with dementia in the community receive no assistance from either informal or formal carers. Most of the carers or almost two-thirds are women and are aged 65 years and above, and around 76% of them are either a spouse/partner or son/daughter. One of the key implications of being a carer is the impact on employment as nearly half of all informal carers are employed in the labour force (47.7%) (AIHW, 2012). These figures indicate that dementia impacts on the potential earnings from the perspective of both the person with dementia and the carer.

The estimation of indirect costs in this report follows several studies (O'Shea and O'Reilly, 2000; Suh et al, 2006; Kang et al, 2007) where the calculation of indirect costs consists primarily of forgone earnings from persons with dementia and the potential loss of earnings from caregivers.

## 6.2 LITERATURE REVIEW

One of the key studies in the last two decades to estimate the indirect cost of dementia was conducted by Langa et al, (2001), utilising data from the survey of asset and health dynamics (AHEAD) in the U.S. The result classified the incremental caregiving hours per week based on the degree of dementia severity. For people with mild dementia caregiving was 8.5 hours, equalising to \$AUD4,722 in a mid-range estimated cost of informal care per year. In moderate dementia, the hours of caregiving increased to almost double (17.4 hours) or equal to \$AUD9,560 p.a., while in severe cases the caregiving hours were similar to a full time job (41.5 hours) or equal to \$AUD23,020 p.a.

The study by O'Shea and O'Reilly (2000) also calculated the average care hours per day from a carer in Ireland. This was 11 hours and equal with £123 million in aggregate. Moreover, the study by Kang et al, (2006) in the case of Korea identified indirect costs based on productivity loss from patient and carer. The average total annual indirect costs from all patients were \$52,834 and from caregiver were \$456,252. The

estimation of indirect costs reflects the activities of daily living that caregivers provide assistance with. The recent study by Michalowsky et al, (2016) shows that caregivers with an average age of 64 years, worked 32.4 hours/week in providing care, representing a significant productivity loss per year.

Studies related to the estimation for indirect cost of dementia in Australia are relatively scarce. A report from Access Economics (2007) suggests that only 73% of people with dementia have an informal carer based on data from the Pathways in Aged Care (PIAC) project. The AIHW (2012) report contains data from the 2009 SDAC which alongside the findings presented earlier in this report provide sufficient information related to carers and the implication to the labour market to be useful in estimating the indirect costs of dementia.

## 6.3 METHODOLOGY FOR INDIRECT COSTS ESTIMATION

The report has developed a methodology to estimate indirect costs of people with dementia. The method follows studies (Langa et al, 2000, Kang et al, 2006; Michalowsky et al, 2016) that estimate forgone earnings not only from carers but also from people with dementia. The estimations apply all the indicator data on carers from sources such as the AIHW 2012 report, Aged Care Assessment Program (ACAP) and 2009 and 2012 SDACs to the prevalent number of people with dementia in 2016. Data from the Household, Income and Labour Dynamics in Australia (HILDA) survey is also used to calculate the average earnings by gender and age groups. The latest longitudinal data (wave 14) are applied for total earnings. The estimation for total indirect costs follows several assumptions and characteristics which are noted in the Technical Notes.

## 6.4 THE TOTAL INDIRECT COSTS OF DEMENTIA

### 6.4.1 The annual forgone earnings from people with dementia and primary carers

The total forgone earnings for people with dementia in the situation that they are unable to work again is given in Figure 8. For a person with dementia leaving a full-time job, the average forgone earnings in 2016 are \$96,750 for males and \$73,247 for females in the age group 30-64 years, while in the age group 65-69 years the forgone earnings are \$96,676 for males and \$80,385 for females.

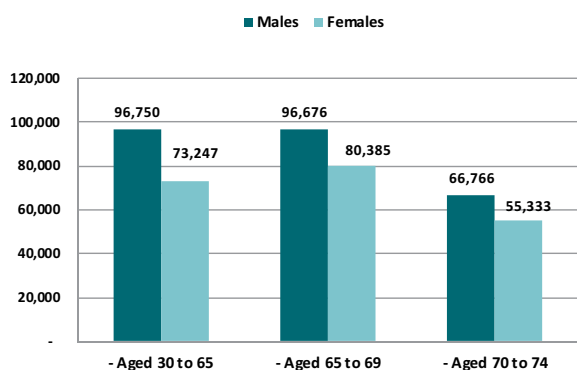
In terms of part-time workers, the average forgone earnings are more than half those gained from full-time work. In the age group between 30 and 64 years, the potential losses of income for people with dementia are \$40,463 for males and \$36,797 for females, while in the age group of 65-69 years the losses are \$40,632 for males and \$30,211 for females.

At the aggregate (national) level, the total indirect costs of forgone earnings of people with dementia in 2016 are estimated by multiplying these per capita costs by the prevalence number (Table 19). For males, the aggregate forgone earnings in 2016 are \$1.5 billion and females \$754 million, which gives a total potential loss of productivity for people with dementia who are no longer able to work at almost \$2.3 billion in 2016.

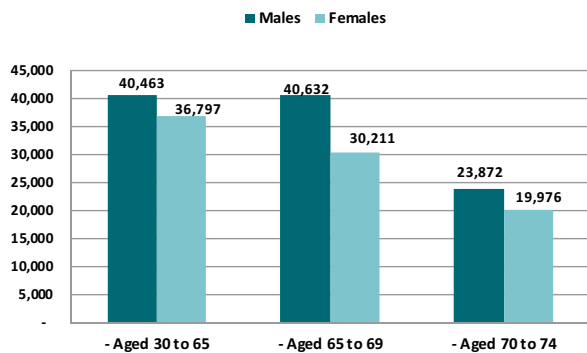
In terms of primary carers, the average potential losses if they spend their whole time taking care of a person with dementia is \$26,255 for males and \$24,351 for females. The number applies to all age groups of carers, considering their time is described in productive working hours. By multiplying these figures with the prevalence number of people with dementia and the weight of the proportion of people with dementia living in the community and living with others (assumption iii), the aggregate forgone earnings for carers are \$1.8 billion for males and \$1.4 billion for females. In total, the potential loss of productivity from paid work from carers being fully occupied providing assistance to people with dementia is \$3.2 billion (Table 20).

**Figure 8 The forgone earnings for people with dementia by gender and age groups in 2016 (\$AUD 2016)**

**a. The average forgone earnings from full-time work for people with dementia by gender and age groups (\$AUD 2016)**



**b. The average forgone earnings from part-time work for people with dementia by gender and age groups (\$AUD 2016)**



Source: NATSEM's calculations from HILDA Wave 14, taking into account full-time and part-time employment rates and wage

In total, by combining the potential loss of income from people with dementia (\$2.3 billion) and carers (\$3.2 billion), the total indirect cost of dementia in 2016 is \$5.5 billion. The proportion of the total indirect costs attributable to persons with dementia is 41%, while the proportion for carers is 59% in 2016.

The total indirect costs of dementia can be calculated for the States and Territories and by gender and age (Table 21). The state of New South Wales remains as having the largest share of total indirect cost in 2016 (\$1.7 billion), followed by Victoria (\$1.4 billion), Queensland (\$960 million), Western Australia (\$707 million), South Australia (\$415 million), Tasmania (\$98 million), the Australian Capital Territory (99 million), and the Northern Territory (\$53 million). Figure 10 displays the proportion of total indirect cost shared by the States and Territories.

**Table 19 The total forgone earnings for people with dementia by age groups and gender in 2016 (\$AUD 2016 million)**

Age Groups	No of people with dementia	Full-time employment rate (%)	Annual full-time wage/worker (\$)	Part-time employment rate (%)	Annual part-time wage/worker (\$)	Total forgone earnings (\$ mil)	Total forgone earnings (\$ mil)
	(1)	(2)	(3)	(4)	(5)	(6)	(6)
<b>Male</b>	<b>178,167</b>					<b>1,498</b>	<b>1,498</b>
30 - 64	13,309	74.0	96,750	9.8	40,463	1,005	1,005
65 - 69	17,669	13.9	96,676	14.8	40,632	342	342
70 - 74	27,320	5.2	66,766	8.4	23,872	151	151
75 - 79	33,605						
80 - 84	34,303						
85+	51,961						
<b>Female</b>	<b>222,660</b>					<b>754</b>	<b>754</b>
30 - 64	12,090	36.5	73,247	31.9	36,797	465	465
65 - 69	26,865	6.6	80,385	14.0	30,211	257	257
70 - 74	19,764	1.5	55,333	3.8	19,976	32	32
75 - 79	36,039						
80 - 84	41,030						
85+	86,872						
<b>Total</b>	<b>400,827</b>					<b>2,252</b>	<b>2,252</b>

Notes: (1) The prevalence number of people with dementia. (2), (3), (4), (5) NATSEM's calculations from HILDA Wave 14. (6) Total forgone earnings of people with dementia = (1)\*(2)\*(3)+(4)\*(5)/100, with an assumption that all people with dementia cannot work. All values are modified at June 2016 values

**Table 20 Total forgone earnings for carers by age groups and gender in 2016 (\$AUD 2016 million)**

Age Groups	No of people with dementia	Prop living in community (%)	Prop living with others (%)	Avg carer per patient	Avg earnings per carer (\$)	Forgone earnings of carers (\$ mil)
	(1)	(2)	(3)	(4)	(5)	(6)
<b>Male</b>	<b>178,167</b>					<b>1,797</b>
30 - 64	13,309	83.2	70.5	0.66	26,255	134
65 - 69	17,669	83.2	70.5	0.66	26,255	178
70 - 74	27,320	83.2	70.5	0.66	26,255	276
75 - 79	33,605	83.2	70.5	0.66	26,255	339
80 - 84	34,303	83.2	70.5	0.66	26,255	346
85+	51,961	83.2	70.5	0.66	26,255	524
<b>Female</b>	<b>222,660</b>					<b>1,400</b>
30 - 64	12,090	70.8	61.45	0.59	24,351	76
65 - 69	26,865	70.8	61.45	0.59	24,351	169
70 - 74	19,764	70.8	61.45	0.59	24,351	124
75 - 79	36,039	70.8	61.45	0.59	24,351	227
80 - 84	41,030	70.8	61.45	0.59	24,351	258
85+	86,872	70.8	61.45	0.59	24,351	546
<b>Total</b>	<b>400,827</b>					<b>3,197</b>

Source: NATSEM calculation from AIHW (2012) and HILDA wave 14

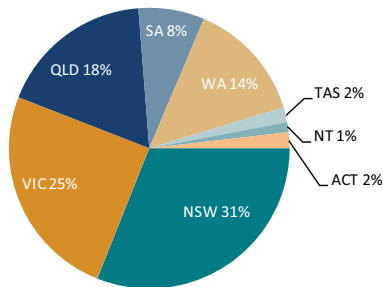
Notes: (1) The prevalence number of people with dementia. (2) See Section 4 of this report. (3) Using rates from Table 8 of this report with an assumption that for the category 'Informal and formal assistance', a half comes from informal assistance. (4) Using ratios calculated from Section 4 of this report. (5) Average annual wage (\$) per carer (See Table 23). (6) Total forgone earnings of carers who take care of people with dementia = (1)\*(2)/100\*(3)/100\*(4)\*(5). All values are adjusted at June 2016 values

**Table 21 Total indirect costs in 2016 (\$AUD 2016 million)**

State/ Territory	People with Dementia	Carers	Total
<b>NSW</b>	699	1,024	1,723
<b>VIC</b>	560	835	1,396
<b>QLD</b>	402	558	960
<b>SA</b>	171	243	415
<b>WA</b>	314	392	707
<b>TAS</b>	39	59	98
<b>NT</b>	26	27	53
<b>ACT</b>	41	58	99
<b>Australia</b>	<b>2,253</b>	<b>3,198</b>	<b>5,451</b>

Sources: NATSEM Calculation, AIHW (2012), and HILDA wave 14

**Figure 9 The proportion of indirect costs by State/Territory in 2016**



Source: NATSEM calculation

## 6.5 PROJECTIONS OF TOTAL INDIRECT COSTS BETWEEN 2016 AND 2056

The projection for the total indirect costs at the national level and by State and Territory suggests that the indirect costs of dementia in Australia will grow from \$5.5 billion in 2016 to \$12.8 billion in 2056 (Table 22). Table 22 displays the projection results for selected years with the results for all years being given in Appendix 6.

At the State level, the total indirect cost in New South Wales is projected to rise from \$1.7 billion in 2016 to \$3.5 billion in 2056, followed by Victoria from \$1.4 billion to \$3.3 billion, Queensland from \$964 million to \$2.5 billion, Western Australia from \$701 million to \$2.3 billion, South Australia from \$418 million to \$776 million, the Australian Capital Territory from \$92 million to \$245 million, Tasmania from \$94 million to \$157 million, and the Northern Territory from \$56 million to \$150 million (Table 23, Appendix 7).

The projection of total indirect costs by gender suggests that on average the proportion attributable to males is higher than for females between 2016 and 2056. The cost is projected to grow from \$3.3 billion in 2016 to \$7.7 billion in 2056 for males, while for females the indirect cost increases from \$2.2 billion in 2016 to \$5 billion in 2056 (Table 24). Results for all years are given in Appendix 8.

The projection for the age groups shows that the working age group between 30 and 64 years has the most significant increase over time, from \$1.7 billion in 2016 to \$2.8 billion in 2056. Figure 10 shows the projection pattern of indirect cost of dementia by age group between 2016 and 2056 and Table 25 provides the details (results for all years are given in Appendix 9).

**Table 22 The projection of total indirect costs, 2016-2056 (\$AUD 2016 million)**

Years	People with Dementia	Carers	Total
2016	2,253	3,198	5,451
2017	2,296	3,301	5,597
2018	2,345	3,403	5,748
2019	2,395	3,512	5,907
2020	2,443	3,626	6,069
2021	2,494	3,748	6,242
2022	2,537	3,887	6,424
2023	2,578	4,023	6,601
2024	2,616	4,163	6,779
2025	2,644	4,309	6,952
2026	2,665	4,458	7,123
2031	2,827	5,274	8,101
2036	2,970	6,113	9,083
2041	3,129	6,851	9,980
2046	3,444	7,546	10,990
2051	3,732	8,197	11,928
2056	3,917	8,855	12,772

Source: NATSEM calculation

**Table 23 The projection of total indirect costs by State/Territory 2016-2056 (\$AUD 2016 million)**

Years	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	Australia
2016	1,706	1,375	964	418	701	94	56	92	5,451
2017	1,747	1,410	994	429	725	96	59	95	5,597
2018	1,789	1,447	1,024	439	750	99	61	98	5,748
2019	1,832	1,487	1,057	450	776	101	63	101	5,907
2020	1,877	1,526	1,091	460	804	104	65	104	6,069
2021	1,924	1,569	1,127	471	832	106	68	107	6,242
2022	1,975	1,615	1,166	480	863	109	70	111	6,424
2023	2,023	1,659	1,202	491	894	111	73	115	6,601
2024	2,071	1,703	1,240	501	926	114	75	118	6,779
2025	2,116	1,747	1,276	511	957	116	77	122	6,952
2026	2,160	1,791	1,311	521	988	118	80	125	7,123
2031	2,412	2,043	1,517	580	1,167	130	91	146	8,101
2036	2,668	2,298	1,720	629	1,361	140	103	167	9,083
2041	2,890	2,536	1,904	670	1,559	146	113	185	9,980
2046	3,128	2,804	2,118	711	1,799	153	126	207	10,990
2051	3,338	3,055	2,316	744	2,047	156	139	226	11,928
2056	3,518	3,273	2,504	776	2,273	157	150	245	12,772

Source: NATSEM calculation

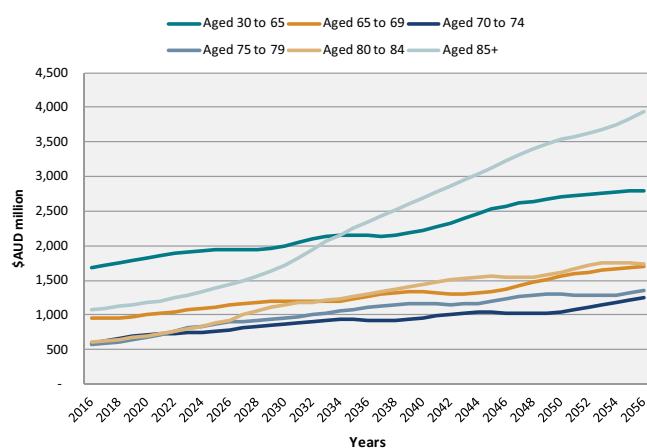


**Table 24 The projection of total indirect cost by gender 2016-2056 (\$AUD 2016 million)**

Years	Male	Female	Total
2016	3,296	2,155	5,451
2017	3,393	2,204	5,597
2018	3,491	2,257	5,748
2019	3,592	2,315	5,907
2020	3,693	2,376	6,069
2021	3,801	2,441	6,242
2022	3,912	2,512	6,424
2023	4,021	2,581	6,601
2024	4,130	2,650	6,779
2025	4,235	2,717	6,952
2026	4,338	2,784	7,123
2031	4,928	3,173	8,101
2036	5,500	3,583	9,083
2041	6,034	3,946	9,980
2046	6,645	4,345	10,990
2051	7,207	4,722	11,928
2056	7,739	5,033	12,772

Source: NATSEM calculation

**Figure 10 The projection pattern of total indirect costs by age groups 2016-2056 (\$AUD 2016 Million)**



Source: NATSEM calculation

**Table 25 The projection of total indirect cost by age groups 2016-2056 (\$AUD 2016 millions)**

Years	30 - 64	65 - 69	70 - 74	75 - 79	80 - 84	85+	Total
2016	1,681	946	583	566	604	1,071	5,451
2017	1,716	946	626	589	624	1,096	5,597
2018	1,748	960	662	611	646	1,120	5,748
2019	1,785	978	686	641	673	1,144	5,907
2020	1,817	998	708	673	702	1,171	6,069
2021	1,852	1,021	728	708	729	1,205	6,242
2022	1,884	1,045	728	763	762	1,243	6,424
2023	1,911	1,068	739	809	792	1,283	6,601
2024	1,930	1,094	753	839	834	1,329	6,779
2025	1,939	1,118	769	868	879	1,380	6,952
2026	1,938	1,144	788	894	927	1,433	7,123
2031	2,050	1,196	885	976	1,179	1,814	8,101
2036	2,147	1,268	928	1,102	1,299	2,340	9,083
2041	2,270	1,319	985	1,157	1,473	2,776	9,980
2046	2,574	1,376	1,027	1,232	1,552	3,229	10,990
2051	2,727	1,593	1,076	1,285	1,664	3,583	11,928
2056	2,798	1,703	1,249	1,349	1,740	3,935	12,772

Source: NATSEM calculation

# 7. BURDEN OF DISEASE

## KEY POINTS

- In 2011 dementia was the third leading cause of disease burden for females and was the 10th top cause for males.
- Dementia is the second leading cause of burden of disease in men aged 85+ years and the leading cause of disease burden in women aged 85+ years.
- The burden of disease from dementia is now jointly related to the disability and to the premature mortality caused by the condition.
- The annual growth rate in the burden of disease over the past decade has been in the order of 8.1% for men and 7.2% for women.

Dementia not only has major health and financial impacts, but also confers a significant burden on the social well-being of people with dementia and their informal carers. Estimates of the burden of disease attempt to measure the amount of healthy life lost due to premature mortality and prolonged disability (AIHW, 2012; AIHW, 2016). Thus burden of disease considers both the non-fatal (living with dementia) and fatal (dying from dementia) effects. Burden of disease is measured in terms of Disability Adjusted Life Years (DALY) which represent the total years of healthy life lost. The DALY combines the estimates of years of life lost due to premature death (YLL) and years lived in ill health or with disability (YLD) (AIHW 2016).

Dementia is a leading cause of burden of disease in both men and women, especially in the older age groups. Findings from the most recent Australian Burden of Disease study (2016) show in 2011 dementia was the sixth leading cause of disease burden accounting for 3.4% (total DALYs 151,308) of the total burden of disease experienced by Australians. In 2011 dementia was the third leading cause of disease burden for females and was the 10th top cause for males (Table 26). However, when age is taken into account, dementia becomes a very significant cause of disease burden for both men and women from age 75 years onwards, and becomes the leading cause of disease burden for women aged 85 years and above.

**Table 26 Burden of disease caused by dementia, by age and gender, 2011**

	Males			Females		
	DALY	Rank	% of total	DALY	Rank	% of total
<b>&lt;65 years</b>	5,293			4,416		
<b>65-74 years</b>	9,400	10	2.3	10,800	7	3.6%
<b>75-84 years</b>	22,000	3	6.1	30,900	2	9.4
<b>85-94 years</b>	17,500	2	11	43,100	1	18.0
<b>95+ years</b>	1,400	2	15	6,500	1	23.0
<b>Total</b>	55,593	10	2.3	95,716	3	4.6

Source: AIHW (2016)

Years of life lost through premature mortality caused by dementia contributes to slightly more than half of the total burden of disease from dementia in both men and women, with dementia being ranked higher as a leading cause of years of life lost than years of life lived with disability (Table 28). This ratio is much higher than earlier estimates that suggested the burden due to dementia was related to the disabling nature of the condition, with three-quarters due to disability and one-quarter to premature mortality (AIHW, 2012).

As can be seen from both Table 26 and 27, women account for a greater proportion of the burden of disease from dementia than men – 63% vs 37% with a slight bias towards YLD (66%) compared with YLL (61%).

With the increases in incidence and prevalence of dementia in the Australian population predicted in this report, dementia will continue to grow in importance as a leading cause of burden of disease especially in the older age groups. Over the 8 years from 2003 to 2011 the burden of disease from dementia in males increased by 65% and 58% in females (AIHW, 2007; AIHW 2016). This represents an annual growth rate of 8.1% in males and 7.2% in females.

**Table 27 Non-fatal (YLD) and fatal burden of disease from dementia (2011)**

	Males			Females			Persons		
	DALY	Rank	% of total	DALY	Rank	% of total	DALY	Rank	% of total
<b>YLD (non-fatal)</b>	24,273	15	2.2	46,385	9	4.1	70,658	11	3.2
<b>YLL (fatal)</b>	31,320	10	2.4	49,330	5	5.2	80,650	6	3.6
<b>DALY (total)</b>	55,993	10	2.3	95,716	3	3.4	151,308	6	3.4

Source: AIHW (2016)

# 8. MODELLING REDUCTIONS IN COSTS OF DEMENTIA

## KEY POINTS

- A 5% reduction in the annual incidence of dementia in persons aged 65 years and over leads to a 23.7% reduction in the prevalent number of persons with dementia by 2056.
- If the incidence of dementia in persons aged 65 years or over could be reduced by 5% then this would generate total savings in the direct costs of dementia of \$76.6 billion and \$43.8 billion in indirect costs over the next 40 years.
- A second scenario assumes five yearly improvements from technological reduce the cost of hospitalisation of people with dementia. If the cost of dementia is assumed to reduce by 10% then a savings in the order of \$122.2 billion will be delivered over the 40 years 2016-2056.

Studies related to the estimation of total dementia costs often include sensitivity analyses in order to measure costs in different scenario settings. A study by Guk-Hee Suh et al, (2002) for example calculates a sensitivity analysis based on changes in the unit costs of dementia in the case of Korea. Recent studies by Dixon et al, (2015) and Michalowsky et al, (2016) also include a sensitivity analysis examining different scenarios of income and degrees of severity. These studies also include the impact of continuous research funding in reducing hospital treatment costs. This section provides results of a sensitivity analysis based on the modelling of two scenarios. The first examines the impact of a 5% reduction in the annual incidence of dementia and the second investigates the impact of technological change in reducing the cost of hospital treatment.

## 8.1 IMPACT OF REDUCED INCIDENCE OF DEMENTIA ON COSTS

The lifestyle risk and protective factors for dementia (Section 3.4) offer very real opportunities for whole of population primary prevention and/or targeted at-risk group secondary prevention programs to reduce the number of Australians developing dementia each year. Alzheimer's Australia has long advocated areas where individuals can reduce their risk of dementia. The ANU Alzheimer's Disease Risk Index<sup>11</sup> which is an evidence-based tool aimed at assessing individual exposure to risk factors associated with an increased risk of developing Alzheimer's disease in late-life also identifies changes individuals can make to reduce their risk. In this scenario, the current annual incidence of dementia in older persons is reduced by 5% which is a very realistic target given current opportunities for reducing dementia risk.

In the scenario, it is assumed that

- i. The 5% of individuals who previously would have developed dementia will no longer be at risk of dementia over the remainder of their life.
- ii. The intervention becomes effective from 2017 and onwards.
- iii. The intervention only impacts on people aged 65 years and over i.e. it does not influence the incidence of younger onset dementia.
- iv. The change in prevalence numbers takes into account both the reduction in incident cases plus changes in the expected number of deaths per year.

Reducing the number of new cases of dementia in older persons each year changes the prevalence of the disorder within the population. The difference between the prevalence of dementia for the period 2016-2056 under the scenario compared with the base case projection is shown in Table 28 (data on all years is provided in Appendix 10). As shown, the impact of the intervention accumulates significantly over time, such that in 20 years the expected number of persons with dementia in Australia would be reduced by 13% and by 2056 by nearly 24%.

The impact of the changes in the prevalence of dementia on total direct costs is shown in Table 29 for selected years 2016-2056 (results for all years are given in Appendix 11) and Figure 11. The gap in costs relative to the base case projection steadily grows over time such that by 2036 total direct costs of dementia would be 89.7% of those projected under current trends (base case projection) and by 2056 82.8%. This represents a savings in 2016 dollars of \$1,619.9 billion in 2036 and \$4,131.8 billion in 2056. The trend in costs compared with the base case projections is charted in Figure 11. Over the

11. <http://anuadri.anu.edu.au/>

**Table 28 Change in Prevalence of Dementia from a 5% Reduction in Annual Incidence, selected years 2016-2056**

	Scenario: Reduced Incidence			Base Case Projection			Scenario/Base Case %		
	Males	Females	Total	Males	Females	Total	Males	Females	Total
2016	178,169	222,664	400,833	178,169	222,664	400,833	100.0	100.0	100.0
2017	183,306	226,395	409,701	184,868	228,238	413,106	99.2	99.2	99.2
2018	188,115	230,233	418,349	191,367	234,049	425,416	98.3	98.4	98.3
2019	193,162	234,600	427,762	198,152	240,434	438,586	97.5	97.6	97.5
2020	198,413	239,403	437,816	205,213	247,318	452,532	96.7	96.8	96.7
2021	204,000	244,603	448,603	212,705	254,696	467,401	95.9	96.0	96.0
2022	210,495	251,000	461,495	221,121	263,288	484,408	95.2	95.3	95.3
2023	216,631	257,130	473,761	229,291	271,724	501,015	94.5	94.6	94.6
2024	222,950	263,633	486,583	237,713	280,602	518,314	93.8	94.0	93.9
2025	229,387	270,406	499,793	246,334	289,830	536,164	93.1	93.3	93.2
2026	235,910	277,339	513,249	255,171	299,351	554,521	92.5	92.6	92.6
2031	270,700	317,105	587,805	302,542	353,154	655,695	89.5	89.8	89.6
2036	303,182	358,961	662,143	349,509	411,163	760,672	86.7	87.3	87.0
2041	328,095	391,666	719,761	390,949	462,101	853,049	83.9	84.8	84.4
2046	349,167	418,175	767,342	430,454	509,175	939,629	81.1	82.1	81.7
2051	366,596	439,250	805,846	468,038	552,362	1,020,400	78.3	79.5	79.0
2056	384,556	455,382	839,939	508,147	592,743	1,100,890	75.7	76.8	76.3

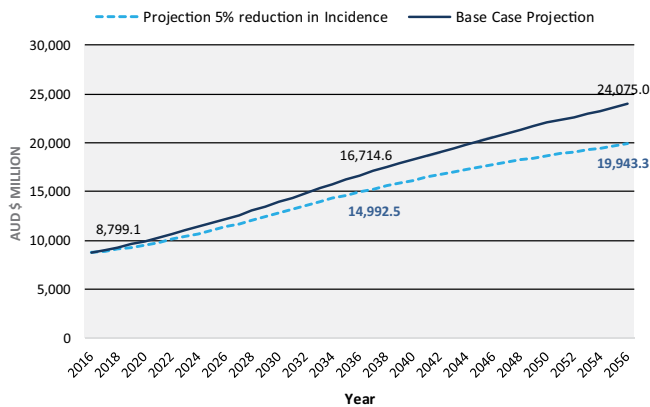
Source: NATSEM calculation

**Table 29 The projection of total direct costs of dementia with 5% reduction in incidence, selected years 2016-2056 (\$AUD 2016 million)**

Years	Projection 5% Reduction in Incidence	Base Case Projection	Reduced Incidence/ Base Case %	Annual Savings	Cumulative Savings
2016	8,799.1	8,799.1	100.0	0.0	0.0
2017	8,881.0	9,069.3	97.9	188.4	188.4
2018	9,093.4	9,340.4	97.4	247.0	435.4
2019	9,323.1	9,630.4	96.8	307.2	742.6
2020	9,567.5	9,937.3	96.3	369.8	1,112.4
2021	9,829.2	10,264.7	95.8	435.6	1,548.0
2022	10,136.7	10,639.3	95.3	502.6	2,050.6
2023	10,432.2	11,005.0	94.8	572.8	2,623.4
2024	10,740.4	11,385.8	94.3	645.4	3,268.8
2025	11,058.1	11,778.7	93.9	720.6	3,989.4
2026	11,382.7	12,182.6	93.4	799.9	4,789.3
2031	13,176.9	14,407.4	91.5	1,230.5	10,046.1
2036	14,992.5	16,714.6	89.7	1,722.2	17,645.3
2041	16,473.6	18,743.9	87.9	2,270.3	27,879.3
2046	17,768.3	20,646.5	86.1	2,878.3	41,033.5
2051	18,889.2	22,422.7	84.2	3,533.5	57,370.6
2056	19,943.3	24,075.0	82.8	4,131.8	76,572.9

Source: NATSEM calculation

**Figure 11 The projection of total direct costs of dementia with 5% reduction in annual incidence compared with base case, 2016-2056**



Source: NATSEM calculation

40 year projection period, a 5% reduction in the incidence of dementia would lead to an estimated total savings of \$76,572.9 billion in direct costs.

This intervention also impacts on the indirect costs of dementia. Given that the incidence of younger onset dementia is unchanged, the impact on indirect costs primarily comes from a reduction in the number of carers providing assistance to older persons with dementia and thus a reduction in the lost productivity due to caring roles.

The results of the scenario with respect to indirect costs are given in Table 30 (results for all years are given in Appendix 12) and Figure 12. The overall trend is not dissimilar to that modelled for direct costs. By 2056, the annual reduction in indirect costs is over \$2.5 billion in today's dollars, representing 80% of the indirect costs incurred if current trends in the incidence of dementia continue. If the incidence of dementia in persons aged 65 years or over could be reduced by 5% then this would generate total savings of \$43.776 billion over the next 40 years.

## 8.2 IMPACT OF TECHNOLOGICAL CHANGE ON COSTS

This report applies a similar method of sensitivity analysis to other studies by estimating the impact of funding research that reduces hospitalisation costs in general for people with dementia. In order to implement this scenario, the estimation is based on two assumptions:

1. The estimation assumes that the impact of research funding will promote technological changes in the treatment of dementia. In the projection, the impacts occur on a regular basis every 5 years. The improvements from technological change deliver an impact chiefly on reducing the cost of hospitalisation of people with dementia.
2. The cost of dementia is assumed to go down by 10% with these technological changes. Therefore, the cost components of the price weight (PE) and national efficient price (NEP) are also adjusted by 10% (see Technical Notes).

From the estimation, technological changes contribute to lowering the aggregate dementia costs at the national level. Table 31 presents the results of the scenario modelling which show a significant change to total direct costs of dementia in Australia between 2016 and 2056 (Appendix 13 gives all years 2016-2056). In the first two decades or until 2036, the total direct cost increases from \$8.8 billion in 2016 to \$13.7 billion in 2036 under this scenario, compared with \$16.7 billion without technological changes. Meanwhile, comparing 2016 and 2056, the projection shows a very significant impact. With continuous research funding bringing technological improvements over the next 40 years, the total annual costs increase from \$8.8 billion in 2016 to \$16.9 billion in 2056, compared with \$24.1 billion for the baseline projection. Figure 8 presents the comparison between the base case projection and the projection with technological changes in dementia treatment. Over the 40 years from 2016-2056, this change in the treatment of dementia would lead to a total savings in direct costs of \$122.207 billion (in 2016 dollars).

It is assumed that this scenario does not affect indirect costs.

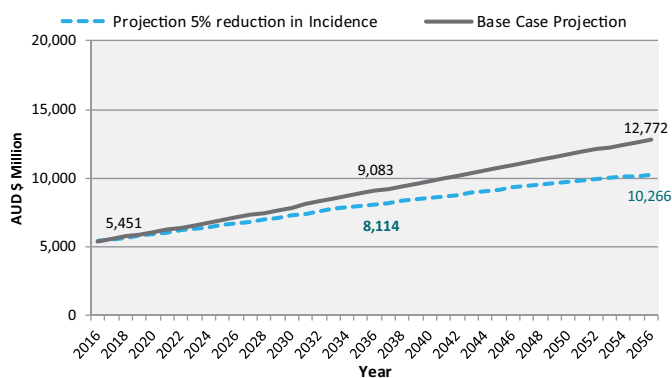
**Table 30 The projection of total indirect costs of dementia with 5% reduction in incidence, selected years 2016-2056 (\$AUD 2016 million)**

Years	Projection 5% Reduction in Incidence	Base Case Projection	Reduced Incidence/ Base Case %	Annual Savings	Cumulative Savings
2016	5,451	5,451	100.0	0	0
2017	5,563	5,597	99.4	34	34
2018	5,677	5,748	98.8	72	106
2019	5,798	5,907	98.2	109	215
2020	5,921	6,069	97.6	149	364
2021	6,054	6,242	97.0	188	552
2022	6,195	6,424	96.4	229	781
2023	6,328	6,601	95.9	273	1,054
2024	6,461	6,779	95.3	318	1,372
2025	6,588	6,952	94.8	364	1,736
2026	6,710	7,123	94.2	413	2,149
2031	7,430	8,101	91.7	672	4,967
2036	8,114	9,083	89.3	970	10,230
2041	8,682	9,980	87.0	1,298	15,014
2046	9,323	10,990	84.8	1,667	22,601
2051	9,859	11,928	82.7	2,069	32,136
2056	10,266	12,772	80.4	2,506	43,779

Source: NATSEM calculation

The relative distribution of costs among the States and Territories would remain unchanged under this scenario unless the 'intervention' program was rolled-out differently across Australia.

**Figure 12 The projection of total indirect costs of dementia with 5% reduction in annual incidence compared with base case, 2016-2056**

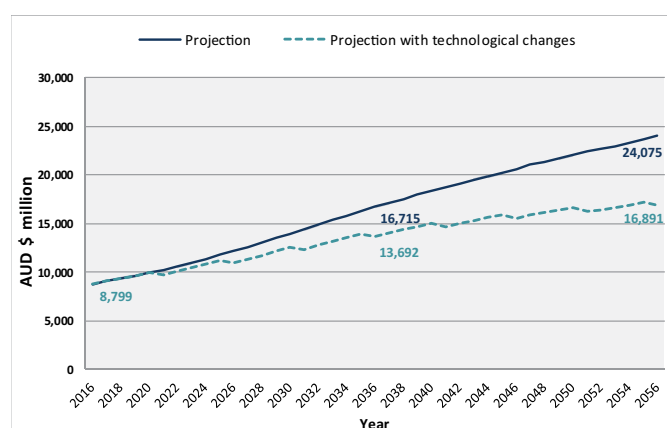


**Table 31 The projection of total direct costs of dementia with technological changes, selected years 2016-2056 (\$AUD 2016 million)**

Years	Projection with tech. changes	Base Projection	Annual Savings	Tech. Change / Base Case %
2016	8,799	8,799	0	100.0
2017	9,069	9,069	0	100.0
2018	9,340	9,340	0	100.0
2019	9,630	9,630	0	100.0
2020	9,937	9,937	0	100.0
2021	9,725	10,265	540	94.7
2022	10,080	10,639	559	94.7
2023	10,426	11,005	579	94.7
2024	10,787	11,386	599	94.7
2025	11,159	11,779	620	94.7
2026	10,965	12,183	1,218	90.0
2031	12,354	14,407	2,053	85.7
2036	13,692	16,715	3,023	81.9
2041	14,707	18,744	4,037	78.5
2046	15,559	20,647	5,088	75.4
2051	16,271	22,423	6,152	72.6
2056	16,891	24,075	7,184	70.2

Source: NATSEM calculation

**Figure 13 The projection of total costs of dementia with technological changes 2016-2056**



Source: NATSEM calculation



# 9. DISCUSSION AND CONCLUSIONS

## KEY POINTS

- In 2016, the cost of dementia to Australia was \$14.25 billion which equated to an average cost of \$35,550 per person with dementia. In 2017, the total cost of dementia is expected to increase by 2.9% to \$14.67 billion in 2016 dollars.
- Direct costs such as the cost of hospitalisation, visits to GPs and medical specialists, care, pharmaceuticals, transport and other direct costs, contribute to 62% of the total costs of dementia, and indirect costs through the lost productivity of both persons with dementia and carers to 38% of total costs.
- Over the next 20 years, direct costs will increase by 90% to \$16.72 billion in 2016 and indirect costs by 67% to \$9.08 billion with the total cost of dementia reaching \$25.80 billion in 2036.
- By 2056 the total cost of dementia in Australia will have reached \$36.85 billion, a 2.6 fold increase in costs from 2016. This comprises \$24.08 billion in direct costs and \$12.77 billion in indirect costs.

Dementia is one of the major chronic diseases of this century. The health, social and economic costs of the disorder are enormous as shown in this cost of illness study and these will only grow in the future as the population with dementia rises sharply over coming decades. There is a significant economic burden from dementia for persons with dementia and their families, the health and aged care systems and on the economy as a whole. The increasing prevalence of dementia means that there is both an economic and social imperative for governments to develop initiatives to address dementia and ensure that people with dementia have access to appropriate care and support from the moment of diagnosis.

The number of Australians with probable dementia is projected to increase from 400,833 persons in 2016 to 1,100,890 individuals by 2056. Currently 237 persons are developing dementia each day. The number of new cases of dementia will increase 3.6 fold to over 650 people per day by 2056.

## 9.1 COSTS OF DEMENTIA

Access Economics estimated the cost of dementia in 2002 to be \$6.6 billion – \$3.4 billion in direct costs (including home and community care costs) (52%) and \$3.2 billion in indirect costs (48%). The AIHW (2012) estimated total direct health and aged care system expenditure on people with dementia was at least \$4.9 billion in 2009–10. Although different methodologies have been used in these studies, the modelling undertaken in this report indicates that the costs

of dementia in 2016 are closer to \$14.25 billion – \$8.8 billion in direct costs (62%) and \$5.5 billion in indirect costs (38%). This level of expenditure equates to an average annual cost of \$35,550 per person with dementia. If current trends in treatment, service use and care continue over the next 40 years then costs are expected to multiple 2.6 fold to \$36.8 billion (in 2016 \$AUD). In keeping with the recommendations by Schaller and colleagues (2015) in their systematic review of cost of illness studies of dementia, the significant variation of cost estimates for different care settings, duration of dementia and disease severity underlines the need to understand and address the financial burden of dementia from all perspectives.

Initiatives that focus on prevention and early intervention and timely diagnosis, and on supporting people with dementia to live in the community, are particularly important given the long-term benefits they deliver. As shown, a 5% reduction in the annual incidence of dementia in persons aged 65 years or over would mean there would be 98,529 fewer people with dementia in 2036 and almost 261,000 fewer people by 2056 compared with the current projections. This would deliver total savings of \$26.8 billion in the costs of dementia over the next twenty years and \$120.4 billion by 2056. Building our capacity to address dementia now will save billions in direct costs and lost productivity for years to come, as well as improving the quality-of-life of the millions of Australians who are in some way impacted by dementia.

12. Report for the Department of Health and Ageing commissioned from Alzheimer's Australia, December 2011

## 9.2 INADEQUACY OF ONGOING AGED CARE REFORMS

The policy implications of the latest data highlights the urgent need for the government to implement a funded, holistic national plan to tackle dementia over the next decade and more, with a focus on providing appropriate services and supports including addressing the social isolation and stigma associated with dementia. This plan must include a comprehensive approach to improving quality of care and supporting people in the community, as well as better care through our health and aged care systems. The results of this study indicate that in 2016, an estimated 305,923 individuals with dementia (76%) were living in the community and another 94,910 people with dementia (24%) residing in cared accommodation. The results suggest that there may be as many as 118,000 individuals with dementia living alone in the community. Further, people with dementia now represent just over half of all residents in RACFs and these individuals tend to have much higher care needs than residents who do not have dementia.

Current ongoing changes to the aged care system have a significant impact on how consumers access and receive services. Alzheimer's Australia supports the government's commitment to aged care reform and the broader intent and ongoing implementation of Consumer Directed Care (CDC) across the aged care system. CDC aims to provide consumers with greater control over their own health and wellbeing by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when.

Concern remains about the current inability of mainstream services to deliver appropriate care and support for people with dementia. Specialist services such as dementia specific advocacy, information and support are critical. Evidence suggests that the complex needs of people with dementia cannot be supported through mainstream health and aged care services alone.<sup>12</sup> There is a need to also fund dementia-specific specialist services, which can provide the care, support and social engagement that people with dementia and their families need. Targeted programs and services can lessen the burden and reduce dementia-related costs across the broader health and aged care sector.

## 9.3 AGED CARE SECTOR WORKFORCE

The analyses in this report show that there are currently 92,000 paid carers looking after people with dementia in the residential aged care setting, and 190,500 carers of people with dementia in the community, the majority of whom are family members providing informal care. The core business of both residential and home-based aged care services increasingly includes providing care to people with dementia. The demand for carers will rise over the coming decades as the number of people with dementia in the population increases. The modelling undertaken in this report indicates that the number of carers needed to provide assistance to people with dementia will double by 2056 to around 525,540 carers in the community and 250,420 paid carers in the residential aged care sector. It remains to be seen whether this level of demand will be able to be met from current growth rates in the paid aged carer workforce and availability of family and friends as informal caregivers.

As the prevalence of dementia increases in the community, it is critical that all aged care services are well-equipped and motivated to provide safe, high-quality care for people with dementia, as part of their core business. The aged care sector workforce is a critical element in the provision of quality services, and this workforce must be available in the future in sufficient numbers, and at a high quality.

To ensure quality care, management in aged care services must be committed to person-centred, high-quality care, and services must have adequate numbers of skilled, qualified staff. The workforce must have the appropriate education and training, skills, and attributes to provide quality care for older people, including people with dementia, who frequently have complex care needs.

## 9.4 URGENT CALL FOR A NATIONAL DEMENTIA STRATEGY

Backed by the evidence provided in this report, Alzheimer's Australia strongly urges the government to develop and implement a National Dementia Strategy to ensure a comprehensive and co-ordinated approach to addressing dementia in Australia. A comprehensive approach has the potential to produce significant social and economic benefits.

While dementia is not curable, effective risk reduction and preventative health measures can delay the onset of dementia for up to five years. Effective early intervention and psychosocial support for people with dementia and their carers can increase quality of life, reduce stress and sometimes delay admission to residential care. Effective programs in the community and residential care can reduce unnecessary admissions to hospital; and dementia-focused programs in acute care can reduce length of hospital stay and associated expenditure.

A holistic approach to dementia care begins with raising awareness amongst the general population, and spans the provision of services to people with dementia and their families from point of diagnosis, through to appropriate end of life care. An individualised approach to care involves understanding not only the unique characteristics of the disease, but also what it means for that person to live well with dementia and how they can be supported to do so. This involves focusing on the social, emotional, physical, and health needs of the person with dementia as well as their carers and family members.

To achieve any real change, a national strategy for dementia is urgently needed that will prepare Australia for the challenges of the coming decades as portrayed in this report. For effective policy planning, this strategy needs to encompass:

- Greater effort to promote awareness of the risk factors for dementia and risk reduction, so that fewer people develop dementia;
- Timely diagnosis and post-diagnostic support, including early intervention, so that people can live successfully in the community for longer, and admissions to aged and acute care facilities are delayed or avoided;
- Effective education and training for health professionals and others working in the field;
- Improved carer support and respite, so that the experience of carers is improved, and carers can continue to participate socially and economically;
- Better access to ongoing support and treatment services, so that the journey for people with dementia, and their carers, is improved;
- Better access to end-of-life palliative care; and
- Increased investment in dementia research, with emphasis on translational research and consumer involvement in all aspects of dementia research in Australia.

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# TECHNICAL NOTES

## INCIDENCE RATIO

Ratio of incident cases of dementia to prevalent cases used by AIHW (2012) to estimate the total number of new cases in the population each year. These ratios were calculated from the AIHW projections of the prevalent number of persons with dementia and incident cases in 2003 and 2011 (AIHW, 2007; AIHW, 2012).

### Ratio of Incident cases to Prevalence

	Males	Females
<b>0-64</b>	0.200	0.231
<b>65-74</b>	0.212	0.221
<b>75-84</b>	0.223	0.210
<b>85+</b>	0.237	0.201

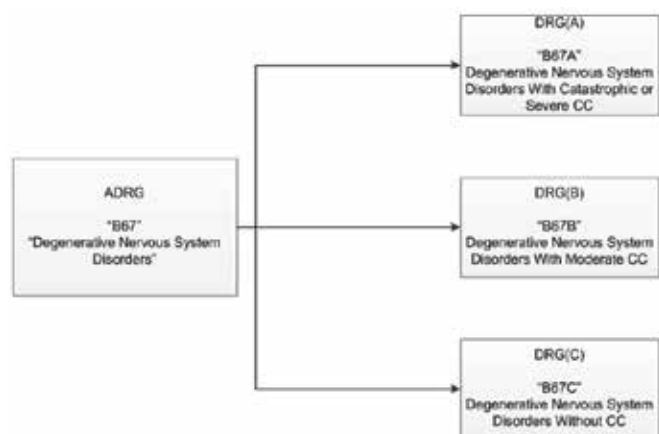
## METHODOLOGY FOR DIRECT COST ESTIMATION

### Direct Medical Costs

- i. The identification of the initial cost follows the method of costing estimation by AIHW (2013). Using the HDS data, the diagnosis of dementia applies the Australian Refined Diagnosis Related Group (AR-DRG). DRGs define a patient classification system that relates types of treatment in a hospital to the required resources (AIHW 2013). The levels are classified on several factors such as diagnoses/procedures, severity, and patient clinical complexity. In terms of the diagnosis of dementia, the code classification of DRGs is "B67", classified as 'Degenerative Nervous System Disorder'.
- ii. In order to estimate the degree of severity (Jonsson et al. 2006; Quentin et al. 2010; Leicht et al. 2011), the calculation also follows the AIHW 2013 approach (see the Figure below) on DRGs sub classification of code "B67". First, the DRG code of "B67A" of "Degenerative Nervous System Disorder with Catastrophic or Severe clinical condition (CC)" is classified as people with dementia in a severe condition. Second, DRG code of "B67B" of "Degenerative Nervous System Disorder with Moderate CC" classifies people with dementia in a moderate condition. The last DRG code is "B67C" of "Degenerative Nervous System Disorder without CC" classifies people with dementia in a mild condition.
- iii. The pricing of DRGs follows the national pricing model specification of the National Weighted Activity Units (NWAU), provided by the Independent Hospital Pricing Authority (IHPA)<sup>13</sup>. The NWAU applies the pricing model 2016-2017 as this model also becomes a base pricing model for the projection cost from 2016 to 2036. The calculation follows the provided standard in the NWAU calculation. As the DRG code of "B67" is classified as an acute admitted service, the activity based funding (ABF) is calculated using the standard formula below:

13. The technical specifications of the national pricing model describe how the independent hospital pricing authority develops the pricing standard every year to determine the National Efficient Price (NEP). It becomes a guide for Activity Based Funding (ABF) model for each hospital services. <https://www.ihsa.gov.au/what-we-do/technical-specifications-and-nwau-calculators>

## The DRGs classification for people with dementia as the main diagnosis



Source: AIHW 2013

## The standard formula of hospitalisation cost

$$\{[PW * A_{Paed} * (1 + A_{SPA}) * (1 + A_{Ind} + A_A + A_{RT} + A_{Dia}) + (A_{ICU} * ICU \text{ hours})] - [(PW + A_{ICU} * ICU \text{ hours} * A_{PPS} + LOS * A_{Acc})] * NEP$$

[1]

Where PW is the price weight for an ABF activity related to the classification of admitted services (IHPA 2015), is the paediatric adjustment, is the specialist psychiatric age adjustment, is the indigenous adjustment, is the remoteness area adjustment, is the radiotherapy adjustment, is the dialysis adjustment, is the intensive care unit (ICU) adjustment, is the private patient service adjustment, is the private patient accommodation adjustment, and NEP is the national efficient price 2016-2017. By using the ABF, it is assumed that the cost components include hospital costs (bed and treatment), related-pharmaceutical costs in the hospitals, GPs and specialists.

- iv. The length of stay (LOS) refers to the AIHW study in 2012 based on the hospitalisation expenditure in 2009-2010 for people with dementia and the study by Bail et al. (2015) and Annear et al. (2016) for the LOS for those aged 70 years and under. The data provided by the National Hospital Data Collection shows the average LOS for a person with dementia was 17.7 days. The data also relate to gender and age groups. The calculation defines the initial costs for people with dementia. The following years classified as the next episodes with a shorter LOS for the hospitalisation costs. Therefore, the calculation of LOS refers to the AIHW study in 2013 of cost and strategies, using HDS data from NSW public hospitals. The average LOS from the study was 2.4 days for people with dementia.
- v. The aggregate estimation costs correspond to the prevalence number of people with dementia provided in the previous section. The total costs are classified by age groups, gender, and states/territories.
- vi. Cost components such as pharmaceutical costs, transportation, and other costs are also estimated by following the Access Economics calculation in 2003, which is also based on AIHW data. The weighted value of these other costs is estimated at 6% from the total of direct medical costs. Therefore, additional costs are added in the component of the costs. The pharmaceutical cost is recognised as a treatment cost outside of hospitals<sup>14</sup>. The cost of drugs for the treatment of dementia provided under the Pharmaceutical Benefit Scheme (PBS) are not estimated directly from PBS benefits but rather are included in the estimation of the component costs.

14. AIHW (2012, p.82) identified the prescription and expenditure for people with dementia in 2009-2010. The pharmaceutical treatments outside hospital includes Donepezil, Galantamine, Rivastigmine, and Memantine.

## Direct Non-Medical Costs

- i. The costs of care are divided into two categories of care: i. home care (non-institutionalised setting), ii. aged care homes or nursing homes (institutionalised setting). The classification follows several studies in terms of cost differentiation (Beeri et al. 2002; Allegri et al. 2007; Masterton et al. 2010; Kraft et al. 2010).
- ii. The estimation follows the Australian Government Welfare payments system for home care and aged care homes
- iii. The cost for home care setting refers to the basic daily fee for a home care package that service providers in Australia are regulated to charge at \$19.94 per day (based on government maximum rate package of \$139.58 per person per fortnight). The rate is from 20 September 2016 and increases every 6 months following the indexation of the consumer price index (CPI). The effect of CPI is included in the projection calculation.
- iv. The cost for institutionalised age care homes applies the maximum basic daily of 85% of the single person rate of the basic age pension. The rate for this payment is \$48.44 per day (based on the single pension rate of \$797.9 per fortnight). The rate is from 20 September 2016 and increases every 6 months following the indexation of CPI. The effect of CPI is included in the projection calculation.
- v. The effect of welfare system such as income and asset means testing is excluded from the estimation. The subsidies and supplements from the Australian Government are also excluded from the estimation (AIHW 2011).
- vi. The calculation for the total annual cost of dementia refer to assumption v in the direct medical costs, which refers to the average LOS in the initial costs when dementia is diagnosed and the average of LOS in subsequent episodes.

## The extended formula for total cost

The total direct costs of dementia can be divided into two conditions and into two care settings. First, the total direct costs of dementia in the initial year when a person is diagnosed with dementia in a home care setting. This is estimated using the formula below:

$$\begin{aligned} & \{[PW * A_{Paed} * (1 + A_{SPA}) * (1 + A_{Ind} + A_A + A_{RT} + A_{Dia}) + (A_{ICU} * ICU \text{ hours})] \\ & - [(PW + A_{ICU} * ICU \text{ hours} * A_{PPS} + LOS * A_{Acc}) * NEP] * [LOS_t] + \{[H_{max} * (365 \\ & - LOS_t)\} \end{aligned} \quad [2]$$

Where  $LOS_t$  is the average length of stay for patients when they are diagnosed with dementia in the initial year.  $H_{max}$  is the maximum basic daily fee for home care setting. The total direct cost of dementia in the year after that follows the formula below:

$$\begin{aligned} & \{[PW * A_{Paed} * (1 + A_{SPA}) * (1 + A_{Ind} + A_A + A_{RT} + A_{Dia}) + (A_{ICU} * ICU \text{ hours})] \\ & - [(PW + A_{ICU} * ICU \text{ hours} * A_{PPS} + LOS * A_{Acc}) * NEP] * [LOS_{t+n}] + \{[H_{max} * (365 \\ & - LOS_{t+n})\} \end{aligned} \quad [3]$$

Where  $LOS_{t+n}$  is the average length of stay in hospital for people with dementia in the following year after the diagnosis and n (1,2,3,...,n).

15. The basic daily for home care includes support services, personal care, nursing and care coordination, while the basic fee for aged care or nursing homes includes service in home care and day-to-day living costs such as meals, cleaning and laundry. The basic daily fee for home is \$19.94 and for aged care/nursing homes is 48.44 per September 2016 <http://www.myagedcare.gov.au/estimate-fees-for-aged-care-services>



Meanwhile, the total direct cost of dementia in residential aged care or a nursing home setting for the initial year and the subsequent years follows the formula below:

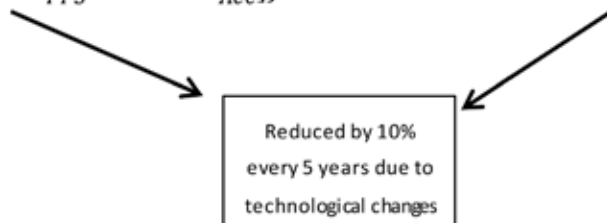
$$\begin{aligned} & \{ [PW * A_{Paed} * (1 + A_{SPA}) * (1 + A_{Ind} + A_A + A_{RT} + A_{Dia}) + (A_{ICU} * ICU \text{ hours})] \\ & \quad - [(PW + A_{ICU} * ICU \text{ hours} * A_{PPS} + LOS * A_{Acc}) * NEP] * [LOS_t] + \{ [N_{max} * (365 \\ & \quad - LOS_t) \} \end{aligned} \tag{4}$$

$$\begin{aligned} & \{ [PW * A_{Paed} * (1 + A_{SPA}) * (1 + A_{Ind} + A_A + A_{RT} + A_{Dia}) + (A_{ICU} * ICU \text{ hours})] \\ & \quad - [(PW + A_{ICU} * ICU \text{ hours} * A_{PPS} + LOS * A_{Acc}) * NEP] * [LOS_{t+n}] + \{ [N_{max} * (365 \\ & \quad - LOS_{t+n}) \} \end{aligned} \tag{5}$$

Where  $N_{max}$  is the maximum basic daily fee for aged care or nursing homes setting.

#### The formula for sensitivity analysis

$$\{ [PW * A_{Paed} * (1 + A_{SPA}) * (1 + A_{Ind} + A_A + A_{RT} + A_{Dia}) + (A_{ICU} * ICU \text{ hours})] - [(PW + A_{ICU} * ICU \text{ hours} * A_{PPS} + LOS * A_{Acc}) * NEP] \}$$



## METHODOLOGY FOR INDIRECT COST ESTIMATION

- i. Following AIHW (2012), the estimations for carers focuses on primary carers of people with dementia and who are living in the community. The SDAC in 2009 and 2012 suggest that on average the largest proportion of primary carers are between age 45 and 64 years (41.4%), followed by age group 65-74 years (34.6%), and aged group 75 years and over (20.5%). The table below shows the proportion of primary carers by gender.

### Primary carers of people with dementia living in the community by gender and age groups (2009)

Age	Primary carers(a)		
	Males	Females	Persons
<b>Under 45</b>	**6.7	**2.1	**3.4
<b>45-64</b>	*41.9	41.3	41.4
<b>65-74</b>	*29.0	37.0	34.6
<b>75+</b>	*22.5	19.6	20.5
<b>Total</b>	100.0	100.0	100.0

\* Estimate has a relative standard error of 25% to 50% and should be used with caution.

\*\* Estimate has a relative standard error greater than 50% and is considered too unreliable for general use.

(a) These SDAC data pertain to co-resident carers/primary carers and thus exclude those living in a different household.

Source: AIHW analysis of the ABS 2009 Survey of Disability, Ageing and Carers confidentialised unit record file.

- ii. The proportion of primary carers by gender utilising the four different care packages – Community Aged Care Package (CACP), the Extended Aged Care at Home (EACH), the Extended Aged Care at Home Dementia (EACHD), and the National Respite for Carers Program (NRCP) – is given in Table 22. The average proportion of primary carers by gender is 33.7% for males and 66.3 for females. The figures are consistent with the findings from AIHW (2012) that around two-third of primary carers are women.

### Primary carers involved in community aged care packages for dementia

Gender	With Dementia				Average
	CACP	EACH	EACHD	NRCP	
<b>Males</b>	37.1	32.2	37.7	27.7	33.7
<b>Females</b>	62.9	67.8	62.3	72.3	66.3

Source: AIHW analysis of the 2008 Community Care Census

- iii. The calculation of forgone earnings of carers is estimated by weighting the proportion of people with dementia in community care. The data is based on AIHW (2009, 2012) and is projected to the 2016 prevalence numbers. Data shows that the average proportions of people with dementia living in the community are 83.2% for males and 70.8 for females.
- iv. The average annual wages by age groups and gender uses the data from HILDA wave 14 to calculate the forgone earnings for carers that spend their whole time taking care of people with dementia. By combining the average wages and the proportion of primary carers, the calculation is able to estimate the average annual wage per primary carer (see the table below). Therefore, the average annual wages per carer for males is \$26,255 and females is \$24,351. The figures can also be used to reflect the total forgone earnings of a carer.

- v. The average number of carers per person with dementia is calculated based on: (1) the distribution of people with dementia by residency, severity and sex (Table 2.2 in AHIW (2012)) and (2) a suggestion from AIHW (2012) that 0.5 carers are needed for people with mild dementia; 0.7 for those with moderate dementia; and 1.6 for those with severe dementia. Taking into account this information, the average number of carers per person is calculated at 0.66 for males with dementia and 0.59 for females with dementia.
- vi. In terms of forgone earnings for people with dementia, the estimation of the potential loss of earnings also applies the HILDA data wave 14 for full-time annual average wage and the part-time annual average wage. The proportions of full-time workers and part-time workers were obtained from HILDA and multiplied by the prevalence number of people with dementia. It is also assumed that people with dementia are unable to work either on a full-time basis or part-time basis. While many people with dementia continue to work in the initial stages of the disorder, there is a lack of data indicating employment patterns. Several qualitative studies recount the experiences of a small number of people with dementia and their work experiences. Some retire immediately following diagnosis, some are dismissed, some go on sick leave and eventually leave paid work, and some reduce their hours and workloads (Chaplin and Davison, 2016; Evans 2016).

#### The Annual forgone earnings per carer on taking care people with dementia in 2016

Age Groups	Male carer		Female carer		Avg annual wage (\$) per carer	Prop caring male patient (%)	Prop caring female patient (%)
	Average annual wage (\$)	Prop of primary carers (%)	Average annual wage (\$)	Prop of primary carers (%)			
	(1)	(2)	(3)	(4)			
<b>Aged 25 to 44</b>	73588	33.7	38733	66.3	50479.1	6.7	2.1
<b>Aged 45 to 64</b>	70258	33.7	37379	66.3	48459.2	41.9	41.3
<b>Aged 65 to 74</b>	13645	33.7	6423	66.3	8856.81	29	37
<b>Average annual wage (\$) per carer</b>						26,255	24,351

Notes: (1),(3) NATSEM's calculations from HILDA Wave 14, taking into account full-time and part-time employment rates and wages. 2), (4) Using rates from Table 5.6 (AIHW 2012). 5)=[(1)\*(2)+(3)\*(4)]/100. (6), (7) Using rates from Table 5.5 (AIHW 2012). Average annual wage (\$) per carer in row 4 = Average of column (5) using weights from columns (6) and (7). All values are modified at June 2016 values

# APPENDICES

**Appendix 1. Projected prevalence of dementia by age and gender, 2016-2056**

	30 to 64		65 to 69		70 to 74		75 to 79		80 to 84		85+		ALL		Total
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	
2016	13,310	12,090	17,670	26,867	27,320	19,765	33,605	36,038	34,304	41,030	51,960	86,874	178,169	222,664	400,833
2017	13,567	12,371	17,617	26,935	29,358	21,256	35,017	37,497	35,686	41,946	53,623	88,233	184,868	228,238	413,106
2018	13,808	12,635	17,824	27,426	31,058	22,472	36,268	38,911	37,210	43,031	55,200	89,575	191,367	234,049	425,416
2019	14,087	12,921	18,113	28,032	32,153	23,298	38,049	40,879	38,967	44,483	56,783	90,822	198,152	240,434	438,586
2020	14,329	13,181	18,450	28,661	33,159	24,102	39,935	43,003	40,880	45,987	58,460	92,383	205,213	247,318	452,532
2021	14,580	13,468	18,869	29,345	34,040	24,873	42,005	45,185	42,604	47,473	60,607	94,353	212,705	254,696	467,401
2022	14,826	13,721	19,290	30,072	34,009	24,963	45,293	48,682	44,597	49,532	63,107	96,317	221,121	263,288	484,408
2023	15,031	13,929	19,689	30,761	34,469	25,441	48,018	51,525	46,361	51,520	65,723	98,549	229,291	271,724	501,015
2024	15,179	14,067	20,173	31,518	35,081	26,023	49,806	53,475	48,844	54,270	68,629	101,249	237,713	280,602	518,314
2025	15,259	14,116	20,600	32,219	35,787	26,626	51,453	55,375	51,461	57,221	71,773	104,273	246,334	289,830	536,164
2026	15,269	14,075	21,059	33,004	36,650	27,281	52,903	57,190	54,302	60,232	74,988	107,569	255,171	299,351	554,521
2027	15,279	14,042	21,507	33,696	37,511	27,973	52,978	57,475	58,809	65,064	78,762	111,644	264,847	309,894	574,740
2028	15,343	14,055	21,866	34,259	38,330	28,630	53,803	58,641	62,467	68,943	82,261	115,752	274,070	320,281	594,351
2029	15,506	14,203	22,089	34,607	39,311	29,350	54,845	60,036	64,888	71,624	86,831	121,263	283,470	331,083	614,553
2030	15,771	14,442	22,149	34,696	40,179	30,017	56,035	61,485	67,112	74,233	91,648	127,187	292,894	342,059	634,953
2031	16,166	14,867	22,038	34,509	41,110	30,763	57,469	63,049	69,069	76,710	96,690	133,256	302,542	353,154	655,695
2032	16,537	15,258	21,931	34,343	42,014	31,419	58,889	64,692	69,352	77,223	104,240	142,518	312,963	365,452	678,416
2033	16,793	15,506	21,955	34,327	42,738	31,952	60,237	66,252	70,588	78,894	110,339	150,174	322,652	377,105	699,757
2034	16,937	15,598	22,198	34,704	43,193	32,284	61,831	67,949	72,066	80,842	115,556	157,035	331,779	388,412	720,192
2035	17,024	15,622	22,646	35,340	43,323	32,372	63,241	69,518	73,744	82,866	120,648	163,970	340,625	399,687	740,313
2036	16,983	15,466	23,378	36,515	43,121	32,203	64,754	71,270	75,744	85,034	125,528	170,675	349,509	411,163	760,672
2037	16,984	15,362	24,049	37,585	42,930	32,054	66,218	72,809	77,708	87,298	130,117	177,009	358,005	422,117	780,122
2038	17,098	15,386	24,453	38,227	42,998	32,048	67,394	74,064	79,589	89,465	134,843	183,627	366,376	432,817	799,193
2039	17,317	15,527	24,611	38,422	43,496	32,409	68,143	74,849	81,788	91,811	139,223	189,924	374,577	442,942	817,519
2040	17,630	15,780	24,630	38,405	44,392	33,009	68,373	75,064	83,747	93,990	143,810	196,368	382,582	452,616	835,198
2041	18,061	16,161	24,375	37,880	45,847	34,113	68,092	74,693	85,874	96,428	148,700	202,827	390,949	462,101	853,049
2042	18,542	16,597	24,192	37,488	47,173	35,115	67,836	74,372	87,915	98,560	153,359	209,139	399,017	471,271	870,288
2043	19,080	17,108	24,216	37,440	47,975	35,716	68,001	74,391	89,559	100,307	158,078	215,593	406,909	480,556	887,464
2044	19,573	17,594	24,456	37,718	48,294	35,900	68,855	75,269	90,632	101,407	163,011	222,107	414,821	489,995	904,816
2045	20,048	18,066	24,886	38,306	48,342	35,887	70,329	76,697	90,990	101,722	167,846	228,568	422,442	499,245	921,687
2046	20,419	18,432	25,584	39,270	47,861	35,404	72,691	79,295	90,705	101,268	173,194	235,507	430,454	509,175	939,629
2047	20,717	18,730	26,402	40,403	47,523	35,047	74,831	81,642	90,479	100,895	178,281	241,918	438,233	518,636	956,869
2048	20,940	18,955	27,359	41,756	47,591	35,011	76,122	83,046	90,847	101,015	182,915	247,929	445,773	527,713	973,486
2049	21,178	19,191	28,224	43,042	48,082	35,278	76,652	83,482	92,164	102,326	186,985	253,074	453,286	536,393	989,679
2050	21,415	19,420	29,058	44,291	48,948	35,835	76,753	83,459	94,284	104,360	190,066	257,058	460,525	544,423	1,004,948
2051	21,589	19,621	29,710	45,256	50,340	36,743	76,038	82,364	97,599	107,996	192,762	260,382	468,038	552,362	1,020,400
2052	21,733	19,774	30,228	46,040	51,967	37,809	75,561	81,570	100,564	111,244	195,423	263,492	475,474	559,929	1,035,404
2053	21,867	19,894	30,606	46,631	53,866	39,080	75,723	81,521	102,342	113,165	198,617	267,126	483,021	567,417	1,050,437
2054	21,977	19,973	31,022	47,261	55,583	40,287	76,565	82,178	103,104	113,771	202,720	271,935	490,971	575,405	1,066,376
2055	22,061	20,033	31,448	47,878	57,238	41,459	78,001	83,508	103,293	113,749	207,173	276,942	499,215	583,568	1,082,783
2056	22,167	20,085	31,738	48,414	58,536	42,366	80,277	85,657	102,457	112,333	212,972	283,888	508,147	592,743	1,100,890

## Appendix 2. Projected number of incident cases of dementia by age and gender, 2016-2056

	30 to 64		65 to 69		70 to 74		75 to 79		80 to 84		85+		ALL		Total
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	
2016	2,662	2,790	3,748	5,946	5,795	4,374	7,508	7,567	7,664	8,616	12,324	17,445	39,700	46,738	86,438
2017	2,713	2,855	3,737	5,961	6,227	4,704	7,823	7,874	7,972	8,808	12,718	17,718	41,191	47,920	89,111
2018	2,762	2,916	3,781	6,070	6,588	4,973	8,102	8,170	8,313	9,036	13,092	17,988	42,638	49,152	91,790
2019	2,817	2,982	3,842	6,204	6,820	5,156	8,500	8,584	8,705	9,340	13,468	18,238	44,153	50,504	94,657
2020	2,866	3,042	3,914	6,343	7,034	5,334	8,922	9,030	9,133	9,656	13,866	18,552	45,733	51,957	97,690
2021	2,916	3,108	4,003	6,494	7,221	5,505	9,384	9,488	9,518	9,968	14,375	18,947	47,416	53,510	100,926
2022	2,965	3,166	4,092	6,655	7,214	5,525	10,119	10,222	9,963	10,401	14,968	19,342	49,320	55,311	104,631
2023	3,006	3,214	4,176	6,808	7,312	5,630	10,727	10,819	10,357	10,818	15,588	19,790	51,167	57,079	108,247
2024	3,036	3,246	4,279	6,975	7,441	5,759	11,127	11,229	10,912	11,396	16,277	20,332	53,073	58,937	112,009
2025	3,052	3,258	4,370	7,130	7,591	5,893	11,495	11,628	11,497	12,015	17,023	20,939	55,027	60,863	115,890
2026	3,054	3,248	4,467	7,304	7,774	6,038	11,819	12,009	12,131	12,647	17,786	21,601	57,031	62,847	119,878
2027	3,056	3,240	4,562	7,457	7,957	6,191	11,835	12,068	13,138	13,662	18,681	22,419	59,229	65,039	124,268
2028	3,069	3,243	4,638	7,582	8,131	6,336	12,020	12,313	13,955	14,477	19,511	23,244	61,323	67,196	128,519
2029	3,101	3,278	4,685	7,659	8,339	6,495	12,253	12,606	14,496	15,040	20,595	24,351	63,469	69,429	132,898
2030	3,154	3,333	4,698	7,679	8,523	6,643	12,518	12,911	14,993	15,587	21,737	25,541	65,624	71,693	137,317
2031	3,233	3,431	4,675	7,637	8,720	6,808	12,839	13,239	15,430	16,107	22,933	26,759	67,830	73,982	141,812
2032	3,307	3,521	4,652	7,600	8,912	6,953	13,156	13,584	15,494	16,215	24,724	28,619	70,245	76,493	146,738
2033	3,359	3,578	4,657	7,597	9,066	7,071	13,457	13,912	15,770	16,566	26,170	30,157	72,479	78,881	151,360
2034	3,387	3,600	4,709	7,680	9,162	7,145	13,813	14,268	16,100	16,975	27,407	31,534	74,579	81,202	155,781
2035	3,405	3,605	4,804	7,821	9,190	7,164	14,128	14,597	16,475	17,400	28,615	32,927	76,616	83,515	160,131
2036	3,397	3,569	4,959	8,081	9,147	7,127	14,466	14,965	16,922	17,855	29,773	34,274	78,663	85,871	164,534
2037	3,397	3,545	5,101	8,318	9,106	7,094	14,793	15,288	17,360	18,331	30,861	35,545	80,619	88,122	168,741
2038	3,420	3,551	5,187	8,460	9,121	7,093	15,056	15,552	17,781	18,786	31,982	36,874	82,546	90,315	172,862
2039	3,463	3,583	5,221	8,503	9,226	7,172	15,223	15,717	18,272	19,278	33,021	38,139	84,426	92,393	176,819
2040	3,526	3,642	5,225	8,500	9,417	7,305	15,275	15,762	18,709	19,736	34,109	39,433	86,260	94,377	180,637
2041	3,612	3,729	5,171	8,383	9,725	7,550	15,212	15,684	19,185	20,248	35,269	40,730	88,173	96,324	184,497
2042	3,708	3,830	5,132	8,296	10,006	7,771	15,155	15,617	19,641	20,696	36,374	41,997	90,016	98,208	188,223
2043	3,816	3,948	5,137	8,286	10,176	7,904	15,192	15,621	20,008	21,062	37,493	43,294	91,822	100,115	191,936
2044	3,915	4,060	5,188	8,347	10,244	7,945	15,382	15,805	20,248	21,293	38,663	44,602	93,639	102,053	195,692
2045	4,010	4,169	5,279	8,478	10,254	7,942	15,712	16,105	20,328	21,359	39,810	45,899	95,392	103,952	199,344
2046	4,084	4,254	5,427	8,691	10,152	7,835	16,240	16,650	20,264	21,264	41,078	47,292	97,244	105,987	203,231
2047	4,143	4,322	5,600	8,942	10,081	7,756	16,718	17,143	20,213	21,186	42,285	48,580	99,040	107,929	206,969
2048	4,188	4,374	5,803	9,241	10,095	7,748	17,006	17,438	20,296	21,211	43,384	49,787	100,772	109,800	210,571
2049	4,236	4,429	5,987	9,526	10,199	7,807	17,124	17,529	20,590	21,486	44,349	50,820	102,485	111,598	214,083
2050	4,283	4,482	6,164	9,802	10,383	7,931	17,147	17,525	21,063	21,913	45,080	51,620	104,120	113,273	217,393
2051	4,318	4,528	6,302	10,016	10,678	8,132	16,987	17,295	21,804	22,677	45,719	52,288	105,809	114,935	220,743
2052	4,347	4,563	6,412	10,189	11,023	8,368	16,881	17,128	22,466	23,359	46,350	52,912	107,479	116,519	223,998
2053	4,373	4,591	6,492	10,320	11,426	8,649	16,917	17,118	22,864	23,762	47,108	53,642	109,180	118,082	227,262
2054	4,395	4,609	6,580	10,459	11,790	8,916	17,105	17,256	23,034	23,890	48,081	54,608	110,986	119,737	230,723
2055	4,412	4,623	6,671	10,596	12,141	9,175	17,426	17,535	23,076	23,885	49,137	55,613	112,864	121,427	234,291
2056	4,433	4,635	6,732	10,715	12,417	9,376	17,934	17,986	22,889	23,588	50,512	57,008	114,919	123,307	238,226

**Appendix 3. Projected number of carers for people with dementia by sector, 2016-2056**

	<b>In the Community</b>	<b>In Cared Accommodation</b>	<b>Total number of Carers</b>
<b>2016</b>	190,505	92,005	282,510
<b>2017</b>	196,491	94,672	291,163
<b>2018</b>	202,468	97,373	299,842
<b>2019</b>	208,842	100,283	309,126
<b>2020</b>	215,577	103,380	318,957
<b>2021</b>	222,752	106,687	329,439
<b>2022</b>	230,941	110,487	341,428
<b>2023</b>	238,931	114,203	353,135
<b>2024</b>	247,243	118,085	365,329
<b>2025</b>	255,812	122,099	377,911
<b>2026</b>	264,620	126,231	390,851
<b>2027</b>	274,314	130,789	405,103
<b>2028</b>	283,697	135,229	418,926
<b>2029</b>	293,350	139,815	433,165
<b>2030</b>	303,090	144,455	447,544
<b>2031</b>	313,001	149,164	462,164
<b>2032</b>	323,839	154,340	478,179
<b>2033</b>	334,007	159,214	493,221
<b>2034</b>	343,724	163,899	507,623
<b>2035</b>	353,275	168,529	521,805
<b>2036</b>	362,931	173,223	536,154
<b>2037</b>	372,156	177,705	549,862
<b>2038</b>	381,207	182,096	563,303
<b>2039</b>	389,924	186,295	576,219
<b>2040</b>	398,344	190,335	588,680
<b>2041</b>	406,882	194,381	601,263
<b>2042</b>	415,125	198,289	613,414
<b>2043</b>	423,320	202,200	625,520
<b>2044</b>	431,591	206,159	637,750
<b>2045</b>	439,625	210,017	649,641
<b>2046</b>	448,156	214,130	662,287
<b>2047</b>	456,365	218,073	674,438
<b>2048</b>	464,281	221,869	686,151
<b>2049</b>	472,016	225,548	697,564
<b>2050</b>	479,329	228,998	708,327
<b>2051</b>	486,752	232,467	719,219
<b>2052</b>	493,978	235,818	729,795
<b>2053</b>	501,229	239,164	740,393
<b>2054</b>	508,911	242,718	751,629
<b>2055</b>	516,826	246,369	763,195
<b>2056</b>	525,541	250,418	775,959

**Appendix 4. Total costs of dementia by cost components 2016-2056 (\$AUD 2016 million)**

Year	Hospitalisation	GPs and Specialists	Pharmaceuticals	Transportation and Other Costs	Care cost	Total Direct Cost
2016	4,624	564	242	117	3,252	8,799
2017	4,766	581	250	121	3,352	9,069
2018	4,909	598	257	124	3,452	9,340
2019	5,062	617	265	128	3,558	9,630
2020	5,223	637	274	132	3,671	9,937
2021	5,396	658	283	137	3,792	10,265
2022	5,593	682	293	142	3,930	10,639
2023	5,786	705	303	146	4,064	11,005
2024	5,986	730	314	152	4,205	11,386
2025	6,193	755	324	157	4,349	11,779
2026	6,406	781	336	162	4,498	12,183
2027	6,640	809	348	168	4,662	12,627
2028	6,867	837	360	174	4,821	13,059
2029	7,101	865	372	180	4,985	13,503
2030	7,337	894	384	186	5,150	13,951
2031	7,577	923	397	192	5,319	14,407
2032	7,840	955	411	198	5,503	14,907
2033	8,086	986	424	205	5,676	15,376
2034	8,322	1,014	436	211	5,842	15,825
2035	8,555	1,043	448	217	6,005	16,267
2036	8,790	1,071	461	222	6,170	16,715
2037	9,015	1,099	472	228	6,328	17,142
2038	9,235	1,126	484	234	6,483	17,561
2039	9,447	1,151	495	239	6,631	17,963
2040	9,651	1,176	506	244	6,775	18,352
2041	9,857	1,201	516	249	6,919	18,744
2042	10,056	1,226	527	255	7,059	19,123
2043	10,255	1,250	537	260	7,199	19,500
2044	10,455	1,274	548	265	7,339	19,881
2045	10,650	1,298	558	270	7,476	20,252
2046	10,858	1,323	569	275	7,622	20,647
2047	11,057	1,348	579	280	7,762	21,026
2048	11,250	1,371	589	285	7,896	21,391
2049	11,437	1,394	599	289	8,028	21,747
2050	11,614	1,415	609	294	8,151	22,083
2051	11,792	1,437	618	298	8,277	22,423
2052	11,855	1,445	621	300	8,413	22,634
2053	12,029	1,466	630	304	8,535	22,965
2054	12,214	1,489	640	309	8,664	23,316
2055	12,404	1,512	650	314	8,798	23,677
2056	12,613	1,537	661	319	8,944	24,075

Source: NATSEM calculation. All estimations based on 2016 price

**Appendix 5. Total direct costs of dementia by State and Territory 2016-2056 (\$AUD 2016 million)**

Year	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	Australia
2016	2,969	2,234	1,645	748	835	224	32	111	8,799
2017	3,049	2,299	1,705	766	869	231	34	116	9,069
2018	3,129	2,365	1,766	784	903	237	36	120	9,340
2019	3,214	2,435	1,831	803	939	245	38	125	9,630
2020	3,305	2,509	1,901	824	976	252	40	130	9,937
2021	3,402	2,589	1,974	845	1,016	260	43	135	10,265
2022	3,513	2,680	2,057	872	1,062	269	45	142	10,639
2023	3,621	2,769	2,138	897	1,107	278	47	148	11,005
2024	3,733	2,861	2,223	924	1,155	287	50	154	11,386
2025	3,849	2,956	2,311	951	1,203	296	52	160	11,779
2026	3,967	3,056	2,401	979	1,252	306	55	166	12,183
2027	4,097	3,165	2,499	1,010	1,308	316	57	174	12,627
2028	4,224	3,271	2,594	1,041	1,363	326	60	180	13,059
2029	4,355	3,381	2,692	1,071	1,419	336	62	187	13,503
2030	4,486	3,492	2,791	1,102	1,476	345	65	194	13,951
2031	4,619	3,607	2,890	1,134	1,535	354	67	201	14,407
2032	4,764	3,733	2,998	1,169	1,600	365	70	209	14,907
2033	4,900	3,851	3,100	1,200	1,662	374	73	216	15,376
2034	5,028	3,965	3,198	1,229	1,724	383	75	223	15,825
2035	5,154	4,077	3,295	1,258	1,785	391	77	230	16,267
2036	5,281	4,191	3,393	1,286	1,849	399	80	236	16,715
2037	5,401	4,300	3,487	1,312	1,911	406	82	243	17,142
2038	5,520	4,407	3,580	1,336	1,973	413	84	249	17,561
2039	5,631	4,511	3,669	1,359	2,033	419	86	255	17,963
2040	5,737	4,612	3,756	1,380	2,094	424	88	261	18,352
2041	5,842	4,715	3,844	1,401	2,156	429	91	266	18,744
2042	5,943	4,813	3,930	1,421	2,217	433	93	272	19,123
2043	6,044	4,913	4,016	1,439	2,279	437	94	278	19,500
2044	6,142	5,014	4,104	1,458	2,342	441	96	284	19,881
2045	6,236	5,112	4,191	1,476	2,405	445	98	289	20,252
2046	6,337	5,216	4,283	1,495	2,472	448	101	296	20,647
2047	6,432	5,315	4,372	1,511	2,539	451	103	302	21,026
2048	6,523	5,412	4,459	1,526	2,605	453	105	308	21,391
2049	6,609	5,507	4,544	1,541	2,671	456	107	313	21,747
2050	6,686	5,598	4,625	1,553	2,737	457	109	319	22,083
2051	6,764	5,689	4,706	1,566	2,804	458	111	325	22,423
2052	6,824	5,762	4,772	1,562	2,857	444	98	316	22,634
2053	6,898	5,851	4,851	1,573	2,925	445	100	322	22,965
2054	6,978	5,946	4,934	1,585	2,996	446	102	328	23,316
2055	7,061	6,042	5,020	1,598	3,070	447	105	334	23,677
2056	7,156	6,147	5,114	1,612	3,149	449	107	341	24,075

Source: NATSEM calculation. All estimations based on 2016 price



**Appendix 6. Projection of total indirect costs, 2016-2056 (\$AUD 2016 million)**

<b>Years</b>	<b>People with Dementia</b>	<b>Carers</b>	<b>Total</b>
2016	2,253	3,198	5,451
2017	2,296	3,301	5,597
2018	2,345	3,403	5,748
2019	2,395	3,512	5,907
2020	2,443	3,626	6,069
2021	2,494	3,748	6,242
2022	2,537	3,887	6,424
2023	2,578	4,023	6,601
2024	2,616	4,163	6,779
2025	2,644	4,309	6,952
2026	2,665	4,458	7,123
2027	2,686	4,622	7,307
2028	2,709	4,780	7,489
2029	2,741	4,943	7,684
2030	2,778	5,107	7,885
2031	2,827	5,274	8,101
2032	2,872	5,456	8,329
2033	2,906	5,628	8,534
2034	2,932	5,791	8,723
2035	2,955	5,951	8,906
2036	2,970	6,113	9,083
2037	2,988	6,267	9,255
2038	3,012	6,419	9,431
2039	3,042	6,566	9,608
2040	3,082	6,707	9,789
2041	3,129	6,851	9,980
2042	3,184	6,990	10,174
2043	3,249	7,128	10,378
2044	3,315	7,268	10,582
2045	3,383	7,403	10,785
2046	3,444	7,546	10,990
2047	3,503	7,684	11,186
2048	3,560	7,817	11,377
2049	3,619	7,947	11,567
2050	3,680	8,071	11,751
2051	3,732	8,197	11,928
2052	3,777	8,319	12,096
2053	3,817	8,443	12,259
2054	3,854	8,573	12,427
2055	3,887	8,708	12,595
2056	3,917	8,855	12,772

Source: NATSEM calculation

**Appendix 7. The projection of total indirect costs by State/Territory and for Australia, 2016-2056 (\$AUD 2016 million)**

Years	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	Australia
2016	1,706	1,375	964	418	701	94	56	92	5,451
2017	1,747	1,410	994	429	725	96	59	95	5,597
2018	1,789	1,447	1,024	439	750	99	61	98	5,748
2019	1,832	1,487	1,057	450	776	101	63	101	5,907
2020	1,877	1,526	1,091	460	804	104	65	104	6,069
2021	1,924	1,569	1,127	471	832	106	68	107	6,242
2022	1,975	1,615	1,166	480	863	109	70	111	6,424
2023	2,023	1,659	1,202	491	894	111	73	115	6,601
2024	2,071	1,703	1,240	501	926	114	75	118	6,779
2025	2,116	1,747	1,276	511	957	116	77	122	6,952
2026	2,160	1,791	1,311	521	988	118	80	125	7,123
2027	2,207	1,839	1,350	533	1,022	120	82	129	7,307
2028	2,254	1,886	1,388	544	1,055	122	84	133	7,489
2029	2,304	1,936	1,428	555	1,091	125	86	137	7,684
2030	2,356	1,988	1,471	567	1,128	127	89	141	7,885
2031	2,412	2,043	1,517	580	1,167	130	91	146	8,101
2032	2,473	2,101	1,565	593	1,208	133	94	151	8,329
2033	2,527	2,153	1,608	604	1,247	135	96	155	8,534
2034	2,576	2,203	1,647	613	1,285	137	98	159	8,723
2035	2,623	2,251	1,685	622	1,322	138	100	163	8,906
2036	2,668	2,298	1,720	629	1,361	140	103	167	9,083
2037	2,712	2,344	1,755	637	1,399	141	105	170	9,256
2038	2,756	2,391	1,790	644	1,438	142	107	174	9,431
2039	2,800	2,438	1,826	652	1,477	143	109	178	9,608
2040	2,844	2,486	1,864	661	1,517	145	111	181	9,789
2041	2,890	2,536	1,904	670	1,559	146	113	185	9,980
2042	2,937	2,586	1,946	679	1,603	148	115	190	10,174
2043	2,985	2,640	1,989	688	1,649	149	118	194	10,378
2044	3,033	2,695	2,032	696	1,698	150	120	198	10,582
2045	3,081	2,749	2,075	704	1,747	151	123	203	10,785
2046	3,128	2,804	2,118	711	1,799	153	126	207	10,990
2047	3,173	2,857	2,159	717	1,850	153	128	211	11,186
2048	3,216	2,909	2,199	724	1,900	154	131	215	11,377
2049	3,259	2,960	2,238	731	1,950	155	134	219	11,567
2050	3,299	3,008	2,278	737	1,999	155	136	223	11,751
2051	3,338	3,055	2,316	744	2,047	156	139	226	11,928
2052	3,373	3,098	2,354	750	2,092	156	141	230	12,096
2053	3,408	3,140	2,390	757	2,136	156	143	233	12,259
2054	3,443	3,184	2,428	763	2,181	157	145	237	12,427
2055	3,479	3,227	2,465	769	2,226	157	148	241	12,595
2056	3,518	3,273	2,504	776	2,273	157	150	245	12,772

Source: NATSEM calculation

**Appendix 8. Projection of total indirect costs by gender, 2016-2056 (\$AUD 2016 million)**

<b>Years</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>
2016	3,296	2,155	5,451
2017	3,393	2,204	5,597
2018	3,491	2,257	5,748
2019	3,592	2,315	5,907
2020	3,693	2,376	6,069
2021	3,801	2,441	6,242
2022	3,912	2,512	6,424
2023	4,021	2,581	6,601
2024	4,130	2,650	6,779
2025	4,235	2,717	6,952
2026	4,338	2,784	7,123
2027	4,450	2,857	7,307
2028	4,559	2,929	7,489
2029	4,676	3,008	7,684
2030	4,797	3,088	7,885
2031	4,928	3,173	8,101
2032	5,064	3,265	8,329
2033	5,185	3,349	8,534
2034	5,295	3,428	8,723
2035	5,401	3,506	8,906
2036	5,500	3,583	9,083
2037	5,598	3,658	9,255
2038	5,699	3,732	9,431
2039	5,804	3,803	9,608
2040	5,914	3,875	9,789
2041	6,034	3,946	9,980
2042	6,156	4,018	10,174
2043	6,281	4,097	10,378
2044	6,404	4,178	10,582
2045	6,526	4,260	10,785
2046	6,645	4,345	10,990
2047	6,760	4,426	11,186
2048	6,872	4,505	11,377
2049	6,986	4,581	11,567
2050	7,097	4,653	11,751
2051	7,207	4,722	11,928
2052	7,312	4,784	12,096
2053	7,416	4,844	12,259
2054	7,522	4,905	12,427
2055	7,629	4,966	12,595
2056	7,739	5,033	12,772

Source: NATSEM calculation

**Appendix 9. Projection of total indirect costs by age, 2016-2056 (\$AUD 2016 million)**

<b>Years</b>	<b>30 - 64</b>	<b>65 - 69</b>	<b>70 - 74</b>	<b>75 - 79</b>	<b>80 - 84</b>	<b>85+</b>	<b>Total</b>
2016	1,681	946	583	566	604	1,071	5,451
2017	1,716	946	626	589	624	1,096	5,597
2018	1,748	960	662	611	646	1,120	5,748
2019	1,785	978	686	641	673	1,144	5,907
2020	1,817	998	708	673	702	1,171	6,069
2021	1,852	1,021	728	708	729	1,205	6,242
2022	1,884	1,045	728	763	762	1,243	6,424
2023	1,911	1,068	739	809	792	1,283	6,601
2024	1,930	1,094	753	839	834	1,329	6,779
2025	1,939	1,118	769	868	879	1,380	6,952
2026	1,938	1,144	788	894	927	1,433	7,123
2027	1,937	1,168	807	896	1,003	1,497	7,307
2028	1,943	1,187	825	912	1,064	1,558	7,489
2029	1,964	1,199	846	931	1,105	1,639	7,684
2030	1,997	1,203	864	952	1,144	1,725	7,885
2031	2,050	1,196	885	976	1,179	1,814	8,101
2032	2,099	1,191	904	1,001	1,186	1,948	8,329
2033	2,132	1,191	920	1,025	1,209	2,058	8,534
2034	2,149	1,204	929	1,051	1,236	2,154	8,723
2035	2,157	1,227	932	1,075	1,265	2,249	8,906
2036	2,147	1,268	928	1,102	1,299	2,340	9,083
2037	2,142	1,304	923	1,126	1,333	2,426	9,256
2038	2,153	1,326	924	1,146	1,366	2,516	9,431
2039	2,178	1,334	935	1,158	1,403	2,599	9,608
2040	2,216	1,334	954	1,162	1,436	2,686	9,789
2041	2,270	1,319	985	1,157	1,473	2,776	9,980
2042	2,331	1,307	1,014	1,152	1,507	2,863	10,174
2043	2,400	1,307	1,031	1,154	1,535	2,951	10,378
2044	2,464	1,318	1,038	1,168	1,552	3,042	10,582
2045	2,526	1,340	1,038	1,192	1,558	3,131	10,785
2046	2,574	1,376	1,027	1,232	1,552	3,229	10,990
2047	2,613	1,418	1,019	1,269	1,548	3,321	11,187
2048	2,642	1,468	1,020	1,290	1,552	3,405	11,377
2049	2,673	1,514	1,029	1,299	1,574	3,479	11,567
2050	2,704	1,558	1,047	1,299	1,608	3,535	11,751
2051	2,727	1,593	1,076	1,285	1,664	3,583	11,928
2052	2,747	1,620	1,110	1,276	1,714	3,629	12,096
2053	2,763	1,641	1,150	1,277	1,744	3,684	12,259
2054	2,776	1,663	1,186	1,289	1,756	3,756	12,427
2055	2,786	1,685	1,221	1,312	1,758	3,832	12,595
2056	2,798	1,703	1,249	1,349	1,740	3,935	12,772

Source: NATSEM calculation

**Appendix 10. Change in Prevalence of Dementia from a 5% Reduction in Annual Incidence, 2016-2056**

Years	Scenario: Reduced Incidence			Base Case Projection			Scenario/Base Case %		
	Males	Females	Total	Males	Females	Total	Males	Females	Total
2016	178,169	222,664	400,833	178,169	222,664	400,833	100.0	100.0	100.0
2017	183,306	226,395	409,701	184,868	228,238	413,106	99.2	99.2	99.2
2018	188,115	230,233	418,349	191,367	234,049	425,416	98.3	98.4	98.3
2019	193,162	234,600	427,762	198,152	240,434	438,586	97.5	97.6	97.5
2020	198,413	239,403	437,816	205,213	247,318	452,532	96.7	96.8	96.7
2021	204,000	244,603	448,603	212,705	254,696	467,401	95.9	96.0	96.0
2022	210,495	251,000	461,495	221,121	263,288	484,408	95.2	95.3	95.3
2023	216,631	257,130	473,761	229,291	271,724	501,015	94.5	94.6	94.6
2024	222,950	263,633	486,583	237,713	280,602	518,314	93.8	94.0	93.9
2025	229,387	270,406	499,793	246,334	289,830	536,164	93.1	93.3	93.2
2026	235,910	277,339	513,249	255,171	299,351	554,521	92.5	92.6	92.6
2027	243,309	285,309	528,617	264,847	309,894	574,740	91.9	92.1	92.0
2028	250,090	292,973	543,064	274,070	320,281	594,351	91.3	91.5	91.4
2029	256,999	300,992	557,991	283,470	331,083	614,553	90.7	90.9	90.8
2030	263,822	309,107	572,928	292,894	342,059	634,953	90.1	90.4	90.2
2031	270,700	317,105	587,805	302,542	353,154	655,695	89.5	89.8	89.6
2032	278,459	326,424	604,882	312,963	365,452	678,416	89.0	89.3	89.2
2033	285,330	334,928	620,258	322,652	377,105	699,757	88.4	88.8	88.6
2034	291,541	342,977	634,519	331,779	388,412	720,192	87.9	88.3	88.1
2035	297,336	350,842	648,177	340,625	399,687	740,313	87.3	87.8	87.6
2036	303,182	358,961	662,143	349,509	411,163	760,672	86.7	87.3	87.0
2037	308,525	366,427	674,953	358,005	422,117	780,122	86.2	86.8	86.5
2038	313,670	373,587	687,257	366,376	432,817	799,193	85.6	86.3	86.0
2039	318,578	380,071	698,649	374,577	442,942	817,519	85.0	85.8	85.5
2040	323,135	385,996	709,130	382,582	452,616	835,198	84.5	85.3	84.9
2041	328,095	391,666	719,761	390,949	462,101	853,049	83.9	84.8	84.4
2042	332,649	396,887	729,536	399,017	471,271	870,288	83.4	84.2	83.8
2043	336,898	402,113	739,011	406,909	480,556	887,464	82.8	83.7	83.3
2044	341,163	407,476	748,639	414,821	489,995	904,816	82.2	83.2	82.7
2045	344,918	412,398	757,316	422,442	499,245	921,687	81.6	82.6	82.2
2046	349,167	418,175	767,342	430,454	509,175	939,629	81.1	82.1	81.7
2047	353,082	423,353	776,435	438,233	518,636	956,869	80.6	81.6	81.1
2048	356,653	428,084	784,736	445,773	527,713	973,486	80.0	81.1	80.6
2049	360,163	432,369	792,532	453,286	536,393	989,679	79.5	80.6	80.1
2050	363,208	435,838	799,047	460,525	544,423	1,004,948	78.9	80.1	79.5
2051	366,596	439,250	805,846	468,038	552,362	1,020,400	78.3	79.5	79.0
2052	369,785	442,169	811,954	475,474	559,929	1,035,404	77.8	79.0	78.4
2053	372,951	444,826	817,778	483,021	567,417	1,050,437	77.2	78.4	77.9
2054	376,470	447,977	824,448	490,971	575,405	1,066,376	76.7	77.9	77.3
2055	380,132	451,091	831,224	499,215	583,568	1,082,783	76.1	77.3	76.8
2056	384,556	455,382	839,939	508,147	592,743	1,100,890	75.7	76.8	76.3

Source: NATSEM calculation

**Appendix 11. The projection of total direct costs of dementia with 5% reduction in incidence compared with base case, 2016-2056 (\$AUD 2016 million)**

<b>Years</b>	<b>Projection 5% reduction in Incidence</b>	<b>Base Case Projection</b>	<b>Reduced Incidence/ Base Case %</b>	<b>Annual Savings</b>	<b>Cumulative Savings</b>
2016	8,799	8,799	100.0	0	0
2017	8,881	9,069	97.9	188	188
2018	9,093	9,340	97.4	247	435
2019	9,323	9,630	96.8	307	743
2020	9,568	9,937	96.3	370	1,112
2021	9,829	10,265	95.8	436	1,548
2022	10,137	10,639	95.3	503	2,051
2023	10,432	11,005	94.8	573	2,623
2024	10,740	11,386	94.3	645	3,269
2025	11,058	11,779	93.9	721	3,989
2026	11,383	12,183	93.4	800	4,789
2027	11,748	12,627	93.0	879	5,668
2028	12,096	13,059	92.6	963	6,631
2029	12,455	13,503	92.2	1,048	7,679
2030	12,815	13,951	91.9	1,136	8,816
2031	13,177	14,407	91.5	1,231	10,046
2032	13,585	14,907	91.1	1,322	11,368
2033	13,958	15,376	90.8	1,418	12,786
2034	14,308	15,825	90.4	1,517	14,303
2035	14,647	16,267	90.0	1,620	15,923
2036	14,993	16,715	89.7	1,722	17,645
2037	15,314	17,142	89.3	1,828	19,473
2038	15,626	17,561	89.0	1,935	21,408
2039	15,919	17,963	88.6	2,044	23,452
2040	16,195	18,352	88.2	2,157	25,609
2041	16,474	18,744	87.9	2,270	27,879
2042	16,736	19,123	87.5	2,387	30,266
2043	16,993	19,500	87.1	2,507	32,773
2044	17,254	19,881	86.8	2,627	35,401
2045	17,497	20,252	86.4	2,755	38,155
2046	17,768	20,647	86.1	2,878	41,034
2047	18,021	21,026	85.7	3,005	44,039
2048	18,257	21,391	85.3	3,134	47,173
2049	18,483	21,747	85.0	3,265	50,437
2050	18,683	22,083	84.6	3,400	53,837
2051	18,889	22,423	84.2	3,534	57,371
2052	19,082	22,634	84.3	3,552	60,923
2053	19,271	22,965	83.9	3,694	64,617
2054	19,478	23,316	83.5	3,838	68,455
2055	19,691	23,677	83.2	3,986	72,441
2056	19,943	24,075	82.8	4,132	76,573

Source: NATSEM calculation

**Appendix 12. The projection of total indirect costs of dementia with 5% reduction in incidence compared with base case, 2016-2056 (\$AUD 2016 million)**

<b>Years</b>	<b>Projection 5% reduction in Incidence</b>	<b>Base Case Projection</b>	<b>Reduced Incidence/ Base Case %</b>	<b>Annual Savings</b>	<b>Cumulative Savings</b>
2016	5,451	5,451	100.0	0	0
2017	5,563	5,597	99.4	34	34
2018	5,677	5,748	98.8	72	106
2019	5,798	5,907	98.2	109	215
2020	5,921	6,069	97.6	149	364
2021	6,054	6,242	97.0	188	552
2022	6,195	6,424	96.4	229	781
2023	6,328	6,601	95.9	273	1,054
2024	6,461	6,779	95.3	318	1,372
2025	6,588	6,952	94.8	364	1,736
2026	6,710	7,123	94.2	413	2,149
2027	6,848	7,307	93.7	459	2,608
2028	6,978	7,489	93.2	511	3,119
2029	7,122	7,684	92.7	562	3,681
2030	7,271	7,885	92.2	614	4,295
2031	7,430	8,101	91.7	672	4,967
2032	7,603	8,329	91.3	726	5,693
2033	7,749	8,534	90.8	785	6,478
2034	7,878	8,723	90.3	845	7,323
2035	7,999	8,906	89.8	907	8,230
2036	8,114	9,083	89.3	970	9,200
2037	8,225	9,255	88.9	1,030	10,230
2038	8,336	9,431	88.4	1,095	11,325
2039	8,447	9,608	87.9	1,161	12,486
2040	8,559	9,789	87.4	1,230	13,716
2041	8,682	9,980	87.0	1,298	15,014
2042	8,805	10,174	86.5	1,369	16,383
2043	8,936	10,378	86.1	1,442	17,825
2044	9,066	10,582	85.7	1,516	19,341
2045	9,192	10,785	85.2	1,593	20,934
2046	9,323	10,990	84.8	1,667	22,601
2047	9,438	11,186	84.4	1,748	24,349
2048	9,552	11,377	84.0	1,825	26,174
2049	9,662	11,567	83.5	1,905	28,079
2050	9,764	11,751	83.1	1,988	30,067
2051	9,859	11,928	82.7	2,069	32,136
2052	9,944	12,096	82.2	2,153	34,289
2053	10,019	12,259	81.7	2,240	36,529
2054	10,099	12,427	81.3	2,328	38,857
2055	10,180	12,595	80.8	2,416	41,273
2056	10,266	12,772	80.4	2,506	43,779

Source: NATSEM calculation

**Appendix 13. Projection of total direct costs of dementia with technological change in treatment compared with base case 2016-2056 (\$AUD 2016 million)**

Years	Projection with tech. changes	Base Projection	Tech. Change/ Base Case %	Annual Savings	Cumulative Savings
2016	8,799	8,799	100.0	0	0
2017	9,069	9,069	100.0	0	0
2018	9,340	9,340	100.0	0	0
2019	9,630	9,630	100.0	0	0
2020	9,937	9,937	100.0	0	0
2021	9,725	10,265	94.7	540	540
2022	10,080	10,639	94.7	559	1,099
2023	10,426	11,005	94.7	579	1,678
2024	10,787	11,386	94.7	599	2,277
2025	11,159	11,779	94.7	620	2,897
2026	10,965	12,183	90.0	1,218	4,115
2027	11,366	12,627	90.0	1,261	5,376
2028	11,754	13,059	90.0	1,305	6,681
2029	12,154	13,503	90.0	1,349	8,030
2030	12,557	13,951	90.0	1,394	9,424
2031	12,354	14,407	85.7	2,053	11,477
2032	12,783	14,907	85.8	2,124	13,601
2033	13,185	15,376	85.8	2,191	15,792
2034	13,570	15,825	85.8	2,255	18,047
2035	13,949	16,267	85.8	2,318	20,365
2036	13,692	16,715	81.9	3,023	23,388
2037	14,042	17,142	81.9	3,100	26,488
2038	14,385	17,561	81.9	3,176	29,664
2039	14,715	17,963	81.9	3,248	32,912
2040	15,033	18,352	81.9	3,319	36,231
2041	14,707	18,744	78.5	4,037	40,268
2042	15,004	19,123	78.5	4,119	44,387
2043	15,301	19,500	78.5	4,199	48,586
2044	15,600	19,881	78.5	4,281	52,867
2045	15,891	20,252	78.5	4,361	57,228
2046	15,559	20,647	75.4	5,088	62,316
2047	15,845	21,026	75.4	5,181	67,497
2048	16,120	21,391	75.4	5,271	72,768
2049	16,388	21,747	75.4	5,359	78,127
2050	16,641	22,083	75.4	5,442	83,569
2051	16,271	22,423	72.6	6,152	89,721
2052	16,450	22,634	72.7	6,184	95,905
2053	16,690	22,965	72.7	6,275	102,180
2054	16,944	23,316	72.7	6,372	108,552
2055	17,206	23,677	72.7	6,471	115,023
2056	16,891	24,075	70.2	7,184	122,207

Source: NATSEM calculation. All estimation based on 2016 price









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