Dementia in Australia

2012

Australian Institute of Health and Welfare
Canberra
Cat. no. AGE 70

The Australian Institute of Health and Welfare is a major national agency which provides reliable, regular and relevant information and statistics on Australia's health and welfare. The Institute's mission is *authoritative information and statistics to promote better health and wellbeing*.

© Australian Institute of Health and Welfare 2012

This product, excluding the AIHW logo, Commonwealth Coat of Arms and any material owned by a third party or protected by a trademark, has been released under a Creative Commons BY 3.0 (CC-BY 3.0) licence. Excluded material owned by third parties may include, for example, design and layout, images obtained under licence from third parties and signatures. We have made all reasonable efforts to identify and label material owned by third parties.

You may distribute, remix and build upon this work. However, you must attribute the AIHW as the copyright holder of the work in compliance with our attribution policy available at <www.aihw.gov.au/copyright/>. The full terms and conditions of this licence are available at <http://creativecommons.org/licenses/by/3.0/au/>.

Enquiries relating to copyright should be addressed to the Head of the Communications, Media and Marketing Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

ISBN 978-1-74249-349-7

Suggested citation
Australian Institute of Health and Welfare 2012. Dementia in Australia 2012. Cat. no. AGE 70. Canberra: AIHW.

Australian Institute of Health and Welfare
Board Chair
Dr Andrew Refshauge

Director
David Kalisch

Any enquiries about or comments on this publication should be directed to:
Communications, Media and Marketing Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Tel: (02) 6244 1032
Email: info@aihw.gov.au

Published by the Australian Institute of Health and Welfare

Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.aihw.gov.au> for any amendments.

Contents

Acknowledgments

This report was prepared by Dr Adriana Vanden Heuvel, Charles Hudson and Jessica Cargill from the Australian Institute of Health and Welfare's Ageing and Aged Care Unit.

Many others made contributions during the course of the project, including: Gail Brien, Tracy Dixon, Dr John Goss, Barbara Gray, Justin Harvey, Barbara Levings, Nick Mann, Simon Margrie, Ann Peut, Sam Topalidis, Dr Adrian Webster and Dr Xingyan Wen.

Brent Diverty and Judith Abercromby provided advice, direction and support.

The authors also thank those who took the time to review and comment on this report, in particular Alison Verhoeven and Phil Anderson.

The Australian Government Department of Health and Ageing funded this report. The authors received valuable advice and comments from staff of the Department's Ageing and Aged Care Division.

Finally, the project team acknowledges the expert advice and guidance received from the report's Working Group:

- Dr Annie Dullow (Department of Health and Ageing)
- Ann Atkinson (Dementia Policy Section, Ageing and Aged Care Division, Department of Health and Ageing)
- Mark Gaukroger (Dementia Policy Section, Ageing and Aged Care Division, Department of Health and Ageing)
- Julieanne Le Comte (Policy & Evaluation Branch, Ageing and Aged Care Division, Department of Health and Ageing)
- Professor Brian Draper (Dementia Collaborative Research Centre, University of New South Wales)
- Professor Kaarin Anstey (Ageing Research Unit, Australian National University)
- Professor Dimity Pond (School of Medicine and Public Health, University of Newcastle)
- Glenn Rees (Alzheimer's Australia)
- Ann Eayrs (Alzheimer's Australia)
- Anne Cumming (NSW Dementia Policy Team, NSW Health)
- Joan Hughes (Carers Australia).

Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAS	Aged Care Assessment Service
ACAT	Aged Care Assessment Team
ACFI	Aged Care Funding Instrument
ACT	Australian Capital Territory
ADI	Alzheimer's Disease International
ADL	activity of daily living
AIDS	acquired immunodeficiency syndrome
AIHW	Australian Institute of Health and Welfare
ALOS	average length of stay
APOE	apolipoprotein E
ASR	age-standardised rate
ATC	Anatomical Therapeutic Chemical
BEACH	Bettering the Evaluation and Care of Health
CACP	Community Aged Care Package
CCC	Community Care Census
CDR	Clinical Dementia Rating
CURF	confidentialised unit record file
DAE	Deloitte Access Economics
DALY	disability-adjusted life year
DBMAS	Dementia Behaviour Management Advisory Service
DCRC	Dementia Collaborative Research Centre
DoHA	Australian Government Department of Health and Ageing
DRG	Diagnosis Related Group
DSM	Diagnostic and Statistical Manual of Mental Disorders
DUSC	Drug Utilisation Sub-Committee
DVA	Australian Government Department of Veterans' Affairs
DYNOPTA	Dynamic Analyses to Optimise Ageing
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
EuroCoDe	European Collaboration on Dementia
GP	general practitioner
GPCOG	General Practitioner assessment of Cognition
HACC	Home and Community Care
HDS	Hospital Dementia Services

HIV	human immunodeficiency virus
ICD-10	International Statistical Classification of Diseases and Related Health
ICD-10-AM	International Statistical Classification of Diseases and Related Health, 10th revision, Australian Modification
ICPC-2	International Classification of Primary Care, 2nd edition
MBS	Medicare Benefits Schedule
MMSE	Mini-Mental State Examination
MRI	Magnetic Resonance Imaging
NCMHCD	National Community Mental Health Care Database
NDSP	National Dementia Support Program
NFAD	National Framework for Action on Dementia
NHCDC	National Hospital Cost Data Collection
NHMD	National Hospital Morbidity Database
NHPA	National Health Priority Area
NMD	National Mortality Database
NRCP	National Respite for Carers Program
NRMHCD	National Residential Mental Health Care Database
NSMHW	National Survey of Mental Health and Wellbeing
NSW	New South Wales
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
PIAC	Pathways in Aged Care
Qld	Queensland
RPBS	Repatriation Pharmaceutical Benefits Scheme
RSE	relative standard error
SA	South Australia
SAND	Supplementary Analysis of Nominated Data
SDAC	Survey of Disability, Ageing and Carers
Tas	Tasmania
TCP	Transition Care Program
VHC	Veterans’ Home Care
Vic	Victoria
WA	Western Australia
WHO	World Health Organization
YLD	years lost due to disability
YLL	years of life lost

Symbols

$	Australian dollars
%	per cent
mg	milligram
mL	millilitre
'000	thousands
—	nil or rounded to zero
. .	not applicable
n.a.	not available
n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data
*	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
>	more than
<	less than

Summary

This report provides a comprehensive picture of dementia in Australia, illustrated by the latest available data and information on trends over time.

Number of people with dementia is expected to increase markedly

An estimated 298,000 Australians had dementia in 2011, of whom 62% were women, 74% were aged 75 and over, and 70% lived in the community.

Dementia poses a substantial challenge to health, aged care and social policy. Based on projections of population ageing and growth, the number of people with dementia will reach almost 400,000 by 2020. Although projection methods vary, the number of people with dementia is projected to triple between 2011 and 2050, to reach around 900,000 by 2050.

Dementia is a leading cause of death and burden of disease

Dementia was the third leading cause of death in 2010 (accounting for 6% of all deaths), with an average of 25 people dying from dementia every day that year. Twice as many women as men died from dementia (6,083 and 2,920 respectively). The number of deaths due to dementia increased 2.4 times between 2001 and 2010 (from 3,740 to 9,003 deaths). Some of this increase is due to population ageing and growth, but some may be due to changes in how dementia is recorded on death certificates. Dementia was recorded as the underlying or an additional cause of 14% of deaths in 2010.

Estimates of burden of disease quantify the amount of healthy life lost due to premature death and prolonged illness or disability. Estimates for 2011 suggest that dementia was the fourth leading cause of overall burden of disease, and the third leading cause of disability burden. For people aged 65 and over, dementia was the second leading cause of overall burden of disease and the leading cause of disability burden, accounting for a sixth of the total disability burden in older Australians.

People with dementia rely heavily on health and aged care services

An estimated 552,000 GP attendances (0.5%) in 2010–11 involved the management of dementia. In 2009–10, dementia was a diagnosis for 83,226 (1 in every 100) hospitalisations, and was the principal diagnosis for 12,286 (1 in every 1,000). In that year, 392,796 (0.2%) government-subsidised prescriptions were dementia-specific.

Total direct health and aged care system expenditure on people with dementia was at least $4.9 billion in 2009–10, of which about $2.0 billion was directly attributable to dementia. Of this, $1.1 billion was for permanent residents in residential aged care facilities and $408.0 million was for community aged care services.

Many people with dementia have other health conditions, and many need high care

In 2009, people with dementia aged 65 and over had a substantially higher average number of health conditions (5.4) than all people in that age group (2.9). In 2009–10, 53% of permanent residents in residential aged care facilities had dementia. Residents with dementia were more likely than those without dementia to require high care (87% vs. 63%).

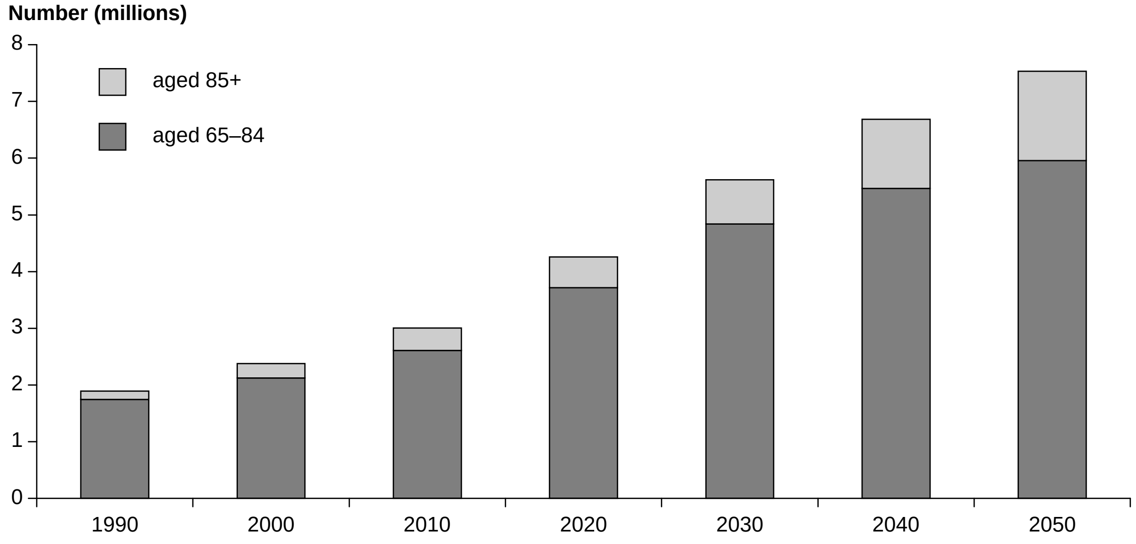
Substantial demand placed on informal carers

Estimates suggest that, in 2011, there were around 200,000 informal carers of people with dementia living in the community. Co-resident primary carers of people with dementia were almost twice as likely as all co-resident primary carers to provide 40 or more hours of care per week (81% versus 42%).

1 Introduction

Dementia is a major health problem in Australia. It has profound consequences for the health and quality of life of people with the condition, as well as for their families and friends. Because dementia is generally a progressive condition, its impact increases with the growing severity of the condition. Eventually, people with dementia become dependent on their care providers in most, if not all, areas of daily living (unless they die from another condition first).

Although dementia is not an inevitable part of ageing and can affect young people, it is increasingly common with age and primarily affects older people. Thus, one of the expected consequences of the continued growth and ageing of Australia's population is an increase in the number of people with dementia over time. As shown in Figure 1.1, the number of people aged 65 and over is projected to more than double between 2010 and 2050 (from about 3 million to 7.5 million), while the number aged 85 and over will quadruple (from less than half a million to about 1.6 million). In the absence of effective prevention or cure options, estimates suggest that between 2010 and 2050, the number of Australians with dementia will triple, rising to around 900,000 by 2050 (see Chapter 2).



Note: Data for this figure are shown in Appendix Table A1.1.

Sources: ABS 2008a, 2012a.

Figure 1.1: Historical and projected Australian population aged 65 and over, 1990–2050

The increasing number of people with dementia will pose numerous challenges to Australia's health and aged care systems. These challenges arise from the need to deliver high quality services to the growing number of people with dementia, as well as to provide support for carers, deliver relevant training for health professionals and aged care workers, and fund research into areas such as effective treatment strategies and prevention.

1.1 What is dementia?

Dementia is not a single specific disease. It is 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 (which includes Pick disease). See Box 1.1 for a description of each. The literature is inconsistent in terms of how common the various types of dementia are, with the proportions shown in Box 1.1 taken from the *World Alzheimer Report* (ADI 2009). This inconsistency may be partially explained by the lack of distinct borders between the different types of dementia. Another explanation may be that a definitive diagnosis cannot be made until autopsy evidence is available. Also, rather than having a single form of dementia, many people have mixed forms (for example, Alzheimer disease and vascular dementia, or Alzheimer disease and dementia with Lewy bodies) (ADI 2009). Note that the coexistence of Alzheimer disease and vascular dementia is sometimes referred to as 'mixed dementia', but there is no consensus on the definition and diagnostic criteria for this form (Seeher et al. 2011).

Box 1.1: Description of the most common types of dementia

Alzheimer disease is the most common type of dementia, accounting for about 50% to 75% of dementia cases worldwide. It is characterised by short-term memory loss, apathy and depression in the early stages. Onset is gradual and decline is progressive. This form is most common among older people with dementia, particularly among women.

Vascular dementia is generally considered to be the second most common type of dementia, with about 20% to 30% of dementia cases thought to be this type. It is caused by cerebrovascular conditions (for example, stroke). Symptoms in the early stages are similar to Alzheimer disease, but memory loss is not as great and mood fluctuations are more prominent. Physical frailty is also evident. Onset can be sudden. The course of the disease is less predictable than Alzheimer disease, with decline more likely to be stepwise.

Frontotemporal dementia is thought to account for about 5% to 10% of cases and is relatively more common in males with a younger onset of dementia. Early symptoms include personality and mood changes, disinhibition and language difficulties.

Dementia with Lewy bodies accounts for up to 5% of cases and is associated with the development of abnormal cells, called Lewy bodies, in the brain. Characteristic symptoms include marked fluctuation in cognitive ability and visual hallucinations, as well as symptoms similar to Parkinson disease (for example, tremor and rigidity). Progression tends to be more rapid than Alzheimer disease.

Sources: ADI 2009; Draper 2011; Seeher et al. 2011.

In addition to the four most common types of dementia, there are many other less common types including dementia in other diseases (such as Parkinson disease, Huntington disease and Creutzfeldt-Jakob disease), alcohol-related dementia, HIV/AIDS-related dementia, and dementia due to metabolic causes or trauma.

The course of dementia is often characterised as occurring in three stages:

- mild or early-stage dementia
- moderate or middle-stage dementia
- severe or late-stage dementia.

Table 1.1 presents a general overview of these stages based on the Clinical Dementia Rating (CDR) scale (Morris 1993) and a review of the topic by Draper (2011). See Appendix Table A1.2 for a full description of the CDR. As noted by Draper, there are overlaps between the three stages and identifying the stage that a person has reached is not always straightforward.

Table 1.1: An overview of the stages of dementia

Stage	Description
Mild or early	Deficits are evident in a number of areas (such as memory and personal care) but the person can still function with minimal assistance. Symptoms include: moderate memory loss especially for recent events, some disorientation in time, moderate difficulties with problem solving, reduced interest in hobbies, and the need for prompting regarding personal care tasks.
Moderate or middle	Deficits become more obvious and severe, and increasing levels of assistance are required to help the person maintain their functioning in the home and community. Symptoms include: severe memory loss, considerable difficulty orienting to time and place, obvious difficulties in finding words, severe impairment of judgement and problem solving, need for assistance with personal care tasks, and emergence of behavioural difficulties (for example, wandering, aggression, sleep disturbance and disinhibited behaviour).
Severe or late	Characterised by almost total dependence on the care and supervision by others. Symptoms include: very severe memory loss, very limited language skills, unable to make judgements or solve problems, regularly not recognising familiar people, frequent incontinence, requires substantial assistance with personal care, and increased behavioural difficulties. By this stage the majority of people with dementia are in residential care.

Sources: Draper 2011; Morris 1993.

One frequently raised question is the impact of dementia on life expectancy and what factors influence the survival of people with dementia. This is an important issue for individuals, families and clinicians, as well as for health policy. While studies consistently show that there is an increased risk of dying among people with dementia compared with those without, and that dementia is a major cause of death (see Section 2.4), estimating the probable survival time is more difficult. A recent review of this topic by Brodaty et al. (2012) noted that average survival times varied considerably from one study to another (ranging from 3 to 10 years). Factors that have been found to influence reported survival times are:

- characteristics of the individual (such as age, sex and other co-existing conditions)
- nature of the dementia (for example, type of dementia and severity at diagnosis)
- differences in study design, such as whether time from onset of symptoms or from diagnosis was considered, the diagnostic criteria used and the scope of the sample (community, clinics, institutions, etc.) (Brodaty et al. 2012; Guehne et al. 2005; Rait et al. 2010; Xie et al. 2008).

The literature also notes that studies about survival estimate *average* survival time. Survival for any one individual may be longer or shorter, depending on their unique circumstances (Brodaty et al. 2012).

1.2 Assessment and diagnosis

The importance and value of obtaining a diagnosis of dementia for individuals and their families is increasingly recognised (Draper 2011; Phillips et al. 2011; Prince et al. 2011). The benefits of timely diagnosis are said to include: the optimisation of medical management of the condition; timely access to information, advice and support; providing time for people with dementia and their family to plan for the future in regard to legal and financial affairs, care options and living arrangements; and affording eligibility for those dementia-related services and interventions which require a diagnosis.

There is no single or simple test that will definitively diagnose dementia. The assessment process may vary according to who is conducting it and the symptoms the person presents with. In general, the aim of the assessment is to gather sufficient information about changed behaviours, functional capacity, psychosocial issues and relevant medical conditions to allow for a diagnosis to be made. Often, the information gathering process includes input from third parties (for example, carers, family members and service providers) and the use of screening tools. A wide range of screening tools are available, including the Mini-Mental State Examination (MMSE), the General Practitioner assessment of Cognition (GPCOG) and the 7-Minute Screen (see AIHW 2007; Draper 2011; Phillips et al. 2011; Seeher et al. 2011).

If the results from a screening test suggest cognitive impairment, a referral for a more comprehensive assessment by a medical specialist (such as a geriatrician, psychiatrist or neurologist) is generally recommended. During this second assessment stage, a number of other tests, such as radiological and laboratory investigations, may be undertaken.

There are many conditions other than dementia that may have cognitive impairment as part of their presentation. Examples are depression, thyroid disease, vitamin deficiency, side effects from medication and age-related cognitive decline. Thus, a key component of the diagnostic process involves determining if dementia or some other condition is the cause of the symptoms (Draper 2011; First et al. 1995; Phillips et al. 2011).

A number of international classifications assist with identifying and classifying dementia. The two most commonly used ones are:

- the International Statistical Classification of Diseases and Related Health Problems (ICD), which approaches the classification of dementia from a disease perspective, attempting to identify the underlying aetiology
- the Diagnostic and Statistical Manual of Mental Disorders (DSM), which approaches the classification of dementia from a perspective of functional outcomes.

See the previous *Dementia in Australia* report (AIHW 2007) for a detailed description of these and other classifications used when diagnosing dementia.

1.3 Risk and protective factors

The causes of dementia are complex and influenced by many factors acting in combination. The prevention of dementia and the delay of disease onset and progression depend on an understanding of these determinants. Many risk and protective factors have been identified. However, as detailed in a review by Seeher et al. (2011), relatively few of these factors have been definitively established, with most considered either probable determinants or inconclusive.

The main risk factor for most types of dementia is advancing age. The literature consistently suggests that the prevalence of dementia increases exponentially with age from about age 65, doubling every 5 or 6 years (ADI 2009; Lobo et al. 2000; Mathers & Leonardi 2006). The literature is less consistent about whether the risk increases past the age of 90 (Corrada et al. 2010; Draper 2011; EuroCoDe 2009). In these older age groups, there is greater uncertainty about the boundary between 'normal' age-related decline and mild dementia, with these boundaries not clearly defined at either a research or clinical level (Draper 2011). As discussed in more detail in Chapter 2, onset before the age of 65 is very uncommon and occurrence before this age, in regard to Alzheimer disease at least, often suggests a genetic cause (ADI 2009).

Research in relation to other risk factors has mainly focused on Alzheimer disease and vascular dementia. Established risk factors for Alzheimer disease, other than age, are: a family history of the condition, Down syndrome, and a common genetic polymorphism (namely, the apolipoprotein E (APOE) ε4 gene) (McCullagh et al. 2001; Seeher et al. 2011). Other suggested (but non-established) risk factors for Alzheimer disease—many of which are modifiable—include vascular risk factors (such as smoking, sedentary lifestyle, obesity, insulin-dependent diabetes and hypertension), head trauma, depression and exposure to chemical toxins such as heavy metals (ADI 2009; McCullagh et al. 2001).

Established risk factors for vascular dementia are older age and stroke (Seeher et al. 2011). As well, a number of rare genetic diseases have been shown to be associated with stroke and subsequent vascular dementia, and some studies have also identified the APOE-ε4 polymorphism as a risk factor for stroke (McCullagh et al. 2001).

There are no definitive protective factors for dementia although many factors thought to probably protect against developing dementia have been identified. These include better cardiovascular health, maintaining a physically, socially and cognitively active lifestyle throughout middle age, and higher levels of education (ADI 2009; Seeher et al. 2011). There are numerous other possible protective factors for which evidence is less conclusive, including intake of omega-3 fatty acids, and use of cholesterol-lowering medications, non-steroidal anti-inflammatory medications and aspirin (Seeher et al. 2011).

1.4 National policy and service responses

Governments at all levels in Australia have developed a range of policy and service responses to dementia. In this section, the focus is on national-level responses from 2005 onwards.

In 2005, the Australian Government announced four years of funding for the Dementia Initiative (formerly known as the Dementia—A National Health Priority Initiative) (DoHA 2005). This was aimed at supporting people with dementia and their carers through the implementation of three measures:

- the establishment of high-level community care places specifically for people with dementia (namely, Extended Aged Care at Home Dementia (EACHD) places)
- new training programs for health professionals, carers and community workers (for example, Dementia Training Study Centres)
- additional research (such as Dementia Collaborative Research Centres), improved care initiatives (such as Dementia Behaviour Management Advisory Services), early

intervention programs (including activities funded under the National Dementia Support Program), and other areas.

For more details, see the *Dementia Initiative national evaluation* report by the LAMA Consortium (2009).

In 2006, Australian Health Ministers agreed to the National Framework for Action on Dementia 2006–2010 (NFAD) to bring together strategies from all jurisdictions 'to treat, improve care of and delay onset or progression of dementia' (AHMC 2006). The Framework focussed on outcomes that could best be achieved nationally with the cooperation of different levels of government. Five priority action areas were identified: care and support services, access and equity, information and education, research, and workforce and training strategies.

The NFAD was reviewed in 2011, with five recommendations put forward (Quantum Australia Consulting 2011). Those recommendations, which included the development of a second Framework, were endorsed by Australian Health Ministers at their September 2011 meeting. Meanwhile, a decision was made to continue using the existing NFAD, pending the development of a second Framework.

As part of the 2011–2012 Federal Budget, changed arrangements for funding health and aged care programs were introduced with the establishment of Flexible Funds, including the Aged Care Service Improvement and Healthy Ageing Grants Fund which came into operation on 1 July 2011 (DoHA 2011a). This fund consolidated funding from a range of existing ageing and aged care programs in order to, according to the Australian Government, 'cut red tape for grant recipients, increase flexibility, and more efficiently provide evidence-based funding for the delivery of health outcomes in the community' (DoHA 2011a:3). One of the priority areas for this fund is directly related to dementia, namely to respond to existing and emerging challenges, including dementia care. Many of the other priority areas are also of significance to dementia care, including the priority areas of:

- supporting activities that build the capacity of aged care services to deliver high quality care
- supporting activities to assist carers to maintain their caring role.

In March 2012, an inquiry on *Dementia: early diagnosis and intervention* was announced by the Australian Government (DoHA 2012a). Under the terms of reference, the House of Representatives Standing Committee on Health and Ageing will focus on how early diagnosis and intervention of dementia can:

- improve quality of life and assist people with dementia to remain independent for as long as possible
- increase opportunities for continued social engagement and community participation for people with dementia
- help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements.

As well, the committee will consider how best to deliver awareness and communication on dementia and dementia-related services into the community. By May 2012, 95 submissions had been received; three public hearings were held in June. The outcomes of the enquiry will be detailed in a report due for release in early 2013.

In April 2012, the Australian Government released an aged care reform package entitled *Living Longer. Living Better* (DoHA 2012b). This package includes $268.4 million over five years for dementia-related programs and services. The package was substantially informed by the Productivity Commission's inquiry into *Caring for Older Australians* (2011) and the ensuing community and stakeholder consultations. A central plank of the package is the increased level of support to enable people with dementia (and other older Australians) to receive care in their own home. Additional funding is also being targeted at improving the quality of care for people with dementia in both community and residential care settings. Further details about the dementia-related measures in the package are provided in Box 1.2.

Box 1.2: Dementia-related measures in the Australian Government's 2012 *Living Longer. Living Better.* Aged Care Reform package

Community care: The number of community-based care packages will be increased and two new levels of care will be added to the existing two levels so that a smoother continuum of care and support is available to individuals as their care needs increase. A new Dementia Supplement will be introduced from July 2013 to support people with dementia who are receiving a community-based care package, as well as those receiving care through a number of other programs such as Transition Care. As a result, existing EACHD packages will be discontinued from July 2013.

Quality of care across the health and aged care systems: Examples of measures that pertain to the quality of care across the health and aged care systems are:

- additional funding for residential aged care providers to support the additional costs associated with caring for aged care residents with severe dementia
- the development and dissemination of nationally-agreed principles and protocols for the management of people with dementia admitted to hospitals, with the aim of improving outcomes for patients (such as reducing the length of hospital stays and the likelihood of adverse events such as falls while in hospital, and improved nutrition)
- expanding the scope of Dementia Behaviour Management Advisory Services from assisting staff in aged care services to include staff in primary care and hospital settings, so that health professionals in all of these sectors will be better able to support people with dementia
- support for general practitioners to make a more timely diagnosis of dementia
- assistance for younger people with dementia and their carers to access better coordinated care and support.

Sources: DoHA 2012b, 2012d.

On 10 August 2012, the Australian Health Ministers recognised dementia as the ninth National Health Priority Area (NHPA) (DoHA 2012c). According to the Australian Government, this will:

- help focus attention and effort on dementia
- drive collaborative efforts aimed at tackling dementia at national, local, and state and territory government levels
- support collaboration with non-government organisations, health experts, clinicians and consumers
- enhance recognition of current and proposed work undertaken as part of the NFAD.

There are two key national bodies involved in advisory and coordination functions for dementia policy and services: the Minister's Dementia Advisory Group and the Dementia Working Group which reports to the Standing Council on Health through the Australian

Health Minister's Advisory Council. The Minister's Dementia Advisory Group was established to provide advice to the Federal Minister with responsibility for Ageing and to the Department of Health and Ageing in relation to the implementation and monitoring of programs and dementia-related issues. The Dementia Working Group is central to activating the NFAD and associated priorities across jurisdictions. It provides a forum through which jurisdictions can share information and discuss progress on jurisdictional initiatives against the NFAD's key priority areas.

1.5 Purpose and structure of this report

The purpose of this report is to provide a comprehensive overview of national statistics on dementia. The aim is to increase understanding about this condition and to inform the development, implementation and evaluation of policies and programs affecting people with dementia and their carers.

Information is provided on:

- the estimated number of people with dementia in Australia, as well as the number of deaths and the burden of disease due to dementia (Chapter 2)
- the characteristics of people with dementia, including sociodemographic and disability-related characteristics (Chapter 3)
- the use of a range of health and aged care services by people with dementia, including consumer support programs, health care services, community aged care packages and residential aged care services (Chapter 4)
- the number and characteristics of carers of people with dementia, as well as the types of assistance they provide and the effect of the caring role on them (Chapter 5)
- estimates of expenditure in the health and aged care sectors due to dementia (Chapter 6).

What is new in this report?

This is AIHW's second report on this topic. It differs from the first, *Dementia in Australia: national data analysis and development* (AIHW 2007), in a number of ways.

Revised estimates of the prevalence of dementia are presented, based on the most current and comprehensive rates available.

A number of new data sets have become available since the release of the previous report. Three examples—the 2009 Australian Bureau of Statistics' (ABS) Survey of Disability, Ageing and Carers (SDAC), data collected through the Aged Care Funding Instrument (ACFI), and the 2008 Community Care Census (CCC)—are briefly described in Box 1.3. More detailed descriptions are provided in Appendix B.

Updated estimates of health and aged care system expenditure on dementia during 2009–10 are provided. These estimates encompass expenditure on an expanded range of programs, including a number of consumer support programs, respite services and flexible aged care services. Unlike in the 2007 report, ACFI data have been used to help estimate dementia-related expenditure in residential aged care facilities.

New and/or additional information is presented on topics such as mortality due to dementia, the use of specialised mental health services, and hospitalisations for palliative care.

Box 1.3: New data sources used in this report

One new data source used extensively in this report is the **2009 Survey of Disability Ageing and Carers (SDAC)**. The primary aim of this national survey was to collect information about three population groups: people with a disability, older people (those aged 60 and over) and carers (ABS 2010, 2011a). As part of the survey, data were collected about people living in the community, as well as people living in cared accommodation (94% of whom were in residential aged care facilities). Compared with the 2003 SDAC, the sample size of the household component of the survey increased by 77% (from 36,241 in 2003 to 64,213 in 2009) and the sample size of the cared accommodation component increased by 84% (from 5,145 in 2003 to 9,470 in 2009). These increases in sample size have meant that more in-depth analyses on some topics were possible. The 2009 survey also included new questions about, for example, unmet support needs of carers; responses to a number of the new questions were analysed for this report.

A second new data source was information collected through the **Aged Care Funding Instrument (ACFI)**, which introduced by the Australian Government in March 2008 as a resource allocation tool for funding places in residential aged care facilities (DoHA 2009a). Data collected through the ACFI provide information about permanent residents who had dementia in Australian Government-subsidised aged care facilities. Almost all (99%) of those who were permanent residents of subsidised aged care facilities at 30 June 2011 had been assessed using the ACFI tool. The ACFI allows for the reporting of the number, characteristics and care needs of permanent residents with dementia in aged care facilities without requiring the indirect methods of estimation used in previous AIHW reports (e.g. AIHW 2004a, 2007).

The third new data source is the **2008 Community Care Census (CCC)** (DoHA 2010a) which collected information about people receiving assistance through three types of community aged care packages, as well as through the National Respite for Carers Program.

This report has also drawn on some of the latest Australian research conducted through the Dementia Collaborative Research Centres (DCRCs) and the Dementia Research Grant program. For example, the Dementia Research Mapping Project, updated in 2010 by the DCRC–Assessment and Better Care, has been an invaluable resource (Seeher et al. 2011), while a number of other DCRC-funded projects have provided context for understanding aspects of reported data. A brief summary of the outcomes from the Hospital Dementia Services project, funded by a Dementia Research Grant, is also provided in this report.

Lastly, the previous report provided a guide for improving national dementia data collections and identified possible data elements suitable for inclusion in a range of data collection contexts. The current report has not repeated this information. The AIHW is working on a separate report that will include an updated discussion of the strengths and limitations of dementia-related data, as well as recommendations about how data collections can be improved.

Data sources

To present a comprehensive overview of national statistics on dementia, this report draws upon data from a wide variety of data sources. These sources are described in Appendix B.

In addition, there are a number of longitudinal data sources that collect information relevant to gaining a better understanding about dementia. These are particularly valuable when addressing questions related to the effect of, for example, the type of dementia, treatments given, or timing of diagnosis upon subsequent disease progression and outcomes. While covering such issues is beyond the scope of this report, information about a selection of longitudinal studies can be found in Appendix C.

Terminology and data interpretation

Supplementary tables to each chapter are included in Appendix A.

The approach used to identify those with dementia differs from one data source to another, as described in Appendix B. In this report, the phrase 'with dementia' is used to indicate people who were identified as having dementia in a particular data collection, regardless of the method used. The one exception pertains to the discussion about the prevalence of dementia in Chapter 2. In that chapter, the aim is not to describe the number or characteristics of people identified with dementia in a particular data set, but to estimate the number of people who would be identified with dementia if everyone in the population were to be screened for dementia and then, when relevant, diagnostically assessed.

For some data sources used in this report, it was possible not only to identify those with dementia, but also to identify those with mild cognitive impairment. As indicated in the literature, most types of dementia are preceded by a phase of mild cognitive impairment, but not all such impairment leads to dementia (Chertkow et al. 2008; Draper 2011; Seeher et al. 2011). For this reason, only those people identified as having at least mild dementia were included in analyses for this report, while those with 'only' mild cognitive impairment were excluded.

One of the data sources used extensively for this report is the 2009 SDAC. Since these data are from a sample survey, there is a level of error associated with them. All tables that provide data from the SDAC include an indication, where relevant, of any estimates that have a high level of uncertainty about them, as measured by the relative standard error (RSE). Estimates with RSEs lower than 25% are considered sufficiently reliable for most purposes. Estimates with RSEs between 25% and 50% should be used with caution, while estimates with RSEs of more than 50% are considered too unreliable for most purposes. Additional information about RSEs and how they were calculated can be found in the ABS's summary of SDAC findings (ABS 2010).

To take into account differences in age structure and population size when making comparisons between groups (such as across time or by jurisdiction), age-standardised rates are at times presented in this report. This is especially important in regard to data about dementia since the likelihood of a person having dementia increases with age (as discussed in Chapter 2). Further information on age-standardisation and a number of other statistical techniques can be found in Appendix D.

A number of different classifications are referred to in this report, such as the International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10) and the Australian Standard Geographical Classification Remoteness Area classification. Information about these is provided in Appendix E.

2 Prevalence, mortality and burden of disease

Key points

- In 2011, there were an estimated 298,000 people with dementia, of whom 62% were women and 70% lived in the community. Among Australians aged 65 and over, almost 1 in 10 (9%) had dementia, and among those aged 85 and over, 3 in 10 (30%) had dementia.
- There were an estimated 23,900 Australians under the age of 65 with dementia in 2011.
- Dementia was classified as 'mild' in 163,900 people (55% of people with dementia), 'moderate' in 89,400 people (30%) and 'severe' in 44,700 (15%).
- The number of people with dementia is projected to triple to around 900,000 by 2050.
- Dementia was the third leading cause of death in 2010, recorded as the underlying cause of 9,003 deaths across Australia—on average, 25 people died from dementia every day.
- In 2011, dementia was responsible for an estimated 4% of the total disease burden in Australia and was the fourth leading cause of burden of disease. Most (74%) of the burden was related to the disabling nature of the condition.
- For people aged 65 and over, dementia was the second leading cause of burden of disease and the leading cause of disability burden, accounting for a sixth of the total disability burden in older Australians in 2011.
- Dementia is projected to remain the fourth leading cause of burden of disease and the third leading cause of disability burden until at least 2020.

2.1 Introduction

Estimates of the current and projected number of Australians with dementia are essential to inform an understanding of the overall impact of the condition, and for policymaking and service planning. This chapter provides an estimate of the number of Australians who, if everyone were screened for dementia and then (when relevant) diagnostically assessed, would be found to have dementia. As explained below, dementia is often unrecognised or under-reported, especially in the early stages. Thus, the actual prevalence cannot be determined by relying on information on the number of people who report having the condition or the number who have been diagnosed with dementia.

In addition to providing an estimate of the number of people with dementia in 2011, projected estimates are also provided, as is a discussion about how the estimates in this report compare with those in the first *Dementia in Australia* (AIHW 2007) report and in a recent report by Deloitte Access Economics (DAE 2011).

This chapter also presents information on:

- the incidence of dementia
- mortality due to dementia
- the burden of disease associated with dementia.

For the latter, projections of the burden of disease due to dementia are provided for 2011, as well as to 2020. Information is also presented on how dementia ranks, relative to other health conditions, in terms of the overall burden of disease, and the burden due to disability.

2.2 Prevalence of dementia

Prevalence refers to the total number of people who have a particular condition at a specified point in time. For most conditions, such as cancer, cardiovascular disease or diabetes, prevalence is generally determined by the number of people diagnosed with, or reporting, the condition (in a population survey, for example). These approaches are inadequate for dementia since the condition is often unrecognised and/or undiagnosed until it is in the later stages.

For dementia, there tends to be a substantial gap between when symptoms are first noticed and when assistance is first sought from a health professional, and a further gap before the condition is actually diagnosed. For example, a six-country European survey found that the average time from first noticing symptoms of Alzheimer disease to first consulting with a physician was about 11 months, while the average time from symptom recognition to a diagnosis was 20 months (Bond et al. 2005). A New South Wales study reported an average time of about 23 months between when symptoms were first noticed and the first health professional consultation, and about 37 months before a firm diagnosis was made (Speechly et al. 2008).

A substantial body of literature, including a number of recent reviews (Bradford et al. 2009; Koch & Iliffe 2010; Phillips et al. 2011), has examined the reasons for the delay in diagnosis. This literature indicates that there is a complex combination of barriers to diagnosis at the mild (rather than a later) stage, including factors relating to:

- the patient and carers—such as not recognising the early symptoms of dementia; thinking the symptoms were due to other medical conditions or were a part of 'normal ageing'; delaying seeking help due to stigma, denial or fear (Bond et al. 2005; Koch & Iliffe 2010; Phillips et al. 2011)
- disease factors—dementia is generally a condition that progresses slowly and early symptoms are often difficult or impossible to distinguish from mild cognitive impairment (Draper 2011)
- primary health care providers—such as a lack of knowledge and/or time to recognise and diagnose dementia; limited access to specialists to confirm the diagnosis; concerns about the value of providing a diagnosis; difficulties in communicating the diagnosis to patients and families (Bradford et al. 2009; Koch & Iliffe 2010; Phillips et al. 2011; Robinson et al. 2008; Speechly et al. 2008; Wilkinson et al. 2005)
- systemic factors—such as the lack of a definitive diagnostic test and the lack of sufficiently accurate biomarkers that enable early diagnosis; the complexity of the diagnosis process; diagnostic criteria that require symptoms to have been present for a stated period of time (for example, 6 months); financial constraints for health care providers (Berr et al. 2005; Bradford et al. 2009; Phillips et al. 2011).

Together, these factors contribute to the under-diagnosis, as well as the under-disclosure, of dementia. As a result, data sources that rely on respondents to report the existence of health conditions are less reliable when it comes to determining the presence of dementia and thus cannot be used to accurately describe the prevalence of this condition. Examples of such data sources are the National Health Survey and the household component of the SDAC. Indeed, as detailed in Section 3.4, of those living in the community, most (84%) people who were identified as having dementia by the SDAC were reported as being severely or profoundly disabled. Thus, surveys such as the SDAC are thought to substantially underestimate cases of mild and moderate dementia.

Multistage surveys in which participants are systematically assessed for dementia using both screening tools and clinical diagnostic assessments may be of more value in deriving comprehensive prevalence estimates, because they are more likely to detect mild and moderate cases of dementia, and cases are clinically established. This approach was taken in Canada, for example, where a national study of the prevalence of dementia among those aged 65 and over was conducted in the early 1990s (CSHAWG 1994).

In Australia, no such national study has been undertaken. The two available data sets that might be considered—namely data from the 2007 ABS National Survey of Mental Health and Wellbeing (NSMHW) and the Dynamic Analyses to Optimise Ageing (DYNOPTA) project—have shortcomings in terms of allowing for the estimation of dementia prevalence (see Note 2.1 in Appendix D for further details).

The lack of national data on which to base estimates of dementia prevalence is not unique to Australia. The usual solution is to use rates which have been derived through meta-analyses and apply them to population data. This approach was taken by the AIHW in the first *Dementia in Australia* report (2007) and by Deloitte Access Economics (DAE 2011).

This approach has also been used in this report although with a new set of underlying rates. Specifically, dementia prevalence rates for people aged 60 and over are based on the rates released by Alzheimer's Disease International (ADI 2009) in the *World Alzheimer Report 2009*. These rates, which were produced by international experts, are the most current and comprehensive rates of dementia prevalence available. The process of producing these rates began with a systematic review of the world literature on the prevalence of dementia, with a total of 2,017 publications evaluated using a rigorous three-stage quality assessment process. As well, in contrast to previous prevalence estimates produced by AIHW and DAE, the rates used in this report take account of Australian data.

Since the ADI rates pertain to people aged 60 and over, estimated prevalence rates for those aged under 60 are based on Harvey et al. (2003), as was done for the 2007 AIHW report. Further details about past meta-analyses and the method used to derive dementia prevalence estimates for this report can be found in Note 2.2 in Appendix D. For ease of description, the rates used here to derive estimates of the prevalence of dementia are referred to as the 'ADI rates' in the remainder of this report although, as noted, they also include rates derived from Harvey et al. for those aged under 60.

Estimated prevalence of dementia in 2011

When the ADI prevalence rates are applied to 2011 ABS population estimates, there were an estimated 298,000 Australians with dementia in 2011 (Table 2.1). The majority (62%) of these were women. The data also suggest that in 2011:

- of all Australians, 1 in 77 (1.3%) had dementia
- of all Australians aged 65 and over, 1 in 11 (9%) had dementia
- of all Australians aged 85 and over, 3 in 10 (30%) had dementia.

Table 2.1: Estimated number of people with dementia, by age and sex, 2011

	Summary age-specific rates[(a)] (per 100 population)			Number[(b)]			Per cent		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 65	0.1	0.1	0.1	12,600	11,300	23,900	11.1	6.1	8.0
65–74	3.1	3.4	3.2	25,200	28,900	54,100	22.3	15.6	18.1
75–84	8.8	10.4	9.7	39,800	57,500	97,400	35.2	31.1	32.7
85+	24.4	32.3	29.5	35,600	87,000	122,600	31.5	47.1	41.1
Total: 65+	**7.1**	**10.3**	**8.8**	**100,700**	**173,400**	**274,100**	**88.9**	**93.9**	**92.0**
Total	**1.0**	**1.6**	**1.3**	**113,300**	**184,700**	**298,000**	**100.0**	**100.0**	**100.0**

(a) Summary rates (per 100 population) were calculated using population data as at 30 June 2011 (ABS 2012a). See Table D2.4 in Appendix D for a complete list of the age-specific rates.

(b) Numbers may not sum to the total due to rounding.

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003).

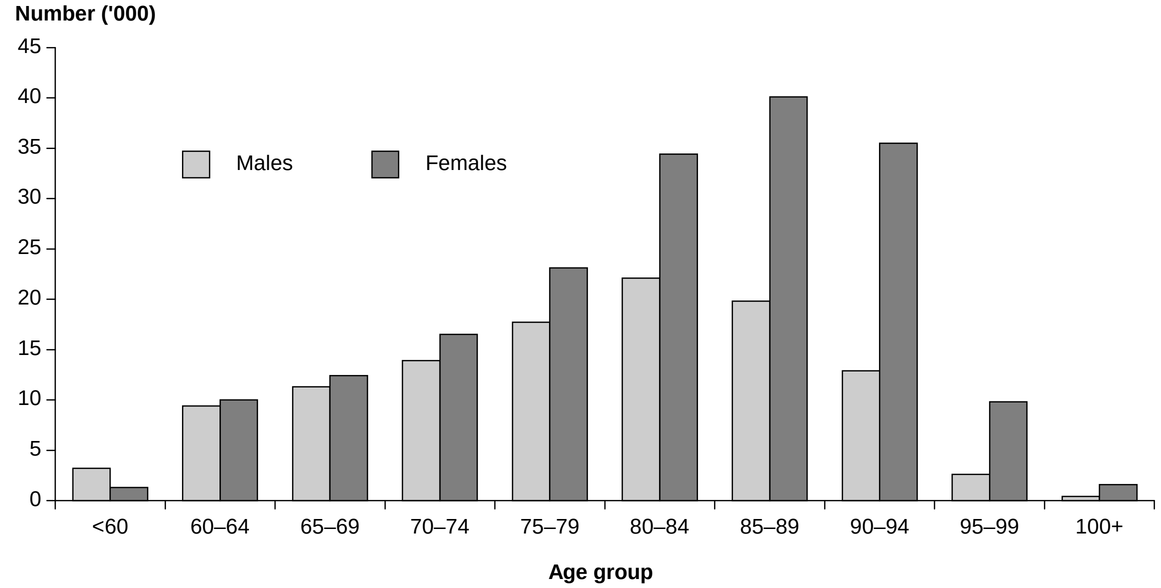
The number of people estimated to have dementia in Australia in 2011 (298,000) is substantially higher than the 222,000 people projected for 2011 in the previous *Dementia in Australia* report (2007) because new prevalence rates have been applied. The use of these new prevalence rates does not imply that the actual rates in the population have changed, but that the methods of estimating those prevalence rates are improving.

When the estimated number of people with dementia using the new rates was compared with the estimated number using the 2007 rates (and applying the same population data for 2011), the largest proportion (25%) of the increase was due to higher estimates of the prevalence of dementia among women aged 85 and over (see Appendix Table A2.1). An additional 14% was due to higher estimates among men aged 85 and over. This same finding was noted by EuroCoDe (2009), whose authors suggest that this increase among the oldest age groups does not reflect an increase in the rate of dementia over time but instead that more recent studies better reflect the true rate in this previously under-surveyed group.

The estimated number of people with dementia by age group is shown in Figure 2.1. Overall, one-third (33%) of people with dementia were aged 75 to 84, and 41% were aged 85 and over, but there were clear differences by sex. Almost half (47%) of women with dementia were aged 85 and over, compared with 31% of men. Also, the estimated number of men with dementia increased up to age 80–84 and then declined in the remaining age groups. In contrast, among women, the estimated number increased up to the age of 85–89.

The estimated number of women with dementia was higher than the estimated number of men in all but one of the age groups, and particularly so in the older age groups. Indeed, in each of the age groups from 85-89 onwards, the estimated number of women with dementia was at least double the estimated number of men. This is partly due to higher prevalence rates from the age group 60–64 for women, and more women in these age groups.

The one age group in which the number of men was higher was the under 60 age group; however, whether this represents a ‘real’ difference is not known. On the one hand, Harvey et al. (2003) found no statistically significant difference between the rates for men and women on which these estimates were based. On the other hand, as part of an expert review of dementia prevalence rates in Europe, the prevalence of dementia was considered to be higher in men than in women among those aged 50 to 65 (Knapp et al. 2007).



Note: Data for this figure are shown in Table D2.4 in Appendix D.

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003).

Figure 2.1: Estimated number of people with dementia, by age and sex, 2011

Younger onset dementia

Younger onset dementia typically refers to the onset of dementia before the age of 65. There were an estimated 23,900 Australians under the age of 65 who had dementia in 2011, with men accounting for just over half (53%). Those under 65 represented 8% of all people with dementia in Australia.

By comparison, in the first *Dementia in Australia* (AIHW 2007) report, projections suggested there would be 10,000 people aged under 65 with dementia in 2011. Meanwhile, DAE (2011) estimated that there were 16,329 people aged under 65 with dementia in 2011. The higher estimate presented in this report is, however, in line with a recent World Health Organization (WHO 2012) report which suggests that the prevalence of younger onset dementia is often underestimated and that such cases account for about 6% to 9% of all dementia cases.

Dementia prevalence by residency and severity

Estimates of the number of people with dementia according to whether or not they live in the community and the severity of the condition are important for service planning purposes. No one data source provides such estimates and thus data from a variety of sources have been used to derive these estimates.

Estimated prevalence by residency

To apportion the number of people with dementia according to whether they lived in the community or in cared accommodation, the number who lived in cared accommodation was estimated first. Data collected through the ACFI and the 2009 SDAC are the best available data on which to estimate this number (see Appendix B for more information on these data sources and Note 2.3 in Appendix D for further information on the estimation process). As defined in the SDAC, 'cared accommodation' includes residential aged care facilities and other types of facilities (such as hospitals) if the person had been, or was expected to be, a usual resident of that (or another) facility for three months or more (ABS 2010).

According to the ACFI data, 85,159 people (52%) of the 163,849 permanent residents who had an ACFI appraisal at 30 June 2011 had a diagnosis of dementia. This number of people with dementia excludes those living in 'other types' of cared accommodation (rather than residential aged care facilities). According to the 2009 SDAC, 5.7% of people with dementia who were living in cared accommodation lived in other types of cared accommodation. Thus, to derive an estimate of the number of people with dementia living in cared accommodation, the number of people with dementia in residential aged care from the ACFI data (85,159) was scaled up 5.7%, resulting in an estimated 90,000 people with dementia living in cared accommodation.

The number of people with dementia living in the community can be calculated by subtraction, using information on the overall number estimated to have dementia (298,000) minus the estimated 90,000 living in cared accommodation. Thus, an estimated 208,000 lived in the community (Table 2.2).

These estimates of prevalence by residency suggest that 30% of people with dementia lived in cared accommodation in 2011, while 70% lived in the community. These proportions match the findings of an ADI survey in high-income countries which indicated that 30% of people with dementia lived in 'care homes' (WHO 2012). However, in the previous *Dementia in Australia* report (AIHW 2007), 43% were estimated to be living in cared accommodation in 2003, a proportion that is higher than the 30% estimated here for 2011. This difference may reflect the use of different rates and data sources to derive the proportions and/or a real increase over time in the proportion of people with dementia living in the community. An increase would be in line with the increasing number of government programs and services for those with dementia (and their carers) aimed at allowing them to remain living in the community as long as possible (DoHA 2012b) (see Chapter 4 for information on the use of such programs and services).

Estimated prevalence by severity

As in the previous edition of *Dementia in Australia* (AIHW 2007), the estimated severity distribution of dementia reported here is based on information from a study of degenerative diseases among older people (Barendregt & Bonneux 1998). In that study, severity was defined according to the Clinical Dementia Rating (CDR) scale. The CDR score is derived by rating impairment in six domains: memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care (see Appendix Table A1.2). The study reported that 55% of dementia was classified as mild (CDR of 1), 30% as moderate (CDR of 2) and 15% as severe (CDR of 3).

This overall distribution was applied to the estimated prevalence of dementia in 2011 (Table 2.2) and the following estimates were derived:

- 163,900 people with mild dementia
- 89,400 people with moderate dementia, and
- 44,700 people with severe dementia.

Table 2.2: Estimated number of people with dementia, by residency, severity and sex, 2011

	Number(a)			Per cent by place of residency			Per cent of total with dementia		
Residency/severity(b) of dementia	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Cared accommodation									
Mild	1,800	3,600	5,500	7.0	5.6	6.1	1.6	1.9	1.8
Moderate	15,900	40,400	56,300	61.9	62.8	62.6	14.0	21.9	18.9
Severe	8,000	20,200	28,200	31.1	31.4	31.3	7.1	10.9	9.5
Total: cared accommodation	**25,700**	**64,300**	**90,000**	**100.0**	**100.0**	**100.0**	**22.7**	**34.8**	**30.2**
Community									
Mild	60,500	98,000	158,400	69.1	81.4	76.2	53.4	53.1	53.2
Moderate	18,100	15,000	33,100	20.7	12.5	15.9	16.0	8.1	11.1
Severe	9,000	7,500	16,500	10.3	6.2	7.9	7.9	4.1	5.5
Total: community	**87,600**	**120,400**	**208,000**	**100.0**	**100.0**	**100.0**	**77.3**	**65.2**	**69.8**
Total									
Mild	62,300	101,600	163,900	55.0	55.0	55.0	55.0	55.0	55.0
Moderate	34,000	55,400	89,400	30.0	30.0	30.0	30.0	30.0	30.0
Severe	17,000	27,700	44,700	15.0	15.0	15.0	15.0	15.0	15.0
Total	**113,300**	**184,700**	**298,000**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Numbers may not sum to the total due to rounding.

(b) Severity according to the Clinical Dementia Rating (CDR) scale. See Table A1.2 for more information.

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003); 2009 Survey of Disability, Ageing and Carers confidentialised unit record file; Barendregt & Bonneux (1998).

Estimated prevalence by severity and residency

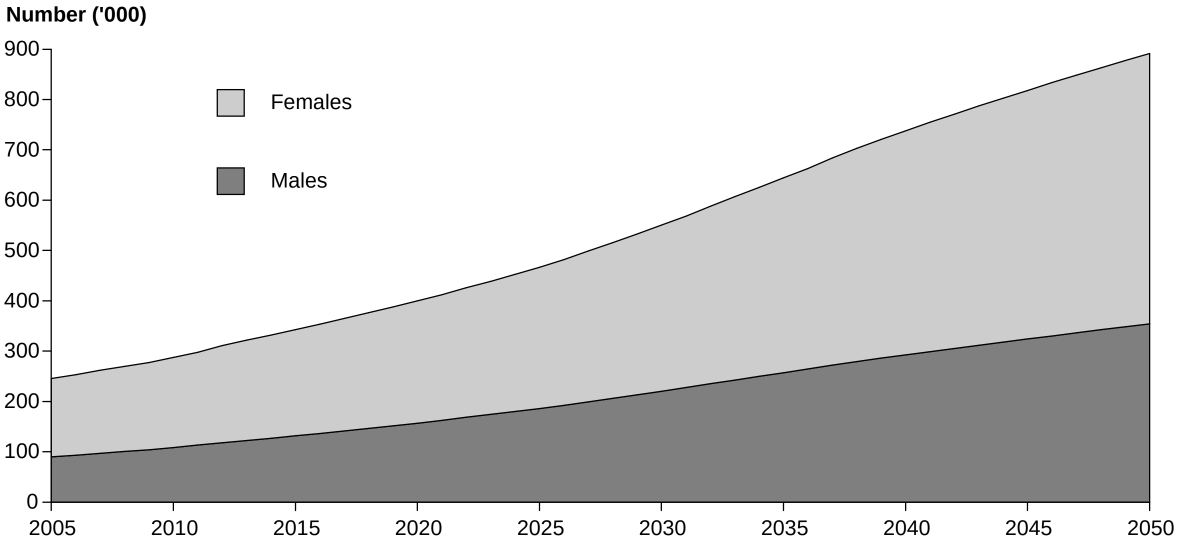
To estimate the severity distribution of dementia by residency (community versus cared accommodation), the method used in the previous *Dementia in Australia* report (AIHW 2007) was applied (see Appendix D, Note 2.3). It was estimated that (Table 2.2):

- the majority (63%) of those with dementia in cared accommodation had moderate dementia, while the majority (76%) of those in the community had mild dementia
- those with mild dementia living in the community accounted for just over half (53%) of all Australians with dementia
- of the 44,700 people with severe dementia, more than 1 in 3 (37% of 16,500 people) were estimated to live in the community.

The estimates also suggest that there are some differences in patterns of residency and severity by sex. For instance, men with dementia were more likely to live in the community than women (77% and 65% respectively). Among those living in the community, almost 1 in 3 men (31%) with dementia were estimated to have moderate or severe dementia, compared with a smaller proportion (19%) of women.

Change over time in dementia prevalence

Estimates of the number of people with dementia between 2005 and 2050 are shown in Figure 2.2 and Table 2.3. These estimates have been derived by applying the same prevalence rates to ABS population data (for 2005 to 2011) and ABS population projections (for 2012 onwards) (ABS 2008a, 2012a). Of the three population projection series that the ABS produces, the mid-range 'Series B' projections were used. These projections reflect current trends in fertility, life expectancy at birth, net overseas migration and net interstate migration.



Note: Data for this figure are shown in Appendix Table A2.2.

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003) and applied to population data for 2005 to 2011 (ABS 2012a) and population projections for 2012 to 2050 (ABS 2008a).

Figure 2.2: Estimated number of people with dementia, by sex, 2005 to 2050

The application of the same prevalence rates across time assumes that dementia prevalence rates have been stable since 2005 and will continue to be so until 2050. This assumption is commonly made since there is no evidence to suggest changes in age-specific prevalence rates over time (ADI 2009; EuroCoDe 2009; Lobo et al. 2000). As a result, the projections presented in this report provide estimates of the number of Australians who would have dementia into the future, with change over time due solely to projected population growth and continued ageing of the population. No modelling was done to take into account any other changes that might occur in the future.

Changes in risk factors and in the prevention, management and treatment of the condition may affect the accuracy of these estimates. For example, improved medical and social care might increase prevalence by allowing more people to survive longer with dementia (Draper 2011). The estimates are also sensitive to deviations from projected changes in the age-sex structure or total size of the projected populations. Therefore, these estimates (especially those further into the future) should be interpreted with caution.

Using this method, the number of people with dementia in 2005 is estimated to have been 245,400. This suggests that the number of Australians with dementia increased by 21% (52,600 people) between 2005 and 2011 (Figure 2.2). Over that period, the number of men with dementia grew at a faster pace than the number of women (26% and 19% respectively).

The number of people projected to have dementia in 2012 is 311,300, the majority (62%) of whom are women (193,200) (Appendix Table A2.2). Eight per cent (24,000) were estimated to be aged under 65, while 42% were estimated to be aged 85 and over (Table 2.3)

Table 2.3: Estimated number of people with dementia, by age, 2005 to 2050 (selected years)

	2005	2011	2012	2020	2030	2040	2050	% change: 2011 to 2050
Number[(a)]								
Under 65	18,900	23,900	24,000	27,300	29,400	31,500	36,800	53.7
65–74	45,000	54,100	57,200	78,100	93,100	100,400	108,700	101.1
75–84	90,700	97,400	99,400	125,700	192,500	232,700	253,800	160.7
85–94	81,300	108,400	114,600	142,100	198,700	313,700	393,800	263.4
95+	9,500	14,200	16,100	26,600	36,600	59,300	98,300	590.0
Total	**245,400**	**298,000**	**311,300**	**399,800**	**550,200**	**737,600**	**891,400**	**199.1**
Per cent								
Under 65	7.7	8.0	7.7	6.8	5.3	4.3	4.1	-48.6
65–74	18.3	18.1	18.4	19.5	16.9	13.6	12.2	-32.8
75–84	37.0	32.7	31.9	31.4	35.0	31.5	28.5	-12.9
85–94	33.1	36.4	36.8	35.5	36.1	42.5	44.2	21.5
95+	3.9	4.8	5.2	6.7	6.6	8.0	11.0	130.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**0.0**
% change over decade	**. .**	**. .**	**. .**	***39.1***	***37.6***	***34.1***	***20.9***	**. .**

(a) See Appendix Table A2.2 for more detailed information. Numbers may not sum to the total due to rounding.

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003) and applied to population data for 2005 to 2011 (ABS 2012a) and population projections for 2012 to 2050 (ABS 2008a).

Between 2011 and 2020, the number of Australians with dementia is projected to increase from 298,000 to 399,800. It is estimated that the decade to 2020 will see the largest growth in the number of people with dementia (39% increase). This is largely explained by the 'baby boomers' moving into older age groups, where the risk of dementia is higher.

Between 2011 and 2050, using the age-sex specific rates described earlier, the number of people with dementia is projected to increase from 298,000 to an estimated 891,400, an increase of more than half a million people. The projected tripling of the number of those with dementia is in contrast to the projected doubling of the total number of people aged 65 and over (see Appendix Table A1.1). Projections suggest that by 2050, women will continue to account for about 60% of all of those with dementia.

The projections suggest an increase in the proportion of older people with dementia. For example, the number of people with dementia aged 95 and over is estimated to increase by around 90% between 2011 and 2020 (from 14,200 to 26,600) and by nearly 600% (from 14,200 to 98,300) by 2050. Because of this rapid growth, people aged 95 and over will account for a larger share of those with dementia over time—from 5% in 2011 to 11% in 2050. Likewise, those aged 85–94 will represent a greater share of those with dementia over coming decades.

In contrast, people under 65 are expected to account for a smaller share of those with dementia over time (from 8% in 2011 to 4% in 2050). While the number of people with dementia aged under 65 is projected to continue to grow over the coming decades (from 24,000 in 2011 to 36,800 in 2050), the rate of growth is not expected to be as large as that of the other age groups. This is in line with the expected ageing of the population and a relatively large increase in the number of older people (rather than younger people) over coming decades.

See Box 2.1 for a comparison of the ADI-based estimates and projections with those from the recent Deloitte Access Economics report (2011).

Estimated prevalence of dementia by state and territory

To give an indication of the estimated number of people with dementia in each state and territory, the ADI prevalence rates were applied to ABS population data for each jurisdiction. Differences by age, sex and population size were taken into account when applying these rates. However, other factors that might affect the prevalence of dementia in any particular jurisdiction are not taken into account. For example, there is some evidence that the prevalence rate of dementia in Indigenous communities may be higher than in the general population (Smith et al. 2008; see Section 3.2). If this is the case, the rate of dementia in jurisdictions with a higher proportion of Indigenous Australians (such as the Northern Territory) may be higher than in other jurisdictions. However, as no data are available on whether or not the prevalence of dementia varies geographically across Australia, the estimated prevalence rates derived for this report are used to estimate the prevalence of dementia among the states and territories.

Box 2.1: Comparing dementia projections

The dementia prevalence projections based on ADI rates differ somewhat from those reported by DAE (2011) but demonstrate a similar overall trend. In particular, DAE suggested that in 2020, there would be 384,396 people with dementia (Table 2.4). This is slightly less (by 15,400 people) than the projection of 399,800 based on the ADI rates.

By 2030, DAE's estimates are slightly higher than those based on the ADI rates and by 2050, DAE projected that there will be 942,624 people with dementia compared with the projection of 891,400 reported here for that year.

Table 2.4: A comparison of the estimated number of people with dementia, 2011 to 2050 (selected years)

	2011	2012	2020	2030	2040	2050
Estimates based on ADI rates	298,000	311,300	399,800	550,200	737,600	891,400
DAE estimates[a]	266,574	278,707	384,396	553,285	760,131	942,624

(a) DAE rates applied to population data sourced from DAE's in-house demographic model as reported by DAE (2011).

Sources: Table 2.3; DAE 2011.

In general, DAE's estimated dementia prevalence *rates* per age-sex group are lower than those derived from the ADI rates (see Tables D2.2 and D2.4 in Appendix D) and, in turn, their estimates of the number of people with dementia are initially lower than those presented in this report. The fact that DAE's estimates are initially lower but then are higher from 2030 onwards is not due to differences in rates, but rather due to assumptions made in their model about the future size, age and characteristics of the population, and about the probable impact of increased rates of population risk factors for dementia in the future. AIHW's projections do not involve modelling; instead, age-sex prevalence rates are simply applied to ABS population projections. Regardless, both approaches point to an estimated number of around 900,000 people with dementia in 2050, which is about three times the estimate for 2011.

As shown in Table 2.5, estimates of the number of people with dementia in 2011 by jurisdiction ranged from 1,000 people in the Northern Territory to 101,800 people in New South Wales. The extent of change in the number of people estimated to have dementia by 2020 varied considerably across the jurisdictions. The greatest increase (51%) was estimated for the Northern Territory. Relatively large growth was also projected for Western Australia and Queensland (both 44%), followed by the Australian Capital Territory (43%). The smallest projected increase was for South Australia (27%). These differences reflect different projected growth patterns and age structures across the jurisdictions.

2.3 Incidence of dementia

Incidence data refer to the number of new cases of a disease which occur in a specified period (usually a year). In the first *Dementia in Australia* report (AIHW 2007), estimates suggested that there were about 37,100 incident cases of dementia in Australia in 2003, with women accounting for 63% of these. Incidence increased with age among both men and women, but decreased for those aged 85 and over.

Methodological challenges in estimating the incidence of dementia include a lack of relevant data, for example, on duration of illness and relative risk of mortality (AIHW 2007; Access Economics 2009a). Given the lack of new data sources on the incidence of dementia, producing revised incidence estimates is beyond the scope of this report.

Table 2.5: Estimated number of people with dementia, by sex, and state and territory, 2011 and 2020

	2011[(a)]			2020[(a)]			% change
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Persons**
NSW	38,200	63,600	101,800	51,300	80,800	132,100	29.8
Vic	28,600	47,300	75,900	38,900	61,300	100,200	32.0
Qld	21,500	33,300	54,700	31,800	46,800	78,600	43.5
WA	10,500	16,400	26,900	15,600	23,200	38,800	44.0
SA	9,700	16,700	26,500	12,800	20,700	33,500	26.7
Tas	2,900	4,700	7,600	3,900	6,000	9,900	31.1
ACT	1,400	2,200	3,600	2,000	3,100	5,200	42.5
NT	500	500	1,000	700	800	1,500	51.2
Australia[(b)]	**113,300**	**184,700**	**298,000**	**157,000**	**242,800**	**399,800**	**34.2**

(a) Numbers may not sum to the total due to rounding.

(b) Includes external territories (e.g. Cocos (Keeling) Islands and Christmas Island) which are not included in the state and territory totals.

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003) and applied to population data for 2011 (ABS 2012a) and population projections for 2020 (ABS 2008a).

Having said that, if the same assumptions made by AIHW in 2007 still applied in 2011 (and thus the ratio of the number of incident cases to prevalence was the same), then the number of incident cases in 2011 would be around 63,300. This suggests that each day across Australia in 2011, an estimated 173 Australians joined the group of people with dementia. As onset usually occurs with mild symptoms, these symptoms may not have been recognised initially as being due to dementia. However, since dementia is generally not reversible, these people will eventually become part of the visible prevalent population with the condition (unless they die from other causes first). In 2009, Access Economics (2009a) estimated that there would be about 79,100 incident cases of dementia in 2011.

2.4 Mortality due to dementia

Studies that have compared people with and without dementia have consistently reported that dementia increases the risk of death (Brodaty et al. 2012; Gühne et al. 2006; Rait et al. 2010), with death arising from complications and causes that can be directly or indirectly related to dementia. Research has also shown that the risk of death increases with increasing severity of the condition (Ganguli et al. 2005; Gühne et al. 2006). Yet, even among those with mild dementia, the risk of death has been found to be higher than for those without dementia (Andersen et al. 2010; Dewey & Saz 2001).

In this section, data are presented on the number of deaths for which the underlying cause was recorded as dementia. This information is sourced from death certificates (see Box 2.2). These data must be used with the following caveats. First, the literature suggests that the difficulties associated with disentangling the cause of death for older individuals who had multiple comorbidities can lead to the under-reporting of dementia (Ives et al. 2009; Kuller & Ives 2009). Second, medical practitioners' views about attributing dementia as the cause of death or limitations of reimbursements for care prior to death are thought to have an influence on the recording of dementia as the underlying cause of death (Ganguli et al. 2005; Hoyert & Rosenberg 1999; Kuller & Ives 2009). Third, 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 (Ives et al. 2009; Kuller & Ives 2009; Sahyoun et al. 2001).

The data described in this section were sourced from the AIHW National Mortality Database (for 2001 to 2005), and from causes of death data compiled by the ABS (for 2006 to 2010). See Appendix B for information about these data sources and the specific ICD-10 codes used to identify deaths due to dementia.

Box 2.2: Death registration in Australia

Registration of death is a legal requirement in Australia. The death must be certified by either a medical practitioner using the Medical Certificate of Cause of Death or by a coroner. As part of the registration process, information about the cause of death is supplied and subsequently provided to the ABS for coding and compilation into aggregate statistics. The ICD-10 is currently used by the ABS for the coding of causes of death statistics. See ABS (2012b) for further information about causes of death data and the quality of such data.

All diseases, morbid conditions and injuries that either resulted in or contributed to the death are entered on the death certificate, with these conditions coded as either the underlying cause of death or as associated causes. The **underlying cause** of death is defined to be 'the disease or injury which initiated the train of morbid events leading directly to a person's death or the circumstances of the accident or violence which produced the fatal injury, as represented by a code' (WHO 2004). All other causes are considered to be **associated causes** of death.

In this report, data on deaths are presented based on the year of registration, not the year of death. For most deaths, these are the same but, for some, there may be a lag between the actual death and its registration (ABS 2012b).

Deaths due to dementia in 2010

Dementia was recorded as the underlying cause of 9,003 deaths in Australia in 2010 (Table 2.6). This means that, on average, 25 people in Australia died from dementia every day in that year. Twice as many women as men died from dementia. Overall, deaths due to dementia accounted for 6% of all deaths in 2010, 9% of female deaths and 4% of male deaths. The age-standardised death rate was significantly higher for women than men (36.0 versus 28.4 per 100,000 population).

Table 2.6: Deaths with an underlying cause of dementia, by sex, 2010

	Males	Females	Persons
Number of deaths	2,920	6,083	9,003
Per cent of all deaths	4.0	8.7	6.3
Age-standardised rate[(a)]	28.4	36.0	33.3
95% confidence interval	27.4–29.5	35.1–37.0	32.6–34.0

(a) The rates were standardised to the Australian population as at 30 June 2001 and are expressed per 100,000 population.

Source: AIHW analysis of ABS unpublished causes of death data.

Table 2.7 shows a ranking of causes of death, as published by the ABS (2012b). Causes of death can be grouped in many different ways, and the method chosen will affect the ranking of particular causes of death. The ranking of leading causes of death by the ABS is based on research presented in the Bulletin of the World Health Organization (Becker et al. 2006). Using this approach, dementia was the third leading cause of death in 2010, following ischaemic heart diseases (such as angina, blocked arteries of the heart and heart attacks) which accounted for 21,708 deaths, and cerebrovascular diseases (such as haemorrhages and strokes) (11,204 deaths). For women, dementia was the third leading cause of death, while for men, it was the sixth leading cause.

Table 2.7: Leading causes of death, by sex, 2010

	Males		Females		Persons	
Cause of death (ICD-10 code)	**Number**	**Rank**	**Number**	**Rank**	**Number**	**Rank**
Ischaemic heart diseases (I20–I25)	11,704	1	10,004	1	21,708	1
Cerebrovascular diseases (I60–I69)	4,333	3	6,871	2	11,204	2
Dementia (F01, F03, G30)	2,920	6	6,083	3	9,003	3
Trachea, bronchus and lung cancer (C33–C34)	4,934	2	3,165	4	8,099	4
Chronic lower respiratory diseases (J40–J47)	3,224	5	2,898	5	6,122	5

Source: ABS 2012b.

More than one cause for a death can be recorded on a death certificate. No other causes were recorded for 11.9% of deaths due to dementia in 2010; this is lower than the average of 18.1% for all deaths (ABS 2012b). The associated causes of death most frequently reported with dementia were:

- influenza and pneumonia: 30.5%
- hypertensive diseases: 12.1%
- ischaemic heart disease: 12.1%
- diseases of the kidney and urinary system: 11.7%.

Cancer was reported as an associated cause of death in only 4.9% of deaths due to dementia in 2010, although it was listed as an associated cause of death for a third (33.6%) of all deaths that year (ABS 2012b).

While the mortality data presented in this chapter pertain to deaths for which dementia was the underlying cause, some data on dementia as either the underlying or associated cause of death have been published by the ABS (2012b). Those data indicate that there were a total of 20,645 deaths in Australia in 2010 (or 57 deaths a day on average) for which dementia was listed as either the underlying or an additional cause. This represented 14.4% of all deaths that year.

Deaths due to dementia by age group

Deaths due to dementia are heavily concentrated in the older age groups (Table 2.8). For both men and women, the number of such deaths increased with age until the age group of 85–89 was reached. Of all female deaths due to dementia in 2010, around 89% were aged 80 and over at the time of death. For men, the proportion was lower at 79%.

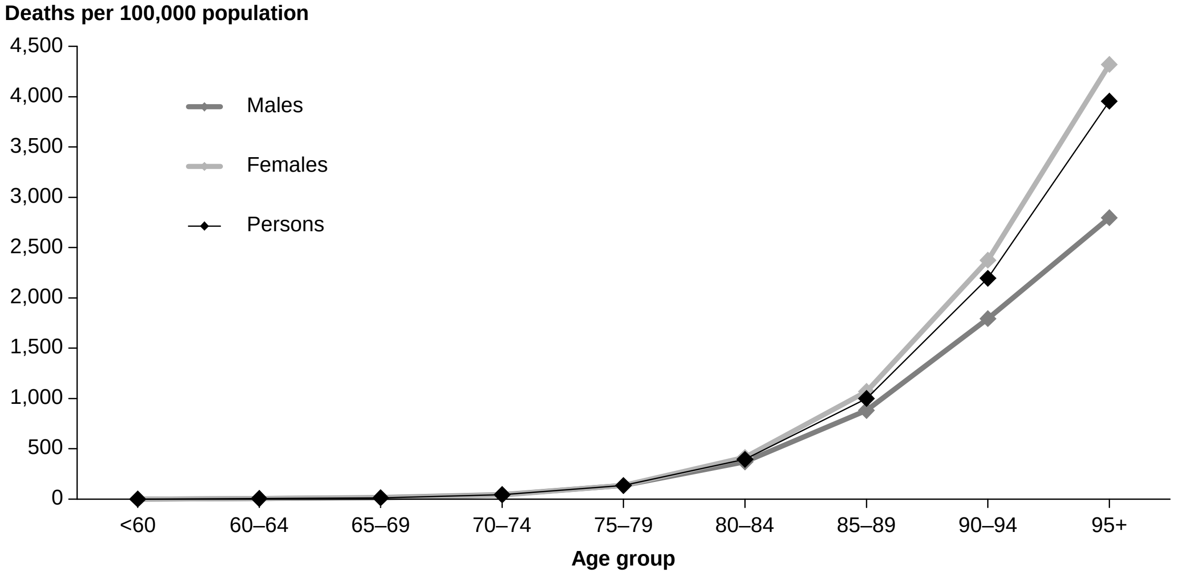
Table 2.8: Deaths with an underlying cause of dementia, by age and sex, 2010

	Number[(a)]			Per cent[(a)]		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 60	16	29	41	0.5	0.5	0.5
60–64	27	32	59	0.9	0.5	0.7
65–69	64	52	116	2.2	0.9	1.3
70–74	153	153	306	5.2	2.5	3.4
75–79	345	397	742	11.8	6.5	8.2
80–84	699	1,037	1,736	23.9	17.0	19.3
85–89	864	1,790	2,654	29.6	29.4	29.5
90–94	557	1,636	2,193	19.1	26.9	24.4
95+	196	958	1,154	6.7	15.7	12.8
Total	**2,920**	**6,083**	**9,003**	**100.0**	**100.0**	**100.0**

(a) Data cells with small values (excluding 0) were randomly assigned by the ABS to protect confidentiality. Therefore, numbers may not sum to the total.

Source: AIHW analysis of ABS unpublished causes of death data.

While Table 2.8 provides details on the number of deaths due to dementia in different age groups, it does not take into account the number of people at those ages in the overall population. To make such a comparison, age-specific rates for 2010 are shown in Figure 2.3. The age-specific mortality rate with dementia as the underlying cause was low for those aged under 65, but increased rapidly with age, with the rate more than doubling for each subsequent 5-year age category up to the 90–94 age group. The highest rate was observed for those aged 95 and over, with 4.0% of people in that age group dying from dementia in 2010.



Note: Data for this figure are shown in Appendix Table A2.3.

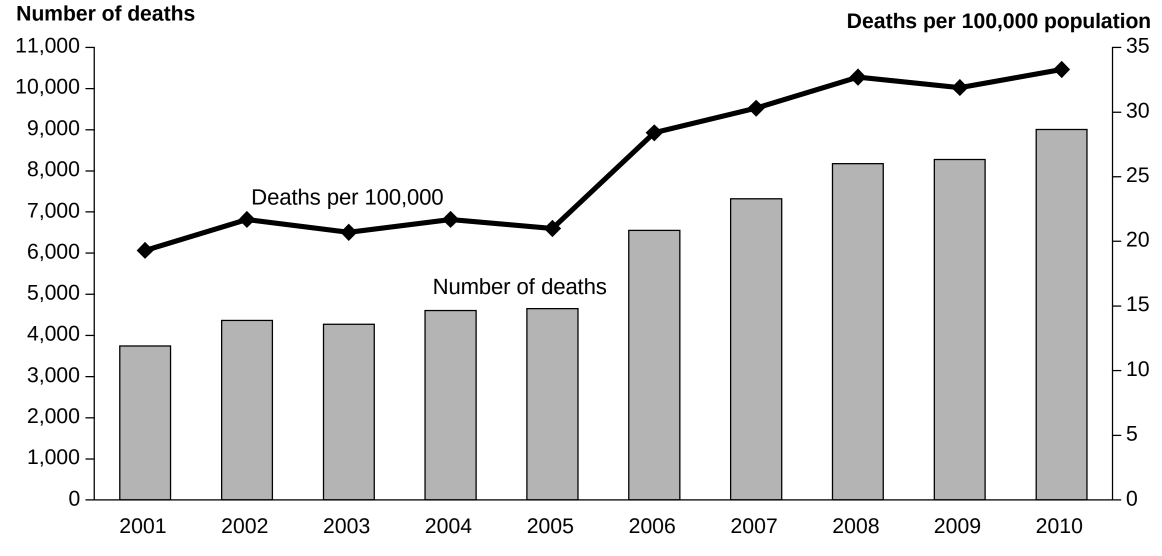
Sources: AIHW analysis of ABS unpublished causes of death data; population data for 2010 (ABS 2012a).

Figure 2.3: Age-specific rate of deaths with an underlying cause of dementia, by sex, 2010

The mortality rates due to dementia for men and women were similar up until the 75–79 age group. While the rates continued to increase by age for both men and women for the subsequent age groups, they increased at a more rapid pace for women than for men. For both sexes, the highest mortality rate due to dementia was observed for the 95 and over age group, but the mortality rate for women (4.3% of women in that age group) was substantially higher than for men (2.8%).

Change over time in deaths due to dementia

Overall, the number of deaths attributed to dementia more than doubled between 2001 and 2010 (from 3,740 to 9,003 deaths) but the increase was by no means steady (Figure 2.4). Instead, between 2001 and 2005, the number of deaths due to dementia tended to increase slightly from year to year, with an increase of 25% over the 5-year period. This increase can be attributed to the growth and ageing of the population since the age-standardised rate remained relatively stable over this period.



Note: Data for this figure are shown in Appendix Table A2.4.

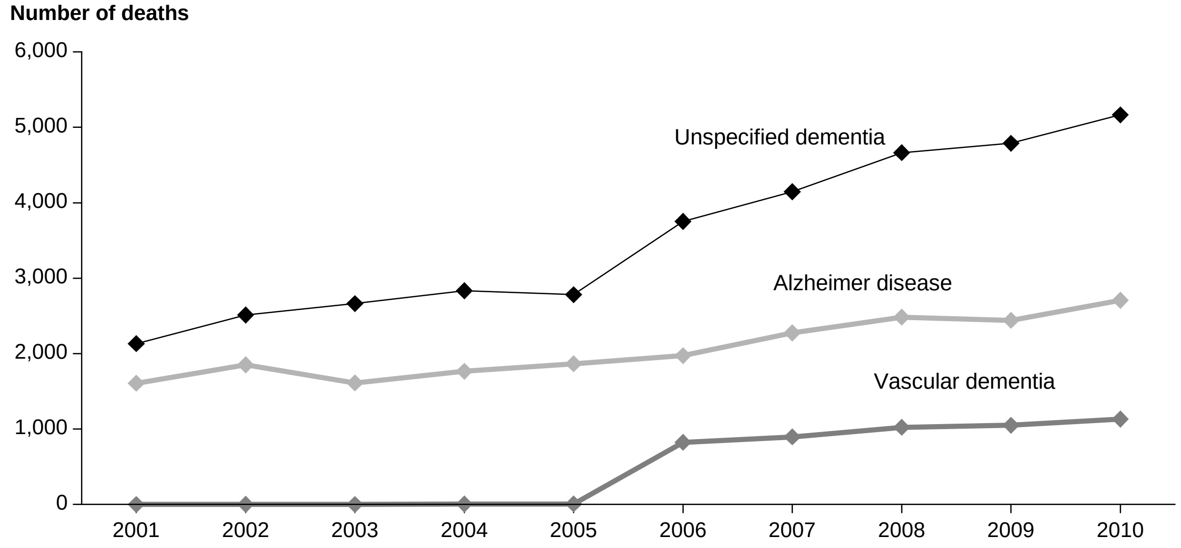
Sources: National Mortality Database (2001 to 2005); AIHW analysis of ABS unpublished causes of death data (2006 to 2010).

Figure 2.4: Number and age-standardised rate of deaths with an underlying cause of dementia, 2001 to 2010

In contrast, the increase in the number of deaths that was observed in subsequent years cannot be explained solely by changes in the age structure and size of the population. The biggest change was between 2005 and 2006, with the number of deaths due to dementia increasing by 41%, from 4,653 to 6,550. This was not due to population change alone, since the age-standardised rate also increased sharply (by 35%). In subsequent years, the number of deaths due to dementia continued to increase but at a more subdued pace. Again, not all of that change can be attributed to changes in population ageing and growth since the age-standardised rate rose from 30.3 per 100,000 population in 2007 to 33.3 per 100,000 population in 2010 (Appendix Table A2.4).

The clear break in trend between 2005 and 2006 has been explained by the ABS as being due to two factors (ABS 2012b). From 2006 onwards, updates to the coding instructions in ICD-10 resulted in the coding of some deaths to vascular dementia which may have been coded to cerebrovascular diseases previously. Second, a promotional campaign was launched that informed health professionals about changes to various Acts (including the *Military Rehabilitation and Compensation Act 2004*) that allowed for death from vascular dementia of veterans or members of the defence forces to be related to relevant service. These changes are believed to have increased the number of deaths that were recorded as being due to dementia since 2006. Given that the impact of coding and related changes may be spread over a number of years as awareness of the changes increases, it is unclear if the continued increase in the rate of deaths due to dementia can be explained by these changes or if they represent an actual increase in the number of deaths due to dementia.

Figure 2.5 presents information on the number of deaths attributed to various types of dementia between 2001 and 2010. The number of deaths attributed to *Alzheimer disease* tended to increase slightly and steadily, with an overall increase of 68% over the 10-year period. In contrast, the number of deaths attributed to *Vascular dementia* increased from a miniscule number between 2001 and 2005, to 825 deaths in 2006. In 2010, over 1,000 (1,132) deaths were attributed to *Vascular dementia*. This growth is in line with coding and entitlement changes for this type of dementia. However, the data also indicate a clear jump in the number of deaths due to *Unspecified dementia* between 2005 and 2006, with a steady increase in following years to more than double over the 10 years to 2010. It is unclear whether this increase is related to coding or other changes.



Note: Data for this figure are shown in Appendix Table A2.5.

Sources: ABS (2012b); AIHW National Mortality Database (2001 to 2005); AIHW analysis of ABS unpublished causes of death data (2006 to 2010).

Figure 2.5: Deaths with an underlying cause of dementia, by type of dementia, 2001 to 2010

2.5 Burden of disease due to dementia

The effect of dementia on the health of Australians can be summarised by using a variety of different measures that combine information on both fatal and non-fatal health outcomes into a single number. Of the available measures, the most commonly used is the disability-adjusted life year (DALY), which is frequently referred to as 'burden of disease'. The DALY combines information on the extent of:

- premature death—which is measured by the years of life lost (YLL) due to disease or injury, and
- non-fatal health outcomes—which is measured by years of 'healthy' life lost (YLD) due to disease, disability or injury.

In order to combine these two health measures into a summary measure, the DALY uses time as a common 'currency'. Hence, the DALY is a measure of the years of healthy life lost due to premature death (YLL) or disease, disability or injury (YLD), or a combination of the two, with one DALY equal to one lost year of 'healthy' life. The more DALYs associated with a particular disease, the greater the burden. The main advantage of DALYs is that they give weight to health problems that cause substantial illness and disability even if they are not fatal, and also to conditions that may not cause many deaths but, when they do, those deaths are of younger people (AIHW 2012a). Additional information about DALYs can be found in AIHW's 2007 report on the burden of disease (Begg et al. 2007).

The most recent national burden of disease analysis, conducted by the AIHW and the University of Queensland, was based on 2003 data (Begg et al. 2007). In order to produce updated estimates for this report, the rates that were derived for 2003 were applied to current ABS population data and projections (see Note 2.4 in Appendix D).

In 2011, the burden of disease due to dementia was projected to be 121,737 DALYs (Table 2.9). This equates to 4% of the total disease burden in Australia, making dementia the fourth leading cause of burden of disease for Australians in 2011.

Women accounted for more of the projected burden due to dementia than men (63% compared with 37%). People aged 75 and over accounted for the majority (72%) of the burden due to dementia, with 40% attributable to people aged 75–84, and another 32% to people aged 85 and over.

Most of the projected burden due to dementia was related to the disabling nature of the condition, with three-quarters (74%) due to disability (90,193 YLDs) and one-quarter (26%) to premature mortality (31,545 YLLs). This finding holds true for both men (76% of burden due to YLDs) and women (73%). In 2011, dementia ranked as the third leading cause of disability burden (preceded by anxiety and depression, and Type 2 diabetes).

Likewise, for each age group considered in Table 2.9, the majority of burden due to dementia was attributable to disability, although the proportion differed by age. In particular, the proportion of the burden associated with years lost due to disability, rather than years lost due to death, was substantially lower for those aged 85 and over (60%) than for the other age groups. Nonetheless, for this oldest age group, dementia accounted for more than one-quarter (28%) of total burden due to disability, as well as 7% of all burden due to premature mortality.

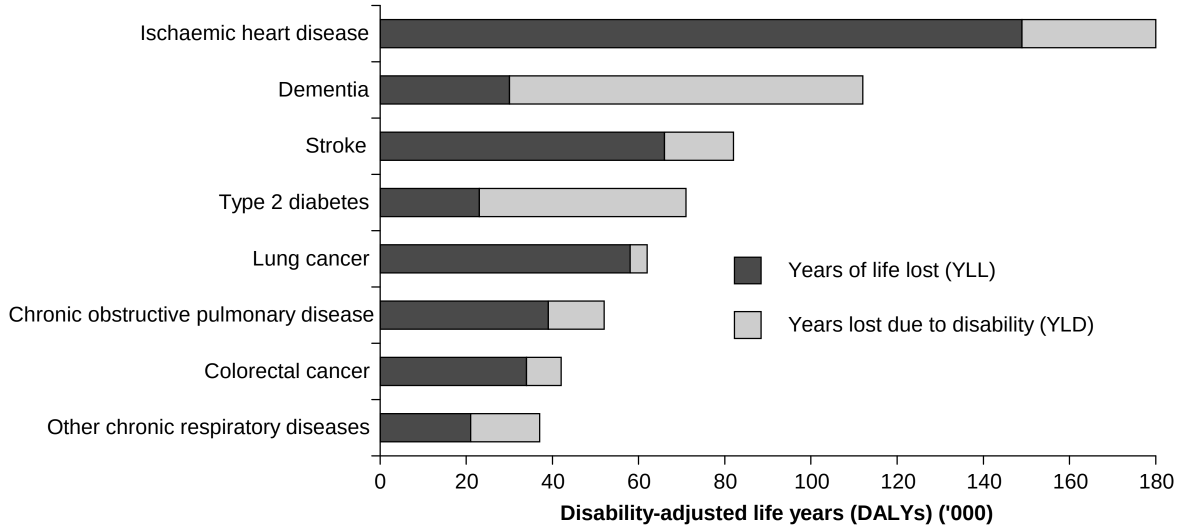
Figure 2.6 presents data pertaining to the leading causes of disease burden for older Australians. In 2011, dementia was the second leading cause of overall burden of disease for people aged 65 and over (9% of total DALYs), with ischaemic heart disease being the leading cause (15%).

When only years lost due to disability (YLD) are considered, dementia is the leading cause of disability burden among those aged 65 and over, accounting for 1 out of every 6 (17%) years lost due to disability for this age group (Appendix Table A2.6).

Table 2.9: Burden of disease due to dementia by fatal and non-fatal components, by age and sex, 2011

	Years of life lost (YLLs)			Years lost due to disability (YLDs)			Disability-adjusted life years (DALYs)			Proportion of DALYs due to YLD		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Due to dementia												
<65	951	962	1,913	4,938	3,449	8,387	5,889	4,411	10,300	83.9	78.2	81.4
65–74	1,776	1,950	3,726	8,856	11,259	20,115	10,632	13,208	23,840	83.3	85.2	84.4
75–84	4,239	6,428	10,667	13,829	24,739	38,567	18,068	31,166	49,234	76.5	79.4	78.3
85+	3,824	11,415	15,239	6,821	16,302	23,123	10,646	27,717	38,362	64.1	58.8	60.3
Total: 65+	**9,840**	**19,792**	**29,632**	**29,506**	**52,300**	**81,805**	**39,346**	**72,092**	**111,437**	**75.0**	**72.5**	**73.4**
Total	**10,791**	**20,754**	**31,545**	**34,444**	**55,749**	**90,193**	**45,234**	**76,503**	**121,737**	**76.1**	**72.9**	**74.1**
Proportion of total burden due to dementia (%)												
<65	0.3	0.5	0.4	0.9	0.6	0.8	0.7	0.6	0.6	. .	. .	. .
65–74	1.1	1.7	1.3	7.5	10.8	9.1	3.8	6.0	4.8	. .	. .	. .
75–84	2.7	4.5	3.6	16.7	25.5	21.5	7.5	13.0	10.3	. .	. .	. .
85+	4.9	8.9	7.4	22.7	31.6	28.3	9.9	15.4	13.3	. .	. .	. .
Total: 65+	**2.5**	**5.1**	**3.8**	**12.8**	**20.7**	**16.9**	**6.3**	**11.3**	**8.8**	**. .**	**. .**	**. .**
Total	**1.5**	**3.5**	**2.4**	**4.5**	**6.9**	**5.7**	**3.0**	**5.4**	**4.2**	**. .**	**. .**	**. .**
Rank relative to other health conditions												
Total: 65+	10	4	6	1	1	1	2	2	2	. .	. .	. .
Total	19	7	10	4	3	3	7	4	4	. .	. .	. .

Sources: AIHW projection of burden of disease based on rates from Begg et al. (2007) and population data for 2011 (ABS 2012a).



Note: Data for this figure are shown in Appendix Table A2.6.

Sources: AIHW projection of burden of disease based on rates from Begg et al. (2007) and population data for 2011 (ABS 2012a).

Figure 2.6: Leading causes of burden of disease by fatal and non-fatal components, for people aged 65 and over, 2011

When the disability burden is considered by sex, dementia is found to be the leading cause of disability burden for older men (accounting for 13% of total disability burden for men aged 65 and over), as well as older women (21%).

Change over time

The burden of disease due to dementia for selected years from 2003 to 2020 is shown in Table 2.10. It is estimated to have grown by 30% between 2003 and 2011. Projections suggest that by 2020, dementia will be responsible for the loss of just over 166,000 years of healthy life, accounting for 5% of the total burden of disease. Burden due to disability is projected to grow faster between 2011 and 2020 than burden due to premature mortality (38% compared with 32%), especially in men (42% compared with 36% in women).

The projections to 2020 also suggest that the ranking of dementia, relative to other health conditions, will not change in terms of both the total burden of disease (fourth leading cause) and the disability burden (third leading cause) based on the current 2003 rates.

For people aged 65 and over, the projected data suggest that in 2020, dementia will account for 1 out of every 10 years of healthy life lost (10% of total DALYs), and 1 out of every 6 years lost due to disability (18% of YLDs). It will continue to be the second leading cause of total burden, and the first leading cause of disability burden for those aged 65 and over.

Table 2.10: Burden of disease due to dementia by fatal and non-fatal components, by sex, 2003 to 2020 (selected years)

	Years of life lost (YLLs)			Years lost due to disability (YLDs)			Disability-adjusted life years (DALYs)		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
Burden due to dementia									
2003	7,986	15,773	23,758	25,310	44,410	69,719	33,295	60,182	93,478
2011	10,791	20,754	31,545	34,444	55,749	90,193	45,234	76,503	121,737
2015	12,257	23,948	36,204	40,417	64,118	104,535	52,673	88,066	140,739
2020	14,036	27,535	41,571	49,021	75,881	124,902	63,057	103,416	166,473
Proportion of total burden due to dementia (%)									
2003	1.1	2.8	1.9	3.9	6.4	5.2	2.4	4.8	3.6
2011	1.5	3.5	2.4	4.5	6.9	5.7	3.0	5.4	4.2
2015	1.6	3.9	2.7	4.9	7.4	6.2	3.4	6.0	4.6
2020	1.9	4.4	3.0	5.4	8.0	6.7	3.8	6.6	5.2
Ranking relative to other conditions									
2003	25	7	10	5	3	3	11	6	5
2011	19	7	10	4	3	3	7	4	4
2015	14	7	8	4	3	3	7	4	4
2020	12	5	7	4	3	3	5	3	4

Sources: AIHW estimation of burden of disease, based on rates from Begg et al. (2007), population data for 2003 and 2011 (ABS 2012a) and population projections for 2015 and 2020 (ABS 2008a).

3 Characteristics of people with dementia

Key points

- People with dementia aged 65 and over had a substantially higher average number of health conditions than all people in this age group (5.4 and 2.9 respectively).
- The majority (88%) of people with dementia in private dwellings lived with others; men (93%) were more likely than women (84%) to do so.
- Among people living in the community, those with dementia were most likely to need help with health care (84%), mobility (80%) and private transport (80%). For those in cared accommodation, 99% required help with health care, 98% with self-care activities, and 91% with cognitive or emotional tasks.
- Three-quarters (75%) of people with dementia made use of a combination of formal and informal assistance to obtain help in the areas for which they needed assistance, while 22% relied solely on informal assistance.
- Among permanent residents in residential aged care, those with dementia were more likely than those without dementia to need high care (87% versus 63%), and to have higher care needs in relation to activities of daily living and behaviour, but not in relation to complex health care. The majority of residents with dementia had a diagnosis of Alzheimer disease, with the proportion higher in women (79%) than men (67%).

3.1 Introduction

This chapter describes the characteristics of people with dementia, with a distinction made according to whether the person lived in the community or not. The characteristics considered are:

- sociodemographic characteristics including age, sex, remoteness, country of birth, Indigenous status and living arrangements
- type of dementia
- level of disability
- co-existing health conditions
- care needs and how those needs are met.

The most relevant and recent national data sources are the 2009 SDAC and data collected through the ACFI in 2009–10. While detailed descriptions of these data sources can be found in Appendix B, some key points about these data are noted here.

The SDAC provides detailed information from a sample of people reported to have dementia who either lived in the community or in cared accommodation in 2009. As noted in Chapter 2, people with mild and moderate dementia are likely to be under-represented in the SDAC. This may have an effect on the data reported for a number of the characteristics including age, level of disability, care needs and residency. For example, the SDAC data suggest that 63% of those with dementia lived in cared accommodation, with 37% living in the community. This is different from the estimated proportion of 30% living in cared accommodation and 70% in the community, as discussed in Chapter 2. This under-representation of people with mild and moderate dementia should be taken into account when considering data from the SDAC.

Data collected through the ACFI include information about permanent residents of Australian Government-subsidised aged care facilities who had a diagnosis of dementia. Almost all (99%) permanent residents of subsidised aged care facilities in 2009–10 had been assessed using the ACFI tool. Note that ACFI data do not capture people with dementia who lived in non-government-subsidised aged care facilities or in other non-mainstream facilities (such as a Multi-Purpose Service). ACFI data in this chapter relate to 213,130 permanent residents with ACFI appraisals that were valid during the 2009–10 financial year, with 112,139 (53%) of these residents having a diagnosis of dementia.

3.2 Sociodemographic characteristics

Age and sex

In Table 3.1, the age and sex distribution of people reported to have dementia according to the SDAC are shown, with a distinction made between those living in the community and those in cared accommodation. Note that most (94%) people with dementia who lived in cared accommodation were living in residential aged care facilities.

Table 3.1: People with dementia, by age, sex and residency, 2009 (per cent)

	Community			Cared accommodation			Total		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 65	**8.1	**4.8	*6.4	4.1	1.5	2.2	*6.2	*2.5	3.8
65–69	*7.7	**3.3	*5.5	3.8	1.7	2.3	*5.8	*2.2	3.5
70–74	*21.1	*5.8	13.3	6.6	3.2	4.1	14.1	*3.9	7.6
75–79	20.5	*15.2	17.8	12.3	9.5	10.3	16.6	11.1	13.1
80–84	26.1	25.3	25.7	26.7	21.8	23.1	26.4	22.8	24.1
85+	*16.5	45.7	31.2	46.4	62.4	58.0	31.0	57.5	48.0
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**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.

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

The majority of people with dementia were female (64%) according to the SDAC, although a substantial difference by residency is evident. Half of those with dementia in the community were women, compared with 72% in cared accommodation (Appendix Table A3.1).

Given the increasing prevalence of dementia with age, and the longer life expectancy of women compared with men (AIHW 2010a), it is not surprising that people with dementia are mostly older women (Appendix Table A3.1). According to the SDAC, almost 6 in 10 (59%) of those with dementia were women aged 75 and over. Again, a clear difference is observed according to residency (68% in cared accommodation and 43% in the community).

The age profile of those with dementia living in the community is substantially younger than that of those living in cared accommodation. For instance, 31% of those with dementia in the community were aged 85 and over, compared with 58% of those in cared accommodation. As well, the age profile of men with dementia is different from that of women in both residency groups, with the difference starker among those living in the community, where 17% of men were aged 85 and over compared with 46% of women. The corresponding proportions among those living in cared accommodation were 46% for men and 62% for women.

According to 2009–10 ACFI data, 70% of permanent residents with dementia in Australian Government-subsidised aged care facilities were women. This is similar to the 72% observed in the SDAC data for those in cared accommodation (Appendix Table A3.1) and the 71% as derived in the estimates presented in Table 2.2.

As shown in Table 3.2, 44% of those with dementia who lived in residential aged care facilities were aged under 85, 30% were aged 85–89, 19% were aged 90–94, and 7% were aged 95 and over. As was also suggested by the SDAC data, the majority of those with dementia living in residential aged care settings (or, for the SDAC data, in cared accommodation) were aged 85 and over (Figure 3.1).

The ACFI data also allow a calculation of the average age of permanent residents with dementia in residential aged care facilities. For women with dementia living in this setting, the average age was 86, compared with 82 for men.

Table 3.2: Permanent residents with dementia in aged care facilities[(a)], by age and sex, 2009–10 (per cent)

Age	Males	Females	Persons
Under 65	3.7	1.4	2.1
65–69	4.0	1.5	2.3
70–74	7.9	3.8	5.1
75–79	15.2	9.6	11.3
80–84	25.3	21.9	23.0
85–89	26.9	31.7	30.2
90–94	13.3	20.8	18.5
95+	3.7	9.1	7.5
Total	**100.0**	**100.0**	**100.0**
Average (mean) age	82.2	85.7	84.6

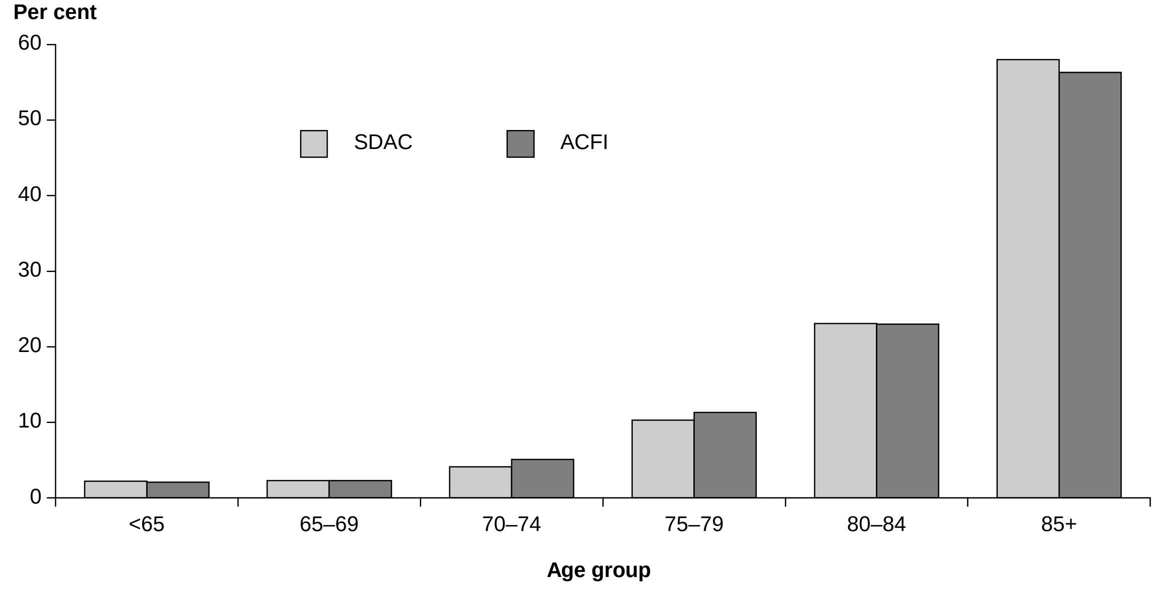
(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Younger onset dementia

Younger onset dementia is much less common than dementias occurring at later ages. Furthermore, research suggests that, compared with late onset dementia (that is, dementia diagnosed among those aged 65 and over), younger onset dementia is more frequently misdiagnosed (Mendez 2006). One reason is said to be the greater variation in the types of dementia diagnosed among those with younger onset dementia. In particular, compared with those with late onset dementia, Alzheimer disease is believed to be less common (although still the most common dementia diagnosis), while dementias attributed to alcohol abuse, head trauma, human immunodeficiency virus (HIV) and a number of other causes are considered to be more common among those with younger onset dementia (Mendez 2006; McMurtray et al. 2006; Werner et al. 2009). In Chapter 2, it was estimated that 23,900 people under the age of 65 had dementia.

The Dementia Collaborative Research Centre at the University of New South Wales is undertaking a 3-year study (INSPIRED—Improving Service Provision for Early Onset Dementia) to improve understanding of the characteristics and needs of this group of people (DCRC–ABC 2012).



Note: Data for this figure are shown in Tables 3.1 and 3.2.

Sources: AIHW analysis of the ABS 2009 Survey of Disability, Ageing and Carers confidentialised unit record file; AIHW analysis of data collected with the Aged Care Funding Instrument 2009–10.

Figure 3.1: People with dementia, by age: a comparison of cared accommodation data from the Survey of Disability Ageing and Carers (SDAC) and residential aged care data from the Aged Care Funding Instrument (ACFI)

State and territory

According to the SDAC data, 42% of people with dementia lived in New South Wales, 22% in Victoria and 17% in Queensland in 2009 (Table 3.3). The relative proportions vary among those living in the community and those in cared accommodation. For example, among those with dementia living in the community, 34% lived in New South Wales whereas 46% of those in cared accommodation lived in New South Wales.

The ACFI data suggest a similar distribution of those with dementia across the states and territories (Appendix Table A3.2), with the exception of New South Wales, where 35% of people with dementia lived in residential aged care.

Remoteness

People living in more inaccessible regions of Australia may be disadvantaged in a number of ways, including in access to goods and services. To examine differences in the proportion of people with dementia, according to the remoteness of the area in which they usually lived, the Australian Standard Geographical Classification Remoteness Area classification (ABS 2001) has been used. This classification divides all areas of Australia into five categories—*Major cities*, *Inner regional*, *Outer regional*, *Remote* and *Very remote*—depending on the distance of the area from differently sized urban centres (see Appendix E for further information). The population size of the urban centre is considered to govern the range and type of services available. Note that the SDAC excluded from its scope people living in *Very remote* areas. Furthermore, for the SDAC analyses presented in this report, the categories of *Outer regional* and *Remote* were collapsed due to the relatively small number of people with dementia in these two categories.

Table 3.3: People with dementia, by residency, and state and territory, 2009 (per cent)

	Community	Cared accommodation	Total
New South Wales	34.4	45.8	41.6
Victoria	19.7	23.4	22.0
Queensland	21.8	14.3	17.1
Western Australia	9.6	5.4	7.0
South Australia	10.5	8.2	9.1
Tasmania	*2.4	*1.6	1.9
Australian Capital Territory	**1.1	*1	*1.0
Northern Territory	**0.4	**0.2	**0.3
Total	**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.

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

In 2009, the SDAC data suggest that 69% of people with dementia lived in *Major cities*, 22% lived in *Inner regional* areas and 9% lived in other areas (Table 3.4). When residency is taken into account, the proportions living in the three remoteness areas are different, although in both cases, the majority lived in *Major cities* (74% for those living in the community and 66% for those living in cared accommodation).

Table 3.4: People with dementia, by remoteness and residency, 2009 (per cent)

Remoteness[(a)]	Community	Cared accommodation	Total
Major cities	74.3	66.2	69.2
Inner regional	16.9	24.6	21.7
Other areas[(b)]	*8.8	9.2	9.1
Total	**100.0**	**100.0**	**100.0**

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

(a) Remoteness was measured using the Australian Standard Geographical Remoteness Area classification (see Appendix E).

(b) 'Other areas' includes *Outer regional* and *Remote*. The SDAC excluded people living in *Very remote* areas.

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

The data collected through the ACFI include information about where permanent residents in aged care facilities live by all five (rather than just three) remoteness categories (Table 3.5). Similar to the SDAC data, these data suggest that the vast majority (71%) of those with dementia living in subsidised aged care facilities during 2009–10 were located in *Major cities* and 21% in *Inner regional* areas. In addition, the ACFI data suggest that 7% lived in *Outer regional* areas, and less than 1% lived in either *Remote* or *Very remote* areas. A similar distribution of remoteness was observed among permanent residents without dementia (Table 3.5), although more with dementia (71%) than those without dementia (66%) lived in *Major cities*.

Table 3.5: Permanent residents in aged care facilities(a), by remoteness and dementia status, 2009–10 (per cent)

Remoteness(b)	With dementia	Without dementia
Major cities	70.8	66.1
Inner regional	21.3	24.8
Outer regional	7.2	8.4
Remote	0.5	0.6
Very remote	0.2	0.2
Total	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) Remoteness is based on the location of the most recent facility the resident was in before the end of the 2009–10 financial year. Remoteness was measured using the Australian Standard Geographical Remoteness Area classification (see Appendix E).

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Country of birth

According to the SDAC, 61% of people with dementia were born in Australia, 15% in the 'Main English-speaking countries' (namely, New Zealand, Ireland, United Kingdom, United States of America, Canada and South Africa) and 24% in 'Other countries' (Table 3.6). These proportions varied by residency, with a relatively lower proportion of those living in the community having been born in Australia (47% compared with 69% in cared accommodation) and a higher proportion having been born in 'Other countries' (33% of those living in the community compared with 19% of those in cared accommodation).

Table 3.6: People with dementia, by country of birth and residency, 2009 (per cent)

Country of birth	Community	Cared accommodation	Total
Australia	46.9	68.7	60.6
Main English-speaking countries(a)	20.1	11.9	15.0
Other countries	33.0	19.4	24.4
Total	**100.0**	**100.0**	**100.0**

(a) Includes people born in New Zealand, Ireland, United Kingdom, United States of America, Canada and South Africa.

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

Among those with dementia living in cared accommodation, the SDAC data indicate that 69% were born in Australia. Similarly, the ACFI data indicate that 70% of permanent residents with dementia in aged care facilities were born in Australia (Appendix Table A3.3). According to the ACFI data, the most common countries of origin, other than Australia, were the United Kingdom and the Republic of Ireland (11%), followed by Southern and Eastern Europe (10%) and other North-West European countries (3%).

Main language spoken

According to the SDAC, 75% of people with dementia living in the community spoke mainly English at home.

Data collected through the ACFI indicate that 89% of permanent residents with dementia in aged care facilities spoke English as their preferred language. The most common other preferred languages were Italian (3%), followed by Greek, Polish and German (each 1%). The extent to which English was the preferred language of permanent residents with dementia varied by the remoteness of the location of the aged care facility (Table 3.7).

Table 3.7: Whether English was preferred language of permanent residents with dementia in aged care facilities[(a)], by remoteness[(b)], 2009–10 (per cent)

	Major cities	Inner regional	Outer regional	Remote & Very remote	Australia
English is preferred language	86.0	97.0	95.1	78.9	89.0
English is not preferred language	13.9	2.9	4.9	21.0	10.9
Indigenous language	0.0	0.0	0.2	19.0	0.1
Not Indigenous language	13.8	2.9	4.6	2.0	10.8
Total[(c)]	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) Remoteness is based on the location of the most recent facility the resident was in before the end of the 2009–10 financial year. Remoteness was measured using the Australian Standard Geographical Remoteness Area classification (see Appendix E).

(c) The total includes residents for whom the preferred language was not stated or inadequately described.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Among those in aged care facilities in *Inner regional* and *Outer regional* areas, English was the preferred language for nearly all residents (97% and 95% respectively). In contrast, English was preferred by 86% in *Major cities*. In *Remote* and *Very remote* areas, English was the preferred language for 79% of the residents, while an Indigenous language was the preferred language for about 1 in 5 (19%) of these residents.

Indigenous status

Due to the lack of national data on the prevalence of dementia among Indigenous Australians, most information is drawn from a small number of localised, largely community-based studies (Arkles et al. 2010). One such study was undertaken by Smith et al. (2008) in a remote area of Western Australia. This study, which involved screening 363 Indigenous Australians aged 45 and over, found that 45 of those screened had dementia. This equates to a prevalence rate of 12% (with a 95% confidence interval of 9% to 16%). In contrast, using the estimated prevalence rates described in Chapter 2, an estimated 3.4% of all Australians aged 45 and over had dementia in 2011. The results from Smith et al. therefore suggest a rate higher than in the general population. Given the small sample size and localised nature of the study, it is not possible to know how indicative these findings are of the overall prevalence of dementia among Indigenous Australians.

Research also suggests that dementia affects Indigenous Australians at an earlier age than in the general population, with a relatively larger proportion of Indigenous Australians in the 45 to 69 year age group affected (Arkles et al. 2010). Further information about dementia prevalence among Indigenous Australians is expected to become available from the Koori Growing Old Well Study (KGOWS), a recently commenced study involving urban Aboriginal communities in New South Wales. The primary aim of that study is to determine the prevalence of cognitive impairment and dementia among urban Indigenous populations aged 60 and over (NeuRA 2012; see Appendix C).

Although information on Indigenous status is available from the ACFI data (as discussed below), it is not available from the SDAC, and all people living in Indigenous communities were excluded from the scope of that survey (ABS 2010). Some information on Indigenous status is available for community aged care program recipients and National Respite for Carers Program recipients and is discussed in Chapter 4.

Indigenous people with dementia in residential aged care facilities

According to the ACFI data, 683 permanent residents with dementia living in subsidised aged care facilities in 2009–10 were Indigenous Australians. This equates to 0.6% of permanent residents with dementia which is similar to the proportion (0.7%) of permanent residents without dementia who were Indigenous Australians (Table 3.8). Of the Indigenous permanent residents with dementia, 60% were women.

Table 3.8: Indigenous status of permanent residents in aged care facilities[(a)], by dementia status and sex, 2009–10 (per cent)

	With dementia			Without dementia
	Males	**Females**	**Persons**	**Persons**
Indigenous	0.8	0.5	0.6	0.7
Non-Indigenous	98.3	98.1	98.2	98.0
Not stated	1.0	1.3	1.2	1.3
Total	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

These data underestimate the actual number of Indigenous permanent residents with dementia in all types of aged care facilities. Firstly, and most importantly, the ACFI data do not include those residents living in residential aged care places provided in a Multi-Purpose Service setting or under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. For the providers of such 'non-mainstream' places to receive Australian Government funding, an appraisal of residents using the ACFI is not required. It is likely though, that Indigenous Australians living in more remote areas of Australia will make use of residential care places provided under these alternative programs (see Box 3.1). Secondly, as shown in Table 3.8, of those residents with dementia who received an ACFI appraisal, 1.2% did not have Indigenous status reported; some of those residents may have been Indigenous Australians.

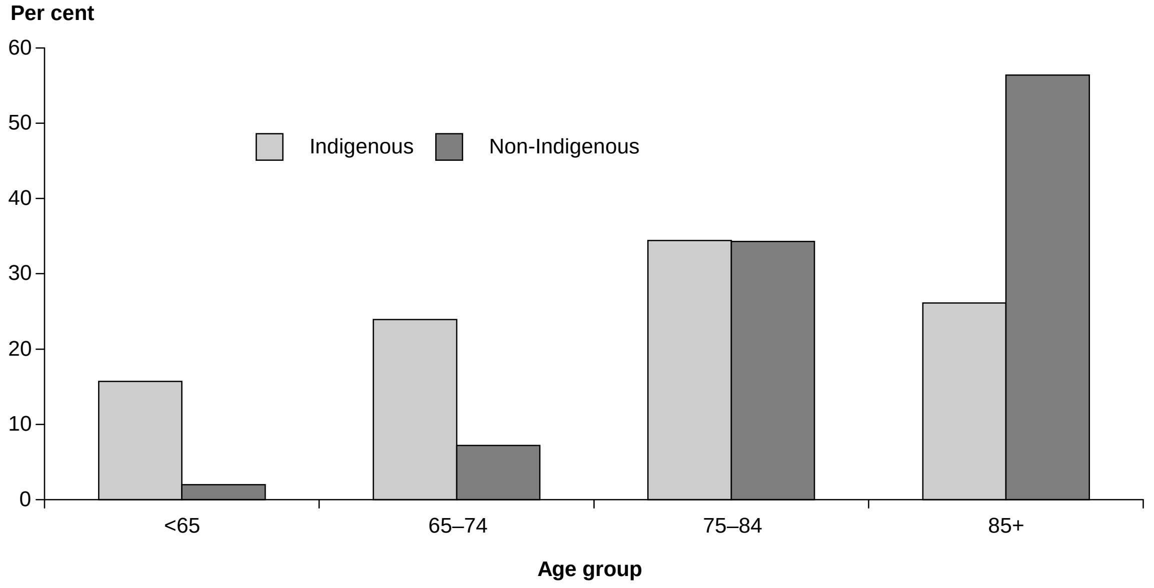
Box 3.1: Under-identification of Indigenous residents with dementia in *Very remote* areas

As at 30 June 2010, there were 331 operational residential aged care places in *Very remote* areas for which an appraisal using the ACFI was required (and thus the use of these places by Indigenous Australians would be included in the ACFI data). A further 235 places were available in Multi-Purpose Services and 170 operational places were funded under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, equalling a total of 405 'non-mainstream' places in *Very remote* areas (AIHW 2011b).

No data are available about the dementia status of permanent residents who accessed non-mainstream residential aged care places in 2009–10. However, nearly all residents occupying places funded through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program are thought to be Indigenous and it is likely that some of those who occupied Multi-Purpose Service places were Indigenous Australians.

Since the ACFI data cover fewer than half of the total Australian Government-subsidised operational permanent residential aged care places in *Very remote* areas, the proportions of Indigenous residents with dementia in these areas and, in total, are underestimated using the available data.

According to the ACFI data, Indigenous aged care residents with dementia were more likely to be younger than non-Indigenous Australians (Figure 3.2). One in six (16%) were aged less than 65 compared with 2% of their non-Indigenous counterparts. The proportions for those aged 65–74 were 24% for Indigenous residents and 7% for non-Indigenous residents. Around 26% of Indigenous permanent residents with dementia were aged 85 and over compared with 56% of non-Indigenous residents. The average (mean) age of Indigenous permanent residents with dementia was 76 (median 78), compared with 85 (median 87) for non-Indigenous residents (Appendix Table A3.4).



Notes: Data for those for whom Indigenous status was not reported are not shown. Data for this figure are shown in Appendix Table A3.4.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Figure 3.2: Age of permanent residents with dementia in aged care facilities, by Indigenous status, 2009–10

Table 3.9 indicates the distribution of Indigenous permanent residents with dementia in 'mainstream' residential aged care places by state and territory, according to the ACFI data. The proportion of Indigenous residents among all residents in each of the states and territories was less than 2%, with one exception—in the Northern Territory, 34% of permanent residents were Indigenous.

Of the 683 Indigenous permanent residents with dementia, the largest proportion lived in aged care facilities in Western Australia (25% of Indigenous residents), followed by Queensland (24%), New South Wales (22%) and the Northern Territory (15%).

The proportion of Indigenous permanent residents with dementia varied substantially by level of remoteness, according to the ACFI data. Less than 1% of residents in mainstream residential aged care facilities in *Major cities* and *Inner regional* areas were Indigenous while 2% of those in *Outer regional* areas were Indigenous. This compares with 18% in *Remote* areas and 59% in *Very remote* areas (Appendix Table A3.5).

Table 3.9: Indigenous status of permanent residents with dementia in aged care facilities[(a)], by state and territory[(b)], 2009–10 (per cent)

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Indigenous	0.4	0.2	0.8	1.8	0.3	0.5	0.3	33.6	0.6
Non-Indigenous	98.3	99.3	96.8	97.6	98.4	99.2	99.1	65.4	98.2
Not stated	1.3	0.6	2.4	0.6	1.4	0.2	0.6	1.0	1.2
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) State and territory is based on the location of the most recent facility the resident was in before the end of the 2009–10 financial year.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Living arrangements

Data from the SDAC provide information on the living arrangements of those with dementia who lived in private dwellings (rather than other types of dwellings in the community such as self-care aged accommodation, hotels, boarding houses, etc.). Almost 9 in 10 (88%) people with dementia who lived in private dwellings lived with others, while 12% lived alone (Table 3.10). Men were more likely than women to have been living with others (93% and 84% respectively).

Table 3.10: People with dementia living in private dwellings in the community, by living arrangements and sex, 2009 (per cent)

	Males	Females	Persons
Lives with others	93.0	83.5	88.1
Lives alone	**7.0	*16.5	*11.9
Total	**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.

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

3.3 Type of dementia

While no information was collected as part of the SDAC on the type of dementia that people had, such information is available in the ACFI data (see AIHW 2011a for details on the coding of diagnoses in ACFI data).

In 2009–10, 76% of all permanent residents with dementia in subsidised aged care facilities had *Alzheimer disease* (Table 3.11). This was followed by *Vascular dementia* (10%), *Other dementia* (8%), and *Dementia in other specified diseases* (such as Huntington disease, Parkinson disease, Pick disease, HIV, etc.) (4%). More than one type of dementia was recorded for 2% of the residents with dementia.

Table 3.11: Permanent residents with dementia in aged care facilities(a), by type of dementia and sex, 2009–10 (per cent)

Type of dementia	Males	Females	Persons
Alzheimer disease	67.3	79.3	75.7
Vascular dementia	13.1	8.9	10.2
Dementia in other specified diseases	5.7	3.3	4.0
Other dementia	11.3	7.2	8.4
More than one type of dementia	2.6	1.4	1.7
Total	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

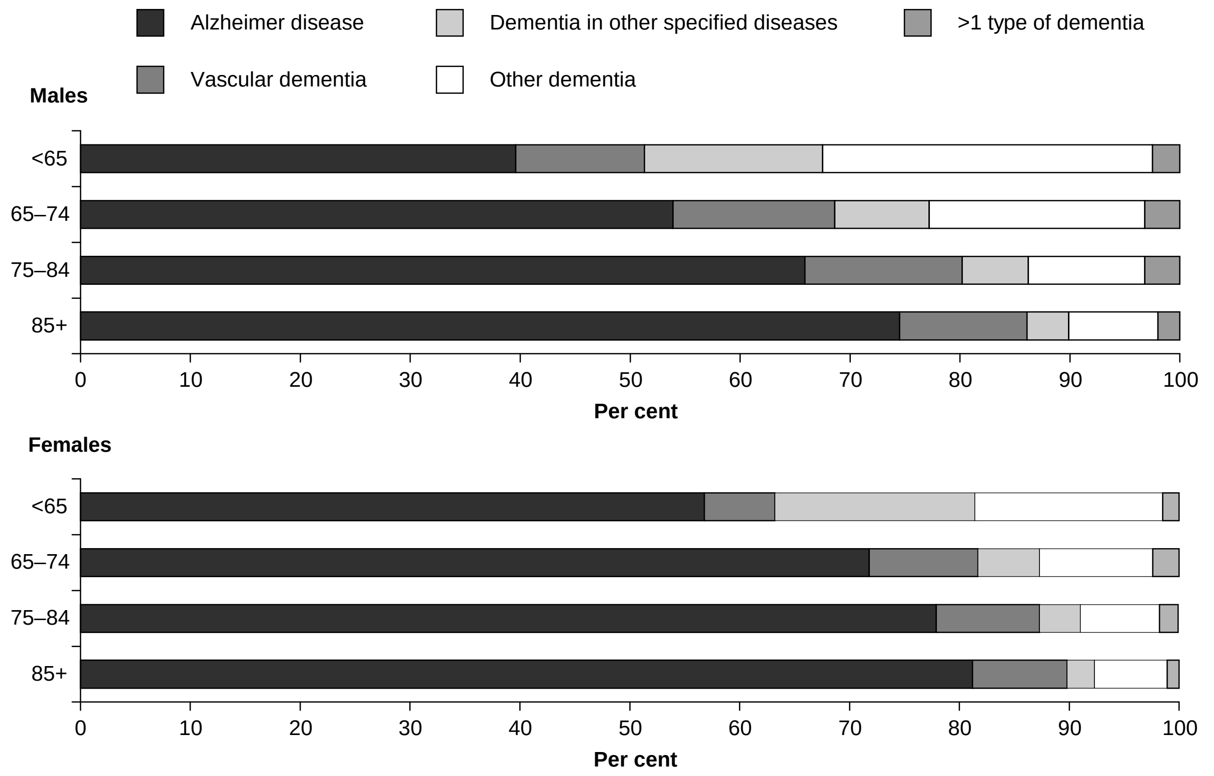
Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

The type of dementia varied by sex. Although *Alzheimer disease* was the most common type for both sexes, it was recorded for 79% of women in residential aged care facilities compared with 67% of men. A larger proportion of men than women had been diagnosed with *Vascular dementia* (13% and 9% respectively) and *Other dementia* (11% and 7%).

The types of dementia diagnosed for men and women in residential aged care facilities varied substantially by age. For example, 40% of men with dementia aged under 65 had been diagnosed with *Alzheimer disease*; this proportion increased with age, reaching 75% for men aged 85 and over (Figure 3.3). Likewise for female residents, *Alzheimer disease* was less frequently diagnosed for women in the youngest age group (57%), compared with 81% of women with dementia aged 85 and over.

Differences by type of dementia were also observed according to Indigenous status (Table 3.12). *Alzheimer disease* was less commonly diagnosed among Indigenous residents with dementia (63%) than other Australians (76%), while *Other dementia* was more commonly diagnosed (20% compared with 8%). The category of *Other dementia* includes Lewy body dementia, alcoholic dementia and dementia due to traumatic brain injury. People from an Indigenous background are at increased risk of developing these forms of dementia because they have a higher risk of alcohol abuse and of head injury resulting in cognitive damage (Arkles et al. 2010).

Furthermore, clear differences by sex among Indigenous Australians with dementia are seen, with 51% of the Indigenous men diagnosed with *Alzheimer disease* compared with 71% of the women. In contrast, *Other dementia* was substantially more common in Indigenous men (29%) than women (14%).



Note: Data for this figure are shown in Appendix Table A3.6.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Figure 3.3: Type of dementia of permanent residents with dementia in aged care facilities, by sex and age, 2009–10

Table 3.12: Permanent residents with dementia in aged care facilities[(a)], by type of dementia, Indigenous status[(b)] and sex, 2009–10 (per cent)

	Indigenous			Non-Indigenous		
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**
Number						
Alzheimer disease	51.1	70.7	63.0	67.4	79.3	75.7
Vascular dementia	14.1	10.7	12.0	13.1	8.9	10.2
Dementia in other specified diseases	3.7	2.7	3.1	5.8	3.3	4.0
Other dementia	28.9	14.0	19.9	11.1	7.1	8.4
More than one type of dementia	2.2	1.9	2.0	2.6	1.4	1.7
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) Only those residents with a known Indigenous status are included. As shown in Table 3.8, there is a high level of missing data on the Indigenous status data item.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

3.4 Level of disability

Information from the SDAC can be used to describe the level of disability of those with dementia. The survey collects information about the need for assistance in a number of areas, including self-care, mobility and communication. These three areas are referred to as 'core activities of daily living'. As described in Box 3.2, four levels of core activity limitation can be determined based on whether a person needs help, has difficulty, or uses aids or equipment with any of the core activities (ABS 2010). The number with a 'severe or profound core activity limitation' (sometimes shortened to 'severe or profound limitation') is a commonly used measure to describe disability at the higher end of the severity spectrum (AIHW 2011b).

Box 3.2: Measuring the severity of disability using SDAC data

In the SDAC, a person is considered to have a **disability** if they have a limitation, restriction or impairment that has lasted, or is likely to last, for at least six months and restricts everyday activities. Note that most (78%) but not all people with a disability were considered to have a core activity limitation.

Four levels of **core activity limitation** are determined based on whether a person needs help, has difficulty, or uses aids or equipment with any of the core activities (self-care, mobility and communication). A person's overall level of core activity limitation is determined by their highest level of limitation in these activities.

The four levels of limitation are:

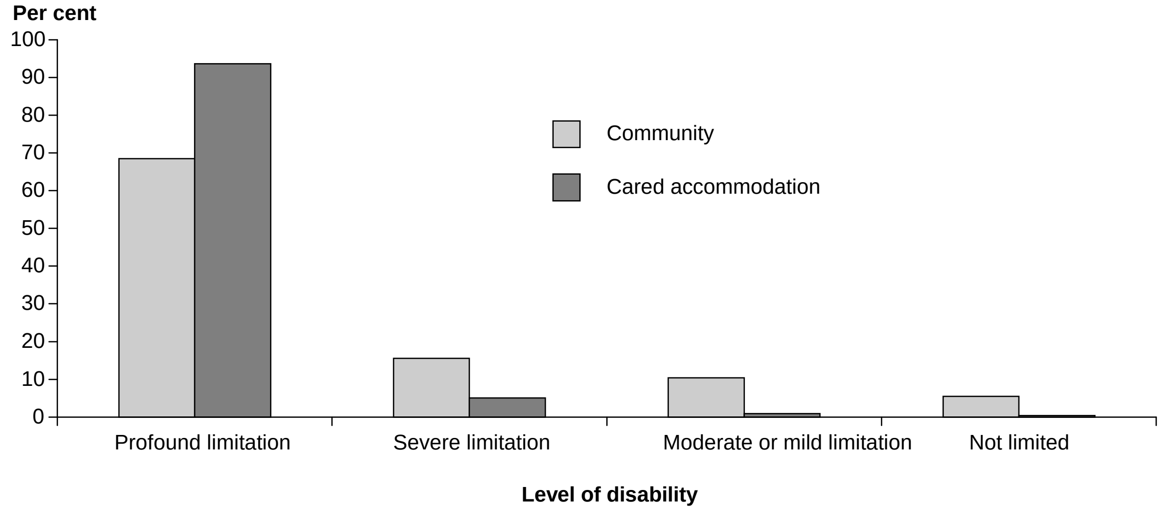
- profound—the person is unable to do, or always needs help with, a core activity task
- severe—the person sometimes needs help with a core activity task, has difficulty understanding or being understood by family or friends, or can communicate more easily using sign language or other non-spoken forms of communication
- moderate—the person needs no help but has difficulty with a core activity task
- mild—the person needs no help and has no difficulty with core activity tasks, but: uses aids and equipment, cannot easily walk 200m, cannot walk up and down stairs without a handrail, cannot easily bend to pick up an object from the floor, cannot use public transport, or can use public transport but has difficulty using it or needs help or supervision.

Source: ABS 2010.

According to the SDAC, 84% of people with dementia had a profound level of limitation in core activities, while an additional 9% had a severe level of limitation (Appendix Table A3.7). This re-iterates the view that those in earlier stages of dementia are under-represented in the SDAC.

As expected, clear differences were observed according to whether the person lived in the community or in cared accommodation, with 94% of people with dementia in cared accommodation having a profound limitation and a further 5% having a severe limitation (Figure 3.4). Thus overall, 99% of those with dementia in cared accommodation had a severe or profound limitation. Meanwhile, 84% of those with dementia in the community had a severe or profound limitation, with 69% having a profound limitation and 16% a severe limitation.

Among those with dementia in cared accommodation and the community, the proportion of men and women at the various levels of disability was fairly similar (Appendix Table A3.7).



Notes: Level of disability is measured by the extent of limitation in core activities of daily living (see Box 3.2). Data for this figure are shown in Appendix Table A3.7.

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

Figure 3.4: Level of disability of people with dementia, by residency, 2009

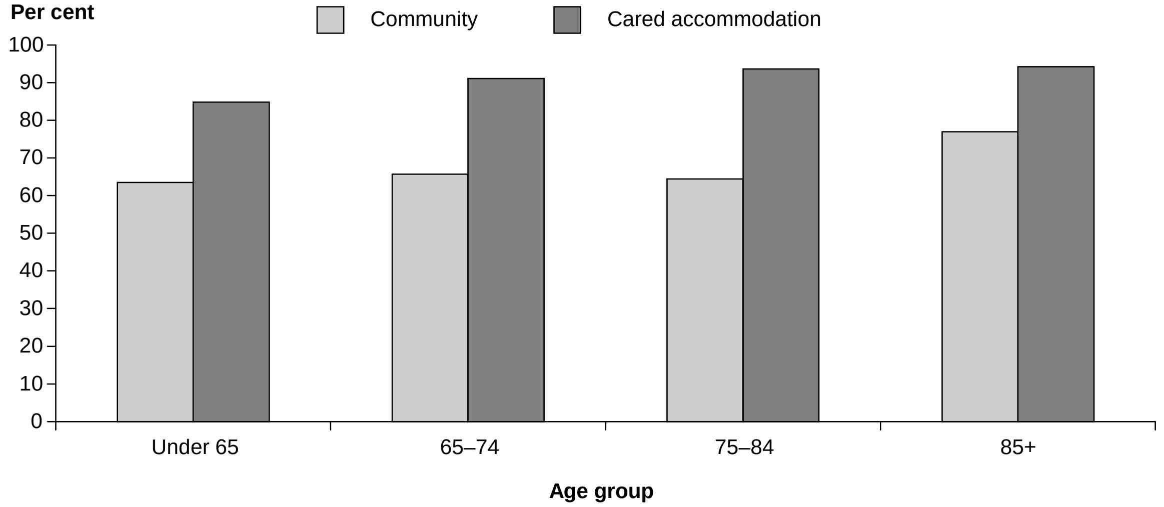
The level of disability varied with age. Around 71% of those with dementia under the age of 65 were profoundly limited in core activities. This rose to 75% of those aged 65–74, 81% of those aged 75–84, and 90% of those aged 85 and over (Appendix Table A3.8). The pattern was quite different for people with dementia living in the community compared with those in cared accommodation (Figure 3.5). The likelihood of people with dementia in the community being profoundly limited in core activities remained fairly steady (around 65%) in the three youngest age groups, but then jumped to 77% for those aged 85 and over. In contrast, among people with dementia in cared accommodation, around 85% of those aged under 65 had a profound limitation; this rose to 91% of those aged 65–74 and 94% in both the oldest age groups.

3.5 Co-existing conditions

Co-existing health conditions generally affect the quality of life of those with dementia, as well as increasing or complicating their care needs. Information is available from both the SDAC and the ACFI data on other health conditions experienced by those with dementia.

In the SDAC, data were collected on long-term health conditions, with such a condition defined as:

- a disease or disorder which has lasted, or was likely to last, for 6 months or more, or
- a disease, disorder or event (such as a stroke, accident, etc.) which produces an impairment or restriction which has lasted or is likely to last for at least 6 months (ABS 2011a).



Notes: A profound limitation in core activities of daily living includes those who were unable to do, or always needed help with, a core activity task (see Box 3.2). Data for this figure are shown in Appendix Table A3.8.

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

Figure 3.5: People with dementia with profound limitation, by age and residency, 2009

For persons for whom more than one long-term health condition was reported, the SDAC identified which of these was the main condition (the one that gave the person the 'most problems'). As shown in Table 3.13, for 63% of those who had dementia, this was the main health condition. This proportion varied by residency, with dementia reported as the main condition for 53% of those with dementia who lived in the community, compared with 69% of those in cared accommodation.

Table 3.13: People with dementia, by whether dementia was main condition and residency, 2009 (per cent)

	Community	Cared accommodation	Total
Main condition[(a)]	53.2	69.3	63.3
Not main condition	46.8	30.7	36.7
Total	**100.0**	**100.0**	**100.0**

(a) The main condition was a long-term condition identified as the one 'causing the most problems'.

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

For people with dementia, an average (mean) of 5.4 long-term health conditions were reported (Table 3.14). The average number of such health conditions for those with dementia living in the community was smaller (4.9 conditions) than for those in cared accommodation (5.6 conditions).

While the average number of health conditions of people with dementia did not vary greatly by sex, the average number increased with age. Those aged under 65 living in the community had an average of 3.7 conditions, while those aged 85 and over had an average of 5.8. The number of conditions for those with dementia living in cared accommodation was 4.2 for those under 65 and 5.8 for those 85 and over.

Table 3.14: Average number of health conditions for those with dementia and all people, by sex, age and residency, 2009

	Community	Cared accommodation	Total
	People with dementia[(a)]		
Sex			
Males	5.0	5.6	5.3
Females	4.9	5.6	5.4
Age			
Under 65	3.7	4.2	3.9
65–74	4.6	5.0	4.7
75–84	4.7	5.4	5.1
85+	5.8	5.8	5.8
Total	**4.9**	**5.6**	**5.4**
Total: 65+	**5.0**	**5.6**	**5.4**
	All people		
65+ with severe or profound core activity limitation	4.7	5.5	4.9
Total: 65+	**2.8**	**5.4**	**2.9**

(a) The average (mean) number of health conditions includes dementia.

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

Looking just at those aged 65 and over, the SDAC suggests a substantial difference in the average number of health conditions between those with dementia (5.4) and all Australians (2.9). While, the difference is small among those living in cared accommodation (average of 5.6 conditions for those with dementia and 5.4 for all people), the same cannot be said about those living in the community. People with dementia aged 65 and over living in the community had an average of 5.0 health conditions, compared with an average of 2.8 conditions for all people aged 65 and over in the community. This difference narrows substantially when comparing against people aged 65 and over living in the community with severe or profound core activity limitation, who had an average of 4.7 conditions.

The 20 most common co-existing health conditions for those with dementia according to the SDAC data are shown in Table 3.15. The most common were *Arthritis and related disorders* (40%), *Hypertension (high blood pressure)* (37%) and *Deafness or hearing loss* (37%). More than 1 in 5 had *Depression or other mood affective disorders* (22%) and 21% had had a *Stroke*.

Regardless of whether the person lived in the community or in cared accommodation, the top three co-existing conditions remained the same, although the proportions varied somewhat:

- *Arthritis and related disorders* (43% of those living in the community and 37% of those in cared accommodation)
- *Hypertension* (42% and 34%)
- *Deafness or hearing loss* (25% and 44%).

Table 3.15: Twenty most common co-existing long-term health conditions for people with dementia, 2009 (per cent)

Long-term health condition[(a)]	Per cent[(b)]
Arthritis and related disorders	39.6
Hypertension (high blood pressure)	37.1
Deafness/Hearing loss	36.8
Depression/mood affective disorders (excluding postnatal depression)	21.9
Stroke	20.9
Diabetes	15.5
Other heart diseases	14.3
Other diseases of the nervous system	13.2
Osteoporosis	12.9
High cholesterol	11.6
Back problems (dorsopathies)	10.9
Other mental and behavioural disorders	8.9
Phobic and anxiety disorders	8.5
Restriction in physical activity or physical work	8.1
Other long term condition	7.9
Heart disease	7.9
Head injury/acquired brain damage	7.3
Asthma	6.4
Other diseases of the eye and adnexa	6.4
Disorders of the thyroid gland	6.3
Total with dementia[(b)]	**100.0**

(a) The code list used by the ABS to classify health conditions was based on the ICD-10 (see Appendix E for information about ICD-10).

(b) Any one individual could have multiple co-existing conditions; thus, the sum of the proportions exceeds 100%.

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

Nonetheless, there were some notable differences by residency (Appendix Table A3.9). *High cholesterol*, for example, was reported for 22% of those with dementia living in the community, yet was not one of the top 20 conditions for those living in cared accommodation. *Back problems (dorsopathies)* were a co-existing health condition for 18% of those in the community but not in the top 20 for those in cared accommodation.

In the data collected through the ACFI, up to three mental and behavioural disorders (including dementia or delirium) can be reported, as can up to three other medical conditions, with the instructions indicating that only those conditions that impact on care needs should be recorded. As a consequence, as well as the limit on the number of health conditions that may be reported, it is possible that not all of a resident's co-existing conditions are identified using the ACFI. Note, for example, that while 76% of residents with dementia had the highest rating of need with continence and 68% did with toileting (see Section 3.6), *Stress/urinary incontinence, Unspecified urinary incontinence* and *Bowel/faecal incontinence* were recorded as co-existing conditions for only 9%, 7% and 5% of residents with dementia respectively (Table 3.16).

Table 3.16: Most common co-existing conditions among permanent residents in aged care facilities[(a)], by dementia status, 2009–10 (per cent)

Organ system/condition[(b)]	With dementia	Without dementia
Diseases of the circulatory system	**56.0**	**58.9**
Hypertension (high blood pressure)	23.7	21.0
Stroke (CVA)-cerebrovascular accident unspecified	12.0	14.9
Acute & chronic ischaemic heart disease	7.5	7.8
Heart disease	6.7	7.1
Congestive heart failure (congestive heart disease)	6.0	8.1
Diseases of the musculoskeletal system & connective tissue	**44.5**	**44.3**
Other arthritis & related disorders	29.5	29.2
Osteoporosis	13.5	12.1
Mental & behavioural disorders other than dementia or delirium	**40.4**	**50.4**
Depression, mood & affective disorders, bi-polar	33.1	37.8
Neurotic, stress-related & somatoform disorders	7.3	12.5
Symptoms & signs or condition not otherwise specified or not elsewhere classified	**34.4**	**33.2**
Falls (frequent with unknown aetiology)	7.7	6.0
Unspecified urinary incontinence	7.1	3.7
Bowel/faecal incontinence	5.4	2.2
Abnormalities of gait & mobility (includes ataxic & spastic gait, difficulty in walking, not elsewhere classified)	5.3	6.4
Endocrine, nutritional & metabolic disorders	**19.9**	**20.4**
Diabetes mellitus-Type 2 (NIDDM)	11.5	12.2
Diseases of the genitourinary system	**17.9**	**13.2**
Stress/urinary incontinence	9.0	5.3
Diseases of the eye & adnexa (e.g. glaucoma, poor vision, blindness)	**13.4**	**14.6**
Diseases of the nervous system	**12.4**	**14.5**
Parkinson's disease	5.2	4.8
Diseases of the digestive system	**9.3**	**8.6**
Diseases of the intestine	5.9	5.3
Diseases of the respiratory system	**9.2**	**13.9**
Chronic lower respiratory diseases	8.0	12.4
Total residents[(b)]	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities. Most common co-existing conditions for those with dementia are shown.

(b) Any one resident could have multiple co-existing conditions; thus, the sum of the proportions exceeds 100%. Residents with more than one diagnosis within an organ system or for a condition were counted only once for that organ system or condition.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

According to the ACFI data, *diseases of the circulatory system* was the most prevalent group of co-existing conditions among permanent residents with dementia in subsidised aged care facilities (56%) (Table 3.16). Among such diseases, *Hypertension (high blood pressure)* was the most common co-existing condition reported (24%). *Diseases of the musculoskeletal system and* *connective tissue* (45%) were also common among those with dementia, most notably *Other arthritis and related disorders* (30%). In addition, *Depression, mood and affective disorders and bi-polar* was reported as a co-existing condition for 33% of those with dementia.

The information shown in Table 3.16 also allows for co-existing conditions of those with dementia to be compared with the conditions of other permanent residents. There is a marked degree of similarity in the relative proportions of conditions, with the one notable difference being that half (50%) of the other residents had *Mental and behavioural disorders other than dementia or delirium* listed as a condition, compared with 40% of those with dementia.

Although cancer was not one of the most common co-existing conditions, it is interesting to observe in the ACFI data that 7% of residents with dementia had cancer recorded as a co-existing condition, compared with 10% of those without dementia. This difference may be related to the observation from a number of studies that people with dementia appear to have a lower risk of cancer (Attner et al. 2010; Driver et al. 2012). Some have suggested that the main reason for this may be that cancer is underdiagnosed among those with dementia (Andersen et al. 2010; Attner et al. 2010; Ganguli et al. 2005).

3.6 What assistance is needed?

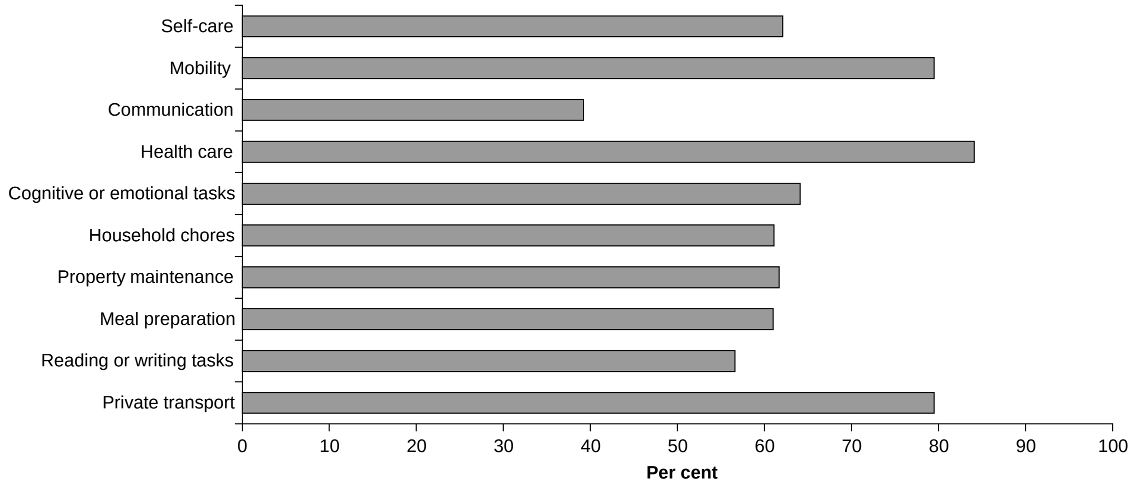
In this section, information is first provided on the types of activities for which assistance was required by those with dementia based on SDAC data. Second, data from the ACFI are used to describe the care needs of people with dementia in residential aged care facilities.

Assistance needs of those living in the community (SDAC)

The SDAC collected information about whether respondents living in the community needed help with various activities, with a distinction made between 'core' and 'non-core' activities of daily living. Core activities relate to self-care, communication and mobility, and non-core activities relate to health care, cognitive or emotional tasks, household chores, property maintenance, meal preparation, reading and writing tasks, and transport.

Of the three core activities, people with dementia living in the community were most likely to need assistance with mobility (80%), followed by self-care (62%) (Figure 3.6). They were least likely (39%) to need help with communication; indeed, of all the activities considered, people with dementia living in the community were least likely to need assistance in this area. There was little difference between men and women in the proportion needing assistance with the three core activities (Appendix Table A3.10).

Health care was the most common non-core activity that people needed help with (84%), followed by private transport (80%) and cognitive or emotional tasks (64%). Women were more likely than men to need assistance with cognitive or emotional tasks (69% compared with 59% respectively) and household chores (75% and 47%), while men were more likely than women to need assistance with property maintenance (67% and 57% respectively) (Appendix Table A3.10).



Note: Data for this figure are shown in Appendix Table A3.10.

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

Figure 3.6: Need for assistance for people with dementia living in the community, 2009 (per cent of those needing assistance in each activity)

Assistance needs of those in cared accommodation (SDAC)

The SDAC also collected information about the care needs of people living in cared accommodation. As shown in Table 3.17, in regard to the core activities, 98% of people with dementia in cared accommodation needed help with self-care, and 91% needed help with mobility. People with dementia living in cared accommodation were twice as likely (80%) as those in the community (39%) to need help with communication (Table A3.10).

Table 3.17: Need for assistance for people with dementia living in cared accommodation, by sex, 2009 (per cent of those needing assistance with each activity)

	Males	Females	Persons
Core activities			
Self-care[(a)]	96.5	98.2	97.7
Mobility[(a)]	89.0	91.4	90.7
Communication[(a)]	79.2	80.6	80.2
At least one core activity[(b)]	*98.0*	*99.0*	*98.7*
Non-core activities[(c)]			
Health care[(a)]	98.2	99.2	98.9
Cognitive or emotional tasks[(a)]	91.8	91.3	91.4
Reading or writing tasks	87.3	87.4	87.3
At least one core or non-core activity[(b)]	*99.5*	*99.7*	*99.6*
Total living in cared accommodation	**100.0**	**100.0**	**100.0**

(a) These questions were only asked of persons with disability. Those with dementia who did not have a disability recorded were assumed not to need assistance with the activity.

(b) Total may be less than the sum of the proportions because people may need assistance with more than one activity.

(c) Need for assistance data were only collected for a selection of non-core activities for people in cared accommodation.

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

The level of need for assistance for non-core activities was also very high with, for example, 99% requiring assistance with health care. Across both the core and non-core activities, the need for assistance was similar for men and women.

Assistance needs of those in residential aged care

Data on the care needs of permanent residents in subsidised residential aged care places are available through the ACFI. As the ACFI is a resource allocation tool, it only captures information about the care needs that most contribute to the cost of individual care. Each resident is appraised in each of three funding domains: 'Activities of daily living', 'Behaviour characteristics' and 'Complex health care needs'. The information from that appraisal is used to determine the classification for funding and the overall classification as a 'low care' or 'high care' resident (see Box 3.3 for further information).

In the information that follows, the needs for assistance among those in subsidised residential aged care are described according to:

- their overall need for care as determined by whether they were considered to be a low care or a high care resident
- their need for care in each of the three ACFI domains: Activities of daily living, Behaviour characteristics, and Complex health care needs.

Box 3.3: Care need information as collected in the Aged Care Funding Instrument

The ACFI includes 12 questions about care needs which fall across three funding domains:

- The 'Activities of daily living' (ADL) domain includes 5 questions about care needs which cover nutrition, mobility, personal hygiene, toileting and continence.
- The 'Behaviour characteristics' domain has 5 questions about cognitive skills, wandering, verbal behaviour, physical behaviour and depression.
- The 'Complex health care needs' domain includes 2 questions about assistance needed with the administration of medications, and the residents' need for the management of complex health care procedures.

Responses to each question are scored as 'A', 'B', 'C', or 'D' (with 'A' indicating the lowest level of need and 'D' the highest level). Details on the various aspects of the need for care considered for each question are provided in the *Aged Care Funding Instrument user guide* (DoHA 2009a).

Information from the 12 questions is used to categorise a resident's needs as 'nil', 'low', 'medium', or 'high' within each of the three domains. These categories are used to:

- determine the level of care funding, with funding provided for each domain based on whether the needs of the person were assessed as 'low', 'medium' or 'high' in each of the three domains (no funding is provided for a particular domain where the person was appraised as not having any need in that area)
- classify a resident as 'low care' or 'high care'; the rules used to define whether a resident required high versus low care are described in Note 3.1 in Appendix D.

A low level of care focuses on: personal care services, accommodation, support services (for example, laundry and meals), and some allied health services such as physiotherapy. In contrast, a high level of care provides 24-hour care, either by registered nurses or under the supervision of registered nurses, for those who need almost complete assistance with most activities of daily living. Nursing care is combined with accommodation, support services, personal care services, and allied health services.

Sources: DoHA 2009b, 2011b.

Overall level of care required

Almost 9 in 10 (87%) residents with dementia in subsidised aged care facilities were classified as needing a high level of care, with no difference by sex in this proportion (Table 3.18). Residents without dementia were substantially less likely to need a high level of care (63%) and this proportion differed by sex (66% of men classified as high care compared with 62% of women).

Table 3.18: Assessed overall need for care of permanent residents with dementia in aged care facilities[(a)], by dementia status and sex, 2009–10 (per cent)

Overall need for care[(b)]	With dementia			Without dementia		
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**
High care	87.2	86.5	86.7	66.1	61.8	63.2
Low care	12.8	13.5	13.3	33.9	38.2	36.8
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) See Box 3.3 for a description of the approach used to classify a resident as high versus low care.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

The proportion of permanent residents with dementia who were classified as high care was fairly consistent over the age groups considered (between 86% and 88%) (Appendix Table A3.11). However, some differences were evident by state and territory (Appendix Table A3.12). South Australia had the highest proportion who were high care (90%), while the lowest proportions were in the Northern Territory (81%) and Tasmania (83%). For each of the other state and territories, the proportion was close to average (around 87%).

Differences by level of remoteness were also evident in the ACFI data for 2009–10. The general pattern suggests a decline in the proportion of high care residents with increasing remoteness, from 88% in *Major cities* to 73% in *Remote* areas (Table 3.19). However, the proportion increases to 81% among those in *Very remote* aged care facilities. It is not clear whether these data reflect a 'real' difference in the proportion who were high care residents in *Remote* and *Very remote* areas, or if the difference is more a consequence of the relatively small number of residents with dementia in *Very remote* facilities, meaning these data may be quite variable over time.

Table 3.19: Assessed overall need for care of permanent residents with dementia in aged care facilities[(a)], by remoteness[(b)], 2009–10 (per cent)

Overall need for care[(c)]	Major cities	Inner regional	Outer regional	Remote	Very remote	Australia
High care	87.7	85.2	82.5	73.2	81.0	86.7
Low care	12.3	14.8	17.5	26.8	19.0	13.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

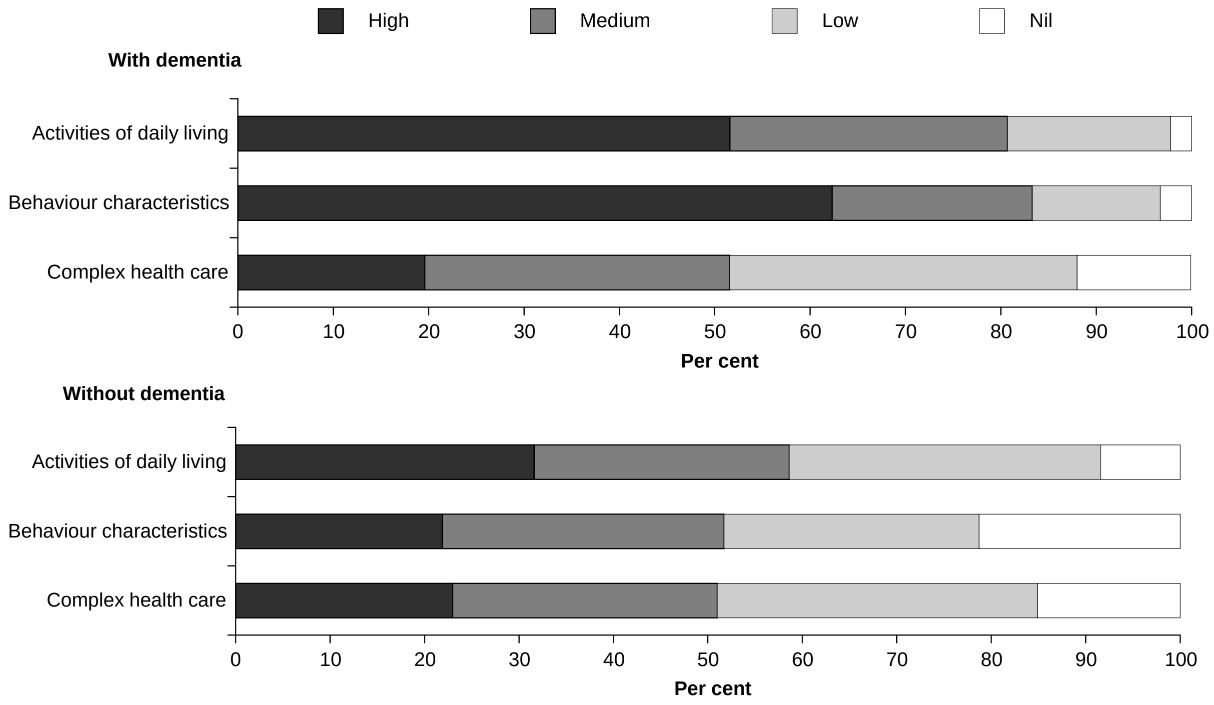
(b) Remoteness is based on the location of the most-recent facility the resident was in before the end of the 2009–10 financial year. Remoteness was measured using the Australian Standard Geographical Remoteness Area classification (see Appendix E).

(c) See Box 3.3 for a description of the approach used to classify a resident as high versus low care.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Care needs by ACFI domain

As described in Box 3.3, based on responses to 12 questions in the ACFI, the needs of permanent residents are categorised as 'nil', 'low', 'medium', or 'high' within each of three domains: Activities of daily living, Behaviour characteristics and Complex health care needs. As detailed in this section, residents with dementia were more likely than those without dementia to have been rated with higher care needs in the ADL and the Behaviour characteristics domains, but not in the Complex health care domain (Figure 3.7).



Note: Data for this figure are shown in Appendix Table A3.13.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

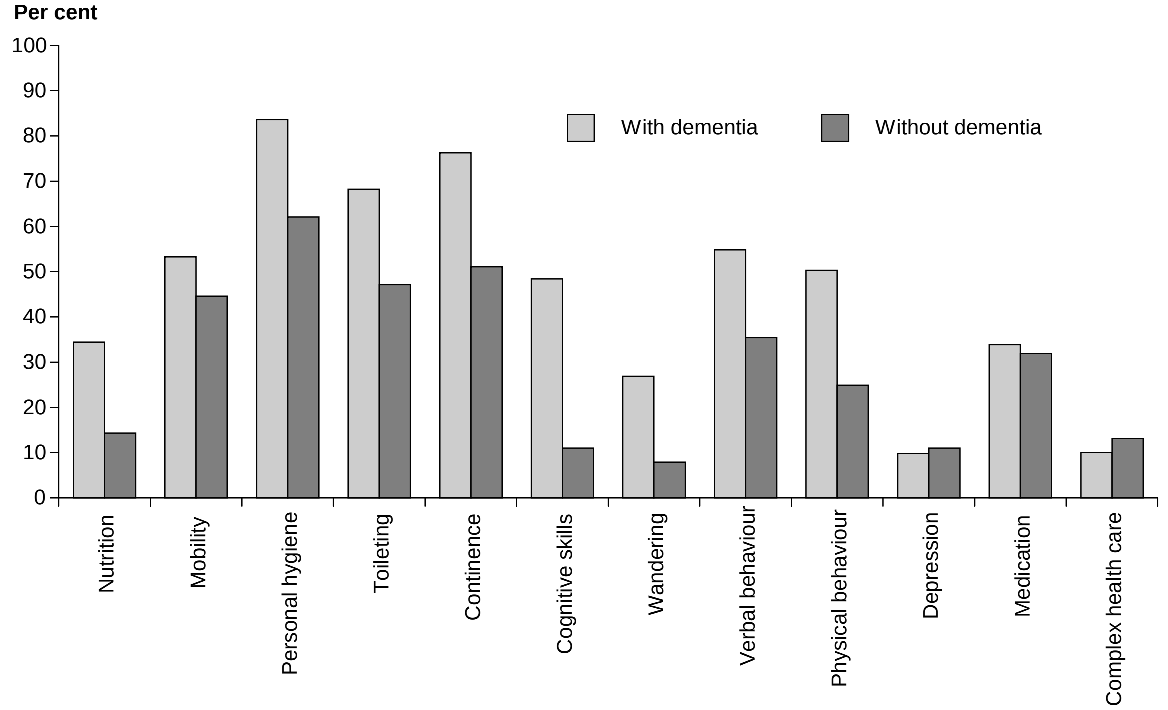
Figure 3.7: Assessed need for care in each ACFI domain for permanent residents in aged care facilities, by dementia status, 2009–10

Activities of daily living

Just over half (52%) of permanent residents with dementia had a 'high' rating in the 'ADL domain' compared with about a third (32%) of those without dementia (Figure 3.8). At the other end of the scale, 19% of those with dementia had a rating of 'low' or 'nil'; this compares with 41% of those without dementia.

Of the five areas considered when determining the rating for the ADL domain, residents with dementia were found to be most dependent in tasks associated with personal hygiene (that is, dressing and undressing, washing and drying, and grooming) with almost 84% given the highest rating of need (that is, a rating of 'D') in this area (Figure 3.8). By comparison, 62% of residents without dementia were given such a rating.

Continence was the next most common area of need for assistance among those with dementia (76% had the highest rating), followed by toileting (68%). The proportions of residents without dementia who were given a rating of 'D' in these two areas were relatively low (51% and 47% respectively). For the area of nutrition (which considered both readiness to eat and requirement for supervision while eating), more than twice as many residents with dementia (34%) than without dementia (14%) had the highest rating of need in this area.



Note: Data for this figure are shown in Table A3.14.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Figure 3.8: Permanent residents in aged care residents with highest care need rating based on 12 ACFI care-related questions, by dementia status, 2009–10

Behaviour characteristics

About 62% of residents with dementia in subsidised aged care facilities had the highest possible rating in the 'Behaviour characteristics' domain. This is almost three times higher than the proportion of other residents given this rating (22%) (Figure 3.7). Meanwhile, relatively few (3%) of those with dementia had a rating of 'nil' for this domain, while 21% of those without dementia did so.

As explained in Box 3.3, five areas relating to behaviour (namely, cognitive skills, wandering, verbal behaviour, physical behaviour and depression) are assessed as part of the ACFI. More than half (55%) of residents with dementia had a rating of 'D' in the verbal behaviour area, which means they exhibited problematic verbal behaviour twice a day or more, at least 6 days a week (Figure 3.8). Problematic verbal behaviours are considered to be: verbal refusal of care, being verbally disruptive, having paranoid ideation that disturbs others, and inappropriate verbal sexual advances (DoHA 2009a). An additional 14% of residents with dementia exhibited such behaviours once a day at least 6 days a week (a rating of 'C') (Appendix Table A3.14). By comparison, 35% of those without dementia had the highest possible rating of 'D', while 16% had a rating of 'C'.

Half (50%) of all residents with dementia exhibited problematic physical behaviours (that is, physically threatening or harmful behaviour, socially inappropriate physical behaviour and constant physical agitation (DoHA 2009a)) twice a day or more, at least 6 days a week. This is twice the proportion of those without dementia exhibiting such behaviours with the same level of frequency.

In terms of cognitive skills, residents with dementia were more than four times as likely (48%) as those without dementia (11%) to have been rated as having severe cognitive skills impairment.

In terms of wandering behaviour, the ACFI appraisal considers repeated attempts to enter areas where his/her presence is 'unwelcome' or 'inappropriate', and interfering with or disturbing other people or their belongings while wandering (DoHA 2009a). About one-quarter (27%) of residents with dementia displayed the most severe frequency of wandering behaviour (that is, wandering occurring twice a day or more, at least 6 days a week) compared with 8% of residents without dementia. Note that wandering behaviour will be affected by mobility and, as shown in Figure 3.8, just over half (53%) of residents with dementia and 45% of those without dementia were assessed as having the highest possible rating of need.

As part of the Behaviour characteristics domain, the ACFI is also used to assess symptoms associated with depression and chronic mood disturbance. Those symptoms which have occurred regularly and persistently, and were not related to day-to-day events in their environment, are considered (DoHA 2009a). The ratings pertaining to symptoms of depression were similar between residents with and without dementia (Appendix Table A3.14). For example, 10% of those with dementia and 11% of those without dementia had a rating of 'D' in this area (Figure 3.8), indicating that symptoms of depression caused major interference with the person's ability to function and participate in regular activities, and that they either had a diagnosis (or a provisional diagnosis) of depression or such a diagnosis was being sought.

Complex health care

While permanent residents with dementia were more likely than those without dementia to have been rated with higher care needs in the two domains discussed thus far, this was not the case for the 'Complex health care' domain (Figure 3.7). Instead, a 'high' rating was less common among residents with dementia (20%) than those without dementia (23%) for this domain.

One of the two areas considered in the Complex health care domain is the need for assistance in taking medication. The profile of need for assistance with medication was similar between those with and without dementia, with around 1 in 3 from each group requiring the highest level of assistance with medication: 34% of those with dementia and 32% of those without dementia (Figure 3.8).

The second area considered in this domain pertains to complex health care procedures. This area relates to the assessed need for ongoing complex health care procedures and activities, with the rating determined by the technical complexity and frequency of the procedures (DoHA 2009). Examples of health care procedures considered are:

- blood glucose measurement for the monitoring of a diagnosed condition at least daily
- catheter care programs
- management of chronic infectious conditions
- management of oxygen therapy or ongoing tube feeding

- palliative care program where ongoing care will involve very intensive clinical care and/or complex pain management.

The profile of care needs for complex health care procedures was fairly similar between residents with and without dementia (Appendix Table A3.14). About 1 in 10 of those with dementia (10%) and without dementia (13%) had a rating of 'D' (Figure 3.8), while about 1 in 3 residents in each group (32% and 31% respectively) required no complex health care procedures.

3.7 Source of assistance

In the SDAC, information was collected on whether the needs for assistance among those living in the community were met through formal means, informal means or a combination of the two. See Box 3.4 for definition of formal and informal assistance. Note that informal assistance encompasses both assistance provided by carers (see Chapter 5), as well as assistance provided by other family and friends on a more intermittent basis.

Box 3.4: Definition of key terms in the 2009 Survey of Disability, Ageing and Carers

Formal assistance is help provided to persons with one or more disabilities by:

- organisations or individuals representing organisations (whether profit making or non-profit making, government or private), or
- other persons who provide assistance on a regular, paid basis and who were not associated with any organisation (excluding family, friends or neighbours who provided informal assistance).

Informal assistance is unpaid help or supervision that is provided to persons with one or more disabilities or persons aged 60 and over living in households. It only includes assistance that is provided because of a person's disability or because they are older. Informal assistance may be provided by family, friends or neighbours. Any assistance received from family or friends living in the same household was considered to be informal assistance regardless of whether or not the provider was paid. It does not include providers whose care is privately organised.

Source: ABS 2010.

In 2009, 75% of people with dementia living in the community made use of a combination of formal and informal assistance to obtain help in all of the areas for which they needed assistance, while 22% relied solely on informal assistance (Table 3.20). Men (30%) were more likely than women (16%) to make exclusive use of informal assistance to meet their care needs.

Figure 3.9 indicates the source of care for each type of activity considered in the SDAC. Well over half of those with dementia living in the community who needed help in the core activities of self-care (59%) and mobility (68%) received assistance from only informal sources. A combination of informal and formal assistance was used by 22% of those who needed help with self-care and by 27% of those who needed help with mobility. For the core activity of communication, 86% relied on informal assistance only.

Table 3.20: Source of assistance for people with dementia living in the community for activities in which assistance was needed, by sex, 2009 (per cent)

	Males	Females	Persons
Informal assistance only	29.6	*15.6	22.4
Informal and formal assistance	70.4	80.2	75.4
Formal assistance only	—	**2.2	**1.1
No assistance(a)	—	**2.0	**1.0
Total(b)	**100.0**	**100.0**	**100.0**

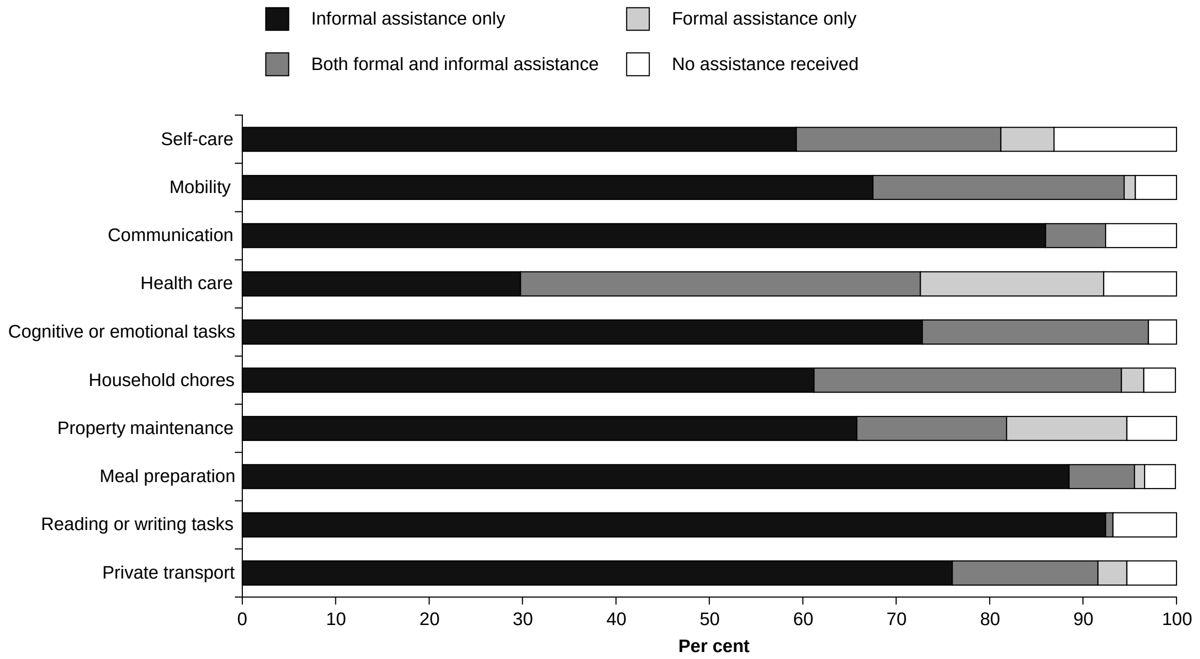
* Estimate has a relative standard error of 25% to 50% and should be used with caution.

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

(a) Includes only those who received no assistance for all activities in which assistance was needed.

(b) Includes only those who needed assistance with at least one core or non-core activity (regardless of whether they received assistance).

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



Note: Data for this figure are shown in Appendix Table A3.15.

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

Figure 3.9: Source of assistance for people with dementia living in the community, 2009 (per cent of those needing assistance in activity)

A similar pattern was found for all but one non-core activity, with the majority of those who required assistance with such activities receiving help from their informal networks only. Assistance with reading or writing tasks (92%) and meal preparation (89%) were the most likely kinds of non-core activities to be provided through informal sources for those with dementia living in the community. In addition, about three-quarters of those with dementia in the community who needed help with private transport (76%) or with cognitive and emotional tasks (73%) received such assistance from informal sources only. The one non-core activity that was an exception is health care (that is, dressing wounds, taking medication, having injections and using medical equipment). A relatively small proportion (30%) of those with dementia living in the community relied solely on informal assistance for this type of care, with an additional 43% using a combination of informal and formal assistance.

While the importance of informal care networks in meeting the needs of those with dementia who live in the community is shown clearly by the SDAC data, many people used formal assistance as well. Overall, 77% of those with dementia who lived in the community received some formal assistance in one or more areas in which they required help (Appendix Table 3.15). The activity for which they were most likely to receive some formal assistance (either in conjunction with informal help or on its own) was health care (62%), with 20% relying solely on formal assistance for this activity. Other areas in which formal assistance was commonly used, most often in conjunction with informal assistance, were household chores (35%), property maintenance (29%), mobility (28%) and self-care (28%).

For each of the activities considered in the SDAC, between 1 and 13% of those who needed assistance in a particular area did not receive any assistance in that area (Figure 3.9). Note, however, that due to relatively high uncertainty about these estimates, the proportions should be interpreted cautiously (see Appendix Table A3.15).

4 Use of health and aged care services

Key points

- An estimated 552,000 GP visits in 2010–11 involved the management of dementia.
- In 2009–10, there were 83,226 hospitalisations for which dementia was recorded as a diagnosis. This equates to 1 out of every 100 hospitalisations that year. For 15% of these hospitalisations (12,286), dementia was recorded as the principal diagnosis.
- In 2009–10, a total of 392,796 subsidised dementia-specific medications were dispensed, 74% more than in 2002–03.
- Among people whose care needs were assessed in 2008–09 through the Aged Care Assessment Program, 48,725 (or 27%) had dementia.
- According to the 2008 Community Care Census, almost 7,000 recipients of CACP, EACH and EACHD community aged care packages had dementia. This equates to 17% of all recipients of these packages.
- During 2009–10, almost 20,000 (or 60%) of all care recipients who received respite through the NRCP had dementia. Primary carers of people with dementia were more likely than those of people without dementia to access NRCP respite care due to emotional stress and strain (49% versus 38%).
- Just over half (53%) of permanent residents of subsidised aged care facilities, or about 112,000 people, were recorded as having dementia in 2009–10.
- In 2009–10, 90,308 community mental health service contacts were assigned a principal diagnosis of dementia. This equates to 1.4% of all community mental health service contacts.

4.1 Introduction

While many people with dementia living in the community are able to live independently without assistance or with the help of family and friends, others (especially those in the later stages of the condition) require formal services to allow them to remain living in the community. As discussed in Chapter 3, SDAC data show that 77% of people with dementia living in the community made use of formal services to meet their needs. People with dementia living in residential aged care facilities also need to use formal services for a variety of reasons, including the assessment, diagnosis and management of dementia.

The use of formal services by someone with dementia depends on many factors including the number and nature of the person’s health conditions, the activities in which assistance is required, the availability of social resources (such as informal carers), personal preferences and cultural influences, financial resources and accessibility of services.

This chapter describes the use of the following formal services (also referred to as organised services) by people with dementia and their carers:

- consumer support programs
- health care (including care provided by general practitioners and in hospital) and pharmaceutical services

- aged care assessment services
- respite care via the National Respite for Carers Program
- community aged care packages and other community aged care services
- flexible aged care services
- residential aged care services
- specialised mental health care services.

Lastly, this chapter looks at information on unmet demand for formal assistance.

In contrast to Chapter 3, the data presented in this chapter are service specific and so are not generalisable. Data from a range of sources are used, including two surveys—the SDAC and the Bettering the Evaluation and Care of Health survey of general practitioners—as well as from a variety of administrative data collections (for example, the National Hospital Morbidity Database and program-specific collections). Dementia-specific services funded and operated solely by state and territory governments are not covered in this chapter. See Appendix B for more information on data sources.

Despite the range of data sources used in this chapter, the available data do not provide a comprehensive picture of the use of all types of health and aged care services by people with dementia and their carers. This is partly because, for some programs, the dementia status of clients cannot be identified.

Another issue is that individual people with dementia, like all older and/or disabled people receiving assistance, may access multiple services. The service populations described in this chapter are not mutually exclusive. For example, an assessment through the Aged Care Assessment Program is required to access Australian Government-funded community aged care packages and residential aged care services administered under the *Aged Care Act 1997* (DoHA 2011b). Thus, it is often not possible to provide a complete view of combinations of service use or transitions related to the progression of dementia over time.

Dementia typically occurs alongside other age-related conditions which also give rise to a need for assistance (see Section 3.5). Thus, there is the added complexity that the use of formal services for a person with dementia can occur in three main contexts:

- a service is received because the person has dementia (for example, a person receives an aged care assessment because of the impact of dementia on daily living)
- a service is received for some other reason but the service episode is affected by the presence of dementia (for example, a patient undergoes surgery in hospital for another condition but rehabilitation is slower or recovery is otherwise complicated by the presence of dementia)
- a service is received that is incidental and mostly unrelated to and unaffected by the presence of dementia (for example, a person with dementia sees a general practitioner because of an unrelated health condition).

In the existing data sets, it is not always possible to determine which of these three contexts was applicable when a person with dementia was recorded as having used a formal service although, where possible, whether or not the person received the service because of their dementia is described.

4.2 Consumer support programs

The National Dementia Support Program (NDSP) and the Dementia Behaviour Management Advisory Service (DBMAS) are directly targeted at providing support to people with dementia, their carers and those working with people with dementia.

The National Dementia Support Program

The Australian Government funds Alzheimer's Australia and its state and territory member organisations to deliver the NDSP, which aims to improve the quality of life of people with dementia and their carers and, where appropriate, support those with dementia to remain in their homes (Alzheimer's Australia 2011a). Alzheimer's Australia provides a range of free support services to people living with dementia, their families, carers and health professionals through the NDSP. Information on the number of *contacts* there were for each service type, not the number of *people* who used each service, is recorded (see Box 4.1).

Box 4.1: Definition of a 'contact' in National Dementia Support Program data

A **contact** is a record of an interaction between a staff member and client regarding information about dementia or caring-related issues requiring expert support from program staff. An initial contact is often made to the National Dementia Helpline and Referral Service. Incidents of service subsequently taken up, such as counselling, participation in education and information sessions or activities, are counted separately. All people attending group sessions, such as information or counselling sessions, are also counted separately. Limited interactions (for example, telephone messages and very brief discussions of 2 to 3 minutes) are not counted.

Source: Alzheimer's Australia, personal communication, 21 July 2011.

In 2010–11, there were 118,759 contacts with the NDSP (Table 4.1). About a quarter of these were with the National Dementia Helpline and Referral Service. The Helpline provides a first point of contact for, and easy access to, dementia information, education and awareness raising, resources, counselling and support services, and referral to health and community services for people with dementia, their carers and families.

Table 4.1: National Dementia Support Program contacts, by service type, 2010–11

Service type	Number	Per cent
National Dementia Helpline and Referral Service	28,296	23.8
Information, awareness, education and training	52,638	44.3
Support and counselling	37,825	31.9
Total services	**118,759**	**100.0**

Source: Alzheimer's Australia 2011a.

Around 44% of NDSP service contacts were for 'Information, awareness, education and training' purposes, which include community education, workshops and outreach activities. Another 32% of contacts were for 'Support and counselling' which involves the provision of programs, services and resources to support people living with memory loss, their families and carers. In addition to contacts, there were also 191,747 visits to the national Alzheimer's Australia website between January and June 2011. Information on NDSP services, including the Helpline, is available on that website.

In July 2010, Alzheimer's Australia introduced a new client information system called The Client Manager (Alzheimer's Australia 2011a). Although still in the early stages of implementation, it will become the primary database for the management of service delivery by Alzheimer's Australia and, in turn, is expected to provide a new source of data about NDSP contacts and clients.

Dementia Behaviour Management Advisory Service

The DBMAS program, which was implemented in 2007, is funded by the Australian Government as one of a number of measures to support people with dementia and their carers (DoHA 2011b, 2012e). These services have been established in each state and territory to provide appropriate clinical interventions to help aged care staff and carers improve their care of people with dementia where the behaviour of the person with dementia impacts upon their care. The DBMAS consists of multi-disciplinary teams that may include, but are not limited to, psychologists, registered nurses and allied health professionals. Their core functions include:

- provision of information and advice
- undertaking assessments and short-term case management including mentoring and modelling management techniques
- delivery of tailored information and education workshops.

Each DBMAS is also allocated brokerage funds, which can be used at their discretion, to provide short-term interventions and direct services not otherwise available through residential aged care or hostel services or as part of other community care arrangements. Such funds have been used to, for example:

- produce teaching material, such as posters and leaflets about delirium
- provide allied health, psycho-geriatric, geriatric and clinical psychologist services
- provide sensory equipment such as alarms and ID bracelets.

Information on the total number of people assisted through DBMAS is not available. However, Department of Health and Ageing data on the number of telephone calls received through the DBMAS 24-hour-a-day telephone support line indicate that there were 9,924 telephone calls across Australia during 2010–11.

4.3 General practice services

General practitioners (GPs) play a key role in the initial identification and management of dementia (and other health conditions) and in supporting those with dementia, their family and carers. One survey found that 84% of carers of people with dementia in New South Wales reported that a GP was the first health professional who patients saw about their symptoms (Speechly et al. 2008). Services that GPs may provide are:

- initial identification and assessment of cognitive impairment
- relevant information about dementia
- initial and ongoing management and related advice
- referrals to specialists for further diagnosis and specialised care, if necessary
- advice and information about available support services

- support for family and carers
- management of other medical needs.

Guidelines for the care of people with dementia were published by the Royal Australian College of General Practitioners in 2003 and are currently being reviewed and updated (DCRC–ABC 2012). The advisory committee undertaking the review has developed a short guide for general practitioners covering topics such as the presentation, assessment, management and referral of people with dementia (DCRC–ABC & RACGP 2011).

A number of gaps between current GP practice in identifying, assessing and managing dementia and best practice, as described in official guidelines, were identified through a review of international literature published between 1995 and 2008 (Pond et al. 2011). The review gave a number of reasons for these gaps, including limited time, poor remuneration, limited access to information from carers, and screening tool limitations at the individual level. The perceptions and attitudes of GPs were also found to be important, with some GPs reluctant to diagnose dementia due to the social stigma and the poor prognosis it carries.

In this section of the report, information is presented on services provided by GPs to those with dementia from 2006–07 to 2010–11 using data from the Bettering the Evaluation and Care of Health (BEACH) program. The BEACH program includes a continuous national survey of general practice activity, as well as sub-studies which investigate various aspects of patient health or health care delivery not captured by the consultation-based information in the regular data collection. A sub-study of dementia screening was undertaken in 2010 and information from that sub-study is also presented in this section. Appendix B provides further details about the BEACH program, including how dementia-related encounters were identified, while Box 4.2 presents definitions of key terms.

Box 4.2: Definition of key terms in the Bettering the Evaluation and Care of Health program

General practitioners are medical practitioners who provide comprehensive and continuing care to patients and their families within the community.

Encounter refers to any professional interchange between a patient and a GP. It includes face-to-face encounters and indirect encounters where there is no face-to-face meeting but where a service is provided (for example, a prescription or referral).

Problem managed is a statement of the provider's understanding of a health problem presented by a patient, family or community. GPs are instructed to record at the most specific level possible from the information available at the time; this level may be limited to the level of symptoms. Up to four problems managed can be recorded per encounter.

Source: Britt et al. 2011.

Number of encounters and patient characteristics

In 2010–11, dementia was managed during 444 encounters reported to the BEACH survey (Table 4.2). This equates to a rate of 5 encounters for the management of dementia for every 1,000 GP encounters (or 0.5%). Applying this rate to all Medicare-claimed GP consultations in 2010–11 (as sourced from DoHA (2012f)) suggests that about 552,000 GP visits during this period involved the management of dementia.

Between 2006–07 and 2010–11, the rate of GP encounters in which dementia was managed did not differ significantly.

Table 4.2: GP-patient encounters where dementia was managed, 2006–07 to 2010–11

	2006–07	2007–08	2008–09	2009–10	2010–11
Number of dementia encounters	428	422	554	476	444
Total encounters	91,805	95,898	96,688	101,349	95,839
Number per 1,000 encounters[(a)]	4.7	4.4	5.7	4.7	4.6
95% confidence interval	3.9–5.4	3.2–5.5	4.5–7.0	3.8–5.6	3.7–5.6

(a) The rate indicates the number of encounters in which dementia was managed per 1,000 GP encounters; the 95% confidence interval is also shown.

Source: AIHW analysis of Bettering the Evaluation and Care of Health survey data.

In 2010–11, women accounted for 68% of encounters where dementia was managed, while 86% of such encounters were for those aged 75 and over, and 4% were for those under 65 (Table 4.3). These sex and age distributions were generally consistent over the 5-year period considered.

Table 4.3: GP-patient encounters where dementia was managed: characteristics of patients, 2006–07 to 2010–11 (per cent)

	2006–07	2007–08	2008–09	2009–10	2010–11
Sex					
Males	33.7	33.8	29.7	27.3	30.6
Females	65.1	65.3	69.7	71.2	68.4
Not stated	1.2	1.0	0.6	1.5	1.0
Age					
Under 65	4.4	3.8	4.4	2.1	3.9
65–74	12.2	11.6	9.4	10.3	10.4
75–84	41.6	37.0	40.3	44.3	41.6
85–94	36.5	41.0	39.7	37.5	38.8
95+	5.3	6.5	6.2	5.7	5.3
Type of dementia					
Dementia (not further described)	69.7	70.2	81.2	76.6	73.7
Alzheimer disease	27.6	25.3	18.0	19.1	25.6
Other[(a)]	2.7	4.5	0.8	4.3	0.7
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Total number of dementia encounters	**428**	**422**	**554**	**476**	**444**

(a) Includes senile dementia; alcoholic dementia; AIDS dementia complex, presenile, arteriosclerotic and senile psychoses; frontal lobe syndrome; and more than one type of dementia (see Appendix B for further details).

Source: AIHW analysis of Bettering the Evaluation and Care of Health survey data.

In around three-quarters of all encounters, the type of dementia was not recorded. In turn, the data suggest an unexpectedly low proportion of dementia encounters for which Alzheimer disease was recorded as the type of dementia (19% in 2009–10 and 26% in 2010–11, for example). This compares with 76% of permanent residents with dementia in residential aged care facilities recorded as having Alzheimer disease in 2009–10 (Section 3.3). Thus, the BEACH data on type of dementia must be used with caution.

Management actions

The BEACH survey form allows GPs to record several aspects of patient management for each problem, with strategies that GPs may use to manage a problem grouped as follows:

- medication: prescribing, providing or recommending medication
- imaging: ordering imaging tests
- pathology: ordering pathology tests
- referrals: referring the patient to a medical specialist or other health professional or service
- other treatments: includes clinical treatment (such as providing advice or counselling, making an assessment or providing education) or procedural treatments (for example, stitches or injections).

As shown in Table 4.4, the most common management strategy for dementia in 2010–11 was medication, either prescribed, GP-supplied or advised for over-the-counter purchase. This was also the most common form of management of all encounters (Britt et al. 2011). Other common management actions for dementia were 'other treatments' and ordering pathology tests. Note that medication was not the most common management strategy in all of the years considered; for 2008–09 and 2009–10, 'other treatments' was the most common management strategy, followed by medication.

Table 4.4: Actions taken for the management of dementia by GPs, 2006–07 to 2010–11 (actions per 100 dementia problems managed)

Actions	2006–07	2007–08	2008–09	2009–10	2010–11
Medication	31.9	30.5	23.8	26.0	34.4
95% confidence interval	24.3–39.4	24.4–36.6	18.1–29.5	19.2–32.8	26.1–42.6
Imaging	5.4	2.6	4.9	2.9	2.0
95% confidence interval	1.9–9.0	0.5–4.6	2.4–7.4	0.7–5.2	0.7–3.2
Pathology	24.4	16.3	22.1	27.9	23.4
95% confidence interval	12.4–36.4	7.5–25.1	13.0–31.3	16.1–39.8	14.6–32.1
Referrals	12.5	7.9	12.4	11.9	11.2
95% confidence interval	8.2–16.8	4.6–11.1	8.6–16.1	7.4–16.4	7.9–14.6
Other treatments[(a)]	19.3	27.3	27.0	31.8	31.8
95% confidence interval	14.8–23.7	17.8–36.9	21.7–32.2	25.4–38.2	24.7–38.9

(a) Includes clinical and procedural treatments.

Source: AIHW analysis of Bettering the Evaluation and Care of Health survey data.

In 2010–11, there were 153 medications prescribed, supplied or recommended during GP encounters reported in the BEACH survey in which dementia was being managed. This equates to 34 medications per 100 dementia problems managed. This rate did not vary significantly between 2006-07 and 2010-11. Most of the medications were prescribed (95%), rather than the GP supplying the patient with the medication (3%) or recommending a particular medication for over-the-counter purchase (2%). The most common medications prescribed by GPs to manage dementia in 2010–11 were donepezil (39 out of 145 prescriptions), risperidone (28 prescriptions) and galantamine (11 prescriptions).

Imaging tests were not commonly used in the management of dementia by GPs participating in the BEACH survey, with 2 tests ordered per 100 dementia problems managed in 2010–11. This rate did not vary significantly from the rates for the previous 4 years. When ordered, the most common imaging tests were CT scans of the brain or head.

Twenty-three pathology tests were ordered for every 100 dementia problems managed in 2010–11. This rate did not vary significantly over the 5-year period to 2010–11. The most common test ordered in each of the 5 years was a full blood count (20% of pathology tests ordered in 2010–11). Other common tests included urine tests, liver function tests, tests for electrolyte imbalance, urine tests and thyroid-stimulating hormone (TSH) tests.

GPs participating in the 2010–11 BEACH survey wrote 50 referrals for dementia management, equating to 11 referrals per 100 dementia problems managed. Again, no statistically significant variation in this rate was observed over the 5-year period. The most common referral was to a geriatrician, followed by a referral for an assessment through the Aged Care Assessment Program, and for neurologist consultation.

'Other treatments' were provided for 32 per 100 dementia problems managed by GPs in 2010–11. Most of these treatments were clinical in nature (as opposed to procedural), the most common of which was psychological counselling. When the rate of 'other treatments' is compared over time, the data suggest a trend towards higher rates of such treatments in recent years, with the rate significantly higher in 2009–10 and 2010–11 than in 2006–07.

Screening for dementia

During a 5-week period in 2010, a sub-study on dementia screening by GPs was undertaken as part of the BEACH program. It used a sample of 2,690 patients seen by 91 GPs (AIHW: AGPSCC 2010). The GPs indicated that 226 (8%) of these patients had been screened at some time for dementia. This proportion rose significantly with age, reaching 44% in patients aged 75 and over. No significant difference was found in the proportion of men and women screened.

GPs were asked to record all reasons for having screened the patient for dementia. The reasons given were:

- concern of the GP (36%)
- dementia signs and symptoms (31%)
- family concerns (20%)
- family history of dementia (10%)
- concern of other health professional (8%)
- other reasons (for example, age of patient, health assessment) (34%).

In 91% of the cases, the MMSE was used to conduct the screening. Of those screened, 54 patients (24%) had also been diagnosed with dementia.

4.4 Hospital services

In this section, details are provided on the number and characteristics of admitted patient hospitalisations for people with dementia between 2004–05 and 2009–10. Such information is available from the National Hospital Morbidity Database (NHMD). As described in more detail in Appendix B, the NHMD provides information on the characteristics of admitted patients in public and private hospitals for each 'episode of care', referred to in this report as a 'hospitalisation'. Information is also provided in Appendix B on the ICD-10-AM codes used to identify hospitalisations with either a principal diagnosis or an additional diagnosis of dementia.

Note that any one person may have multiple hospitalisations during the course of a year, but data on the number of unique people hospitalised with a particular disease (such as dementia) are not available. Note also that information on outpatient care and emergency department care is not discussed in this chapter since national data on the diagnoses related to such care are not available.

As part of the collection of data in Australian hospitals, a principal diagnosis is assigned to each episode of admitted patient care, and one or more additional diagnoses may also be assigned (see Box 4.3). People who are admitted to hospital may have dementia recorded as either the principal diagnosis or as an additional diagnosis. A person with dementia may be admitted to hospital for the management of their dementia or for a variety of other reasons. The coding rules specify that only those conditions that were significant in terms of treatment required, investigations needed and resources used during the 'episode of care' are to be coded as an additional diagnosis (NCCH 2010). For this reason, the number of hospitalisations with a principal diagnosis or an additional diagnosis of dementia may not capture everyone with dementia who was hospitalised in a particular year. Note that, as discussed further below, the extent to which the additional diagnosis data include people with dementia is likely to have changed over time due to a clarification in the coding standards which came into effect in July 2008.

Box 4.3: Definition of key terms in the National Hospital Morbidity Database

Admitted patients are patients who undergo a hospital's formal admission process to receive treatment and/or care.

A **hospitalisation** (or 'separation') refers to an episode of admitted patient care which can be either a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of Care type (for example, from *Acute care* to *Palliative care*).

The **principal diagnosis** is the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of admitted patient care.

An **additional diagnosis** is a condition or complaint that either coexists with the principal diagnosis or arises during the episode of care.

Patient day means the occupancy of a hospital bed (or chair in the case of some same-day patients) by an admitted patient for all or part of a day. The **length of stay** for an overnight patient is calculated by subtracting the date the patient was admitted from the date of separation and deducting any days the patient was 'on leave'.

A **same-day patient** is a patient who is admitted and separated from the hospital on the same day. Such patients are allocated a length of stay of 1 day.

An **overnight-stay patient** is a patient who receives hospital treatment for a minimum of 1 night; that is, they are admitted to and separated from the hospital on different dates.

Source: AIHW 2011c.

Number of hospitalisations in 2009–10

In 2009–10, there were more than 8.5 million hospitalisations in Australia (AIHW 2011c). Dementia was recorded as the principal diagnosis for 12,286 of these, a rate of 1 in every 1,000 hospitalisations (Table 4.5).

Women accounted for 51% of hospitalisations with dementia recorded as the principal diagnosis. Nonetheless, when differing population age and sex structures are taken into account, the data indicate a higher rate of such hospitalisations for men (34.1 hospitalisations per 10,000 men aged 60 and over) than for women (25.3 per 10,000 women aged 60 and over).

Table 4.5: Hospitalisations with a diagnosis of dementia, by sex, 2009–10

	Principal diagnosis			Principal or additional diagnosis		
	Number	**Per cent**	**ASR[(a)]**	**Number**	**Per cent**	**ASR[(a)]**
Males	6,032	49.1	34.1	35,665	42.9	205.3
Females	6,254	50.9	25.3	47,561	57.1	181.8
Total	**12,286**	**100.0**	**28.9**	**83,226**	**100.0**	**192.1**

(a) The age-standardised rates, which apply to people aged 60 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.

Source: AIHW National Hospital Morbidity Database.

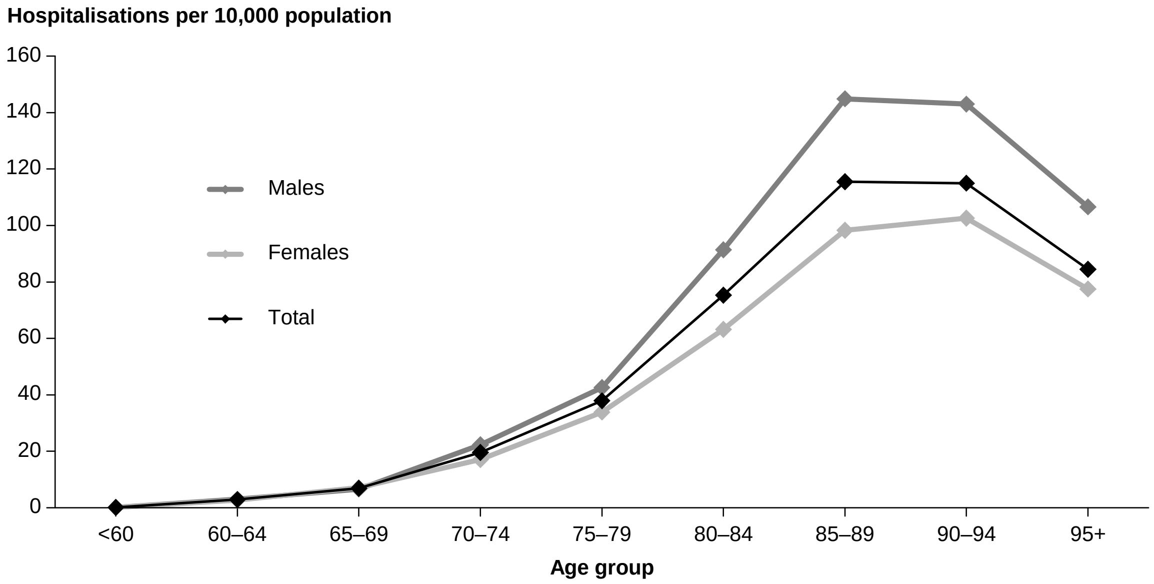
There were 83,226 hospitalisations with dementia recorded as either the principal or an additional diagnosis, accounting for 1 out of every 100 hospitalisations in 2009–10 (1%). Hospitalisations where dementia was the principal diagnosis represented 15% of these.

Women accounted for 57% of hospitalisations with dementia as a principal or additional diagnosis but, again, the age-standardised rates indicate a higher rate of hospitalisations for men (205.3 per 10,000 men aged 60 and over) than women (181.8 per 10,000 women aged 60 and over).

Differences by age

People aged under 75 accounted for 21% of hospitalisations with dementia recorded as the principal diagnosis, while 44% of those hospitalisations were for people aged 75 to 84, and 36% were for people aged 85 and over (Appendix Table A4.1). Women who were hospitalised with a principal diagnosis of dementia had an older age profile than men: 40% were aged 85 and over compared with 31% of the men.

The age-specific rates of hospitalisations are shown in Figure 4.1. As expected, the rate of hospitalisations with dementia as the principal diagnosis generally increased with age. A difference by sex is also evident, with the age-specific rates for men higher than for women for almost all of the age groups. For example, rates in the age groups from 70–74 upwards were at least 20% higher for men than women. The highest rate for men occurred among those in the 85–89 age group. For this age group, there were 144.9 hospitalisations with dementia as the principal diagnosis per 10,000 men. The highest rate for women was among those in the 90–94 age group, with a rate of 102.6 hospitalisations per 10,000 women.



Note: Data for this figure are shown in Appendix Table A4.1.

Source: AIHW National Hospital Morbidity Database.

Figure 4.1: Age-specific rates of hospitalisations with dementia as the principal diagnosis, by sex, 2009–10

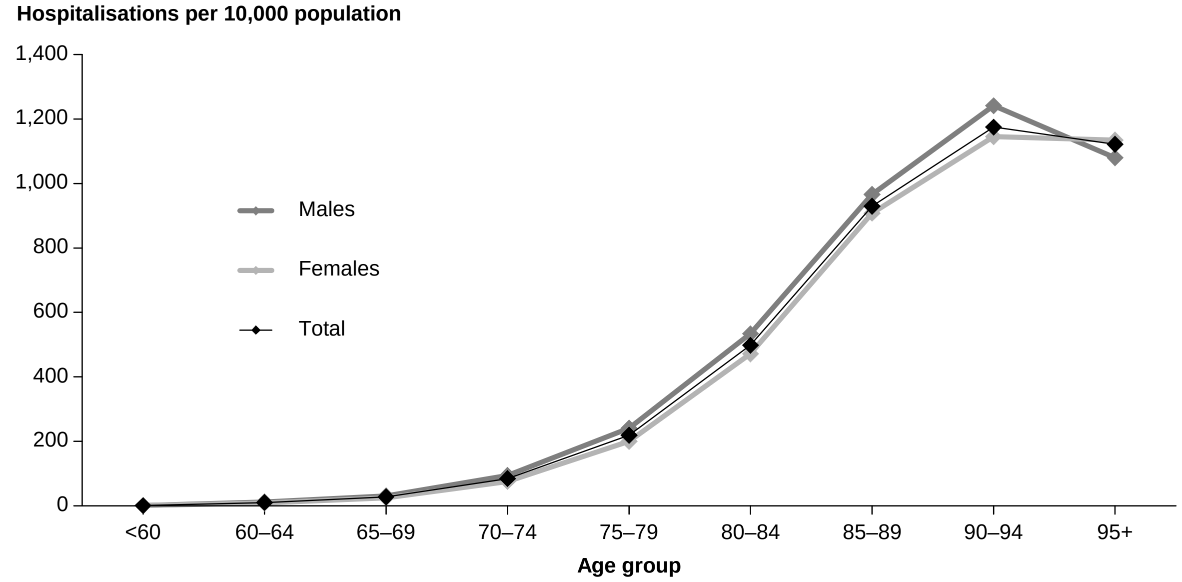
When hospitalisations with dementia as either the principal or an additional diagnosis are examined, a somewhat older age profile is observed (Appendix Table A4.1). People under 75 accounted for 13% of these hospitalisations, while those aged 85 and over accounted for 47%; the corresponding proportions for hospitalisations with dementia as the principal diagnosis were 21% and 36%.

As shown in Figure 4.2, the differences by sex are not as evident when one examines the rate of hospitalisations with dementia as the principal or an additional diagnosis, compared with dementia as the principal diagnosis. In particular, for those aged 95 and over, the rate for women was higher than that for men (1,134.8 and 1,079.9 per 10,000 population, respectively). For both sexes, the highest age-specific rates were observed for those aged 90–94.

Differences by Indigenous status

The quality of Indigenous data in the NHMD is not consistent across jurisdictions. For 2009–10, the NHMD data were considered to be of acceptable quality for analysis in New South Wales, Victoria, Queensland, Western Australia, South Australia and public hospitals in the Northern Territory (see AIHW 2011c). Thus, comparisons by Indigenous status in this section only include data from those six jurisdictions.

In 2009–10, 102 (or 1%) hospitalisations with a principal diagnosis of dementia were for Indigenous Australians (Table 4.6). Women accounted for the majority of these hospitalisations (62%) compared with 51% of all hospitalisations with a principal diagnosis of dementia.



Note: Data for this figure are shown in Appendix Table A4.1.

Source: AIHW National Hospital Morbidity Database.

Figure 4.2: Age-specific rates of hospitalisations with dementia as the principal or an additional diagnosis, by sex, 2009–10

Indigenous Australians account for a smaller proportion of hospitalisations for dementia than of hospitalisations for all causes. While Indigenous Australians represented about 305,000 or 4% of hospitalisations for all causes (AIHW 2011c), they represented only 1% of hospitalisations with a principal diagnosis of dementia. When only hospitalisations of people aged 65 and over are considered, however, Indigenous Australians represented a similar proportion of hospitalisations for dementia (0.7%) and hospitalisations for all causes (1.1%).

Table 4.6: Hospitalisations with dementia as the principal diagnosis, by Indigenous status and sex, selected states and territories[(a)], 2009–10

	Number			Per cent		
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**
Indigenous	39	63	102	0.7	1.0	0.9
Non-Indigenous	5,721	5,914	11,635	97.5	96.9	97.2
Not stated	109	125	234	1.9	2.0	2.0
Total	**5,869**	**6,102**	**11,971**	**100.0**	**100.0**	**100.0**

(a) For data quality reasons, data for Tasmania, the Australian Capital Territory and private hospitals in the Northern Territory were excluded.

Source: AIHW National Hospital Morbidity Database.

Change over time

The number of hospitalisations with dementia as the principal diagnosis increased by 19% between 2004–05 and 2009–10 (Table 4.7). The bulk of this increase occurred between 2005–06 and 2008–09, while numbers changed very little between 2008–09 and 2009–10. The age-standardised rate among people aged 60 and over fluctuated over the 6 years, with rates increasing between 2005–06 and 2008–09, and then decreasing between 2008–09 and 2009–10. The decrease in rates between 2008–09 and 2009–10 was evident for both men and women.

However, the overall change in the rates of hospitalisations with dementia as the principal diagnosis differed by sex, with a negligible change for women (from 25.0 to 25.3 per 10,000) and an increase for men (from 32.8 to 34.1 per 10,000).

Table 4.7: Hospitalisations with dementia as the principal diagnosis, by sex, 2004–05 to 2009–10

	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10	Total change (%)	Average annual change (%)
Number								
Males	4,807	4,783	5,269	5,684	6,005	6,032	25.5	4.6
Females	5,548	5,356	5,719	6,214	6,295	6,254	12.7	2.4
Total	**10,355**	**10,139**	**10,988**	**11,898**	**12,300**	**12,286**	**18.6**	**3.5**
Age-standardised rate for those aged 60 and over[(a)]								
Males	32.8	31.5	33.4	34.6	35.3	34.1	4.0	0.8
Females	25.0	23.4	24.7	26.3	26.2	25.3	1.2	0.2
Total	**28.1**	**26.7**	**28.2**	**29.7**	**29.9**	**28.9**	**2.7**	**0.5**

(a) The rates which apply to people aged 60 and over were age standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.

Source: AIHW National Hospital Morbidity Database.

A different picture emerges when the number of hospitalisations with dementia as the principal or an additional diagnosis is considered (Table 4.8). The total number of such hospitalisations fell considerably between 2007–08 and 2008–09, and then again between 2008–09 and 2009–10, albeit to a smaller degree. Overall, the number of these hospitalisations was lower in 2009–10 (83,226) than in 2004–05 (87,780), a 5% decrease.

It is likely that much (if not all) of the decrease in the number of hospitalisations is due to a clarification in the Australian Coding Standards that came into effect from July 2008 (NCCH 2008). This clarification specified stricter rules for when a condition should be coded as an additional diagnosis. Since then, dementia was more likely to be recorded as an additional diagnosis *only* when there was documented evidence of active treatment, investigation or management of the condition during that particular hospitalisation. Previously, it would have been more likely for dementia to be reported as an additional diagnosis simply because the patient was known to have the condition.

As shown in Table 4.8, the age-standardised rate among people aged 60 and over fell from one year to the next over the 6-year period, with one exception (between 2005–06 and 2006–07). Overall, the rate of hospitalisations with dementia as the principal or an additional diagnosis decreased by 20% between 2004–05 and 2009–10. Although the overall decrease in these rates was greater for women than for men aged 60 and over (a fall of 21% and 18% respectively), the same pattern was seen for both sexes.

Table 4.8: Hospitalisations with dementia as the principal or an additional diagnosis, by sex, 2004–05 to 2009–10

	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10	Total change (%)	Average annual change (%)
Number								
Males	35,311	35,550	37,174	38,695	35,835	35,665	1.0	0.2
Females	52,463	51,606	53,278	54,151	49,342	47,561	-9.3	-1.9
Total[(a)]	**87,780**	**87,156**	**90,456**	**92,846**	**85,177**	**83,226**	**-5.2**	**-1.1**
Age-standardised rate for those aged 60 and over[(b)]								
Males	250.0	241.9	242.3	241.3	214.0	205.3	-17.9	-3.9
Females	230.7	218.8	219.9	217.3	193.5	181.8	-21.2	-4.7
Total[(a)]	**239.0**	**228.6**	**229.6**	**227.7**	**202.5**	**192.1**	**-19.6**	**-4.3**

(a) The total includes those hospitalisations for which sex was not reported.

(b) The rates which apply to people aged 60 and over were age standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.

Source: AIHW National Hospital Morbidity Database.

Type of dementia

Information on the type of dementia is shown in Table 4.9. Of hospitalisations with dementia as the principal diagnosis, *Unspecified dementia* was recorded for 36%, while *Alzheimer disease* was specified for 32%, *Delirium superimposed on dementia* for 17% and *Vascular dementia* for 10%.

The proportion for *Alzheimer disease* was very similar for men and women (32% and 33% respectively). However, some small differences by sex were observed for other types of dementia. *Vascular dementia* was more commonly recorded for men (13%) than for women (7%), but a principal diagnosis of *Unspecified dementia* was more commonly recorded for women (38%) than for men (34%).

For the NHMD analyses in this report, a diagnosis of *Other degenerative diseases of nervous system, not elsewhere classified* was considered to indicate a principal diagnosis of dementia if a dementia-specific code was recorded as an additional diagnosis for that hospitalisation (see Appendix B). In 2009–10, such hospitalisations accounted for 4% of those with a principal diagnosis of dementia. For these hospitalisations, the most common type of dementia recorded as the additional diagnosis was *Dementia in other diseases* (91%).

The specific type of dementia recorded for hospitalisations for which dementia was either a principal or additional diagnosis is also shown in Table 4.9. Again, *Unspecified dementia* was recorded most often, although in this case, it was specified for more than half (57%) of the hospitalisations for dementia (53% for men and 61% for women). Meanwhile *Alzheimer disease* was specified for about 20% of these hospitalisations. For 3% of these hospitalisations, more than one type of dementia had been specified.

Table 4.9: Hospitalisations with a diagnosis of dementia, by type of dementia and sex, 2009–10

	Number			Per cent		
	Males	**Females**	**Total**	**Males**	**Females**	**Total**
Principal diagnosis (ICD-10-AM code)						
Alzheimer disease (F00, G30)	1,949	2,042	3,991	32.3	32.7	32.5
Vascular dementia (F01)	774	466	1,240	12.8	7.5	10.1
Dementia in other diseases (F02)	3	3	6	—	—	—
Unspecified dementia (F03)	2,040	2,374	4,414	33.8	38.0	35.9
Delirium superimposed on dementia (F05.1)	970	1,153	2,123	16.1	18.4	17.3
Other degenerative diseases of nervous system, not elsewhere classified (G31)[(a)]	296	216	512	4.9	3.5	4.2
Total	**6,032**	**6,254**	**12,286**	**100.0**	**100.0**	**100.0**
Principal or additional diagnosis (ICD-10-AM code)						
Alzheimer disease (F00, G30)	6,909	9,755	16,664	19.4	20.5	20.0
Vascular dementia (F01)	3,631	2,930	6,561	10.2	6.2	7.9
Dementia in other diseases (F02)	2,632	1,522	4,154	7.4	3.2	5.0
Unspecified dementia (F03)	18,734	28,925	47,659	52.5	60.8	57.3
Delirium superimposed on dementia (F05.1)	2,485	3,268	5,753	7.0	6.9	6.9
More than one type of dementia	1,274	1,161	2,435	3.6	2.4	2.9
Total	**35,665**	**47,561**	**83,226**	**100.0**	**100.0**	**100.0**

(a) Includes only those with a principal diagnosis code of 'Other degenerative diseases of nervous system, not elsewhere classified' (G31) and an additional diagnosis code of F00, F01, F02, F03, F05.1 or G30.

Source: AIHW National Hospital Morbidity Database.

Principal diagnosis for those with an additional diagnosis of dementia

As previously indicated, in 2009–10 there were 70,940 hospitalisations for people with an additional diagnosis of dementia. The most common *principal* diagnoses recorded for these hospitalisations were *Rehabilitation procedures* (7%), *Hip fracture* (6%), *Waiting for admission to residential aged care* (5%) and *Urinary tract infection* (5%) (Table 4.10). Other common principal diagnoses recorded for these hospitalisations included *Respiratory diseases*, *Cardiovascular diseases* and *Septicaemia.*

Length of hospitalisations

The 12,286 hospitalisations with dementia as the principal diagnosis accounted for almost 217,500 patient days in hospital in 2009–10 (Table 4.11). This equates to 0.8% of all patient days (AIHW 2011c). Yet, such hospitalisations accounted for a smaller proportion (0.1%) of all hospitalisations (as discussed earlier). This means that hospitalisations with dementia as the principal diagnosis consume considerably more patient days than average. Specifically, the average length of stay for hospitalisations with a principal diagnosis of dementia was 18 days, 6 times higher than the average length of stay of 3 days for all hospitalisations (AIHW 2011c).

Table 4.10: Most common principal diagnoses for hospitalisations in which dementia was an additional diagnosis, 2009–10

Principal diagnosis (ICD-10-AM code)	Number	Per cent
Care involving use of rehabilitation procedures (Z50)	4,978	7.0
Fracture of femur (S72)	4,689	6.6
Hip fracture (S72.0–S72.2)	4,382	6.2
Problems related to medical facilities and other health care (Z75)	4,294	6.1
Person awaiting admission to residential aged care (Z75.11)	3,593	5.1
Other disorders of urinary system (N39)	3,474	4.9
Urinary tract infection, site unspecified (N39.0)	3,469	4.9
Pneumonia, organism unspecified (J18)	2,984	4.2
Pneumonitis due to solids and liquids (J69)	1,936	2.7
Heart failure (I50)	1,781	2.5
Other sepsis (A41)	1,278	1.8
Acute myocardial infarction (I21)	1,220	1.7
Syncope and collapse (R55)	1,158	1.6
Type 2 diabetes (E11)	1,156	1.6
Other chronic obstructive pulmonary disease (J44)	1,059	1.5
Other principal diagnoses	40,933	57.7
Total hospitalisations with dementia recorded as an additional diagnosis	**70,940**	**100.0**

Source: AIHW National Hospital Morbidity Database.

Data on length of hospital stay distinguish between 'same-day' and 'overnight' stays (see Box 4.3 for definitions of these terms). Most (80%) hospitalisations with a principal diagnosis of dementia involved an overnight stay. When only these overnight hospitalisations are considered, the average length of stay is higher, at 22 days. In contrast, the average length of stay for all hospitalisations that involved an overnight stay was 6 days (AIHW 2011c).

Table 4.11: Hospitalisations with dementia as a diagnosis: patient days and average length of stay, 2009–2010

	Same-day(a)	Overnight		Total		% that were overnight
	Patient days	Patient days	ALOS (days)	Patient days	ALOS (days)	
Principal diagnosis	2,435	215,033	21.8	217,468	17.7	80.2
Principal or additional diagnosis	13,743	1,112,481	16.0	1,126,224	13.5	83.5

(a) By definition, the average length of stay (ALOS) for same-day hospitalisations equals 1 day.

Source: AIHW National Hospital Morbidity Database.

The median length of stay for overnight hospitalisations with dementia as the principal diagnosis was 12 days. The difference between the average (that is, the mean) and median length of stay can be explained by a small group of people with a principal diagnosis of dementia who stayed in hospital for extended periods of time. That is, 5% of these hospitalisations involved a stay of 2 months or longer. These hospitalisations accounted for

71,773 patient days, or 33% of all patient days for hospitalisations with a principal diagnosis of dementia.

Hospitalisations where dementia was either a principal or an additional diagnosis accounted for more than 1.1 million patient days in hospital, with an average length of stay of 14 days. Most hospitalisations involved an overnight stay (84%). When only overnight hospitalisations were considered, the average length of stay was higher, at 16 days.

As shown in Table 4.12, the average length of stay for men with dementia as the principal diagnosis was longer than that for women (19 days compared with 16 days). Among both men and women, the average length of stay tended to decrease with age. Of the age groups considered, the longest stays were observed for those younger than 70 (31 days for men, 22 days for women), while the shortest were for those aged 95 and older (14 days for men, 13 days for women).

Table 4.12: Hospitalisations with dementia as the principal diagnosis, patient days and average length of stay, by sex and age, 2009–10

Sex/age	Hospitalisations (number)	Patient days	Average length of stay (days)
Males			
Under 70	596	18,648	31.3
70–74	751	12,599	16.8
75–79	1,089	27,093	24.9
80–84	1,701	27,688	16.3
85–89	1,396	21,414	15.3
90–94	425	7,313	17.2
95+	74	1,022	13.8
Total	**6,032**	**115,777**	**19.2**
Females			
Under 70	583	12,797	22.0
70–74	616	11,291	18.3
75–79	1002	16,480	16.5
80–84	1,574	25,093	15.9
85–89	1,622	23,731	14.6
90–94	687	10,032	14.6
95+	170	2,267	13.3
Total	**6,254**	**101,691**	**16.3**
Persons			
Total	**12,286**	**217,468**	**17.7**

Source: AIHW National Hospital Morbidity Database

The average stay for hospitalisations with dementia as the principal diagnosis decreased from 25 days in 2004–05 to 18 days in 2009–10 (Table 4.13). The average length of stay for all hospitalisations decreased by less than 1 day (from 3.4 to 3.1 days) over that time (AIHW 2010b, 2011c).

When same-day hospitalisations are excluded, the average stay for hospitalisations with dementia as the principal diagnosis decreased by 7 days (from 29 to 22 days) between 2004–05 and 2009–10. The comparable decrease for all hospitalisations was again less than 1 day (from 6.3 to 5.9 days) (AIHW 2010b, 2011c).

Table 4.13: Hospitalisations with dementia as the principal diagnosis, patient days and average length of stay (ALOS), 2004–05 to 2009–2010

	Same-day[(a)]	Overnight		Total		% that were overnight
	Patient days	Patient days	ALOS (days)	Patient days	ALOS (days)	
2004–05	1,361	260,501	29.0	261,862	25.3	86.9
2005–06	1,250	245,231	27.6	246,481	24.3	87.7
2006–07	1,743	233,893	25.3	235,636	21.4	84.1
2007–08	2,586	244,048	26.2	246,634	20.7	78.3
2008–09	2,725	224,240	23.4	226,965	18.5	77.8
2009–10	2,435	215,033	21.8	217,468	17.7	80.2

(a) By definition, the average length of stay (ALOS) for same-day hospitalisations equals 1 day.

Source: AIHW National Hospital Morbidity Database.

How was the care completed?

Information on the 'mode of separation' describes the status of a patient at the end of the hospital episode in terms of where they were discharged to or if they died (Table 4.14). A *statistical discharge* is assigned to patients for whom the intent of care changed during their stay in hospital (for example, from *Acute care* to *Palliative care*). The *Other* option includes those who were discharged to their own accommodation, their usual residence (which could be a residential aged care facility) or a welfare institution (such as a prison, hostel or group home primarily providing welfare services).

Table 4.14: Hospitalisations with dementia as the principal diagnosis, by separation mode and sex, 2009–10

	Number			Per cent		
Separation mode	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**
Discharge or transfer to:						
• an(other) acute hospital	671	584	1,255	11.1	9.3	10.2
• residential aged care service[(a)]	1,203	1,324	2,527	19.9	21.2	20.6
• an(other) psychiatric hospital	96	70	166	1.6	1.1	1.4
• other health care accommodation	113	160	273	1.9	2.6	2.2
Statistical discharge (including from leave)	1,065	1,050	2,115	17.7	16.8	17.2
Left against medical advice/discharge at own risk	31	18	49	0.5	0.3	0.4
Died	238	166	404	3.9	2.7	3.3
Other[(b)]	2,615	2,882	5,497	43.4	46.1	44.7
Total	**6,032**	**6,254**	**12,286**	**100.0**	**100.0**	**100.0**

(a) Excludes those for whom a residential aged care facility was their usual place of residence.

(b) Includes discharge to usual residence, own accommodation or a welfare institution (including prisons, hostels and group homes primarily providing welfare services).

Source: AIHW National Hospital Morbidity Database.

In 2009–10, 45% of all hospitalisations with dementia as the principal diagnosis had a mode of separation of *Other*, which generally indicates discharge to the person's usual residence. This proportion was less than the 92% of all hospital separations assigned this separation mode (AIHW 2011c). About 21% of hospitalisations with dementia as the principal diagnosis ended with a discharge or transfer to a residential aged care facility. This only captures those newly admitted to the residential aged care facility since those returning to such a facility after a hospital stay should be assigned the separation mode of *Other.* About 17% of hospitalisations with dementia as the principal diagnosis ended with a *Statistical discharge*, while 10% ended with discharge or transfer to another acute hospital and 3% ended with the death of the patient. Note, however, that several AIHW studies have shown that there are inconsistencies in the reported post-hospital destination, particularly for people identified through data linkage to be moving between hospital and residential aged care (AIHW: Karmel & Rosman 2007; AIHW 2012d).

Palliative care for those with dementia

Australian and overseas research has consistently shown that cancer patients comprise the majority of those using palliative care services (AIHW 2011e; Currow et al. 2008; Rosenwax & McNamara 2006). A number of different explanations have been posited for this finding, including: difficulties in estimating the prognosis of decline and predicting the disease trajectory for non-cancer patients; resource implications; and the skills of current palliative care specialists (Coventry et al. 2005; Murray & Sheik 2008; Teno et al. 2001). Nonetheless, many have pointed to the need to extend palliative care provision beyond the traditional focus on cancer patients to those nearing the end of life with other diseases, including dementia (Albinsson 2003; DoHA 2010b; Sachs et al. 2004; Sampson 2010; van der Steen 2010).

In this section, information is provided on hospitalisations for patients with a diagnosis of dementia for which palliative care was a substantial component of the care provided. Such hospitalisations were defined as those for which the principal clinical intent of the care was palliation during part or all of the hospitalisation, as evidenced by a code of *Palliative care* for the 'Care type' and/or diagnosis data items in the NHMD (for further information on identifying palliative care hospitalisations in the NHMD, see AIHW 2011d). This report does not cover palliative care provided in settings other than in admitted patient care. The information in this section was sourced from two AIHW palliative care reports (AIHW 2011e, 2012b).

As shown in Table 4.15, in 2008–09, there were 198 palliative care hospitalisations for which the principal diagnosis was dementia and 227 in 2009–10. In both years, these hospitalisations accounted for fewer than 1% of all palliative care hospitalisations. When both the principal diagnosis and additional diagnoses are considered, the data suggest there were about 2,800 palliative care hospitalisations with dementia as a diagnosis, accounting for about 5% of all palliative care hospitalisations.

Table 4.15: Palliative care hospitalisations with dementia[a] as a diagnosis, 2008–09 and 2009–10

	Principal diagnosis of dementia		Principal or additional diagnosis of dementia	
	Number	Per cent[b]	Number	Per cent[b]
2008–09	198	0.4	2,775	5.3
2009–10	227	0.4	2,809	5.0

(a) For these analyses, dementia was identified by the ICD-10-AM codes of F00 to F03 and G30.

(b) The percentage is based on the total number of palliative care hospitalisations: 52,347 in 2008–09 and 55,983 in 2009–10.

Sources: AIHW 2011e, 2012b.

In addition to considering all hospitalisations for palliative care, one can also consider the subset of such hospitalisations that ended with the patient's death. In 2008–09, of admitted patients with a principal diagnosis of dementia who died, 37% had been a palliative care patient during their final hospitalisation (Table 4.16). This proportion was 43% in 2009–10. Note that those admitted patients who died in hospital but who were not identified as 'palliative care patients' may well have received some palliation during the hospitalisation that ended with their death. However, for those patients, palliation was not recorded as being a substantial component of the care provided.

Table 4.16: Palliative care patients with dementia(a) as a diagnosis who died as an admitted patient, 2008–09 and 2009–10

	Principal diagnosis of dementia			Principal or additional diagnosis of dementia		
	Palliative care patient deaths(b)	Total admitted patient deaths	% palliative care patient deaths(c)	Palliative care patient deaths(b)	Total admitted patient deaths	% palliative care patient deaths(c)
2008–09	114	310	36.8	1,620	6,037	26.8
2009–10	134	314	42.7	1,624	5,638	28.8

(a) For these analyses, dementia was identified by the ICD-10-AM codes of F00 to F03 and G30.

(b) Refers to patients for whom palliative care was the principal clinical intent during part or all of the hospitalisation that ended with their death.

(c) Indicates the proportion of all admitted patient deaths of people with a diagnosis of dementia that were palliative care patients.

Sources: AIHW 2011e, 2012b.

The proportion of those who were palliative care patients during the hospitalisation that ended with their death tended to vary widely by disease, with the highest proportion observed for cancer patients (AIHW 2011e). For example, in 2009–10, among admitted patients with cancer as the principal diagnosis who died, 71% had been a palliative care patient during their final hospital stay (AIHW 2012b).

In 2008–09, 27% of all admitted patient deaths for which dementia was a diagnosis (either the principal or an additional diagnosis) were palliative care patients during the hospitalisation that ended with their death. The corresponding proportion for 2009–10 was 29%. For patients with a cancer diagnosis, the comparable proportion in 2009–10 was 62% (AIHW 2012b).

Linked hospital data

At the national level, hospital data relate to individual episodes of care. Such 'episodes' may end for a range of reasons including a patient being transferred to another hospital or simply a change in 'Care type'. To allow for an examination of complete hospital 'stays', information on single hospital episodes in New South Wales during 2006–07 were linked as part of the Hospital Dementia Services (HDS) project. For the purposes of the HDS project, a 'stay' was defined as the period from admission into the hospital system to either discharge from the hospital system or death in hospital (Draper et al. 2011). A hospital stay, as defined in the HDS project, differs from a hospitalisation, as reported elsewhere in this report, since a stay cannot have ended due to the patient being transferred to another hospital or due to a change in 'Care type'. Thus, one hospital stay may include information about multiple hospitalisations. Further information about the HDS project and some related findings are provided in Box 4.4.

Box 4.4: Description of the Hospital Dementia Services project

The Hospital Dementia Services (HDS) project is a study that uses linked hospital data from New South Wales to provide information about the number of people with dementia who were hospitalised and the characteristics of their hospital stays (AIHW 2011f). The study population consists of people aged 50 and over who spent at least one night in, and were discharged from, a New South Wales public hospital between 1 July 2006 and 30 June 2007. Around 252,700 people (called HDS patients) met these criteria. Data relating to single hospital episodes for these patients were combined to identify and provide information on complete hospital 'stays' for individual patients.

Dementia was recorded as either the principal or an additional diagnosis for 20,793 HDS patients (8%) (Draper et al. 2011). These patients, between them, had 38,046 stays in 2006–07, equalling an average of 1.8 stays per person in the study year. Among HDS patients with dementia, 14% were aged between 50 and 74 and 42% were aged 85 and over.

Dementia was the principal (rather than an additional) diagnosis for 6% of multi-day stays for HDS patients with dementia (Draper et al. 2011). There were 35,612 multi-day stays in 2006–07 for HDS patients with dementia where dementia was an additional diagnosis rather than the principal diagnosis. The most common principal diagnoses for those stays were lower respiratory tract infections (8%), fractured femur (6%), urinary tract infections (6%), head injury (3%) and stroke (3%).

Patients with dementia spent longer in hospital than those without dementia. In 2006–07, the average length of multi-day stays for HDS patients with dementia was 17 days compared with 9 days for HDS patients without dementia. Differences in length of stays were even more pronounced among younger patients. Patients aged 50–54 with dementia had an average length of stay of 15 days compared with 7 days for patients without dementia. The corresponding numbers for those aged 55–59 was 21 days for patients with dementia and 7 days for those without (Draper et al. 2011). In comparison, among patients aged 90–94 the average length of stay for those with dementia was 15.5 days, and 13.3 days for those without.

4.5 Medications

There are currently no known drugs that can reverse or cure the various forms of dementia, although some medications have been found to reduce some symptoms (such as memory impairment) experienced by those with Alzheimer disease.

This section presents information from two sources on the dispensing of prescriptions for dementia-specific medications. First, information is presented from Medicare Australia on dispensed dementia-specific drugs that were subsidised by the Australian Government through the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS). Under these two schemes, Medicare Australia makes payments to pharmacists to subsidise pharmaceutical products that:

- have been assessed by the Pharmaceutical Benefits Advisory Committee and found to be safe, clinically effective and cost-effective, and
- are listed in the *Schedule of Pharmaceutical Benefits* (DoHA 2012g).

Second, data are presented for non-subsidised dementia-specific prescriptions from the Drug Utilisation Sub-Committee (DUSC) database (DoHA 2011c). This database contains estimates of non-subsidised prescriptions dispensed—including private prescriptions and those that cost the patient less than the co-payment amount required under the PBS—based on a Pharmacy Guild survey of pharmacies (DoHA 2011c). Use of the DUSC-sponsored survey enables a more comprehensive picture of the dispensing of dementia-specific medications than is possible through the use of the PBS and RPBS data alone. Further information about both the DUSC data and the PBS and RPBS data can be found in Appendix B.

Four dementia-specific drugs are subsidised through the PBS and RPBS for patients who have a diagnosis of Alzheimer disease confirmed by (or in consultation with) a specialist or consultant physician, subject to specific clinical criteria being met (DoHA 2012g). The drugs (and their trade names) are:

- donepezil (Aricept®)
- galantamine (Reminyl®, Galantyl®)
- rivastigmine (Exelon®)
- memantine (Memanxa®, Ebixa®, APO-Memantine®).

These are described further in Box 4.5. Information on the relevant PBS and RPBS item numbers for these medications is provided in Appendix Table A4.2.

Information on prescriptions in this section refers to data on medications prescribed by medical practitioners and subsequently dispensed. Consequently, the data are a count of prescriptions *dispensed*, not a count of prescriptions *written* by medical practitioners or a count of medications actually *used* by patients.

Box 4.5: Dementia-specific medications subsidised through the PBS and RPBS

The four subsidised dementia-specific medications fall into two categories: Acetylcholinesterase inhibitors (also called cholinergic treatments) and Memantine.

- ***Acetylcholinesterase inhibitors:*** Three of the subsidised dementia-specific medications—namely, donepezil hydrochloride, galantamine hydrobromide and rivastigmine hydrogen tartrate—are *Acetylcholinesterase inhibitors*. These medications, which have been approved in Australia for the treatment of those with mild- to moderately-severe Alzheimer disease, work by blocking the actions of an enzyme called acetylcholinesterase which destroys a major neurotransmitter for memory, acetylcholine. The use of these medications may lead to increased communication between nerve cells and appear to slow the progress of the disease for about 12 to 18 months. Preliminary research has also suggested that these medications may benefit people with other forms of dementia.
- ***Memantine:*** The newest of the subsidised dementia-specific medications—Memantine hydrochloride—falls into the category of *Memantine* medications. A neurotransmitter called glutamate is present in high levels when a person has Alzheimer disease. Memantine hydrochloride works to block the excess glutamate, thus reducing damage to brain cells. This medication tends to be prescribed for people with moderately-severe to severe Alzheimer disease.

Sources: Alzheimer's Australia 2012; Draper 2011.

Data on the number of PBS- and RPBS-subsidised dementia-specific prescriptions dispensed are presented according to the type of medication. Individual prescriptions vary in the number of doses, the size of the dose, the potency of each individual dose and the type of preparations (such as a tablet, capsule, solution or patch) (see Appendix Table A4.2). Also any one person may have obtained several subsidised dementia-specific prescriptions in any one period. This section also presents information on the estimated amount, by weight ('000 mg), of each type of medication prescribed.

The data presented in this section do not capture all medications used by those with dementia, nor do they capture drugs that may have been prescribed specifically to manage a person's dementia but can also be used to treat other diseases, as these data are not available.

Subsidised dementia-specific medications

Number of prescriptions

In 2009–10, a total of 392,796 subsidised dementia-specific medications were dispensed (Table 4.17). This equates to 0.2% of the total 197 million subsidised prescriptions for all medications dispensed that year (Medicare Australia 2012).

Table 4.17: Government-subsidised dementia-specific prescriptions[(a)], by type of medication, 2002–03 to 2009–10

	Donepezil	Galantamine	Rivastigmine	Memantine[(b)]	Total
Number					
2002–03	166,692	31,495	27,918	. .	226,105
2003–04	188,192	57,406	24,994	. .	270,592
2004–05	208,358	82,566	23,590	. .	314,514
2005–06	212,688	99,667	19,725	. .	332,080
2006–07	222,903	107,763	16,596	. .	347,262
2007–08	231,313	112,844	14,059	. .	358,216
2008–09	243,979	115,579	19,741	6,893	386,192
2009–10	240,633	109,290	29,383	13,490	392,796
Per cent					
2002–03	73.7	13.9	12.3	. .	100.0
2003–04	69.5	21.2	9.2	. .	100.0
2004–05	66.2	26.3	7.5	. .	100.0
2005–06	64.0	30.0	5.9	. .	100.0
2006–07	64.2	31.0	4.8	. .	100.0
2007–08	64.6	31.5	3.9	. .	100.0
2008–09	63.2	29.9	5.1	1.8	100.0
2009–10	61.3	27.8	7.5	3.4	100.0
Change between 2002–03 and 2009–10					
Total change (%)	44.4	247.0	5.2	. .	73.7
Average annual change (%)	5.4	19.5	0.7	. .	8.2

(a) Refers to number of dementia-specific prescriptions subsidised through the PBS or RPBS. See Appendix Table A4.2 for a list of the relevant PBS/RPBS item numbers.

(b) Memantine was not a government-subsidised medication until 2008–09.

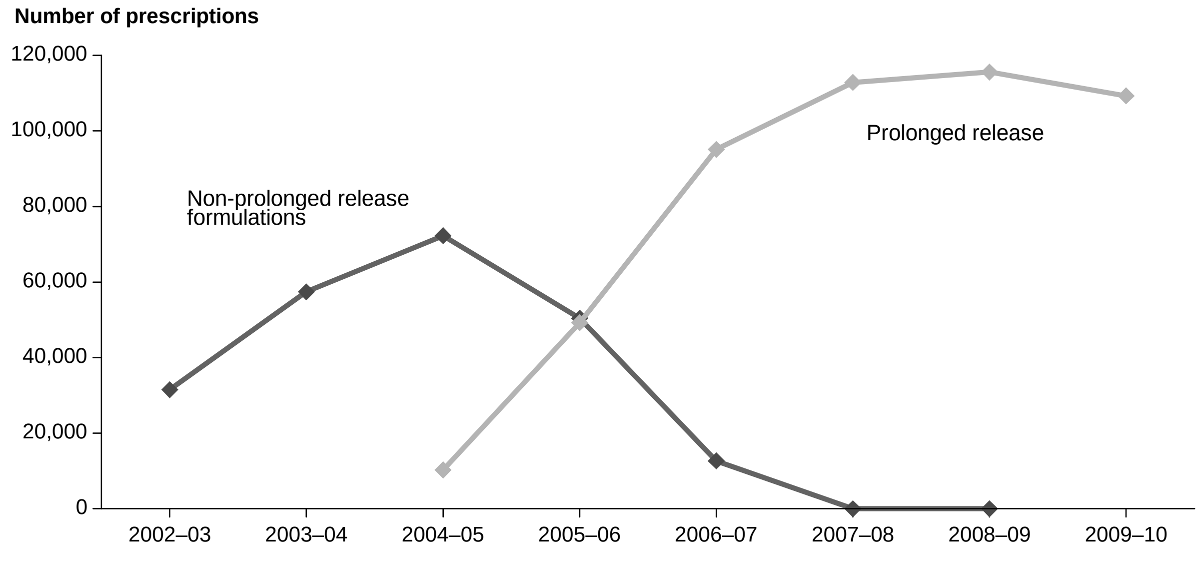
Source: Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data from Medicare Australia (2012).

The number of subsidised dementia-specific medications grew steadily, with 74% more dispensed in 2009–10 than in 2002–03. This represents an average annual change in the dispensing of subsidised dementia-specific medications of 8% each year between 2002–03 and 2009–10.

In 2009–10, 61% of subsidised prescriptions for dementia-specific drugs were for donepezil, 28% for galantamine, 8% for rivastigmine and 3% for memantine. Although the number of donepezil prescriptions increased by 44% between 2002–03 and 2009–10 and, despite being the most common subsidised dementia-specific prescription in each of the years considered, its share of all dementia-specific prescriptions fell over the years.

The number of subsidised prescriptions for rivastigmine fell steadily each year between 2002–03 and 2007–08, but increased from 2008–09 onwards. A main reason for this increase was the listing of a rivastigmine patch on the *Schedule of Pharmaceutical Benefits* in 2008. Compared with other formulations (such as the oral version), the patch was found to be more tolerable for patients and had the additional advantage of once daily dosing.

There was an annual increase in the number of subsidised galantamine prescriptions dispensed between 2002–03 and 2008–09, followed by a decrease between 2008–09 and 2009–10. Overall, the number of galantamine prescriptions dispensed between 2002–03 and 2009–10 increased by 247%. There was considerable change over the years in the formulation of galantamine prescribed. When it was first released, it had twice daily dosing. However such formulations were considered to be inconvenient to patients and clinicians were less willing to prescribe it, especially once the prolonged-release formulations were available. The twice daily dosing formulations were delisted from the *Schedule of Pharmaceutical Benefits* on 30 November 2006. As shown in Figure 4.3, the number of prescriptions for non-prolonged release galantamine formulations peaked in 2004–05 and then dropped sharply. Meanwhile, there was a sharp increase in the number of prescriptions for the prolonged-release formulations between 2004–05 and 2008–09, although the number decreased between 2008–09 and 2009–10.



Note: Data for this figure are shown in Appendix Table A4.3.

Source: Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data from Medicare Australia (2012).

Figure 4.3: Government-subsidised galantamine prescriptions, by type of formulation, 2002–03 to 2009–10

For each of the states and territories, the number of prescriptions for subsidised dementia-specific medications increased between 2002–03 and 2009–10. However, there was considerable variation in the extent of average annual change (Table 4.18). The largest increase (19% on average each year) was observed for the Northern Territory, followed by Victoria (11%) and New South Wales (9%). Western Australia (3%) and Tasmania (5%) had the smallest average annual increase over the 8-year period.

Table 4.18: Government-subsidised dementia-specific prescriptions[(a)], by state and territory[(b)], 2002–03 and 2009–10

			Change between 2002–03 and 2009–10		Provision ratio per 1,000 population 2009–10[(c)]
	2002–03	2009–10	Total change (%)	Average annual change (%)	
New South Wales	73,663	132,299	79.6	8.7	179.8
Victoria	56,205	114,399	103.5	10.7	211.2
Queensland	39,680	63,810	60.8	7.0	159.0
Western Australia	22,637	28,580	26.3	3.4	144.4
South Australia	26,286	41,655	58.5	6.8	222.5
Tasmania	2,319	3,187	37.4	4.6	56.2
Australian Capital Territory	4,879	7,410	51.9	6.2	291.4
Northern Territory	436	1,456	233.9	18.8	102.3
Australia	**226,105**	**392,796**	**73.7**	**8.2**	**181.8**

(a) Refers to the number of dementia-specific prescriptions subsidised through the PBS or RPBS. See Appendix Table A4.2 for a list of the relevant PBS/RPBS item numbers.

(b) State/territory is determined according to the address of the pharmacy supplying the item.

(c) Ratio of PBS/RPBS prescriptions for dementia-specific medications dispensed in 2009–10 per 1,000 population aged 70+,as well as Indigenous Australians aged 50 to 69 (that is, all Indigenous Australians aged 50+) at 30 June 2010 (based on ABS population estimates).

Source: AIHW analysis of Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data from Medicare Australia (2012).

While somewhat crude, a provision ratio allows one to take into account differing population sizes and structures across the states and territories. The ratios shown in Table 4.18 compare the number of subsidised dementia-specific medications dispensed in 2009–10 with the size of the 'older population' (70 years and over, or 50 years and over for Indigenous Australians) in each of the states and territories. Based on these ratios, the number of prescriptions dispensed in 2009–10 was relatively high in the Australian Capital Territory (291 prescriptions per 1,000 population) and South Australia (223), but relatively low in Tasmania (56). There could be a number of reasons for these jurisdictional differences, including different prescribing patterns (for example, prescribing different types and dosage of drugs) and different rates of dementia (and specifically Alzheimer disease) among the older population, resulting in differing levels of need for such medications.

Amount of medication prescribed

Rather than look at the *number* of subsidised prescriptions for dementia-specific drugs, the following data consider the amount, by *weight*, of such drugs prescribed. These amounts are estimates based on the number of subsidised prescriptions dispensed, dosage and maximum quantity prescribed per drug (see Note 4.1 in Appendix D for further details on the method used).

As shown in Table 4.19, overall, the estimated amount by weight of the four subsidised dementia-specific medications dispensed increased between 2002–03 and 2009–10, with the largest increase observed for galantamine. The amount of subsidised galantamine dispensed increased by an annual average of 22% over the 8-year period. The overall increase in the amount of this medication prescribed (by weight) was more than 300% over this time, a larger increase than that indicated by analysing the number of prescriptions alone (see Table 4.17).

Table 4.19: Amount (by weight) of government-subsidised dementia-specific medications[(a)], by type of medication, 2002–03 to 2009–10 ('000mg)

	Donepezil	Galantamine	Rivastigmine	Memantine[(b)]
2002–03	39,424	11,761	5,635	. .
2003–04	45,064	22,163	5,154	. .
2004–05	50,558	33,663	4,956	. .
2005–06	51,924	42,317	4,194	. .
2006–07	54,327	46,169	3,532	. .
2007–08	56,510	48,710	2,919	. .
2008–09	59,658	50,736	6,138	3,855
2009–10	59,108	48,513	11,070	7,547
Change between 2002–03 and 2009–10				
Total change (%)	49.9	312.5	96.5	. .
Average annual change (%)	6.0	22.4	10.1	. .

(a) Refers to amount of dementia-specific medication, as measured by weight, subsidised through the PBS or RPBS. See Appendix Table A4.2 for a list of the relevant PBS/RPBS item numbers. See Note 4.1 in Appendix D for details on method used to calculate weights dispensed.

(b) Memantine was not a government-subsidised medication until 2008–09.

Sources: AIHW analysis of Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data from Medicare Australia (2012); DoHA 2012h.

The number of rivastigmine prescriptions decreased between 2002–03 and 2007–08, but increased from 2008–09 onwards (Table 4.17). A similar pattern is observed in the data on the amount, by weight, of this medication but the increase in later years is even more marked (from 2,919,000 mg in 2007-08 to 11,070,000 mg in 2009–10) (Table 4.19). As indicated above, a patch formulation of rivastigmine was listed on the *Schedule of Pharmaceutical Benefits* in 2008.

Non-subsidised dementia-specific medications

As previously noted, the PBS and RPBS data on prescriptions for dementia-specific medications drawn from Medicare Australia records do not cover non-subsidised prescriptions. However, using data from an ongoing survey of community pharmacies (the DUSC-sponsored Pharmacy Guild survey), it is possible to estimate the number of non-subsidised dementia-specific prescriptions dispensed.

The DUSC database combines estimates of non-subsidised prescriptions (that is, prescriptions that cost the patient less than the co-payment amount required under the PBS) and private prescriptions, with actual counts of PBS- and RPBS-subsidised prescriptions submitted to Medicare Australia. DUSC data are based on the date of supply of prescriptions. This differs from information shown in the previous section, which is based on the date the prescriptions were processed by Medicare Australia. Therefore, the PBS and RPBS data shown in earlier tables will not exactly match those presented below.

Based on the DUSC database, 16,490 non-subsidised dementia-specific prescriptions were dispensed in 2009–10 (Table 4.20). This equates to 4% of all dementia-specific prescriptions dispensed in that year. About 59% of the non-subsidised prescriptions were memantine. Furthermore, compared with the other dementia-specific medications, a considerably higher proportion of memantine was dispensed through non-subsidised prescriptions (41%). Less than 3% of each of the other three medications were dispensed via non-subsidised prescriptions.

Table 4.20: Government-subsidised and non-subsidised dementia-specific prescriptions dispensed[(a)], by type of medication, 2009–10

	Number			Per cent		
	Subsidised[(b)]	Non-subsidised[(c)]	Total	Subsidised[(b)]	Non-subsidised[(c)]	Total
Donepezil	244,153	3,939	248,092	98.4	1.6	100.0
Galantamine	110,684	1,894	112,578	98.3	1.7	100.0
Rivastigmine	30,721	849	31,570	97.3	2.7	100.0
Memantine	14,245	9,808	24,053	59.2	40.8	100.0
Total	**399,803**	**16,490**	**416,293**	**96.0**	**4.0**	**100.0**

(a) These data are based on the date of supply of the medication.

(b) Refers to the number of dementia-specific prescriptions subsidised through the PBS or RPBS. See Appendix Table A4.2 for a list of the relevant PBS/RPBS item numbers.

(c) Refers to the number of non-subsidised dementia-specific prescriptions. This data includes the same dementia-specific medications as listed in Appendix Table A4.2.

Sources: Unpublished data supplied by DoHA which are based on Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data from Medicare Australia and Drug Utilisation Sub-Committee database (DoHA) as at March 2012.

4.6 Aged care assessments

The assessment of care needs is an integral step for people seeking access to Australian Government-subsidised aged care services. Such assessments are conducted by Aged Care Assessment Teams (ACATs) (or by Aged Care Assessment Services (ACASs) in Victoria) which operate under the Aged Care Assessment Program (ACAP). The Australian Government co-funds state and territory governments to manage and administer the ACAP. As at 30 June 2011, 108 ACATs operated across Australia, with teams based in hospitals or in the local community (DoHA 2011b).

The outcomes of an ACAT assessment determine eligibility of a person for various programs. For instance, an ACAT assessment is mandatory for admission to permanent residential aged care and residential respite care, as well as various community and flexible care services (such as Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) packages and Extended Aged Care at Home Dementia (EACHD) packages). It is not required for a person to receive services through the Home and Community Care (HACC) program, the National Respite for Carers Program or the Department of Veterans' Affairs (DVA) Veterans' Home Care (VHC) and Community Nursing programs. However, ACATs can refer clients to these programs when they are considered to be the most appropriate for meeting individual needs.

Following a detailed assessment that considers physical, psychological, medical, cultural and social needs, ACATs make recommendations about the types of services and/or accommodation considered to best meet the client's long-term needs for care and support.

For further information about the ACAT recommendations and approvals process, see Box 4.6.

Box 4.6: ACAT recommendations and approvals for care and support

A completed ACAT assessment results in recommendations for long-term care and program support (including an appropriate setting) as part of a care plan. The recommendations do not always match the approvals given by the ACAT delegate. For example, a client may be recommended for high-level residential care, but be approved to receive high-level permanent residential care, as well as an EACH package and/or residential respite care. Differences between recommendations and approvals may arise because:

- Some approvals are 'just in case', where a client may be recommended to live in the community but is eligible for low-level residential care and approved for this in case it is needed
- Some approvals are for support that is 'interim until entry to residential care', such as for the client in the example above who is recommended for permanent residential care but packaged care and residential respite care may be provided in the interim.

Once a type of care is approved, the client's receipt of services is subject to a number of considerations including whether they apply for the service and the availability of places. Under the *Aged Care Act 1997*, a client can be recommended and approved for a type of care whether or not he or she has applied for it.

Sources: ACAP NDR 2009; DoHA 2011b, 2011e.

The target population for an ACAT assessment is people aged 70 and over, or Indigenous Australians aged 50 and over. Younger people with disability may receive an ACAT assessment if their needs cannot be met through other means.

Before 1 July 2009, approvals for some types of subsidised care automatically lapsed after 12 months. From July 2009, amendments to the *Aged Care Act 1997* came into effect such that approvals for residential respite care, high level residential care, EACH and EACHD made since 1 July 2008 no longer lapsed. However an ACAP client can still be reassessed at any time if their care needs change. This amendment saw a drop in the number of completed ACAT assessments between 2008–09 and 2009–10 (DoHA 2011b).

In this section of the report, data from completed ACAT assessments are used to describe the characteristics of ACAP clients in 2008–09. When a client had more than one ACAT assessment during 2008-09, data from the most recent assessment were used. See Appendix B for further information on ACAP data.

Number of ACAP clients

In 2008-09, ACATs completed 201,626 assessments (DoHA 2011b) for 179,098 clients (or 1.1 assessments per client). Of these clients, 48,725 (or 27%) were recorded as having dementia (Table 4.21). This proportion varied according to the age of the clients. Less than 20% of those aged under 65 had dementia, compared with 29% of those aged 75 to 89, and 25% of those aged 90 and over. Overall, 86% of those with dementia were aged 75 and over (this compares with 82% of those without dementia). The majority of ACAP clients with dementia were women (61%).

Table 4.21: Aged Care Assessment Program clients with dementia, by age and sex, 2008–09

	Number with dementia			Per cent with dementia				
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Without dementia (%)**	**% of total with dementia**
Under 50	41	37	78	0.2	0.1	0.2	0.7	8.2
50–64	689	562	1,251	3.7	1.9	2.6	4.2	18.7
65–69	869	757	1,626	4.6	2.5	3.3	5.0	20.1
70-74	1,775	1,929	3,704	9.4	6.5	7.6	8.6	24.9
75-79	3,515	4,673	8,188	18.7	15.6	16.8	15.4	29.0
80-84	5,385	8,244	13,629	28.6	27.6	28.0	24.8	29.6
85-89	4,523	8,611	13,134	24.0	28.8	27.0	24.9	28.8
90+	2,037	5,075	7,112	10.8	17.0	14.6	16.5	24.9
Total[(a)]	**18,836**	**29,889**	**48,725**	**100.0**	**100.0**	**100.0**	**100.0**	**27.2**

(a) The total includes clients with unknown age.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Of ACAP clients in 2008–09 with dementia, 67% were born in Australia, 12% were born overseas in a 'main English-speaking country', 19% were born in another country, and the birthplace was not reported in 2% of cases.

One per cent of ACAP clients with dementia identified as an Aboriginal or Torres Strait Islander, the same proportion as those without dementia.

Dementia as the main condition

As part of the ACAT assessment, the assessor can record up to 10 'diagnosed diseases or disorders that have an impact on the person's need for assistance with activities of daily living and social participation' (DoHA 2011f). The condition with the greatest impact on the person's need for assistance is designated the 'main health condition'. Dementia was recorded as the main health condition for 73% of clients who had dementia listed as a condition (Table 4.22).

Table 4.22: Aged Care Assessment Program clients with dementia, by whether dementia was the main condition and age, 2008–09

	Number				Per cent			
	15–64	**65–84**	**85+**	**Total[(a)]**	**15–64**	**65–84**	**85+**	**Total[(a)]**
Main condition	912	20,217	14,327	35,458	68.6	74.5	70.8	72.8
Not main condition	417	6,930	5,919	13,267	31.4	25.5	29.2	27.2
Total	**1,329**	**27,147**	**20,246**	**48,725**	**100.0**	**100.0**	**100.0**	**100.0**

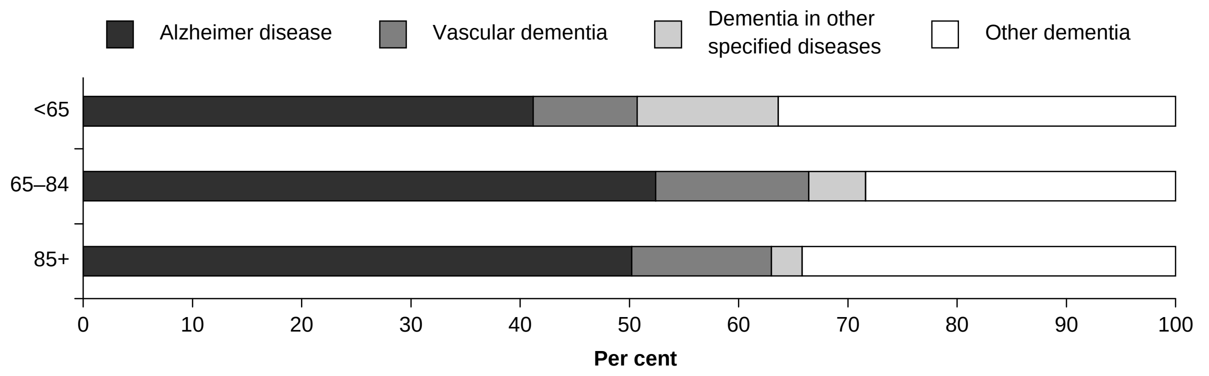
(a) The total includes clients with unknown age.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Type of dementia

Alzheimer disease was the most common dementia diagnosis recorded, accounting for 51% of all dementia cases (Appendix Table A4.4). This is lower than the 76% suggested by the ACFI data described in Chapter 3 (see Table 3.11). This may be due to the fact that *Other dementia* was reported for a relatively high proportion (32%) of ACAP clients with dementia. An unknown proportion of those clients may have had Alzheimer disease. *Vascular dementia* was recorded for 13% of ACAP clients with dementia, and *Dementia in other diseases* for 4%. These proportions are fairly similar to those suggested by the ACFI data (10% and 4% respectively).

As shown in Figure 4.4, *Alzheimer disease* was a relatively less common diagnosis for younger ACAP clients with dementia, while *Dementia in other specified diseases* was more common.



Note: Data for this figure are shown in Appendix Table A4.4.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Figure 4.4: Type of dementia of ACAP clients with dementia, by age, 2008–09

Accommodation and living arrangements

Eighty-five per cent of ACAP clients with dementia were living in the community at the time of assessment in 2008–09, compared with 94% of those without dementia. In both groups, most of those not living in the community were in low-level residential care (84% of those with dementia and 82% of those without dementia).

Of those ACAP clients with dementia living in the community, 62% were living with family and 34% lived alone (Table 4.23). Among their counterparts without dementia, 49% lived with family and 47% lived alone. Women with dementia were more likely to live alone than men (41% and 22% respectively).

Table 4.23: Living arrangements of Aged Care Assessment Program clients with dementia living in the community, by sex, 2008–09

	Number			Per cent		
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**
Lives alone	3,678	10,177	13,855	22.2	41.1	33.6
Lives with family	12,165	13,574	25,739	73.6	54.8	62.3
Lives with others	574	849	1,423	3.5	3.4	3.4
Not reported	116	150	266	0.7	0.6	0.6
Total[(a)]	**16,533**	**24,750**	**41,283**	**100.0**	**100.0**	**100.0**

(a) Due to the business rules that apply to the collection of ACAP data, some questions are not asked of all clients. Consequently, there may be slight discrepancies between tables as to the reported total number of ACAP clients living in the community.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Care needs

During an ACAT assessment, the care needs of clients are assessed in relation to a number of specific activities, as listed in Table 4.24. The first four activities—self-care, movement activities, moving around places at or away from home, and communication—are used to identify severe or profound core activity restrictions. The identification of a need for assistance in the other categories helps the ACAT to determine need for those types of assistance usually provided by government-funded community care programs (DoHA 2011f).

Table 4.24: Need for assistance at time of ACAT assessment, by activity type and dementia status, 2008–09

	People with dementia		People without dementia	
Activity type	**Number**	**Per cent**	**Number**	**Per cent**
Self-care	39,275	80.6	84,965	65.2
Movement activities	16,268	33.4	37,297	28.6
Moving around places at or away from home	32,247	66.2	74,795	57.4
Communication	17,829	36.6	19,905	15.3
Health care tasks	45,088	92.5	94,445	72.4
Transport	45,703	93.8	112,636	86.4
Social and community participation	44,243	90.8	102,793	78.8
Domestic chores	38,648	79.3	112,956	86.6
Meals	37,838	77.7	97,322	74.6
Home maintenance	31,088	63.8	87,917	67.4
Other	2,578	5.3	6,175	4.7
Total needing assistance with at least one activity	**48,394**	**99.3**	**128,167**	**98.3**
Number of clients[(a)]	**48,725**	**100.0**	**130,373**	**100.0**
Average number of activities for which assistance was required	7.2	. .	6.4	. .

(a) The sum of the activity types for which assistance was required exceeds the total number of clients since a client may have required assistance in more than one area.

Source: Unpublished Aged Care Assessment Program data from DoHA.

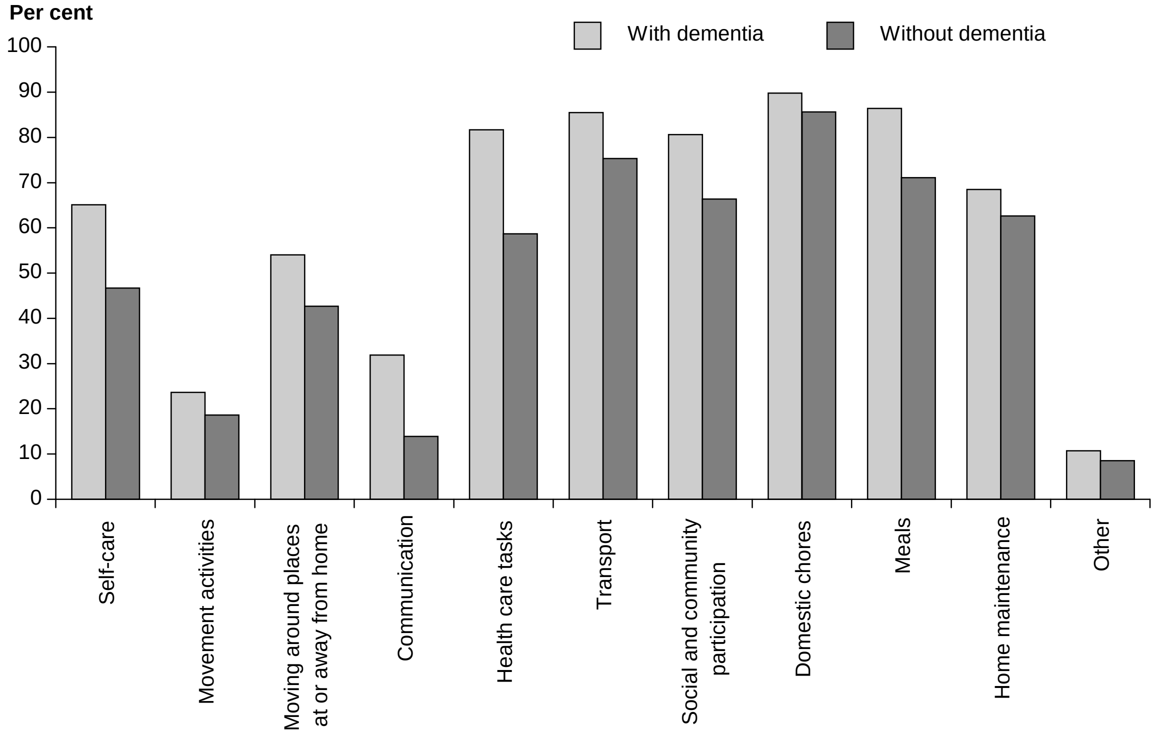
In 2008-09, almost all ACAP clients with dementia (99%) needed assistance with at least one activity. The most common activities for which assistance was needed were transport (94%), health care tasks (93%), and social and community participation (91%). Around 4 in 5 needed help with self-care (81%), domestic chores (79%) and meals (78%). On average, people with dementia needed assistance with 7.2 activities.

While nearly all clients needed assistance in at least one activity area, regardless of whether they had dementia, the proportion of those with dementia needing assistance for each of the individual areas was, in most cases, higher than those without dementia. The largest differences were evident for communication—with twice as many ACAP clients with dementia requiring assistance (37% compared with 15%)—and health care tasks (93% and 72%). There was also a substantial difference in regard to self-care, with 81% of those with dementia needing assistance, compared with 65% of those without dementia.

Nine in ten (91%) ACAP clients with dementia who lived in the community had a carer who provided assistance. Further details about these carers are provided in Chapter 5.

Receipt of formal assistance

In addition to examining the presence of informal carers, the ACAT assessment collects information about the use of formal assistance. Among ACAP clients with dementia living in the community, 95% were receiving formal assistance with at least one activity. Formal assistance with domestic chores (90%) was most common, followed by meals (86%) and transport (86%) (Figure 4.5). On average, clients received formal assistance with 6.8 different types of activities. People with dementia were considerably more likely than those without dementia to be receiving formal assistance with health care tasks, self-care, communication and meals (Appendix Table A4.5).



Note: Data for this figure are shown in Appendix Table A4.5.

Source: Unpublished Aged Care Assessment data from DoHA.

Figure 4.5: Formal assistance received at time of ACAT assessment, by activity type and dementia status, for people living in the community, 2008–09

Recommendations for long-term care setting

One outcome of the assessment of the client's care needs is a recommendation on the accommodation setting most appropriate to their long-term care needs. Long-term care setting recommendations for ACAP clients with dementia are shown in Table 4.25 in relation to the clients' usual accommodation setting. Overall, the recommendation for 42% of these clients was that the client live in the community, and for another 41% that the client receive high-level care in a residential aged care facility.

Table 4.25: Recommended long-term care setting for Aged Care Assessment Program clients with dementia, by usual accommodation setting, 2008-09

	Recommended long-term care setting (%)						
		Institutional care					
Usual accommodation setting	**Community living**	**Low-level residential aged care**	**High-level residential aged care**	**Other institutional care**	**Total institutional care**	**Total[(a)]**	**Total (number)[(a)]**
Lives in community[(b)]	49.5	18.2	32.1	0.1	50.4	100.0	41,436
Institutional care							
Low-level residential aged care	0.5	8.4	91.0	0.1	99.4	100.0	6,027
High-level residential aged care	2.8	7.7	88.9	0.5	97.2	100.0	775
Other institutional care	3.8	17.8	74.4	3.8	95.9	100.0	394
Total institutional care	*1.0*	*8.8*	*89.8*	*0.3*	*99.0*	*100.0*	*7,196*
Total[(c)]	**42.4**	**16.8**	**40.6**	**0.1**	**57.6**	**100.0**	**48,725**

(a) The total for recommended long-term care setting includes the 28 cases for which the recommended setting was not reported.

(b) Due to the business rules that apply to the collection of ACAP data, some questions are not asked of all clients. Consequently, there may be slight discrepancies between tables as to the reported total number of ACAP clients living in the community.

(c) The total for usual accommodation setting includes the 93 cases for which the usual accommodation setting was not reported.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Not surprisingly, the recommendations varied according to the usual setting of the client at the time of the assessment. The recommendation for 50% of ACAP clients with dementia living in the community was that they remain there, either in a private residence (94% of these clients) or elsewhere in the community such as independent living within a retirement village (5%) or supported community accommodation (1%). For 32% of ACAP clients with dementia living in the community, the recommendation was to move to high-level care in a residential aged care facility, and for 18%, to move to low-level residential care.

The recommendation for 91% of clients in low-level care in a residential aged care facility was to move into high-level care. For those already in high-level care, the recommendation was that 89% of these clients remain in such a care setting. Note that, as indicated earlier, amendments to the *Aged Care Act 1997* which took effect on 1 July 2009 mean that since that time, ACAP approvals for a number of different types of care, including high-level residential care, no longer lapse. Thus, more recent data than those presented here are unlikely to show a large number of people already in high-level care being reassessed.

4.7 Community aged care packages

There is an ongoing emphasis in Australia on the provision of innovative and flexible community care to help people remain living in the community rather than enter residential care. Community-based services provided under the *Aged Care Act 1997* largely consist of community care packages offering different levels of assistance, depending on the needs of the client. As detailed in Box 4.7, low-level packaged care is provided to people in their own homes through programs such as the CACP program, while intensive home-based care and support are provided through programs such as EACH and EACHD.

Box 4.7: Description of three community aged care packages

Community Aged Care Packages (CACPs) target older people living in the community with care needs equivalent to at least low-level residential aged care. The types of assistance available through a CACP include help with personal care, meals, domestic assistance and transport.

Extended Aged Care at Home (EACH) packages target older people living at home with care needs equivalent to high-level residential aged care. EACH packages are flexible but generally include qualified nursing input, particularly in the design and ongoing management of the package. Services available may include clinical care, personal assistance, meal preparation, continence management, assistance to access leisure activities, emotional support, therapy services, and home safety and modification.

Extended Aged Care at Home Dementia (EACHD) packages provide individually tailored packages of care for older people with dementia who:

- have complex care needs
- have been assessed and approved by an ACAT as requiring high-level care
- wish to remain living at home and are able to do so with the assistance of an EACHD package.

An EACHD package provides similar support as an EACH package but offers additional levels of service to meet the specific needs of care recipients who experience behaviours of concern and psychological symptoms associated with dementia.

Source: DoHA 2011b.

Most community care programs offer services that can be received over variable periods of time. Services such as domestic assistance and personal care may be ongoing, whereas other services such as home maintenance may be required less often. As at 30 June 2010, there were 40,134 CACP recipients, 5,250 EACH recipients and 2,296 EACHD recipients (AIHW 2011g).

In this section of the report, the use of CACP, EACH and EACHD packages by those with dementia is described. The main data source is the 2008 Community Care Census, with these data describing care recipients who were accessing packaged care during a seven-day period (referred to as census week) in early 2008. As detailed in Appendix B, the number of people with dementia is likely to be under-reported in the CCC due to the manner in which they were identified.

Routine administrative data from DoHA about CACP, EACH and EACHD packages are also used in this section. Only limited use can be made of these data because information on the dementia status of the client is not available. Note that for the purposes of calculating the total number of EACHD recipients with dementia and the expenditure attributable to them (see Section 6.8), all recipients of EACHD packages are assumed to have dementia.

How many people with dementia access community care?

About 6,900 recipients (17%) of the three community care packages considered in the 2008 CCC were reported to have dementia (Table 4.26). Most (73%) were CACP recipients.

One in seven (14%) CACP recipients had dementia, while almost one in five (18%) EACH recipients had dementia. The majority (88%) of EACHD recipients were recorded to have dementia; as noted above, the means of identifying people with dementia in the 2008 CCC may have led to under-reporting of dementia status.

Table 4.26: Community aged care package recipients, by dementia status, 2008

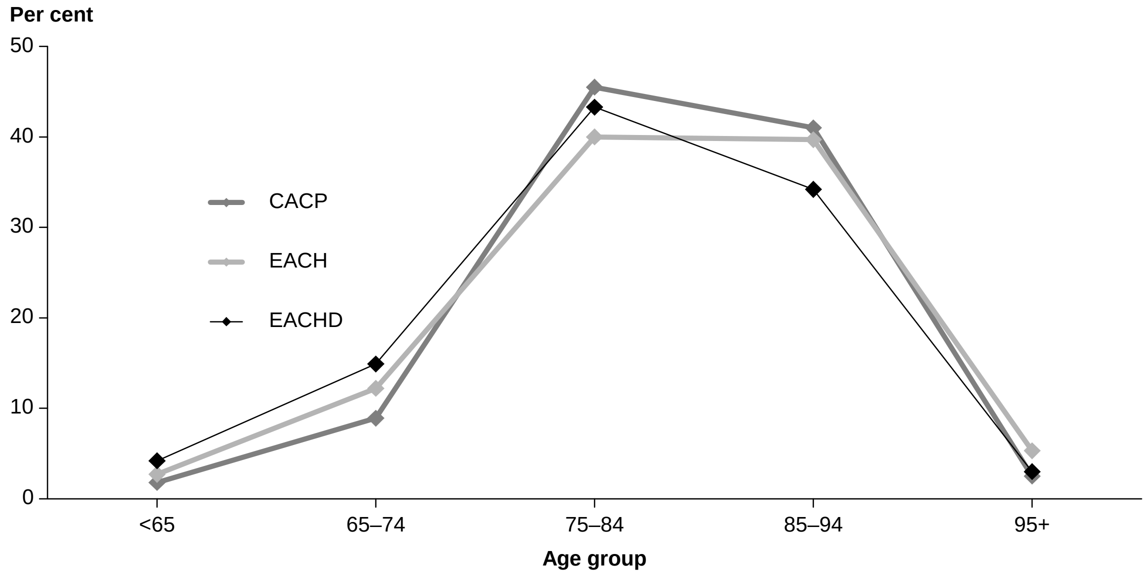
	Number				Per cent			
	CACP	EACH	EACHD	All packages	CACP	EACH	EACHD	All packages
With dementia	5,032	665	1,219	6,916	14.3	18.4	88.1	17.2
Without dementia	30,246	2,958	164	33,368	85.7	81.6	11.9	82.8
Total	**35,278**	**3,623**	**1,383**	**40,284**	**100.0**	**100.0**	**100.0**	**100.0**

Source: AIHW analysis of the 2008 Community Care Census.

For each of the three care packages, the 2008 CCC data suggest that about two in three recipients with dementia were women: 69% of CACP recipients, 65% of EACH recipients and 63% of EACHD recipients (Appendix Table A4.6). By way of comparison, 70% of all packaged care recipients were women (DoHA 2010a).

As seen in Figure 4.6, while the majority of community care package recipients with dementia were aged 75 or over, this proportion was highest for CACP recipients (89%); the corresponding proportion for EACH recipients was 85% and for EACHD recipients, 81%. The EACHD package had the highest proportion of recipients under 75.

Although the administrative data collections for CACP and EACH packages do not include information on whether the recipient had dementia, a more up-to-date estimate of the number of recipients with dementia can be derived by applying the proportions with



Note: Data for this figure are shown in Appendix Table A4.6.

Source: AIHW analysis of the 2008 Community Care Census.

Figure 4.6: Age of community aged care package recipients with dementia, by package, 2008

dementia estimated from the 2008 CCC to the total number of recipients of these care packages, as sourced from the administrative data collections. This suggests an estimated 5,739 CACP recipients and 966 EACH recipients had dementia as at 30 June 2010. Assuming that all EACHD recipients had dementia, the number of EACHD recipients with dementia at 30 June 2010 was 2,296. Thus, in total, an estimated 9,001 community care recipients had dementia as at 30 June 2010.

The administrative data for EACHD recipients as at 30 June 2010 are similar to the 2008 CCC data in terms of the proportion of recipients who were female (62%) and the proportion aged 75 or over (81%) (Appendix Table A4.7).

Remoteness

As seen in Table 4.27, for each of the three community care packages, data from the 2008 CCC suggest that about two-thirds of recipients lived in *Major cities*, between a quarter and one-fifth lived in *Inner regional* areas, and about 1 in 10 lived in *Other* areas of Australia.

Table 4.27: Community aged care package recipients with dementia, by remoteness, 2008

	Number			Per cent		
	CACP	EACH	EACHD	CACP	EACH	EACHD
Major cities	3,274	449	800	65.1	67.5	65.6
Inner regional	1,018	148	294	20.2	22.3	24.1
Other[(a)]	522	65	112	10.4	9.8	9.2
Unknown	218	3	13	4.3	0.5	1.1
Total	**5,032**	**665**	**1,219**	**100.0**	**100.0**	**100.0**

(a) ‘Other’ includes *Outer regional*, *Remote* and *Very remote*.

Source: AIHW analysis of the 2008 Community Care Census.

Country of birth and preferred language

According to the CCC, 64% of recipients of community aged care packages with dementia were born in Australia. This compares with 67% of all recipients of these packages (DoHA 2010a). Among those with dementia, the proportion of Australian-born recipients was higher among CACP recipients (66%) than among EACH (58%) and EACHD recipients (57%).

Overall, the CCC data indicated that English was the main language spoken at home for 84% of community care package recipients (DoHA 2010a). A similar proportion was observed for those with dementia (83%). The relevant proportions for recipients with dementia in each of the three community care packages were as follows: 85% of CACP, 74% of EACH and 78% of EACHD recipients.

Indigenous status

The lack of information on the dementia status of clients in the CACP and EACH databases means that up-to-date information is not available on how many Indigenous Australians with dementia access these programs. If we assume that all EACHD recipients have dementia, administrative data for 30 June 2010 suggest that 1% of EACHD recipients identified as being Indigenous Australians (AIHW 2011g).

When all recipients are considered (not just those with dementia), the usage rates of CACP, EACH and EACHD packages by Indigenous Australians have been found to be relatively high compared with their non-Indigenous counterparts (AIHW 2011b). For example, as at 30 June 2010, Indigenous Australians aged 75 and over used almost 80 CACPs per 1,000 population—more than three times the rate among non-Indigenous Australians in that age group (23 CACPs per 1,000 population). This may reflect the poorer health of Indigenous Australians, the different age distributions of the populations, different levels of usage and access to other services, and different preferences.

Meanwhile, CCC data suggest that 1% (or 96) community care package recipients with dementia identified as Indigenous Australians (Table 4.28). This is lower than the corresponding proportion of 4% of all recipients of these packages (DoHA 2010a). As discussed in Appendix B, the CCC data are likely to under-estimate the number of packaged care recipients who were Indigenous Australians.

Table 4.28: Community aged care package recipients, by dementia status and Indigenous status, 2008

	With dementia		Without dementia		Total	
	Number	**%**	**Number**	**%**	**Number**	**%**
Indigenous	96	1.4	1,567	4.7	1,663	4.1
Non-Indigenous	6,810	98.5	31,717	95.1	38,527	95.6
Total[(a)]	**6,916**	**100.0**	**33,368**	**100.0**	**40,284**	**100.0**

(a) The total includes those for whom Indigenous status was not reported.

Source: AIHW analysis of the 2008 Community Care Census.

Indigenous Australians with dementia may access other community care services provided, for example, under the National Aboriginal and Torres Strait Islander Flexible Aged Care program or by Multi-Purpose Services. Both of these target areas outside major cities. No information on the dementia status of people accessing these programs is available.

A study by Alzheimer's Australia NT (2002) investigated the extent of, and barriers to, service use by Indigenous Australians with dementia. The results suggested that in remote areas, the availability of culturally appropriate services influenced access, whereas in urban areas, reduced access was more likely to be related to social isolation and other personal and health factors. The study found that unmet need for services included community support, appropriate diagnostic tools for dementia and residential aged care. Researchers advocate an approach to dementia in this population that takes into account the impact of history, context and culture (Arkles et al. 2010).

Living arrangements

The CCC indicates that the living arrangements of community care package recipients differed with the type of package received (Table 4.29). The majority (53%) of CACP recipients with dementia lived alone, while 44% lived with family. CACP recipients with dementia were less likely to live alone than the average CACP care recipient (63%) (DoHA 2010a). Meanwhile, 72% of people with dementia accessing an EACH package and 75% of those with an EACHD package lived with family.

According to administrative data on EACHD packages, as at 30 June 2010, the distribution of living arrangements was similar to that seen in the CCC, with 74% living with family (AIHW 2011g).

Table 4.29: Community aged care package recipients with dementia, by living arrangements, 2008

	Number				Per cent			
	CACP	EACH	EACHD	All packages	CACP	EACH	EACHD	All packages
Lives alone	2,685	168	281	3,134	53.4	25.3	23.1	45.3
Lives with family	2,227	479	919	3,625	44.3	72.0	75.4	52.4
Lives with others	116	16	17	149	2.3	2.4	1.4	2.2
Total[(a)]	**5,032**	**665**	**1,219**	**6,916**	**100.0**	**100.0**	**100.0**	**100.0**

(a) The total includes those for whom living arrangements were not reported.

Source: AIHW analysis of the 2008 Community Care Census.

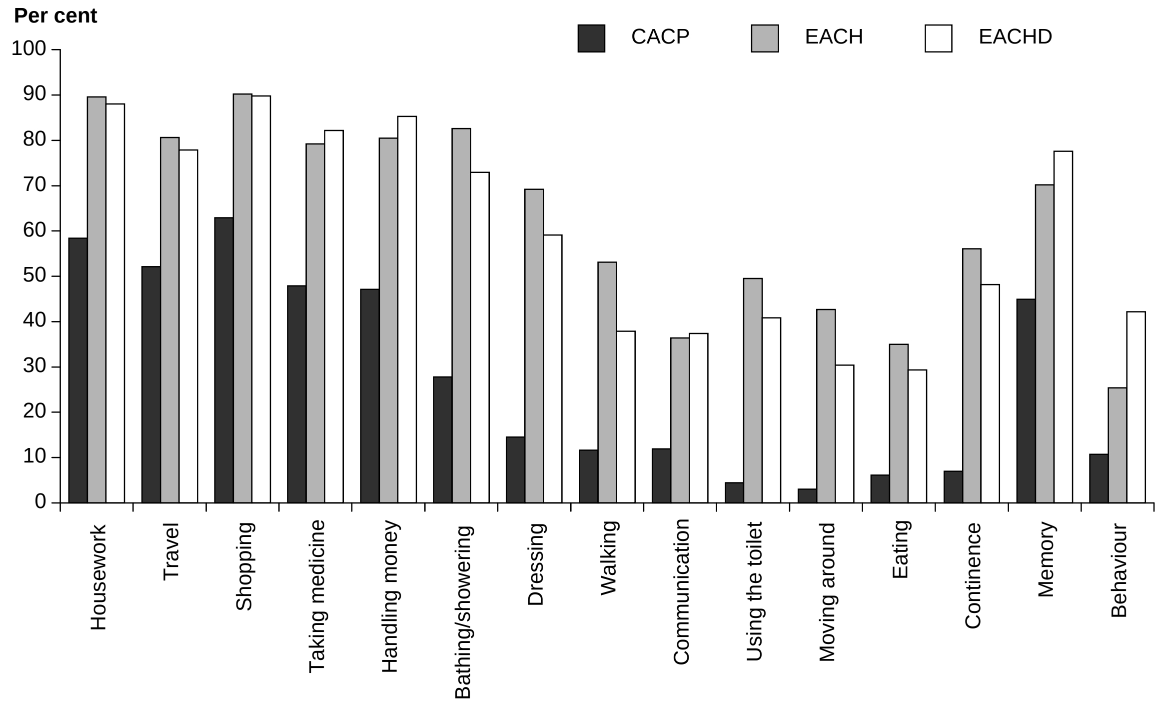
Care needs

Information about the extent of assistance or supervision that recipients needed with specific activities was also collected in the CCC. For each activity type, there were three possible responses: 'always needs assistance', 'needs some assistance' and 'can do without assistance'. The specific activities fell into three groups (DoHA 2010a):

- *instrumental activities of daily living*: this included five activities that supported independent living: housework, travel (getting to places out of walking distance), shopping, taking medicine and handling money
- *activities of daily living*: this consisted of seven personal care activities: bathing/showering, dressing, walking, communication, using the toilet, moving around (getting out of bed and moving around) and eating
- *aspects of self-management*: this included three aspects of self-management: continence (whether the recipient required assistance managing their bladder and bowel function), memory (whether assistance was required with tasks requiring memory and/or

organisational skills) and behaviour (whether assistance was required managing behaviour such as aggression, wandering or agitation).

As would be expected, the proportion of care recipients with dementia always needing assistance with the various activities was much lower among CACP recipients than among EACH or EACHD recipients (Figure 4.7). Furthermore, for virtually all activities for each of the three packages considered, people with dementia were more likely than the average care recipient to always require assistance (DoHA 2010a).



Note: Data for this figure are shown in Appendix Table A4.8.

Source: AIHW analysis of the 2008 Community Care Census.

Figure 4.7: Community aged care package recipients with dementia who 'always needed assistance' with specified activities, 2008

Of those with dementia receiving CACP packages, 63% always needed assistance with shopping and 59% always needed assistance with housework, while 45% always needed help with memory and organisational tasks (Appendix Table A4.8).

Of those with dementia receiving either an EACH or EACHD package, in each of the five *instrumental activities of daily living* around 80% or more always needed assistance. Around half of the recipients with dementia (56% in EACH and 48% in EACHD) always needed help with continence management and more than two-thirds always needed help with memory and organisational skills (70% of EACH and 78% of EACHD recipients).

4.8 Other community aged care services

In addition to assistance provided through community aged care packages, there are a number of other community aged care services that people with dementia may access. Three of these are:

- the Home and Community Care (HACC) program
- DVA Veterans' Home Care, which is designed to assist veterans, war widows and widowers who wish to continue living independently but who need a small amount of practical help
- DVA Community Nursing Program, which meets clinical and/or personal care needs of veterans, war widows and widowers by providing access to community nursing services.

For each of these three programs, no national information is available on whether those accessing the services have dementia. However, the number of people with dementia who used HACC services can be estimated.

Home and Community Care

HACC is a central element of the Australian Government's aged care policy and, in terms of client numbers, is the largest of the community care programs in Australia. In 2009–10, there were 893,224 HACC clients across Australia, 83% of whom were aged 60 and over (DoHA 2011g). Through HACC, services such as domestic assistance, personal care, professional allied health care and nursing services are provided to older Australians, younger people with disability and their carers to allow them to be more independent at home and in the community (DoHA 2012i).

No information on dementia status is captured in the HACC data collection. However, some data on dementia and/or functional status of HACC clients is available from data on around 12,000 clients assessed by Silver Chain (a major provider of HACC services in Western Australia) during 2010. Based on those data, the AIHW estimates that 10.2% of HACC clients aged 60 years and over had dementia. Applying this proportion to the total number of HACC clients aged 60 and over for 2009–10 (736,978 people) suggests that, across Australia, an estimated 75,200 people with dementia made use of services delivered through the HACC program in that year.

4.9 Flexible aged care services

Apart from mainstream residential and community care programs, the Australian Government also funds flexible aged care services that provide aged care in alternative and innovative ways (DoHA 2011b). Flexible aged care services include EACH and EACHD packages, which have been described in Section 4.7. Other flexible aged care services include the Transition Care Program (TCP), Innovative Care services, Multi-Purpose Services and the Aboriginal and Torres Strait Islander Flexible Aged Care Program. Available data about these services do not include information about whether or not recipients had dementia. However, the number of people with dementia accessing the TCP can be estimated as described below.

Transition Care Program

The TCP provides goal-oriented and therapy-focused services to older people after a hospital stay, including low intensity therapy, case management, and nursing support or personal care (DoHA 2011h). The program was established in 2004–05 as a jointly-funded initiative between the Australian and state and territory governments, and is managed by the state and territory governments. In 2009–10, there were 14,976 TCP recipients (DoHA 2010c).

While no information on their dementia status is collected through the TCP, an estimate of the number of people with dementia who accessed this program can be derived using Aged Care Assessment Program data. To access TCP, a person must first have been assessed through the ACAP and approved as eligible for transition care. In 2009–10, 15.6% of those approved for transition care had dementia. Applying this proportion to the total number of TCP clients in 2009–10 suggests that about 2,300 people with dementia received transition care services during this period.

4.10 Respite care

Respite care offers support to older people and their carers who may need a break or who require some extra care for a short period (such as during, or while recovering from, illness). Care may be provided for a few hours on a one-off or regular basis, for a couple of days or for a few weeks. Respite can occur in a variety of settings, including homes, centres, residential aged care services and other locations, with care provided by volunteers and/or paid respite workers. Respite is especially important for people caring for someone with dementia. As discussed further in Chapter 5, the demands of the caring role may involve the provision of substantial amounts of physical, psychological, cognitive and social support, while behaviour changes may add to the complexity of caring.

The SDAC provides some insight into the use of respite care services by co-resident primary carers of people with dementia who are living in the community (see Box 5.1 for a definition of 'primary carers' as defined for SDAC purposes). When asked generally about their need for respite care, 63% of these carers indicated they did not need respite care (Table 4.30). Most (61%) co-resident primary carers of people with dementia reported they had never used respite services. The main reasons given were that they did not need the service (38%) or the services were not wanted by either the carer or care recipient (39%). Conversely, 39% of co-resident primary carers of people with dementia had used respite care, with most of these carers having done so in the previous three months.

The use of respite services by primary carers of people with dementia was higher than the use of these services by all co-resident primary carers. About 89% of all co-resident carers had never used respite services and 68% of these indicated the main reason was that they did not need it.

Table 4.30: Use of respite services: primary carers[a] of people with dementia and all primary carers of those living in the community, 2009 (per cent)

	Primary carers of people with dementia	All primary carers
Need for respite services		
Does not need respite care	63.0	86.8
Needs respite care	37.0	13.2
Total	**100.0**	**100.0**
Use of respite care		
Used respite care in last 3 months	28.1	6.4
Used respite care but not in last 3 months	*10.5	4.7
Never used respite care	61.4	89.0
Total	**100.0**	**100.0**
Main reason for never using respite care[b]		
Does not need service	38.0	67.9
Available services not suited to needs	*9.7	2.3
Care recipient does not want service	30.2	13.0
Carer does not want service	*9.3	8.6
Other reasons	*12.9	8.2
Total	**100.0**	**100.0**

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

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

(b) Includes primary carers who indicated they had never used respite care.

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

Use of the National Respite for Carers Program

The National Respite for Carers Program (NRCP) is funded by the Australian Government and targets carers of four groups: the frail elderly, younger people with disabilities, people with dementia, and people with dementia who have ‘changed behaviours’ (DoHA 2011b). The program provides direct respite care in a number of settings, including day respite in community settings, in the home and in respite cottages (but not in residential aged care facilities). Indirect respite care, such as domestic assistance, social support and personal care for the care recipient, is also provided by the NRCP. An ACAT assessment is not required to access the NRCP, but the program has assessment procedures focussing on the needs of the carers and the people for whom they care.

One of the data sources used in this section is the 2008 CCC, which collected data on all primary carers and care recipients who received respite assistance through the NRCP during census week. These data represent only part of the total NRCP population as the census pertained to a one-week period. Also, as noted in Appendix B, the number of NRCP recipients reported to have dementia in the 2008 CCC may be an underestimate.

While details about carers who accessed respite through the NRCP are provided in Chapter 5, data from the CCC are used in this chapter to describe NRCP care recipients and attributes of service use. See Box 5.2 for details on how ‘primary carer’ and ‘carer’ were defined in the CCC survey. In addition to data about the NRCP from the CCC, this section also presents administrative Service Activity Report data relating to NRCP care recipients for 2009–10, as provided by DoHA (see Appendix B for further information).

Note that while care recipients who access the NRCP may also receive care through the CACP, EACH or EACHD programs, CCC data suggest that packaged care and the NRCP are generally targeting different people in the community (DoHA 2010a).

How many people with dementia access NRCP?

According to service activity data supplied by DoHA, the NRCP assisted 37,220 primary carers through respite during 2009–10, with 32,831 care recipients provided with respite care during that period. Of the care recipients, almost 20,000 (or 60%) were identified by service providers as having dementia (Table 4.31). Nine in ten (92%) of those with dementia were aged 65 or over, compared with 64% of NRCP care recipients without dementia.

Table 4.31: National Respite for Carers Program care recipients, by dementia status and age, 2009–10

	Number			Per cent		
	<65	65+	Total	<65	65+	Total
With dementia	1,512	18,142	19,654	7.7	92.3	100.0
Without dementia	4,771	8,406	13,177	36.2	63.8	100.0
Total	**6,283**	**26,548**	**32,831**	**19.1**	**80.9**	**100.0**

Source: Unpublished National Respite for Carers Program data provided by DoHA.

Sociodemographic characteristics

Age and sex

The CCC data indicate that 48% of all NRCP care recipients during census week were aged 75–84, just over a quarter (28%) were aged 85–94 and few (2%) were aged 95 and over (Figure 4.8). The age distribution of care recipients with dementia was similar for men and women. NRCP recipients with dementia tended to be younger than their counterparts who accessed CACP, EACH and EACHD packages during census week in 2008 (see Figure 4.6).

The CCC data suggest that 57% of NRCP care recipients with dementia were women (Appendix Table A4.9) compared with 60% of all NRCP care recipients (DoHA 2010a).

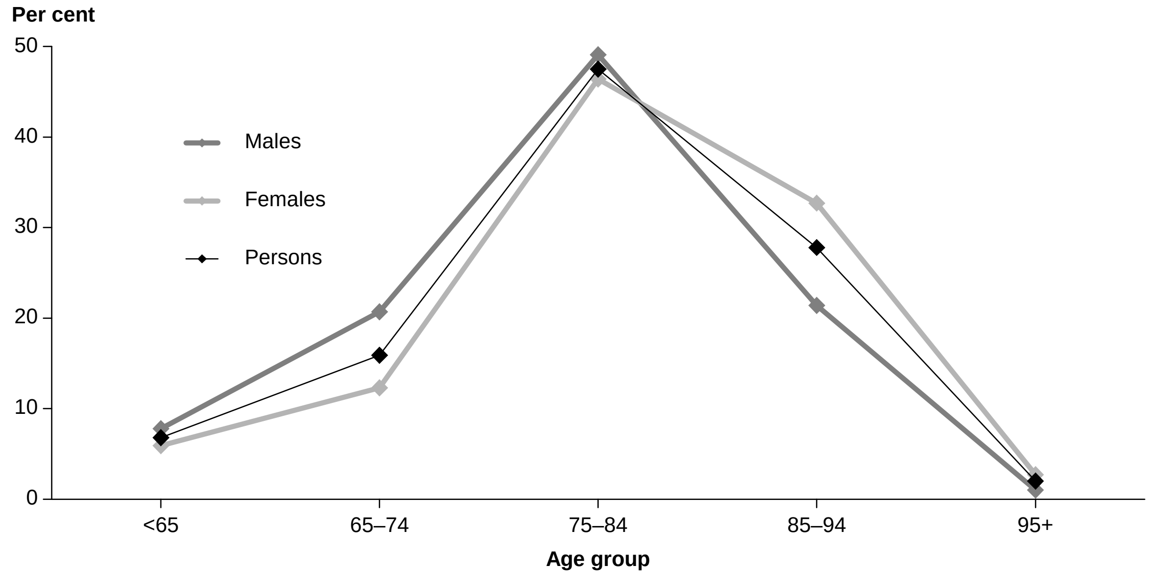
Remoteness

The majority of NRCP care recipients with dementia lived in *Major cities* (62% or 2,313 people), 23% lived in *Inner regional* areas and 12% in other areas. Remoteness information was not available for 4% of these care recipients.

Country of birth and preferred language

The majority (63%) of NRCP care recipients with dementia were born in Australia. Similarly, 65% of all NRCP care recipients were born in Australia (DoHA 2010a).

English was the main language spoken at home for around 4 in 5 NRCP care recipients, both with (81%) and without (79%) dementia (DoHA 2010a).



Note: Data for this figure are shown in Appendix Table A4.9.

Source: AIHW analysis of the 2008 Community Care Census.

Figure 4.8: Age of National Respite for Carers Program care recipients with dementia, by sex, 2008

As part of the CCC, information was collected on whether care recipients accessed additional NRCP services that specifically addressed the absence of English language skills, for example bilingual brochures or an interpreter. Almost one in five (18%) recipients with dementia received additional services that specifically addressed the absence of English; this was similar to the proportion of all recipients receiving these services (20%).

Indigenous status

CCC data suggest that 1% of NRCP care recipients with dementia were Indigenous Australians, compared with 2% of all NRCP care recipients (Table 4.32).

Table 4.32: National Respite for Carers Program care recipients, by dementia status and Indigenous status, 2008

	With dementia		Without dementia		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
Indigenous	32	0.9	160	3.2	192	2.2
Non-Indigenous	3,703	98.9	4,733	96.1	8,436	97.3
Total[(a)]	**3,746**	**100.0**	**4,927**	**100.0**	**8,673**	**100.0**

(a) The total includes those care recipients for whom Indigenous status was not reported.

Source: AIHW analysis of the 2008 Community Care Census.

While information on the Indigenous status of recipients with dementia was not available in the unpublished 2009–10 NRCP service activity data, those data indicate that 5% of all NRCP recipients in that year were Indigenous Australians; this is a larger proportion than that indicated in the Census data. A number of explanations can be posited for this difference: the proportion of recipients who were Indigenous Australians may have differed considerably between 2008 and 2009–10, the unpublished NRCP data may have overestimated the proportion who were Indigenous, or the CCC may have underestimated the proportion of NRCP care recipients who were Indigenous Australians.

Living arrangements

According to the CCC, 16% of care recipients with dementia lived alone (Table 4.33). This proportion is considerably lower than the rate among their counterparts with a CACP package (53%) and, to a lesser degree, among EACH and EACHD recipients (25% and 23% respectively) (see Table 4.29). Most NRCP care recipients with dementia lived with family (82%). By comparison, 73% of all NRCP care recipients lived with family and 22% lived alone.

Table 4.33: National Respite for Carers Program care recipients, by dementia status and by living arrangements, 2008

	With dementia		Without dementia		Total	
	Number	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Lives alone	594	15.9	1,345	27.3	1,939	22.4
Lives with family	3,080	82.2	3,265	66.3	6,345	73.2
Lives with others	62	1.7	102	2.1	164	1.9
Total	**3,746**	**100.0**	**4,927**	**100.0**	**8,673**	**100.0**

(a) The total includes those care recipients for whom living arrangements were not reported.

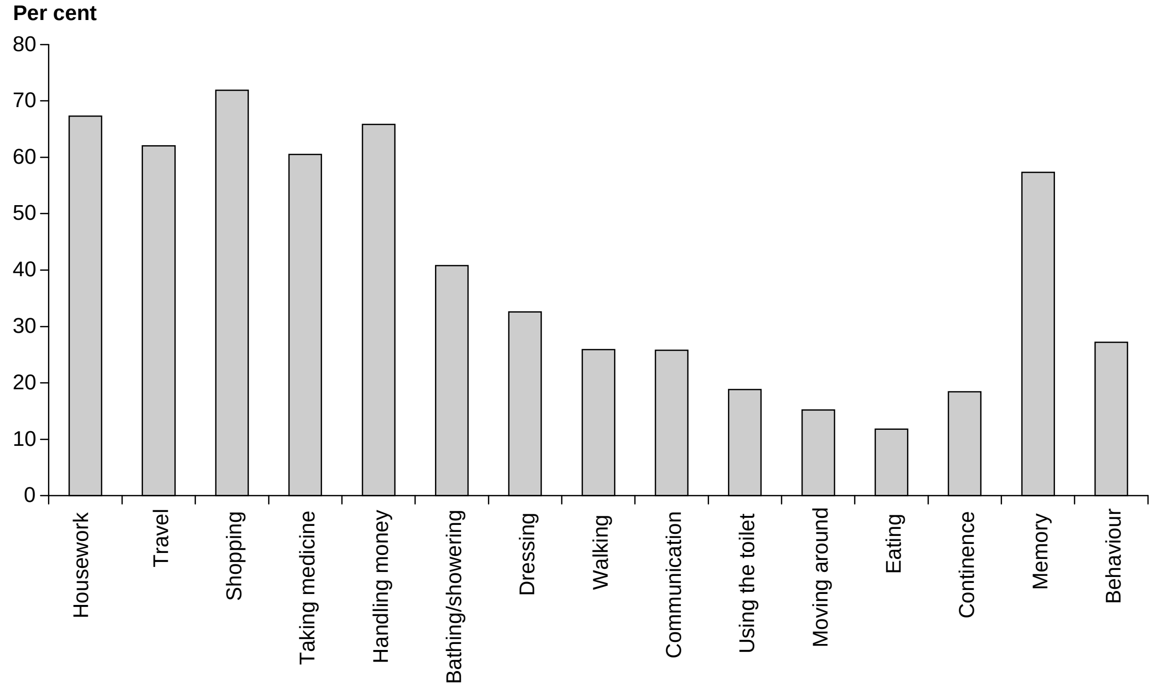
Source: AIHW analysis of the 2008 Community Care Census.

Care needs

As with the community aged care packages (described earlier), the CCC collected information about the extent of assistance required by NRCP care recipients with dementia, with three possible responses: ‘always needs assistance’, ‘needs some assistance’ and ‘can do without assistance’. The activities with which NRCP care recipients most commonly reported ‘always requiring assistance’ were: shopping (72%), housework (67%), handling money (66%) and travel (62%) (Figure 4.9). The CCC data also indicated that 27% always needed assistance with ‘managing behaviour’, while 39% sometimes required assistance in this area (Appendix Table A4.10).

Information on the number of care recipients who were reported to have ‘dementia with challenging behaviour’ is available from NRCP service activity data for 2009–10. Such care recipients are defined as those ‘with dementia and challenging behaviour who require intervention or management strategies as a result of their challenging behaviour’ (DoHA 2006).

As shown in Table 4.34, the NRCP service activity data suggest that 32% of NRCP care recipients with dementia were recorded as having challenging behaviour. This is similar to the proportion of those with dementia recorded in the CCC as always requiring assistance with ‘managing behaviour’ (27%).



Note: Data for this figure are shown in Appendix Table A4.10.

Source: AIHW analysis of the 2008 Community Care Census.

Figure 4.9: National Respite for Carers Program care recipients with dementia who 'always needed assistance' with specified activities, 2008

Table 4.34: National Respite for Carers Program care recipients with dementia, by age and whether they had challenging behaviour, 2009–10

	Number			Per cent		
	<65[(a)]	65+[(a)]	Total	<65[(a)]	65+[(a)]	Total
With challenging behaviour	621	5,645	6,266	41.1	31.1	31.9
With no challenging behaviour	891	12,497	13,388	58.9	68.9	68.1
Total	**1,512**	**18,142**	**19,654**	**100.0**	**100.0**	**100.0**

(a) For care recipients who were Aboriginal or Torres Strait Islanders, the '<65' age group refers to those under 50, and the '65+' age group refers to those aged 50 and over.

Source: Unpublished National Respite for Carers Program data provided by DoHA.

Reasons for accessing respite

Carers may seek respite care services for a number of reasons. According to the CCC, 49% of primary carers of recipients with dementia said that the main reason for first accessing respite care was emotional stress and strain; this compares with 38% of carers of recipients without dementia giving this response (Table 4.35). Other reasons for seeking respite among primary carers of people with dementia were the increasing needs of the care recipient (22%), carer employment issues (9%) and the carer's need for time to maintain regular activities (7%).

Table 4.35: Primary carers[a] of National Respite for Carers Program care recipients with and without dementia, by key reason for carer first accessing respite care, 2008

	Primary carers of recipients with dementia		Primary carers of recipients without dementia	
	Number	Per cent	Number	Per cent
Carer-related reasons	**2,788**	**74.4**	**3,391**	**68.8**
Emotional stress and strain	1,846	49.3	1,872	38.0
Employment issue	343	9.2	525	10.7
Maintain regular activities	248	6.6	515	10.5
Slow physical health deterioration	132	3.5	183	3.7
Acute physical exhaustion/illness	131	3.5	155	3.1
Other carer-related reasons	88	2.3	141	2.9
Care recipient reasons	**915**	**24.4**	**1,365**	**27.7**
Increasing needs of care recipient	831	22.2	1,049	21.3
Other care-recipient reasons	84	2.2	316	6.4
Other reasons[b]	**43**	**1.1**	**171**	**3.5**
Total	**3,746**	**100.0**	**4,927**	**100.0**

(a) See Box 5.2 in Chapter 5 for a definition of primary carer, as it pertains to these data.
(b) 'Other reasons' includes 'One-off event' and 'Don't know'.

Source: AIHW analysis of the 2008 Community Care Census.

4.11 Residential aged care services

The Australian Government funds aged care facilities to provide residential aged care to older Australians whose needs are such that they can no longer remain in their own homes. Facilities provide suitable accommodation and related services (such as meals, laundry and cleaning), as well as personal care services (such as assistance with the activities of daily living). Nursing care and equipment are provided to residents needing such assistance. Residential aged care is available on a permanent or respite basis.

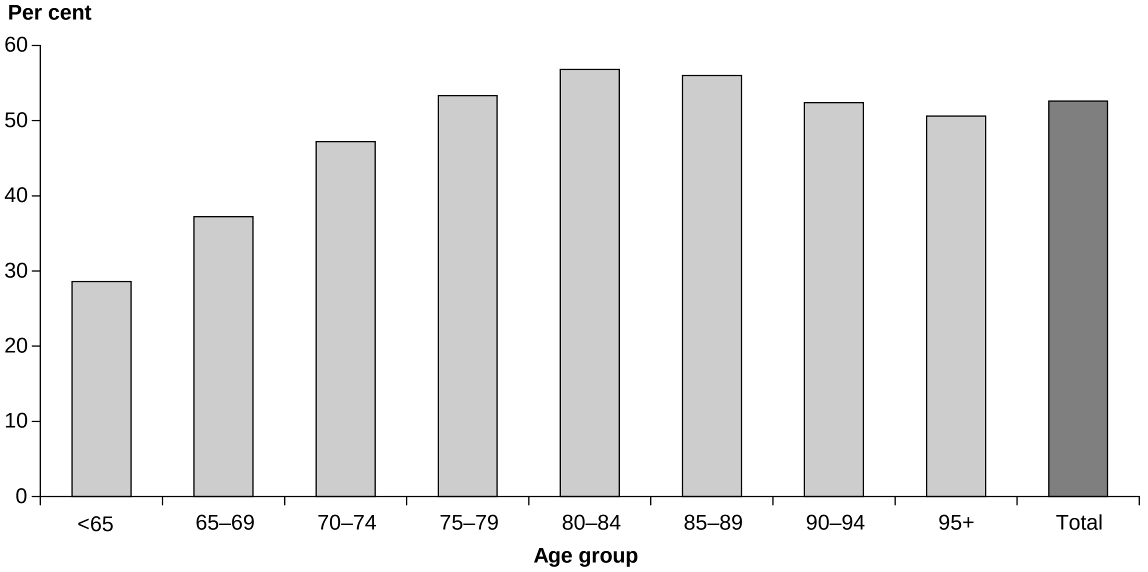
At 30 June 2010, 2,772 service providers provided 179,749 Australian Government-subsidised residential aged care places across Australia (excluding places that flexible programs provided) (AIHW 2011h). The majority (60%) of service providers were in the not-for-profit sector, such as religious and community organisations. A further 29% were private for-profit establishments, and the remaining 11% were state and local government facilities. The average facility size has grown from 46 places in 1998 to 65 in 2010.

Permanent residents

Information about the care needs and dementia status of people in residential aged care facilities is collected through the ACFI. These data do not include information on:

- people who accessed respite care in residential aged care facilities
- people in residential care places under the Multi-Purpose Service Program or the National Aboriginal and Torres Strait Islander Flexible Aged Care Program
- people in residential aged care facilities that were not subsidised by the Australian Government.

About 53% (112,139 residents) of all permanent residents in Australian Government-subsidised aged care facilities in 2009–10 had a diagnosis of dementia. As shown in Figure 4.10, this proportion varied by age group. Almost 3 in 10 (29%) under the age of 65 had dementia. The proportion increased to 57% among residents aged 80–84, and then fell to 51% for those aged 95 and over.



Note: Data for this figure are shown in Appendix Table A4.11.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Figure 4.10: Proportion of permanent residents with dementia in aged care facilities, by age, 2009–10

Considering differences by jurisdiction, the proportion of residents with dementia in subsidised aged care facilities ranged from 51% (in Victoria, Tasmania and Queensland) to 57% (in the Northern Territory) (Appendix Table A4.12).

Further details about the characteristics of permanent residents with dementia in residential aged care are provided in Chapter 3. In short, 70% of permanent residents with dementia were women, and the average age was 85 years. Most residents with dementia (87%) had high-care needs, compared with 63% of other residents.

Length of stay in residential aged care

Data on the length of stay in residential aged care facilities of all permanent residents with an ACFI appraisal who had separated at any time during 2009–10 are shown in Table 4.36. The term 'separated' refers to residents leaving the residential aged care facility for reasons such as admission to hospital, transfer to another facility (excluding those who transfer directly from one facility to another), returning to the community, or death. Although it is not common, some residents may 'separate' from a residential aged care facility more than once in a year (1% of permanent residents did so in 2009–10). Thus, these data on length of stay pertain to separations, not to individual people. Note that the data on length of stay do not take into account the date at which a resident was diagnosed with dementia, nor do they consider diagnosed comorbidities that could have an impact on a resident's length of stay.

As such, it reports the completed length of stay for residents who had a diagnosis of dementia at the time of their separation.

Table 4.36: Length of stay for all separations from permanent residential care[(a)] during 2009–10, by dementia status

	Number			Per cent		
Length of stay[(b)]	**With dementia**	**Without dementia**	**Total**	**With dementia**	**Without dementia**	**Total**
Under 6 months	5,904	7,934	13,838	20.0	33.3	25.9
6 to <12 months	3,201	2,828	6,029	10.9	11.9	11.3
1 to <3 years	8,688	6,205	14,893	29.5	26.0	27.9
3 to <5 years	5,483	3,124	8,607	18.6	13.1	16.1
5 years+	6,206	3,770	9,976	21.1	15.8	18.7
Total	**29,482**	**23,861**	**53,343**	**100.0**	**100.0**	**100.0**

(a) Pertains to separations by permanent residents living in Australian Government-subsidised aged care facilities who separated from the aged care facility during 2009–10.

(b) Length of stay is defined as the amount of time a resident was in an aged care facility from admission to separation to: a hospital, another residential facility, the community or died.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

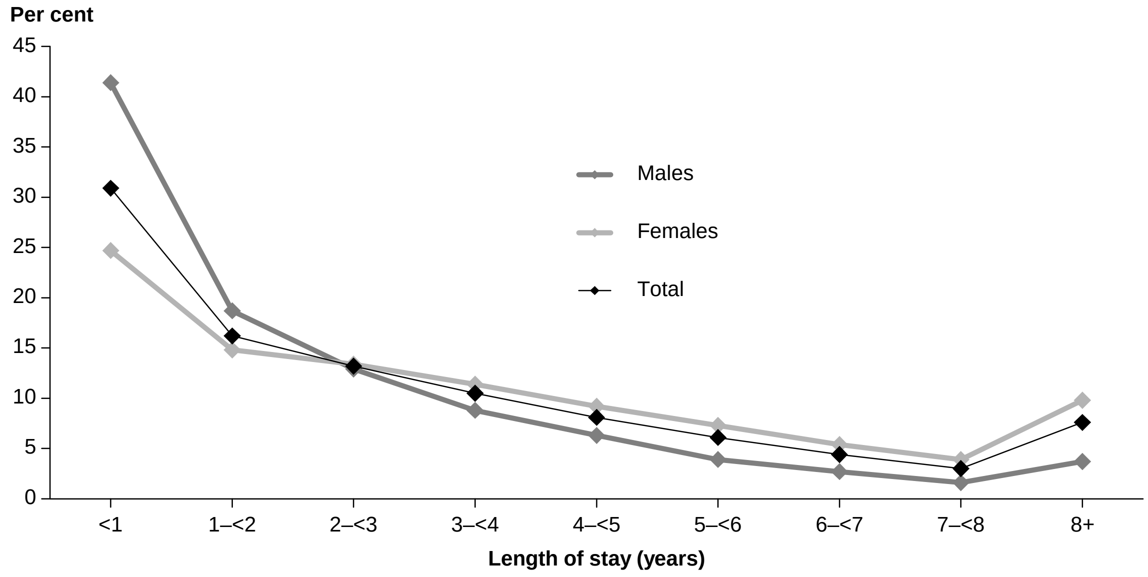
The length of stay for 31% of separations of permanent residents with dementia was less than 12 months, while it was between 1 year and less than 3 years for 30% of separations, and 3 years or more for 40% of separations. The length of stay of residents without dementia tended to be shorter, with 29% of their stays lasting 3 years or more.

Differences by sex in the length of stay, for all separations from residential aged care facilities of people with dementia, are shown in Figure 4.11. Among those who separated in 2009–10, men were more likely than women (41% versus 25% respectively) to have stayed in residential aged care for less than 12 months. At the other end of the scale, 10% of women had been there for 8 years or more, compared with 4% of men.

Respite care in residential aged care facilities

Residential respite care provides emergency or planned care in a residential aged care facility on a short-term basis. It can be provided as either low- or high-level care and is designed to provide a break for people living in the community and their carers (DoHA 2009b). Approval by an ACAT is required, and a person with a valid approval may use up to 63 days of respite care in a financial year (with the possibility of extensions). In 2010–11, there were a total of 61,687 admissions to residential respite care, providing an estimated 1.43 million respite days. On average, each client received 1.4 episodes of residential respite care during 2010–11 and their average length of stay per episode was 23.5 days (DoHA 2011b).

No data are available on the number of residential respite care clients who had dementia. Nonetheless, some data are available on the use of residential respite care by carers of those with dementia based on data from the Pathways in Aged Care (PIAC) project. Using data on those members of the PIAC cohort who had an approval for residential respite care use from an ACAT in 2003–04 (32,000 people), this study found that about 32% of people with dementia who were approved for residential respite care used it within 12 months of the approval. This was significantly higher than the 25% of those without dementia who used



Note: Data for this figure are shown in Appendix Table A4.13.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Figure 4.11: Length of stay for all separations from permanent residential care of those with dementia during 2009–10, by sex

such care in the 12 months following approval. Further details about the results of the PIAC study in relation to the take-up of residential respite care are available in the *Dementia and the take-up of residential respite care* bulletin (AIHW 2010c).

4.12 Pathways through aged care services

A 2009 review found there was no clear understanding of the common care pathways through aged care services that people with dementia take, especially in relation to the use of hospitals, community care and early intervention programs such as memory clinics (Runge et al. 2009). While there was a considerable amount of evidence about admission and predictors of entry to long-term residential care, there were little data on the predictors of community care use and transitions to and from these services. The care pathways and transitions experienced by people with dementia from special population groups such as Indigenous Australians, people from culturally and linguistically diverse backgrounds, those living in rural and remote areas, and people with intellectual disabilities were found to be similarly under-researched.

The PIAC project has sought to fill some of these research gaps. This project linked ACAP data for the PIAC cohort to data sets which showed use of five main aged care programs (HACC, VHC, CACP, EACH and EACHD) and residential aged care between 2002–03 and 2006–07 (AIHW 2011i).

Using data from about 33,300 people in the PIAC cohort who had had a completed ACAT assessment in 2003–04 and had not used aged care services prior to the assessment, the study found that people with dementia or cerebrovascular disease as their main health condition (as recorded during the ACAT assessment) were more likely to enter residential aged care than those with heart disease or musculoskeletal conditions (Karmel et al. 2012). Three in five cohort members with dementia used permanent residential care within 2 years of their first assessment, with just under half of these people having used community aged care services before entering residential care. People with dementia were also more likely than average to have used residential respite care (28% versus 20%). Conversely, fewer people with dementia had no service use (16%) or used only community aged care services (17%) compared with the whole cohort (24% and 29% respectively).

The rate of take-up of care was highest in the first month after assessment (43% of people with dementia). Much of this early program use was in community care (27%). Take-up of permanent residential care was more gradual: 13% of people with dementia entered permanent residential care within one month of assessment and 24% within 3 months. About 40% of those with dementia who would use residential care within 2 years of their first assessment had taken up their place in the first 3 months after assessment (Karmel et al. 2012).

4.13 Specialised mental health care services

In addition to accessing general health and aged care services, people with dementia may also make use of specialised mental health care services. As noted by Draper (2011), dementia is commonly associated with a range of behavioural and psychological symptoms, including depression, anxiety and psychosis.

In this section, information is provided on dementia-related care during 2009–10 in community mental health care and residential mental health care services. The aim of this section is not to present the total use of these services by people with dementia, but rather to identify service use for which dementia was the primary cause of the need for care. Thus, data pertain only to community mental health service contacts and residential mental health service episodes with a principal (rather than an additional) diagnosis of dementia. When interpreting the data presented in this section, note that the quality of principal diagnosis data may be affected by variability in collection and coding practices (see Appendix B and AIHW 2012c for further information). Also note that specialised mental health services may be provided in hospital; information on admitted patient care for people with dementia is presented in Section 4.4.

Community mental health care

Much of the treatment of mental illness is carried out by community mental health care services, operated by state and territory governments. This section presents information on the use of community mental health care services by people with dementia, with data derived from the National Community Mental Health Care Database (NCMHCD). The NCMHCD provides information on contacts between a client and a specialised mental health care service provider (see Box 4.8). Each mental health service contact is assigned a principal diagnosis, so contacts for which dementia was the principal diagnosis can be identified. Any one person may have had more than one service contact over a reporting period but, in the aggregated national data, it is currently not possible to reliably determine the number of unique clients with dementia who used community mental health care services. Appendix B provides further information about the coverage and data quality of this collection.

Box 4.8: Key concepts about community mental health care

Community mental health care refers to government-operated specialised mental health care provided by community mental health care services and hospital-based ambulatory care services, such as outpatient and day clinics.

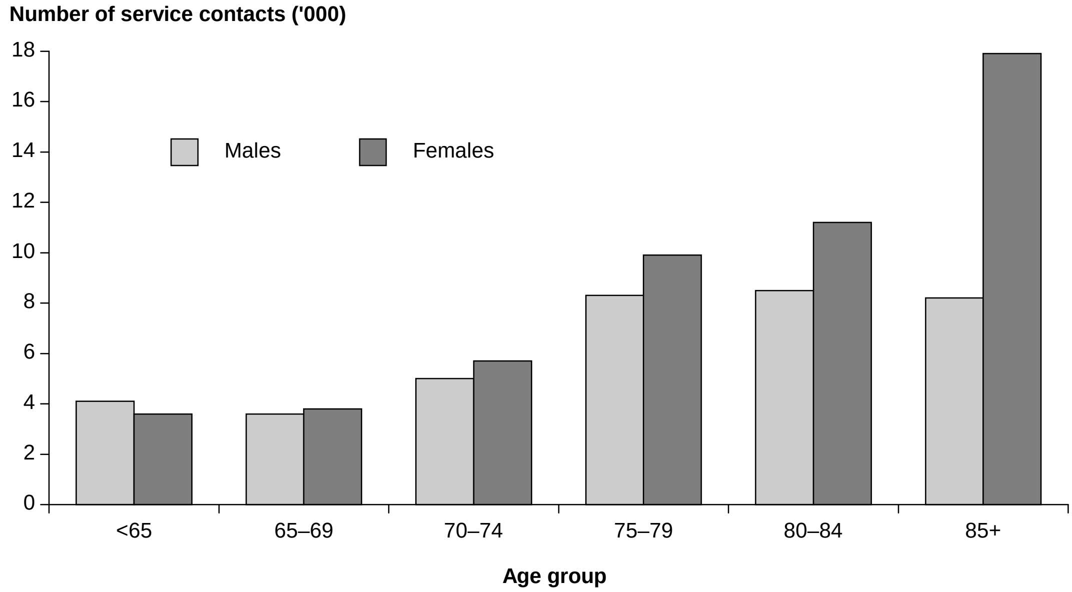
Service contacts are defined as the provision of a clinically significant service by a specialised mental health service provider for a patient/client, other than those admitted to psychiatric hospitals or designated psychiatric units in acute care hospitals and those resident in 24-hour staffed specialised residential mental health services, where the nature of the service would normally warrant a dated entry in the clinical record of the patient/client in question. Service contacts are not restricted to face-to-face communication, but can include telephone, video link or other forms of direct communication. Service contacts can be either with the patient or with a third party (such as a carer, a family member, another service provider).

Source: AIHW 2012c.

Number of service contacts

In 2009–10, a total of 6.6 million community mental health care service contacts were reported nationally. Of these, 90,308 were assigned a principal diagnosis of dementia; this equates to 1.4% of all community mental health service contacts. Of those service contacts for people aged 65 and over, 13% were assigned a principal diagnosis of dementia.

Women accounted for 58% of community mental health service contacts for dementia (Figure 4.12). As expected, given the increasing prevalence of dementia with age, the number of service contacts for dementia increased with the age of the clients. That is, only 8% of contacts were for clients younger than 65, while 29% of contacts were for those aged 85 and over. This latter proportion was higher for women (34%) than men (22%).



Note: Data for this figure are shown in Appendix Table A4.14.

Source: AIHW National Community Mental Health Care Database.

Figure 4.12: Community mental health service contacts with dementia as the principal diagnosis, by age and sex, 2009–10

Change over time

The number of community mental health service contacts for people with a principal diagnosis of dementia varied over the five years to 2009–10, from a high of 90,990 in 2005–06 to a low of 84,877 in 2008–09, with no clear trend evident (as seen in Table 4.37). The decrease in the number of contacts recorded between 2007–08 and 2008–09 may be partly due to Queensland transitioning to a new clinical information system that affected activity data reporting (AIHW 2012c).

Client characteristics

The NCMHCD provides information about the usual residence of people accessing community health care services (regardless of the location or jurisdiction of the service provider). In 2009–10, most service contacts for dementia were for people living in *Major cities* (60%), while 30% of contacts were for people living in *Inner regional* areas, 8% for people in *Outer regional* areas, and 1% in *Remote* and *Very remote* areas.

Table 4.37: Community mental health service contacts with dementia as the principal diagnosis, by sex, 2005–06 to 2009–10

	2005–06	2006–07	2007–08	2008–09	2009–10
Males	37,778	34,165	36,982	35,259	37,723
Females	51,191	50,866	51,713	49,028	52,123
Total(a)	**90,990**	**85,450**	**89,079**	**84,877**	**90,308**

(a) Includes service contacts for which sex was not reported.

Source: AIHW National Community Mental Health Care Database.

Information on mental health service contacts for dementia by Indigenous status is shown in Table 4.38. These data should be interpreted with caution since the data quality and completeness of Indigenous identification in the NCMHCD varies across jurisdictions (see Appendix B for more information). Due to this, the number of service contacts for Indigenous Australians is likely to be underestimated. In 2009–10, a total of 1,186 (or 1%) community mental health service contacts for dementia were for Indigenous Australians. This is consistent with the proportion of community aged care package recipients recorded as being Indigenous Australians, as discussed in Section 4.7.

Table 4.38: Community mental health service contacts with dementia as the principal diagnosis, by Indigenous status, 2009–10

Indigenous status(a)	Number	Per cent
Indigenous	1,186	1.3
Non-Indigenous	85,211	94.4
Not reported	3,911	4.3
Total	**90,308**	**100.0**

(a) These data should be interpreted with caution since the data quality and completeness of Indigenous identification varies across jurisdictions (see Appendix B for more information).

Source: AIHW National Community Mental Health Care Database.

Type of dementia

The number of community mental health service contacts for dementia in 2009–10 according to type of dementia is shown in Table 4.39. About 42% of these service contacts had a principal diagnosis of *Alzheimer disease*. A diagnosis of *Unspecified dementia* was recorded for 41% of these service contacts, while a further 13% of contacts were for people with *Vascular dementia*. The high proportion of *Unspecified dementia* diagnoses limits interpretation of these data, but the pattern appears quite different from that observed among permanent residents in subsidised aged care facilities, where 76% of residents with dementia were reported to have *Alzheimer disease* (see Section 3.3). However, it is similar to the proportion of those recorded as having Alzheimer disease who had an ACAT assessment in 2008–09 (51%). Those data also had a large proportion with a diagnosis of *Other dementia* (see Section 4.6).

Table 4.39: Community mental health service contacts with dementia as the principal diagnosis, by type of dementia and sex, 2009–10

	Number			Per cent		
Principal diagnosis (ICD-10-AM code)	**Males**	**Females**	**Total[(a)]**	**Males**	**Females**	**Total[(a)]**
Alzheimer disease (F00, G30)	15,424	22,084	37,967	40.9	42.4	42.0
Vascular dementia (F01)	6,386	4,969	11,356	16.9	9.5	12.6
Dementia in other diseases (F02)	1,827	1,335	3,164	4.8	2.6	3.5
Unspecified dementia (F03)	13,656	22,920	36,576	36.2	44.0	40.5
Delirium superimposed on dementia (F05.1)	430	815	1,245	1.1	1.6	1.4
Total	**37,723**	**52,123**	**90,308**	**100.0**	**100.0**	**100.0**

(a) Includes service contacts for which sex was not reported.

Source: AIHW National Community Mental Health Care Database.

Little difference was observed in the proportion of service contacts with *Alzheimer disease* according to sex (41% for men and 42% for women). In contrast, a diagnosis of *Vascular dementia* was more common for service contacts for men (17%) than for women (10%), and, a principal diagnosis of *Unspecified dementia* was more frequently assigned to service contacts for women (44%) than for men (36%).

Type of service contact

Community mental health care service contacts may involve an individual or group. They can be conducted with the client present or with a third party, such as a carer, family member and/or other professional or mental health worker. Table 4.40 shows that 43% of service contacts for dementia were individual contacts with the client present, while a further 45% were individual contacts with the client absent. In total, about 87% of service contacts for dementia were individual rather than group contacts. In regard to the group contacts, 59% were conducted in the absence of the client.

Mental health legal status

Each jurisdiction in Australia has legislation governing the treatment of people with mental illness in hospitals, residential care and the community. While such legislation varies between jurisdictions, all contain provisions for the assessment, admission and treatment of people on an involuntary basis. Five per cent (4,959 service contacts) of all community mental health care service contacts in 2009–10 for dementia involved a client with an involuntary mental health legal status, although this status may or may not have been due to dementia.

Table 4.40: Community mental health service contacts with dementia as the principal diagnosis, by type of contact, 2009–10

	Number	Per cent
Individual contact		
Client present	38,452	42.6
Client absent	40,193	44.5
Subtotal	*78,645*	*87.1*
Group contact		
Client present	4,815	5.3
Client absent	6,848	7.6
Subtotal	*11,663*	*12.9*
Total	**90,308**	**100.0**

Source: AIHW National Community Mental Health Care Database.

Residential mental health care

Residential mental health care services provide rehabilitation, treatment or extended care in a domestic-like environment on an overnight basis. Data on the use of these services are available from the National Residential Mental Health Care Database (NRMHCD). Information is collected about episodes of residential care (not about individual people) with principal diagnosis recorded for each episode, thus allowing for the identification of those episodes with a principal diagnosis of dementia.

The NRMHCD contains data on all episodes of residential care provided by government-funded residential mental health services in Australia, except those residential care services that were receiving funding under the *Aged Care Act 1997* and were subject to Commonwealth reporting requirements. As a result, this collection does not overlap with information collected about people with dementia in residential aged care facilities (reported in Section 4.11). Appendix B provides further information about the coverage and data quality of this collection, including a definition for 'episodes of residential care'.

In 2009–10, a total of 3,964 residential episodes were recorded in the NRMHCD. For 62 (or 1.6%) of these episodes, the principal diagnosis was dementia (Table 4.41). Considering only residential episodes for people aged 65 and over, 16% were for dementia.

The 62 residential episodes for dementia were associated with 5,193 residential care days. The majority of residential episodes were for men (58%) and for those aged 75 and over (76%).

Table 4.41: Residential mental health care episodes with dementia as the principal diagnosis, by sex and age, 2009–10

	Number	Per cent
Sex		
Males	36	58.1
Females	26	41.9
Age		
Under 75	15	24.2
75+	47	75.8
Total	**62**	**100.0**

Source: AIHW National Residential Mental Health Care Database.

4.14 Are services meeting needs?

Whether or not the available services are meeting the needs of people with dementia is influenced by a range of supply and demand factors. Government planning processes and budgets influence the supply of aged care places, which determines the number of places available, and the subsequent take-up and delivery of place allocations by service providers. Planning and provision for other services, such as primary health care and community health services, can also influence the level of supply of services, and thus the ability of people with dementia in the community to access those services. In addition, consumers must be aware of the services in order to make use of them.

Data on the level of unmet need among people with dementia are scarce, but the 2009 SDAC provides some information on this issue. Those living in the community who indicated that they had an unmet need for assistance were asked whether this unmet need related to *formal* and/or *informal* assistance.

According to the SDAC, of the core activities, the highest levels of unmet need were observed for mobility, followed by self-care (Table 4.42).

- Of those with dementia with an unmet need for assistance in one or more of the core activities, 22% had an unmet need for *formal* assistance.
- Of these core activities, those with an unmet need for assistance with mobility were the most likely to need formal assistance (19%), followed by those with an unmet need for assistance with self-care (14%).

Of those with dementia with an unmet need for assistance in one or more of the non-core activities, about 23% indicated an unmet need for formal assistance.

Table 4.42: Unmet need for formal assistance among people with dementia living in the community, by activity in which they had an unmet need, 2009 (per cent)

	Yes[(a)]	No	Don't know	Total
Core activities				
Self-care	*14.2	80.5	**5.3	100.0
Mobility	19.1	69.5	*11.4	100.0
Communication	**5.8	78.3	*15.9	100.0
Total core activities[(b)]	*21.7*	. .	. .	*100.0*
Non-core activities[(c)]				
Total non-core activities[(d)]	*23.1*	. .	. .	*100.0*
Total needing assistance[(e)]	**32.1**	**. .**	**. .**	**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) 'Yes' includes all those who indicated an unmet need for formal services; this includes reasons for unmet need of 'Did not know of service', 'Need not important enough', 'Won't ask or pride', 'Unable to arrange service', 'No services available', 'Not eligible for service', 'Service costs too much', 'Service doesn't provide sufficient hours' and 'Other reason'.

(b) Includes those with unmet need in at least one core activity.

(c) 'Non-core activities' includes health care, cognitive or emotional tasks, household chores, home maintenance or gardening, meal preparation, reading or writing, and private transport.

(d) Includes those with unmet need in at least one non-core activity.

(e) Includes those with unmet need in at least one core or non-core activity.

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

5 Carers of people with dementia

Key points

- In 2009, about 9 in 10 (92%) people with dementia living in the community were receiving care from one or more carers.
- Estimates suggest that around 200,000 Australians were carers of a person with dementia living in the community in 2011.
- About two-thirds of carers of people with dementia living in the community were women, and roughly half were aged 65 and over.
- Around 42% of main carers of a person with dementia were the spouse/partner of the care recipient and 44% were the son or daughter. When only *co-resident* primary carers were considered, 57% were the spouse/partner and 36% were the son or daughter.
- Co-resident primary carers of people with dementia were more likely than all co-resident primary carers to:
  - be providing continuous, rather than episodic, care (94% and 72% respectively)
  - be providing 40 or more hours of care per week (81% and 42%)
  - report at least one of four negative consequences (such as feeling weary or frequently feeling worried) due to their role as carer (57% and 48%)
  - have their sleep interrupted either frequently or occasionally due to their caring role (66% and 49%)
  - need additional support or an improvement in their situation (52% and 33%), with the greatest area of need for carers of people with dementia being more respite care.

5.1 Introduction

Carers such as family members and friends play a vital role in the lives of people with dementia who live in the community, particularly when the condition has progressed beyond the early stages. They often help with personal care, transport, housework and other activities, as well as managing behavioural problems and providing supervision. For those with dementia, access to such assistance can improve their quality of life, and may also help them delay or avoid entry into residential aged care services (Dramé et al. 2012).

While there is no single definition of 'carer', the term loosely refers to someone who provides ongoing informal assistance to a person living in the community who cannot care for themselves because of a disability, mental illness, chronic health condition or frailty. It does not include paid workers or volunteers arranged by an organisation or formal service. The terms carer, 'informal carer' and 'family carer' are often used interchangeably in the literature but carer is not interchangeable with 'informal assistance'. As discussed in Section 3.7, informal assistance is a broader term that includes the ongoing care provided by carers, as well as assistance provided by other family and friends on a more intermittent basis.

In this chapter, information is presented on the proportion of people with dementia living in the community who had a carer, as well as information about these carers.

What data are available?

Data from the following three data collections are used to describe carers of people with dementia living in the community: the 2009 SDAC, the ACAP and the 2008 CCC. Although information is provided about these collections in Appendix B, the following points should be noted.

The SDAC is the main source of national population data about carers, with information collected about carers and primary carers of care recipients living in the community (see Box 5.1 for definitions). Although information on the number of both co-resident (that is, living in the same household as the care recipient) and non-co-resident carers was collected in the 2009 SDAC, more detailed information was only collected about co-resident carers. Carers data collected in the 2003 SDAC (and described in AIHW 2007) are not directly comparable with those in this chapter. In addition, SDAC data presented in this report were extracted from the SDAC 2009 confidentialised unit record file (CURF). To protect confidentiality, some records were removed from the CURF by the ABS before making it available for analysis (ABS 2011b). Therefore, data shown in this report may not exactly match those in ABS published reports. For further details about the approach used to identify carers and primary carers in the 2009 SDAC, and differences from the 2003 SDAC, see Note 5.1 in Appendix D.

Box 5.1: Definitions of key terms in the 2009 Survey of Disability, Ageing and Carers

A **carer** is a person of any age who provides any informal assistance, in terms of help or supervision, to people with disabilities or long-term conditions, or people who are elderly (that is aged 60 or over). This assistance has to be ongoing, or likely to be ongoing, for at least 6 months.

Assistance to a person in a different household relates to 'everyday types of activities', without specific information on the activities. Where the care recipient lives in the same household, the assistance is for one or more of the following activities: cognition or emotion, communication, health care, household chores, meal preparation, mobility, property maintenance, reading or writing, self-care, or transport.

A **primary carer** is a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least 6 months and be provided for one or more of the core activities (communication, mobility and self-care). In this survey, primary carers only include people aged 15 and over for whom a personal interview was conducted. People aged 15 to 17 were only interviewed personally if parental permission was granted.

A **co-resident carer** is a carer who lives in the same household as the recipient of their care.

Sources: ABS 2010, 2011a.

As noted in Appendix B, the approach used to collect information about health conditions in the SDAC means that the data likely do not identify many people in the earlier stages of dementia. Information on carers of people in these stages may differ from that on carers of people in later stages.

The ACAP data collection provides information on whether its clients who live in the community have a carer and, if so, the characteristics of those carers. As noted in Section 4.6, the assessment of care needs for people who wish to access government-subsidised aged care services is made through the ACAP. Information on only one carer—the 'main carer'—is collected, with this carer defined as the person identified by the client and/or a carer as providing the most significant amount and type of care related to the client's capacity to remain living at home (see Box 5.2). The main carer may or may not live in the same household as the person for whom they provide care. Information was not collected about carers of ACAP clients who were permanent residents of residential aged care services or in hospital at the time of the assessment. ACAP data presented in this chapter relate to around 38,000 main carers of ACAP clients with dementia.

Box 5.2: Carer definitions in the Aged Care Assessment Program data collection and the 2008 Community Care Census

Aged Care Assessment Program

In the ACAP collection, a **carer** is someone, such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services (including paid staff in funded group houses), who has been identified by the individual, carer or significant other as providing regular and sustained care and assistance to the person without payment other than a pension or benefit. The carer may or may not live with the person for whom they care. Information is only collected about one carer in this collection, who is referred to as the **main carer**. The main carer is the person who is identified by the client and/or a carer as providing the most significant amount and type of care and assistance related to the client's capacity to remain living at home.

2008 Community Care Census

For the 2008 CCC, a **carer** was defined as a person such as a family member, friend or neighbour who provided regular and sustained care and assistance to another person, without receiving payment other than a pension or benefit. Formal care services such as care or assistance provided by paid workers or volunteers arranged by formal services were excluded. A **primary carer** was the person who provided the most informal (unpaid) care on an ongoing basis to the care recipient. This could include coordination of formal care but excluded formal care services such as care or assistance provided by paid workers or volunteers arranged by formal services.

Sources: DoHA 2008, 2010a, 2011f.

As part of the CCC, basic information was collected about the primary carers of recipients of assistance through the following government programs: CACP, EACH, EACHD and NRCP. The definition of 'primary carer', as used in the CCC, is in Box 5.2. The CCC data presented in this chapter relate to around 3,900 primary carers of CACP recipients with dementia, 600 primary carers of EACH recipients with dementia, 1,100 primary carers of EACHD recipients with dementia, and 3,700 primary carers of NRCP recipients with dementia.

The CACP provides older people living in the community with personal care services and other assistance at home (see Section 4.7). These packages are available to eligible people whose care needs are equivalent to at least low-level residential aged care. In contrast, the EACH and EACHD programs provide coordinated and managed packages of high-level care, tailored to the needs of people living in the community with complex care needs who would require a high level of residential care (DoHA 2011b). The NRCP offers respite for carers by providing direct respite care in a number of settings (including the home and respite cottages), as well as indirect respite such as personal care and domestic assistance for the care recipient (see Section 4.8).

In the CCC, information was collected about primary carers who lived in the same or a different household as the care recipient. The information collected about the carers included their sex, age, whether they lived in the same household as the recipient, and their familial relationship to the recipient.

The information about carers in the three data collections all pertain to carers providing assistance to recipients living in the community. Although family members and friends continue to provide assistance to people with dementia living in residential care, the literature suggests this care focuses more on giving social and emotional support than on meeting the daily needs of the recipient (Schofield 2001; Schofield et al. 1998). The collections also all focus on the carer providing the most care, who is referred to as the primary carer in both the SDAC and the CCC, and the main carer in the ACAP data.

The information from the data collections differs in terms of how 'ongoing' care is defined. While each collection requires a person to be providing care on an ongoing basis for him or her to be identified as a carer, only in the SDAC is this concept specified as 'for at least 6 months'. Further, the information available on primary carers of people with dementia from the SDAC pertains to co-resident primary carers, since information about primary carers living in a different household than the care recipient was not available. In contrast, the CCC and the ACAP data include information on the main carers, regardless of whether they lived in the same household as the care recipient. Finally, while the SDAC data on carers are derived from a population survey, data on carers from the ACAP and the CCC are restricted in coverage to those who participated in the relevant programs (and their carers). Thus, information from those two collections is not necessarily representative of all carers of people with dementia. Nonetheless, given the ACAP and CCC include details about non-co-resident carers of people with dementia (which are not available from the SDAC), considering information from them provides a broader picture of the characteristics of carers of people with dementia than is possible by examining the SDAC data alone.

In summary, the information in this chapter about carers from the different collections may differ not only because of the different coverage and scope of the collections, but because of the different definitions and subsets of carers considered.

5.2 What proportion had carers?

According to the SDAC, of the people with dementia living in the community, 92% were identified as receiving care from one or more carers (Table 5.1).

Table 5.1: People with dementia living in the community, by carer status, 2009

Carer status	Per cent
Had one or more carers	92.1
No carers	*7.9
Total	**100.0**

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

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

Information from the 2008–09 ACAP data collection also indicates that 9 in 10 (91%) people with dementia living in the community had a carer (Table 5.2). These data suggest that among those with an ACAP assessment, people with dementia were more likely than those without to have a carer (91% and 80% respectively).

Table 5.2: ACAP clients with and without dementia living in the community, by carer status, 2008–09 (per cent)

Carer status	With dementia	Without dementia
Had carer	91.5	80.3
Did not have carer	7.6	18.6
Not stated	0.9	1.0
Total	**100.0**	**100.0**

Source: Unpublished Aged Care Assessment Program data from DoHA.

Information from the 2008 CCC also details the proportion of people with dementia who had carers (Table 5.3). A total of 86% of CACP clients with dementia had a carer (for 77% this was a primary carer). As noted earlier, the care needs of EACH and EACHD recipients tend to be higher than CACP recipients. Not surprisingly, then, the proportion of people with dementia who were reported to have a carer was somewhat higher among EACH and EACHD recipients (both 96%) than CACP recipients (86%).

These data are in line with the SDAC and ACAP data, with each collection suggesting that about 9 in 10 people with dementia living in the community receive assistance from a carer.

Table 5.3: Community aged care recipients, by dementia and carer status, 2008 (per cent)

	With dementia				Without dementia			
	CACP	EACH	EACHD	NRCP	CACP	EACH	EACHD	NRCP
Primary carer								
Co-resident	42.5	71.7	72.0	81.4	26.6	63.0	. .	69.6
Non-co-resident	34.1	14.3	15.3	18.3	24.7	13.8	. .	29.8
Unknown	0.2	0.3	0.3	0.3	0.2	0.4	. .	0.7
Subtotal	*76.8*	*86.3*	*87.6*	*100.0*	*51.5*	*77.2*	. .	*100.0*
Other carer (but no primary carer)	9.1	9.5	8.0	0.0	11.2	13.9	. .	0.0
Subtotal: carer	*85.9*	*95.8*	*95.7*	*100.0*	*62.7*	*91.0*	. .	*100.0*
No carer	14.1	4.2	4.3	0.0	37.3	9.0	. .	0.0
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**. .**	**100.0**

Source: AIHW analysis of the 2008 Community Care Census.

The CCC data also indicate that among CACP recipients, those with dementia (86%) were more likely to have a carer than those without (63%). Although the gap is not as large, EACH package recipients with dementia were also more likely than those without dementia to have a carer (96% and 91% respectively).

By definition, all NRCP care recipients had a primary carer, but those with dementia were more likely than those without to have a primary carer living with them in the same household (81% and 70% respectively).

5.3 How many carers are there?

Comprehensive data on the number of carers of people with dementia living in the community are not available. Instead, estimates must be derived using available information. As described below, depending on the approach adopted, the number of carers of people with dementia in 2011 is estimated to range from 58,200 to 240,300, with a likely figure around 200,000.

Minimum estimates of the number of carers of people with dementia can be derived directly from the SDAC data which suggested people with dementia were assisted by an estimated 58,200 carers (Table 5.4). These data suggest that two-thirds (68%) of carers of people with dementia were co-resident carers. Most of the co-resident carers were identified as the primary carer.

Table 5.4: Carers of people with dementia living in the community, by type of carer, 2009

Type of carer	Number	Per cent
Co-resident carer	39,700	68.2
Primary co-resident carer	27,000	46.4
Not primary co-resident carer	12,700	21.9
Carer that was not co-resident	18,500	31.7
Total	**58,200**	**100.0**

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

As noted in Chapter 2, SDAC is thought to substantially underestimate cases of mild and moderate dementia. Furthermore, SDAC data allow for some but not all non-co-resident carers of people with dementia in the community to be estimated (however, the extent of underestimation of such carers may be quite low; see Note 5.2 in Appendix D).

To derive a second estimate, data from SDAC on the average number of carers per person with dementia by disability level were first calculated. This suggested, for example, that people with milder forms of dementia had an average of 0.7 carers, while those with severe forms had an average of 1.6 carers. These averages were then applied to the estimated numbers of people with dementia in the community (Table 2.2). See Note 5.3 in Appendix D for further information on the method used. Using this approach, there were an estimated 240,300 carers of people with dementia in the community in 2011.

Since the SDAC under-represents those in the earlier stages of dementia, the derived average number of carers of people with milder forms of dementia (0.7 per person) may be too high. Thus, it is likely that the estimate of 240,300 carers is 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.

Note that Access Economics estimated that in 2008 there were 165,538 carers of people with dementia (2009b). That estimate includes carers of people with dementia in residential aged care facilities and thus is not directly comparable with the estimates shown above.

5.4 Who are the carers?

Note that the SDAC data described in the rest of this chapter pertain to carers of people with dementia in the community who were *co-resident* carers. No information is available on how these carers compare with carers who did not live in the same household as the person with dementia.

Sex and age

Data from the SDAC suggest that the majority of co-resident carers of people with dementia are women (Table 5.5). Of all co-resident carers of people with dementia living in the community, 65% were women. Of co-resident primary carers, 71% were women.

Table 5.5: Carers of people with dementia living in the community, by age and sex, 2009 (per cent)

	Carers[(a)]			Primary carers[(a)]		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 45	*24.1	*12.6	*16.6	**6.7	**2.1	**3.4
45–64	38.9	37.7	38.1	*41.9	41.3	41.4
65–74	*20.7	32.1	28.1	*29.0	37.0	34.6
75+	*16.3	17.7	17.2	*22.5	19.6	20.5
Total	**100.0**	**100.0**	**100.0**	**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.

The ACAP data for 2008–09, like the SDAC data, indicate that about two-thirds (65%) of carers of those with dementia in the community were women (Appendix Table A5.1). The ACAP data also show that there was no difference in the proportion of carers of people with and without dementia who were women (65% and 66% respectively).

CCC data also indicate that the majority of carers were women, although the exact proportion varied between the programs (Table 5.6). The lowest proportion was observed for EACHD recipients, where 62% of primary carers were women. A similar proportion of carers of CACP recipients with dementia were women (63%). The highest proportions were found in the EACH and NRCP programs, with women making up 68% and 72%, respectively, of primary carers.

Table 5.6: Primary carers of community aged care recipients with and without dementia, by sex of carer, 2008 (per cent)

	With dementia				Without dementia			
	CACP	**EACH**	**EACHD**	**NRCP**	**CACP**	**EACH**	**EACHD**	**NRCP**
Males	37.1	32.2	37.7	27.7	36.0	36.7	. .	27.4
Females	62.9	67.8	62.3	72.3	64.0	63.3	. .	72.6
Persons	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**. .**	**100.0**

Source: AIHW analysis of the 2008 Community Care Census.

According to the SDAC data, 45% of carers of people with dementia living in the community were aged 65 and over (Table 5.5). Some difference in the ages of carers was evident by sex, with 37% of male carers aged 65 and over compared with 50% of female carers.

For primary carers of people with dementia, 55% were aged 65 and over. This compares with 29% of all co-resident primary carers. Again, some differences were evident by sex: 51% of male primary carers of people with dementia were aged 65 and over, compared with 57% of female primary carers.

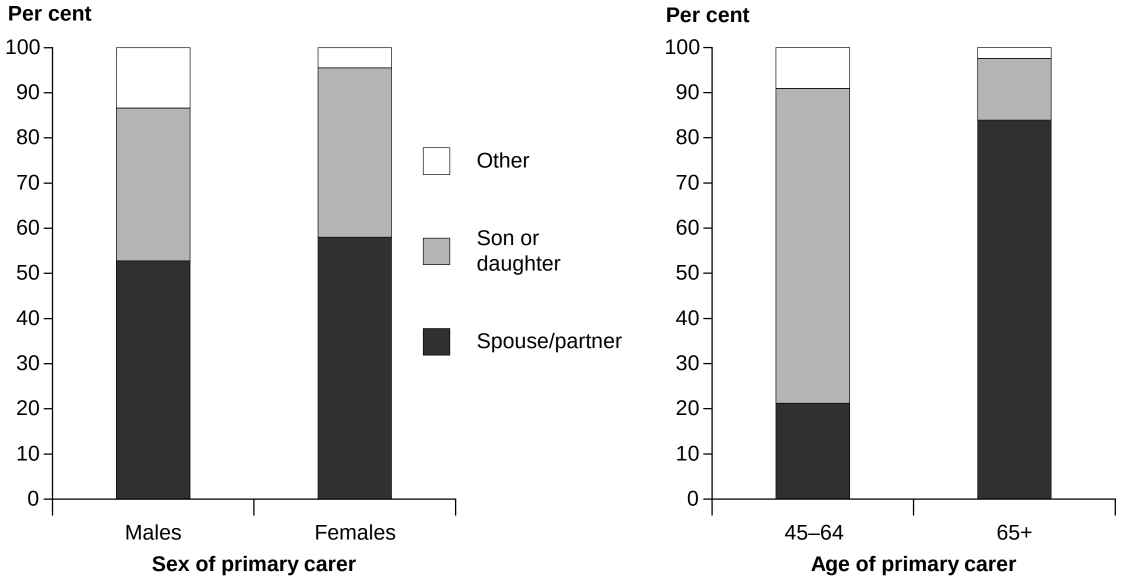
CCC data also provide information on the age of the carers (Appendix Table A5.2). The proportion of carers aged 65 and over differed across the programs, ranging from 35% for carers of people with dementia in the CACP program, to 49% in the EACHD program.

In summary, despite the different definitions and subsets of carers considered in the various collections, each suggests that about two-thirds of carers of people with dementia are female. Further, while there is some variation by the sex of the carer and the specific subset of carers being considered, the data generally suggest that about half of the carers of people with dementia are 65 and over.

Relationship of carer to care recipient

According to the SDAC data, the most common relationship between the co-resident primary carer and the person with dementia was a spouse or partner caring for the other (57%) (Appendix Table A5.3). This is similar to the 56% of all co-resident primary carers who were the spouse or partner of the care recipient.

Just over one-third (36%) of primary carers were the son or daughter of the person with dementia, and 7% were another relative, friend or neighbour. As shown in Figure 5.1, female primary carers were more likely than male primary carers to be the spouse or partner of the care recipient (58% and 53% respectively).



Note: Data for this figure are shown in Appendix Tables A5.3 and A5.4.

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

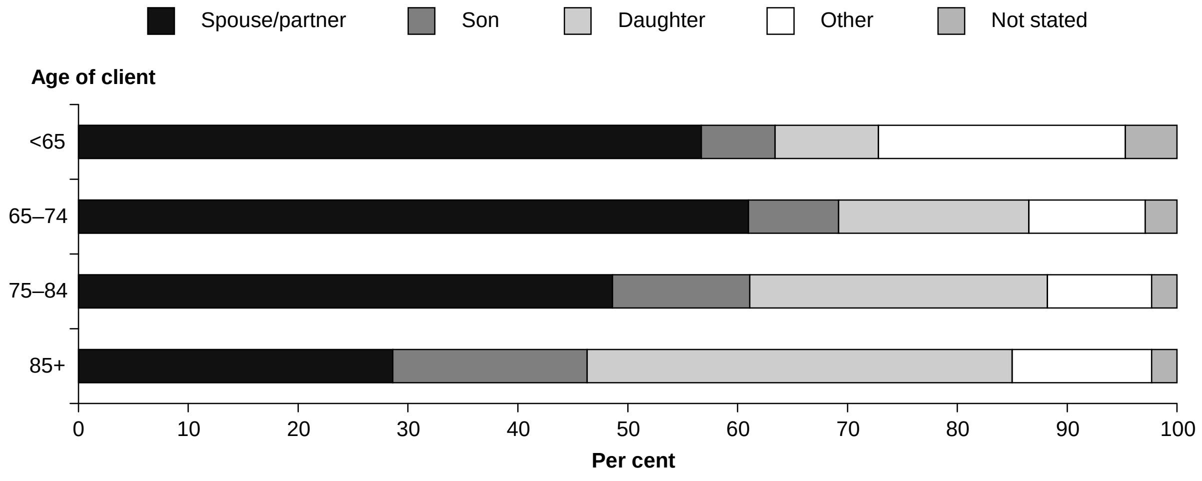
Figure 5.1: Relationship of primary carer to care recipient with dementia living in the community, by sex and age of primary carer, 2009

Figure 5.1 also provides information on the relationship of the primary carer to the care recipient according to the age of the primary carer. The SDAC data indicate that of primary carers aged 65 and over of people with dementia, most (84%) were the spouse or partner of the care recipient. In contrast, primary carers aged 45–64 were most commonly the child of the recipient (70%). Data for primary carers aged 25 to 44 are unreliable and thus not shown in this figure (see Appendix Table A5.4).

The SDAC also provides information on the relationship of the primary carer and care recipient according to the age of the recipient, rather than the age of the carer. For these data, there was a clear pattern by age, with the proportion of people with dementia who were cared for by their spouse or partner (rather than someone else) decreasing as the age of the care recipient increased (Appendix Table A5.5). Specifically, 95% of care recipients with dementia aged under 75 were cared for by their spouse or partner, compared with 67% of those aged 75–84 and 16% of those aged 85 and over.

As noted earlier in this chapter, the SDAC data about primary carers pertain only to co-resident primary carers, while the ACAP data include information about main carers regardless of whether or not they lived in the same household as the care recipient. Not surprisingly, then, data from the two collections about the relationship of carers to recipients differ. In particular, while the SDAC data suggest that 57% of co-resident primary carers of people with dementia were a spouse or partner of the person with dementia, the 2008–09 ACAP data indicate that this applied to only 42% of main carers (Appendix Table A5.6). Meanwhile, the ACAP data suggest that a carer was more likely to be the son or daughter (44%) than the SDAC data suggested (36%). This implies that non-co-resident main carers were more likely to be children of the care recipients than co-resident main carers.

Figure 5.2 presents ACAP data that compare the relationship of the main carer to the care recipient according to the age of the recipient. Again, the results are different from those of the SDAC. In particular, while the general trend was the same—namely that the proportion of main carers who were spouses or partners decreased as the age of the care recipient



Note: Data for this figure are shown in Appendix Table A5.6.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Figure 5.2: Relationship of main carer to care recipient with dementia living in the community, by age of client, 2008–09

increased—in the SDAC data, the role of the spouse/partner as the predominant carers of recipients aged 75 to 84 was more prominent. While the SDAC data suggested that about two-thirds (67%) of primary carers of people with dementia aged 75–84 were the spouse/partner of the care recipients, the ACAP data suggest that this proportion would be considerably lower (49%) if non-co-resident primary carers were included.

According to 2008–09 ACAP data, daughters made up 30% of main carers of ACAP clients with dementia, while sons accounted for 14% (Appendix Table A5.6). As shown in Figure 5.2, for each of the age groups of care recipients with dementia, daughters outnumbered sons, with the difference increasing as the age of the care recipient increased. The difference was particularly stark for recipients aged 85 and over (39% and 18% respectively).

The third source of information about the relationship of carers to care recipients with dementia is the CCC. Similar to the ACAP data, CCC information pertains to both co-resident and non-co-resident carers. As shown in Table 5.7, the relationship of the primary carer to the care recipient with dementia varied considerably between the programs. In the CACP, 56% of the primary carers were a child of the recipient with dementia and 32% were a spouse or partner. In contrast, for EACHD and NRCP recipients, about half (52% and 49% respectively) of the primary carers were the spouse or the partner of the care recipient with dementia. For EACH recipients with dementia, 47% of primary carers were a son or daughter of the care recipient, while 44% were the spouse or partner.

Table 5.7: Primary carers of community aged care recipients with dementia, by relationship of primary carer to care recipient, 2008 (per cent)

Relationship to care recipient	CACP	EACH	EACHD	NRCP
Spouse/partner	31.5	44.4	51.7	49.1
Son or daughter	55.5	46.7	40.6	42.3
Other	13.0	8.9	7.7	8.6
Total	**100.0**	**100.0**	**100.0**	**100.0**

Source: AIHW analysis of the 2008 Community Care Census.

Country of birth and preferred language of carers

According to the SDAC, 61% of co-resident carers of people with dementia living in the community were born in Australia, 9% in the 'Main English-speaking countries' and 30% in 'Other countries' (Table 5.8). Fairly similar proportions were observed for primary carers of people with dementia. Three-quarters (77%) of primary carers usually spoke English to the care recipient (Table 5.8).

While the CCC did not include questions on the country of birth or language spoken by carers of recipients accessing CACPs, EACH or EACHD packages, it collected information on whether the primary carer of NRCP recipients received additional services that specifically addressed the absence of English language skills (such as an interpreter or bilingual brochures). Primary carers of NRCP recipients with dementia were less likely (15%) than primary carers of NRCP recipients without dementia (20%) to use these services (Table 5.9).

Table 5.8: Carers of people with dementia living in the community, by country of birth and language spoken to main recipient of care, 2009 (per cent)

	Carers[a]	Primary carers[a]
Country of birth		
Australia	60.5	60.6
Main English-speaking countries[b]	*9.2	*12.1
Other countries	30.3	27.2
Whether primary carer usually speaks to care recipient in English		
Yes	. .	76.8
No	. .	23.2
Total	**100.0**	**100.0**

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

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

(b) Includes people born in New Zealand, Ireland, United Kingdom, United States of America, Canada and South Africa.

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

Table 5.9: Primary carers of National Respite for Carers Program care recipients with and without dementia, by receipt of English language support, 2008 (per cent)

Received English language support	Primary carers of recipients with dementia	Primary carers of recipients without dementia
Yes	14.9	20.0
No	85.1	80.0
Total	**100.0**	**100.0**

Source: AIHW analysis of the 2008 Community Care Census.

Indigenous carers

Data on the Indigenous status of carers are scarce, as noted in the 2009 *Inquiry into better support for carers* report (HRSCFCHY 2009). One of the main sources of such data is the 2006 Census of Population and Housing, which was the first Census to collect information on the number of carers aged 15 and over in Australia (ABS 2008b). These data suggest that there were about 32,600 Indigenous carers (aged 15 and over) of people with a disability, long-term illness or problems associated with old age living in the community, with 14% of Indigenous women and 9% of Indigenous men having such caring responsibilities (ABS & AIHW 2008). After adjusting for differences in the age structures of the Indigenous and non-Indigenous populations, the Census data suggest that Indigenous people were more likely than non-Indigenous people to be caring for another person with disability, long-term illness or problems related to old age. Note that the Census data cannot be used to specifically identify carers of people with dementia.

5.5 Motivation to care

In the SDAC, primary carers were asked to indicate why they took on the caring role, with more than one response to this question allowed. The most common reason (60%) given by co-resident primary carers of people with dementia was that it was a family responsibility

(Table 5.10). Other reasons were that they could provide better care than someone else (47%), they felt an emotional obligation to do so (44%), and that no other family or friends were available (32%) or willing (24%) to take on the caring role. About 1 in 5 said that they had no other choice (22%).

Table 5.10: Reasons for taking on caring role: primary carers of people with dementia and all primary carers of those living in the community, 2009 (per cent)

Reason for taking on caring role	Primary carers of people with dementia[(a)]	All primary carers[(a)]
Family responsibility	59.8	52.4
Could provide better care than someone else	47.2	45.1
Emotional obligation	44.3	33.4
No other family or friends available	31.7	18.3
No other family or friends willing	23.7	10.1
Had no other choice	22.0	16.3
Alternative care too costly	*21.4	16.0
Not stated	*8.2	9.4
No other care arrangements available	*6.7	8.8
Other reason	**5.3	6.8
Total[(b)]	**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* primary carers and thus exclude those living in a different household.

(b) The sum of the reasons exceeds the total since any one primary carer could report multiple reasons.

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

Similarly 52% of all co-resident primary carers cited family responsibility as a reason for taking on the caring role, while 45% said they could provide better care than someone else and 33% felt an emotional obligation to do so. However, primary carers of people with dementia were more likely than all primary carers to cite family responsibility (60% and 52% respectively) or related reasons such as that no other family or friends were available (32% and 18%) or willing (24% and 10%) to take on the caring role.

5.6 What assistance do carers provide?

Chapter 3 showed that people with dementia living in the community most commonly received assistance from informal sources. In this chapter, we look at the types of activities carers help with. Note that 82% of people with dementia living in the community who were being cared for by primary carers had a 'profound' level of disability. That is, they were unable to do, or always needed help with, one or more core activities of daily living (namely, self-care, mobility and/or communication). The remaining 18% had either a severe, moderate or mild level of disability (see Box 3.2 for further information about the levels of disability used in the SDAC).

As shown in Table 5.11, primary carers of people with dementia provided assistance with at least one core activity. Specifically, 92% provided assistance to the care recipient with mobility, 85% with self-care and 79% with communication.

The SDAC data also indicated that nearly all (97%) of these primary carers also provided assistance with at least one non-core activity. Further, for each non-core activity, more than 90% of primary carers provided assistance. The one exception was property maintenance, with 69% providing assistance in this area.

Table 5.11: Areas in which primary carers[(a)] of people with dementia living in the community usually provide assistance, 2009

	Per cent
Core activities	
Self-care	84.7
Mobility	91.5
Communication	79.0
At least one core activity	*100.0*
Non-core activities	
Health care[(b)]	92.5
Cognitive or emotional tasks	93.0
Household chores[(b)]	93.5
Property maintenance[(b)]	68.6
Meal preparation[(b)]	94.3
Reading or writing tasks [(b)]	94.4
Transport[(b)]	93.9
At least one non-core activity	*96.8*
Total primary carers	**100.0**

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

(b) These questions were not asked of primary carers who were only identified by the care recipient (rather than by another adult in the household).

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

The high demands on primary carers of people with dementia are reflected not only by the number of tasks they provide assistance with, but also by the amount of time spent providing care. SDAC data show that 94% of co-resident primary carers provided continuous rather than episodic care and 81% were, on average, providing 40 or more hours of care per week (Table 5.12). In contrast, the caring intensity was lower for co-resident primary carers in general, with 72% providing continuous care and 42% providing 40 or more hours of care per week on average. Data were not available on the number of hours of care provided by non-co-resident primary carers of people with dementia.

In terms of the duration of care, 41% of primary carers of people with dementia had been providing care (whether as a primary or non-primary carer) for less than 5 years, while 38% had provided care for 5 to 9 years, and 22% for 10 years or more (Table 5.12). However, a higher proportion of all primary carers in general had been caring for 10 years or more (32%). This difference may reflect the relatively late age of onset of dementia for many and its association with high carer burden as a risk factor for entry into residential aged care.

Table 5.12: Time spent caring: primary carers of people with dementia and all primary carers of people living in the community, 2009 (per cent)

	Primary carers[a] of people with dementia	All primary carers[a]
Whether continuous or episodic care was required[b]		
Continuous care	93.7	71.7
Episodic care	*6.3	28.3
Total	**100.0**	**100.0**
Average weekly hours of care provided		
Under 20 hours	*7.3	38.1
20–39 hours	*8.1	17.9
40+ hours	81.2	41.5
Not stated	**3.5	2.6
Total	**100.0**	**100.0**
Duration of care provision[c]		
Under 5 years	40.8	38.7
5–9 years	37.7	27.9
10–14 years	*13.1	14.0
15+ years	*8.4	18.4
Don't know	–	1.0
Total	**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* primary carers and thus exclude those living in a different household.

(b) This question was not asked of primary carers who were only identified by the care recipient (rather than by another adult in the household).

(c) By definition, primary carers provided assistance on an ongoing, or likely to be ongoing, basis for at least 6 months (see Box 5.1).

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

5.7 Impact of the caring role on carers

Caring for a person with any type of disability or chronic condition can be physically, mentally, emotionally and economically demanding, but existing research suggests that the burden of caregiving is particularly high for those caring for a person with dementia (Kim & Schulz 2008, MetLife 2006). Many factors may affect the level of caregiving burden, including personal characteristics of carers and care recipients, living arrangements, employment and financial situation, and the level of support available from formal services and other family and friends (Kim & Schulz 2008).

This section considers information from the SDAC on the impact of caring for a person with dementia on the co-resident carer's physical and emotional wellbeing, relationships, about force participation and financial situation. Some CCC data about the receipt of government carer payments are also described.

Physical and emotional wellbeing

According to the SDAC, adverse physical or emotional effects of the caring role on the primary carer of a person with dementia included feeling weary or lacking in energy (reported by 34%), and frequently feeling worried or depressed (33%) (Table 5.13).

Table 5.13: Physical and emotional effect of caring role on primary carers of people with dementia and all primary carers of people living in the community, 2009 (per cent)

	Primary carers[a] of people with dementia	All primary carers[a]
Adverse effects due to caring role[b]		
Feel weary or lack energy	34.3	32.9
Frequently feel worried or depressed	33.2	30.1
Diagnosed with stress-related illness	*10.3	11.3
Frequently feel angry or resentful	*14.7	12.1
Not stated	*7.9	10.0
One or more of the above adverse effects	*57.2*	*48.2*
Total	**100.0**	**100.0**
Sleep disturbance due to caring role		
Sleep interrupted frequently	34.0	24.2
Sleep interrupted occasionally	32.4	24.4
Sleep not interrupted	26.6	42.0
Other[c]	*7.0	9.4
Total	**100.0**	**100.0**
Satisfaction due to caring role		
Feels satisfied	18.7	20.9
Does not feel satisfied	73.4	69.1
Not stated	*7.9	10.0
Total	**100.0**	**100.0**

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

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

(b) The sum of the adverse effects may exceed the total since any one primary carer could report multiple adverse effects.

(c) Included 'Not stated' and 'Sleep interrupted but frequency not stated'.

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

The data also indicate that a higher proportion of primary carers of people with dementia (57%) reported one or more of these adverse effects compared with primary carers in general (48%).

Primary carers were also asked about sleep disturbance due to the caring role (Table 5.13). Among those caring for a person with dementia, about 66% of co-resident primary carers reported some extent of sleep disturbance. This was a higher proportion than reported by co-resident primary carers generally (49%). Not only were primary carers of people with dementia more likely to have their sleep interrupted, this also occurred more frequently than it did for primary carers generally. For example, 34% of primary carers of people with dementia reported having their sleep interrupted frequently compared with 24% of all primary carers.

Table 5.13 also provides information from the SDAC on how satisfied primary carers felt due to their caring role. About 19% felt satisfied, but 73% reported that they did not. Similarly, 21% of all primary carers felt satisfied due to the caring role, while 69% did not.

Relationships

Being a primary carer can affect not only the relationship of the carer to the care recipient but also the carer's relationship to others. As shown in Table 5.14, primary carers of people with dementia were more likely than primary carers in general to report that the caring role had placed strain on their relationship with the care recipient (34% and 17% respectively), and less likely to say the caring role had brought them closer together (19% compared with 31%). A similar proportion indicated that there was no change in their relationship with the care recipient.

Table 5.14: Effect of caring role on primary carers' relationships: primary carers of people with dementia and all primary carers of people living in the community, 2009 (per cent)

	Primary carers[(a)] of people with dementia	All primary carers[(a)]
Main effect of caring role on relationship with care recipient		
No change	40.7	41.7
Brought closer together	18.6	31.2
Placed strain on relationship	33.7	17.4
Not stated	*7.0	9.6
Total	**100.0**	**100.0**
Main effect of caring role on friendships		
No change	36.8	53.8
Circle of friends has increased or changed	*17.0	13.7
Lost, or are losing touch, with existing friends	39.1	22.7
Not stated	*7.0	9.9
Total	**100.0**	**100.0**

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

(a) These SDAC data pertain to *co-resident* 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.

Primary carers of people with dementia were more likely than all primary carers to indicate they had lost touch (or were losing touch) with existing friends due to the caring role (39% and 23% respectively), and they were less likely to say there had been no change (37% and 54%).

Labour force participation

For caregivers in the paid workforce, the demands of caring for a person with dementia may have implications for their employment. In this section, we look at various aspects of labour force participation for co-resident carers of 'traditional working age'—that is, those aged 15 to 64. Just over half (54%) of carers people with dementia (and 45% of primary carers) were in this age range.

As shown in Table 5.15, carers aged 15 to 64 of people with dementia had a labour force participation rate of 56% in 2009; the corresponding rate for primary carers of people with dementia was 38%. This is a much lower rate of participation than all co-resident primary carers in the same age range (50%), as well as the general population (79%) (AIHW 2011). The differences in participation rates cannot be explained fully by the demands of caring for a person with dementia, as differences in the age and sex structures of the various populations and labour market opportunities could also affect labour force participation.

Table 5.15: Labour force status of carers aged 15 to 64 of people with dementia living in the community, 2009 (per cent)

	Carers[(a)]	Primary carers[(a)]
In the labour force	56.3	*37.7
Employed	*47.7	*34.2
Unemployed	**8.6	**3.5
Not in the labour force	43.7	62.3
Total	**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.

As part of the SDAC, primary carers who were either unemployed or not in the labour force were asked if they would like to be employed while in the caring role. About 4 in 5 (79%) primary carers aged 15 to 64 of people with dementia who were not employed said 'no' to this question (Table 5.16).

Information was also collected as part of the SDAC from those primary carers who were not employed at the time of the survey and who had left their job in order to provide care. The most common reason given for leaving their job by primary carers of people with dementia was that no alternative care arrangements were available (74%).

Primary carers who were in the paid workforce were asked about the effect on their weekly hours of work since they began providing care. The majority of employed primary carers of people with dementia said that there had not been any change in their hours worked (80%).

Table 5.16: Primary carers[a] aged 15 to 64 of people with dementia living in the community: employment-related issues related to caring role, 2009 (per cent)

	Per cent
Would like to be employed while in caring role[b]	
Yes	*20.7
No	79.3
Total	**100.0**
Main reason had to leave job to provide care[c]	
No alternative care arrangements available	74.1
Financial considerations or cost of alternative care arrangements	–
Unable to change working arrangements	–
Emotional obligations or preferred to care full-time, or Other reason	**25.9
Total	**100.0**
Effect on weekly hours worked since commencing caring role[d]	
No change in hours worked	80.2
Increase in hours worked	–
Reduction in hours worked	**19.8
Total	**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* primary carers and thus exclude those living in a different household.

(b) Includes primary carers who were not employed at the time of the survey.

(c) Includes those who were not working at the time of the survey who indicated that they had left the job they had just before beginning the caring role to begin or provide additional care.

(d) Includes primary carers who were employed at the time of the survey.

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

Financial situation and government carer payments

According to the SDAC, the main source of cash income for co-resident primary carers of people with dementia was government pensions and allowances (76%) (Table 5.17). As expected, this proportion differed according to the age of the primary carer, with a larger proportion of those aged 65 and over (81%) than those aged 15 to 64 (69%) indicating that this was their main source of income.

One of the types of government payments that carers can receive is the Carer Payment—a means-tested income support payment provided to informal carers. There are two types of Carer Payments: one for those caring for a person aged 16 and over—referred to as the Carer Payment (adult)—and another for those caring for a person aged under 16. The Carer Payment (adult) is paid to carers of people aged 16 and over who have a disability or medical condition or are 'frail aged', where the demands of caring severely restrict or prevent the carer from undertaking substantial paid employment (Centrelink 2012). The adult care recipient must undergo an assessment with the Adult Disability Assessment Tool, demonstrating that significant levels of assistance are required in activities of daily living, such as mobility, communication and hygiene (Edwards et al. 2008). In some cases, the Carer Payment is payable where a person cares for an adult with moderate care needs and care is also provided for their dependent child.

Table 5.17: Primary carers[(a)] of people with dementia living in the community: income source and effect of caring role on financial situation, by age, 2009 (per cent)

	15–64	65+	Total
Main source of cash income			
Employee income	*25.9	**2.4	*12.9
Government pensions and allowances	68.8	80.9	75.5
Other income	**5.3	*12.5	*9.3
No cash income	—	**4.3	**2.4
Total	**100.0**	**100.0**	**100.0**
Main effect of caring role on financial situation			
Income not affected	*28.7	36.9	33.2
Income increased	—	*15.3	*8.4
Income decreased	37.4	**8.0	21.2
Extra expenses	*25.5	33.9	30.1
Not stated	**8.4	**5.9	*7.0
Total	**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* 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.

SDAC data indicate that 29% of primary carers of people with dementia received the Carer Payment, 39% did not receive it but had looked into their eligibility, and 32% did not receive it and had not looked into their eligibility (Table 5.18). Those in the latter group were asked about the main reason they had not looked into their eligibility. The most common response was that they would not be eligible or that they were eligible for a payment type that meant they would not be eligible for this payment as well (35%).

Data about the receipt of the Carer Payment by primary carers of NRCP recipients were also collected as part of the CCC (though not for carers of CACP, EACH or EACHD recipients). About 12% of primary carers of NRCP care recipients with dementia were receiving the Carer Payment (Table 5.19). The same proportion of primary carers who were caring for people without dementia indicated that they were receiving this payment. As noted earlier, in contrast with the SDAC data, primary carers who lived in the same household as well as those who lived in different households than the care recipient were in scope of the CCC data collection. Therefore, one reason the proportion of primary carers receiving the Carer Payment is lower in this data source may be because of the inclusion of non-co-resident primary carers. However, it is also important to note that only those primary carers caring for a NRCP care recipient during the census week for the CCC are represented by this collection; how representative they may be of all primary carers of people with dementia is not known.

Table 5.18: Primary carers[(a)] of people with dementia living in the community: receipt of Carer Payment, 2009 (per cent)

	Per cent
Receipt of Carer Payment	
Receives Carer Payment	29.3
Does not receive Carer Payment but has looked into eligibility	39.3
Does not receive Carer Payment and has not looked into eligibility	31.5
Total	**100.0**
Main reason for not looking into eligibility for Carer Payment[(b)]	
Not heard of it	*22.6
Does not think of self as a carer	*12.3
Would not be eligible or dual eligibility (i.e. eligible for conflicting payment type)	*35.4
Not necessary	*14.9
Other reasons, including pride	*14.7
Total	**100.0**

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

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

(b) Includes primary carers who were not receiving the Carer Payment and had not looked into their eligibility for it.

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

CCC data also provide information about the receipt of the Carer Allowance by primary carers of NRCP recipients. The Carer Allowance is a supplementary payment that is not subject to an income or assets test. Carer Allowance (adult) is provided to carers of people aged over 16 with a disability or medical condition who need additional care and attention. The care must be provided in the carer's home, the home of the care recipient or in hospital. The care recipient is assessed using the Adult Disability Assessment Tool (Centrelink 2012; Edwards et al. 2008). As shown in Table 5.19, 25% of primary carers of NRCP recipients with dementia received the Carer Allowance. In contrast, only 15% of primary carers of NRCP recipients without dementia received this allowance.

Table 5.19: Primary carers of National Respite for Carers Program recipients with and without dementia, by receipt of Carer Payment and Carer Allowance, 2008 (per cent)

	Carers of recipients with dementia	Carers of recipients without dementia
Receives Carer Payment	12.3	12.2
Receives Carer Allowance	24.8	15.2
Total number of primary carers	**100.0**	**100.0**

Note: Some carers may have received both types of payments.

Source: AIHW analysis of the 2008 Community Care Census.

The SDAC also captured information on the main effect of the caring role on the financial situation of primary carers. As shown in Table 5.17, the responses to this question differed according to the age group of carers considered. For primary carers aged 65 and over of people with dementia, the most common response was that their income had not been affected (37%). One reason for this may be that many would have been retired and on a pension. Nonetheless, about 2 in 5 in this age group indicated that their financial situation was adversely affected either due to extra expenses or a decrease in their income. In contrast, of those primary carers in the 'traditional working ages' of 15 to 64, 63% indicated that their financial situation had been adversely affected due to their caring role, including 37% who said their income had decreased.

5.8 Areas of unmet support

As part of the SDAC, primary carers were asked whether they felt they needed additional support or an improvement in their situation to aid in their role as a carer. Primary carers of people with dementia (52%) were more likely than primary carers in general (33%) to report needing such support (Table 5.20).

Those who indicated they needed additional support were asked to indicate the main area of unmet support. The greatest area of unmet demand was for more respite care, with 48% of co-resident primary carers of people with dementia who required additional support saying this was the main area in which they needed help. In contrast, 15% of all co-resident primary carers indicated that the main area in which they needed assistance was respite care.

Table 5.20: Unmet support needs: primary carers of people with dementia and all primary carers of people living in the community, 2009 (per cent)

	Primary carers[a] of people with dementia	All primary carers[a]
Whether additional support is required		
Yes	52.4	32.9
No	34.2	51.2
Not stated	*13.4	15.9
Total	**100.0**	**100.0**
Main unmet source of support[b]		
More respite care	48.0	15.3
More financial assistance	*17.5	38.8
More physical assistance	*11.9	11.6
More emotional support	*18.0	11.7
An improvement in carer's own health	**1.7	9.3
Other[c]	**2.9	13.3
Total	**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* primary carers and thus exclude those living in a different household.

(b) Includes those primary carers who indicated they required additional support.

(c) 'Other' includes responses of 'More aids/equipment to help in your role as a carer', 'More courses available on how to care for persons with particular disabilities', 'More training on correct use of equipment', 'More training in correct methods of lifting to prevent injury to self' and 'Other reasons'.

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

6 Expenditure on dementia

Key points

- Total direct health and aged care system expenditure on people with dementia was estimated to be at least $4.9 billion in 2009–10, of which about $2.0 billion was directly attributable to dementia.
- $1.1 billion or 55% of this directly attributable expenditure was by the Australian Government for permanent residents in subsidised residential aged care facilities.
- Expenditure on community aged care services was estimated at $408.0 million (21% of directly attributable expenditure).
- An estimated $144.5 million (7% of directly attributable expenditure) was spent on hospitalisations for which the principal diagnosis was dementia, with the average cost for such hospitalisations estimated at $664 per patient day.
- Expenditure for the National Respite for Carers Program of $119.8 million, pharmaceutical expenditure of $79.9 million, and flexible aged care services expenditure of $42.7 million were also attributed to dementia.

6.1 Introduction

The provision of services for people with dementia and their carers depends on extensive resources. A workforce of trained health professionals, the various methods and therapies they use, and associated facilities and technology all play a part. This chapter provides estimates of direct expenditure on caring for people with dementia from across the health and aged care sectors. These include community support programs, hospital services, out–of–hospital medical services, medications, assessment services and a range of aged care services. For most of the types of expenditure considered, data on government expenditure are the only data available. However, non-government-expenditure (for example, by individuals, private health insurers and other non-government sources) is included in relation to hospital services, out-of-hospital medical services and non-dementia-specific medications.

Due to the lack of relevant data, not all dementia-related health and aged care system expenditure is captured in this chapter. For example, expenditure for hospital services for non-admitted patients (such as out-patient and emergency department services), for specialised mental health care services and for respite care in residential aged care facilities is not included. In addition, not all dementia-related state and territory government expenditure is captured. Furthermore, only a portion of direct expenditure by individuals and their carers, and no indirect expenditure (that is, travel cost for patients, the social and economic burden on carers and family, and lost wages and productivity) have been incorporated into these estimates. At the same time, data available from the numerous programs, packages and services vary widely, so the ability to estimate expenditure *attributable* to dementia (as opposed to expenditure *on* people with dementia) also varies. Thus, the total estimated expenditure for dementia as described in this chapter should be interpreted with caution.

The expenditure estimates are based on 2009–10 data for all areas except out-of-hospital medical services and non-dementia-specific medications, where the most recent data available (2008–09) have been inflated to equate to 2009–10 prices. All estimates are GST inclusive.

In a number of sections of this chapter, data are shown for earlier years as well as for 2009–10 for comparative purposes. The data for those earlier years are shown in 'constant' (rather than 'current') prices to take inflation into account.

Since the release of the previous issue of *Dementia in Australia* (AIHW 2007), the Australian Government has changed the funding system that underpins much of the funding for dementia. In particular, the introduction of the ACFI has had substantial implications for the nature of the estimates provided in this chapter, with the inclusion of dementia status data allowing more comprehensive estimates of both subsidies and supplements for funding for aged care places for people with dementia. In addition, this report includes estimates for dementia-related expenditure for a number of programs that were not included in the previous version. As a result, total expenditure for dementia and many of the estimates for individual components of such expenditure are not directly comparable with those presented in the 2007 report.

6.2 Total estimated expenditure on dementia

Total direct health and aged care system expenditure directly attributable to dementia was estimated to be around $2.0 billion in 2009–10 (Table 6.1). Residential aged care services ($1.1 billion) accounted for 55% of this expenditure. There was also a substantial cost for people with dementia using community aged care services ($408.0 million or 21% of directly attributable expenditure), admitted patient hospital services ($144.5 million or 7%) and the National Respite for Carers Program ($119.8 million or 6%).

As described in Section 6.11, there was an additional $3 billion of expenditure on people with dementia in residential aged care which was not directly attributable to the dementia. Adding this to the expenditure that was directly attributable to dementia suggests that the total direct health and aged care system expenditure on people with dementia was at least $4.9 billion. This excludes expenditure for people with dementia in hospital who were admitted for some other reason.

6.3 Consumer support programs

The National Dementia Support Program is funded by the Australian Government and delivered by individual Alzheimer's Australia organisations in each jurisdiction (see Section 4.2 for further information). The Australian Government provided $9 million in 2009–10 to fund this program (Alzheimer's Australia 2011b).

Dementia Behaviour Management Advisory Services have been established in each state and territory to provide support and education to aged care staff and to carers of people with dementia whose behaviour is having an impact on their care (see Section 4.2). In 2009–10, Australian Government expenditure on DBMASs was about $10 million (DoHA 2010c).

Table 6.1: Estimated health and aged care system expenditure attributable to dementia, 2009–10

Service category/program[a]	$ million	Per cent
Consumer support programs	**19.0**	**1.0**
National Dementia Support Program	9.0	0.5
Dementia Behaviour Management Advisory Service	10.0	0.5
Out-of-hospital medical services[b]	**42.0**	**2.1**
Unreferred services by GPs and practice nurses[b]	24.6	1.3
Pathology and imaging services[b]	6.4	0.3
Specialist and other medical services[b]	11.0	0.6
Hospital medical services	**144.5**	**7.4**
Admitted patient hospital services	144.5	7.4
Hospital services for non-admitted patients	Unknown	. .
Medications	**79.9**	**4.1**
Dementia-specific medications	58.7	3.0
Other medications[b]	21.2	1.1
Aged care assessments	**19.8**	**1.0**
Community aged care services	**408.0**	**20.8**
Community Aged Care Packages (CACP)	72.7	3.7
Extended Aged Care at Home (EACH) packages	37.9	1.9
Extended Aged Care at Home Dementia (EACHD) packages	99.6	5.1
Home and Community Care (HACC) program	164.4	8.4
Veterans' Home Care program	11.7	0.6
DVA Community Nursing Program	21.7	1.1
Flexible aged care services	**42.7**	**2.2**
Transition Care Program	30.0	1.5
National Aboriginal and Torres Strait Islander Flexible Aged Care Program	12.7	0.6
Other types of flexible aged care services (e.g. Multi-Purpose Services)	Unknown	. .
Respite services	**119.8**	**6.1**
National Respite for Carers Program (NRCP)	119.8	6.1
Other types of respite services (e.g. residential respite care)	Unknown	. .
Residential aged care services for permanent residents	**1,089.2**	**55.4**
Specialised mental health care services	**Unknown**	**. .**
Total	**1,964.9**	**100.0**

(a) See remainder of chapter for a description of the method used to derive estimates for each of these service categories/programs.

(b) Expenditure for out-of-hospital medical services and other medications is for 2008–09 financial year inflated to 2009–10 prices.

Sources: See remainder of chapter for source of data for each estimate shown in table.

6.4 Out-of-hospital medical services

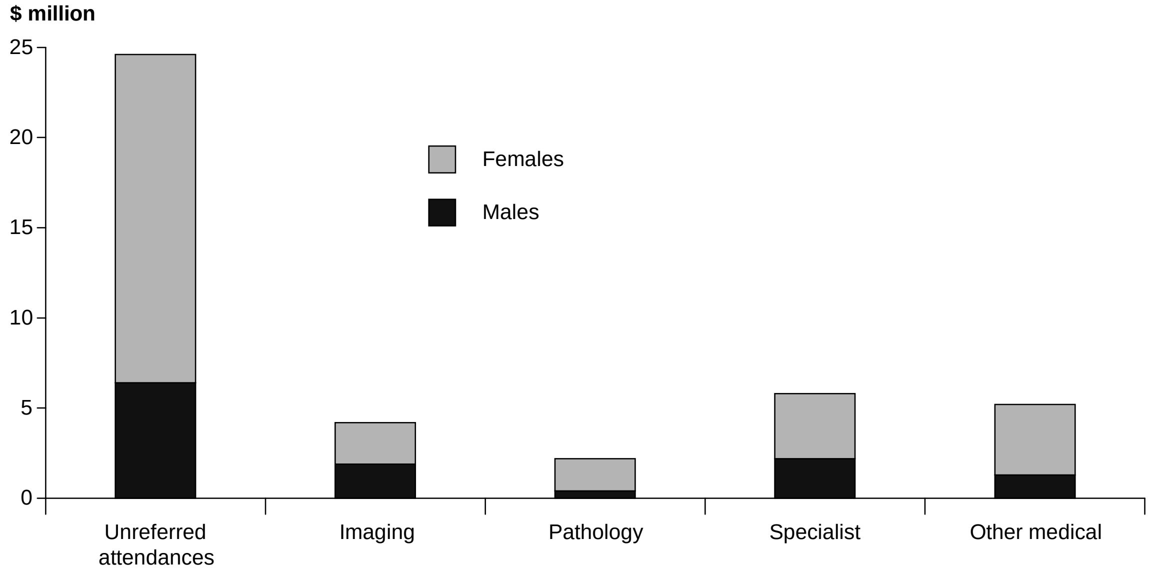
Despite the fact that out-of-hospital medical care accounts for a substantial proportion of all health expenditure, there is no national data collection that comprehensively records this expenditure. To estimate such expenditure for dementia, data from the BEACH survey of GPs were used to estimate the proportion of Medicare Benefits Scheme (MBS) expenditure (including GP and specialist expenditure as well as expenditure for tests and other referrals) likely to be attributable to dementia.

As described in Appendix B, the BEACH survey is a national ongoing survey that collects information from approximately 1,000 GPs each year about the reason(s) for the encounter, diagnostic information regarding the problem(s) managed and the management actions taken, including tests ordered and referrals.

Using the BEACH data, an estimate of the proportion of GP attendances in which dementia was managed can be derived (see Section 4.3). The proportion of these encounters in which a referral was made or a test ordered for the care of dementia can also be determined. Estimates include both Australian Government expenditure and non-government expenditure (for example, from individuals and private health insurance funds). People with dementia often have other conditions which are also managed by a GP. These estimates do not relate to these other conditions, but only to attendances where dementia was managed.

Based on this method, it is estimated that in 2008–09, $40.4 million was spent on out-of-hospital services for dementia. When inflated to 2009–10 prices, this equates to $42.0 million (Table A6.1). The majority (59% or $24.6 million in 2009–10 prices) of this expenditure was for 'unreferred attendances'—that is, primary care services provided by GPs and practice nurses (Figure 6.1). The remainder of out-of-hospital medical expenditure was made up of the following components:

- $5.8 million (14%) for specialist services
- $4.2 million (10%) for imaging services
- $2.2 million (5%) for pathology services
- $5.2 million (12%) for 'other' medical services such as anaesthetics and operations.



Notes: Expenditure is for 2008–09 inflated to 2009–10 prices. Data for this figure are shown in Appendix Table A6.1.

Sources: AIHW analysis of Bettering the Evaluation and Care of Health data; AIHW disease expenditure database.

Figure 6.1: Out-of-hospital medical expenditure for dementia, by sex, 2009–10

Overall, 71% of out-of-hospital expenditure for dementia was for women (Appendix Table A6.1). This proportion varied somewhat when the various components of out-of-hospital expenditure were considered; for example, women accounted for 81% of dementia-related pathology expenditure, 74% of unreferred attendances and 55% of imaging services.

Differences in out-of-hospital expenditure by age are shown in Table 6.2. As would be expected, given the age profile of those with dementia (as discussed in Chapters 2 and 3), a relatively small proportion (4%) of such expenditure was for people aged under 65 ($1.8 million) and 14% was for those aged 65–74 ($5.7 million). In contrast, 46% was for those aged 75–84 ($19.1 million) and 37% for those aged 85 and over ($15.3 million). These proportions differ markedly by sex; for example, those aged 85 and over accounted for 42% of out-of-hospital expenditure for women, compared with 22% for men.

Table 6.2: Out-of-hospital medical expenditure for dementia, by age and sex, 2009–10[(a)]

	$ million			Per cent		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 65	0.4	1.4	1.8	3.4	4.7	4.3
65–74	2.6	3.1	5.7	21.6	10.3	13.6
75–84	6.4	12.7	19.1	52.5	42.8	45.6
85+	2.7	12.6	15.3	22.4	42.2	36.5
Total	**12.2**	**29.8**	**42.0**	**100.0**	**100.0**	**100.0**

(a) Expenditure is for 2008–09 inflated to 2009–10 prices.

Sources: AIHW analysis of Bettering the Evaluation and Care of Health survey data; AIHW disease expenditure database.

6.5 People with dementia in hospital

For this report, the cost associated with all admitted patient hospitalisations with a principal diagnosis of dementia was used to estimate the proportion of hospital expenditure related to dementia (see Note 6.1 in Appendix D for details on the method). The information in this section only applies to hospital expenditure related to admitted patients. No data are available that allow for the estimation of expenditure due to dementia that occurs in, for example, out-patient hospital services or emergency services.

In 2009–10, there were 12,286 hospitalisations for which dementia was recorded as the principal diagnosis, as well as 70,940 hospitalisations for which dementia was recorded as an additional diagnosis (see Section 4.4).

No attempt has been made in this report to estimate the proportion of the cost of hospitalisations with an additional diagnosis of dementia that can be attributed to dementia (rather than to other health conditions) since no agreed method exists to do so using available data. Therefore, the estimate of hospital expenditure based on principal diagnosis alone is an underestimate of the actual expenditure attributable to dementia in admitted patient settings.

The amount of dementia-related admitted patient expenditure as reported in the previous *Dementia in Australia* report (AIHW 2007) included estimated expenditure for hospitalisations in which dementia was an additional diagnosis, and cannot be compared with the estimate given in this report. However, in order to allow for a comparison over time, estimates for 2005–06 to 2009–10 (which are all based on the method as described above) are provided.

In 2009–10, total expenditure for hospitalisations for which the principal diagnosis was dementia was estimated as $144.5 million (Table 6.3). Just over half (51%) of this expenditure was for female patients ($73.6 million) while 49% was for male patients ($70.9 million). For both men and women, half (51%) of hospital expenditure was for patients aged 80 to 89 years. In contrast, those aged 90 and over accounted for 8% of expenditure for men and 14% of expenditure for women.

Table 6.3: Expenditure for hospitalisations with dementia as the principal diagnosis, by sex and age, 2009–10

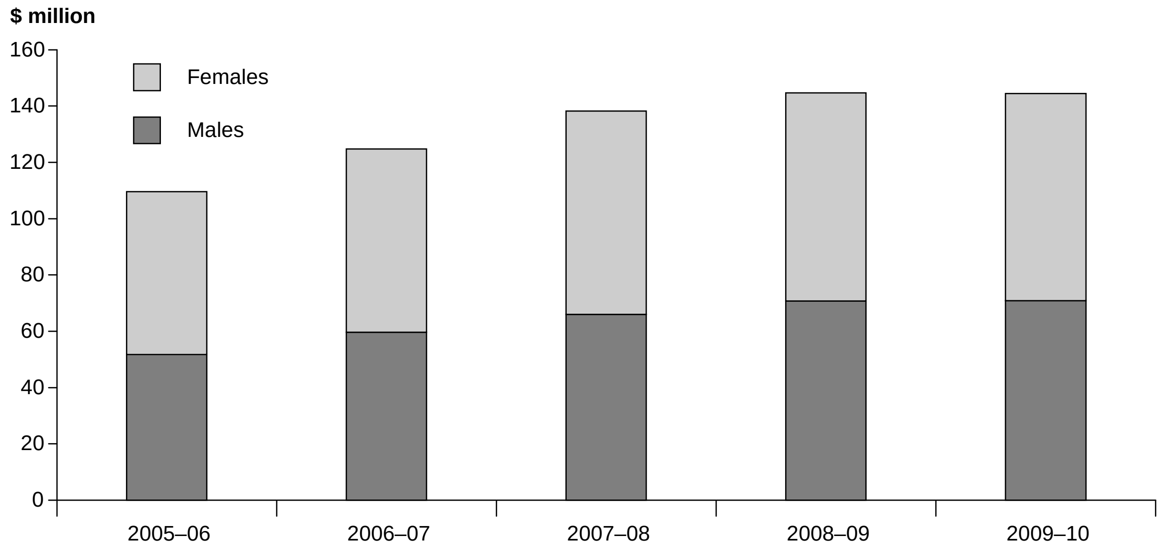
Sex/age	Hospitalisations (number)	Patient days	Expenditure ($ million)	Average length of stay (days)	Cost per hospitalisation ($)	Cost per patient day ($)
Males						
Under 70	596	18,648	6.9	31.3	11,511	367.89
70–74	751	12,599	8.8	16.8	11,766	701.37
75–79	1,089	27,093	12.8	24.9	11,790	473.89
80–84	1,701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

Sources: AIHW National Hospital Morbidity Database; National Hospital Cost Data Collection.

By taking into account the average length of stay in hospital by age group, the average cost per patient day for patients with a principal diagnosis of dementia was calculated. This cost was $664. For both men and women, those aged under 70 years had the lowest cost per patient day ($368 and $517 respectively). The average cost per hospitalisation for people with a principal diagnosis of dementia was $11,761.

The amount of hospital expenditure attributable to dementia increased by $34.9 million from $109.6 million in 2005–06 to $144.5 million in 2009–10 (taking inflation into account) (Figure 6.2). Overall, this suggests a 32% increase in expenditure over the 5 years. However, the growth in expenditure was centred on the earlier years, particularly between 2005–06 and 2006–07 (14% growth) and between 2006–07 and 2007–08 (11% growth). Growth slowed to 5% between 2007–08 and 2008–09, and there was no change between 2008–09 and 2009–10.

This pattern is similar to that observed when examining change over time in the number of hospitalisations with dementia as the principal diagnosis (Section 4.4).



Notes: Expenditure for 2005–06 to 2008–09 is expressed in terms of 2009–10 dollars. Data for this figure are shown in Appendix Table A6.2.

Sources: AIHW National Hospital Morbidity Database; National Hospital Cost Data Collection.

Figure 6.2: Expenditure for hospitalisations with dementia as the principal diagnosis, by sex, 2005–06 to 2009–10, constant prices

6.6 Medications for dementia

As described in Section 4.5, four dementia-specific drugs—donepezil, galantamine, rivastigmine and memantine—are subsidised by the Australian Government through the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS). Information from Medicare Australia on the amount of subsidy paid for each drug is used in this section to describe Australian Government expenditure on dementia-specific medications. The person prescribing the drugs may have been either a GP or a specialist.

Based on PBS and RPBS data, Australian Government expenditure on dementia-specific medications in 2009–10 was $58.7 million (Table 6.4). More than half (62%) of this expenditure was for donepezil, 29% was for galantamine, 7% for rivastigmine and 3% for memantine. These proportions mirror those of the relative number of each type of medication dispensed in 2009–10 (as shown in Table 4.17).

Change over time in government expenditure on dementia-specific medications is also shown in Table 6.4 (with inflation taken into account). There was a substantial increase in such expenditure between 2007–08 and 2008–09 (from $53.7 to $57.9 million), with a relatively smaller increase between 2008–09 and 2009–10 (from $57.9 to $58.7 million).

In addition to the use of dementia-specific medications, people with dementia may be prescribed other types of medication to manage their dementia. Data from the BEACH survey can be used to estimate the amount and type of such medications prescribed by GPs, with the cost of these medications derived from Medicare Australia data. Further information on the methodology used can be found in *Health system expenditure on disease and injury in Australia, 2004–05* (AIHW 2010d). This approach captures both Australian

Government expenditure and non-government expenditure (for example, from individuals and private health insurance funds) for medications prescribed by GPs, but not medications prescribed by specialists.

Table 6.4: Benefit paid for government-subsidised dementia-specific prescriptions[(a)], by type of medication, 2007–08 to 2009–10, constant prices[(b)]

	$ million			Per cent		
Drug name	**2007–08**	**2008–09**	**2009–10**	**2007–08**	**2008–09**	**2009–10**
Donepezil	35.0	36.8	36.2	65.1	63.5	61.7
Galantamine	17.3	17.8	16.8	32.2	30.7	28.6
Rivastigmine	1.4	2.5	4.2	2.6	4.4	7.2
Memantine[(c)]	. .	0.8	1.5	. .	1.4	2.6
Total	**53.7**	**57.9**	**58.7**	**100.0**	**100.0**	**100.0**

(a) Refers to expenditure on dementia-specific prescriptions subsidised through the PBS or RPBS as prescribed by GPs and specialists.

(b) Expenditure for 2007–08 and 2008–09 is expressed in terms of 2009–10 prices.

(c) Memantine was not a government-subsidised medication until 2008–09.

Source: Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data from Medicare Australia (2012).

According to estimates derived from the BEACH survey, expenditure on dementia-specific medications that were prescribed by GPs (rather than by both GPs and specialists) was $37.7 million (Table 6.5). A number of other medications, totalling $21.2 million in value, were also prescribed by GPs to manage dementia. The most common of these were antipsychotics, with an estimated expenditure of $19.1 million for this type of medication.

Table 6.5: Estimated expenditure for prescriptions to manage dementia as prescribed by GPs[(a)], 2009–10[(b)]

Type of medication (ATC group[(c)])	Benefit paid ($'000)	Benefit paid (per cent)
Anti-dementia drugs (N06D)	37,718	64.0
Antipsychotics (N05A)	19,113	32.4
Anxiolytics (N05B)	80	0.1
Antidepressants (N06A)	637	1.1
Sedatives and hypnotics (N05C)	30	0.1
Other analgesics and antipyretics (N02B)	25	0.0
Other GP-prescribed medications	1,334	2.3
Total	**58,938**	**100.0**

(a) Prescriptions written by specialists are not included in this analysis.

(b) Expenditure is for 2008–09 inflated to 2009–10 prices.

(c) The Anatomical Therapeutic Chemical (ATC) classification system is described in Appendix E.

Sources: AIHW analysis of Bettering the Evaluation and Care of Health data and Pharmaceutical Benefits Scheme data.

6.7 Aged care assessments

As detailed in Section 4.6, assessments of the needs of people seeking access to Australian Government-subsidised aged care services are conducted through the Aged Care Assessment Program. The Australian Government funds state and territories to manage and administer the ACAP, with the states and territories also contributing funds for this program

(ACAP NDR 2009). Only information on Australian Government expenditure on the ACAP is available.

In 2009–10, this was $76.4 million (DoHA 2010c). This included, for example, recurrent funding for Aged Care Assessment Teams, Evaluation Units and ACAT training. Just over one in four (25.9%) ACAP clients had a diagnosis of dementia. Thus, an estimated $19.8 million of Australian Government expenditure on the ACAP in 2009–10 can be attributed to dementia. This is an increase from $15 million in 2003–04, after adjusting for inflation (AIHW 2007).

6.8 Community aged care services

Data on expenditure on community aged care services that are attributable to dementia are limited. In most cases, there is neither routine monitoring of the proportion of clients within a program with dementia, nor information on the costs associated with such care. It is also generally unclear what proportion of the costs associated with caring for a particular client with dementia is related to dementia per se, as opposed to other health issues.

In most cases, an estimate of expenditure attributable to dementia must be derived by first estimating the proportion of clients with dementia in a particular program and then applying that proportion to total government expenditure for that program. As described more fully below, this is the approach used in much of this section. Thus, by definition, the information in this section pertains solely to government expenditure; expenditure by the clients themselves is not included.

Community aged care packages

Community based services provided under the *Aged Care Act 1997* largely consist of community aged care packages offering care at different levels of assistance, depending on the needs of the client. As detailed further in Section 4.7, low-level packaged care is provided to people in their own homes through the CACP program, while intensive home-based care and support are provided through EACH and EACHD packages.

The Australian Government contributes to the cost of these packages. Recipients also contribute to the cost (DoHA 2010c). Information is not available on the amount that recipients with dementia paid for these packages, nor is information available on total Australian Government expenditure for those packages that can be attributed to dementia. In order to estimate government expenditure, the approach outlined in Box 6.1 was used.

Estimates suggest that, in 2009–10, Australian Government expenditure for community aged care package recipients with dementia totalled $210.2 million (Table 6.6). The EACHD program accounted for almost half of this ($99.6 million), followed by the CACP ($72.7 million) and the EACH program ($37.9 million).

In 2003–04, Australian Government expenditure for community aged care package recipients with dementia was $96.4 million (after adjusting for inflation). This is less than half of what it was in 2009–10. In particular, for people with dementia, expenditure on the EACH program grew substantially over the period, while there was a decrease in such expenditure in CACP. As rollout of the EACHD packages began in 2005 no comparable data for 2003–04 are available.

Box 6.1: Estimating Australian Government expenditure on community aged care package recipients with dementia

Information on the proportion of CACP and EACH package recipients with dementia was obtained from the 2008 *Community Care Census* (14.3% and 18.4% respectively) (see Section 4.7). Unlike the administrative data available from DoHA about these programs, the 2008 CCC collected information on the dementia status of clients (although it did not collect data on the cost of providing a package to a particular client).

All recipients of EACHD packages were assumed to have dementia.

The proportion of clients with dementia in each program was applied to the total Australian Government expenditure for that program to derive an estimate of expenditure due to dementia.

Note that as discussed in Appendix B, the number of people with dementia is likely to have been under-reported in the 2008 CCC. Thus, the expenditure figures shown in this section are likely to underestimate the cost of dementia in these programs.

Table 6.6: Australian Government expenditure for community aged care package recipients with dementia, 2003–04 and 2009–10, constant prices[(a)]

	2003–04	2009–10		
	Expenditure due to dementia ($ million)	Total expenditure for program ($ million)	% of recipients with dementia	Expenditure due to dementia ($ million)
CACP	89.8	508.7	14.3	72.7
EACH	6.6	206.0	18.4	37.9
EACHD[(b)]	. .	99.6	100.0	99.6
Total	**96.4**	**814.3**	**. .**	**210.2**

(a) Expenditure for 2003–04 is expressed in terms of 2009–10 dollars.

(b) EACHD packages were not available in 2003–04 and thus comparable data for that year are not available.

Sources: AIHW 2007; AIHW analysis of the 2008 Community Care Census; DoHA 2010c.

Other community aged care services

Home and Community Care

The HACC program delivers a range of maintenance and support services for older Australians, younger people with disability and their carers to allow them to be more independent at home and in the community. In terms of client numbers, this is the largest of the community care programs in Australia. Total Australian Government and state and territory Government funding for HACC in 2009–10 was $1,944 million (DoHA 2010c).

No information on the clients' diagnoses is available from the HACC data. In the previous *Dementia in Australia* report (AIHW 2007), information from Western Australia was used to estimate that 5% of HACC funding was for people with dementia. More recent data from Western Australia suggests that an estimated10.2% of HACC clients aged 60 and over had dementia in 2009–10 (see Section 4.8). Information from DoHA indicates that in that same year, 82.9% of HACC clients nationally were 60 years and over (DoHA 2011g). Applying these proportions to total HACC funding for 2009–10 suggests that at least $164.4 million of HACC funds were attributable to dementia.

Veterans' home care

The Veterans' Home Care (VHC) program, which is administered by DVA, is designed to help veterans, war widows and widowers who wish to continue living independently but who need a small amount of practical help. The program provides domestic assistance, safety-related home and garden maintenance, personal care and respite care (DVA 2010). In 2009–10, VHC provided services to almost 77,000 clients (AIHW 2011b) and total funding was $115.0 million (DVA 2010).

No data are available on the proportion of those assisted by this program who had dementia. Given it is a low-level care program, the same proportion as for the HACC program has been applied (that is, 10.2% of clients aged 60 and over). Since the average age of people approved for Veterans' Home Care Services was 83 years (DVA 2010), it is assumed that all clients of this program were 60 years and over. Based on these assumptions, a total of $11.7 million of Veteran's Home Care funding is estimated to be attributable to dementia.

DVA Community Nursing Program

The DVA Community Nursing Program is designed to meet clinical and/or personal care needs of veterans, war widows and widowers by providing access to community nursing services, with the aim of helping clients avoid early admissions to hospitals or residential care (DVA 2010). During 2009–10, the Community Nursing Program assisted almost 33,000 clients (AIHW 2011b) and the DVA spent $117.7 million on this program (DVA 2010).

No data are available on the proportion of clients with dementia who used this program. Given that this program is likely to provide a relatively high level of care, similar to that of the EACH program, the same proportion that was applied for EACH (18.4%) was applied to total government expenditure for the DVA Community Nursing Program. Thus, of the total amount spent on this program in 2009–10, $21.7 million is estimated to be attributable to dementia.

6.9 Flexible aged care services

Flexible aged care services are funded by the Australian Government to address the needs of care recipients in either a residential or community care setting in ways other than the care provided through mainstream residential and community care services (DoHA 2010c). Estimates of government expenditure related to dementia for two types of flexible care programs are shown in this section: the Transition Care Program, and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. As detailed below, expenditure during 2009–10 for these two programs that was attributable to dementia is estimated to be $42.7 million.

No attempt has been made to estimate the amount of expenditure attributable to dementia for other flexible care programs, such as:

- Multi-Purpose Services: services which provide a mix of aged care, health and community services in rural and remote communities
- Innovative Care services: services which support the development and testing of flexible models of service delivery in areas where mainstream aged care services may not meet the needs of a location or a target group (DoHA 2010c).

Transition Care Program

The Transition Care Program (TCP) provides goal-oriented and therapy-focused services to older people after a hospital stay, including low intensity therapy, case management, and nursing support or personal care (DoHA 2010c). The program was established in 2004–05 as a jointly-funded initiative between the Australian and state and territory governments, and is managed by the state and territory governments. To be eligible for admission to a transition care service, an older person must have been assessed by an Aged Care Assessment Team (through the ACAP) as being eligible for residential care and for transition care. Total government expenditure on the TCP in 2009–10 was $192.2 million, with $107.5 million of this provided by the Australian Government, and $84.6 million by state and territory governments (DoHA 2010c).

The TCP does not collect information on whether or not the person has dementia. However, ACAP data can be used to determine the proportion with dementia of all those who were found eligible for the TCP during the ACAT assessment. Data for 2009–10 indicate that 15.6% of those found eligible for transition care during an ACAT assessment had dementia. Applying this proportion to total Transition Care Program funding for 2009–10 suggests that $30.0 million of such funds were attributable to dementia.

National Aboriginal and Torres Strait Islander Flexible Aged Care Program

As well as accessing aged care services funded under the *Aged Care Act 1997*, Aboriginal and Torres Strait Islander people can access services funded through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. The aim of this program is to provide culturally appropriate aged care services in residential and community care settings to older Indigenous Australians close to their homes and communities (DoHA 2010d). At 30 June 2010, 29 aged care services were funded through this program, delivering more than 650 aged care places (DoHA 2010c). Australian Government funding for this program was $23 million in 2009–10 (DoHA 2010d).

No information is available on the dementia status of people accessing these services and it is difficult to find a comparable program from which to derive an estimate of the proportion of clients with dementia. In order to provide an estimate, data on permanent residents in Australian Government-subsidised residential aged care facilities were used. According to the data, 55% of expenditure for Indigenous Australians in these facilities was for people with dementia. Using this proportion, it is estimated that $12.7 million of the Aboriginal and Torres Strait Islander Flexible Aged Care Program funding can be attributed to dementia.

The accuracy of this estimate depends on the quality of Indigenous identification in the ACFI. It also depends on how similar the proportion of Indigenous people with dementia in government-subsidised residential aged care facilities is to those using services in the Aboriginal and Torres Strait Islander Flexible Aged Care Program.

6.10 National Respite for Carers Program

As described in Chapter 4, the National Respite for Carers Program (NRCP) is funded by the Australian Government. One of the target groups for this program is carers of people with dementia (DoHA 2011b). The program provides direct respite care in a number of settings, (but not respite care in residential aged care facilities), as well as indirect respite care, such as domestic assistance, social support and personal care for the care recipient. An ACAT assessment is not required. Australian Government expenditure on this program was $200.0 million in 2009–10 (DoHA 2010c).

NRCP data from DoHA for 2009–10 suggest that 59.9% of recipients whose carers received respite through this program had dementia. Using this proportion, it is estimated that 2009–10 Australian Government expenditure for this program attributable to dementia is $119.8 million.

6.11 Residential aged care services

Residential aged care services are subsidised by the Australian Government for approved residents, with approvals based on the outcome of an ACAT assessment (see Chapter 4 for information on ACAT assessments). The government payment consists of a basic subsidy plus supplements for special needs, less any reduction specific to the resident's circumstances. Examples of special needs are requiring oxygen to aid breathing or needing help with feeding when a resident has difficulty swallowing. Reductions may result from income-testing of residents, where those who can afford to do so pay for more of their own care (DoHA 2009b, 2010c). In 2009–10, Australian Government recurrent residential care funding for permanent residents totalled $6,870 million.

Since March 2008, the amount of basic subsidy payable for permanent residents has been assessed using the ACFI (see Box 3.3 for further information about the ACFI). As detailed in Appendix B, information about the care needs and dementia status of permanent residents in subsidised residential aged care facilities is available from ACFI data. As noted in Section 3.1, in 2009–10, 99% of permanent residents of Australian Government-subsidised aged care facilities had received an ACFI assessment.

Data collected though the ACFI, along with related administrative data maintained by DoHA, are used in this section to estimate Australian Government expenditure for permanent residents with dementia in residential aged care facilities. Note that these estimates are not comparable with those shown in the previous *Dementia in Australia* report (AIHW 2007) since ACFI data were not available at that time. Note also that since the expenditure estimates relate only to permanent residents in subsidised aged care facilities who received ACFI assessments, the estimate does not include government expenditure on:

- people who accessed respite care in residential aged care facilities
- those in residential care places under other programs such as the Multi-Purpose Service Program or the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (see Section 6.9 for an estimate of expenditure for the latter of these).

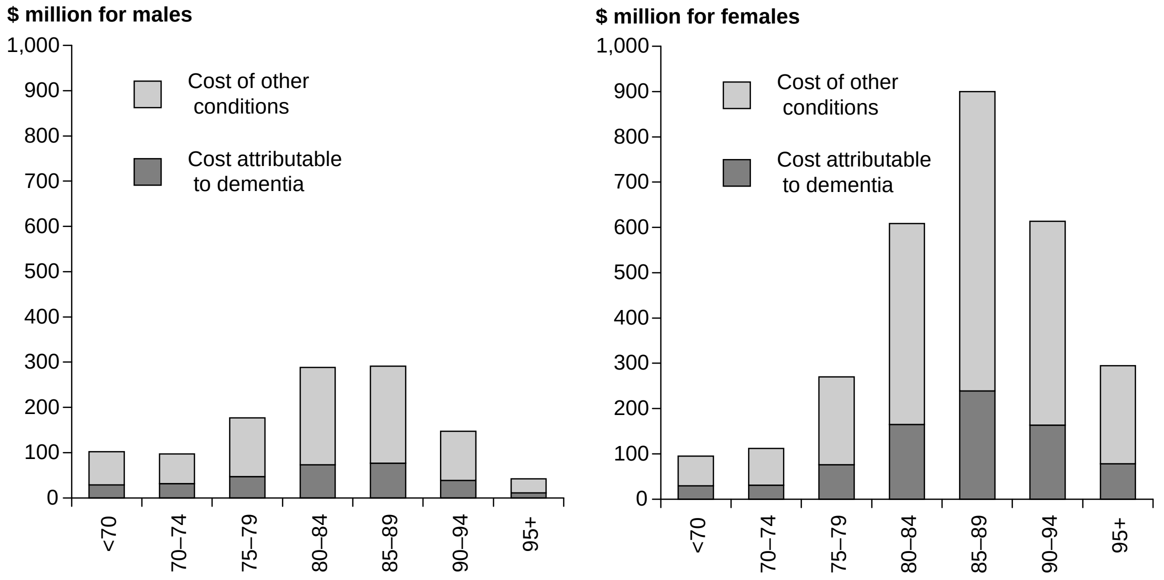
Therefore, the expenditure estimates shown in this section represent a minimum estimate of government expenditure on residential aged care services that is attributable to dementia.

Data collected using the ACFI suggest that 53% of permanent residents had a diagnosis of dementia in 2009–10 (see Section 4.11). According to data provided by DoHA, the total cost of care for those residents was estimated to be $4,044.0 million. This equates to 59% of total government residential aged care expenditure for permanent residents.

The $4,044.0 million is the estimated total cost of caring for residents with dementia, rather than the proportion of cost of care that is attributable to dementia. As discussed in Section 3.5, people with dementia often have a number of co-existing conditions; some of their care would be related to these other conditions. For example, they may need assistance with mobility due to a stroke, or they may need assistance with communication because of both hearing loss and dementia. According to 2009 SDAC data, people with dementia living in cared accommodation had an average of 5.6 health conditions (Table 3.14).

Expenditure that could be solely attributed to dementia was separated from the costs related to care for conditions which co-existed with dementia. The approach used to do so is described in Note 6.2 in Appendix D.

Based on that approach, government expenditure on permanent residents in residential aged care that is solely attributable to dementia was estimated to be $1.1 billion in 2009–10 (Appendix Table A6.3). This equates to just over one-quarter (27%) of the total expenditure for caring for permanent residents with dementia. Figure 6.3 shows that this proportion was fairly similar across each of the age groups for both men and women (with the proportion ranging from 26% to 32%).



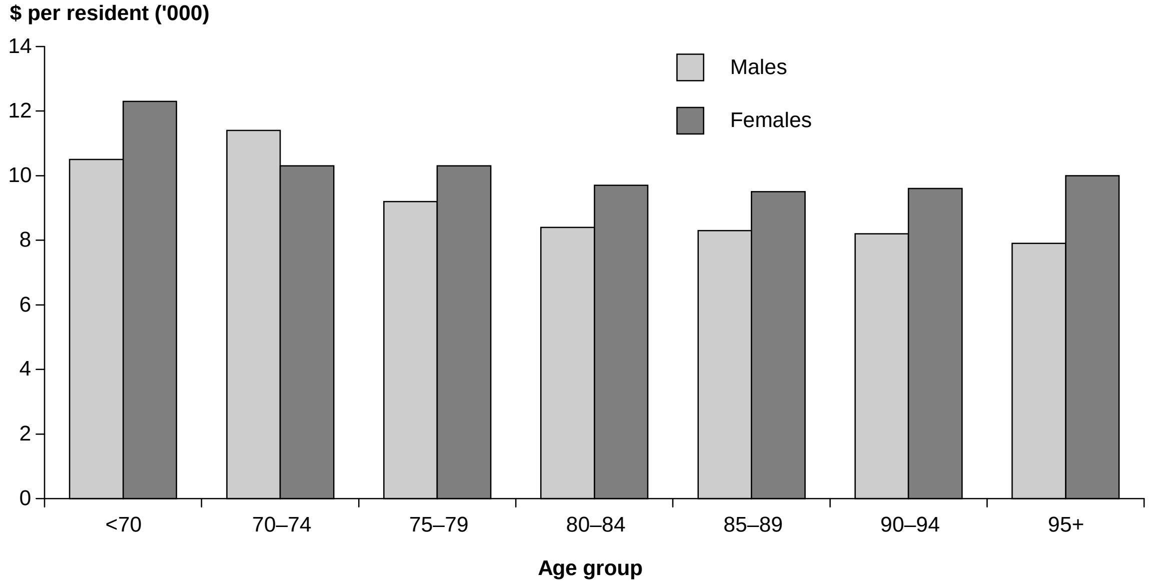
Note: Data for this figure are shown in Appendix Table A6.3.

Source: AIHW analysis of unpublished residential aged care service data provided by DoHA.

Figure 6.3: Australian Government expenditure for permanent residents with dementia in aged care facilities, by sex and age, 2009–10

The amount of residential aged care expenditure attributable to dementia was highest for women aged 85–89 ($239.2 million), accounting for 31% of such expenditure for women. In contrast, for men, residential aged care expenditure attributable to dementia was relatively high for both the 80–84 age group ($73.4 million) and the 85–89 age group($76.6 million), with these two groups accounting for 49% of expenditure for men.

Total expenditure attributable to dementia for the various age groups is, of course, heavily influenced by the number of permanent residents in those groups. To examine expenditure without this influence, Figure 6.4 presents information on expenditure attributable to dementia per resident with dementia. On average, estimated expenditure per resident was about $1,000 more for female residents with dementia ($9,803) than male residents with dementia ($8,823). Indeed, for each age group except one (70–74), the estimated expenditure attributable to dementia was higher per female resident than male resident with dementia.



Note: Data for this figure are shown in Appendix Table A6.4.

Source: AIHW analysis of unpublished residential aged care service data provided by DoHA.

Figure 6.4: Australian Government expenditure attributable to dementia, per permanent resident with dementia in aged care facilities, by age and sex, 2009–10

Average expenditure per resident attributable to dementia tended to be higher among younger residents. This is due, at least in part, to the fact that younger residents tend to have fewer co-morbidities than older residents (Table 3.14). Thus, for the younger residents, a greater proportion of the total cost of care will be attributable to dementia, while for older residents, a greater proportion of the total cost of care will be attributable to other health conditions.

Appendix A: Additional tables

Table A1.1: Historical and projected Australian population aged 65 and over, 1990–2050 (selected years) ('000s)

Year	65–84	85+	Total 65+
Historical			
1990	1,746.2	147.2	1,893.4
2000	2,126.6	252.7	2,379.3
2010	2,611.2	394.4	3,005.6
2011	2,687.9	415.3	3103.2
Projected(a)			
2012	2,817.8	438.8	3,256.6
2020	3,713.6	547.0	4,260.5
2030	4,837.2	783.4	5,620.6
2040	5,468.5	1,214.6	6,683.1
2050	5,959.2	1,570.4	7,529.6

(a) ABS 'Series B' population projections have been used. Details on the assumptions that underlie that projection series can be found in ABS (2008a).

Sources: ABS 2008a, 2012a.

Table A1.2: Clinical Dementia Rating (CDR) scale

Category	Rating of 0: Healthy	Rating of 0.5: Very mild impairment	Rating of 1: Mild	Rating of 2: Moderate	Rating of 3: Severe
Memory	No memory loss or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; 'benign' forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss, only fragments remain
Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disorientated in time, often to place	Oriented to person only
Judgement & problem solving	Solves everyday problems; handles business and financial affairs well; judgement good in relation to past performance	Slight impairment in solving problems, similarities and differences	Moderate difficulty in handling problems, similarities and differences; social judgement usually maintained	Severely impaired in handling problems, similarities, differences; social judgement usually impaired	Unable to make judgements or solve problems
Community affairs	Independent function at usual level in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities though may still be engaged in some; appears normal to casual inspection	No pretence of independent function outside home; appears well enough to be taken to functions outside a family home	No pretence of independent function outside home; appears too ill to be taken to functions outside a family home
Home and hobbies	Life at home, hobbies and intellectual interests are well maintained	Life at home, hobbies and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in home
Personal care	Fully capable of self-care	Fully capable of self-care	Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

Note: For this scale, impairment is defined as decline from the person's usual level of functioning due to cognitive loss alone for each category, not due to other factors, such as injury or depression. For scoring purposes, memory is the primary category and the score given for memory is used for the global score unless three or more of the secondary categories score higher or lower than the memory score.

Source: Morris 1993.

Table A2.1: Estimated number of people with dementia, by age and sex, 2011: a comparison of AIHW 2007 and ADI rates

	Using rates from AIHW 2007[(a)]			Using ADI rates[(a)]			% of difference		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 65	6,900	3,500	10,400	12,600	11,300	23,900	7.2	10.0	17.2
65–74	16,300	14,600	30,800	25,200	28,900	54,100	11.4	18.2	29.5
75–84	34,000	52,200	86,100	39,800	57,500	97,400	7.5	6.8	14.3
85+	24,900	67,000	91,900	35,600	87,000	122,600	13.6	25.3	39.0
Total[(b)]	**82,000**	**137,200**	**219,200**	**113,300**	**184,700**	**298,000**	**39.7**	**60.3**	**100.0**

(a) Estimates were calculated using population data as at 30 June 2011 (ABS 2012a).

(b) Numbers may not sum to the total due to rounding.

Sources: Calculations by AIHW using rates reported in AIHW (2007) and derived by the AIHW based on ADI (2009) and Harvey et al. (2003).

Table A2.2: Estimated number of people with dementia, by sex and age, 2005 to 2050 (selected years)

	2005	2010	2011	2012	2013	2014	2015	2020	2025	2030	2035	2040	2045	2050
Sex														
Males	89,900	108,600	113,300	118,100	122,600	127,000	131,700	157,000	186,200	220,400	257,200	292,700	324,100	354,300
Females	155,500	178,800	184,700	193,200	199,100	204,900	211,100	242,800	280,700	329,900	387,100	444,900	493,700	537,100
Age														
Under 60	4,200	4,500	4,500	4,600	4,700	4,700	4,800	5,000	5,200	5,400	5,600	6,100	6,400	6,600
60–64	14,700	18,900	19,400	19,400	19,700	20,000	20,300	22,300	23,900	24,000	25,700	25,400	28,600	30,200
65–69	19,000	22,600	23,700	25,600	27,200	28,200	29,300	31,600	34,800	37,400	37,500	40,300	39,800	44,800
70–74	26,000	29,500	30,400	31,600	32,600	34,100	35,800	46,500	50,400	55,700	59,900	60,100	64,600	64,000
75–79	40,100	40,300	40,800	42,100	43,400	45,100	46,800	57,200	74,700	81,400	90,200	97,200	97,900	105,400
80–84	50,600	56,100	56,600	57,200	57,400	57,700	58,100	68,500	84,600	111,100	121,700	135,500	146,600	148,400
85–89	44,200	57,900	59,900	62,100	63,900	65,400	66,900	70,300	84,100	105,300	139,200	154,000	173,000	188,600
90–94	37,100	44,600	48,500	52,500	56,000	59,200	61,700	71,800	76,600	93,400	119,200	159,700	179,600	205,300
95+	9,500	13,200	14,200	16,100	16,800	17,500	19,200	26,600	32,600	36,600	45,300	59,300	81,200	98,300
Total	**245,400**	**287,500**	**298,000**	**311,300**	**321,600**	**332,000**	**342,800**	**399,800**	**466,900**	**550,200**	**644,300**	**737,600**	**817,700**	**891,400**

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003) and applied to population data for 2005 to 2011 (ABS 2012a) and population projections for 2012 to 2050 (ABS 2008a)

Table A2.3: Age-specific rate[(a)] of deaths with an underlying cause of dementia, by sex, 2010

	Males	Females	Persons
Under 60	0.2	0.3	0.2
60–64	4.5	5.3	4.9
65–69	14.2	11.3	12.8
70–74	44.6	41.7	43.1
75–79	134.3	134.1	134.2
80–84	369.9	413.3	394.6
85–89	881.1	1,070.1	1,000.3
90–94	1,794.3	2,374.6	2,194.4
95+	2,797.6	4,321.5	3,955.6

(a) Number of deaths per 100,000 population by age group as at 30 June 2010.

Sources: AIHW analysis of ABS unpublished causes of death data; population data for 2010 (ABS 2012a).

Table A2.4: Deaths with an underlying cause of dementia, by sex, 2001 to 2010

	Number			Per cent of total deaths	Age-standardised rate[(a)]	95% confidence interval
	Males	Females	Persons			
2001	1,177	2,563	3,740	2.9	19.3	18.7–19.9
2002	1,390	2,974	4,364	3.3	21.7	21.1–22.4
2003	1,351	2,924	4,275	3.2	20.7	20.1–21.3
2004	1,414	3,192	4,606	3.5	21.7	21.1–22.3
2005	1,434	3,219	4,653	3.6	21.0	20.4–21.6
2006	2,076	4,474	6,550	4.9	28.4	27.7–29.0
2007	2,414	4,904	7,318	5.3	30.3	29.6–31.0
2008	2,708	5,464	8,172	5.7	32.7	32.0–33.4
2009	2,787	5,492	8,279	5.9	31.9	31.2–32.6
2010	2,920	6,083	9,003	6.3	33.3	32.6–34.0

(a) The rates were standardised to the Australian population as at 30 June 2001 and are expressed per 100,000 population.

Sources: AIHW National Mortality Database (2001 to 2005); AIHW analysis of ABS unpublished causes of death data (2006 to 2010).

Table A2.5: Deaths with an underlying cause of dementia, by type of dementia, 2001 to 2010

	Number				Per cent			
	Vascular dementia (F01)	Unspecified dementia (F03)	Alzheimer disease (G30)	Total	Vascular dementia (F01)	Unspecified dementia (F03)	Alzheimer disease (G30)	Total
2001	—	2,133	1,607	**3,740**	—	57.0	43.0	**100.0**
2002	n.p.	2,512	>1,849	**4,364**	n.p.	57.6	>42.3	**100.0**
2003	—	2,663	1,612	**4,275**	—	62.3	37.7	**100.0**
2004	6	2,834	1,766	**4,606**	0.1	61.5	38.3	**100.0**
2005	7	2,781	1,865	**4,653**	0.2	59.8	40.1	**100.0**
2006	825	3,752	1,973	**6,550**	12.6	57.3	30.1	**100.0**
2007	897	4,146	2,275	**7,318**	12.3	56.7	31.1	**100.0**
2008	1,024	4,664	2,484	**8,172**	12.5	57.1	30.4	**100.0**
2009	1,050	4,788	2,441	**8,279**	12.7	57.8	29.5	**100.0**
2010	1,132	5,165	2,706	**9,003**	12.6	57.4	30.1	**100.0**

Sources: ABS (2012b); AIHW National Mortality Database (2001 to 2005); AIHW analysis of ABS unpublished causes of death data (2006 to 2010).

Table A2.6: Leading causes of burden of disease by fatal and non-fatal components, for people aged 65 and over, 2011

	Years of life lost (YLLs)			Years lost due to disability (YLDs)			Disability-adjusted life years (DALYs)		
Leading causes[(a)]	No.	% of total	Rank	No.	% of total	Rank	No.	% of total	Rank
Ischaemic heart disease	148,579	19.0	1	31,489	6.5	4	180,068	14.2	1
Dementia	29,632	3.8	6	81,805	16.9	1	111,437	8.8	2
Stroke	66,025	8.4	2	15,798	3.3	7	81,823	6.5	3
Type 2 diabetes	22,925	2.9	9	47,860	9.9	2	70,784	5.6	4
Lung cancer	58,185	7.4	3	3,846	0.8	26	62,031	4.9	5
Chronic obstructive pulmonary disease	39,332	5.0	4	12,603	2.6	11	51,935	4.1	6
Colorectal cancer	33,589	4.3	5	7,737	1.6	14	41,326	3.3	7
Other chronic respiratory diseases	21,240	2.7	10	15,647	3.2	8	36,887	2.9	8
Total for all causes	**783,657**	**100.0**	. .	**482,846**	**100.0**	. .	**1,266,504**	**100.0**	. .

(a) Leading causes shown are based on DALYs.

Sources: AIHW projection of burden of disease based on rates from Begg et al. (2007) and population data for 2011 (ABS 2012a).

Table A3.1: People with dementia, by residency, age and sex, 2009 (per cent)

	Community			Cared accommodation			Total		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 65	*62.2	*37.8	**100.0**	51.8	48.2	**100.0**	*58.4	*41.6	**100.0**
65–69	*69.8	**30.2	**100.0**	46.1	53.9	**100.0**	*60.1	39.9	**100.0**
70–74	78.2	*21.8	**100.0**	44.3	55.7	**100.0**	66.6	33.4	**100.0**
75–79	57.1	42.9	**100.0**	33.2	66.8	**100.0**	45.3	54.7	**100.0**
80–84	50.3	49.7	**100.0**	31.9	68.1	**100.0**	39.2	60.8	**100.0**
85+	*26.1	73.9	**100.0**	22.1	77.9	**100.0**	23.1	76.9	**100.0**
Total	49.5	50.5	**100.0**	27.6	72.4	**100.0**	35.8	64.2	**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.

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

Table A3.2: Permanent residents with dementia in aged care facilities[(a)], by state and territory, 2009–10 (per cent)

State/territory	Per cent
New South Wales	35.1
Victoria	24.9
Queensland	17.5
Western Australia	8.7
South Australia	9.9
Tasmania	2.6
Australian Capital Territory	1.1
Northern Territory	0.3
Total	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.3: Permanent residents with dementia in aged care facilities[(a)], by country or region of birth, 2009–10 (per cent)

Country/region of birth[(b)]	Per cent
Australia	69.9
Other Oceania/New Zealand/Antarctica	1.1
UK/Ireland	11.1
Other North-West Europe	3.2
Southern/Eastern Europe	10.1
North Africa/Middle East	0.8
Sub-Saharan Africa/South Africa	0.5
South-East Asia	0.8
North-East Asia	0.8
Southern Asia/Central Asia	0.8
North America	0.3
Other America/Caribbean	0.3
Other/Not stated/Not classified	0.3
Total	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) The classification of countries of birth was based on the ABS Standard Classification of Countries 1998 (ABS 1998).

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.4: Age of permanent residents with dementia in aged care facilities[(a)], by Indigenous status, 2009–10 (per cent)

Age	Indigenous	Non-Indigenous	Not reported	Total
Under 65	15.7	2.0	2.9	2.1
65–74	23.9	7.2	8.4	7.4
75–84	34.4	34.3	27.7	34.2
85+	26.1	56.4	61.0	56.3
Total	**100.0**	**100.0**	**100.0**	**100.0**
Mean age	76.1	84.7	85.3	84.6
Median age	78.0	86.0	87.0	86.0

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.5: Indigenous status of permanent residents with dementia in aged care facilities[(a)], by remoteness[(b)], 2009–10 (per cent)

	Major cities	Inner regional	Outer regional	Remote	Very remote	Australia
Indigenous	0.3	0.4	2.1	18.1	58.6	0.6
Non-Indigenous	98.3	98.8	97.3	81.4	40.8	98.2
Not stated	1.4	0.8	0.7	0.5	0.6	1.2
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) Remoteness is based on the location of the most recent facility the resident was in before the end of the 2009–10 financial year. Remoteness was classified using the Australian Standard Geographical Remoteness Area classification (see Appendix E).

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.6: Type of dementia of permanent residents with dementia in aged care facilities[(a)], by sex and age, 2009–10 (per cent)

Sex/type of dementia	Under 65	65–74	75–84	85+	Total
Males					
Alzheimer disease	39.6	53.9	65.9	74.5	67.3
Vascular dementia	11.7	14.7	14.3	11.6	13.1
Dementia in other specified diseases	16.2	8.6	6.0	3.8	5.7
Other dementia	30.0	19.6	10.6	8.1	11.3
More than one type of dementia	2.5	3.2	3.2	2.0	2.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Females					
Alzheimer disease	56.8	71.8	77.9	81.2	79.3
Vascular dementia	6.4	9.9	9.4	8.6	8.9
Dementia in other specified diseases	18.2	5.6	3.7	2.5	3.3
Other dementia	17.1	10.3	7.2	6.6	7.2
More than one type of dementia	1.5	2.4	1.7	1.1	1.4
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Persons					
Alzheimer disease	47.7	63.0	73.6	79.6	75.7
Vascular dementia	9.2	12.3	11.2	9.3	10.2
Dementia in other specified diseases	17.1	7.1	4.5	2.8	4.0
Other dementia	23.9	14.8	8.4	7.0	8.4
More than one type of dementia	2.1	2.8	2.3	1.3	1.7
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.7: Level of disability of people with dementia, by residency and sex, 2009 (per cent)

Core activity limitation[a]	Community			Cared accommodation			Total		
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Profound limitation	66.8	70.1	68.5	92.2	94.1	93.6	79.1	87.1	84.2
Severe limitation	*17.7	*13.6	15.6	5.8	4.9	5.1	*11.9	7.4	9.0
Severe or profound limitation	*84.5*	*83.7*	*84.1*	*98.0*	*99.0*	*98.7*	*91.0*	*94.5*	*93.3*
Moderate or mild limitation	*11.4	**9.5	*10.4	*1.3	*0.7	0.9	*6.5	*3.3	*4.4
No limitation[b]	**4.2	*6.8	*5.5	*0.7	*0.3	*0.4	**2.5	*2.2	*2.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**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) Level of disability is measured by the extent of limitation in core activities of daily living (see Box 3.2).

(b) Includes people with dementia for whom a disability was not recorded and those with disability but with no core activity limitation.

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

Table A3.8: Level of disability of people with dementia, by residency and age, 2009 (per cent)

	Community					Cared accommodation					Total				
Core activity limitation[(a)]	**<65**	**65–74**	**75–84**	**85+**	**Total**	**<65**	**65–74**	**75–84**	**85+**	**Total**	**<65**	**65–74**	**75–84**	**85+**	**Total**
Profound limitation	*63.5	65.7	64.4	76.9	68.5	84.8	91.1	93.6	94.2	93.6	71.2	74.9	80.8	90.0	84.2
Severe limitation	**16.0	**10.7	*19.9	*12.6	15.6	*13.3	*6.6	4.5	5.0	5.1	**15.0	*9.2	*11.2	6.9	9.0
Moderate or mild limitation	**4.1	**7.8	*12.4	**10.5	*10.4	—	**1.5	*1.6	*0.4	0.9	**2.6	**5.5	*6.3	**2.9	*4.4
No limitation[(b)]	**16.4	*15.8	**3.3	—	*5.5	**2.0	**0.8	**0.3	*0.4	*0.4	**11.1	*10.4	**1.6	*0.3	*2.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**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) Level of disability is measured by the extent of limitation in core activities of daily living (see Box 3.2).

(b) Includes people with dementia for whom a disability was not recorded and those with disability but with no core activity limitation.

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

Table A3.9: Twenty most common co-existing long-term health conditions for people with dementia, by residency, 2009 (per cent)

Community		Cared accommodation	
Condition[(a)]	Per cent[(b)]	Condition[(a)]	Per cent[(b)]
Arthritis and related disorders	43.4	Deafness/hearing loss	43.9
Hypertension (high blood pressure)	42.0	Arthritis and related disorders	37.3
Deafness/hearing loss	24.8	Hypertension (high blood pressure)	34.2
Stroke	22.1	Depression/mood affective disorders (excluding postnatal depression)	26.0
High cholesterol	21.8	Stroke	20.2
Diabetes	18.3	Other heart diseases	18.7
Back problems (dorsopathies)	18.2	Other diseases of the nervous system	17.5
Depression/mood affective disorders (excluding postnatal depression)	15.1	Osteoporosis	16.0
Heart disease	*11.7	Diabetes	13.9
Deafness/hearing loss (noise induced)	*10.9	Other mental and behavioural disorders	12.4
Asthma	*9.5	Phobic and anxiety disorders	11.7
Head injury/acquired brain damage	*9.4	Other long term condition	10.2
Angina	*8.9	Other symptoms/signs and abnormal clinical and laboratory findings not elsewhere classified	9.1
Restriction in physical activity or physical work	*7.8	Other diseases of the intestine	8.9
Osteoporosis	*7.6	Pain, no further details	8.5
Disorders of the thyroid gland	*7.2	Restriction in physical activity or physical work	8.3
Other heart diseases	*7.0	Diseases of the digestive system	7.8
Nervous tension/stress	*6.3	Sight loss	7.8
Other diseases of the musculoskeletal system and connective tissue	*6.2	Kidney and urinary system (bladder) disorders (except incontinence)	7.1
Deafness/hearing loss congenital	*5.9	Other diseases of the eye and adnexa	7.0
Total people in community[(b)]	**100.0**	**Total people in cared accommodation[(b)]**	**100.0**

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

(a) The code list used by the ABS to classify health conditions was based on the ICD-10 (see Appendix E for information).

(b) Any one individual could have multiple co-existing conditions; thus, the sum of the proportions exceeds 100%.

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

Table A3.10: Need for assistance for people with dementia living in the community, by sex, 2009 (per cent of those needing assistance in each activity)

	Males	Females	Persons
Core activities			
Self-care(a)	62.9	61.4	62.1
Mobility(a)	79.8	79.2	79.5
Communication(a)	38.0	40.3	39.2
At least one core activity(b)	*83.5*	*83.3*	*83.4*
Non-core activities			
Health care(a)	85.7	82.6	84.1
Cognitive or emotional tasks(a)	59.4	68.7	64.1
Household chores	46.6	75.4	61.1
Property maintenance	67.0	56.5	61.7
Meal preparation	55.6	66.3	61.0
Reading or writing tasks	51.6	61.6	56.6
Private transport	83.3	75.7	79.5
At least one core or non-core activity(b)	*92.9*	*95.3*	*94.1*
Total in the community	**100.0**	**100.0**	**100.0**

(a) These questions were only asked of persons with disability. Those with dementia who did not have a disability recorded were assumed not to need assistance with the activity.

(b) The total is less than the sum of the proportions because people may need assistance with more than one activity.

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

Table A3.11 Assessed overall need for care of permanent residents with dementia in aged care facilities(a), by age, 2009–10 (per cent)

Overall need for care(b)	Under 65	65–74	75–84	85+	Total
High care	88.1	87.1	85.9	87.0	86.7
Low care	11.9	12.9	14.1	13.0	13.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) See Box 3.3 for a description of the approach used to classify a resident as high versus low care.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.12: Assessed overall need for care of permanent residents with dementia in aged care facilities[(a)], by state and territory[(b)], 2009–10 (per cent)

Overall need for care[(c)]	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
High care	86.4	86.9	85.6	86.5	90.4	82.9	85.7	81.1	86.7
Low care	13.6	13.1	14.4	13.5	9.6	17.1	14.3	18.9	13.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) State/territory is based on the location of the most-recent facility the resident was in before the end of the 2009–10 financial year.

(c) See Box 3.3 for a description of the approach used to classify a resident as high versus low care.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.13: Assessed need for care in each ACFI domain for permanent residents in aged care facilities[(a)], by dementia status, 2009–10 (per cent)

	With dementia			Without dementia		
Need for care[(b)]	Activities of daily living	Behaviour characteristics	Complex health care	Activities of daily living	Behaviour characteristics	Complex health care
High	51.6	62.3	19.6	31.6	21.9	23.0
Medium	29.1	21.0	32.0	27.0	29.8	28.0
Low	17.1	13.4	36.4	33.0	27.0	33.9
Very low or nil	2.2	3.3	11.9	8.5	21.3	15.1
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) See Box 3.3 for a description of the approach used to determine care requirements for each ACFI domain.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.14: Care need rating by ACFI care-related question for permanent residents in aged care facilities[(a)], by dementia status, 2009–10 (per cent)

	With dementia					Without dementia				
ACFI care-related question[(b)]	**A (low)**	**B**	**C**	**D (high)**	**Total**	**A (low)**	**B**	**C**	**D (high)**	**Total**
Activities of daily living										
Nutrition	7.3	21.5	36.8	34.4	**100.0**	20.6	31.1	34.0	14.3	**100.0**
Mobility	6.8	8.9	31.0	53.3	**100.0**	12.4	12.8	30.2	44.6	**100.0**
Personal hygiene	0.9	5.3	10.2	83.6	**100.0**	5.3	12.2	20.5	62.1	**100.0**
Toileting	9.5	12.7	9.7	68.2	**100.0**	25.4	17.9	9.7	47.1	**100.0**
Continence	14.4	3.5	5.8	76.3	**100.0**	35.7	5.9	7.3	51.1	**100.0**
Behaviour characteristics										
Cognitive skills	3.9	18.1	29.7	48.4	**100.0**	32.7	37.3	19.0	11.0	**100.0**
Wandering	56.3	9.9	7.0	26.9	**100.0**	80.1	7.8	4.2	7.9	**100.0**
Verbal behaviour	17.6	13.4	14.2	54.8	**100.0**	31.7	16.7	16.2	35.4	**100.0**
Physical behaviour	24.3	13.1	12.3	50.3	**100.0**	51.1	13.8	10.2	24.9	**100.0**
Depression	54.1	25.9	10.2	9.8	**100.0**	53.5	24.5	11.0	11.0	**100.0**
Complex health care										
Medication	1.0	28.6	36.5	33.9	**100.0**	4.6	28.8	34.7	31.9	**100.0**
Complex health care	31.7	36.6	21.8	10.0	**100.0**	31.1	33.3	22.6	13.1	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) For each question, need for care was rated ‘A’, ‘B’, ‘C’, or ‘D’, with ‘A’ indicating the lowest level and ‘D’ the highest level (see Box 3.3).

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A3.15: Source of assistance for people with dementia living in the community, 2009 (per cent of those needing assistance in activity)

	Informal assistance only	Informal & formal assistance	Formal assistance only	*Any informal assistance*[(a)]	*Any formal assistance*[(b)]	No assistance	Total needing assistance
Core activities							
Self-care	59.3	21.9	*5.7	81.2	27.6	*13.1	100.0
Mobility	67.5	26.9	**1.2	94.4	28.1	*4.4	100.0
Communication	86.0	**6.4	—	92.4	**6.4	**7.6	100.0
All core activities[(c)]	62.3	36.1	**0.4	98.4	36.5	**1.2	100.0
Non-core activities							
Health care	29.8	42.8	19.6	72.6	62.3	*7.9	100.0
Cognitive or emotional tasks	72.8	24.2	—	97.0	24.2	**3.0	100.0
Household chores	61.2	32.9	**2.4	94.2	35.4	**3.4	100.0
Property maintenance	65.8	*16.0	*12.9	81.8	28.9	**5.3	100.0
Meal preparation	88.5	*7.0	**1.1	95.6	*8.2	**3.3	100.0
Reading or writing tasks	92.4	**0.8	—	93.2	**0.8	**6.8	100.0
Private transport	76.0	*15.6	**3.1	91.6	*18.7	*5.3	100.0
All non-core activities[(d)]	23.6	72.7	**1.1	96.3	73.8	**2.6	100.0
Total activity[(e)]	22.4	75.4	**1.1	97.9	76.6	**1.0	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) Includes those who used 'Informal assistance only' and 'Formal and informal assistance'.

(b) Includes those who used 'Formal assistance only' and 'Formal and informal assistance'.

(c) Includes only those who received 'Informal assistance only', 'Formal assistance only' or some combination of informal and formal assistance for those core activities in which assistance was needed and received. The 'no assistance' category includes those who received no assistance for all core activities in which assistance was needed.

(d) Includes only those who received 'Informal assistance only, 'Formal assistance only' or some combination of informal and formal for those non-core activities in which assistance was needed and received. The 'no assistance' category includes those who received no assistance for all non-core activities in which assistance was needed.

(e) Includes only those who received 'Informal assistance only', 'Formal assistance only' or some combination of informal and formal assistance for all activities in which assistance was needed and received. The 'no assistance' category includes those who received no assistance for all activities in which assistance was needed.

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

.

Table A4.1: Hospitalisations with dementia as a diagnosis, by sex and age, 2009–10

	Principal diagnosis			Principal or additional diagnosis		
Sex/age	**Number**	**Per cent**	**Rate[(a)]**	**Number**	**Per cent**	**Rate[(a)]**
Males						
Under 60	126	2.1	0.1	586	1.6	0.6
60–64	180	3.0	3.0	712	2.0	12.0
65–69	290	4.8	6.6	1,347	3.8	30.6
70–74	751	12.5	22.3	3,176	8.9	94.2
75–79	1,089	18.1	42.6	6,160	17.3	240.9
80–84	1,701	28.2	91.4	9,933	27.9	533.9
85–89	1,396	23.1	144.9	9,311	26.1	966.3
90–94	425	7.0	143.0	3,690	10.3	1,241.3
95+	74	1.2	106.6	750	2.1	1,079.9
Total	**6,032**	**100.0**	**5.5**	**35,665**	**100.0**	**32.3**
Females						
Under 60	103	1.6	0.1	430	0.9	0.5
60–64	161	2.6	2.7	516	1.1	8.6
65–69	319	5.1	7.1	1,107	2.3	24.7
70–74	616	9.8	17.1	2,721	5.7	75.4
75–79	1,002	16.0	33.9	5,910	12.4	199.9
80–84	1,574	25.2	63.2	11,741	24.7	471.4
85–89	1,622	25.9	98.3	14,979	31.5	907.9
90–94	687	11.0	102.6	7,669	16.1	1,145.6
95+	170	2.7	77.5	2,488	5.2	1,134.8
Total	**6,254**	**100.0**	**5.6**	**47,561**	**100.0**	**42.8**
Total						
Under 60	229	1.9	0.1	1,016	1.2	0.6
60–64	341	2.8	2.9	1,228	1.5	10.3
65–69	609	5.0	6.9	2,454	2.9	27.6
70–74	1,367	11.1	19.6	5,897	7.1	84.5
75–79	2,091	17.0	37.9	12,070	14.5	218.9
80–84	3,275	26.7	75.3	21,674	26.0	498.1
85–89	3,018	24.6	115.5	24,290	29.2	929.4
90–94	1,112	9.1	115.0	11,359	13.6	1,175.0
95+	244	2.0	84.5	3,238	3.9	1,121.6
Total	**12,286**	**100.0**	**5.5**	**83,226**	**100.0**	**37.6**

(a) Number of hospitalisations per 10,000 population in age group.

Source: AIHW National Hospital Morbidity Database.

Table A4.2: Description of Government-subsidised dementia-specific drugs

Drug name	PBS/RPBS item number	Description	Maximum quantity
Donepezil	8495D	Tablet 5 mg *(Aricept®)*	28
	8496E	Tablet 10 mg *(Aricept®)*	28
Galantamine	8536G[(a)]	Tablet 4 mg (base) (Reminyl®)	56
	8537H[(a)]	Tablet 8 mg (base) (Reminyl®)	56
	8756W[(a)]	Tablet 12 mg (base) (Reminyl®)	56
	8770N	Capsule 8 mg (base) (prolonged release) (Reminyl®, Galantyl®)	28
	8771P	Capsule 16 mg (base) (prolonged release) (Reminyl®, Galantyl®)	28
	8772Q	Capsule 24 mg (base) (prolonged release) (Reminyl®, Galantyl®)	28
Rivastigmine	8497F	Capsule 1.5 mg (base) (Exelon®)	56
	8498G	Capsule 3 mg (base) (Exelon®)	56
	8499H	Capsule 4.5 mg (base) (Exelon®)	56
	8500J	Capsule 6 mg (base) (Exelon®)	56
	8563Q	Oral solution 2 mg (base) per mL, 120 mL (Exelon®)	1
	9161E	Transdermal patch 9 mg (releasing approximately 4.6 mg per 24 hours) (Exelon® Patch 5)	30
	9162F	Transdermal patch 18 mg (releasing approximately 9.5 mg per 24 hours) (Exelon® Patch 10)	30
Memantine	1956Y	Tablet 10 mg (Ebixa®, Memanxa®, APO-Memantine®)	56
	9306T	Tablet 20 mg (Ebixa®)	28
	2059J	Oral drops 10 mg per mL, 50 g (Ebixa®)	1

(a) On 30 November 2006, these items were delisted from the *Schedule of Pharmaceutical Benefits* and thus were no longer subsidised by the Australian Government.

Sources: DoHA 2011d, 2012h.

Table A4.3: Government-subsidised galantamine prescriptions[(a)], by type of formulation, 2002–03 to 2009–10

	Non-prolonged release formulations[(b)]	Prolonged release formulations[(c)]	Total
2002–03	31,495	0	**31,495**
2003–04	57,406	0	**57,406**
2004–05	72,291	10,275	**82,566**
2005–06	50,420	49,247	**99,667**
2006–07	12,683	95,080	**107,763**
2007–08	5	112,839	**112,844**
2008–09	14	115,565	**115,579**
2009–10	0	109,290	**109,290**

(a) Refers to number of dementia-specific prescriptions subsidised through the PBS or RPBS.

(b) Includes PBS/RPBS item numbers 8536G, 8537H and 8756W; on 30 November 2006, these items were delisted from the *Schedule of Pharmaceutical Benefits* and thus were no longer subsidised by the Australian Government.

(c) Includes PBS/RPBS item numbers 8770N, 8771P and 8772Q.

Source: Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data from Medicare Australia (2012).

Table A4.4: Type of dementia of ACAP clients with dementia, by age, 2008–09

	Number				Per cent			
Type of dementia	**<65**	**65–84**	**85+**	**Total[(b)]**	**<65**	**65–84**	**85+**	**Total**
Alzheimer disease	547	14,226	10,171	24,945	41.2	52.4	50.2	51.2
Vascular dementia	126	3,814	2,586	6,526	9.5	14.0	12.8	13.4
Dementia in other specified diseases	171	1,401	575	2,147	12.9	5.2	2.8	4.4
Other dementia[(a)]	500	8,001	7,061	15,564	37.6	29.5	34.9	31.9
Number of clients[(c)]	**1,329**	**27,147**	**20,246**	**48,725**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Includes ‘delirium superimposed on dementia’, ‘alcoholic dementia’, ‘unspecified dementia (presenile and senile) and ‘other dementia’.

(b) The total includes clients with unknown age.

(c) The sum of the types of dementia exceeds the total number of clients since a client may have been reported as having more than one type of dementia.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Table A4.5: Formal assistance received at time of ACAT assessment, by activity type and dementia status, for people living in the community, 2008–09

	With dementia		Without dementia	
Activity type	**Number**	**Per cent**	**Number**	**Per cent**
Self-care	26,965	65.1	57,426	46.7
Movement activities	9,779	23.6	22,824	18.6
Moving around places at or away from home	22,387	54.0	52,496	42.7
Communication	13,234	31.9	17,043	13.9
Health care tasks	33,872	81.7	72,160	58.7
Transport	35,428	85.5	92,484	75.3
Activities involved in social and community participation	33,415	80.6	81,601	66.4
Domestic chores	37,218	89.8	105,217	85.6
Meals	35,797	86.4	87,425	71.1
Home maintenance	28,363	68.5	76,988	62.6
Other	4,451	10.7	10,455	8.5
At least one activity	*39,540*	*95.4*	*113,870*	*92.7*
Number of clients[(a)(b)]	**41,436**	**100.0**	**122,894**	**100.0**
Average number of activities for which formal assistance was received	*6.8*	. .	*5.5*	. .

(a) The sum of the activity types for which assistance was required exceeds the total number of clients since a client may have required assistance in more than one area.

(b) Due to the business rules that apply to the collection of ACAP data, some questions are not asked of all clients. Consequently, there may be slight discrepancies between tables as to the reported total number of ACAP clients living in the community.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Table A4.6: Community aged care package recipients with dementia, by age and sex, 2008

	CACP			EACH			EACHD		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Number									
Under 65	34	59	93	6	12	18	23	28	51
65-74	170	280	450	41	40	81	87	95	182
75-84	721	1,571	2,292	112	154	266	208	320	528
85-94	575	1,487	2,062	67	197	264	116	301	417
95+	39	88	127	7	28	35	8	29	37
Total[(a)]	**1,541**	**3,491**	**5,032**	**234**	**431**	**665**	**445**	**774**	**1,219**
Per cent									
Under 65	2.2	1.7	1.8	2.6	2.8	2.7	5.2	3.6	4.2
65-74	11.0	8.0	8.9	17.5	9.3	12.2	19.6	12.3	14.9
75-84	46.8	45.0	45.5	47.9	35.7	40.0	46.7	41.3	43.3
85-94	37.3	42.6	41.0	28.6	45.7	39.7	26.1	38.9	34.2
95+	2.5	2.5	2.5	3.0	6.5	5.3	1.8	3.7	3.0
Total[(a)]	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) The total includes recipients for whom reported age was too unreliable.

Source: AIHW analysis of the 2008 Community Care Census.

Table A4.7: EACHD package recipients, by sex and age, 30 June 2010

	Number	**Per cent**
Sex		
Males	880	38.3
Females	1,416	61.7
Age		
Under 65	95	4.1
65–74	349	15.2
75–84	992	43.2
85–94	788	34.3
95+	72	3.1
Total	**2,296**	**100.0**

Source: AIHW 2011g.

Table A4.8: Community aged care package recipients with dementia, by extent of assistance required[(a)] with specified activities, 2008 (per cent)

	CACP				EACH				EACHD			
	Always	Sometimes	None	Total[(b)]	Always	Sometimes	None	Total[(b)]	Always	Sometimes	None	Total[(b)]
Instrumental activities of daily living												
Housework	58.4	38.1	3.5	**100.0**	89.6	9.2	1.1	**100.0**	88.0	11.1	0.7	**100.0**
Travel[(c)]	52.1	37.0	10.9	**100.0**	80.6	16.4	3.0	**100.0**	77.9	19.0	3.0	**100.0**
Shopping	62.9	32.7	4.4	**100.0**	90.2	8.6	1.2	**100.0**	89.8	9.0	1.0	**100.0**
Taking medicine	47.9	36.8	14.9	**100.0**	79.2	16.8	3.6	**100.0**	82.2	15.9	1.7	**100.0**
Handling money	47.1	38.0	14.3	**100.0**	80.5	14.0	4.4	**100.0**	85.3	12.0	2.4	**100.0**
Activities of daily living												
Bathing/showering	27.8	33.3	38.7	**100.0**	82.6	12.9	4.5	**100.0**	72.9	22.8	4.1	**100.0**
Dressing	14.5	33.1	52.2	**100.0**	69.2	23.0	7.8	**100.0**	59.1	31.8	9.0	**100.0**
Walking	11.6	28.5	59.8	**100.0**	53.1	30.8	16.1	**100.0**	37.9	32.8	29.1	**100.0**
Communication	11.9	35.8	52.2	**100.0**	36.4	34.7	28.9	**100.0**	37.4	39.5	23.1	**100.0**
Using the toilet	4.4	13.8	81.5	**100.0**	49.5	27.1	23.3	**100.0**	40.8	32.6	26.5	**100.0**
Moving around[(d)]	3.0	11.4	85.5	**100.0**	42.7	26.2	31.1	**100.0**	30.4	28.2	41.3	**100.0**
Eating	6.1	24.3	69.5	**100.0**	35.0	38.8	26.2	**100.0**	29.3	43.3	27.4	**100.0**
Self-management												
Continence	7.0	20.7	71.5	**100.0**	56.1	27.2	16.5	**100.0**	48.2	28.3	23.5	**100.0**
Memory[(e)]	44.9	49.9	5.2	**100.0**	70.2	26.9	2.6	**100.0**	77.6	20.9	1.4	**100.0**
Behaviour[(f)]	10.7	34.9	53.6	**100.0**	25.4	33.1	40.8	**100.0**	42.2	38.6	18.2	**100.0**

(a) Refers to those who 'always required assistance', 'sometimes required assistance' or 'did not require assistance'.

(b) The total includes those cases for which the response was 'don't know'.

(c) Refers to ability to get to places out of walking distance.

(d) Refers to getting out of bed and moving around.

(e) Refers to tasks requiring memory and/or organisational skills.

(f) Refers to managing behaviour such as aggression, wandering or agitation.

Source: AIHW analysis of the 2008 Community Care Census.

Table A4.9: Age of National Respite for Carers Program care recipients with dementia, by sex, 2008

	Number			Per cent		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Under 65	126	127	253	7.8	5.9	6.8
65–74	333	262	595	20.7	12.3	15.9
75–84	790	991	1,781	49.1	46.4	47.5
85–94	344	698	1,042	21.4	32.7	27.8
95+	16	58	74	1.0	2.7	2.0
Total[(a)]	**1,609**	**2,137**	**3,746**	**100.0**	**100.0**	**100.0**

(a) The total includes those cases in which the age was too unreliable to report.

Source: AIHW analysis of the 2008 Community Care Census.

Table A4.10: National Respite for Carers Program care recipients with dementia, by extent of assistance required[(a)] with specified activities, 2008

	Number					Per cent				
	Always	Sometimes	None	Don't know	Total	Always	Sometimes	None	Don't know	Total
Instrumental activities of daily living										
Housework	2,520	1,026	124	76	**3,746**	67.3	27.4	3.3	2.0	**100.0**
Travel[(b)]	2,322	1,087	300	37	**3,746**	62.0	29.0	8.0	1.0	**100.0**
Shopping	2,695	864	122	65	**3,746**	71.9	23.1	3.3	1.7	**100.0**
Taking medicine	2,265	1,097	282	102	**3,746**	60.5	29.3	7.5	2.7	**100.0**
Handling money	2,466	928	232	120	**3,746**	65.8	24.8	6.2	3.2	**100.0**
Activities of daily living										
Bathing/showering	1,528	1,334	816	68	**3,746**	40.8	35.6	21.8	1.8	**100.0**
Dressing	1,222	1,472	987	65	**3,746**	32.6	39.3	26.3	1.7	**100.0**
Walking	971	1,199	1,540	36	**3,746**	25.9	32.0	41.1	1.0	**100.0**
Communication	966	1,464	1,281	35	**3,746**	25.8	39.1	34.2	0.9	**100.0**
Using the toilet	703	1,076	1,917	50	**3,746**	18.8	28.7	51.2	1.3	**100.0**
Moving around[(c)]	569	878	2,199	100	**3,746**	15.2	23.4	58.7	2.7	**100.0**
Eating	441	1,022	2,228	55	**3,746**	11.8	27.3	59.5	1.5	**100.0**
Self-management										
Continence	690	964	1,962	130	**3,746**	18.4	25.7	52.4	3.5	**100.0**
Memory[(d)]	2,148	1,440	131	27	**3,746**	57.3	38.4	3.5	0.7	**100.0**
Behaviour[(e)]	1,018	1,475	1,148	105	**3,746**	27.2	39.4	30.6	2.8	**100.0**

(a) Refers to those who 'always required assistance', 'sometimes required assistance' or 'did not require assistance'.

(b) Refers to ability to get to places out of walking distance.

(c) Refers to getting out of bed and moving around.

(d) Refers to tasks requiring memory and/or organisational skills.

(e) Refers to managing behaviour such as aggression, wandering or agitation.

Source: AIHW analysis of the 2008 Community Care Census.

Table A4.11: Permanent residents in aged care facilities(a), by dementia status and age, 2009–10

Age	Number			Per cent of residents with dementia
	With dementia	Without dementia	Total	
Under 65	2,373	5,918	8,291	28.6
65–69	2,556	4,318	6,874	37.2
70–74	5,693	6,372	12,065	47.2
75–79	12,651	11,068	23,719	53.3
80–84	25,755	19,613	45,368	56.8
85–89	33,921	26,613	60,534	56.0
90–94	20,798	18,900	39,698	52.4
95+	8,392	8,188	16,580	50.6
Total	**112,139**	**100,990**	**213,129**	**52.6**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A4.12: Permanent residents in aged care facilities(a), by dementia status, and state and territory, 2009–10

State/territory	Number			Per cent of residents with dementia
	With dementia	Without dementia	Total	
New South Wales	39,322	33,461	72,783	54.0
Victoria	27,894	27,091	54,985	50.7
Queensland	19,596	18,926	38,522	50.9
Western Australia	9,781	8,127	17,908	54.6
South Australia	11,104	9,276	20,380	54.5
Tasmania	2,902	2,826	5,728	50.7
Australian Capital Territory	1,239	1,060	2,299	53.9
Northern Territory	301	224	525	57.3
Total	**112,139**	**100,991**	**213,130**	**52.6**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

Source: AIHW analysis of data collected with the Aged Care Funding Instrument.

Table A4.13: Length of stay for all separations from permanent residential care(a) of those with dementia during 2009–10, by sex

	Number			Per cent		
Length of stay(b)	**Males**	**Females**	**Total**	**Males**	**Females**	**Total**
<1 year	4,498	4,607	9,105	41.4	24.7	30.9
1 to <2 years	2,027	2,760	4,787	18.7	14.8	16.2
2 to <3 years	1,402	2,499	3,901	12.9	13.4	13.2
3 to <4 years	952	2,132	3,084	8.8	11.4	10.5
4 to <5 years	681	1,718	2,399	6.3	9.2	8.1
5 to <6 years	426	1,361	1,787	3.9	7.3	6.1
6 to <7 years	291	1,001	1,292	2.7	5.4	4.4
7 to <8 years	175	724	899	1.6	3.9	3.0
8+ years	400	1,828	2,228	3.7	9.8	7.6
Total	**10,852**	**18,630**	**29,482**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities who separated from the aged care facility during 2009–10.

(b) Length of stay is defined as the amount of time a resident was in an aged care facility from admission to separation to one of the following: a hospital, another residential facility, the community or died.

Source: AIHW analysis of unpublished residential aged care service data provided by DoHA.

Table A4.14: Community mental health service contacts with dementia as the principal diagnosis, by age and sex, 2009–10

	Number			Per cent		
Age	**Males**	**Females**	**Total(a)**	**Males**	**Females**	**Total(a)**
Under 65	4,082	3,558	7,640	10.8	6.8	8.5
65–69	3,618	3,770	7,388	9.6	7.2	8.2
70–74	4,996	5,731	10,727	13.2	11.0	11.9
75–79	8,316	9,943	18,259	22.0	19.1	20.2
80–84	8,470	11,197	19,672	22.5	21.5	21.8
85+	8,241	17,922	26,171	21.8	34.4	29.0
Total(a)	**37,723**	**52,123**	**90,308**	**100.0**	**100.0**	**100.0**

(a) Includes service contacts for which demographic information was not reported.

Source: AIHW National Community Mental Health Care Database.

Table A5.1: Sex of main carers of ACAP clients with and without dementia living in the community[(a)], 2008–09 (per cent)

Sex of main carer	With dementia	Without dementia
Males	33.0	31.7
Females	64.5	65.5
Not stated	2.5	2.8
Total	**100.0**	**100.0**

(a) Excludes ACAP clients who did not have a carer and those who were permanent residents of residential aged care services, multipurpose services (or multipurpose centres), hospitals or other institutional settings at the time of assessment.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Table A5.2: Primary carers of community aged care recipients with dementia, by age of carer, 2008 (per cent)

Age of carer	CACP	EACH	EACHD	NRCP
Under 55	33.0	24.6	24.7	27.7
55-64	25.8	28.4	21.6	25.7
65-74	10.5	14.3	18.2	19.1
75-84	15.6	21.8	21.7	22.2
85+	8.4	8.5	9.6	5.0
Not reported	6.6	2.4	4.2	0.3
Total	**100.0**	**100.0**	**100.0**	**100.0**

Source: AIHW analysis of the 2008 Community Care Census.

Table A5.3: Relationship of primary carer[(a)] to care recipient with dementia living in the community, by sex of primary carer, 2009 (per cent)

	Males	Females	Persons
Spouse/partner	52.8	58.0	56.5
Son or daughter	*33.8	37.5	36.4
Other relative, friend or neighbour	**13.4	4.5	7.1
Total	**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* 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.

Table A5.4: Relationship of primary carer[(a)] to care recipient with dementia living in the community, by age of primary carer, 2009 (per cent)

	15–44	45–64	65+	Total
Spouse/partner	**43.4	*21.2	83.9	56.5
Son or daughter	—	69.7	*13.7	36.4
Other relative, friend or neighbour[(b)]	**56.6	**9.2	**2.4	*7.1
Total	**100.0**	**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* primary carers and thus exclude those living in a different household.

(b) Includes 'mother or father'.

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

Table A5.5: Relationship of primary carer[(a)] to care recipient with dementia living in the community, by age of care recipient, 2009 (per cent)

	Under 75	75–84	85+	Total
Spouse/partner	94.6	66.6	*16.4	56.5
Son or daughter	**5.4	*25.0	73.3	36.4
Other relative, friend or neighbour[(b)]	—	**8.4	**10.3	*7.1
Total	**100.0**	**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* primary carers and thus exclude those living in a different household.

(b) Includes 'mother or father'.

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

Table A5.6: Relationship of main carer to care recipient with dementia living in the community[a], by sex and age of care recipient, 2008–09 (per cent)

Sex/age	Spouse/ partner	Son	Daughter	Other[b]	Not stated	Total
Males						
Under 65	55.9	4.0	7.6	27.0	5.6	100.0
65–74	73.0	5.0	9.4	9.9	2.7	100.0
75–84	68.3	7.4	14.1	7.5	2.7	100.0
85+	54.2	11.5	22.3	9.5	2.5	100.0
Total[c]	**63.7**	**8.4**	**16.0**	**9.2**	**2.7**	**100.0**
Females						
Under 65	57.6	9.6	11.3	17.7	3.8	100.0
65–74	49.4	11.3	24.8	11.2	3.2	100.0
75–84	34.2	16.1	36.5	10.9	2.2	100.0
85+	15.1	21.0	47.5	14.3	2.2	100.0
Total[c]	**27.9**	**17.6**	**39.6**	**12.6**	**2.3**	**100.0**
Persons						
Under 65	56.7	6.7	9.4	22.5	4.7	100.0
65–74	61.0	8.2	17.3	10.6	3.0	100.0
75–84	48.6	12.5	27.1	9.5	2.4	100.0
85+	28.6	17.7	38.7	12.7	2.3	100.0
Total[c]	**42.3**	**13.9**	**30.1**	**11.2**	**2.5**	**100.0**

(a) Excludes ACAP clients who did not have a carer and those who were permanent residents of residential aged care services, multipurpose services (or multipurpose centres), hospitals or other institutional settings at the time of assessment.

(b) 'Other' includes son/daughter-in-law, other relatives, friends and neighbours.

(c) The total includes ACAP clients with unknown age.

Source: Unpublished Aged Care Assessment Program data from DoHA.

Table A6.1: Out-of-hospital medical expenditure for dementia, by sex and age, 2009–10[(a)] ($ million)

	Number						Per cent					
Sex/age	**Unreferred attendances[(b)]**	**Imaging**	**Pathology**	**Specialist**	**Other medical**	**Total**	**Unreferred attendances[(b)]**	**Imaging**	**Pathology**	**Specialist**	**Other medical**	**Total**
Males												
Under 65	0.3	—	—	0.1	0.1	0.4	4.6	—	—	3.4	4.0	3.4
65–74	0.8	0.7	0.1	0.6	0.4	2.6	12.8	39.3	31.7	25.9	29.1	21.6
75–84	3.4	1.0	0.2	1.1	0.7	6.4	53.7	51.1	39.1	52.8	52.1	52.5
85+	1.9	0.2	0.1	0.4	0.2	2.7	28.9	9.6	29.2	17.9	14.8	22.4
Total	**6.4**	**1.9**	**0.4**	**2.2**	**1.3**	**12.2**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Females												
Under 65	0.4	0.5	0.1	0.3	0.1	1.4	2.3	22.3	5.3	7.4	2.6	4.7
65–74	1.7	0.4	0.4	0.5	0.2	3.1	9.3	15.6	20.2	13.1	4.6	10.3
75–84	6.3	1.2	0.6	1.9	2.6	12.7	34.9	52.9	34.3	53.0	68.1	42.8
85+	9.7	0.2	0.7	1.0	1.0	12.6	53.5	9.2	40.2	26.5	24.7	42.2
Total	**18.2**	**2.3**	**1.8**	**3.6**	**3.9**	**29.8**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Persons												
Under 65	0.7	0.5	0.1	0.3	0.2	1.8	2.9	12.2	4.3	5.9	2.9	4.3
65–74	2.5	1.1	0.5	1.0	0.6	5.7	10.2	26.3	22.3	17.9	10.9	13.6
75–84	9.8	2.2	0.8	3.1	3.3	19.1	39.8	52.0	35.2	52.9	64.0	45.6
85+	11.6	0.4	0.8	1.3	1.2	15.3	47.1	9.4	38.1	23.3	22.2	36.5
Total	**24.6**	**4.2**	**2.2**	**5.8**	**5.2**	**42.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Expenditure is for 2008–2009 inflated to 2009–10 prices.

(b) Refers to primary care attendances to GPs and practice nurses.

Note: — represents less than $50,000 (including zero).

Sources: AIHW analysis of Bettering the Evaluation and Care of Health data; AIHW disease expenditure database.

Table A6.2: Expenditure for hospitalisations with dementia as the principal diagnosis, by sex and age, 2005–06 to 2009–10, constant prices[(a)]

	$ million					Per cent				
Sex/age	**2005–06**	**2006–07**	**2007–08**	**2008–09**	**2009–10**	**2005–06**	**2006–07**	**2007–08**	**2008–09**	**2009–10**
Males										
Under 70	5.5	6.4	6.7	6.8	6.9	10.6	10.7	10.2	9.6	9.7
70–74	6.0	6.0	7.7	8.4	8.8	11.6	10.1	11.7	11.8	12.5
75–79	11.8	12.8	15.4	14.6	12.8	22.8	21.4	23.4	20.6	18.1
80–84	14.4	18.4	18.5	21.2	19.9	27.9	30.8	28.0	30.0	28.1
85–89	9.1	10.9	12.3	13.7	16.5	17.6	18.2	18.7	19.4	23.3
90–94	4.0	4.5	4.6	4.9	5.0	7.8	7.6	6.9	7.0	7.1
95+	0.9	0.8	0.7	1.1	0.9	1.8	1.3	1.1	1.5	1.2
Total	**51.7**	**59.7**	**66.0**	**70.7**	**70.9**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Females										
Under 70	4.1	5.1	7.2	6.1	6.6	7.0	7.8	10.0	8.3	9.0
70–74	4.2	5.9	6.3	7.0	7.3	7.3	9.0	8.8	9.5	9.9
75–79	10.2	11.2	12.7	13.9	11.9	17.7	17.2	17.6	18.8	16.1
80–84	16.3	17.6	19.2	18.3	18.5	28.2	27.1	26.6	24.7	25.2
85–89	14.1	15.8	16.9	18.1	19.2	24.3	24.3	23.4	24.4	26.1
90–94	7.2	7.5	8.0	8.4	8.1	12.4	11.5	11.1	11.3	11.0
95+	1.8	2.0	1.9	2.2	2.0	3.0	3.1	2.7	3.0	2.7
Total	**57.9**	**65.1**	**72.2**	**74.0**	**73.6**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(continued)

Table A6.2 (continued): Expenditure for hospitalisations with dementia as the principal diagnosis, by sex and age, 2005–06 to 2009–10, constant prices[(a)]

	$ million					Per cent				
Sex/age	**2005–06**	**2006–07**	**2007–08**	**2008–09**	**2009–10**	**2005–06**	**2006–07**	**2007–08**	**2008–09**	**2009–10**
Persons[(b)]										
Under 70	9.5	11.5	13.9	12.9	13.5	8.7	9.2	10.1	10.1	9.3
70–74	10.2	11.9	14.0	15.4	16.1	9.3	9.5	10.2	10.2	11.1
75–79	22.0	24.0	28.1	28.5	24.7	20.1	19.2	20.4	20.4	17.1
80–84	30.7	36.0	37.7	39.5	38.5	28.1	28.8	27.3	27.3	26.6
85–89	23.2	26.7	29.2	31.8	35.7	21.1	21.4	21.1	21.1	24.7
90–94	11.2	12.0	12.6	13.3	13.2	10.2	9.6	9.1	9.1	9.1
95+	2.7	2.8	2.6	3.3	2.9	2.4	2.2	1.9	1.9	2.0
Total	**109.6**	**124.8**	**138.2**	**144.7**	**144.5**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Expenditure for 2005–06 to 2008–09 is expressed in terms of 2009–10 dollars.

(b) Includes expenditure for admitted patients whose sex is unknown.

Sources: AIHW National Hospital Morbidity Database; National Hospital Cost Data Collection.

Table A6.3: Australian Government expenditure for permanent residents with dementia in aged care facilities(a), by age and sex, 2009–10

	$ million			Per cent		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Total expenditure for people with dementia						
Under 70	102.4	95.3	197.6	8.9	3.3	4.9
70–74	97.3	112.1	209.4	8.5	3.9	5.2
75–79	176.5	270.3	446.8	15.4	9.3	11.0
80–84	288.4	608.6	897.0	25.2	21.0	22.2
85–89	291.3	900.1	1,191.4	25.4	31.1	29.5
90–94	147.4	613.7	761.1	12.9	21.2	18.8
95+	41.9	294.6	336.5	3.7	10.2	8.3
Total(b)	**1,145.1**	**2,894.8**	**4,044.0**	**100.0**	**100.0**	**100.0**
Expenditure attributable to dementia						
Under 70	28.9	29.2	58.1	9.4	3.7	5.3
70–74	31.2	31.0	62.2	10.2	4.0	5.7
75–79	47.3	76.2	123.5	15.4	9.7	11.3
80–84	73.4	165.0	238.4	23.9	21.1	21.9
85–89	76.6	239.2	315.9	24.9	30.6	29.0
90–94	38.8	163.1	201.9	12.6	20.9	18.5
95+	11.0	78.3	89.3	3.6	10.0	8.2
Total(b)	**307.2**	**782.0**	**1,089.2**	**100.0**	**100.0**	**100.0**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) The total includes expenditure for residents for whom age and/or sex was not reported.

Source: AIHW analysis of unpublished residential aged care services data provided by DoHA.

Table A6.4: Australian Government expenditure attributable to dementia, per permanent resident with dementia in aged care facilities(a), by age and sex, 2009–10

	Estimated cost per resident ($)		
Age	**Males**	**Females**	**Persons**
Under 70	10,509	12,264	11,323
70–74	11,387	10,272	10,802
75–79	9,220	10,322	9,871
80–84	8,369	9,703	9,249
85–89	8,262	9,483	9,158
90–94	8,153	9,633	9,308
95+	7,857	9,999	9,674
Total(b)	**8,823**	**9,803**	**9,492**

(a) Pertains to permanent residents living in Australian Government-subsidised aged care facilities.

(b) The total includes expenditure for residents for whom age and/or sex was not reported.

Source: AIHW analysis of unpublished residential aged care services data provided by DoHA.

Appendix B: Data sources

This report draws upon data from a wide range of sources to present a comprehensive overview of dementia in Australia. This appendix provides descriptions of these data sources, with sources listed alphabetically. Details of the approach used to identify people with dementia are provided, as are points to consider when interpreting the data.

Aged Care Assessment Program

ACAP data for the period 2008–09, as provided by the Department of Health and Ageing, are used in Chapters 4, 5 and 6 of this report. Under the ACAP, which is funded by the Australian Government, the care needs of clients are assessed to determine and facilitate access to aged care services appropriate to their needs. These assessments are carried out by a multi-disciplinary Aged Care Assessment Team (ACAT) (or an Aged Care Assessment Service (ACAS) in Victoria) which is comprised of a range of health and other professionals.

As part of the ACAT assessment, up to 10 health conditions that have an impact on the person's 'need for assistance with activities of daily living and social participation' can be recorded (DoHA 2011f). The condition with the greatest impact on the person's need for assistance is designated the 'main health condition'. Reported conditions are coded using the ACAP data dictionary health condition code list, which is based on the ICD-10-AM (DoHA 2011f).

In this report, a person was considered to have dementia if this condition was recorded as the main or another health condition. The ACAP health condition codes of 0500 to 0532 were used to identify people with dementia. ACAP clients can have more than one assessment during a reporting period. For this report, when clients had more than one assessment during the financial year (2008–09), data on the most recently completed assessment were used.

Further information about the ACAP can be found in the *ACAP Program Data Dictionary* (DoHA 2011f) and on the DoHA website <www.health.gov.au>.

Aged Care Funding Instrument

Information collected through the ACFI is used extensively in this report. The ACFI was introduced by the Australian Government in March 2008 as a resource allocation tool for funding places in residential aged care facilities that receive subsidies from the Australian Government (DoHA 2009a). It replaced the Resident Classification Scale which had been in use since 1 October 1997.

Following admission to a subsidised residential aged care facility as a permanent resident, an ACFI appraisal is undertaken, with the requirements stating that this appraisal be conducted between 8 days and 2 months of the resident entering care (DoHA 2009b).

With one exception, data from ACFI appraisals that were valid in 2009–10 are used in this report. The one exception applies to Chapter 2, where ACFI data pertaining to a specific date (namely, 30 June 2011) were used in order to align with population estimates at that same date.

Almost all (99%) permanent residents of Australian Government-subsidised aged care facilities in 2009–10 had been assessed using the ACFI tool and thus these data cover virtually all permanent residents in such facilities. ACFI appraisals generally don't expire and the majority of permanent residents receive only one ACFI appraisal during a 12-month reporting period. However, re-appraisals sometimes occur for reasons such as a major change in care needs. For residents who were appraised more than once in 2009–10, the most recent appraisal was used in the data presented in this report.

Note that the ACFI data do not capture information about people:

- in residential aged care facilities that were not subsidised by the Australian Government
- in residential care places under the Multi-Purpose Service Program or the National Aboriginal and Torres Strait Islander Flexible Aged Care Program
- who accessed respite care in residential aged care facilities.

The proportion of Indigenous permanent residents in aged care facilities, and in turn the number reported to have dementia in these facilities, may be under-estimated for a number of reasons. These include that, as noted above, an ACFI appraisal is not required for people accessing programs such as the National Aboriginal and Torres Strait Islander Flexible Aged Care Program and there is no other source of information that provides the dementia status of people using these services. As well, the ACFI data cover less than half of the total Australian Government-subsidised operational permanent residential aged care places in *Very remote* areas (see Box 3.1). Indigenous Australians are relatively more likely to be living in such areas than other Australians.

The ACFI includes 12 questions about assessed care needs, with these questions falling into one of three funding domains: 'Activities of daily living', 'Behaviour characteristics' and 'Complex health care needs'. The responses to the questions are used to determine the classification for funding and the overall classification as a 'low care' or 'high care' resident. See Box 3.3 for further information. Because the ACFI is a funding tool, the questions about care needs are focussed on those needs that most contribute to the cost of individual care, not on all areas in which a resident may require care. As DoHA (2009a:1) states, the ACFI 'is not a comprehensive assessment package; comprehensive assessment would consider a broader range of care needs than is necessarily required in a funding instrument.'

Identification of those with dementia

The ACFI form includes a 'Mental and behavioural disorders checklist' which allows for the reporting of up to three major mental and behavioural diagnoses for each resident. In addition, a 'Medical diagnosis checklist' allows for the reporting of other health conditions. In both cases, for conditions to be recorded, the instructions indicate that they must be documented and diagnosed and that they must be having an impact on the resident's care needs.

ACFI identifies a resident with dementia in residential aged care if the ACFI form contains a dementia diagnosis code based on the ACAP dictionary code list. The following ACFI diagnostic codes identify residents with dementia:

- 500: Dementia in Alzheimer's disease (includes early onset less than 65 years, late onset greater than 65 years, atypical or mixed type, unspecified)
- 510: Vascular dementia (includes acute onset, multi-infarct, subcortical, mixed cortical & subcortical, other vascular, unspecified)
- 520: Dementia in other diseases (includes Pick's, Creutzfeldt-Jakob, Huntington's, Parkinson's, HIV, Lewy Body, other)

- 530: Other dementia (includes alcoholic, presenile & senile, unspecified).

Since up to three mental and behavioural diagnoses can be recorded, some residents may be identified as having more than one type of dementia. For the purposes of this report, these persons were grouped together for analysis into a fifth category, called *More than one type of dementia.*

The number of people with dementia may be under-estimated using ACFI data, but whether this is the case and the extent of any such underestimation is unknown. As discussed in Chapter 2, dementia is often unrecognised, especially in the earlier stages of the condition. Further, according to submissions to the review of the ACFI, the requirement under the ACFI for a formal medical diagnosis of dementia in order to make a valid claim is problematic for some facilities, particularly when the resident did not have an established relationship with a GP in the area (DoHA 2011i).

Further information can be found in the ACFI users' guide (DoHA 2009a) and on the webpage <http://www.health.gov.au/acfi>.

Bettering the Evaluation and Care of Health survey

The BEACH survey is a national, cross-sectional survey of general practice activity in Australia, involving a random sample of approximately 1,000 practising GPs each year (Britt et al. 2011). Each of these GPs provides details about 100 doctor-patient encounters of all types on structured forms, with data collected from a total of about 100,000 GP-patient encounters per year. Each form collects information about the consultations (for example, the date), the patient (date of birth, sex, reasons for encounter, etc.), the problems managed and the way in which each problem was managed. From the BEACH survey data, extrapolations can be made to provide national estimates for the number of encounters related to specific problems such as dementia.

This report includes BEACH data for the years 2006–07 to 2010–11, during which time the response rate (based on the number of GPs who were successfully contacted rather than the number approached) ranged from a low of 22.9% (in 2006–07) to a high of 32.6% (in 2008–09) (Britt et al. 2008, 2009). The response rate for the 2010–11 survey was 25.5% (Britt et al. 2011).

Health conditions, such as dementia, can be recorded by the GP as one of three reasons for the encounter, or as one of four diagnoses or problems managed. These are coded using the International Classification of Primary Care, version 2 (ICPC–2) which is the standard for data classification in primary care (see Appendix E and Britt et al. 2011 for more information about ICPC-2). For this report, a GP-patient encounter was considered to include the management of dementia if any of following ICPC-2 codes were recorded: all forms of dementia under the P70 rubric, alcoholic dementia (P15004) and AIDS dementia complex (B90005). Note that this is different to the approach used in the BEACH General Practice Series reports (for example, Britt et al. 2011), where only the P70 rubric of dementia is included.

Additional questions about risk factors or special interest topics may be asked of patients in sub-samples of encounters, as part of the Supplementary Analysis of Nominated Data (SAND). In SAND, a section on the bottom of each recording form investigates aspects of patient health or health-care delivery in general practice not covered by the consultation-based information (see Britt et al. 2011 for further information). In 2010, the *Dementia screening, prevalence and management* sub-study (known as SAND abstract No. 159) was conducted (AIHW: AGPSCC 2010).

Causes of death data

Data on causes of death are published by the ABS in an annual report called *Causes of death* (ABS 2012b). Information from that report, as well as unpublished ABS causes of death data, were used in Chapter 2 of this report.

The ABS causes of death collection includes all deaths that occurred and were registered in Australia, including deaths of persons whose usual residence is overseas.

In compiling causes of death statistics, the ABS uses a variety of measures to improve quality. Details about these measures and other relevant processes are described in the ABS' *Causes of death* report (ABS 2012b). Since 1997, the coding of causes of death data has been based on ICD-10.

The ranking of leading causes of death by the ABS is based on research presented in the Bulletin of the World Health Organization (Becker et al. 2006). The ranking is designed to present information on the incidence of mortality rather than the burden of mortality and is thus based solely on the number of deaths.

For the analyses in this report, the following ICD-10 codes were used to identify deaths due to dementia: F01 Vascular dementia, F03 Unspecified dementia and G30 Alzheimer's disease. Note that according to the ICD-10 coding rules, the codes of F00 Dementia in Alzheimer's disease and F02 Dementia in other diseases classified elsewhere cannot be assigned as an underlying cause of death but may be used to capture the involvement of dementia associated with other underlying disease.

Note that the ABS uses a confidentialisation process whereby data cells with small values are randomly assigned to protect confidentiality. As a result, totals may not equal the sum of their components. Cells with 0 values are not affected by the ABS confidentialisation process.

Community Care Census

Data from the 2008 CCC are used in Chapters 4 and 5 of this report. The CCC collected data about recipients of services from service providers funded through the CACP, EACH, EACHD and NRCP programs (DoHA 2010a). Data on 40,284 packaged care recipients and 8,673 NRCP carers and care recipients were collected from around 1,200 service outlets between 1 February and 20 March 2008, with data collection spanning a week for each outlet. The forms were completed by the service providers' staff.

In the previous *Dementia in Australia* report (AIHW 2007), data from the 2002 Community Care Census were used; changes in the survey design do not allow comparisons of those data with data from the 2008 CCC. Note also that the 2002 CCC did not collect information on the NRCP or on the EACHD program, the latter of which was introduced in 2006.

DoHA notes that the exact response rate of the 2008 CCC could not be determined (DoHA 2010a). However, they were able to determine that nearly all non-participating outlets were in rural, remote or very remote locations and that these service outlets provided assistance to between 300 and 600 Indigenous care recipients. Consequently, Indigenous packaged care recipients are under-represented in the CCC data (DoHA 2010a).

In the 2008 CCC, people with dementia were identified in two steps. First, the survey asked the service provider to indicate if the care recipient needed assistance with tasks requiring memory and/or organisational skills, or in managing behaviour such as aggression, wandering or agitation. If the recipient needed such assistance, then the reason for needing assistance was requested, with a number of response options available, including 'diagnosed disability', 'diagnosed dementia or related condition', 'early stage undiagnosed dementia', 'other diagnosed condition' and 'other condition'. In cases where more than one response applied, respondents were asked to select the primary reason for the need for assistance.

For the purposes of this report, recipients were considered to have dementia if the reason for needing assistance was recorded as 'diagnosed dementia or related condition', with this category defined to include dementia or conditions that usually pre-dispose dementia, provided dementia had been diagnosed by a health professional (see DoHA 2008). Note that in some cases, recipients were said to have a 'diagnosed dementia or related condition', even when a 'no' response had been given for the preceding question about the need for assistance with memory, behaviour and/or organizational skills. These care recipients were considered to have dementia for the purposes of this report and were included in the analyses.

Given the process used in the CCC to identify people with dementia, as well as the requirement that dementia be recorded as the primary reason for organizational, memory or behavioural care needs, the number of care recipients with dementia is likely to be under-estimated. The degree to which this is the case is not known.

Further information about the 2008 CCC and community aged care packages, in general, can be found in the *2008 Community Care Census* report (DoHA 2010a) and the *Community Packaged Care Guidelines* (DoHA 2011j).

Disease Expenditure database

The Disease Expenditure database is used in Chapter 6 to produce expenditure estimates for out-of-hospital expenditure on dementia. This AIHW database provides the latest available expenditure estimates allocated to various disease groups, with information in the database from a range of sources including: the ABS; Commonwealth, state and territory health authorities; the Department of Veterans' Affairs; the Private Health Insurance Administration Council; Comcare; and the major workers compensation and compulsory motor vehicle third-party insurers in each state and territory. Further information about the Disease Expenditure database can be found in the health expenditure report published by the AIHW (AIHW 2008, 2010d).

Drug Utilisation Sub-Committee database

Information from the DUSC database is used in Chapter 4 to estimate the number of non-subsidised dementia-specific prescriptions in 2009–10. The database contains estimates of non-subsidised prescriptions dispensed, including private prescriptions and those that cost the patient less than the co-payment amount required under the PBS or RPBS (DoHA 2011c).

These estimates are based on data collected through a monthly Pharmacy Guild survey of a stratified random sample of about 370 pharmacies throughout Australia. In contrast to PBS/RPBS data in which prescriptions are dated according to when they are processed by Medicare Australia, the DUSC data are based on the date of supply of prescriptions.

For the purposes of this report, data on non-subsidised and subsidised prescriptions for the PBS-subsidised dementia-specific medications donepezil, galantamine, rivastigmine and memantine were extracted from the DUSC database and supplied by DoHA.

Further information can be found in the DoHA publication *Australian Statistics on Medicine* (DoHA 2011c).

Dynamic Analyses to Optimise Ageing project

Information from the DYNOPTA project is included in Chapter 2. This multi-disciplinary project, which began in May 2007, broadly aims to identify key incidence rates and risk factors for health outcomes, and thus contribute to an evidence base on ageing to inform planning for Australia's ageing population (Anstey et al. 2009; ANU 2009). As part of the project, a pooled dataset has been constructed that consists of information from 50,652 baseline participants collected by nine longitudinal studies of ageing. Four of these studies—the Sydney Older Persons Study, the Canberra Longitudinal Study, the Personality and Total Health Study (based in Canberra and Queanbeyan) and the Australian Longitudinal Study of Ageing (based in Adelaide)—included information on cognitive decline or dementia and, taken together, provide MMSE scores for about 3,900 Australians aged 65 and over.

Further information can be found in the publications by Anstey et al. (2009, 2010) and on the webpage: <http://dynopta.anu.edu.au/index.php>.

Medicare Benefits Schedule

Medicare Australia data are used in Chapter 6 to provide information on expenditure for services subsidised under the Medicare Benefits Schedule (MBS). The MBS provides access to free treatment to public (Medicare) patients in public hospitals, and to free or subsidised treatment by practitioners such as GPs, specialists, participating optometrists and dentists (DoHA 2010f). Medicare Australia collects data on the activity of all providers making claims through the MBS and provides this information to DoHA. The MBS data include the type of service provided (MBS item number) and the benefit paid by Medicare Australia for the service.

National Community Mental Health Care Database

The NCMHCD contains data on service contacts for specialised mental health services provided by government-operated community mental health care services and hospital outpatient services (AIHW 2012c). Examples of data elements are demographic characteristics of patients (such as age and sex), clinical information (for example, principal diagnosis and mental health legal status) and service provision information (for example, session type). Note that data presented in this report pertain to service contacts rather than to number of clients, since it is not possible to accurately determine the number of clients in the aggregated national data. The NCMHCD is compiled and maintained by the AIHW.

There are variations across jurisdictions in the scope and definition of a service contact. For example, New South Wales, Queensland, South Australia and Tasmania may include written correspondence as service contacts while others do not.

Data on Indigenous status should be interpreted with caution as the data quality and completeness of Indigenous identification varies or is unknown among the jurisdictions. In 2009–10, Indigenous status was missing for 9% of all contacts (and for 4% of contacts with a principal diagnosis of dementia).

Detailed information about this data collection can be found in AIHW's online *Mental Health Services in Australia* report (AIHW 2012c).

A principal diagnosis was reported for 91% of all community mental health care service contacts in 2009–10. For the purpose of this report, a service contact was considered to be for a person with dementia if any of the following ICD-10-AM codes (or equivalent) were recorded as the principal diagnosis: F00 (Dementia in Alzheimer's disease), F01 (Vascular dementia), F02 (Dementia in other diseases classified elsewhere), F03 (Unspecified dementia), F05.1 (Delirium superimposed on dementia) or G30 (Alzheimer's disease).

The quality of principal diagnosis data in the NCMHCD may be affected by the variability in collection and coding practices across jurisdictions. In particular, there are differences:

- among the states and territories in the classification used to code principal diagnosis
- according to the size of the facility in the ability to accurately code principal diagnosis
- in the availability of appropriate clinicians to assign principal diagnoses
- according to whether the principal diagnosis is applied to an individual service contact or to a period of care.

National Hospital Cost Data Collection

Information from the NHCDC is used in Chapter 6 to estimate expenditure on hospital separations with a principal diagnosis of dementia. The NHCDC, coordinated by the Department of Health and Ageing, comprises a voluntary collection of hospital cost and activity data. Both public and private hospital data are included, with the results separately reported for the two sectors. The NHCDC data used in this report were for the 2008–09 financial year (Round 13) for public and private hospitals (DoHA 2010e). Further information is provided in the NHCDC report for 2008–09 (DoHA 2010e).

National Hospital Morbidity Database

Data from the NHMD are used in Chapter 4 to describe hospitalisations for which dementia was recorded as a diagnosis, as well as in Chapter 6 to estimate expenditure for admitted patients with a diagnosis of dementia. The NHMD, which is compiled and maintained by the AIHW, pertain to admitted patients in public and private hospitals in Australia (AIHW 2011c). The NHMD includes administrative data, demographic information about patients, and clinical information including diagnoses and procedures performed. Information from almost all hospitals in Australia is included in the database: from public acute and public psychiatric hospitals, private acute and psychiatric hospitals, and private free-standing day hospital facilities.

For each of the years considered in this report, the coverage of the NHMD has been very good. For 2009–10, coverage for the NHMD was essentially complete: data from all public hospitals were included except for a small mothercraft hospital in the Australian Capital Territory. As well, the great majority of private hospitals were also included. Most of the private facilities that did not report to the NHMD were free-standing day hospital facilities. For 2009–10, complete data were not provided for private free-standing day hospitals in the Australian Capital Territory and the Northern Territory.

As per the standard practice when analysing admitted patient data in the NHMD, the data presented in this report exclude those records for which the 'Care type' data item was reported as *Newborn (unqualified days only)*, *Hospital boarder* or *Posthumous organ procurement*.

Diagnoses are recorded in the NHMD using the ICD-10-AM (see Appendix E for information about this classification). For the 2009–10 data, diagnoses were recorded using the sixth edition of the ICD-10-AM.

For this report, two criteria were used to identify hospitalisations with a principal diagnosis of dementia; these are summarised in Box B.1. In order to identify those hospitalisations with an additional diagnosis of dementia, only the first criterion as listed in Box B.1 is required since the second criterion is redundant (that is, the relevant hospitalisations would already have been identified via the first criterion). Thus, any hospitalisation with either a principal or additional diagnosis of F00, F01, F02, F03, F05.1 or G30 was considered to have a diagnosis code of dementia.

Further information about the NHMD can be found on the AIHW website at <http://www.aihw.gov.au/national-hospital-morbidity-database/>.

Box B.1: Approach used to identify hospitalisations with a principal diagnosis of dementia

A hospitalisation that met one of the following two criteria was considered to have a principal diagnosis of dementia:

(i) Those with a principal diagnosis code of:
  - Dementia in Alzheimer’s disease (F00)
  - Vascular dementia (F01)
  - Dementia in other diseases classified elsewhere (F02)
  - Unspecified dementia (F03)
  - Delirium superimposed on dementia (F05.1)
  - Alzheimer’s disease (G30)

(ii) Those with a principal diagnosis code of ‘Other degenerative diseases of nervous system, not elsewhere classified’ (G31) *and* an additional diagnosis code of one of the dementia codes listed above.

National Mortality Database

The NMD is used in Chapter 2 of this report to provide data for 2001 to 2005 on the number of deaths with dementia as the underlying cause. (Data for later years were sourced directly from the ABS; see description of Causes of death data earlier.) The NMD is maintained by the AIHW and contains information on all registered deaths in Australia, with this information supplied by the Registrars of Births, Deaths and Marriages, the National Coroners Information System and the ABS. Since 1997, the ABS has used the ICD-10 to code causes of death data.

For the analyses in this report, the following ICD-10 codes were used to identify deaths due to dementia: F01 Vascular dementia, F03 Unspecified dementia and G30 Alzheimer’s disease. Note that according to the ICD-10 coding rules, the codes of F00 Dementia in Alzheimer’s disease and F02 Dementia in other diseases classified elsewhere cannot be assigned as an underlying cause of death but may be used to capture the involvement of dementia associated with other underlying disease. Further information can be found on the AIHW website at <http://www.aihw.gov.au/aihw-national-mortality-database/>.

National Residential Mental Health Care Database

The NRMHCD contains data on episodes of residential care provided by government-funded, 24-hour staffed, residential mental health services (AIHW 2012c). The inclusion of government-funded, non-government-operated services and services that are not staffed for 24 hours a day is optional. Queensland does not report to this collection. The NRMHCD is compiled and maintained by the AIHW.

Episodes of residential care are defined as a period of care between the start of residential care (either through the formal start of the residential stay or the start of a new reference period— that is, 1 July) and the end of residential care (either through the formal end of residential care, commencement of leave intended to be greater than 7 days, or the end of the reference period—that is, 30 June). Data collated in the NRMHCD include information relating to each episode of residential care provided by the relevant mental health services. Examples of data elements are demographic characteristics of residents (for example, age and sex) and clinical information (for example, principal diagnosis). Note that Queensland does not have any residential mental health care services.

Detailed information about this data collection can be found in AIHW's online *Mental Health Services in Australia* report (AIHW 2012c).

In 2009–10, a principal diagnosis was specified for nearly all (97%) episodes of residential care. For the purposes of this report, an episode of residential care was considered to be for a person with dementia if any of the following ICD-10-AM codes (or equivalent) were recorded as the principal diagnosis: F00 (Dementia in Alzheimer's disease), F01 (Vascular dementia), F02 (Dementia in other diseases classified elsewhere), F03 (Unspecified dementia), F05.1 (Delirium superimposed on dementia) or G30 (Alzheimer's disease). Note that the quality of principal diagnosis data may be affected by jurisdictional differences in the classification used to code diagnosis.

National Respite for Carers Program

NRCP data are used in Chapter 4 of this report. The program, which is administered by the Department of Health and Ageing, aims to contribute to the support and maintenance of relationships between carers and care recipients by facilitating access to information, respite care and other support appropriate to both the carer's and the care recipient's needs and circumstances (DoHA 2012j).

Service providers delivering services under the NRCP are required to submit Service Activity Reports, which provide data about the number of services delivered and care recipients. As part of that data collection, service providers are asked to provide summary information on two groups of care recipients: those aged under 65 and those aged 65 and over (or 50 if from Aboriginal or Torres Strait Islander background). For each of these groups, service providers are asked to provide the number of care recipients with dementia as well as the number of recipients 'with dementia with challenging behaviour' (DoHA 2012k). The term 'challenging behaviour' is not defined in the instructions provided to service providers. However, DoHA (2012, personal communication 27 March) notes that the definition it tends to use for NRCP purposes is as follows: 'symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia' (IPA 2010).

This report uses unpublished Service Activity Report data relating to care recipients for 2009–10, as provided by DoHA.

Further information about the NRCP can be found on the DoHA website <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-carers-nrcp.htm>.

National Survey of Mental Health and Wellbeing

Issues regarding the use of 2007 NSMHW data to estimate the prevalence of dementia is discussed in Chapter 2 (and related technical notes). As well, rates of probable dementia, as derived by Anstey et al. (2010) are shown.

The 2007 NSMHW was an ABS general household survey of people aged 18 to 85 years who lived in private dwellings, excluding very remote areas. It collected information about selected mental disorders, the use of health services and medication for mental health problems, physical conditions, disability, social networks and caregiving, and demographic and socio-economic characteristics. This was the second such survey to be conducted, with the first one conducted in 1997.

Due to the high level of sensitivity of the survey's content, this survey was conducted on a voluntary basis. Proxy and foreign language interviews were not conducted. A total of 8,841 persons fully completed the survey. This represented a 60% response rate at the national level, which was lower than the ABS expected.

Dementia is not explicitly identified in the NSMHW and the survey was not designed to specifically identify low-prevalence disorders such as dementia (Slade et al. 2009a). Nonetheless, the survey included the MMSE which allows for the identification of cognitive impairment (which is referred to as probable dementia in Anstey et al. 2010). All survey participants aged 65 to 85 were asked the MMSE questions (a total of 1,905 people).

Responses generate a score which is then used to classify the severity of cognitive impairment. Commonly, a MMSE score of less than 24 is used as an indicator of mild cognitive impairment. The purpose of including the MMSE in the NSMHW was to identify, and exclude from the survey, people without sufficient cognitive ability (score of 18 or less) from the survey interview (ABS 2009). The ABS notes that 5 people were excluded from the survey for this reason.

Further information can be found in the *National Survey of Mental Health and Wellbeing: summary of results* report (ABS 2008c) and related publications (ABS 2009; Slade et al. 2009a, 2009b).

Population data

Throughout this report, population data are used to, for example, derive rates or the estimated number of people with dementia. The population data were sourced from the ABS Demography section using the most up-to-date estimates available at the time of analysis.

To derive their estimates of the resident populations, the ABS uses the 5-yearly Census of Population and Housing data and adjusts it as follows:

- all respondents in the Census are placed in their state or territory, statistical local area and postcode of usual residence; overseas visitors are excluded
- an adjustment is made for persons missed in the Census (approximately 2%)
- Australians temporarily overseas on Census night are added to the usual residence Census count.

Estimated resident populations are then updated each year from the Census data using indicators of population change, such as births, deaths and net migration. More information is available from the ABS website <http://www.abs.gov.au>.

Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme

PBS and RPBS data are used in two chapters of this report: Chapter 4 to describe the number of dementia-specific medications dispensed, and Chapter 6 to describe Australian-Government expenditure on such medications.

Medicare Australia collects data on prescriptions funded through the PBS and RPBS. The PBS subsidises the cost of a wide range of prescription medications for permanent residents and citizens of Australia. About 80% of prescription medications dispensed in Australia are subsidised under the PBS (DoHA 2012l). The RPBS provides assistance to eligible war veterans and their dependants for pharmaceuticals listed on the PBS and a supplementary repatriation list, at the same cost as patients entitled to the concessional payment under the PBS.

Prescriptions dispensed are only recorded in the database if they were covered by the PBS or RPBS, and government subsidies were paid because the medication cost more than the amount the consumer must pay (the 'co-payment' amount). The co-payment amount differs substantially between general patients and those who hold government health-care concession cards. Information about prescription medicines dispensed to inpatients in public hospitals, and those dispensed from remote area Aboriginal Health Services, are not available. However, information on prescriptions dispensed to inpatients in private hospitals is included in the PBS/RPBS data.

Items on the PBS and RPBS are classified according to their site of action, and therapeutic and chemical characteristics using the Anatomical Therapeutic Chemical classification (WHO Collaborating Centre for Drug Statistics Methodology 2011). Note that the recorded month of the prescription is determined by the date the service was processed by Medicare Australia, not the date of prescribing or the date of supply by the pharmacy. The jurisdictional data about prescriptions is based on the address of the pharmacy providing the item, not the patient's address (Medicare Australia 2012).

Information about dementia-specific medications subsidised by the PBS and RPBS can be found in the Schedule of Pharmaceutical Benefits (DoHA 2012m), and general information about the PBS/RPBS can be found on the PBS website <www.pbs.gov.au/pbs/home>.

Survey of Disability, Ageing and Carers

SDAC data were used extensively throughout this report. The SDAC is a national survey conducted by the ABS that collects information about people with a disability, older people (aged 60 years and over), and their carers (ABS 2010, 2011a).

The SDAC has two components—the household component and the cared-accommodation component. The household component covers residents in private dwellings (for example, houses and apartments) and non-private dwellings (for example, hotels and short-term caravan parks). This component of the survey was interviewer-administered, and initially involved collecting basic information from a responsible adult in each household about all members of the household. Personal interviews were then conducted with all people residing in the household who met one (or more) of the following criteria:

- had long-term health condition(s)
- were aged 60 or older
- had a disability
- regularly provided informal care in core activities to an older person or someone with a disability, and were considered to provide a greater level of care than others to that care recipient (that is, possible primary carers).

Proxy interviews were conducted if the person was unable to respond for themselves. Note that in the SDAC, information was not collected about primary carers under the age of 15, or about informal carers of people in cared accommodation.

The cared accommodation component covered residents of residential aged care facilities, hospitals and other 'homes' who had been, or were expected to be, living there, or in another health establishment, for at least three months. This survey component was administered via mail-based forms directed to staff members of selected establishments. Consequently, the information provided was based on staff members' knowledge of the selected residents and information on medical, nursing and administrative records. Only a subset of those questions collected in the household component was asked.

This report uses data from the 2009 SDAC survey, which is the sixth such survey since 1981. Note that because of the survey's increased sample size and changed rules for identifying primary carers, data on carers in Chapter 5 of this report are not directly comparable to data based on the 2003 SDAC survey as presented in the previous *Dementia in Australia* (AIHW 2007) report.

Data from the 2009 SDAC were extracted from the SDAC 2009 confidentialised unit record file (CURF) as at September 2011. To protect confidentiality, some records were removed from the CURF by the ABS before making it available for analysis (ABS 2011b). Therefore, estimates shown in this report may not exactly match those in ABS published reports.

Identification of Dementia

In the 2009 SDAC, a person was considered to have a long-term health condition, such as dementia, if he/she had a disease or disorder which had lasted or was likely to last for at least six months, or a disease, disorder or event (for example, stroke) which produced an impairment or restriction which had lasted or was likely to last for at least six months.

For this report, people were defined as having dementia if one of their long-term health conditions was identified as *Alzheimer disease (SDAC diagnosis code 0511)* and/or *Dementia (diagnosis code 0605)*. It is possible that some people with certain types of dementia, such as those arising from Pick or Huntington disease, may have only had the causal condition coded, and consequently would not be identified as having dementia in the SDAC data.

The SDAC appears to under-report milder forms of dementia, with 93% of people with dementia found to be severely or profoundly limited in their core activities (see Section 3.4). Long-term health conditions were not identified by clinical assessment, potentially reducing the identification of people with early-stage dementia, before cognitive or functional impairment may have become apparent. Factors which can contribute to the under-reporting of milder forms of dementia in surveys such as the SDAC are discussed in Chapter 2. At the same time, the fact that proxy-reporting was able to be used in the household component of the survey may have allowed better identification of late-stage dementia (in which people may be unable to respond for themselves) than in other data sources that rely solely on the self-reporting of conditions.

For operational reasons, a number of small populations were not enumerated in the SDAC, with one such population being people living in Indigenous communities. In addition, people living in *Very remote* areas were outside of the scope of the survey. Thus, data from the SDAC do not provide representative information about Indigenous people and consequently these data cannot be used to look at differences by Indigenous status.

Further information about the 2009 SDAC can be found in a number of ABS publications (ABS 2010, 2011a, 2011b).

Appendix C: Australian longitudinal studies

A number of Australian longitudinal studies collect data about cognitive impairment and dementia. Longitudinal studies gather information from the same group of people (a 'cohort') over a period of time. Advantages of this study design include its ability to examine multiple exposures, determinants and outcomes, and to measure time relationships. Such data are particularly valuable when addressing questions pertaining to, for example, the effect of the type of dementia, treatments given or timing of diagnosis upon subsequent disease progression and outcomes. While these types of questions are beyond the scope of this report, brief descriptions of a selection of Australian longitudinal studies are presented alphabetically in this section.

These studies vary in their ability to accurately identify all those with dementia. Of most relevance are those that include *clinical* assessment of dementia. Other studies are limited to the use of screening instruments which allow for the detection of cognitive impairment and probable dementia, while yet other studies rely on the self-reporting of dementia.

Australian Imaging, Biomarker & Lifestyle Flagship Study of Ageing

Launched in 2006, the CSIRO's Australian Imaging, Biomarker & Lifestyle Flagship Study of the Elderly is a large-scale prospective longitudinal study of cognition involving more than 1,100 people aged 60 and over (CSIRO 2012). The study aims to investigate which biomarkers, cognitive characteristics, and health and lifestyle factors determine the development of Alzheimer disease. Participants are recruited from Perth and Melbourne, with the cohort consisting of 211 individuals with Alzheimer disease, 133 individuals with mild cognitive impairment, and 768 healthy individuals at baseline. Data collected as part of the study include blood samples, neuropsychological assessments, questionnaires on diet and exercise, and neuroimaging. More information can be found on the website: <http://www.aibl.csiro.au/index.php>.

Australian Longitudinal Study of Ageing

The Australian Longitudinal Study of Ageing, conducted by the Centre for Ageing Studies at Flinders University, aims to investigate how biomedical, psychosocial, lifestyle and environmental factors influence age-related changes in the health and well-being of older Australians (Luszcz et al. 2007). The cohort consists of people from both community and institutional settings who were aged 70 and over and living in the Adelaide metropolitan area in 1992. A stratified random sample of such people was initially drawn from the South Australian electoral roll, with eligible persons and their spouses (aged 65 and over) and other co-residents (aged 70 and over) asked to participate. At baseline, data were collected from 2,087 people. Initial data collection included a comprehensive personal interview, the assessment of neuropsychological and physiological functions and biochemistry tests. The MMSE was used as a dementia screening tool. Data from this study have been pooled with other studies as part of the DYNOPTA project (also described in this Appendix) to investigate probable dementia prevalence in Australia. Wave 11 of data collection was completed in 2010 (Flinders University 2012). Further information can be found on the website: <http://www.flinders.edu.au/sabs/fcas/alsa/>.

Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health, also known as Women's Health Australia, is a national study that provides information on women's health issues (University of Newcastle 2007). Study investigators include researchers from the University of Newcastle and University of Queensland. Data collection began in 1996. More than 40,000 Australian women in three age cohorts (18-23, 45-50 and 70-75), which were selected from the Medicare Australia database, are surveyed every three years.

The project aims to identify when, if and how the health system meets the health needs of women, and to help guide the development and evaluation of health policy and planning of women's health care services. It collects information on the needs, views, lifestyles, health and factors affecting the health of women in Australia. The study links social, environmental and personal factors in women's lives to health care use data, by record linkage with the Medicare database. Dementia is not a key focus of the study, but data on medical conditions are available from self-report survey responses, as well as, for the oldest (70–75) cohort, information on memory problems. DoHA recently announced funding for a complementary longitudinal study of *male* health to be undertaken by the University of Melbourne (DoHA 2011k). Further information can be found on the website: <http://www.alswh.org.au/>.

Canberra Longitudinal Study of Ageing

The Canberra Longitudinal Study of Ageing was a 12-year study into the health and memory of older people conducted by the Centre for Mental Health Research at the Australian National University. It aimed to determine the prevalence of depressive symptoms, depressive disorders, cognitive impairment and dementia in older Australians (ADA 2012a). The study, which began in 1990, consisted of a single cohort of about 1,000 people living in the community and residential care facilities aged 70 and over. The cohort was randomly selected from the Canberra and Queanbeyan electoral rolls, with subsequent waves in 1994, 1998 and 2002. Interviews incorporated the Canberra Interview for the Elderly which records diagnoses of dementia and contains the MMSE, National Adult Reading Test (a test of crystallised intelligence that relies on the reading of words that are not pronounced phonetically), Symbol-Letter Modalities Test (a measure of cognitive speed), Episodic Memory Test (four short memory tasks) and the Informant Questionnaire on Cognitive Decline. Data from this study is included in the DYNOPTA project (also described in this Appendix). Further information can be found on the website: <http://www.ada.edu.au/longitudinal/01112>.

Concord Health and Ageing in Men Project

Established in 2004, the Concord Health and Ageing in Men Project is a longitudinal study which focuses on the health of older men. About 1,700 men aged 70 and over living in the community in three local government areas of Sydney participated in the study (Cumming et al. 2009). The study consists of a detailed questionnaire followed by a physical assessment which includes measurements of bone density, fat and lean mass, muscle strength, balance and pulmonary function, Addenbrooke's Cognitive Examination, the MMSE, the Informant Questionnaire on Cognitive Decline in the Elderly, and blood tests. The third wave of data collection will be completed in 2013. The study has a particular focus on testosterone levels and the causes of dementia. Further information can be found on the website: <http://www.cera.usyd.edu.au/research_epid_CHAMP.html>.

Dubbo Study of the Health of the Elderly

The Dubbo Study of the Health of the Elderly is a longitudinal study of people born before 1930 living in Dubbo, New South Wales (Simons 2011; Simons et al. 2006). A group of 2,805 non-institutionalised men and women aged 60 and over were first interviewed in 1988. The study aims to investigate the biomedical and social science of healthy ageing, service use, and the onset of disability and age-related diseases such cardiovascular disease and dementia. Study measures include a medical examination and questionnaire. The baseline questionnaire included questions related to social support, education level, cognitive function (Short Portable Mental Status Questionnaire), physical activity, medical history and self-rated health. Postal surveys are conducted every two years, and as participants consented to ongoing record linkage, hospitalisation, residential care admission and death records are monitored continuously. Further information can be found on the website <http://dubbostudy.org/>.

Dynamic Analyses to Optimise Ageing

The Dynamic Analyses to Optimise Ageing (DYNOPTA) project, which began in 2007, has constructed a pooled dataset from nine Australian longitudinal studies of ageing (ANU 2009). The study aims to identify key incidence rates and risk factors for health outcomes, and thus contribute to the evidence base on ageing to inform planning for Australia's ageing population. This dataset is referred to in Chapter 2 and described in more detail in Appendix B. Further information can be found on the website: <http://dynopta.anu.edu.au/>.

Health in Men Study

Beginning in 1996, the Health in Men Study arose from a population-based randomised trial of screening for abdominal aortic aneurysms (Norman et al. 2009; WAIMR 2012). Men aged 65 and over in the Perth metropolitan area were identified from the electoral roll, and about 12,200 men attended baseline screening between 1996 and 1999. While the focus of the initial study was cardiovascular disease, a follow-up survey between 2001 and 2004 also investigated cognitive function and psycho-social elements of health and wellbeing. Participants have been linked to the Western Australia Data Linkage System, which records all inpatient hospital admissions, births, registered cancers, deaths and public sector mental health services in the state. This allows a range of outcomes to be monitored, and allows tracking of those who did not respond. Further information can be found on the website: <http://www.wacha.org.au/hims.html>.

Koori Growing Old Well Study

The Koori Growing Old Well Study investigates healthy ageing and cognition in urban Aboriginal communities (NeuRA 2012). Around 500 Aboriginal people aged 60 and over and their carers/family informants have been recruited so far from five Aboriginal communities in New South Wales, comprising two metropolitan communities and three regional town communities. Pilot testing was completed in 2009 and data collection began in 2010. The study aims to determine the prevalence of dementia, dementia sub-types and cognitive impairment in urban Indigenous people aged 60 years and over. This research aims to establish a longitudinal study of Aboriginal health and ageing. The study is also assessing the relative performance of a number of standard, as well as adapted, instruments for the diagnosis of dementia and cognitive impairment among Indigenous Australians. A pilot study on the suitability of a modified Kimberley Indigenous Cognitive Assessment tool in an urban Aboriginal community was completed mid-2012. Further information can be found on the website: <http://www.neura.edu.au/aboriginal-ageing>.

Men, Women and Ageing Study

Launched in 2007, the Men, Women and Ageing study is investigating the predictors of ageing well (Women's Health Australia 2007; UQ & UWA 2012). It consists of data pooled from two longitudinal research projects—namely, the *Australian Longitudinal Study on Women's Health (*involving more than 12,000 older women from across Australia) and the *Health in Men Study (*involving more than 12,000 older men from Perth in Western Australia). The women's study is slightly larger and has national coverage, while the men's study includes more direct physical measures and has a wider age range. The projects have been designed to be compatible in terms of survey questions and research design, and the pooling of the data will provide greater statistical power and allow cross-gender analyses. Further information can be found on the website: <http://www.menwomenandageing.org/>.

Melbourne Longitudinal Studies on Healthy Ageing

The Melbourne Longitudinal Studies on Healthy Ageing Program is an ongoing population-based longitudinal study of 1,000 people aged 65 and over living in non-institutional settings in Melbourne (Browning & Kendig 2010; Monash University 2010). It consists of a series of three linked studies that form a large longitudinal study on healthy ageing. These three studies are:

- Functional Ageing, Health and Services, A Longitudinal Outcomes Study
- Health, Behaviours and Outcomes of Older Australians
- Health Status of Older People.

Participants have been followed up every 2 years since 1994. Further information can be found on the website: <http://www.med.monash.edu.au/sphc/haru/melsha/>.

Older Australian Twins Study

The Older Australian Twins Study is a longitudinal study that aims to investigate genetic and environmental factors and their associations and interactions in healthy brain ageing and ageing-related neurocognitive disorders (Sachdev et al. 2009). Study participants are more than 200 identical and non-identical twins aged 65 years and older, living in New South Wales, Victoria and Queensland. Recruitment was largely through the Australian Twin Registry, a volunteer register of more than 31,000 twin pairs, as well as through a recruitment drive. The study involves comprehensive psychiatric, neuropsychological, cardiovascular, metabolic, and neuroimaging assessments. Information about lifestyle, diet, and mental and physical activity is also collected, and follow-up assessments are planned for every two years. Further information can be found on the website: <http://www.med.unsw.edu.au/psychweb.nsf/page/brainage_twins/>.

Personality and Total Health Through Life Project

Established in 1999, the Personality and Total Health Through Life Project is a 20-year longitudinal study that aims to investigate the course of depression, anxiety, substance use and cognitive ability, to identify environmental risk and protective factors influencing these courses, and to examine the inter-relationships between depression, anxiety and substance use with cognitive ability and dementia (Anstey et al. 2011; ANU 2011). At baseline, the sample consisted of 7,485 adult community residents randomly selected from the Canberra and Queanbeyan electoral rolls, with three age cohorts (20–24, 40–44 and 60–64) included at commencement. Data collected include demographic, health, personality and lifestyle information, physical and cognitive measures, genetic analysis, neurocognitive assessments and MRI scans. By the end of 2010, there had been three waves of data collection. Further information can be found on the website: <http://ageing.anu.edu.au/research/projects/path.php>.

Sydney Older Person's Study

Beginning in 1991 and spanning a 10-year period, the Sydney Older Persons Study aimed to investigate successful ageing, with a focus on the definition, possible causes and consequences of neurodegenerative disorders (ADA 2012b; CERA 2009). Participants were 327 veterans and war widows randomly sampled from the Department of Veterans' Affairs listing and 320 non-veterans (randomly sampled from census collection districts in the inner west of Sydney), who were aged 75 and over and living in the community. The study included detailed medical, neurological, psychometric and disability assessment by a physician experienced in geriatric medicine. Other data collected included basic demographics, self-rated health, medication use, social networks and social support, and carer stress. Further information can be found on the websites: <http://www.cera.usyd.edu.au/research_epid_sops.html> and <http://www.ada.edu.au/longitudinal/browse/sydney-older-persons-study>.

Sydney Memory and Ageing Study

The Sydney Memory and Ageing Study was initiated in 2005 with the aims of investigating the clinical characteristics and prevalence of mild cognitive impairment (MCI) and related syndromes, as well as the rate of change in cognitive function over time (UNSW 2012). About 1,000 community-dwelling individuals aged 70 to 90 who did not have dementia were recruited from two areas of Sydney. Participants underwent detailed neuropsychiatric and medical assessments, and donated a blood sample for clinical chemistry, proteomic and genomic analysis. Subgroups also participated in studies of falls and balance, metabolic and inflammatory markers, functional MRI and prospective memory. Structural MRI scans were also performed on 554 individuals. The cohort is contacted annually (telephone reviews), and bi-annually (detailed assessments). Further information can be found on the website: <http://www.med.unsw.edu.au/psychweb.nsf/page/brainage_memory>.

The 45 and Up Study

The 45 and Up Study is a large study of health ageing, involving more than 265,000 people aged 45 and over across New South Wales (Banks et al. 2011; Sax Institute 2012; 45 and Up Study Collaborators 2008). Recruitment spanned February 2006 to December 2009, with participants randomly selected from the Medicare Australia database. Individuals in older age groups (80 and over) and rural areas were over-sampled to ensure adequate statistical power in analyses involving these groups.

In addition to demographic data, the baseline questionnaire collected a range of health-related information, including lifestyle and habits, medication use, history of disease and surgical procedures, functional capacity and psychological distress, social support, employment status, paid and unpaid work and income. Every five years, participants receive follow-up questionnaires. As well, participants may consent to have their information linked with their medical records including data from the New South Wales Admitted Patient Data Collection, MBS and PBS datasets, New South Wales Central Cancer Registry and ABS mortality data. Participants can also consent to be approached about sub-studies, which allow for extra information to be obtained from sub-groups of the cohort. Further information can be found on the study website: <http://www.45andup.org.au/>.

Appendix D: Technical information

Data interpretation

Age-specific rates provide information on the incidence of a particular event in a specified age group relative to the total number of people 'at risk' of that event in the same age group. It is calculated by dividing the number of events occurring in each specified age group by the corresponding population in the same group, and then multiplying the result by a constant (for example, 10,000) to derive the rate.

A **crude rate** provides information on the number of events (for example, deaths due to dementia) relative to the population 'at risk' (for example, the entire population) in a specified period. No age adjustments are made when calculating such a rate. Since the likelihood of a person having dementia is associated with age, crude rates are not suitable for making comparisons across time or groups when differences by age structure exist. More meaningful comparisons can be made by using **age-standardised rates**, with such rates adjusted for age in order to facilitate comparisons between populations that have different age structures.

There are two standardisation methods commonly used to adjust for age: direct and indirect. The direct standardisation approach was used for this report. To calculate age-standardised rates, age-specific rates (grouped in five-year intervals) were multiplied against a constant population (namely, the Australian population as at 30 June 2001). This effectively removes the influence of age structure on the rate and it is described as the age-standardised rate.

A **confidence interval** is a range of values that is used to describe the uncertainty around an estimate, usually from a sample survey. Generally speaking, confidence intervals describe how different the estimate could have been if the underlying conditions stayed the same but chance had led to a different set of data. Confidence intervals are calculated with a stated probability which is commonly 95%; using this probability, there is a 95% chance that the confidence interval contains the true value.

Note 2.1: Australian data on dementia prevalence

The 2007 ABS NSMHW and the DYNOPTA project have shortcomings in terms of allowing for the estimation of dementia prevalence.

The 2007 NSMHW was a general household survey of the adult population that aimed to collect information about the prevalence of mental, substance use and behavioural disorders (see Appendix B for further information). The survey was not designed to specifically identify low-prevalence disorders such as dementia (Slade et al. 2009a). Nonetheless, compared with other national surveys such as the National Health Survey and the SDAC (which only capture self- or proxy-reported information on dementia), the NSMHW has the advantage of including the MMSE. The MMSE, which is the most widely used instrument to assess cognitive impairment in Australia, was administered to 1,905 survey respondents aged 65 to 85. Using these data, Anstey et al. (2010) calculated rates of 'probable dementia' for various age groups (see Table D2.1). As expected, the rates increased with age for the three age groups from 65–69 (4.0%) to 75–79 years (7.5%) but, contrary to expectations, the rate decreased for those aged 80–85 (5.3%).

Table D2.1: Proportion of sample with probable dementia, by sex and age (per cent)

	2007 NSMHW			DYNOPTA		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
65–69	4.63	3.43	4.00	3.02	4.47	3.78
70–74	4.34	5.70	5.02	6.22	4.30	5.16
75–79	11.26	4.20	7.53	10.74	10.55	10.63
80–84[(a)]	4.55	5.79	5.26	16.92	15.97	16.32
85–89	. .	. .	. .	25.13	21.02	22.36
90–94	. .	. .	. .	41.27	29.89	32.43
95+	. .	. .	. .	52.75	69.39	67.52
Total: 65+[(b)]	**. .**	**. .**	**. .**	**9.92**	**10.97**	**10.43**
Total number in sample	904	1,001	1,905	1,954	1,954	3,908

(a) Data for the 2007 NSMHW pertain to those aged 80–85.

(b) The proportions of those aged 65 and over with probable dementia were calculated using population data as at 30 June 2011 (ABS 2012a).

Source: Anstey et al. 2010.

The NSMHW has a number of shortcomings in regard to estimating dementia prevalence:

- no clinical follow-up occurred for those who were found to have low MMSE scores and thus only rates of probable dementia can be derived
- the sample only included those living in the community and thus fails to take account of the prevalence of dementia among those living in residential aged care facilities
- the survey excluded people aged 86 and over and thus those in the oldest age groups (for whom the rate of dementia is highest) were not surveyed
- the NSMHW does not allow for proxies (such as other family members) to report on behalf of a selected individual, meaning that people with dementia who were unable to answer for themselves were excluded from the survey
- the MMSE was included in the NSMHW to identify and exclude from the survey those with severe cognitive impairment, with the ABS indicating that 5 people were excluded for this reason; given modest numbers in the survey, this may have affected some of the age-sex specific rates of probable dementia to a small degree.

For these reasons, data from the NSMHW are not suitable for deriving estimates of the prevalence of dementia in Australia. Note that, although the reasons were somewhat different, Anstey et al. (2010) came to the same conclusion.

The second source of data that could potentially be used to derive estimates of the prevalence of dementia is the DYNOPTA project, which is a pooled dataset consisting of data from nine Australian longitudinal studies. Four of these studies included information on cognitive decline or dementia and, taken together, provide MMSE scores for about 3,900 Australians aged 65 and over. The proportions of probable dementia by age group, as derived from the DYNOPTA data by Anstey et al. (2010), are shown in Table D2.1. The most striking difference between the DYNOPTA and the 2007 NSMHW rates are for those aged 80–84, with the proportion of probable dementia suggested by the DYNOPTA data (16.3%) being triple that of the proportion suggested by the NSMHW (5.3%).

While the DYNOPTA data have the advantage of allowing for dementia prevalence rates to be calculated for age groups beyond the age of 85 (unlike the NSMHW), the data are not nationally representative because the four contributing studies were regional studies. In addition, while the sampling for some of the studies included people living in residential aged care facilities, the actual number of such people included in the data set was not published. Thus, how well these data take account of people living in residential aged care is not clear. As noted by Berr et al. (2005), the under-representation of people in residential care can lead to a significant under-estimation of dementia. Furthermore, and similar to the NSMHW, the data allow for the estimation of probable dementia, rather than clinically diagnosable dementia. Finally, Anstey et al. (2010) concluded from their study that the DYNOPTA estimates likely overestimate probable dementia and thus were better indicators of the rates of cognitive impairment in Australia. All of these issues lead to the conclusion that the estimates of probable dementia as derived from the DYNOPTA data are not appropriate for estimating the prevalence of dementia in Australia.

Note 2.2: Estimating dementia prevalence through meta-analyses

Prevalence estimates for dementia are commonly based on rates determined from meta-analyses, with these rates then applied to population data. While the many individual studies that have been undertaken on dementia prevalence show similarity in certain areas, such as increasing prevalence with age, the actual prevalence rates have been found to vary markedly from one study to another (ADI 2009; EuroCoDe 2009; Jorm et al. 1987; Lobo et al. 2000). These differences in reported rates are influenced by methodological differences (such as the definition of dementia used, case-finding methods and sample characteristics) between studies. By pooling data from a number of such studies, the aim of meta-analysis is to produce aggregate estimates with better accuracy than any individual study can provide. A review of many of the key meta-analyses undertaken to estimate the prevalence of dementia between 1987 and 2005 is provided in *Dementia in Australia* (AIHW 2007).

To produce its national estimates of dementia prevalence in 2007, the AIHW used data from a meta-analysis undertaken by Lobo et al. (2000). One reason that rates from Lobo et al. were used was that, unlike many of the other meta-analyses available at the time, it excluded studies undertaken before 1990. Details about other reasons for the selection of the Lobo et al. rates, as well as further information about the methodology used, can be found in *Dementia in Australia* (AIHW 2007). The rates used in that report are shown in Table D2.2. When these rates are applied to 2011 population data, as sourced from the ABS (2012a), the number of people with dementia in Australia in 2011 is estimated to be 219,200 (82,000 men and 137,200 women).

Estimates of the prevalence of dementia have also been produced by Deloitte Access Economics (formerly known as Access Economics), with these estimates also making use of data from meta-analyses. Most recently, DAE released estimates for 2011 (DAE 2011), based on the same approach used in their 2009 report (Access Economics 2009a). Briefly, that approach made use of a combination of four meta-analyses (which were published between 1987 and 2000) and three international studies to derive dementia prevalence rates, with different approaches used to derive rates for each age group considered.

The estimated prevalence rates derived using these methods are shown in Table D2.2.

Table D2.2: Estimated prevalence rates for dementia from various sources, by sex and age (per cent)

	AIHW (2007)		Deloitte Access Economics (2011)	
Age	**Males**	**Females**	**Males**	**Females**
Under 60[(a)(b)]	0.04	0.01	0.03	0.02
60–64	0.59	0.34	1.20	0.60
65–69	1.31	0.96	1.70	1.30
70–74	2.85	2.63	3.50	3.30
75–79	5.63	6.39	5.80	6.30
80–84	10.00	13.13	12.11	12.94
85–89	15.49	21.94	21.09	24.38
90–94	20.14	29.06	31.53	35.74
95+[(b)]	23.45	33.48	37.24	47.31
Total: 65+[(b)]	**5.27**	**7.97**	**6.64**	**8.91**

(a) For AIHW (2007), the rates for those aged under 60 are based on Harvey et al. 2003.

(b) These proportions were calculated using population data as at 30 June 2011 (ABS 2012a).

Sources: AIHW 2007; Access Economics 2009a.

Deriving prevalence rates for those aged 60 and over

The rates used in this report to estimate the prevalence of dementia among people aged 60 and over are based on the prevalence rates released by Alzheimer's Disease International (ADI 2009) in the *World Alzheimer Report 2009*. As detailed by ADI, the process of producing these rates began with a systematic review of the world literature on the prevalence of dementia. A total of 2,017 publications were evaluated using a rigorous three-stage quality assessment process. For example, studies that had the following characteristics were excluded:

- data collected before 1980
- dementia identified solely on the basis of an MMSE (or similar screening tool) score rather than via a clinical diagnosis
- two-phase studies in which screening procedures were inadequate or the methodology was not properly applied
- prevalence of only certain types of dementia (such as Alzheimer disease) considered
- a representative population-based sample not used.

Following their evaluation process, 135 publications (describing 147 studies) met the required standards. Data from those studies were used by ADI to generate age-specific and/or age-sex-specific meta-analysed dementia prevalence estimates for 11 (out of 21) World Health Organization (WHO) Global Burden of Disease world regions, including Australasia (that is, Australia and New Zealand). To generate these estimates, ADI made use of the latest meta-analytic techniques (namely, Poisson random effects exponential regression).

To estimate the number of people with dementia for this report, ADI's estimated prevalence rates for three regions were used: Australasia, Western Europe and North America. The rates are shown in Table D2.3. The rates for Australasia alone (which were based on two regional studies in Australia and one regional study in New Zealand) were not used because, as stated by ADI (2009), coverage for Australasia was considered 'reasonable' rather than 'good'. Thus, rates for Western Europe and North America were also used. These two regions were chosen because results from a WHO study (Mathers & Leonardi 2006) indicated dementia prevalence data from the high income European and North American regions would be more applicable to Australia than data from many Asian countries which were geographically closer. In addition, the overall prevalence rates for Australasia, Western Europe and North America were quite similar (6.91, 6.92, and 6.46, respectively, for people aged 60 and over) compared with the rates for other regions (for example, 5.78 for South Asia and 8.48 for Latin America). Therefore, for this report, prevalence rates for these three regions were used to produce estimated dementia prevalence rates for Australia for those aged 60 and over. Details on how these prevalence rates were derived follow.

Table D2.3: *World Alzheimer Report 2009* estimates of dementia prevalence, by region, sex and age (per cent)

	Australasia[a]	Western Europe			North America		
Age	Persons	Males	Females	Persons	Males	Females	Persons
60–64	1.8	1.4	1.9	1.6	1.3	1.0	1.1
65–69	2.8	2.3	3.0	2.6	2.1	1.8	1.9
70–74	4.5	3.7	5.0	4.3	3.7	3.3	3.4
75–79	7.5	6.3	8.6	7.4	6.8	6.4	6.3
80–84	12.5	10.6	14.8	12.9	12.3	12.5	11.9
85–89	20.3	17.4	24.7	21.7	21.6	23.2	21.7
90+	38.3	33.4	48.3	43.1	45.2	52.7	47.5

(a) Australasia prevalence rates pertain to Australia and New Zealand.

Source: ADI 2009.

Only age-specific rates (rather than age-sex-specific rates) were reported for Australasia in the *World Alzheimer Report 2009* due to the lack of relevant data from the studies that were included in the meta-analysis for this region (ADI 2009). Thus, the first step in producing prevalence rates for Australia was to derive age-sex specific rates for the Australasian region. This was done by calculating average age-sex rate ratios based on the age-sex rates for Western Europe and North America. These ratios were then applied to the overall age-specific Australasian rates.

Second, the age-sex prevalence rates for Australasia, Western Europe and North America were averaged (and thus weighted equally) to produce estimated age-sex dementia prevalence rates for Australia (Table D2.4). Note that three other weighting options were tested, with these options weighting the rates for the three regions according to:

- the number of studies that were used in the meta-analyses for each region
- the number of participants in the studies that were included in the meta-analyses
- the total populations of the regions aged 60 and over.

The impact of each of these alternative weighting options on the estimated dementia prevalence rates was minimal, with the largest difference suggesting an increase of 1.4% (or about 4,000 people) in the total number of Australians aged 60 and over estimated to have dementia in 2011. For the sake of parsimony, the decision was made to equally weight the rates from the three regions.

Table D2.4: Estimated number of people with dementia, by age and sex, 2011

	Rate (%)		Number[(a)]		
Age	**Males**	**Females**	**Males**	**Females**	**Persons**
Under 30	0.000	0.000	0	0	0
30–34	0.005	0.001	36	6	43
35–39	0.010	0.002	78	17	95
40–44	0.022	0.005	172	42	214
45–49	0.050	0.015	386	116	502
50–54	0.114	0.042	845	322	1,167
55–59	0.257	0.118	1,713	803	2,515
60–64	1.517	1.596	9,383	10,027	19,410
65–69	2.395	2.581	11,310	12,403	23,712
70–74	3.928	4.367	13,906	16,461	30,367
75–79	6.780	7.723	17,692	23,077	40,769
80–84	11.499	13.679	22,144	34,442	56,586
85–89	19.081	23.435	19,788	40,129	59,916
90–94	37.221	47.902	12,916	35,544	48,460
95–99	37.221	47.902	2,564	9,750	12,313
100+	37.221	47.902	375	1,553	1,927
Total[(a)]	**1.006**	**1.626**	**113,307**	**184,689**	**297,997**

(a) Based on estimated resident population numbers as at 30 June 2011, sourced from the ABS (2012a).

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003).

Note that in addition to the dementia prevalence rates published by ADI in 2009, another set of such rates was produced by the European Collaboration on Dementia (EuroCoDe 2009). The EuroCoDe undertook a systematic review of 194 studies on the prevalence of dementia in Europe and evaluated them against a range of criteria, such as data collection having occurred in 1990 or later, sample size of 300 or over, and whether the study was community-based. In the end, 26 studies met the inclusion criteria and the prevalence rates from those studies were used in the meta-analyses. The EuroCoDe rates were not utilised in this report for two reasons. First, they pertain only to Europe, while the ADI report provided rates for a broad number of regions. Second, since the studies included in their meta-analyses were limited to people living in the community, EuroCoDe's rates exclude people living in care accommodation. In contrast, ADI did not exclude studies that included a mix of people living in the community and in cared accommodation settings (ADI 2009).

Deriving prevalence rates for those aged under 60

The dementia prevalence rates available from the *World Alzheimer Report 2009* (ADI 2009) pertain to people aged 60 and over. To derive estimated prevalence rates for people under 60, the same rates as were used in the first *Dementia in Australia* report (AIHW 2007) were used for those aged 30 to 59; these rates were based on Harvey et al. (2003) (see Table D2.4). The Harvey et al. rates were also used by DAE (2011) and they continue to be considered the best rates available for estimating dementia prevalence in these younger age groups (EuroCoDe 2009).

Note 2.3: Estimating the number of people with dementia by residency and severity

The ACFI data used in Chapter 2 in the estimation of dementia prevalence pertain to a specific date (30 June 2011) in order to align with population estimates at that same date. Note that the ACFI data considered in the remainder of the report pertain to the 2009–10 financial year.

To estimate the severity distribution of dementia for people living in the community separately from those living in cared accommodation, the same method as was used in the previous *Dementia in Australia* (AIHW 2007) report was adopted. That is, first, severity categories of the CDR were mapped to disability severity measures in the SDAC, based on 'core activity limitations'. The core activities in the SDAC are self-care, mobility and communication (see Box 3.2 for further information about core activity limitations). Such mapping is possible because the CDR domains include a description of the functional outcomes of dementia of different severities. See Table D2.5 for the mapping according to the severity labels of 'mild', 'moderate' and 'severe' as used in Chapter 2.

Table D2.5: Description of severity of dementia categories according to the CDR and SDAC

	Clinical Dementia Rating(a)		Survey of Disability, Ageing and Carers	
Severity	**Rating**	**Definition**	**Need for assistance(b)**	**Definition**
Mild	CDR 1	Significant impact on daily activities but still able to undertake daily activities	Mild(c)	The person needs no help and has no difficulty with any of the core activity tasks but may use aids and equipment
			Moderate	The person needs no help but has difficulty with a core activity task
			Severe	The person sometimes needs help with a core activity task
Moderate	CDR 2	Independent living is not possible without assistance	Profound	The person is unable to do, or always needs help with, a core activity task
Severe	CDR 3	Permanent supervision required		

(a) For a full description of CDR scores, see Appendix Table A1.2.

(b) Need for assistance is based on limitations with communication, self-care and mobility, which may also be caused by a coexisting condition other than dementia. See Box 3.2 for more details on measuring the severity of disability using SDAC data.

(c) The 2009 SDAC data suggest that an estimated **0.04% of those with dementia in cared accommodation had a disability but no core activity limitation. These were included in the 'mild' category for this mapping. Those with reported dementia but no disability were excluded from the analyses shown in Chapter 2.

Sources: ABS 2004; Barendregt & Bonneux 1998.

Note that the CDR and the SDAC scales use terminology that is not equivalent. For example, the SDAC category of 'moderate' disability indicates that the person needs no help but has difficulty with a core activity task. In contrast, people in the CDR 2 'moderate' category have such severe memory loss that only highly learned material is retained and they often require help with personal care. Note also that a person's level of core activity limitation as measured by the SDAC may be partly due to other health conditions, whereas scoring in the CDR is limited to impairment judged to be due to cognitive loss and not other conditions.

This mapping suggests that the proportion of people estimated to have 'mild' dementia in cared accommodation is roughly equivalent to the proportion with mild, moderate or severe core activity limitation according to the SDAC—namely 6.4% or 5,800 people (see Appendix Table A3.7).

According to the SDAC, the remainder (93.6% or 84,200 people) had a profound limitation. To allocate these to the 'moderate' and 'severe' severity categories, use was made of the work by Barendregt and Bonneux (1998), which indicated that 55% of people with dementia were classified as mild (CDR of 1), 30% as moderate (CDR of 2) and 15% as severe (CDR of 3). These proportions suggest a ratio of 2:1 for the number of people with moderate versus severe dementia. When this ratio is applied to the 93.6% of those in cared accommodation with a profound limitation (according to the SDAC), it indicates that 62.6% (56,300 people) had moderate dementia and 31.3% (28,200 people) had severe dementia.

The final step was to calculate the number of people with dementia living in the community by severity. This was done by subtraction, using information from the severity distribution for all those with dementia and the severity distribution for people with dementia in cared accommodation. For example, the above suggests that 56,300 of the estimated 89,400 people with moderate dementia were living in cared accommodation. Thus, an estimated 33,100 people with moderate dementia must have been living in the community.

Note 2.4: Deriving the burden of disease projections

This report presents the estimated burden of disease due to dementia in 2003 and projected to 2011, 2015 and 2020. Numbers of YLLs, YLDs and DALYs were derived by applying the burden of disease rates estimated by Begg et al. (2007) to ABS population data for 2003 and 2011 (ABS 2012a) and to ABS population projections (Series B) for 2015 and 2020 (ABS 2008a). These burden of disease rates were estimated by Begg et al. using data on the burden of dementia from 1979 to 2003. More information about how these rates were derived and the interpretation of burden of disease measures can be found in the AIHW report by Begg et al. (2007). Note that in that report, dementia was defined to include the ICD-10 codes of: F00–F01, F02.0–F02.1, F02.3, F03, G30, G31.0–G31.1 and G31.8–G31.9. This list of codes is slightly different from that used in other sections of this report.

Note 3.1: Classifying a permanent resident in an aged care facility as 'low care' versus 'high care'

As described in Box 3.3, permanent residents in subsidised aged care facilities are appraised using the ACFI in each of three funding domains: 'Activities of daily living (ADL)', 'Behaviour characteristics' and 'Complex health care needs'. The information from that appraisal is used to determine the classification for funding and the overall classification as a 'low care' or 'high care' resident.

As of 1 January 2010, to be defined as requiring a high level of care, the resident must have been assigned:

- a score of high in the ADL domain, or
- a score of high in the Complex health care needs domain, or
- a score of medium or high in at least two of the three domains, or
- a score of high in the Behaviour domain together with a score above nil in at least one of the ADL or Complex health care needs domains.

All other residents were defined as requiring a low level of care.

Before 1 January 2010, to be classified under the ACFI as requiring a high level of care, a resident must have had a score of medium or high in the ADL domain, high in the Behaviour domain, or medium or high in the Complex health care needs domain.

The change in definition of 'high care' occurred during the reporting period for ACFI data considered in this report (namely 2009–10). The process used by the AIHW to assign permanent residents as either 'low care' versus 'high care' was as follows:

- for residents who separated from the residential care facility before 1 January 2010, the rules applicable before 1 January 2010 were used
- for residents who had not separated from the residential care facility before 1 January 2010:
  - if the ACFI appraisal had a valid expiry date, the care level classification was based on the rules in place at the time of expiry of the ACFI appraisal (for example, if the ACFI appraisal had an expiry date of 28 February 2010, the rules applicable from 1 January 2010 onward were used)
  - if the ACFI appraisal did not have a valid expiry date, the rules applicable from 1 January 2010 onward were used.

Note 4.1: Method used to derive amount, by weight, of dementia-specific medications

The amount, by weight, of each subsidised dementia-specific drug dispensed was calculated by multiplying the number of prescriptions dispensed (DoHA 2011d) by the weight per dose (DoHA 2012h), by the maximum quantity per prescription (DoHA 2012h). Note that this approach assumes that the maximum quantity was prescribed in each case; no data are available on whether this is always the case. It is therefore possible that this method overestimates the weight of the drugs dispensed.

All but two of the PBS/RPBS item numbers were in tablet, capsule or patch form. The exceptions were one type of rivastigmine (item number 8563Q) which was an oral solution, and one type of memantine (item number 2059J) which was oral drops. For these item numbers, the dose per mL was multiplied by the number of mL in each bottle dispensed.

Note that comparisons between weights dispensed of different drugs cannot be made as different drugs have different potencies per mg of weight.

Note 5.1: Carers and primary carers in SDAC data

The data about carers as collected in the 2003 SDAC (and described in AIHW 2007) are not comparable to those presented in Chapter 5 of this report for two reasons.

First, for both the 2003 and 2009 surveys, people who had been identified as being a primary carer by *another adult* in the household were subsequently interviewed to confirm their primary carer status. In addition, in 2009 (but not in 2003), people who had been identified as a primary carer by *care recipients* were also interviewed, with many of these carers then confirming their primary carer status. Because of this change, the number of confirmed primary carers identified in 2009 was 27% higher than if the 2003 rules had been used.

Second, the sample size of the household component of the survey increased by 78%, from 36,088 in 2003 to 64,213 in 2009. As a result of these two changes, the numbers of co-resident carers and co-resident primary carers of people with dementia identified in 2009 were substantially higher than in 2003. For the analyses undertaken with the 2003 data, the relatively small numbers of carers and primary carers people with dementia made population estimates unreliable and thus the carer data were analysed as a sample. In contrast, the increased sample size in 2009 allowed population estimates to be analysed. The resulting analyses, as described in this report, are not comparable with those based on the 2003 SDAC data.

Note that the SDAC data on the characteristics of carers (as reported in Chapter 5) relate only to *co-resident* carers and primary carers (that is, they lived with the care recipient with dementia), because the dementia status of people not living in the surveyed household could not be confirmed. In the SDAC, primary carers were identified according to which carer provided the most care to the recipient (see Box 5.1 for a full definition of 'primary carer'). These primary carers could then indicate the person to whom they provided the most care (that is, their 'main recipient of care'); around 80% of all primary carers provided care to one person, but 16% provided care to two people, and 4% provided care to three people. All co-resident primary carers of people with dementia in the 2009 SDAC sample indicated that the main recipient of their care was the person with dementia. To provide a comparison point to these primary carers, the term 'all primary carers', as reported in Chapter 5, relates to the 82% of all primary carers who lived with the main recipient of their care. No carers in the 2009 SDAC sample were co-resident carers of more than one person with dementia.

Note 5.2: Under-estimation of non-co-resident carers in SDAC data

In Section 5.3, it was noted that available 2009 SDAC data do not allow for all non-co-resident carers of people with dementia in the community to be identified. This is due to limitations associated with analysis of these data. Specifically, the confidentialised unit record file (CURF) for the 2009 SDAC only allows two or more non-co-resident carers who had the same relationship to the recipient to be differentiated if, in at least one broad area of assistance, both provided assistance. For example, if one daughter assisted with mobility, communication and cognitive or emotional tasks, and another assisted with property maintenance, they would be counted as one non-co-resident carer. In addition, the survey only allowed up to three broad areas of assistance to be noted for each care provider. Thus, if the first daughter above also assisted with property maintenance, the two sisters would still be counted as only one non-co-resident carer. In this example, if one carer was a son, and the other a daughter, these two carers could be differentiated.

While the proportion of non-co-resident carers of people with dementia in the community provided in this report is the first to be derived from SDAC data, a similar proportion (derived from various non-SDAC sources) was reported in *Dementia in Australia* (AIHW 2007: 128). A comparison of that estimate with that derived from 2009 SDAC data suggests that the extent of any underestimation of the proportion of non-co-resident carers derived using 2009 SDAC data is low.

Note 5.3: Estimating number of carers of people with dementia

To estimate the number of carers of people with dementia living in the community, SDAC data were used to derive the average number of carers per person with dementia by disability level. These averages are shown in Table D5.1.

Table D5.1: Average number of carers of people with dementia living in the community, by disability level, 2009

Level of disability[(a)]	Average number of carers per person
Mild or moderate limitation[(b)]	0.7
Severe limitation	1.6
Profound limitation	1.6
Total	**1.5**

(a) Level of disability is measured by the extent of limitation in core activities of daily living (see Box 3.2).

(b) Includes people with dementia with disability but no core activity limitation. People with reported dementia but without disability were excluded for these analyses.

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

Based on a similar approach to what was done when estimating dementia prevalence (as described in Note 2.3), the levels of disability (as shown in Table D5.1) were mapped to CDR dementia severity levels (namely, mild, moderate and severe) based on work by Barendregt and Bonneux (1998). This mapping was used to apply the average number of carers per person by disability level to the estimated number of people with dementia in the community by dementia severity level (with those estimates shown in Table 2.2).

Note 6.1: Estimating expenditure for hospitalisations in which the principal diagnosis was dementia

In this report, admitted patient expenditure for dementia is estimated based on the Diagnosis Related Group (DRG) codes for patients with a principal diagnosis of dementia using the following approach.

Patients admitted to hospital are assigned a principal diagnosis relating to the main reason they were admitted, as well as a DRG code. The code is based on a range of data collected about the admitted patient, including the diagnosis and procedures undertaken during the hospitalisation. Information on both the principal diagnosis and the DRG are available from the National Hospital Morbidity Database (see Appendix B for information about this database). A cost is assigned to each of these DRG codes, with this cost sourced from the National Hospital Cost Data Collection (see Appendix B). The cost, which includes government and non-government expenditure related to the hospitalisation, is applied to all hospitalisations with a principal diagnosis of dementia to determine total expenditure for these hospitalisations.

In the NHMD, diagnoses are classified using the ICD-10-AM. In this report, a hospitalisation was considered to have a principal diagnosis of dementia if one of the following criteria were met:

(i) any of the following ICD-10-AM codes was recorded as the principal diagnosis: F00, F01, F02, F03, F05.1 or G30

(ii) ICD-10-AM code of G31 was recorded as the principal diagnosis *and* another dementia code (as listed above) was recorded as an additional diagnosis.

Note 6.2: Estimating expenditure in residential aged care facilities attributable to dementia

In order to allocate the proportion of total funding for a permanent resident that is attributable to dementia, information on the resident's comorbidities is required. Due to the approach used to collect information on other health conditions, ACFI data do not provide a complete list of comorbidities, nor do they indicate the relative severity of these conditions. Consequently, it is not possible to use data collected through the ACFI to separate the cost attributable solely to dementia from the total cost of caring for people with dementia in residential aged care facilities. Instead, data from the 2009 SDAC that pertain to people living in residential aged care facilities were used to determine the differences in care needs between people with and without dementia living in such facilities. To do so, the following approach was used. Note that this approach is similar to the one used in the previous *Dementia in Australia* report (AIHW 2007) but, unlike that report, these estimates relate to data collected via the ACFI rather than being based on the Resident Classification Scale.

First, the SDAC questions related to need for assistance (see Section 3.6) were mapped to related ACFI questions such that an estimated ACFI score was created for each SDAC respondent living in residential aged care facilities.

Second, health conditions recorded in the SDAC were allocated across eight categories grouped according to similarities in the likely need for assistance for the condition. For example, arthritis was grouped with hip damage from injury in the group 'Conditions affecting mobility'. The groups were: Dementia and Alzheimer disease, stroke, conditions affecting mobility, mental health, other cardiovascular disease, hearing loss, Parkinson disease, and other conditions. A list of conditions and the groups into which they were categorised can be found in Table 8.6 of the previous *Dementia in Australia* report (AIHW 2007). Each group was only counted once which means that someone who had two conditions that are allocated to the same group only had one of them counted (that is, the disease group is an on/off variable).

Third, a regression model was fitted to the data using the estimated ACFI scores as the dependent variable, and all possible combinations of the eight condition groups (more than 200) as the independent variables. The resultant model had 219 degrees of freedom, an F value of 13.36 ($Pr > F = 0.0001$) and an adjusted R^2 of 0.24. From this model, a predicted ACFI score was generated for each combination of condition groups which provided an average ACFI score and hence level of funding for each combination of condition groups within the model.

Fourth, comparisons were then made between combinations of conditions with dementia and the same combination of conditions, except without dementia, to quantify the impact of dementia on predicted ACFI scores and associated levels of funding. For example, the predicted ACFI score for a resident with dementia, stroke and mobility problems was compared with that of a resident with just stroke and mobility.

Fifth, these results were applied to 2009–10 data for ACFI residents, with age and sex taken into account, and used to estimate the proportion of Australian Government funding for permanent residents in residential aged care that was attributable to dementia.

Appendix E: Classifications used

Health-related classifications have multiple purposes, including the facilitation of data collection and management in the clinical setting, the analysis of data, and the allocation of financial and other resources. This section provides a brief description of the main classification systems referred to in this report.

International Statistical Classification of Diseases and Related Health Problems (ICD)

The ICD, which was developed by the WHO, is used to classify diseases and other health problems (including symptoms and injuries) in clinical and administrative records. In 1903, Australia adopted the ICD to classify causes of death and it was fully phased in by 1906. Since 1906, the ICD has been revised nine times in response to the recognition of new diseases (for example, Acquired Immunodeficiency Syndrome (AIDS)), increased knowledge of diseases, and changing terminology in the description of diseases.

The version currently in use, ICD-10 (WHO 1992), was endorsed by the 43rd World Health Assembly in May 1990 and officially came into use in WHO member states from 1994.

Further information on the ICD is available from the WHO website at <http://www.who.int/classifications/icd/en/>.

International Statistical Classification of Diseases and Related Health Problems, Australian modification (ICD-10-AM)

The Australian modification of ICD-10, which is referred to as the ICD-10-AM (NCCH 2008), is based on ICD-10. ICD-10 was modified for the Australian setting by the National Centre for Classification in Health (NCCH) with assistance from clinicians and clinical coders. Despite the modifications, compatibility with ICD-10 at the higher levels (that is, up to 4 character codes) of the classification has been maintained.

International Classification of Primary Care, 2nd edition (ICPC-2)

The International Classification of Primary Care, 2nd edition (ICPC-2) is a classification method for primary care (that is, general practice) encounters. It allows for the classification of three elements of a health care encounter in relation to the patient: reasons for the encounter, diagnoses or problems, and process of care.

The ICPC-2 is currently being used in electronic health records in clinical general practice as well as in the research of general practice (that is, the BEACH project) and other statistical collections such as the ABS National Health Survey.

The ICPC-2 PLUS (which is also known as the BEACH coding system) is an extended vocabulary of terms classified according to the ICPC-2, which enables greater specificity in coding. The ICPC-2 PLUS is primarily used in the context of Australian general practice.

Further information on ICPC-2 is available from the WHO website at <http://www.who.int/classifications/icd/adaptations/icpc2/en/> and information on ICPC-2 PLUS is available from the BEACH website: <http://www.fmrc.org.au/icpc2plus/>.

ASGC categories of remoteness

The Australian Standard Geographical Classification (ASGC) was developed by the ABS for the collection and dissemination of geographically classified statistics. In this report, ASGC Remoteness Areas were used to assign areas across Australia to a remoteness category (ABS 2006). This classification divides all areas of Australia into five categories—namely, *Major cities*, *Inner regional*, *Outer regional*, *Remote* and *Very remote* (AIHW 2004c). In this publication, the *Outer regional*, *Remote* and *Very remote* categories are sometimes collapsed due to small cell counts.

Anatomical Therapeutic Chemical Classification System

The Anatomical Therapeutic Chemical (ATC) Classification System, which was developed by the WHO, assigns therapeutic drugs to different groups according to the organ or system on which they act, as well as their therapeutic and chemical characteristics. For further information on this classification system, refer to the WHO website at <http://www.whocc.no/atcddd/>.

References

ABS (Australian Bureau of Statistics) & AIHW (Australian Institute of Health and Welfare) 2008. The health and welfare of Australia's Aboriginal and Torres Strait Islander people, 2008. ABS cat. no. 4704.0 & AIHW Cat. no. 21. Canberra: ABS & AIHW.

ABS 1998. Standard Australian Classification of Countries (SACC). ABS cat. no. 1269.0. Canberra: ABS.

ABS 2001. Information paper: ABS views on remoteness, 2001. ABS cat. no. 1244.0. Canberra: ABS.

ABS 2006. Australian Standard Geographical Classification (ASGC), July 2006. ABS cat. no. 1216.0. Canberra: ABS.

ABS 2008a. Population projections, Australia, 2006 to 2101. ABS cat. no. 3222.0. Canberra: ABS.

ABS 2008b. A profile of carers in Australia. ABS cat. no. 4448.0. Canberra: ABS.

ABS 2008c. National Survey of Mental Health and Wellbeing: summary of results, 2007. ABS cat. no. 4326.0. Canberra: ABS.

ABS 2009. National Survey of Mental Health and Wellbeing: users' guide, 2007. ABS cat. no. 4327.0. Canberra: ABS.

ABS 2010. Disability, ageing and carers, Australia: summary of findings, 2009. ABS cat. no. 4430.0. Canberra: ABS.

ABS 2011a. Information paper: disability, ageing and carers, Australia: user guide, 2009. ABS. cat. no. 4331.0.55.001. Canberra: ABS.

ABS 2011b. Basic confidentialised unit record file: disability, ageing and carers, 2009. ABS. cat. no. 4330.0.00.001. Canberra: ABS.

ABS 2012a. Australian demographic statistics, September 2011. ABS cat. no. 3101.0. Canberra: ABS.

ABS 2012b. Causes of death, Australia, 2010. ABS cat. no. 3303.0. Canberra: ABS.

ACAP NDR (Aged Care Assessment Program National Data Repository) 2009. Aged Care Assessment Program National Data Repository Minimum data set report: annual report 2007–2008. Melbourne: La Trobe University.

Access Economics 2003. The dementia epidemic: economic impact and positive solutions for Australia. Canberra: Access Economics.

Access Economics 2009a. Keeping dementia front of mind: incidence and prevalence 2009–2050. Canberra: Access Economics.

Access Economics 2009b. Making choices—future dementia care: projections, problems and preferences. Canberra: Access Economics.

ACPRT (Aged Care Price Review Taskforce) 2004. Review of pricing arrangements in residential aged care: final report. Canberra: DoHA.

ADA (Australian Data Archive) 2012a. Canberra Longitudinal Study. Canberra: ANU. Viewed 25 March 2012, <http://www.ada.edu.au/longitudinal/01112>.

ADA 2012b. Sydney Older Persons Study. Canberra: ANU. Viewed 25 March 2012, <http://www.ada.edu.au/longitudinal/browse/sydney-older-persons-study>.

ADI (Alzheimer's Disease International) 2009. World Alzheimer Report 2009. London: ADI.

AHMC (Australian Health Ministers' Conference) 2006. National framework for action on dementia 2006–2010. Sydney: NSW Department of Health.

AIHW 2004a. The impact of dementia on the health and aged care systems. Cat. no. AGE 37. Canberra: AIHW.

AIHW 2004b. Carers in Australia: assisting frail older people and people with a disability. Aged Care Series. Cat. no. AGE 41. Canberra: AIHW.

AIHW 2004c. Rural, regional and remote health: a guide to remoteness classifications. Cat. no. PHE 53. Canberra: AIHW.

AIHW 2007. Dementia in Australia: national data analysis and development. Cat. no. AGE 53. Canberra: AIHW.

AIHW 2008. Health expenditure Australia 2006–07. Health and welfare expenditure series no. 35. Cat. no. HWE 42. Canberra: AIHW.

AIHW 2010a. Australia's health 2010. Australia's health series no. 12. Cat. no. AUS 122. Canberra: AIHW.

AIHW 2010b. Australian hospital statistics 2008–09. Health services series no. 34. Cat. no. HSE 84. Canberra: AIHW.

AIHW 2010c. Dementia and the take-up of residential respite care. Bulletin no. 78. Cat. no. AUS 124

AIHW 2010d. Health system expenditure on disease and injury in Australia, 2004–05. Cat. no. HSE 87. Canberra: AIHW.

AIHW 2011a. Dementia among aged care residents: first information from the Aged Care Funding Instrument. Aged care statistics series no. 32. Cat. no. AGE 63. Canberra: AIHW.

AIHW 2011b. Australia's welfare 2011. Australia's welfare series no.10. Cat. no. AUS 142. Canberra: AIHW.

AIHW 2011c. Australian hospital statistics 2009–10. Health services series no. 40. Cat. no. HSE 107. Canberra: AIHW.

AIHW 2011d. Identifying admitted patient palliative care separations: technical paper. Cat. no. HWI 113. Canberra: AIHW.

AIHW 2011e. Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

AIHW 2011f. The Hospital Dementia Services Project: a study description. Cat. no. AGE 67. Canberra: AIHW.

AIHW 2011g. Aged care packages in the community 2009–10: a statistical overview. Aged care statistics series no. 34. Cat. no. AGE 65. Canberra: AIHW.

AIHW 2011h. Residential aged care in Australia 2009–10: a statistical overview. Aged care statistics series no. 35. Cat. no. AGE 66. Canberra: AIHW.

AIHW 2011i. Pathways in aged care: program use after assessment. Cat. no. CSI 10. Canberra: AIHW.

AIHW 2012a. Australia's health 2012. Australia's health series no. 13. Cat. no. AUS 156. Canberra: AIHW.

AIHW 2012b (forthcoming). Palliative care services in Australia 2012. Canberra: AIHW.

AIHW 2012c. Mental health services in Australia on-line. Canberra: AIHW. Viewed 28 May 2012, <http://mhsa.aihw.gov.au/home/>.

AIHW 2012d (forthcoming). Deriving key patient variables: a Hospital Dementia Services technical paper. Data linkage series. Canberra: AIHW

AIHW: AGPSCC (Australian GP Statistics and Classification Centre) 2010. SAND abstract no. 159 from the BEACH program: dementia screening, prevalence and management. Sydney: AGPSCC University of Sydney.

AIHW: Karmel R & Rosman D 2007. Comparing name-based and event-based strategies for data linkage: a study linking hospital and residential aged care data for Western Australia. Data linkage series no. 3. Cat. no. CSI 3. Canberra: AIHW.

Albinsson L 2003. Differences in supporting families of dementia patients and cancer patients: a palliative perspective. Palliative Medicine 17:359–67.

Alzheimers Australia 2011a. Annual report 2010–11. Canberra: Alzheimer's Australia.

Alzheimers Australia 2011b. Annual report 2009–10. Canberra: Alzheimer's Australia.

Alzheimers Australia 2012. Alzheimer's Australia. Canberra: Alzheimer's Australia . Viewed 11 February 2012, <http://www.fightdementia.org.au/default.aspx>.

Alzheimers Australia NT 2002. Indigenous dementia project report. Darwin: Alzheimer's Australia NT.

Andersen K, Lolk A, Martinussen T & Kragh-Sørensen P 2010. Very mild to severe dementia and mortality: a 14-year follow-up—the Odense study. Dementia and Geriatric Cognitive Disorders 29:61–7.

Anstey KJ, Burns RA, Birrell CL, Steel D, Kiely KM & Luszcz MA 2010. Estimates of probable dementia prevalence from population-based surveys compared with dementia prevalence estimates based on meta-analyses. BMC Neurology 10:62.

Anstey KJ, Byles JE, Luszcz MA, Mitchell P, Steel D, Booth H et al. 2009. Cohort profile: The Dynamic Analyses to Optimise Ageing (DYNOPTA) project. International Journal of Epidemiology 39(1):44–51.

Anstey KJ, Christensen H, Butterworth P, Easteal S, Mackinnon A, Jacomb T et al. 2011. Cohort Profile: The PATH through life project. International Journal of Epidemiology Epublished ahead of print. doi: 10.1093/ije/dyr025.

ANU (Australian National University) 2009. DYNOPTA—Dynamic Analyses to Optimise Ageing. Canberra: Australian National University. Viewed 20 June 2012, <http://dynopta.anu.edu.au/index.php>.

ANU 2011. Personality and Total Health Through Life. Canberra: ANU. Viewed 25 June 2012, <http://ageing.anu.edu.au/research/projects/path.php>.

Arkles R, Jackson Pulver LR, Robertson H, Draper B, Chalkley S & Broe GA 2010. Ageing, cognition and dementia in Australian Aboriginal and Torres Strait Islander peoples: a life cycle approach, a literature review. Sydney: University of New South Wales.

Attner B, Lithman T, Noreen D & Olsson H 2010. Low cancer rates among patients with dementia in a population-based register study in Sweden. Dementia and Geriatric Cognitive Disorders 30:39–42.

Banks E, Jorm L & Wutzke S 2011. The 45 and Up Study: fostering population health research in NSW. NSW Public Health Bulletin 22:15–16.

Barendregt JJM & Bonneux LGA 1998. Degenerative disease in an aging population: models and conjecture. Enschede: Public Health Department, Erasmus University. PhD thesis.

Becker R, Sili J, Ma Fat D, L'Hours A & Laurenti R 2006. A method for deriving leading causes of death. Bulletin of the World Health Organization 84(4):297–307.

Begg S, Vos T, Barker B, Stevenson C, Stanley L & Lopez AD 2007. The burden of disease and injury in Australia, 2003. Cat. no. PHE 82. Canberra: AIHW.

Berr C, Wancata J & Ritchie K 2005. Prevalence of dementia in the elderly in Europe. European Neuropsychopharmacology 15:463–71.

Bond J, Stave C, Sganga A, O'Connell B & Stanley RL 2005. Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey. International Journal of Clinical Practice 59(Suppl. 146):8–14.

Bradford A, Kunik ME, Schulz P, Williams SP & Singh H 2009. Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. Alzheimer Disease & Associated Disorders 23(4):306–14.

Britt H, Miller GC, Charles J, Bayram C, Pan Y, Henderson J et al. 2008. General practice activity in Australia 2006–07. General practice series no. 21. Cat. no. GEP 21. Canberra: AIHW.

Britt H, Miller GC, Charles J, Henderson J, Bayram C, Pan Y et al. 2009. General practice activity in Australia, 2008–09. General practice series no. 25. Cat. no. GEP 25. Canberra: AIHW.

Britt H, Miller GC, Charles J, Henderson J, Bayram C, Valenti L et al. 2011. General practice activity in Australia 2010–11. General practice series no. 29. Sydney: Sydney University Press.

Brodaty H, Seeher K & Gibson L 2012. Dementia time to death: a systematic literature review on survival time and years of life lost in people with dementia. International Psychogeriatrics 24(7):1034–45.

Browning CJ & Kendig H 2010. Cohort profile: The Melbourne Longitudinal Studies on Healthy Ageing Program. International Journal of Epidemiology 39:e1–e7.

Centrelink 2012. Information you need to know about your claim for Carer Payment, Carer Allowance. Canberra: Centrelink. Viewed 28 May 2012, <http://www.humanservices.gov.au/spw/customer/forms/resources/ci002-1207en.pdf>.

CERA (Centre for Education Research and Ageing) 2009. Sydney Older Persons Study. Sydney: University of Sydney & Concord Repatriation General Hospital. Viewed 25 March 2012, <http://www.cera.usyd.edu.au/research_epid_sops.html>.

CHeReL (Centre for Health Record Linkage) 2009. Centre for Health Record Linkage. Sydney: CHeReL. Viewed 27 July 2010, <http://www.cherel.org.au/>.

Chertkow H, Massoud F, Nasreddine Z, Belleville S, Joanette Y, Bocti C et al. 2008. Diagnosis and treatment of dementia: 3. mild cognitive impairment and cognitive impairment without dementia. CMAJ Canadian Medical Association Journal 178(10):1273–85.

Corrada MM, Brookmeyer R, Paganini-Hill A, Berlau D & Kawas CH 2010. Dementia incidence continues to increase with age in the oldest old: the 90+ study. Annals of Neurology 67(1):114–21.

Coventry PA, Grande GE, Richards DA & Todd CJ 2005. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review. Age and Ageing 34(3):217–27.

CSHAWG (Canadian Study of Health and Aging Working Group) 1994. Canadian Study of Health and Aging: study methods and prevalence of dementia. Canadian Medical Association Journal 150(6):899–913.

CSIRO (Commonwealth Scientific and Industrial Research Organisation) 2012. The Australian Imaging, Biomarkers and Lifestyle Study of Ageing. Canberra: CSIRO. Viewed 2 April 2012, <http://www.aibl.csiro.au/>.

Cumming R, Handelsman D, Seibel M, Creasey H, Sambrook P, Waite L et al. 2009. Cohort profile: The Concord Health and Ageing in Men Project (CHAMP). International Journal of Epidemiology 38(2):374–8.

Currow DC, Agar M, Sanderson C & Abernethy AP 2008. Populations who die without specialist palliative care: does lower uptake equate with unmet need? Palliative Medicine 22:43–50.

DAE (Deloitte Access Economics) 2011. Dementia across Australia: 2011–2050. Canberra: DAE.

DCRC–ABC (Dementia Collaborative Research Centre—Assessment and Better Care) & RACGP (The Royal Australian College of General Practitioners) 2011. 14 essentials for good dementia care in general practice. Sydney: University of New South Wales.

DCRC–ABC 2012. Inspired study: improving service provision for early onset memory and related disorders. Sydney: University of New South Wales. Viewed 7 July 2012, <http://www.inspiredstudy.org/>.

DCRC–ABC 2012. Update dementia guidelines for general practice. Dementia Collaborative Research Centre. Sydney: University of New South Wales, viewed 14 February 2012, <http://www.dementia.unsw.edu.au>.

Dewey ME & Saz P 2001. Dementia, cognitive impairment and mortality in persons aged 65 and over living in the community: a systematic review of the literature. International Journal of Geriatric Psychiatry 16:751–61.

DoHA (Department of Health and Ageing) 2005. Ageing factsheet 1: helping Australians with dementia, and their carers: making dementia a National Health Priority. Canberra: DoHA. Viewed 1 July 2012, <http://www.health.gov.au/internet/budget/publishing.nsf/Content/health-budget2005-abudget-afact1.htm>.

DoHA 2006. National Respite for Carers Program (NRCP) services activity report (SAR): directions and definitions. Canberra: DoHA.

DoHA 2008. Community Care Census 2007–2008: care recipient and carer form guidelines (version 4.0). Canberra: DoHA.

DoHA 2009a. Aged Care Funding Instrument (ACFI) user guide. Publication no. 6281. Canberra: DoHA.

DoHA 2009b. The residential care manual. Canberra: DoHA.

DoHA 2010a. The 2008 Community Care Census. Canberra: DoHA.

DoHA 2010b. Supporting Australians to live well at the end of life: National Palliative Care Strategy 2010. Canberra: DoHA.

DoHA 2010c. Report on the operation of the *Aged Care Act 1997*: 1 July 2009–30 June 2010. Canberra: DoHA

DoHA 2010d. Australian Government Department of Health and Ageing Annual Report 2009–10. Canberra: DoHA.

DoHA 2010e. National Hospital Cost Data Collection cost report round 13, 2008–09. Canberra: DoHA.

DoHA 2010f. Medicare Benefits Schedule Book, effective 1 November 2010. Canberra: Commonwealth of Australia.

DoHA 2011a. Flexible fund guidelines: Aged Care service improvement and healthy ageing grants fund. Canberra: DoHA. Viewed 28 May 2012, <http://www.health.gov.au/internet/main/publishing.nsf/Content/06D95A934AA79B0ACA257979007639AD/$File/FundGuidelines_%20Aged-Care-Service-Improv-Healthy-Ageing-Grants-Fund.pdf>.

DoHA 2011b. 2010–11 report on the operation of the *Aged Care Act 1997*. Canberra: DoHA.

DoHA 2011c. Australian statistics on medicine 2009. Canberra: DoHA.

DoHA 2011d. Medicare Australia: Pharmaceutical Benefits Schedule item reports. Canberra: DoHA. Viewed 20 November 2011, <https://www.medicareaustralia.gov.au/statistics/pbs_item.shtml>.

DoHA 2011e. Aged Care Assessment Team delegations policy. Canberra: DoHA.

DoHA 2011f. Aged Care Assessment Program data dictionary, version 2.2. Canberra: DoHA.

DoHA 2011g. Home and Community Care Program Minimum Data Set 2009–10 annual bulletin. Canberra: DoHA.

DoHA 2011h. Transition Care Program guidelines. Canberra: DoHA.

DoHA 2011i. Review of the Aged Care Funding Instrument Report. Canberra: DoHA

DoHA 2011j. Community Packaged Care Guidelines 2011. Canberra: DoHA

DoHA 2011k. National Male Health. Canberra: DoHA. Viewed 25 June 2012, <http://www.health.gov.au/internet/main/publishing.nsf/Content/male-health-research>.

DoHA 2012a. Inquiry into dementia: early diagnosis and intervention. Canberra: Parliament of Australia, Viewed 6 July 2012,

<http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/dementia/index.htm>.

DoHA 2012b. Living Longer. Living Better. Aged Care Reform Package. Canberra: DoHA.

DoHA 2012c. Dementia made a national health priority area. Canberra: DoHA. Viewed 3 September 2012, <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr12-mb-mb082.htm>.

DoHA 2012d. Fact sheet: Living Longer. Living Better—tackling dementia. Canberra: DoHA. Viewed 3 July 2012, <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-aged-care-review-measures-factsheet-10.htm>.

DoHA 2012e. DBMAS: Dementia Behaviour Management Advisory Service. Canberra: DoHA. Viewed 15 July 2012, <http://dbmas.org.au/>.

DoHA 2012f. Medicare statistics: Table B1A—Medicare: number of services by financial year of processing by broad type of service. Canberra: DOHA. Viewed 18 June 2012, <http://www.health.gov.au/internet/main/publishing.nsf/Content/BF0C7BDDBB0840FBCA2579AD007E3F59/$File/tableb1a.pdf>.

DoHA 2012g. Pharmaceutical Benefits Scheme. Canberra: DoHA. Viewed 14 February 2012, <http://www.pbs.gov.au/pbs/home>.

DoHA 2012h. Pharmaceutical Benefits Scheme publications archive. Canberra: DoHA. Viewed 22 February 2012, http://www.pbs.gov.au/info/publication/schedule/archive>.

DoHA 2012i. Home and Community Care Program Overview. Canberra: DoHA. Viewed 10 February 2012, <http://www.health.gov.au/internet/main/publishing.nsf/content/hacc-index.htm>.

DoHA 2012j. National Respite for Carers Program: respite service providers' program manual. Canberra: DoHA.

DoHA 2012k. NRCP program reporting. Canberra: DOHA. Viewed 19 July 2012, <http://www.nrcpguide.infoxchange.net.au/book/export/html/63>.

DoHA 2012l. About the PBS, Frequently Asked Questions. Canberra: DoHA. Viewed 14 February 2012, <http://www.health.gov.au/internet/main/publishing.nsf/Content/health-pbs-general-faq.htm>

DoHA 2012m. Schedule of Pharmaceutical Benefits: effective 1 January 2012 to 29 February 2012. Canberra: Department of Health and Ageing. Viewed 23 March 2011, <http://www.pbs.gov.au/publication/schedule/2012/01/2012-01-01-general-schedule.pdf>

Dramé M, Lang P, Jolly D, Narbey D et al. 2012. Nursing home admission in elderly subjects with dementia: predictive factors and future challenges. JAMDA 13:83.e17–83.e20.

Draper B 2011. Understanding Alzheimer's & other dementias. Sydney: Longueville Books.

Draper B, Karmel R, Gibson D, Peut A, & Anderson P 2011. The Hospital Dementia Services Project: age differences in hospital stays for older people with and without dementia. International Psychogeriatrics 23(10):1649–58.

Driver JA, Beiser A, Au R, Kreger BE, Splansky GL, Kurth T et al. 2012. Inverse association between cancer and Alzheimer's disease: results from the Framingham Heart Study. British Medical Journal 344:e1442.

DVA (Department of Veterans' Affairs) 2010. Annual Reports 2009–2010. Repatriation Commission, Military Rehabilitation and Compensation Commission, and Department of Veterans' Affairs. Canberra: DVA.

Edwards B, Higgins DJ, Zmijewski N & Kingston M 2008. The nature and impact of caring for family members with disability in Australia. Canberra: Australian Institute of Family Studies.

EuroCoDe (European Collaboration on Dementia) 2009. Prevalence of dementia in Europe: report of WP 7 2006. Brussels: European Commission.

Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M et al. 2005. Global prevalence of dementia: a Delphi consensus study. The Lancet 366:2112–7.

First, MB, Frances A & Pincus HA 1995. DSM–IV handbook of differential diagnosis. 1st edn. Washington DC: American Psychiatric Press Inc.

Flinders University 2012. The Australian Longitudinal Study of Ageing. Canberra: Flinders University. Viewed 29 March 2012, <http://www.flinders.edu.au/sabs/fcas/alsa/>.

Ganguli M, Dodge HH, Shen C, Pandav RS & DeKosky T 2005. Alzheimer disease and mortality: a 15-year epidemiological study. Archives of Neurology 62:779–84.

Guehne U, Riedel–Heller S & Angermeyer MC 2005. Mortality in dementia: a systematic review. Neuroepidemiology 2005, 24:153–62.

Gühne U, Matschinger H, Angermeyer MC & Riedel-Heller SG 2006. Incident dementia cases and mortality results of the Leipzig Longitudinal Study of the Aged (LEILA75+). Dementia and Geriatric Cognitive Disorders 22:185–93.

Harvey RJ, Skelton-Robinson M & Rossor MN 2003. The prevalence and causes of dementia in people under the age of 65 years. Journal of Neurology, Neurosurgery and Psychiatry 74(9):1206–9.

Hoyert DL & Rosenberg HM 1999. Mortality from Alzheimer's disease: an update. National Vital Statistics Reports 47(20).

HRSCFCHY (House of Representatives Standing Committee on Family, Community, Housing and Youth) 2009. Who cares…? Report on the Inquiry into better support for carers. Canberra: Commonwealth of Australia.

IPA (International Psychogeriatric Association) 2010. Behavioural and psychological symptoms of dementia (BPSD) educational pack. Northfield, Illinois: IPA.

Ives DG, Samuel P, Psaty BM & Kuller LH 2009. Agreement between nosologist and cardiovascular health study review of deaths: implications of coding differences. Journal of the American Geriatrics Society 57:133–9.

Jorm AF, Dear KBG & Burgess NM 2005. Projections of future numbers of dementia cases in Australia with and without prevention. Australian and New Zealand Journal of Psychiatry 39(11–12):959–63.

Jorm AF, Korten AE & Henderson AS 1987. The prevalence of dementia: a quantitative integration of the literature. Acta Psychiatrica Scandinavica 76:465–9.

Karmel R, Gibson D, Anderson P, Wells Y & Duckett S 2012. Care trajectories through community and residential aged care services: disease effects. Ageing and Society. Epublished doi:10.1017/S0144686X11001231.

Kim Y & Schulz R 2008. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. Journal of Aging and Health 20(5):483–503.

Knapp M, Prince M, Albanese E, Banerjee S, Dhanasiri S, Fernandez JL et al. 2007. Dementia UK: the full report. London: Alzheimer's Society.

Koch T & Iliffe S 2010. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. BMC Family Practice 11:52.

Kuller LH & Ives DG 2009. Vital records and dementia. Neuroepidemiology 32:70–1.

LAMA Consortium 2009. Dementia Initiative national evaluation: overview and summary of main findings final report. Melbourne: LAMA Consortium.

Lobo A, Launer LJ, Fratiglioni L, Andersen K, Di Carlo A, Breteler MMB et al. 2000. Prevalence of dementia and major subtypes in Europe: a collaborative study of population-based cohorts. Neurology 54(11, supplement 5):S4–S9.

Luszcz M, Giles L, Eckermann S, Edwards P, Browne-Yung K, Hayles C et al. 2007. The Australian Longitudinal Study of Ageing: 15 years of ageing in South Australia. Adelaide: South Australian Department of Families and Communities. Viewed 29 March 2012, <http://www.flinders.edu.au/sabs/fcas-files/Documents/StudyOfAgeing.pdf>.

Mathers C & Leonardi M 2006. Global burden of dementia in the year 2000: summary of methods and data sources. Geneva: WHO.

McCullagh CD, Craig D, McIlroy SP, & Passmore AP 2001. Risk factors for dementia. Advances in Psychiatric Treatment 7:24–31.

McMurtray A, Clark DG, Christine D & Mendex MF 2006. Early-onset dementia: frequency and causes compared to late-onset dementia. Dementia and Geriatric Cognitive Disorders 21:59–64.

Medicare Australia 2012. Medicare Australia: statistics. Canberra: DoHA. Viewed 13 February 2012 <http://www.medicareaustralia.gov.au/provider/pbs/stats.jsp>.

Mendez MF 2006. The accurate diagnosis of early-onset dementia. The International Journal of Psychiatry in Medicine 36(4):401–12.

MetLife 2006. The MetLife study of Alzheimer's disease: the caregiving experience. Westport CT: MetLife Mature Market Institute.

Monash University 2010. Melbourne Longitudinal Studies on Healthy Ageing Program. Melbourne: Monash University. Viewed 25 June 2012, <http://www.med.monash.edu.au/sphc/haru/melsha/>.

Morris JC 1993. The Clinical Dementia Rating (CDR): current version and scoring rules. Neurology 43(11):2412–4.

Murray SA & Sheik A 2008. Care for all at the end of life. British Medical Journal 336:958–9.

NCCH (National Centre for Classification in Health) 2008. The international statistical classification of diseases and related health problems, 10th revision, Australian modification

(ICD-10-AM), Australian Classification of Health Interventions (ACHI) and Australian Coding Standards (ACS), 6th edition. Sydney: University of Sydney.

NCCH 2010. Australian coding standards for ICD-10-AM and ACHI, seventh edition. Sydney: NCCH.

NeuRA (Neuroscience Research Australia) 2012. Koori Growing Old Well Study. Randwick: NeuRA. Viewed 1 June 2012, <http://www.neura.edu.au/aboriginal-ageing>.

Norman PE, Flicker L, Almeida OP, Hankey GJ, Hyde Z & Jamrozik K 2009. Cohort profile: the Health in Men Study (HIMS). The International Journal of Epidemiology 38:48–52.

Phillips J, Pond D & Goode S 2011. Timely diagnosis of dementia: can we do better? Alzheimer's Australia Paper 24.

Pond D, Paterson N, Swain J, Stewart-Williams J & Byrne J 2011. Dementia identification, assessment and management in community-based primary health care: a review of the international literature 1995–2008. Newcastle: University of Newcastle.

Prince M, Bryce R & Ferri C 2011. World Alzheimer Report 2011: the benefits of early diagnosis and intervention. London: Alzheimer's Disease International (ADI).

Productivity Commission 2011. Caring for older Australians: Productivity Commission Inquiry Report No. 53. Canberra: Productivity Commission.

Quantum Consulting Australia 2011. Review of the National Framework for Action on Dementia 2006–10: summary of final report. Perth: Quantum Consulting Australia.

Rait G, Walters K, Bottomley C, Petersen I, Iliffe S & Nazareth I 2010. Survival of people with clinical diagnosis of dementia in primary care: cohort study. British Medical Journal Online First 341:c3584.

Robinson AL, Emden CG, Elder JE & Lea EJ 2008. Multiple views reveal the complexity of dementia diagnosis. Australasian Journal on Ageing 27(4):183–8.

Rosenwax LK & McNamara BA 2006. Who receives specialist palliative care in Western Australia and who misses out. Palliative Medicine 20:439–45.

Runge C, Gilham J & Peut A 2009. Transitions in care of people with dementia: a systematic review. Sydney: Dementia Collaborative Reseach Centres UNSW.

Sachdev PS, Lammel A, Trollor JN, Lee T, Wright MJ, Ames D et al. 2009. A comprehensive neuropsychiatric study of elderly twins: the Older Australian Twins Study. Twin Research and Human Genetics 12:573–82.

Sachs GA, Shega JW & Cox-Hayley D 2004. Barriers to excellent end-of-life care for patients with dementia. Journal of General Internal Medicine 19:1057–63.

Sahyoun NR, Lentzner H, Hoyert D & Robinson KN 2001. Trends in causes of death among the elderly. Centers for Disease Control and Prevention: Aging Trends No.1.

Sampson EL 2010. Palliative care for people with dementia. British Medical Bulletin 96:159–74.

Sax Institute 2012. The 45 and Up Study. Sydney: Sax Institute. Viewed 28 March 2012, <http://www.45andup.org.au/>.

Schofield H, Murphy B, Herrman HE, Bloch S & Singh BS 1998. Carers of people aged over 50 with physical impairment, memory loss and dementia: a comparative study. Ageing and Society 18:355–69.

Schofield V 2001. Rituals of visiting people with dementia in residential care. Australasian Journal on Ageing 20:187–91.

Seeher K, Withall A & Brodaty H (eds) 2011. The dementia research mapping project, the 2010 update: final report. Sydney: Dementia Collaborative Research Centre, University of New South Wales.

Simons LA 2011. The Dubbo Study. An Australian Study of Healthy Ageing. Viewed 5 June 2012, <http://dubbostudy.org>.

Simons LA, Simons J, McCallum J & Friedlander Y 2006. Lifestyle factors and risk of dementia: Dubbo Study of the elderly. Medical Journal of Australia 184:68–70.

Slade T, Johnston A, Oakley Browne MA, Andrews G & Whiteford H 2009a. 2007 National Survey of Mental Health and Wellbeing: methods and key findings. Australian and New Zealand Journal of Psychiatry 43:594–605.

Slade T, Johnston A, Teesson M, Whiteford H, Burgess P, Pirkis J & Saw S 2009b. The Mental Health of Australians 2. Report on the 2007 National Survey of Mental Health and Wellbeing. Canberra: Department of Health and Ageing.

Smith K, Flicker L, Lautenschlager NT, Almeida OP, Atkinson D, Dwyer A et al. 2008. High prevalence of dementia and cognitive impairment in Indigenous Australians. Neurology 71:1470–3.

Speechly CM, Bridges-Webb C & Passmore E 2008. The pathway to dementia diagnosis. Medical Journal of Australia 189(9):487–9.

Teno JM, Weitzen S, Fennell ML & Mor V 2001. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? Journal of Palliative Medicine 4(4):457–64.

University of Newcastle 2007. The Australian Longitudinal Study on Women's Health. Newcastle: University of Newcastle. Viewed 28 March 2012, <http://www.alswh.org.au>.

UNSW (University of New South Wales) 2012. Memory and Ageing Study. Sydney: UNSW, viewed 25 June 2012, <http://www.med.unsw.edu.au/psychweb.nsf/page/brainage_memory>.

UQ (University of Queensland) & UWA (University of Western Australia) 2012. Men, women and ageing. Viewed 25 June 2012, <http://www.menwomenandageing.org/index.html>.

van der Steen JT 2010. Dying with dementia: what we know after more than a decade of research. Journal of Alzheimer's Disease 22:37–55.

WAIMR (Western Australian Institute for Medical Research) 2012. Maintaining the Health in Men Study. Perth: WAIMR. Viewed 25 June 2012, <http://www.wacha.org.au/hims.html>.

Werner P, Stein-Shvachman I & Korczyn AD 2009. Early onset dementia: clinical and social aspects. International Psychogeriatrics 21(4):631–6.

WHO (World Health Organization) 2004. The International Statistical Classification of Diseases and Related Health Problems, 10th revision, (2nd edn). Geneva: WHO.

WHO 1992. International Statistical Classification of Diseases and Related Health Problems, 10th revision. Vol. 1. Geneva: WHO.

WHO Collaborating Centre for Drug Statistics Methodology 2011. Guidelines for ATC classification and DDD assignment 2012. Oslo: WHO

WHO in conjunction with ADI 2012. Dementia: a public health priority. Geneva: WHO.

Wilkinson D, Sganga A, Stave C & O'Connell B 2005. Implications of the Facing Dementia Survey for health care professionals across Europe. International Journal of Clinical Practice 59(Suppl. 146):27–31.

Women's Health Australia 2007. Technical Report 29: The Australian Longitudinal Study on Women's Health. Newcastle: University of Newcastle and University of Queensland. Viewed 19 July 2012, <http://www.alswh.org.au/Reports/Technical/Report29ALSWH.pdf>.

Xie J, Brayne C, Matthews F & the Medical Research Council Cognitive Function and Ageing Study collaborators 2008. Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. British Medical Journal Online First 336:258.

45 and Up Study collaborators 2008. Cohort profile: the 45 and Up Study. International Journal of Epidemiology 37(5):941–7.

List of tables

List of figures