Dementia in Australia

National data analysis and development

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Any enquiries about or comments on this publication should be directed to:

Ann Peut or John Goss
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Phone: (02) 6244 1108 or (02) 6244 1151
Email: ann.peut@aihw.gov.au or john.goss@aihw.gov.au

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Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACCMIS	Aged and Community Care Management Information System
ACFI	Aged Care Funding Instrument
ADAS-Cog	Alzheimer's Disease Assessment Scale, cognitive subscale
ADL	activity of daily living
AGECAT	Automated Geriatric Examination for Computer Assisted Taxonomy
AIDS	acquired immunodeficiency syndrome
AIHW	Australian Institute of Health and Welfare
ALSWH	Australian Longitudinal Study on Women's Health
ATC	Anatomical Therapeutic Chemical
BEACH	Bettering the Evaluation and Care of Health
BPSD	behavioural and psychological symptoms of dementia
CACP	Community Aged Care Packages
CAMDEX	Cambridge Examination for Mental Disorders of the Elderly
CCRC	Commonwealth Carer Respite Centre
CDR	Clinical Dementia Rating
CI	confidence interval
CIBIC	Clinician's Interview-Based Impression of Change
CSHA	Canadian Study of Health and Aging
CSI	Caregiver Strain Index
CSTDA	Commonwealth-State/Territory Disability Agreement
CT	computed tomography
CURF	confidentialised unit record file
DALY	disability-adjusted life year
DESP	Dementia Education and Support Program
DISMOD	DISease MODels
DoHA	Australian Government Department of Health and Ageing
DSM	Diagnostic and Statistical Manual of Mental Disorders
EACH	Extended Aged Care at Home
EURODEM	European Community Concerted Action on the Epidemiology and Prevention of Dementia
fMRI	functional magnetic resonance imaging
GDS	Global Deterioration Scale

GHQ	General Health Questionnaire
GP	general practitioner
GPSCU	General Practice Statistics and Classification Unit
HACC	Home and Community Care
HIV	human immunodeficiency virus
IADL	instrumental activity of daily living
IAM	Institute for Algorithmic Medicine
ICD	International Statistical Classification of Diseases and Related Health Problems
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification
ICF	International Classification of Functioning, Disability and Health
ICPC-2	International Classification of Primary Care, 2nd edition
IEC	International Electrotechnical Commission
ISO	International Standards Organisation
MBS	Medicare Benefits Schedule
MCI	mild cognitive impairment
MDS	minimum data set
METeOR	Metadata Online Registry
MMHA	Mini Mental Health Assessment
MMSE	Mini-Mental State Examination
MRI	magnetic resonance imaging
NCCH	National Centre for Classification in Health
NCSDD	National Community Services Data Dictionary
NHADD	National Housing Assistance Data Dictionary
NHDD	National Health Data Dictionary
NHMD	National Hospital Morbidity Database
NHS	National Health Survey
NMDS	national minimum data set
NRCP	National Respite for Carers Program
OECD	Organisation for Economic Co-operation and Development
PATH	Personality and Total Health
PBS	Pharmaceutical Benefits Scheme
RCS	Resident Classification Scale
RPBS	Repatriation Pharmaceutical Benefits Scheme
RSE	relative standard error
SAND	Supplementary Analysis of Nominated Data
SDAC	Survey of Disability, Ageing and Carers
SPECT	single photon emission computed tomography

WHO	World Health Organization
YLD	years lost due to disability
YLL	years of life lost (due to premature mortality)

Symbols

*	estimate has a RSE of 25% to 50% and should be used with caution
**	estimate has a RSE greater than 50% and is considered too unreliable for general use
—	when used in a table—nil or rounded to zero (including null cells)
. .	when used in a table—not applicable
n.p.	when used in a table—not published by the data source
nec	not elsewhere classified
nfd	not further defined
nos	not otherwise specified

Overview

Dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. The International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision (WHO 1992a:312) defines dementia as:

> *a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.*

Dementia is not a single specific disease and therefore affects people differently and with varying impact of their families and carers. Dementia is not a natural part of ageing, although most people with dementia are older. After the age of 65 the likelihood of living with dementia doubles every five years and it affects 24% of those aged 85 and over (Henderson & Jorm 1998).

Because Australia's population is ageing, there has been growing recognition that dementia represents a significant challenge to health, aged care and social policy. This report estimates that the number of people with dementia will grow from over 175,000 in 2003 to almost 465,000 in 2031, assuming the continuation of current dementia age-specific prevalence rates. Governments at national and state level are developing responses to the challenges posed by dementia, through initiatives such as the Australian Government's *Helping Australians with dementia, and their carers – making dementia a National Health Priority*.

In 2004 the Australian Government Department of Health and Ageing commissioned the Australian Institute of Health and Welfare to undertake the present study to provide a profile of the Australian population who experience dementia and to review the availability and quality of data about dementia. An important objective of the report is to provide a guide for improving national dementia data by identifying possible data elements that would be suitable for inclusion in a range of data collection contexts. Recommendations for these data elements are presented as areas of information and options for potential data element sets that are considered vital to collecting relevant, informative and comparable data on dementia prevalence estimates, management and outcomes.

Integrating data about dementia

There is no single source of data which can be relied on for estimates about the prevalence of dementia, the characteristics and needs of those with dementia or their carers, and the full range of services and treatments that people with dementia are receiving. A range of data sources has been used in this report to ensure that the most significant and available data was brought to bear on these questions. The multiplicity of data sources gives breadth to the report, and also provides opportunities for confirming findings using data from different sources and from different perspectives. The report draws these data together so that we can achieve a better understanding of dementia in the Australian population than would be possible from any single source.

The major data sources used include:

- Survey of Disability, Ageing and Carers (SDAC)

- National Hospital Morbidity Database
- Aged Care Assessment Program
- Bettering the Evaluation and Care of Health
- Medical Benefits Schedule
- Pharmaceutical Benefits Scheme
- National Respite for Carers Program
- Census data from the Community Aged Care Packages and Extended Aged Care at Home programs
- Dementia Education and Support Program.

People with dementia and their carers

Almost 175,000 people had dementia in Australia in 2003, of whom 64% were female and 81% were aged 75 or older (see Chapter 4). Since dementia prevalence is strongly age-related, the number of cases of dementia is expected to increase as the population ages to almost 465,000 by 2031. There are about 37,000 new cases of dementia each year of which 23,000 are female and 14,000 male. Alzheimer's disease was the most common diagnosis of dementia, generally followed by vascular dementia.

Dementia may be classified as *mild* in about 96,000 people (55%), *moderate* in 52,000 people (30%) and *severe* in 26,000 (15%). Most people with mild dementia are living in households and most people with moderate or severe dementia are in cared accommodation.

Most of the 'burden of disease' caused by dementia is due to disability rather than premature death, with disability accounting for about three-quarters of the total disease burden in 2003.

Characteristics of people with dementia (see Chapter 5)

Given the increasing prevalence of dementia with age and longer life expectancy for females, it is not surprising that people with dementia are mostly older women—more than half of the SDAC respondents with dementia, and more than half of people with dementia who sought an aged care assessment or who receive Community Aged Care Packages were women aged 75 years or older. While the majority of people with dementia were born in Australia, a significant minority were born overseas in non-English-speaking countries (16% of SDAC respondents and 18% of clients receiving an aged care assessment).

According to the SDAC, the majority of people with dementia live in cared accommodation including residential aged care facilities. The majority of people with dementia living in households lived with others (usually family) rather than living alone. A smaller proportion of those with dementia lived alone than of those without dementia.

People with dementia have higher levels of dependence in instrumental activities of daily living (and to a lesser extent, higher dependence in activities of daily living) than those without dementia. Almost all people with dementia required assistance with at least one activity (and with at least one personal activity). Those with dementia experience more activity limitations than those without dementia and a larger proportion of people with dementia require assistance with each type of activity than those without dementia.

The activity with which least assistance is required is communication—however, a larger proportion of those with dementia required this type of assistance compared with those without dementia.

The majority of people with dementia also needed assistance with activities such as making decisions or thinking through problems, coping with feelings or emotions, relationships, managing their behaviour or with cognitive or emotional tasks. Additionally, multiple behavioural symptoms (including aggression) appear to be common; a significant proportion of care recipients with dementia experience moderate to severe behavioural symptoms and a significant proportion of their carers experience distress associated with these symptoms.

Among the older population, dementia is more likely than other health conditions to be associated with a severe or profound limitation in self-care, mobility or communication, to be a main disabling condition and to be associated with multiple health conditions. People with dementia reported the third highest mean number of health conditions (5.3 conditions), after those with depression (5.5 conditions) and those with phobic and anxiety disorders (5.3 conditions).

Carers of people with dementia (see Chapter 6)

Carers are family members or friends who provide support to children or adults who have a disability, mental illness, chronic conditions or are frail aged and unable to look after themselves (DoHA 2002b). This ranges from emotional support through financial and practical assistance to supervision and assistance with personal care and other activities for extended periods.

Informal sources of care provided much of the assistance received by people with dementia living in households. The majority of people with dementia living in households have a carer, particularly those who have a more severe level of disability or dependency. Those with dementia were more likely to have a carer than those without dementia.

The review and analysis of data about carers in this report supports the conclusion of Schofield et al. (1996:160) that 'There is limited knowledge about caregivers in Australia in general. Comprehensive data on the prevalence of caregiving are not yet available. Most studies of carers have tended to be small scale and unrepresentative, with study samples often drawn from a client list of a major service provider'.

The only national survey to collect data about carers (SDAC) underestimates the numbers of people with dementia and consequently the numbers of their carers. According to the 2003 SDAC there were approximately 23,200 carers providing assistance to 25,800 people with dementia living in the same household. The SDAC also indicates that approximately 65% of carers of people with dementia live with the person they are caring for. This suggests that there may be approximately 35,900 carers of people with dementia in Australia identified according to Australian Bureau of Statistics (ABS) definitions of a carer. This equates to about four carers for every three people with dementia living in households who receive informal assistance (who are mostly severely or profoundly disabled).

Carers of people with dementia are mostly older women—however, a significant proportion of care is also provided by men. Around three-quarters of carers were married or in de facto relationships. Carers of people with dementia were more likely to live in the same household with the recipient with dementia: 39% of co-resident carers and 65% of co-resident primary carers were a spouse or partner, and 46% of co-resident carers and 30% of co-resident primary carers were children or children-in-law (SDAC).

Although the majority of carers of people with dementia are born in Australia and mainly speak English at home (or speak English as a first language), there is a significant proportion of carers born overseas in non-English-speaking countries.

Most of the available data indicates that carers of people with dementia were either not working or had reduced their hours of work. This reflects partly the age of carers and partly the demands associated with caring for someone with dementia. Consistent with this, government pensions or allowances were the main source of cash income for the majority (53%) of co-resident carers (SDAC).

All co-resident primary carers provided assistance with one or more core daily activities to their main recipient with dementia—91% provided assistance with communication, 91% provided assistance with mobility, and 78% provided assistance with self-care (SDAC). Furthermore, all carers provided assistance with health care, paperwork, housework and meal preparation; and a large majority provided assistance with transport (96%); property maintenance (87%); and cognition or emotion (91%).

Some studies noted that over half of the care recipients with dementia were unable to be left alone (Schofield et al. 1998b), and data from the 2003 SDAC show that around 65% of co-resident primary carers spend 40 hours or more each week actively caring for or supervising the care recipient with dementia.

The mean or median duration of care is often reported to be less than five years, reflecting the late age of onset of dementia and the fact that increased carer burden is a risk factor for entry into residential care. Methodological and study design differences mean that published estimates of the duration of the caring role vary widely. Data from the 2003 SDAC show that the majority of co-resident primary carers (52%) had been caring for their main recipient with dementia for between one and four years. However, consistent with Schofield et al. (1998b), over one-fifth (22%) had been caring for their main recipient with dementia for more than 10 years.

Most carers report a sense of duty to care—a large proportion reported that they provide care because they felt an emotional obligation to take on the role (52%) or that it was a family responsibility (48%) (SDAC). Only 26% of co-resident primary carers reported feeling satisfied due to the caring role and a significant proportion (46%) reported at least one adverse effect due to the caring role. These adverse effects included frequently feeling angry or resentful about their caring role, having been diagnosed with a stress-related illness, feeling weary or lacking energy or frequently feeling worried or depressed because of the caring role. Most Australian studies have reported a link between carer burden and the behavioural and psychological symptoms associated with dementia.

The majority (61%) of co-resident primary carers reported that the caring role had at least one adverse main effect on their relationship with other family members and friends resulting from losing touch with friends and having less time to nurture other relationships (SDAC). But over half of co-resident primary carers (52%) considered that their relationship with the care recipient was unaffected by the care recipient's dementia.

Almost half (48%) of co-resident primary carers stated that they did not have a fall-back carer (SDAC). Around 52% of these carers reporting needing or wanting an improvement or more support in areas such as respite care, financial assistance, physical assistance, emotional support, improvement in their own health or other areas of assistance.

Service use and expenditure

People with dementia and their carers use a substantial amount of health and aged care services (Chapter 7).

In 2003, 83,000 Australians experienced dementia of such severity that they always or sometimes needed assistance with basic daily activities.

- Approximately 68,000 permanent residents with dementia in aged care facilities collectively used 24.7 million residential aged care bed-days.
- People with dementia accounted for 1.4 million patient days for 82,800 hospital separations.
- An estimated 450,000 GP–patient encounters, 82,500 GP-ordered pathology services, 42,000 referrals by GPs to other health care providers and 10,000 GP-ordered imaging services in 2003 were for the diagnosis and management of dementia.

Traditionally, expenditure on health and welfare services provided for dementia has reflected the total expenditure incurred for people with dementia as their main health condition, regardless of the cost impact of any other health conditions experienced by the individual. This report presents the results of a different approach to estimating expenditure that takes account of the presence of other health conditions. This approach results in estimates of expenditure that can be attributed to the dementia condition (see Chapter 8). Based on this approach, total health and welfare system expenditure for dementia in 2003 is estimated at $1.4 billion:

- The majority is in the residential aged care sector where $993 million is attributed to dementia.
- Admitted patient expenditure of $149.3 million, pharmaceutical expenditure of $72.8 million and out-of-hospital medical service expenditure of nearly $20 million are also attributed to dementia.
- Expenditure for community care use by people with dementia, including Home and Community Care, Extended Aged Care at Home, Veterans' Home Care, Community Aged Care Packages and Aged Care Assessment Program is estimated to be $135 million.

The total expenditure for dementia is projected to increase by 225% between 2003 and 2030–31.

While service use can be measured and reported, non-use of potentially valuable service support can be more difficult to identify. Yet service non-use can be an important indicator of the need for improvements in aspects of program design and delivery such as information strategies, access points, intervention design, and so on. For example, given the high levels of stress experienced by those caring for people with dementia it is significant that the majority of co-resident primary carers of people with dementia (70%) reported that they had never used respite care (SDAC). Furthermore, 57% of primary carers stated that they had never received respite care and did not need or want it. Similarly, 73% of relevant Aged Care Assessment Program clients with dementia had not used it. Brodaty et al. (2005) found that 84% of carers in their study did not use respite services, and only 35% of those carers reported needing this service. Perceived lack of need was reported by 65% of carers as the principal reason for non-use of respite services, followed by care recipient's resistance to accepting help from services (12%), not having enquired (9.1%) and lack of knowledge (7.6%).

Review of dementia data in Australian collections

In Australia, information about people with dementia, their carers and their use of health and care services, is collected through a number of administrative (or service by-product) data collections and population and client surveys. The report briefly describes 19 relevant data sources and the type of data collected which is relevant to dementia (see Chapter 3):

Administrative data collections	Surveys
• Dementia Education and Support Program	• National Health Survey
• Medicare Benefits Schedule	• Survey of Disability Ageing and Carers
• Pharmaceutical Benefits Scheme	• Bettering the Evaluation and Care of Health
• National Hospital Morbidity Database	• The Australian Longitudinal Study on Women's Health
• Aged Care Assessment Program	• Australian Longitudinal Study of Ageing
• Home and Community Care	• Sydney Older Person's Study
• Community Aged Care Packages	• Canberra Longitudinal Study of Ageing
• Extended Aged Care at Home	• PATH Through Life Project
• Residential Aged Care	• Dubbo Study of the Health of the Elderly
• National Respite for Carers Program	

Chapter 11 examines and compares dementia-relevant data items in more detail across the major relevant collections. These data items cover the following themes:

- How people with dementia and cognitive impairment are identified (e.g. through data items such as diagnosis status and dementia type)
- Severity of dementia and cognitive impairment
- Extent of behavioural and psychological symptoms of dementia
- Environmental factors (e.g. presence and availability of carers, services and treatments).

Existing national data collections include a wide array of information which is relevant to the identification, treatment and care of people with dementia and the support of carers and family members. However, in many areas there is inconsistency between collections in terms of what type of data is collected, and there is only limited comparability of definitions and value domains.

Based on the analysis undertaken for this report, the limitations and strengths of the data analysed in respect of dementia are summarised (Chapter 9):

Limitations	Strengths
• Poor or inconsistent identification of dementia in a number of relevant collections	• A considerable amount of relevant data is collected
• Non-reporting of collected data	• Formal diagnosis or assessment of dementia in a number of collections
• Non-collection of some relevant data	• The inclusion of cared accommodation in the SDAC contributes strongly to our ability to identify people with dementia in residential aged care
• Little national longitudinal or linked data	
• Study design issues such as sample size and self- or proxy-reporting	
• Limited national data about carers of people with dementia	

Improving dementia data

Four major strategies would contribute to the improvement of data about dementia in Australia:

- better and earlier diagnosis of dementia

- improved consistency of identification of people diagnosed with dementia in all data collections, including through consistent use of agreed classifications and adherence to data standards
- agreement about the extent of information to be collected
- a change in focus from services-focused data to person-focused data through support and encouragement of data linkage efforts and/or the collection and analysis of longitudinal data.

Definition and classification of dementia

A number of international classifications assist with identifying and classifying dementia (see Chapter 2). These include the ICD, which approaches dementia from a disease perspective, attempting to identify the underlying aetiology; and the Diagnostic and Statistical Manual of Mental Disorders and International Classification of Functioning, Disability and Health (ICF) which both approach dementia from a perspective of functional outcomes. The International Classification of Primary Care is used as a classification for general practice or primary care, wherever applicable.

Most existing Australian data sources define, diagnose, classify and/or measure dementia using one or more of these classifications. Estimates of the prevalence of dementia in a population are critical for the planning, funding and provision of appropriate treatment and care of people with dementia. Prevalence estimates vary with the definition and diagnostic criteria used by the classification. At the level of the individual, the use of different diagnostic criteria, and the utility and validity of the screening and assessment tools used, affect the likelihood of receiving a diagnosis, and consequently have an impact on the person's access to appropriate information, treatment and care options.

While analysis of currently available data is constrained by the definitions and classifications used in existing data sources, future data development in respect of dementia needs to be supported by the use of common definitions and classifications of dementia and its outcomes.

This report recommends that **both** the ICD and ICF should be used in Australia for this purpose. Both the ICD and ICF belong to the family of international classifications developed by the World Health Organization (WHO) for application to various aspects of health. The WHO family of international classifications provide a framework to code a wide range of information about health (e.g. diagnosis, functioning and disability, reasons for contact with health services) and uses a standardised common language permitting communication about health and health care across the world in various disciplines and sciences (WHO 2001:3).

Health conditions (e.g. diseases, disorders, injuries) are generally classified using the ICD, which provides diagnosis codes for diseases, disorders or other health conditions. Functioning and disability associated with health conditions are classified using the ICF. The ICD and ICF enable consistent collection of information about diagnosis as well as human functioning. The ICD and ICF are therefore complementary, and WHO encourages the use of these classifications together to provide a more meaningful and complete picture of the health needs of people and populations (WHO 2001:4).

Proposed data elements for data collection about dementia

The development of data about dementia should occur in a way which is consistent with established principles for data development and adheres to recognised data standards (see

Chapter 10). The development of the proposed data elements recommended by this report (see Chapter 12) was overseen and guided by the National Dementia Data Analysis and Development Reference Group. The Reference Group considered the relative importance of the data elements for supporting policy and practice designed to assist people with dementia and their carers. In addition, the Reference Group took account of other data development criteria such as feasibility of collection and consistency with existing data standards. The recommended data elements were developed with reference to both existing data elements collected in Australia and priorities in dementia research.

The menu of data elements is focused on elements of relevance to dementia or cognitive decline. The proposed data elements are grouped within the following categories:

1. Identification of cognitive impairment and dementia
2. Cognitive impairment and dementia diagnosis information
3. Current behaviour related to dementia and its impact on care
4. Coexisting health conditions
5. Impact of caring
6. Reporter details.

Elements about the sociodemographic characteristics of people with dementia and their carers are assumed to be already included in relevant collections and they are not proposed here. Similarly, data elements about activity and participation limitations (e.g. mobility, self-care, shopping) are clearly critical for assessing the care and support needs of people with dementia and their family and carers. However, the scope of this project did not extend to this area of data collection and the report does not propose specific data elements. The ICF provides a well-developed classificatory framework for the collection of data items about functioning.

Framework for proposed dementia data elements

<table>
<tr><td rowspan="4">**6 Reporter details**
6.1: Reporter status
6.2: Relationship of proxy reporter to person of interest</td><td colspan="2">**1 Identification of cognitive impairment and dementia**
1.1: Identification of cognitive impairment
1.2: Identification of a diagnosis of dementia</td></tr>
<tr><td>**2 Cognitive impairment and dementia diagnosis information**
2.1: Type of dementia
2.2: Date of first formal diagnosis
2.3: Medical professional who first identified cognitive impairment or diagnosed dementia
2.4: Severity of dementia
2.5: Treatment with medication for cognitive impairment due to dementia
2.6: Treatment with medication for behavioural and psychological symptoms of dementia</td><td>**3 Current behaviour related to dementia and its impact on care**
3.1: Nature of current challenging behaviour
3.2: Frequency of occurrence of current challenging behaviour
3.3: Duration of episodes of current challenging behaviour
3.4: Disruption due to current challenging behaviour
3.5: Stress experienced as a result of current challenging behaviour</td></tr>
<tr><td colspan="2">**4 Coexisting health conditions**
4.1: Coexisting health conditions</td></tr>
<tr><td colspan="2">**5 Impact of caring**
5.1: Impact of care measure</td></tr>
</table>

Three dementia data collection levels are proposed, which differ in terms of the amount and complexity of elements included:

1. **Essential data elements**: to provide an estimate of the number of people with dementia or cognitive impairment. This level is appropriate for collections or surveys that do not necessarily focus on dementia, include only a relatively small number of people with dementia, or do not require more detailed information about the dementia syndrome for effective and appropriate service delivery.
2. **Highly desirable data elements**: to provide more detailed information about people with dementia, which may be required for appropriate treatment, care and services. This level is appropriate for collections which require more detailed information about the condition, for example programs that provide services to a population that includes a proportion of people with dementia such as the Aged Care Assessment Program and the National Respite for Carers Program.
3. **Desirable data elements**: to provide more detailed information about people with dementia and their carers, which may be required for appropriate treatment and care management. This level is appropriate for collections focusing on the population of Australians with dementia, for example programs that deliver dementia-specific services or deliver services to a population that includes a significant proportion of people with dementia.

The use of any of the levels depends on the underlying purpose, nature and context of the collection. For a comprehensive picture of the population experiencing dementia, it is recommended that the whole suite of elements be used.

Section 1: Dementia definition, classifications and data sources

1 Introduction

1.1 Background

Dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. Dementia is not a single specific disease. It affects people differently, and the impact on their carers and families also varies. Dementia is not a natural part of ageing, although most people with dementia are older. After the age of 65 the likelihood of living with dementia doubles every five years and it affects 24% of those aged 85 and over (Henderson & Jorm 1998).

Dementia is the most significant neurological disorder experienced by those over 80. It is the greatest single contributor to burden of disease due to disability at older ages as well as the second greatest single contributor to the cost of care in residential aged care after incontinence. The service needs experienced by someone with dementia may vary greatly with the severity of the cognitive impairments (AIHW 2004f). People with dementia eventually become dependent on their care providers in most or all areas of daily living placing considerable strain on those who care for them.

Because Australia's population is ageing, there has been growing recognition that dementia represents a significant challenge to health, aged care and social policy. In the 20 years to 2024, the proportion of the population aged over 65 is projected to increase from 13% to 20%. The number and proportion of people in the 'older old' age groups (85 years and over) are expected to rise even more rapidly, more than doubling from 298,300 (1.5%) to 725,300 (2.9%) (AIHW 2005b:138).

The number of people with dementia will grow correspondingly from over 175,000 in 2003 to almost 465,000 in 2031, assuming the continuation of current dementia prevalence rates. In recognition of the challenges this presents to governments, families and health and care providers, the Australian Government introduced the *Helping Australians with dementia, and their carers – making dementia a National Health Priority* in the 2005 Federal Budget. This $320.6 million over five years funding package will support people with dementia and their carers through three measures:

- *Dementia – A National Health Priority*—for additional research, improved care initiatives and early intervention programs for people with dementia
- *Extended Aged Care at Home (EACH) Dementia Packages*—for 2,000 new EACH community care places dedicated to helping people with dementia remain at home and in their community
- *Training to Care for People with Dementia*—for dementia-specific training for aged care workers and community workers.

Caring for people with dementia is a responsibility and a challenge for all levels of government. Looking to the future, Australian health ministers noted that within 10 years dementia is predicted to be the major cause of disability for Australians, overtaking cardiovascular disease, cancer and depression. Ministers agreed that an action program is necessary to address this health problem and endorsed a *National Framework for Action on Dementia* in April 2006. The development of the framework was guided by a nation-wide consultation that included the combined input of governments, health care providers, peak bodies, and people with dementia, their families and carers. The framework focuses on outcomes that can best be achieved nationally, with the cooperation of the Australian, state and territory governments. Consultations culminated in a national forum attended by around 70 stakeholders. This forum supported five key priority areas for action which health ministers had previously identified:

- research
- information and education
- access and equity
- quality, integration and continuum of care
- workforce and training.

1.2 Purpose of this report

In 2004 the Australian Government Department of Health and Ageing (DoHA) commissioned the Australian Institute of Health and Welfare (AIHW) to undertake the present study to provide a profile of the Australian population who experience dementia and to review the availability and quality of data. This would support research, policy planning and program monitoring and evaluation. An important objective of the report is to provide a guide for improving national dementia data by identifying possible data elements that would be suitable for possible inclusion in a range of data collection contexts. Recommendations for these data elements are presented as areas of information and options for potential data element sets that are considered vital to collecting relevant, informative and comparable data on dementia prevalence estimates, management and outcomes.

This report supports work undertaken in relation to the Key Priority Area of Research in the *National Framework for Action on Dementia*. Among the priorities for action are to research the projected prevalence of dementia, including prevalence among groups with diverse needs, and to design and implement uniform and effective data standards and systems which can be used in all jurisdictions and which ensure dementia data elements are included in key minimum data sets (MDS). The data analysis included in this report is, however, undertaken at the national level only.

The report will also support and complement Australian Government initiatives in respect of dementia research and data development activity occurring in community aged care and residential aged care programs. This work has been conducted alongside comparable work in relation to incontinence (AIHW 2006a) and community care data alignment to ensure cross-fertilisation and comparable outcomes.

Any data development activity in relation to dementia data needs to recognise that there are very real issues that affect its collection and quality. There is currently no cure for dementia and treatment approaches are few. Diagnosis is difficult, especially since dementia is a secondary complication for a number of other diseases, for example stroke and other cardiovascular diseases, diabetes, Parkinson’s disease and acquired immunodeficiency syndrome (AIDS). In this context, and particularly while there continues to be stigma associated with dementia, there may be little incentive to seek and/or provide a diagnosis. A diagnosis may also not be obtained while any problems remain manageable, or the symptoms of dementia are masked by symptoms of comorbid health conditions. While these factors remain, it is possible that the availability and quality of data about early stage dementia will continue to be poor. In other words, improving dementia data is not simply a technical process, but will also depend on changes in diagnosis and assessment practices.

1.3 Structure of this report

The **introductory section** includes this introduction and Chapters 2 and 3:

- Chapter 2 describes the definitions and classifications of dementia used in clinical and epidemiological research settings. It also discusses some of the problems encountered in identifying people with dementia.
- Chapter 3 reviews the available data sources and summarises their scope, purpose and content, together with a brief description of data elements related to dementia.

Section 2 provides a profile of dementia in Australia. This section includes the following chapters:

- Chapter 4 reviews Australian and international prevalence estimates of dementia, and discusses differences in prevalence by age, sex, dementia severity and residential setting. The chapter provides estimates of the incidence of dementia, and also estimates the impact of dementia on the quality of life for people in the community and in residential aged care. These estimates are projected to 2030–31.
- Chapter 5 examines some of the relevant characteristics of people with dementia, including their living arrangements and carer support, their level of disability, behavioural and psychological symptoms and need for assistance.
- Chapter 6 examines the data available about carers of people with dementia, including the impact of their caring role on their physical and social wellbeing.
- Chapter 7 explores use of health and aged care services by people with dementia. It includes newly derived estimates of the dependency profile of people with dementia in residential aged care.
- Chapter 8 discusses the expenditure associated with dementia, including estimates of medical, pharmaceutical, hospital and aged care expenditure. Costs are projected to 2030–31.
- Chapter 9 outlines the strengths and limitations of available data as revealed by the previous chapters.

Section 3 of the report focuses on developing dementia data standards. It includes the following chapters:

- Chapter 10 discusses principles of data development and describes key data standards that should be adhered to in developing data recommendations.
- Chapter 11 describes and compares dementia-related data elements currently collected in Australian data collections.
- Chapter 12 recommends possible data elements relevant to dementia for inclusion in data collections.

2 Definition, diagnosis and classification of dementia

The way in which dementia is defined and classified has implications for the accuracy with which we can estimate the prevalence of dementia in the community. The application of diagnostic guidelines which accompany classificatory systems has consequences for the diagnosis, treatment and care of individuals as well as for statistical measurement, for example through the failure to recognise and identify particular types of dementia. Improving the quality and consistency of dementia data must therefore begin with the use of agreed definitions and classifications. This chapter discusses how dementia and its outcomes are defined and classified within relevant international classifications. It briefly examines some of the complications for defining and classifying dementia and describes some of the common screening tests and assessment tools used to identify and diagnose dementia.

2.1 Describing dementia

The term 'dementia' is derived from the Latin word *demens* meaning 'without mind'. Today, dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. These declines[1] in mental function may manifest themselves through different symptoms at various times and often relate to the cause of dementia (see Alzheimer's Australia 2005b). In the early stages of dementia, difficulty may be experienced with familiar tasks such as shopping, driving or handling money. As dementia progresses, more basic or core activities of daily living such as self-care (e.g. eating, bathing, dressing) are affected. More specifically, the cognitive, psychiatric and behavioural manifestations of dementia may include:

- memory problems, especially for recent events (long-term memory usually remains in the early stages)
- communication difficulties through problems with speech and understanding language
- confusion, wandering, getting lost
- personality changes and behaviour changes such as agitation, repetition, following
- depression, delusions, apathy and withdrawal.

There are over 100 illnesses and conditions that can result in dementia—a comprehensive list of these is included in the International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision (WHO 1992a) and the Australian modification (ICD-10-AM) (NCCH 2002b). The most common types of dementia in Australia are:

- dementia in Alzheimer's disease, estimated to be responsible for around 50–70% of dementia cases, involving abnormal plaques and tangles in the brain.

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[1] Use of the term 'decline' excludes people with cognitive impairment due to developmental disorders, but includes people with non-progressive forms of dementia (such as dementia caused by head injury) that involve an initial loss of cognitive functioning.

- vascular dementia (formerly known as arteriosclerotic or multi-infarct dementia), resulting from significant brain damage caused by cerebrovascular disease—onset may be sudden, following a stroke, or gradual, following a number of mini-strokes or because of small vessel disease
- dementia with Lewy bodies, in which abnormal brain cells (Lewy bodies) form in all parts of the brain. Progress of the disease is more rapid than for dementia in Alzheimer's disease
- frontotemporal dementia (e.g. Pick's disease), in which damage starts in the front part of the brain, with personality and behavioural symptoms commonly occurring in the early stages
- mixed dementia, in which features of more than one type of dementia are present. For example, many people with dementia have features of both Alzheimer's disease and vascular dementia.

There are also a number of less common types of dementia, including:

- dementia in Parkinson's disease, resulting from the loss of the neurotransmitter, dopamine, in the brain (dopamine is implicated in the control of voluntary movements)—dementia is common in people with Parkinson's but not everyone with Parkinson's develops dementia
- alcohol-induced dementia (e.g. Wernicke/Korsakoff syndrome), in which brain function deterioration is associated with excess alcohol consumption, particularly in conjunction with a diet low in Vitamin B1 (thiamine)
- drug-related dementia, where neurological deficits result from substance abuse, such as petrol sniffing
- head injury dementia, which involves brain damage resulting from head injuries
- Huntington's disease, an inherited disorder of the central nervous system, which is characterised by jerking or twisting movements of the body and is usually eventually accompanied by dementia
- other forms of dementia such as that developing in the course of human immunodeficiency virus (HIV), or Creutzfeldt-Jakob disease
- reversible forms of dementia, such as dementia from B12 deficiency or hypothyroidism, which, although rare, are important to identify.

A definitive diagnosis of many of the diseases associated with the syndrome of dementia is often only possible after death, based on post-mortem examination of the brain, although serial magnetic resonance imaging (MRI) scans show potential in helping diagnose some types of dementia. However, the syndrome of dementia is more amenable to diagnosis and a number of screening tests, assessment and diagnostic tools and international classifications, are available for its diagnosis and classification.

Cognitive impairment and dementia

Cognitive impairment is generally considered to be the defining feature of dementia, although dementia is also associated with functional impairment and changes in behaviour that result in care and support needs. Additionally, the level of cognitive impairment, including any behavioural manifestations, has an impact on carers of people with dementia. Memory loss, reduced capacity for decision making and problem solving, unacceptable social behaviour and nocturnal activity all contribute to the labour intensity and distress that can be associated with caring for a person with dementia.

The number of screening tests and neuropsychological assessments that focus on various domains of cognition (see Section 2.2), reflects the large number of specific mental functions that comprise cognition. *Cognitive impairment* is impairment in one or more of these functions, which include short-term memory (learning skills), long-term memory, executive function (abstract thinking, judgement, problem solving) or other higher cortical function (aphasia, apraxia, agnosia, constructional abilities, calculation), among others. Cognitive impairment is generally defined in respect of the disease or condition being discussed, as the specific cognitive domains that are affected may vary.

It is generally accepted that there are states of memory and other cognitive impairments that fall short of criteria for a diagnosis of dementia (Henderson 1994a). The concept of subclinical cognitive impairment has been the focus of intense research, and there are many existing terms that describe this concept, each with different definitions and criteria. Generally, subclinical cognitive impairment has been considered as an intermediate stage between normal ageing and dementia, and the condition has been viewed as either physiological ageing or the beginnings of a pathological process—*mild cognitive impairment* has received the most attention (Peterson 2004, cited in Chong & Sahadevan 2005). Whether a number of these subclinical cognitive impairments progress to dementia, particularly Alzheimer's disease, is still debated. A number of authors, including Ritchie & Touchon (2000), Burns & Zaudig (2002) and Feldman & Jacova (2005) have reviewed the concept of subclinical cognitive impairment, and a significant proportion of the following discussion is drawn from these sources.

Kral (1962) first proposed *benign senescent forgetfulness* which describes a stable impairment commonly featuring depressive symptoms, characterised by an awareness of memory problems, an inability to recall remote rather than recent events and loss of memory for minor details. Crook et al. (1986) developed the notion of *age-associated memory impairment*, quantifying the degree of memory impairment required for diagnosis as at least one standard deviation below the mean for young adults. *Late-life forgetfulness* was defined by Blackford & LaRue (1989) as a more severe form of this concept, requiring a score of between one and two standard deviations below the mean established for age on at least two of at least four tests.

However, Levy (1994) argued that cognitive impairment occurs in domains other than memory, and that memory impairment itself occurs with other impairments. *Ageing-associated cognitive decline* refers to an impairment of one standard deviation below age- and education-corrected norms in one of a wider range of cognitive functions such as attention, memory, learning, thinking, language and visuospatial function. A similar concept, *age-related cognitive decline*, is included in the Diagnostic and Statistical Manual of Mental Disorders (DSM), Fourth Edition, Text Revision, and is defined as a complaint of difficulties in recalling names and appointments or in problem solving, which cannot be related to a specific mental problem or a neurological disorder (American Psychiatric Association 2000). However, strict criteria of deviation from a population norm are not specified for diagnosis.

Although these concepts are all regarded as falling within the (extreme) limits of normal ageing, Ritchie & Touchon (2000) question whether they may be partly due to underlying disease which may be differentiated from normal ageing-related physiological changes—subjects with objectively demonstrated deficits have been shown to be at increased risk for neurodegenerative disease, and to show quantitative and qualitative differences in cerebral imaging and share common biologic and environmental risk factors. *Mild cognitive disorder* and *mild neurocognitive disorder,* defined in the ICD and DSM, are examples of conditions due to underlying disease which occur at any age and involve symptoms as well as memory loss (Table 2.1).

Table 2.1: Definition of mild cognitive disorder in the ICD and age-related cognitive decline and mild neurocognitive disorder in the DSM

Classification	Terminology	Definition
ICD-10 & ICD-10-AM	Mild cognitive disorder	A disorder characterised by impairment of memory, learning difficulties & reduced ability to concentrate on a task for more than brief periods. There is often a marked feeling of mental fatigue when mental tasks are attempted, & new learning is found to be subjectively difficult even when objectively successful. None of these symptoms is so severe that a diagnosis of either dementia (F00–F03) or delirium (F05.–) can be made. This diagnosis should be made only in association with a specified physical disorder, & should not be made in the presence of any of the mental or behavioural disorders classified to F10–F99. The disorder may precede, accompany or follow a wide variety of infections & physical disorders, both cerebral & systemic, but direct evidence of cerebral involvement is not necessarily present. It can be differentiated from postencephalitic syndrome (F07.1) & post-concussional syndrome (F07.2) by its different aetiology, more restricted range of generally milder symptoms & usually shorter duration.
DSM-IV-TR	Age-related cognitive decline	This category can be used when the focus of clinical attention is an objectively identified decline in cognitive functioning consequent to the ageing process that is within normal limits given the person's age. Individuals with this condition may report problems remembering names or appointments or may experience difficulty in solving complex problems. This category should be considered only after it has been determined that the cognitive impairment is not attributable to a specific mental disorder or neurological condition.
	Mild neurocognitive disorder (included as an example of cognitive disorder not otherwise specified)	The essential feature is the development of impairment in neurocognitive functioning that is due to a general medical condition. By definition, the level of cognitive impairment & the impact on everyday functioning is mild (e.g. the individual is able to partially compensate for cognitive impairment with additional effort). Individuals with this condition have a new onset of deficits in at least two areas of cognitive functioning. These may include disturbances in memory (learning or recalling new information), executive functioning (e.g. planning, reasoning), attention or speed of information processing (e.g. concentration, rapidity of assimilating or analysing information), perceptual motor abilities (e.g. integrating visual, tactile or auditory information with motor activities) or language (e.g. word-finding difficulties, reduced fluency). The report of cognitive impairment must be corroborated by the results of neuropsychological testing or bedside standardised cognitive assessment techniques. Furthermore, the cognitive deficits cause marked distress or interfere with the individual's social, occupational or other important areas of functioning & represent a decline from a previous level of functioning. The cognitive disturbance does not meet the criteria for a delirium, a dementia, or an amnestic disorder & is not better accounted for by another mental disorder (e.g. substance-related disorder, major depressive disorder).

Sources: American Psychiatric Association 2000; NCCH 2002b; WHO 1992a.

The Canadian Study of Health and Aging (Graham et al. 1997) referred to *cognitive impairment no dementia* which, like mild cognitive disorder and mild neurocognitive disorder, is attributable to an underlying physical disorder. This diagnostic grouping includes individuals with problems of memory and/or other areas of cognitive functioning that are insufficient to meet dementia diagnostic criteria—the grouping is the most broad-based and inclusive, as it has virtually no exclusions (Feldman & Jacova 2005). However, there are currently no clear defining criteria for the condition.

Mild cognitive impairment is a term in evolution, seeking precise nosological definition (Burns & Zaudig 2002). Ritchie et al. (2001) describe the difficulties among clinicians in reaching a consensus on diagnostic criteria for mild cognitive impairment. The term was first introduced to denote abnormal cognitive functioning in any domain (Flicker et al. 1991 and Zaudig 1992, cited in Feldman & Jacova 2005). However, Petersen et al. (1999) subsequently refined the term to refer to those with a memory impairment beyond that expected for age and education (yet are not considered as extreme as 'demented'), to describe the transitional state between normal ageing and early or mild (or clinically probable) Alzheimer's disease. Many (but not all) people with mild cognitive impairment were reported to progress to Alzheimer's disease at an accelerated rate. Diagnostic criteria included memory complaint, normal activities of daily living, normal general cognitive function, abnormal memory for age and not demented.

Recognising that other presentations of mild cognitive impairment exist, Petersen et al. (2001) later used the term *amnestic mild cognitive impairment* to emphasise memory loss, and specified diagnostic criteria that included memory complaint (preferably corroborated by an informant), impaired memory function for age and education, preserved general cognitive function, intact activities of daily living and not demented. Other hypothetical presentations of mild cognitive impairment were also proposed, including *multiple domains slightly impaired* (that may progress to Alzheimer's disease, vascular dementia or is possibly associated with normal ageing) and *single non-memory domain* (that may progress to frontotemporal dementia, Lewy body dementia, vascular dementia, primary progressive aphasia, Parkinson's disease or Alzheimer's disease).

Recently, Winblad et al. (2004) proposed an evolved model of mild cognitive impairment, which specifies that individuals are considered to be neither normal nor demented, there is self- and/or informant report of cognitive decline that is supported by impairment on objective cognitive tasks (with evidence of decline over time) and functional activities are mainly preserved with only minimal impairment (particularly on complex instrumental activities of daily living). Individuals are classified as memory impaired or non-memory impaired, and then subclassified as having a single or multi-domain impairment.

Diagnosticians have also noted the difficulties in diagnosing very early dementia—Pond & Brodaty (2004) have documented issues in the early detection of dementia, noting the similarities in manifestations of mild cognitive impairment, early dementia and cognitive impairment associated with depression. The relatively arbitrary nature of dementia diagnosis is based largely on interference with activities (Burns & Zaudig 2002). The difficulties in identifying and distinguishing between early dementia and mild cognitive impairment have implications for measuring the prevalence of dementia.

The term *mild cognitive impairment* may also be used more broadly (like *cognitive impairment no dementia*) to refer to a number of the subclinical cognitive impairments previously discussed—in this report the term is also used more generally to describe the state of cognitive functioning that falls below defined norms, but falls short of dementia in severity (Feldman & Jacova 2005). This definition captures people with cognitive impairment that may or may not progress to dementia, which is due to conditions that may not be associated with ageing, or is actually an early stage of (undiagnosed) dementia. Defining mild cognitive impairment in this way allows for further investigation where the reliability of disease coding is questionable, or where the care requirements for people with dementia are not easily distinguished from other people with similar symptoms.

2.2 Diagnosing dementia

Despite the difficulties associated with diagnosing dementia outlined above, the importance of diagnosing the syndrome as early as possible is becoming more widely accepted. There are a number of benefits of an accurate and early diagnosis of dementia and its causes. Identification and recognition of the problem, as well as involvement of health professionals, may provide some relief to a person with dementia, their family and carers (Ministerial Task Force on Dementia Services in Victoria 1997, cited in Black et al. 2001).

Early diagnosis allows a person with dementia, their family and carers to plan for future living arrangements and care options, organise their financial affairs, and make decisions relating to power of attorney. A diagnosis of dementia also influences decisions relating to rehabilitation programs and provision of aids and services (Wilkinson 2000, cited in Black et al. 2001). Functional assessment enables identification of strategies to reduce risks, maximise independence in daily tasks and identify necessary modifications of the home environment to maximise function (Patterson et al. 1999, cited in Black et al. 2001). Additionally, a diagnosis of dementia can facilitate access to a number of medications that may reduce the symptoms of dementia—for people in the mild or moderate stages of dementia, medications may improve clear thinking and the ability to carry out daily tasks, as well as reducing hallucinations and delusions (Wilkinson 2000, cited in Black et al. 2001).

The diagnostic process may in involve the use of initial screening and/or assessment tools, followed by more comprehensive assessment by a specialist, culminating in a differential diagnosis of dementia. The general practitioner may become aware of the possibility of dementia in their patients in three ways: presenting problems, noting early pointers when treating other conditions, or screening. A significant number of cases of dementia may only become apparent when the individual's carer dies or becomes unable to cope (Bridges-Webb & Wolk 2003:10).

Initial screening and assessment

The purpose of initial screening is to identify people who may benefit from more intense assessment—it has the dual purpose of identifying potential need and also minimising the potential drain on resources caused by unnecessary intense assessment processes. Screening is different from case-finding as it refers to action to determine the presence of likely or possible disease in a person without problems or symptoms pointing to the possibility of dementia (Bridges-Webb & Wolk 2003:31). An assessment of dementia not only aims to determine the condition causing the symptoms (whether to rule out dementia, or determine which disease is causing dementia), but also to assess the needs of the person with dementia and their family and carers.

Barriers to early diagnosis include a lack of routine screening for dementia and a lack of access to specialty consultative services (Shores et al. 2004). However, many experts are reluctant to advocate a population-based screening program, arguing that there is currently insufficient evidence to justify the resources that would be required to implement routine screening for dementia of people who do not display symptoms using existing standardised assessment tools (Bridges-Webb & Wolk 2003:31). Further arguments against the implementation of a screening program are that there does not currently exist a screening test that can reliably detect dementia in a cost-effective manner before patients develop noticeable symptoms, and secondly that, even if such a test did exist, there is no treatment available that can cure dementia if applied in the pre-symptomatic phase (refer to Box 2.1 for characteristics of an effective population-based screening program).

Thus, initial screening and assessment for dementia is generally initiated when a patient or his/her family expresses concern about symptoms, or when the clinician notices changes or signs which may be associated with a dementing illness in the course of their contact with the patient (Bridges-Webb & Wolk 2003:31). This requires that clinicians, in particular general practitioners (GPs), are aware of signs and symptoms that may be associated with dementia and are open to identifying and discussing these with patients and their families if and when they become apparent.

Box 2.1: Criteria for an effective population-based screening program

A screening program must meet certain criteria before it can be considered useful. Important factors influencing the usefulness of a screening program include disease factors, testing factors and therapeutic factors.

The disease being screened for must:

1. *occur in an asymptomatic phase that lasts for a significant length of time*
2. *represent a significant burden to the population*
3. *lead to a bad outcome if left untreated.*

A screening test must be available that is:

1. *able to detect the disease during the asymptomatic phase*
2. *acceptable to patients and practitioners*
3. *cost-effective*
4. *highly sensitive and reasonably specific for the target disease.*

In addition, there must be value in identifying the disease in the asymptomatic phase, that is:

1. *There must be an effective treatment available that can cure or improve the outcome.*
2. *The outcome for the disease must be better if the treatment is applied during the asymptomatic period than later in the course of the disease. Ideally there should be a chance for cure if treatment is given at an early stage of disease.*

Source: Adapted from IAM 2006.

Assessment and screening instruments

A variety of assessment tools exist which may be helpful in screening for, diagnosing and/or monitoring dementia. In the context of dementia, assessment tools are employed for two basic purposes:

1. to screen people for the likely presence/absence of cognitive impairment which may be indicative of dementia
2. for in-depth assessment for the purposes of formal diagnosis, care planning, and monitoring of disease progression or treatment efficacy.

As dementia is a syndrome with several characteristic features (not all of which may be present in any one case), most assessment instruments include separate components, subscales or domains. Few tests are capable of discriminating across all types and levels of dementia. For example, tests that are capable of identifying mild cognitive impairment may not be suitable for differentiating among more advanced stages of dementia and vice versa. Thus, assessment tools are often best used in combination and in the context of other forms of assessment such as clinical interview, informant interview and biological testing (McDowell & Newell 1996:289; Meade & Bowden 2005). A combination of screening tests may be used to increase the rate of diagnosis for those who have dementia, and reduce the likelihood of falsely diagnosing dementia (Flicker et al. 1997, cited in Black et al. 2001), and clinicians are generally encouraged to look for other evidence of symptoms or functional change in everyday life (Meade & Bowden 2005).

Diagnosis cannot be made purely on the basis of screening. People who screen positive for cognitive impairment must undergo further clinical evaluation to confirm or reject a differential diagnosis of dementia (Black et al. 2001). Thus, though GPs may often be the first port of call for people who are worried about their own or a loved one's cognitive functioning, the final diagnosis of dementia is usually made by a neurologist, geriatrician or psychogeriatrician (Wilkinson et al. 2004, cited in Brodaty et al. 2006).

Initial assessment/screening tools must achieve a balance between comprehensiveness and clinical utility. Many standardised tools were initially intended to be a component of a battery of tests in the full assessment and diagnosis of dementia. In applying such items and subscales to initial assessment and screening rather than to diagnosis, a balance must be found between minimising test length and complexity, evaluating total cognitive function and maintaining test accuracy (Boustani et al. 2003). In their entirety, these instruments have more in common with diagnostic protocols (discussed below) than screening instruments.

Box 2.2: Requirement for use of MMSE and/or ADAS-Cog and CIBIC to access subsidised anticholinesterase medication through the PBS

The use of some standard assessment tools is enshrined in administrative requirements of some aspects of Australia's health and aged care systems. For example, some anticholinesterase medication used in the treatment of mild to moderate dementia, donepezil hydrochloride (Aricept), rivastigmine hydrogen tartate (Exelon), and galantamine hydrobromide (Remilyn), are approved for listing on the Pharmaceutical Benefits Scheme (PBS) for people with Alzheimer's disease who meet specific criteria (Alzheimer's Australia 2004).

People who have a diagnosis of mild to moderately severe Alzheimer's disease are able to access Aricept, Exelon or Remilyn at a subsidised cost through the PBS provided that certain criteria are met. In order to establish eligibility for this subsidy, the client must have a diagnosis of mild to moderately severe Alzheimer's disease confirmed by a neurologist, psychogeriatrician, psychiatrist, geriatrician or consultant physician, and a written application for subsidised treatment must be made to Medicare Australia. This application must include the results of a baseline Mini-Mental State Examination (MMSE) test, and to be eligible the client must score 10 or higher, and if the score is 25 points or above, the results of a baseline Alzheimer's Disease Assessment Scale, cognitive subscale (ADAS-Cog), must also be specified. In order to receive continuing subsidised access to the medication beyond the initial six month treatment period, it must be demonstrated that the client has benefited from the pharmacotherapy. The requisite proof of improvement in cognitive function is an increase of at least 2 points from baseline on the MMSE or a decrease of at least 4 points from baseline on the ADAS-Cog for patients with an MMSE baseline score of 25 points or higher (DoHA 2006).

Access to subsidised Aricept, Exelon or Remilyn may be granted to people who score lower than 10 points on the MMSE under the following circumstances, which are non-cognitive factors accepted as limiting the person's ability to complete the MMSE. These are where the patient (DoHA 2006):

- *is from a culturally and linguistically diverse background and has limited English language skills*
- *has less than six years of formal education, and/or is illiterate or innumerate*
- *is an Aboriginal or Torres Strait Islander*
- *has an intellectual disability (developmental or acquired), e.g. Down's syndrome*
- *has significant sensory impairment, despite best correction, which precludes completion of an MMSE test and/or*
- *has prominent dysphasia, out of proportion to other cognitive and functional impairment.*

In such cases, access to continuing subsidised pharmacotherapy requires demonstration of improvement in cognitive function, based on a rating of 'very much improved' or 'much improved' on the Clinician's Interview-Based Impression of Change (CIBIC) scale, which must be completed by the same clinician who initiated treatment (DoHA 2006).

As at April 2006, other tests cannot be used to demonstrate initial or ongoing eligibility for PBS-subsidised pharmacotherapy.

The most widely used cognitive assessment tool in primary care settings is the MMSE (Folstein et al. 1975). The extent to which the MMSE is an effective screening tool depends on the prevalence of dementia within the target population and the cut-off points at which the screening result is determined to be positive or negative (Boustani et al. 2003). Despite its shortcomings (see Table 2.3), the MMSE remains the best-studied clinically feasible cognitive assessment for screening purposes (Boustani et al. 2003), is often incorporated in diagnostic assessments, and is recognised as a method of demonstrating treatment efficacy by the Australian Government (see Box 2.2).

Table 2.3 includes information about the most commonly used tools in Australia, including their application, strengths and weaknesses. A summary of the applications of these tools is in Table 2.2 below.

Table 2.2: Type/use of screening test or assessment tool

Screening test	Provisional diagnosis	Diagnostic suite	Clinical monitoring
Mini-Mental State Examination General Practitioner Assessment of Cognition CogHealth Memory Monitoring System Clock drawing tests 7 Minute Screen Mini-Cog	Alzheimer's Disease Assessment Scale Informant Questionnaire of Cognitive Decline in the Elderly Rowland Universal Dementia Assessment Scale Kimberley Indigenous Cognitive Assessment Psychogeriatric Assessment Scales	Kimberley Indigenous Cognitive Assessment Psychogeriatric Assessment Scales Cambridge Mental Disorders of the Elderly Examination Consortium to Establish a Registry for Alzheimer's Disease	MMSE CogHealth Dementia Rating Scale Clinician's Interview-Based Impression of Change Clinician's Interview-Based Impression of Change with Caregiver Input

Table 2.3: Summary of selected cognitive assessment and screening tools

Screening test/ assessment tool	Authors	Purpose & use	Benefits	Limitations
Mini-Mental State Examination (MMSE)	Folstein et al. (1975)	Most widely used & widely researched cognitive assessment tool in primary care settings Can be used as a clinical screening instrument A MMSE score is usually required to establish eligibility for access to subsidised anticholinesterases through the PBS Used to screen for entry into dementia research studies	Brief, structured mental status examination, requiring 10–15 minutes to administer Screens orientation, memory, attention, naming, comprehension & praxis Portable—requires only a pen & paper for administration Provides a unitary score which is often used as a basis for classifying severity of cognitive impairment Scoring system is helpful in following change over time Does not require specific qualifications to administer & can therefore be used by a wide variety of personnel in various settings (with some training) Free for research purposes	Insensitive to patients with mild cognitive impairment Lacks diagnostic specificity Lacks frontal lobe domain tests Does not take into account levels of education, premorbid ability & cultural & linguistic diversity Some doubt about the ability to monitor change in individuals over time, due to the relatively high measurement error Influenced by premorbid intelligence, social class, physical disability, age, gender & education—dementia may be missed in some individuals & individuals without dementia may be misclassified 10–15 minutes administration time makes the tool impractical for use within a standard GP consultation
Alzheimer's Disease Assessment Scale (e.g. ADAS-Cog)	Rosen et al. (1984)	Developed to sample the cognitive functions typically impaired in Alzheimer's disease & to express these as an overall summary score Used as the primary outcome measure in many antidementia drug trials May be used as supplementary evidence to establish eligibility for access to anticholinesterases through the PBS (see Box 2.2)	More thorough than the MMSE Effective, brief examination for study of language & memory skills Assesses cognitive function & non-cognitive features associated with dementia	Shares many of the limitations reported for the MMSE, with similarly variable scores for individuals Takes approximately 30 minutes to administer & is therefore impractical for use as a screening tool within a standard GP consultation Requires purchase of a special kit that costs in excess of $400
Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE)	Jorm & Jacomb (1989)	Designed to elicit information about the elderly person's memory & thinking at the time of screening as compared with 10 years before	Collects structured informant-based information in the context of a quantitative survey instrument Appears to be unaffected by patient's education levels Advantages of informant-based assessments include relevance to everyday life, acceptability by subjects, flexibility to assess difficult-to-evaluate patients, administrative ease, longitudinal perspective & cross-cultural portability Not under copyright; however, author requests information about research projects that use the tool	There is mixed evidence about the usefulness of informant-based assessment tools May be influenced by age & gender of the patient Informant reports are subjective & may be influenced by the patient's or informant's emotional states Requires responses from someone close to the person with suspected dementia—some patients have no suitable informant available Some functions associated with dementia are not assessed

(continued)

Table 2.3 (continued): Summary of selected cognitive assessment and screening tools

Screening test/ assessment tool	Authors	Purpose & use	Benefits	Limitations
Psychogeriatric Assessment Scales (PAS)	Jorm et al. (1995)	Designed to assess two major psychogeriatric disorders: dementia & depression	Consists of 6 scales: the patient interview covers cognitive impairment, depression & stroke; the informant interview covers cognitive decline, behaviour change & stroke The patient & informant interviews give independent perspectives on the subject's behaviour, provided the subject & informant are interviewed separately—discrepancies between the two sources can be informative Can be used by non-medical staff after brief training The 6 scales can be treated as independent modules	Only suitable for use with people who are fluent in English The cognitive impairment scale may be influenced by education & premorbid intelligence rather than be symptomatic of cognitive decline (though the cognitive decline scale is not influenced by education or intelligence earlier in life) Informant reports can be influenced by the informant's emotional state, particularly if the informant is depressed
General Practitioner Assessment of Cognition (GPCOG)	Brodaty et al. (2002)	Designed for use as a brief screening tool in general practice in Australia Recommended in the NSW Health *Care of patients with dementia in general practice* guidelines	Assesses cognitive impairment & allows a brief assessment of functional status Can be administered within a standard GP consultation (approximately 7 minutes to administer) Includes a cognitive test & informant questionnaire—either can be used alone with only a slight loss in psychometric properties The informant section can be used alone if language problems preclude cognitive testing	Results of the test may be influenced by: impaired performance due to dysphasia, sight impairment, deafness, poor educational level, cultural factors & awareness of being tested or fear of testing; or factors that may overcome decreased cognition such higher pre-morbid intelligence & education Floor effect so that poor discrimination of low & very low functioning patients May have insufficient range as measure of change; designed as a screening instrument
Kimberley Indigenous Cognitive Assessment (KICA)	LoGiudice et al. (2006)	Designed for use in the Kimberley region of Western Australia, an area with a diverse & widely spread Indigenous population comprising approximately 30 language groups Currently being trialled in the Northern Territory	Comprises a medical history, smoking & alcohol history, cognitive assessment & assessment of emotional well-being (through assessment of the client & family reports), as well as assessment of behaviour & activities of daily living (through family reports) Valid for use within various Indigenous communities & language groups in the Kimberley region, for whom mainstream assessment tools may not be suitable Developed in conjunction with communities, Indigenous health & aged care organisations, language centres & older people in the region—has higher community acceptance & support than other dementia screening & assessment protocols Presented in simple English, enabling it to be translated directly by an interpreter when required	Currently being validated Versions are specific to particular Indigenous communities &/or language groups Labour-intensive to administer—requires specific language skills & cultural knowledge

(continued)

Table 2.3 (continued): Summary of selected cognitive assessment and screening tools

Screening test/ assessment tool	Authors	Purpose & use	Benefits	Limitations
Rowland Universal Dementia Assessment Scale (RUDAS)	Storey et al. (2004)	Developed as a valid cognitive assessment tool for use with people across cultural & language groups Used clinically in New South Wales, South Australia, Victoria & New Zealand Follow-up studies are currently being conducted in New South Wales, South Australia & Victoria	Tests multiple cognitive domains Portable & easily administered by primary health care clinicians Appears not to be affected by gender, years of education, differential performance factors, or preferred language (Rowland et al. 2006) Easily administered in languages other than English & appears to be culturally fair, provided suitable interpreter services are available	
Clock drawing tests	Various authors, 1986 onwards (see McDowell & Newell 1996:297–300)	Tests cognitive function, proposed as a screening test for dementia Initially introduced as an indicator of constructional apraxia Used as a subscale in some other tests, such as the 7 Minute Screen & Mini-Cog	Provides a rapid screening method that respondents may find more interesting (& less insulting) than 'childish' items included in other tools May be more suitable for use with people from culturally and linguistically diverse backgrounds than verbally-based items in other tools May be useful as an adjunct to other assessment tools &/or as part of the diagnosis & care planning process	Easily differentiates 'grossly abnormal' performance from 'normal' performance but gradations of abnormal performance are difficult & subjective to establish Creation of a reliable numerical scoring system for distortions in clock drawing is complex & many scoring systems have been proposed Unsuitable for people with visual impairments or non-cognitive motor impairments May be affected by education & pre-morbid intelligence level Is unlikely to suffice as a screen for dementia in isolation
Dementia Rating Scale (DRS)	Mattis (1973), cited in McDowell & Newell 1996)	Intended for use with severely affected institutionalised patients for whom standard neurological tests would be too demanding	Covers attention, preservation, construction, conceptualisation & verbal & non-verbal memory Can be used to differentiate severity of dementia Appropriate where a clinical rating scale is needed for use for severely ill patients in institutional settings	Must be administered by a clinician Principally useful as a research instrument—not suitable as a screening instrument
7 Minute Screen	Solomon	Brief cognitive assessment for use in primary care settings	Incorporates the Clock Drawing Test, Temporal Orientation Test, Enhanced Cued Recall Test & Verbal Fluency Test Can be administered in less than 10 minutes by anyone with an hour of basic training A useful screening tool for discriminating patients with dementia from cognitively intact patients	

(continued)

Table 2.3 (continued): Summary of selected cognitive assessment and screening tools

Screening test/ assessment tool	Authors	Purpose & use	Benefits	Limitations
CogHealth Memory Monitoring System (CogHealth)	CogState Ltd.	A commercially developed assessment tool designed to detect mild cognitive impairment prior to the patient developing significant symptoms or morbidity Designed to be used directly by individuals under the supervision of a medical practitioner Promoted as a means for anyone who is worried about or may be at risk of developing dementia to establish a baseline for their own cognitive performance & monitor any changes over time Used in some drug trials to test efficacy of pharmacotherapy Currently available for use around Australia	A computerised test designed for baseline & follow-up testing to measure change in performance over time Includes reaction time, choice decision time, working memory & monitoring & learning tasks Takes approximately 15 minutes to complete & can be supervised by non-medical staff—results are returned by email within minutes Uses ordinary playing cards as stimuli, limiting reliance on verbal items—this may improve application across cultural & language groups May be useful for testing for mild cognitive impairment based on improved performance (i.e. learning) over multiple tests administered on the same day May encourage people to be more active in monitoring their own cognitive function Available to anyone who has a credit card and access to the internet—however, CogHealth recommend that testing occur under medical supervision Can be administered in English, German, Spanish, French, Italian, Russian, Norwegian, Danish, Finnish, Greek, Hungarian, Japanese or Chinese Mandarin	Sensitive to cognitive change from any cause, not just dementia. There is a risk that individuals may misinterpret results, especially if medical supervision is absent Requires a computer for administration, & an internet connection & means to pay in order to access scoring services Costs to have the test scored are $70 + GST per test for individuals & between $25 + GST & $45 + GST per test submitted by a medical practitioner Designed to identify intra-individual changes in performance over time, rather than classification/diagnosis of cognitive function based on a single score Performance may be impaired by non-cognitive factors such as fatigue, visual impairment or physical limitations People wishing to download & use the test are encouraged to practise before submitting the test for scoring—practice effects may not be adequately controlled in the absence of medical supervision
Clinician's Interview-Based Impression of Change (CIBIC) & Clinician's Interview-Based Impression of Change with Caregiver Input (CIBIC-plus)		The CIBIC is a global rating scale intended to provide an index of the clinical importance of change that cannot be obtained from quantitative assessment measures such as mental status examinations The CIBIC-plus is the CIBIC with inclusion of input from caregivers or other family informants Most often used to assess efficacy of treatments Widely used in antidementia drug trials	A semi-structured, subjective instrument intended to examine 4 major areas of patient function: general, cognitive, behavioural & activities of daily living Includes clinicians' notes about patients' behaviour, function & cognition, & a 7-point clinical global impression of change scale that summarises patients' changes during treatment May help to identify 'meaningful' cognitive improvements, as clinicians may be sceptical of (& less likely to rate) cognitive changes not supported by like changes in function or behaviour Can be used as evidence to establish eligibility for ongoing access to subsidised anticholinesterases through the PBS, under certain circumstances (see Box 2.2)	Must be performed by a clinician with appropriate expertise—repeat measures should be conducted by the same clinician Global ratings may be more subjective than quantitative assessments Not suitable as a screening instrument, or to establish severity of cognitive impairment

(continued)

Table 2.3 (continued): Summary of selected cognitive assessment and screening tools

Screening test/ assessment tool	Authors	Purpose & use	Benefits	Limitations
Mini-Cog	Borson et al. (2000)	Brief screening tool designed for use in primary care settings Used as a screening test or to test executive functioning where there is a clinical suspicion of cognitive impairment	Incorporates a 3 item word learning & recall task & a clock drawing task (as a distracter before the word recall) Requires less time (approximately 3 minutes) to administer than the MMSE with similar effectiveness Not as susceptible as the MMSE to bias from cultural background, language & education Can detect mild cognitive impairment & a range of types of dementia	Only tests executive functioning May not be useful in patients with visual impairment or difficulty holding a writing implement
Cambridge Mental Disorders of the Elderly Examination (CAMDEX)	Roth et al. (1988)	Provides a formal diagnosis in a number of categories one of which is dementia One of the eight sections is the CAMCOG, designed to assess cognitive function	Covers a wider range of cognitive functions & is able to detect mild levels of impairment Semi-structured diagnostic interviews may be used as a more comprehensive alternative to the MMSE	Provides systematic procedures for the diagnosis of dementia—not suitable as a screening tool Lengthy & time-consuming to administer—may be used on a more routine basis in specialist settings (e.g. memory clinics)
Consortium to Establish a Registry for Alzheimer's Disease (CERAD)	CERAD	Developed as a suite of standardised & reliable procedures for the evaluation & diagnosis of patients with Alzheimer's disease & other dementias Can be used to gather data on normal persons as well as on cognitively impaired or behaviourally disturbed individuals to identify dementia based on clinical, neuropsychological, behavioural &/or neuropathological criteria	Includes clinical history, informant report, systemic disorders, cerebrovascular disease, parkinsonism, depression, the Blessed Dementia Rating Scale, Short Blessed Test, calculation, clock & language tests, physical examination, laboratory studies, the Clinical Dementia Rating scale & finally, a diagnostic impression of either Alzheimer's disease alone, Alzheimer's disease associated with other disorders, or non-Alzheimer's disease dementia The neuropsychological assessment includes measures of verbal fluency, confrontational naming (15-item Boston Naming Test), the MMSE, measures of verbal learning, recall & recognition & constructional praxis performance & recall Covers a wider range of cognitive functions & can detect mild levels of cognitive impairment Semi-structured diagnostic interviews may be used as a more comprehensive alternative to the MMSE Can be administered in languages other than English, including Bulgarian, Chinese, Dutch, Finnish, French, German, Italian, Japanese, Korean, Portuguese & Spanish Can be used for research purposes as well as for patient care	Provides systematic procedures for the diagnosis of dementia—not suitable as a screening tool Lengthy & time-consuming to administer—may be used on a more routine basis in specialist settings (e.g. memory clinics)

Comprehensive assessment

Diagnostic protocols

Diagnostic protocols are standardised forms of major clinical assessments that can be used in diagnosing dementia. They generally include clinical interview (e.g. covering patient history and current situation), standardised testing of cognitive performance, and a series of diagnostic algorithms to guide differential diagnosis. They tend to be time-consuming and are required to be administered by a specialist who is qualified to make a formal diagnosis of dementia. Examples include (McDowell & Newell 1996:332–3):

- Structured Interview for the Diagnosis of Dementia
- British Present State Examination
- American Diagnostic Interview Schedule
- Geriatric Mental State Examination
- Canberra Interview for the Elderly
- Comprehensive Assessment and Referral Evaluation.

Neuropsychological, behavioural and functional assessments

Generally, a clinical diagnosis of dementia is made following a combination of neuropsychological, behavioural and functional assessments. Neuropsychological assessments are usually questionnaires, and are distinguished from screening tests by focusing on specific domains of cognition, rather than performing a broader assessment of cognitive functioning.

Functional and behavioural assessments may be particularly useful in the moderate or more severe stages of dementia. Behavioural assessment considers the non-cognitive aspects of dementia which include personality, mood, psychotic symptoms and behaviours of concern, as well as sleep, eating and sexual disorders. These non-cognitive characteristics can be used to improve diagnostic accuracy and to distinguish different causes of dementia (Mirea & Cummings 2000, cited in Black et al. 2001). Behaviours may be assessed by direct observation, interviews, questionnaires or case notes.

A functional assessment aims to determine a person’s ability to complete activities of daily living and instrumental activities of daily living, and the type and amount of assistance needed to complete these tasks. A functional assessment can be a self-report, a report by a carer or an observation of performance (Black et al. 2001), although the latter methods are preferred as people with dementia tend to exaggerate their ability to complete activities of daily living and instrumental activities of daily living (Carswell & Spiegel 1999, cited in Black et al. 2001).

Blood screening, computed tomography or MRI may be used to confirm or eliminate other (and potentially reversible) causes of cognitive impairment. MRI may also be used to differentiate between mild cognitive impairment and Alzheimer’s disease, and single photon emission computed tomography (SPECT) may be used in early differentiation of frontal dementias from Alzheimer’s disease. However, SPECT, as well as functional magnetic resonance imaging (fMRI), positron emission tomography (PET), electroencephalography (EEG), biomarkers and genetic testing are predominantly used in the research setting rather than as diagnostic tools.

Differential diagnosis

There are many conditions other than dementia that may have cognitive impairment as part of their presentation. It is therefore imperative that comprehensive assessment culminates in a differential diagnosis of dementia. By way of illustration, Table 2.4 provides a summary of how dementia can be differentiated from a range of other conditions using the DSM-IV, as described by First et al. (1995).

Table 2.4: Differential diagnosis for dementia

Dementia (memory and other cognitive impairments) must be differentiated from…	**In contrast to dementia, the other condition…**
Delirium	Is characterised by a disturbance in consciousness and a fluctuating course. Dementia is not diagnosed if the cognitive deficits occur exclusively during delirium. However, periods of delirium can occur in the context of a dementia and should be diagnosed if present.
Amnestic disorder	Is characterised by memory impairment occurring in the absence of other cognitive deficits (i.e. aphasia, agnosia, apraxia, executive functioning). Amnestic disorder is not diagnosed if the memory disturbance occurs exclusively during dementia.
Cognitive impairment in substance intoxication or substance withdrawal	Remits when the acute effects of intoxication or withdrawal subside. In contrast, substance-induced persisting dementia may be diagnosed if the dementia persists long beyond the period of intoxication or withdrawal.
Mental retardation	Must have an onset before age 18 years.
Cognitive impairment and deterioration in functioning in Schizophrenia	Has a generally earlier age at onset, less severe cognitive impairment, a characteristic symptom pattern (e.g. delusions and hallucinations), and is not due to the direct effects of a general medical condition or substance use.
Memory deficits and difficulty concentrating in Major depressive disorder	Improves when the depression remits, is associated with other characteristic depressive symptoms, is often associated with prior history (or family history) of depression, and is not due to the direct effects of a general medical condition or substance use.
Age-related cognitive decline	Is characterised by cognitive impairment that is in keeping with what would be expected for the individual's age and is not due to the direct effects of a general medical condition or substance use.
Mild neurocognitive disorder (i.e. cognitive disorder not otherwise specified)	Does not meet the severity threshold for dementia.

Source: First et al. 1995.

2.3 Defining and classifying dementia and its outcomes

International classifications of dementia

A number of international classifications assist with identifying and classifying dementia. These include the ICD, which approaches dementia from a disease perspective, attempting to identify the underlying aetiology; and the DSM and International Classification of Functioning, Disability and Health (ICF) which both approach dementia from a perspective of functional outcomes. The International Classification of Primary Care (ICPC) is used as a classification for general practice or primary care, wherever applicable.

Most existing Australian data sources define, diagnose, classify and/or measure dementia using one or more of these classifications.

International Statistical Classification of Diseases and Related Health Problems

The purpose of the ICD is to permit the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or areas and at different times. However, in practice the ICD has become the international standard diagnostic classification for all general epidemiological and many health management purposes. These include the analysis of the general health situation of population groups and monitoring of the incidence and prevalence of diseases and other health problems in relation to other variables such as the characteristics and circumstances of the individuals affected.

It is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and hospital records. In addition to enabling the storage and retrieval of diagnostic information for clinical and epidemiological purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics.

The ICD-10 (WHO 1992a:312) and ICD-10-AM (NCCH 2002b:99) define dementia (F00–F03) as:

> *a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.*

Diagnostic guidelines for dementia are included the clinical descriptions and diagnostic guidelines accompanying the ICD-10 in (WHO 1992b:46) and in the mental health manual accompanying the ICD-10-AM (NCCH 2002a:38), which state:

> *the primary requirement for diagnosis is evidence of a decline in both memory and thinking which is sufficient to impair personal activities of daily living. The impairment of memory typically affects the registration, storage, and retrieval of new information, but previously learned and familiar material may also be lost, particularly in the later stages. Dementia is more than dysmnesia: there is also impairment of thinking and of reasoning capacity, and a reduction in the flow of ideas. The processing of incoming information is impaired, in that the individual finds it increasingly difficult to attend to more than one stimulus at one time, such as taking part in a conversation with several persons, and to shift the focus of*

> *attention from one topic to another. If dementia is the sole diagnosis, evidence of clear consciousness is required. However, a double diagnosis of delirium superimposed upon dementia is common (F05.1). The above symptoms and impairments should have been evident for at least 6 months for a confident clinical diagnosis of dementia to be made.*

ICD-10 codes are used in the classification of mortality and morbidity in hospitals in Australia. The ICD-10 and ICD-10-AM also form the basis of health condition codes used in the Aged Care Assessment Program (ACAP), and the Australian Bureau of Statistics (ABS) National Health Survey (NHS) and Survey of Disability, Ageing and Carers (SDAC).

Diagnostic and Statistical Manual of Mental Disorders

The DSM, published by the American Psychiatric Association, contains a listing of mental disorders and corresponding diagnostic codes, as well as diagnostic criteria and information about each disorder, including associated features, complications, course and differential diagnosis. It is utilised by mental health professionals from a variety of disciplines for a range of clinical, research, administrative and educational purposes. The DSM allows for a multiaxial assessment:

- Axis I—clinical disorders and other conditions that may be a focus of clinical attention
- Axis II—personality disorders and mental retardation
- Axis III—general medical conditions
- Axis IV—psychosocial and environmental problems
- Axis V—global assessment of functioning.

The use of a multiaxial system in the DSM facilitates comprehensive and systematic evaluation with attention to the various mental disorders and general medical conditions, psychosocial and environmental problems, and level of functioning that might be overlooked if the focus were on assessing a single presenting problem (American Psychiatric Association 2000). The DSM describes diagnoses in terms of patterns of symptoms that tend to cluster together—the symptoms can be observed by the clinician or reported by the patient or family members. This also avoids incorporating unproven theories into diagnostic definitions, where the cause of most mental disorders is currently unknown and subject to speculation. However, this is also an important limitation, as patients sharing the same diagnostic label do not necessarily have disturbances that share the same aetiology and do not necessarily respond to the same treatment.

Although particular types of dementia are defined, the DSM-IV-TR[2] does not provide a concise definition of dementia itself, simply stating that the disorders in the *Dementia* section are characterised by the development of multiple cognitive deficits (including memory impairment) that are due to the direct physiological effects of a general medical condition, to the persisting effects of a substance, or to multiple aetiologies (e.g. the combined effects of cerebrovascular disease and Alzheimer's disease). The disorders in this section share a common symptom presentation but are differentiated based on aetiology (American Psychiatric Association 2000).

However, the essential feature of a dementia is described as the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning

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[2] There is no difference between the diagnostic criteria for dementia in the DSM-IV and DSM-IV-TR (Pioggiosi et al. 2003).

(American Psychiatric Association 2000). Memory impairment and intellectual impairment must be sufficiently severe to cause significant social and occupational impairments and must represent a decline from a previously higher level of functioning.

The DSM-IV is the international classification used by most clinicians. However, it is evident from the literature that the DSM-III-R is still in use and this edition of the classification will also be discussed, where appropriate.

International Classification of Primary Care

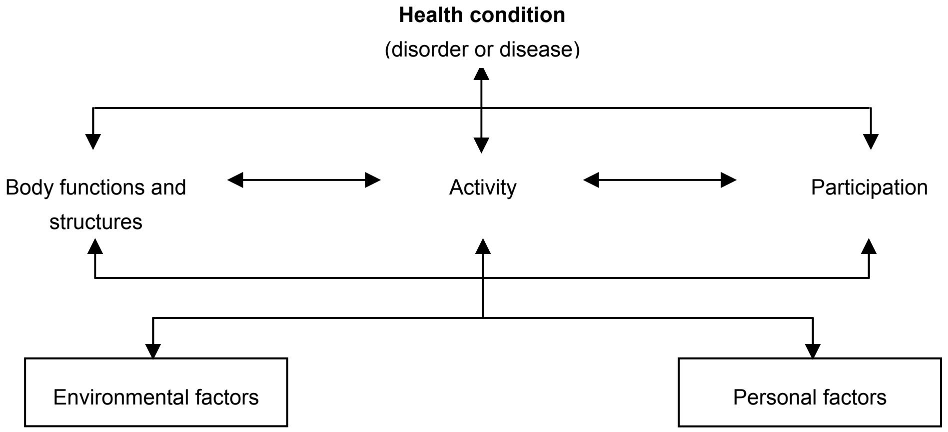
The second edition of the International Classification of Primary Care (ICPC-2) classifies patient data and clinical activity in the domains of general/family practice and primary care, taking into account the frequency distribution of problems seen in these domains. It allows classification of the patient's reason for encounter, the problems/diagnosis managed, interventions, and the ordering of these data in an episode of care structure.

It has a biaxial structure and consists of 17 chapters, each divided into seven components which deal with: symptoms and complaints; diagnostic, screening and preventive procedures; medication, treatment and procedures; test results; administrative; referrals and other reasons for encounter; and diseases. The chapter titled *Psychological* contains codes for dementia and other organic psychosis.

Data about patients seen, reasons people seek medical care, problems managed and treatments provided in general practice in Australia collected by the Bettering the Evaluation and Care of Health (BEACH) survey are coded using ICPC-2 Plus codes.

International Classification of Functioning, Disability and Health

Key to diagnosing dementia according to the ICD and the DSM is that cognitive impairment is 'sufficient to impair personal activities of daily living', or causes significant social and occupational impairments. The ICF provides a framework for the conceptualisation, classification and measurement of functioning (AIHW 2003c). The ICF does not define dementia, but provides a framework for understanding and measuring the functional outcomes of dementia in terms of three components: body functions and structures; activities and participation; and environmental factors (Figure 2.1).



Source: WHO 2001:18.

Figure 2.1: Interactions between components of the ICF

Within each component, a classification structure is provided, which can be used to organise information on various domains of the disability experience. The framework provides a means of describing human functioning on a continuum, with *functioning* used to describe the neutral or positive health states of body functions and structures and activities and participation, and *disability* used to describe impairments, activity limitations or participation restrictions.

Box 2.3: Definitions used in the International Classification of Functioning, Disability and Health

Body functions *are the physiological functions of body systems (including psychological functions)*

Body structures *are anatomical parts of the body such as organs, limbs and their components*

Impairments *are problems in body function and structure as a significant deviation or loss*

Activity *is the execution of a task or action by an individual*

Participation *is involvement in a life situation*

Activity limitations *are difficulties an individual may have in executing activities*

Participation restrictions *are problems an individual may experience in involvement in life situations*

Environmental factors *make up the physical, social and attitudinal environment in which people live and conduct their lives.*

Source: WHO 2001.

Under the ICF framework, different diseases and injuries may cause cognitive impairment which impact on functioning and disability as illustrated with examples in the diagram below (Figure 2.2)—the dementia syndrome can be considered to be a particular type of cognitive impairment. The suggested ICF minimum data requirements for cognition come from the *Body functions* chapter, and include: b140 *attention functions*; b144 *memory functions*; and b164 *higher-level cognitive functions* (WHO 2001:253). The code b117 *intellectual functions* also lists dementia as an inclusion. Additionally, the *Body structures* chapter includes 10 codes for different parts of the brain structure; the *Activities and participation* chapter includes a number of codes that describe activities of daily living and instrumental activities of daily living; and the *Environmental factors* chapter includes codes describing facilitators and barriers.

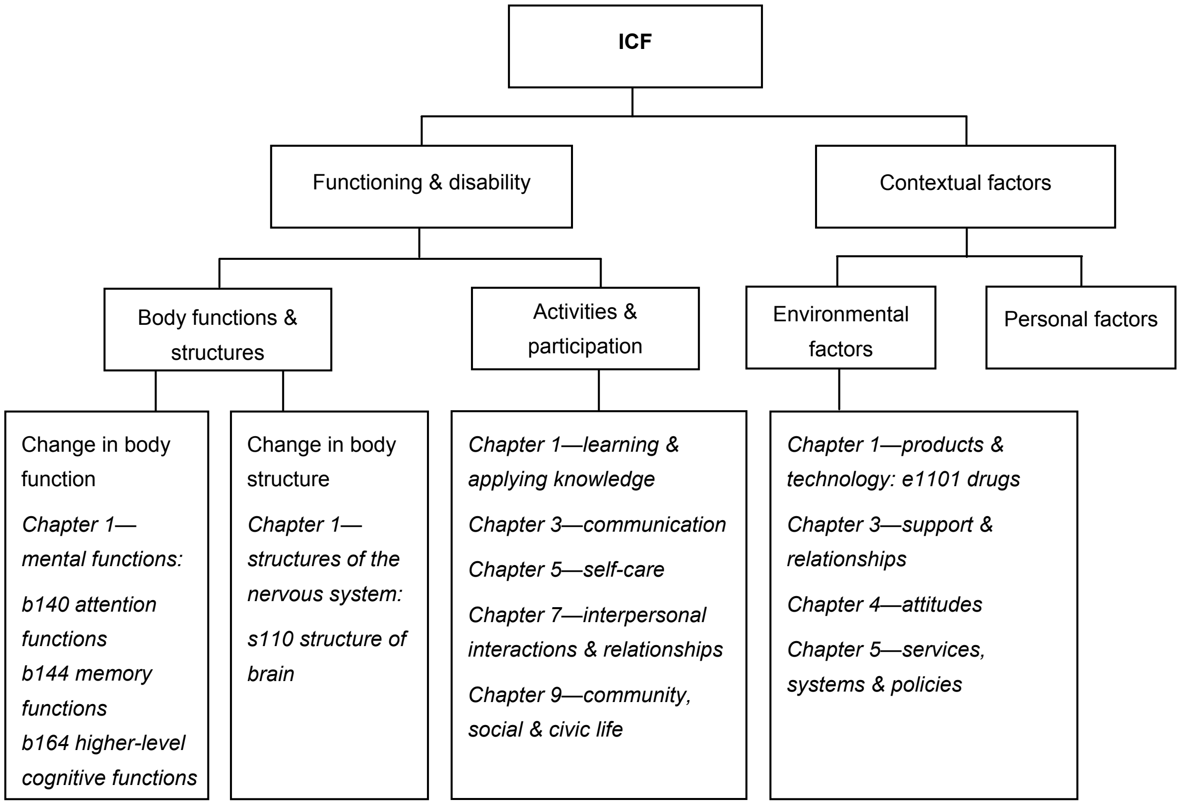


Figure 2.2: Dementia and its outcomes in the structure of the ICF

Muo et al. (2005) recently reported that the ICF is a useful tool to describe health status in patients with Alzheimer's disease in that it underlies important aspects of daily living generally not considered by activity of daily living scales, such as communication, social relationships and recreation and leisure. Its inclusion of environmental factors also encourages consideration of these important factors in the care of people with dementia.

However, use of the ICF as a practical tool to measure behavioural outcomes associated with the syndrome of dementia may have limitations. These would be largely associated with the need to make choices on which ICF domains to focus assessment; the multi-dimensional nature of the ICF may increase user burden in assessment of impairments associated with dementia. At the same time, the multi-dimensional nature of the ICF may improve the extent to which the complexity of dementia and its outcomes is described. This may help with the diagnosis of different types of dementia, describing exactly what is happening for the person with dementia, and examining possible environmental determinants.

On the face of it, the ICF appears not to describe or classify behavioural symptoms of dementia in a way which is helpful for diagnosis, treatment or management. However, it may be useful to differentiate impairments or other functional limitations (e.g. mobility) from signs and symptoms that arise from impairments or other functional limitations (e.g. wandering). For example, wandering and getting lost may be an indication that someone has an impairment of orientation, or possibly a new environment with which they are not familiar. While the behaviour is visible and measurable, it is not actually a function. Similarly, a person may have communication difficulties because of problems with speech, but problems may also be environmentally determined. By separating communication from speech, one can examine the aetiology of the limitations and possible interventions can be better aligned.

The ICF is used to support consistency of data relating to support needs for people with disability between the ABS SDAC, the Commonwealth-State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS), the National Community Services Data Dictionary and the 2006 Census of Population and Housing.

Both the ICD and ICF belong to the family of international classifications developed by the World Health Organization (WHO) for application to various aspects of health, and are complementary. In a recent presentation, Madden (2006) mapped the components of the ICD definition of dementia (i.e. higher cortical function, emotional control, social behaviour and motivation) to domains within the mental functions chapter of the ICF. Table 2.5 provides an example of this mapping. Madden (2006) noted that ICF domains including temperament and personality (b126), energy and drive functions (b130), attention (b140), psychomotor (b147), perceptual (b156) and higher level cognitive functions (b164) were not included in the ICD definition.

AIHW (2004c) also identify a number of codes in the learning and applying knowledge chapter that are relevant to cognitive functioning, for example focusing attention (d160), thinking (d163), reading (d166), writing (d170), calculating (d172), solving problems (d175) and making decisions (d177), but note that registration is not coded in the ICF. Additionally, they note that although behaviour is not separately included in the ICF classification, several codes describe components of behaviour and mental functions relevant to behaviour, for example temperament and personal functions (b126), emotional functions (b152) and complex interpersonal interaction (d720).

Table 2.5: Mapping the ICD definition of dementia to the ICF

Components of ICD definition	Mapped ICF domains	ICF codes
Memory	Memory	b144
Thinking	Thought	b160
Orientation	Orientation	b114
Comprehension	Mental functions of language	b167
	Reading	d166
Calculation	Calculation	b172
Learning capacity	Learning and applying knowledge	d110–d199
Language	Mental functions of language	b167
Judgement	Higher level cognitive functions: Judgement	b164: b1645
Emotional control	Emotional	b152
Social behaviour	Interpersonal interactions and relationships	d710–d799
Motivation	Energy and drive functions: Motivation	b130: b1301

Source: Based on Madden 2006 and advice from AIHW Functioning and Disability Unit.

Comparison of the ICD and DSM classifications of dementia

Each of these classifications has certain limitations in relation to measuring and diagnosing dementia. For example, the ICD-10 and DSM-IV tend to focus on Alzheimer’s disease, with memory loss (along with impairment in other cognitive domains) a requirement for a diagnosis of dementia. Chui (2005) argues that benchmarking other forms of dementia against Alzheimer's disease leads to a marginalisation of non-Alzheimer's disorders and a restriction of the clinical use of both the ICD-10 and DSM-IV. Although the ICD-10 and DSM-IV definitions aim to distinguish dementia from delirium and restricted cognitive impairments such as aphasia or amnestic syndrome, Sachdev (2000) argues that the emphasis on memory loss is restrictive and may delay diagnosis of dementias such as vascular dementia and frontotemporal dementia, where impairment of other cognitive domains may be more prominent in the early stages of the disease. Additionally, memory loss may be present for some time in someone with Alzheimer's disease before other cognitive deficits become apparent, warranting a diagnosis of amnestic syndrome rather than dementia at the early stages of the disease.

Furthermore, the diagnostic guidelines accompanying the ICD-10 do not specify criteria for dementia in Lewy body disease, or frontotemporal dementia, which are no longer rare conditions—DSM-IV mentions them as requiring further research (Chui 2005). Dementia is also difficult to verify using the ICD without the presence of an informant.

The preparation of the DSM-IV was closely coordinated with the preparation of Chapter V (Mental and behavioural disorders) of the ICD-10—consultations between the American Psychiatric Association and the World Health Organization attempted to develop DSM-IV codes and terms that are fully compatible with those of the ICD-10 (American Psychiatric Association 2000). However, the full compatibility of the two systems is fairly limited due to inconsistency of the diagnostic criteria/guidelines between them. Table 2.6 provides a comparison of the classification of dementia in recent versions of the ICD and DSM.

Table 2.6: Comparison of classification of dementia in the ICD and DSM

ICD-10: Organic, including symptomatic mental disorders	DSM-III-R: Organic mental disorders	DSM-IV: Delirium, dementia & amnestic & other cognitive disorders	DSM-IV-TR: Delirium, dementia & amnestic & other cognitive disorders
F00 Dementia in Alzheimer's disease F00.0 Dementia in Alzheimer's disease with early onset	**290.1x Primary degenerative dementia of the Alzheimer type, presenile onset *(also code 331.0 Alzheimer's disease on Axis III)***	**290.1x Dementia of the Alzheimer's type, with early onset *(also code 331.0 Alzheimer's disease on Axis III)***	**294.1x Dementia of the Alzheimer's type, with early onset *(also code 331.0 Alzheimer's disease on Axis III)***
F00.1 Dementia in Alzheimer's disease with late onset	290.10 Uncomplicated	290.10 Uncomplicated	294.10 Without behavioural disturbance
F00.2 Dementia in Alzheimer's disease, atypical or mixed type	290.11 With delirium	290.11 With delirium	294.11 With behavioural disturbance
F00.9 Dementia in Alzheimer's disease, unspecified	290.12 With early onset, with delusions	290.12 With early onset, with delusions	
Specify if (optional):	290.13 With depressed mood	290.13 With depressed mood	**294.1x Dementia of the Alzheimer's type, with late onset *(also code 331.0 Alzheimer's disease on Axis III)***
.x0 without additional symptoms	**290.xx Primary degenerative dementia of the Alzheimer type, senile onset *(also code 331.0 Alzheimer's disease on Axis III)***	**290.xx Dementia of the Alzheimer's type, with late onset *(also code 331.0 Alzheimer's disease on Axis III)***	
.x1 with other symptoms, predominantly delusional			294.10 Without behavioural disturbance
.x2 with other symptoms, predominantly hallucinatory	290.00 Uncomplicated	290.00 Uncomplicated	294.11 With behavioural disturbance
.x3 with other symptoms, predominantly depressive	290.20 With delusions	290.20 Delusions	
	290.21 With depression	290.21 With depressed mood	
.x4 with other mixed symptoms	290.30 With delirium	290.3 With delirium	

(continued)

Table 2.6 (continued): Comparison of classification of dementia in the ICD and DSM

ICD-10: Organic, including symptomatic mental disorders	DSM-III-R: Organic mental disorders	DSM-IV: Delirium, dementia & amnestic & other cognitive disorders	DSM-IV-TR: Delirium, dementia & amnestic & other cognitive disorders
F01 Vascular dementia	**290.4x Multi-infarct dementia**	**290.4x Vascular dementia**	**290.4x Vascular dementia**
F01.0 Vascular dementia of acute onset	290.40 Uncomplicated	290.40 Uncomplicated	290.40 Uncomplicated
F01.1 Multi-infarct dementia	290.41 With delirium	290.41 With delirium	290.41 With delirium
F01.2 Subcortical vascular dementia	290.42 With delusions	290.42 With delusions	290.42 With delusions
F01.3 Mixed cortical & subcortical vascular dementia	290.43 With depression	290.43 With depressed mood	290.43 With depressed mood
F01.8 Other vascular dementia			Specify if: with behavioural disturbance
F01.9 Vascular dementia, unspecified			
Specify if (optional):			
.x0 without additional symptoms			
.x1 with other symptoms, predominantly delusional			
.x2 with other symptoms, predominantly hallucinatory			
.x3 with other symptoms, predominantly depressive			
.x4 with other mixed symptoms			
.xx0 mild			
.xx1 moderate			
.xx2 severe			
F02 Dementia in other diseases classified elsewhere	**Organic mental disorders associated with Axis III physical disorders or conditions or whose aetiology is unknown**	**294.xx Dementia due to other general medical conditions**	**294.1x Dementia due to other general medical conditions**
F02.0 Dementia in Pick's disease	294.10 Dementia	294.9 Dementia due to HIV disease *(also code 042 HIV on Axis III)*	294.1x Dementia due to HIV disease *(also code 042 HIV on Axis III)*
F02.1 Dementia in Creutzfeldt-Jakob disease		294.1 Dementia due to head trauma *(also code 854.00 Head injury on Axis III)*	294.1x Dementia due to head trauma *(also code 854.00 Head injury on Axis III)*
F02.2 Dementia in Huntington's disease		294.1 Dementia due to Parkinson's disease *(also code 331.82 Dementia with Lewy bodies on Axis III)*	294.1x Dementia due to Parkinson's disease *(also code 331.82 Dementia with Lewy bodies on Axis III)*
F02.3 Dementia in Parkinson's disease		294.1 Dementia due to Huntington's disease *(also code 333.4 Huntington's disease on Axis III)*	294.1x Dementia due to Huntington's disease *(also code 333.4 Huntington's disease on Axis III)*
F02.4 Dementia in HIV disease		290.10 Dementia due to Pick's disease *(also code 331.11 Pick's disease on Axis III)*	294.1x Dementia due to Pick's disease *(also code 331.11 Pick's disease on Axis III)*
F02.8 Dementia in other specified diseases classified elsewhere		290.10 Dementia due to Creutzfeldt-Jakob disease *(also code 046.1 Creutzfeldt-Jakob disease on Axis III)*	294.1x Dementia due to Creutzfeldt-Jakob disease *(also code 046.1 Creutzfeldt-Jakob disease on Axis III)*
Dementia in: cerebral lipidosis; epilepsy; hepatolenticular degeneration; hypercalcaemia; hypothyroidism; acquired, intoxications; multiple sclerosis; neurosyphilis; niacin deficiency (pellagra); polyarteritis nodosa; systemic lupus erythematosus; trypanosomiasis; vitamin B_{12} *deficiency*		294.1x Dementia due to [indicate the general medical condition not listed above] *(also code the general medical condition on Axis III)*	294.1x Dementia due to… [indicate the general medical condition not listed above] *(also code the general medical condition on Axis III)*
Specify if (optional):			*Code presence or absence of a behavioural disturbance in the fifth digit for dementia due to a general medical condition*
.x0 without additional symptoms			*0=without behavioural disturbance*
.x1 with other symptoms, predominantly delusional			*1=with behavioural disturbance*
.x2 with other symptoms, predominantly hallucinatory			
.x3 with other symptoms, predominantly depressive			
.x4 with other mixed symptoms			
.xx0 mild			
.xx1 moderate			
.xx2 severe			

(continued)

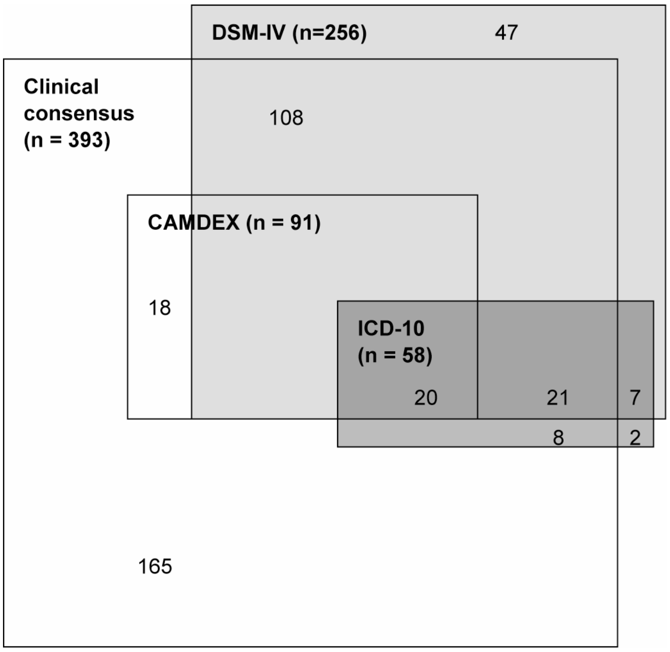
Table 2.6 (continued): Comparison of classification of dementia in the ICD and DSM

ICD-10: Organic, including symptomatic mental disorders	DSM-III-R: Organic mental disorders	DSM-IV: Delirium, dementia & amnestic & other cognitive disorders	DSM-IV-TR: Delirium, dementia & amnestic & other cognitive disorders
F1x.7 Residual and late-onset psychotic disorder F1x.70 Flashbacks F1x.71 Personality or behaviour disorder F1x.72 Residual affective disorder F1x.73 Dementia F1x.74 Other persisting cognitive impairment F1x.73 Late-onset psychotic disorder For use with mental and behavioural disorders due to… F10 use of alcohol F11 use of opioids F12 use of cannabinoids F13 use of sedatives or hypnotics F14 use of cocaine F15 use of other stimulants, including caffeine F16 use of hallucinogens F17 use of tobacco F18 use of volatile solvents F19 due to multiple drug use & use of other psychoactive substances	**291.20 Dementia associated with alcoholism** **292.82 Other or unspecified psychoactive substance dementia**	**—.— Substance-induced persisting dementia *(refer to substance-related disorders for substance-specific codes)*** 291.2 Alcohol-induced persisting dementia 292.82 Substance (Inhalant, sedative, hypnotic & anxiolytic, other (or unknown))-induced persisting dementia	**—.— Substance-induced persisting dementia *(refer to substance-related disorders for substance-specific codes)*** 291.2 Alcohol-induced persisting dementia 292.82 Inhalant-induced persisting dementia 292.82 Sedative-, hypnotic- or anxiolytic-induced persisting dementia 292.82 Other (or unknown) substance-induced persisting dementia
F03 Unspecified dementia Presenile: dementia nos, psychosis nos Primary degenerative dementia nos Senile: dementia nos; (depressed or paranoid type, nos), psychosis nos *Specify if (optional):* *.x0 without additional symptoms* *.x1 with other symptoms, predominantly delusional* *.x2 with other symptoms, predominantly hallucinatory* *.x3 with other symptoms, predominantly depressive* *.x4 with other mixed symptoms* *.xx0 mild* *.xx1 moderate* *.xx2 severe*	**290.00 Senile dementia nos *(specify aetiology on Axis III if known)*** **290.10 Presenile dementia nos *(specify aetiology on axis III if known e.g. Pick's disease, Jakob-Creutzfeldt disease)***	**—.— Dementia due to multiple aetiologies *(code each of the specific aetiologies)*** **294.8 Dementia nos**	**—.— Dementia due to multiple aetiologies *(code each of the specific aetiologies)*** **294.8 Dementia nos**
F05.1 Delirium superimposed on dementia **F06.7 Mild cognitive disorder** *Specify if (optional):* *.70 not associated with a systemic physical disorder* *.71 associated with a systemic physical disorder*		**294.9 Cognitive disorder not other specified** Mild neurocognitive disorder, postconcussional disorder **Other conditions that may be a focus of clinical attention** 780.9 Age-related cognitive decline	**294.9 Cognitive disorder not other specified** Mild neurocognitive disorder, postconcussional disorder **Other conditions that may be a focus of clinical attention** 780.93 Age-related cognitive decline

Sources: American Psychiatric Association 1986, 1994, 2000; WHO 1992a.

Differences between the various classification systems may yield different prevalence estimates when used in the same population (Henderson 1994b). In a survey of 1,045 persons aged 70 years and over, Henderson et al. (1994) found that the ICD-10 identified many fewer cases of dementia (3.2% of the sample), compared with the DSM-III-R (7.3% of the sample). In a study of only 34 nonagenarians and centenarians, Pioggiosi et al. (2003) found that the DSM-III-R and DSM-IV identified 47.1% and 41.2% people as having dementia, whereas the ICD-10 only identified 29.4% as having dementia.

Erkinjuntti et al. (1997) also investigated the effect of different diagnostic criteria on the estimates of dementia prevalence in a sample of 1,879 people. Figure 2.2 shows that the DSM-IV identified 256 people (13.7% of the sample) as having dementia; although not shown in Figure 2.2, the DSM-III-R identified 326 people (17.3% of the sample). In comparison, the ICD-10 only identified 58 people (3.1% of the sample) as having dementia. Despite substantial overlap between the two classifications only 48 people were diagnosed under both criteria.



Source: Reproduced from Erkinjuntti et al. 1997.

Figure 2.3: Subjects identified as having dementia according to various diagnostic classification systems

Although the DSM-III-R and DSM-IV identified many more cases of dementia in the study sample[3] (e.g. the DSM classification systems included more cases with mild dementia[4] and there was a trend toward detecting a shorter mean duration of symptoms), the difference is not simply due to the ICD-10 being more restrictive than the DSM-III-R and DSM-IV. The systems identify different individual subjects as having dementia. Erkinjuntti et al. (1997) identified the factors that best predicted disagreement between the DSM-IV and ICD-10 as:

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[3] The DSM is generally broader than the ICD, and tends to be more inclusive of some types of dementias.

[4] The ICD classification systems are more likely to identify advanced cases of dementia in which the diagnosis is quite apparent (Erkinjuntti et al. 1997).

- impairment of long-term memory (as well as short-term memory) in the DSM-IV (and DSM-III-R)
- executive function—the ICD is stricter in requiring there to be impairment of all three executive functions of abstract thinking, judgement and problem-solving, whereas the DSM only requires there to be impairment of abstract thinking or judgement (or other higher cortical function or behavioural and emotional function)
- the presence or absence of aphasia
- impairment of work or social activities in the DSM-IV (and DSM-III-R) versus impairment of activities of daily living in the ICD-10[5]
- duration of symptoms—although the DSM-IV (and DSM-III-R) requires a decline in functioning before dementia is diagnosed, a six-month history (like that used by the ICD-10) is not imposed. [6]

The factors that best predicted disagreement between the classification systems in the study by Pioggiosi et al. (2003) differed from those reported by Erkinjuntti et al. (1997), although this may be due to the higher cognitive and functional impairment in nonagenarians and centenarians (also, the diagnostic difficulty for dementia increases with age). For example, Pioggiosi et al. (2003) did not find significant differences related to long-term memory impairment, impairment of activities of daily living (versus social function) or to the duration of symptoms. Additionally, all the subjects identified as having dementia by the other classification systems were also identified as having dementia by the DSM-III-R criteria, indicating that the differences were due to the more restrictive nature of the other classifications rather than identifying different individuals. Concordance and agreement between the DSM-III-R and ICD-10 was weaker than that between the other classification systems. As indicated by the study by Erkinjuntti et al. (1997), the DSM-III-R and ICD-10 were differentiated by the weight given to cognitive impairment—all three executive functions have to be impaired according to the ICD-10.

In general, Pioggiosi et al. (2003) reported that there was good concordance and agreement between the DSM-III-R and the DSM-IV. Both Erkinjuntti et al. (1997) and Pioggiosi et al. (2003) reported a similar proportion of cases using the DSM-III-R as compared with using the DSM-IV. Pioggiosi et al. (2003) noted that the factors that best predicted disagreement between DSM-III-R and DSM-IV were calculation impairment and the absence of personality changes. In a study of ageing in Sydney, Waite et al. (2001) (cited in Chui 2005) reported that the DSM-III criteria were more inclusive that the DSM-IV criteria.

Table 2.7 shows that differences also exist when comparing results from the DSM-III, the ICD-9 and the CAMDEX. For example, Erkinjuntti et al. (1997) noted each successive revision of the DSM appeared to extend the diagnosis to fewer subjects with dementia—the inclusion of long-term memory impairment as a requirement for the diagnosis of dementia in the DSM-III-R and DSM-IV had a particularly substantial effect on the prevalence. Sachdev (2000) also noted the problematic nature of memory loss in the DSM classification systems.

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5 The ICD-10 does not include impairment of social function as a criterion for assessing dementia (Pioggiosi et al. 2003).

6 Chui (2005) notes that the six-month time limit demanded by the ICD-10 criteria indicates the statistical median but does not address outliers whose cognitive impairment may be less than the six months (e.g. Creutzfeldt-Jakob disease).

Table 2.7: Criteria for dementia in the classification systems

Domain in which impairment is required	DSM-III	DSM-III-R	DSM-IV	ICD-9	ICD-10	CAMDEX	Clinical consensus
Memory							
Short-term memory (learning skills)	•	+	+	+	+	+	
Long-term memory	•	+	+	(•)	(•)	+	
Executive function (planning, abstraction or problem-solving ability)			•				
Abstract thinking	•	•		+	+	•	
Judgement	•	•		+	+	•	
Problem solving				+	+		
Other higher cortical function	•	•	•			•	
Aphasia (language disturbance)			•		(•)		
Apraxia (impairment of the ability to perform coordinated movements or manipulate objects)			•				
Agnosia (inability to interpret sensory stimuli)							
Constructional abilities							
Calculation					(•)		
Behavioural & emotional function	•	•				•	
Personality				(•)		•	
Emotional control				(•)	(•)	•	
Motivation					(•)		
Social behaviour					(•)		
Social function							
Work	•	•	•	•		+	
Social activities	•	•	•	•			
Activities of daily living					+	+	
Relationships with others		•					
Other features incorporated into criteria							
Impairment		+					
Progressive deterioration					(•)	+	
Decline from function before illness	+	+	+	+	+	+	
Duration of symptoms ≥ 6 months					+	+	
Normal consciousness	+	+	+		+	+	
Assumed organic cause	+	+			+		
Mental retardation as cause					(•)		
Prevalence of dementia (%)							
CHSA sample (Erkinjuntti et al. 1997)	29.1	17.3	13.7	5.0	3.1	4.9	20.9
Nonagenarians & centenarians (Pioggiosi et al. 2003)	—	47.1	41.2	—	29.4	38.2	—

Note: + impairment in domain is always required for diagnosis; • one or more of those bracketed is required; (•) optional, strengthens the diagnosis; CSHA Canadian Study of Health and Aging.

Source: Reproduced from Erkinjuntti et al. 1997 and Pioggiosi et al. 2003.

Furthermore, clinicians and researchers may differ in their use of the same classification, which may also yield different results when used in the same population. However, training or further guidance in the implementation of the classifications tends to lead to greater consistency. The clinical descriptions and diagnostic guidelines accomanying the ICD-10 (WHO 1992b) were prepared with the aim of improving diagnostic practices among health services (Henderson 1994a:6–8).

2.4 Conclusion

Estimates of the prevalence of dementia in a population are critical for the planning, funding and provision of appropriate treatment and care of people with dementia, whether those services are part of dementia-specific programs or where the person's dementia should be taken into account in the provision of other services. These estimates vary with the definition and diagnostic criteria used by different classifications. At the level of the individual, the use of different diagnostic criteria, and the utility and validity of the screening and assessment tools used, affect the likelihood of receiving a diagnosis, and consequently have an impact on the person's access to appropriate information, treatment and care options.

The analysis of data in Section 2 of this report is constrained by the definitions and classifications used in existing data sources. However, the major purpose of Section 3 of this report is to recommend data elements that will form the basis for further work on improving dementia data and data standards. This work needs to be supported by the use of common definitions and classifications of dementia and its outcomes. This report recommends that **both** the ICD and ICF should be used in Australia for this purpose.

Both the ICD and ICF belong to the family of international classifications developed by the WHO for application to various aspects of health. The WHO family of international classifications provides a framework to code a wide range of information about health (e.g. diagnosis, functioning and disability, reasons for contact with health services) and uses a standardised common language permitting communication about health and health care across the world in various disciplines and sciences (WHO 2001:3).

Health conditions (e.g. diseases, disorders, injuries) are generally classified using the ICD, which provides diagnosis codes for diseases, disorders or other health conditions. Functioning and disability associated with health conditions are classified using the ICF. The ICD and ICF enable consistent collection of information about diagnosis as well as human functioning. The ICD and ICF are therefore complementary, and WHO encourages the use of these classifications together to provide a more meaningful and complete picture of the health needs of people and populations (WHO 2001:4).

Although the DSM appears to be the classification used by most clinicians, the ICD is used in the classification of mortality and morbidity in hospitals in Australia and forms the basis of health condition codes used in the ACAP, the NHS and the SDAC. The ICF is used to provide consistency of data relating to support needs for people with disability between the Survey of Disability Ageing and Carers, the Commonwealth-State/Territory Disability Agreement NMDS, the National Community Services Data Dictionary and the 2006 Census of Population and Housing. Additionally, the DSM requires more training and skills to use, and is therefore difficult for non-clinicians to use.

While making this recommendation, this report is not suggesting that the ICD and ICF currently capture all aspects of dementia and its outcomes completely. The WHO constitution, which governs the activities of the Classifications, Assessment and

Terminologies team and the WHO-FIC Network, states that one of the functions of the WHO is to establish and revise as necessary international nomenclatures of diseases, of causes of death and of public health practices (WHO 1994). The ICD has well-established processes for revising its structure and definitions which allow it to respond to developments in research and medical practice. The ICF is a relatively new classification and processes to guide modifications and updates are currently being considered.

A fundamental question for the development of recommendations about standard dementia data elements also concerns whether data collection should include both diagnosed dementia and cognitive impairment more generally.

Where data are collected using dementia diagnosis as the only identifying information, it is likely that the prevalence of dementia in that program or service is underestimated. Reliance on diagnostic criteria excludes a population of people with declines in cognitive functioning who have not yet achieved the criteria for dementia diagnosis, with possible consequences that some individuals do not access services that could improve their quality of life through identifying and managing treatment and care options.

Collection of information about cognitive impairment, as well as dementia diagnosis, results in a potentially larger population being identified, some of whom may not have dementia because their cognitive impairment is attributed to some other disease process. However, it ensures the identification of people who may share some similar care needs as those with diagnosed dementia, some of whom may have early stage dementia, and/or progress to dementia.

This report recommends the collection of information about both dementia diagnosis and the presence of cognitive impairment. This is discussed further in Chapter 12, which also presents recommended data elements.

3 Dementia data in Australian collections

In Australia, information about people with dementia, their carers and their use of health and care services, is collected through a number of administrative data collections and surveys. These collections have different aims, applications and collection methodologies which influence their content, and use different definitions and classifications of dementia.

This chapter briefly describes each of the data sources used in this report, including collection methods, data collection context and scope of each collection. Each description outlines the availability of data elements relevant to dementia, including diagnosis status, type of dementia, cognitive impairment, behaviour, medications/treatments, functioning and carer items. These are summarised in Table 3.1 at the end of this chapter.

In addition to the data sources used for analysis in Section 2 of this report, the chapter also includes information about a selection of Australian longitudinal studies which include data about dementia. Longitudinal studies are particularly valuable when examining progressive conditions such as dementia. A description of the main national health population survey, the NHS, is also included.

A more detailed review and comparison of dementia-relevant data elements is included in Chapter 11.

3.1 Administrative collections

Administrative (or service by-product) data collections are based on information collected as part of the delivery of health or community services. The primary data collected at the point of service delivery can be used to derive data to support secondary (or downstream) information purposes such as reporting, policy, governance and decision support as well as to provide information necessary for patient or client care. The population covered by these collections is generally restricted to the clients of a particular program. Some collections are based on individual client records, while others consist only of aggregated data—this limits the type of analysis that is possible.

Some administrative collections such as hospital-based care collections are mandated for national collection by the National Health Information Group as NMDSs and some of the data elements are used to derive performance indicators required under the Australian Health Care Agreements. Minimum data sets (MDS) contain agreed data elements for collection and reporting relevant to a particular service. The data collected is relevant to the service or care being provided although organisations are not precluded from collecting additional information to meet their own specific needs.

The collections covered in this chapter come from the main national health and care programs that people with dementia and/or people caring for them will access.

Alzheimer's Australia data

Alzheimer's Australia is the national peak body for people with dementia, their families and carers. State and territory organisations provide information, support, advocacy and education services. Alzheimer's Australia delivers the Australian Government's National Dementia Support Program.

The Dementia Education and Support Program (DESP) Database Data Dictionary Version 2.2 (Alzheimer's Australia 2003) contains the data elements that are currently collected by Alzheimer's Australia. These data elements collect information (such as sociodemographic characteristics) about **contacts** with Alzheimer's Australia, whether they are people with dementia, carers of people with dementia or health professionals. Client type categories are used to characterise the individual or group of people involved in the contact.

Identification of people with dementia is based on a range of dementia diagnosis data items recorded across the collections including: dementia diagnosis status, date of diagnosis, diagnosis by whom and type of dementia. A memory and assistance profile collects information about memory impairment and personal care assistance. Data items relevant to carers include carer status and relationship to the person of concern. Additional information about functioning (orientation, judgement, community affairs, home and hobbies and mobility), overall need, carer assistance and carer overall need is collected, but these data items do not appear in the data dictionary.

Medicare Benefits Schedule data

The Medicare Benefits Schedule (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. These subsidies mostly cover out-of-hospital medical services but also apply to medical services delivered in hospitals to private patients. Medicare Australia is responsible for administering payments and information for the Medicare program.

MBS data collected by Medicare Australia (formerly the Health Insurance Commission) cover only those services eligible for Medicare benefits, as listed in the Medicare Benefits Schedule (DoHA 2004b). The MBS data include Medicare item number, Medicare benefit paid, date of service and processing, provider number, recipient of the service and an indication of whether or not the item was provided in a hospital. The unit of measurement in this collection is the **service**.

There are no dementia-specific services in the Medicare Benefits Schedule, but people with dementia may access a range of services that are eligible for Medicare benefits such as: health assessments (e.g. assessment of psychological functions such as cognition); Medication Management Reviews (e.g. Domiciliary Medication Management Reviews where a person with dementia has difficulty managing their own medications); pathology and diagnostic radiology (e.g. thyroid function tests or MRI to investigate possible dementia); and consultations and case conferencing (e.g. for care planning).

Pharmaceutical Benefits Scheme data

The Pharmaceutical Benefits Scheme (PBS) is administered by Medicare Australia and was established to reimburse pharmacists who have dispensed eligible prescription pharmaceuticals at a cost greater than the patient's contribution.

The PBS data collection includes information on prescriptions dispensed to general patients where a pharmacist is eligible for a reimbursement, prescriptions dispensed to persons who have been issued with a health care card, or those who have reached the safety net threshold. The Medicare Australia website contains aggregate statistics, based on PBS items and medication group categories, for each state and territory (Medicare Australia 2005). Data comprises drug codes as classified in the Pharmaceutical Benefits Schedule (DoHA 2006). The unit of measurement in this collection is **prescriptions**.

Three anticholinesterases are funded under the PBS for the treatment of mild to moderately severe Alzheimer's disease: donepezil hydrochloride (Aricept), galantamine hydrobromide (Reminyl) and rivastigmine hydrogen tartrate (Exelon). An authority is required for PBS funding of these medications. The authority application must include the result of the baseline MMSE. This baseline MMSE must be a score of 10 points or more and, if this score is at least 25 points, the result of a baseline ADAS-Cog must also be specified.

In order to qualify for continuing treatment, following initial therapy, of mild to moderately severe Alzheimer's disease there must be a demonstrated improvement in cognitive function as measured by an increase of at least two points from baseline on the MMSE, or for patients with an MMSE baseline score of at least 25 points, a decrease of at least four points from baseline on the ADAS-Cog. The information about cognitive state is recorded with the details of the prescription.

Information about people who self-fund their anticholinesterase medication is not collected. Information about the use of medications for dementia, other than anticholinesterases, cannot be identified in the collection.

National Hospital Morbidity Database

The National Hospital Morbidity Database is a compilation of electronic summary records collected in admitted patient morbidity data collection systems in Australian hospitals:

1. Admitted Patient Care NMDS: reports data on episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities and alcohol and drug treatment centres in Australia.
2. Admitted Patient Mental Health Care NMDS: restricted to episodes of care of admitted patients receiving admitted patient care in psychiatric hospitals or in designated psychiatric units in acute hospitals (the scope does not include patients receiving treatment for psychiatric conditions in other units in acute hospitals).
3. Admitted Patient Palliative Care NMDS: records information about episodes of care for admitted patients receiving palliative care in all public and private acute hospitals, and free standing day hospital facilities.

The database records information on hospital **separations** (not patients), where a separation refers to the episode of care, which can be a total hospital stay, from admission to discharge, transfer or death, or a portion of a hospital stay beginning or ending in a change in type of care (AIHW 2005a).

Principal and additional diagnoses responsible for a patient's episode of care in hospital or contributing to the cost of care, surgical and non-surgical procedures and external causes are recorded using ICD-10-AM codes. A list of procedure codes are given in AIHW (2002b). A principal diagnosis is the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital (or attendance at the health care facility). An additional diagnosis is a condition or complaint either coexisting with the principal diagnosis or arising during the episode of care or attendance at a health care facility (National Health Data Committee 2004b). Dementia (as well as cognitive disorder and age-related cognitive decline) may be recorded as a principal or additional diagnosis.

Aged Care Assessment Program MDS

The ACAP is an Australian, state and territory government funded program to assess the needs of frail, older people and recommend and facilitate access to available care services appropriate to a person's needs. The program uses multi-disciplinary Aged Care Assessment Teams (ACATs) which comprise medical, nursing and allied health professionals, as well as social workers, interpreters and other professionals.

ACAT carry out comprehensive assessments to determine eligibility for admission into residential aged care or residential respite care, and for Community Aged Care Packages (CACP) and EACH places (AIHW 2002b). They may also provide information and refer clients to other suitable services such as services funded by Home and Community Care (HACC), the National Respite for Carers Program (NRCP) and Veterans' Home Care, although they do not determine eligibility for these services. Assessments involve the evaluation of the care needs of a person, incorporating the restorative, physical, medical, psychological, cultural and social dimensions of care (AIHW 2002a; DoHA 2002a).

The ACAP MDS specifies a collection of information on individual assessments (the unit of measurement may be **clients** or **assessments**). Between 1991 and 2001, the MDS underwent a review and then redevelopment, resulting in Version 2.0 of the data collection, designed to report on the core work of ACATs (AIHW 2004c). The ACAP MDS Version 2 was implemented from April 2003. The information collected by ACATs predominantly relates to client characteristics and circumstances, health status, functional abilities, current assistance from services, documentation of the assessment process, and ACAT recommendations for care. Data items relating to carers include carer availability, carer co-residency status and relationship of the carer to the care recipient.

Information about the type of dementia may be recorded as a primary health condition that has the greatest impact on the client's need for assistance, or as one of nine other health conditions that impact on the client's need for assistance—codes are based on the ICD-10-AM. Dementia was the most common primary diagnosis among all ACAP clients in 2002–03—19% of all ACAP clients (or 30,800 clients) had a primary diagnosis of dementia (Lincoln Centre for Ageing and Community Care Research 2004). Body function impairments are based on the ICF, and those particularly relevant to dementia fall under the heading of *Mental functions*. Additional questions focusing on cognitive behaviour/psychological aspects appear on the Aged Care Client Record completed by ACAT, but are not reported in the ACAP MDS.

Home and Community Care program MDS

The HACC program is one of three national programs that provide community-based care services to older people in Australia. HACC is jointly funded by the Australian, state and territory governments, and is the main provider of home-based care services in Australia. The program aims to enhance the independence of frail older people (around 80% of clients) as well as younger people with a disability, and their carers. Some examples of types of assistance provided through the HACC program include assessment, management and planning of requirements, transport, nursing, home maintenance, counselling and personal care.

The HACC MDS is client-based and reported nationally by HACC agencies every three months. Data collected per collection period are only on those clients who have received HACC-funded services from an agency within the three-month reporting period. Therefore, not all clients are necessarily included in each collection period nor are all type(s) of assistance received from HACC-funded agencies necessarily captured for this reason (AIHW 2002b).

Version 2 of the MDS is currently being implemented. No information about dementia is collected in Version 1 of the MDS. Information about dementia diagnosis will not be collected in Version 2 of the MDS, although information about memory problems or confusion and behavioural problems will be collected, as well as 12 other items about functional status. HACC also collects information about carers, including demographic items, existence of a carer, carer residency status, relationship of the carer to the care recipient, and carer for more than one person.

Community care packages data

Community Aged Care Packages data

The CACP program was established in 1992 by the Australian Government to provide assistance to enable frail older people with complex care needs to continue living in the community (AIHW 2004c). Younger people with disabilities may also access a care package in special circumstances as determined by ACAT assessment (DoHA 2002a).

CACPs provide a range of in-home support services, such as personal care, domestic assistance and social support, to people who would otherwise be eligible to receive at least low-level residential aged care. Recipients of CACPs must be assessed for eligibility by an ACAT. A CACP data dictionary has been developed, but the collection has not been implemented as a NMDS.

Ongoing program data are available from payment system data which are stored in the Aged and Community Care Management Information System (ACCMIS). This data source contains no information about health conditions (including dementia), need for assistance or type of assistance received. Nor are there data about carer arrangements.

Extended Aged Care at Home data

The EACH program provides home- and community-based services such as nursing and personal care to frail older people who would otherwise be eligible to receive high level residential aged care. The program provides an extensive range of support to people living in the community including general services, specialised clinical services, care and support services. Recipients of EACH packages must be assessed for eligibility by an ACAT. As for CACP, an EACH data dictionary has been developed, but the collection has not been implemented as a NMDS.

Current ongoing program data are also available from ACCMIS, and contain no information about health conditions (including dementia), need for assistance or type of assistance received. Nor are there data about carer arrangements.

More comprehensive data will be collected following the implementation of EACH Dementia.

Community care packages census data

In 2002, the AIHW, in conjunction with the Department of Health and Ageing, conducted census collections of the CACP and EACH programs. CACP and EACH service providers completed two types of forms—the first form collected information about the provider's characteristics and the second collected data about individual clients[7] and the services delivered to them. Each of the questionnaires for these programs contained a question on whether the client had been formally diagnosed with dementia.

The census also collected demographic information about the client, information about core activity limitations (including communication), as well as items about carer availability, carer co-residency status and relationship of the carer to the care recipient.

Residential Aged Care data

Residential aged care services provide accommodation and support for older people who can no longer live at home. To enter residential care, people must have the appropriate recommendation from an ACAT. In addition to permanent care, short-term respite care services are also provided. Data about residential aged care service providers and residents are also available from ACCMIS.

Available data includes information about resident characteristics including the level of care and supervision provided in respect of 20 specific activities. There are no data about any health conditions (including dementia). However, information about care provided is used in this report and in previous work to estimate the prevalence of dementia among permanent residents and/or their dependency profile.

Data on the care provided to residents are currently collected through 20 questions which form the Resident Classification Scale (RCS). There are eight RCS categories which denote the level of care provided to a resident, with RCS 1 representing the highest level. High level care is generally denoted by RCS categories 1–4, while low level care residents are in categories 5–8. The RCS category for a resident determines the level of subsidy an agency will receive in respect of that person (AIHW 2002b). The appraisal used for the RCS does not consider all of a resident's care needs, just those that have been identified as contributing the most to differences in the total cost of residential care. New clients are assessed within 30 days of entering a residential aged care facility, and are reassessed every 12 months unless a significant change in care needs occurs.

RCS questions about the characteristics, needs or behaviour of the resident that are particularly relevant to dementia include: verbally disruptive or noisy; problem wandering or intrusive behaviour; emotional dependence; understanding and undertaking living activities; physically aggressive; social and human needs; other behaviour; danger to self or others; social and human needs; and communication. Information about the level of care provided with other activities such as personal hygiene and mobility is also collected.

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[7] Although the CACP and EACH programs refer to those individuals receiving CACP or EACH packages as 'recipients' or 'care recipients', the term 'client' will be used in this report, in order to avoid confusion with those individuals that are recipients of care from an informal carer.

Two RCS questions have been previously used to construct an index designed to estimate the prevalence of dementia in residential aged care: question 1, the '*degree of assistance the care recipient needs in communicating with staff, relatives and friends, and other care recipients for whatever reasons*', and question 8, the '*care recipient's ability to remember, understand, plan for, initiate and perform general living activities and to react appropriately to information provided*' (Cuthbertson et al. 1998, cited in AIHW 2004f). Combinations of these scores were used to allocate residents to one of three categories: no dementia, possible dementia and probable dementia.

This current report uses a different methodology to estimate the number of people with dementia in residential aged care, based on a mapping of questions from the RCS to questions on the cared accommodation component of the SDAC. This method is described in Chapters 7 and 8.

A new funding appraisal tool called the Aged Care Funding Instrument (ACFI) is currently being developed and trialled to replace the RCS. The ACFI collects information on the care needs of residents rather than on the care provided to residents and will be used to determine government subsidy levels for each resident, including people who have been diagnosed with dementia and other mental or behavioural disorders (DoHA 2005b). The ACFI is currently being tested in a national trial by a consultancy team led by Dr Richard Rosewarne (Applied Aged Care Solutions) and Associate Professor Peter Foreman (The Lincoln Centre for Ageing at La Trobe University).

The trial version of the ACFI consists of 13 domains, of which domains 6, 7, 8 and 12 relate to cognitive skills, problem wandering, physical and verbal behaviour and mental and behavioural diagnosis (based on ACAP health condition codes), respectively. The trial version also includes questions designed to identify shorter-term needs in complex health, nursing and behavioural areas (ACFI Complex Care Indicator). One of these questions is concerned with identifying dementia and/or behavioural needs in terms of: the complexity of care needs; predictability of the person's response to their condition; and the stability of the condition. Information about the level of care required with other activities, such as eating and drinking and personal hygiene, is also collected. The introduction of the ACFI will obviously improve the data about dementia in residential aged care in the future.

National Respite for Carers Program data

The NRCP funds respite services, Commonwealth Carer Respite Centres, Commonwealth Carer Resources Centres and the National Care Counselling Program. Commonwealth Carer Resource Centres provide carers with up-to-date, relevant information and advice about available services and support, government programs, publications, training and education. Commonwealth Carer Respite Centres are run by a wide variety of community organisations, and may organise, purchase or manage respite care assistance packages for carers, if required. Respite care assistance may include in-home, residential, short-term or emergency respite. Many of the respite services are dementia-specific. Commonwealth Carer Respite Centres also work closely with the Commonwealth Carer Resource Centres to ensure comprehensive support for carers and access to carer information and training materials.

The NRCP MDS consists of two separate data collections, which include information about services provided by Commonwealth Carer Resource Centres and Commonwealth Carer Respite Centres. Where data requirements are the same across these collections, the collections have defined the data elements in the same way. Detailed information is collected about the carer, with additional information collected about the care recipient (e.g. dementia status) and service event. The data are transmitted quarterly to the Department of Health and Ageing collection agency. The MDS in unique in that it is a carer-centred data set which also collects information about care recipients and service events.

As well as demographic information, dementia diagnosis status, primary disability, care needs, level of need and challenging behaviour are collected about the care recipient. Information about the carer and the caring role includes demographics, co-residency status, relationship of the carer to the care recipient, number of care recipients, time spent caring, carer need and use of services.

3.2 Surveys

In contrast to administrative data collections which result from the collection of information necessary to the delivery of a service or program, surveys are primarily designed to collect data for a possible range of purposes. Client surveys focus on the clients of a particular service and on topics that are relevant to service delivery. Like administrative data collections, they allow the estimation of prevalence for client groups. Population surveys, such as the ABS SDAC, may be used to provide prevalence estimates in the population as a whole. The population being surveyed is typically selected through sampling procedures based on household and individual characteristics.

Population and client surveys may be cross-sectional or longitudinal in nature. Cross-sectional surveys collect data at a single point in time. Repeat cross-sectional surveys permit some analysis of the change in populations of interest over time, but do not allow any change in individuals to be examined. However, a longitudinal design that can be used to examine patterns of change at the individual level and investigate causal relationships between variables of interest is particularly useful when considering progressive health conditions such as dementia.

As the prevalence of dementia in the general population is quite low and is concentrated in the older age groups, it is difficult to ensure that there are sufficient cases in a general population survey to permit reasonable analysis. Over-sampling of the older age groups or of people in cared accommodation (a strategy used by the SDAC), or a very large overall sample size, can not only increase the amount of data available and improve the quality of analysis, but also increase the resources required for the study. Alternatively, purpose-designed surveys may use client populations of interest as a sampling frame.

Data may be collected via:

- survey questionnaires (either self-completed or interview administered)—variations on this may include diary completion by respondents
- clinical measurements (e.g. height and weight, or analysis of blood samples)
- researcher observations (e.g. of mobility in the home).

The heavy reliance on self-reporting from questionnaire-based methodologies poses particular challenges for the collection of reliable data about cognitive disorders such as dementia. However, most surveys permit the use of proxy-reporting where the relevant respondent is unable to self-report.

National population surveys

National Health Survey

The NHS is a population survey conducted by the ABS. The NHS is designed to obtain national benchmark information on a range of health-related issues, and to enable changes in health to be monitored over time. Surveys were conducted in 1977–78, 1983, 1989–90, 1995, 2001 and 2004; the 2001 and 2004 surveys are the first two surveys in a new series of triennial ABS health surveys, and covered topics similar to those in the 1995 survey. The NHS is a self-report survey, and is conducted in private dwellings throughout urban and rural areas across all states and territories of Australia (generally excluding sparsely settled areas). No data are collected on people in non-private dwellings, such as cared accommodation.

The content differs between surveys, around a common (or core) data set. For example, the 2001 NHS collected information about:

- the health status of the population, including long-term medical conditions experienced (particularly asthma, cancer, heart and circulatory conditions, diabetes and mental wellbeing) and recent injuries
- use of health services such as consultations with health practitioners and visits to hospital and other actions people have recently taken for their health
- health-related aspects of people's lifestyles, such as smoking, diet, exercise and alcohol consumption
- demographic and socioeconomic characteristics (ABS 2002).

In the 2001 NHS, information about dementia (and cognitive impairment and behaviour) as a long-term health condition is collapsed into the category of *Organic mental health problems* or *Symptoms and signs involving cognition, perceptions, emotional state and behaviour* under *Mental and behavioural problems* (see ABS 2002), and is not separately identifiable in the Mental Health Supplement. The survey does not include any information about functioning or carers.

Survey of Disability Ageing and Carers

The ABS SDAC collects information about people with a disability, older people (i.e. those aged 60 years and over), and people who provide assistance to older people and people with disabilities (ABS 2004). Surveys were conducted in 1981, 1988, 1993, 1998 and 2003. The SDAC collects data about long-term health conditions, and enables national estimates of the prevalence of disability and the conditions, such as dementia, that give rise to it. Other survey data sources that identify long-term conditions (e.g. the NHS) do not collect information in respect of disability and caring. Importantly, the SDAC is the only national survey to collect data about people living in cared accommodation. This is a particularly important consideration when conducting research about dementia.

Information in the 2003 survey was collected from approximately 36,200 respondents from about 14,300 private dwellings (e.g. houses and flats) and non-private dwellings (e.g. hotels and motels), and approximately 5,100 respondents from about 600 cared accommodation establishments such as hospitals and residential aged care establishments. The survey gathers data from people living in both rural and urban areas across Australia.

The survey was conducted using two collection instruments: an interviewer-based computer-assisted collection for all usual members of selected households; and mail-back forms completed by a staff member for residents of cared accommodation facilities. Families with a member (such as parent or child) with a disability were identified, together with families in which a member was a primary carer. The cared accommodation component covered residents of hospitals, residential aged care and other homes, who had been, or were expected to be, living there for at least three months.

Data from the household component of the survey are based on self-report, or reported by a proxy such as a carer where the person of interest was unable to respond for themselves. Long-term health condition(s) were not identified by clinical assessment or other more rigorous methods of diagnosis. This affects estimates of the prevalence of dementia, particularly in terms of identifying people in the early stages of dementia, before any cognitive or functional impairments or changes in behaviour have become apparent. Where dementia was reported by people or their carers, it was overwhelmingly associated with the experience of profound or severe disability. In 2003, it is estimated that of the 101,900 people with dementia, the number sometimes or always needing assistance with self-care, mobility and/or communication—that is, with a severe or profound core activity limitation—was 98,800. Therefore, the survey is likely to underestimate the prevalence of dementia, particularly for people living in households.

In cared accommodation, the survey is not self-reported but is completed by a staff member who is required to record any long-term health conditions. The data collected were limited to the information a staff member could be expected to know from medical, nursing and administrative records (ABS 2004:15–16). The prevalence of dementia in these settings is likely to be more accurate than in the household component, although people who have undiagnosed or early-stage dementia, or whose dementia symptoms are masked by the symptoms of other health conditions and disabilities, may not be identified.

In the 2003 SDAC, long-term health conditions were coded to a classification based on the ICD-10. 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 (e.g. stroke) which produced an impairment or restriction which had lasted or was likely to last for at least six months. A person was considered to have a disability if he or she had a limitation, restriction or impairment which had lasted, or was likely to last, for at least six months and restricted everyday activities.

Dementia, *Alzheimer's disease* and *Parkinson's disease* are coded separately in the list of long-term health conditions. Other types of dementia, such as that arising from Huntington's disease or Pick's disease, fall within other categories such as *Other diseases of the nervous system*, along with other long-term health conditions. Similarly, alcoholic dementia falls within the category *Mental disorders due to alcohol and other psychoactive substance use*.

However, people with Parkinson's disease do not always develop dementia. Therefore, for analytic purposes, only those who report *Alzheimer's disease* and/or *Dementia* as a long-term health condition can be considered to have dementia. People with other forms of dementia, such as dementia in Parkinson's disease or alcoholic dementia, may report having both *Parkinson's disease* or *Mental disorders due to alcohol and other psychoactive substance use* as well as *Dementia*, but it cannot be assumed that this is necessarily the case.

In addition to data about long-term health conditions, a large amount of information about functioning is also collected, including questions on need for assistance with cognitive and emotional tasks, managing own behaviour and making decisions or thinking through problems. Additionally, the SDAC provides some information about carer availability, carer co-residency status, relationship of the carer to the care recipient, impact of the caring role, assistance provided and support access, as well as demographic information. However, the

2003 SDAC CURF only allows co-resident carers of people with dementia to be identified and only collects more detailed information from primary carers.

Further background information about the 1998 and 2003 SDAC can be found in the *Disability, Ageing and Carers* publications (ABS 2000, 2004).

Long-term health conditions in national population surveys

A comparison of the prevalence estimates for long-term health conditions from the National Health Survey and the Survey of Disability, Ageing and Carers highlights the sensitivity of these measures to survey design and methodology.

Overall, the number and proportion of people reporting at least one long-term condition in the 2001 National Health Survey were more than two times those of the 1998 Survey of Disability, Ageing and Carers: 78% of the total population in the NHS compared to about 36% in the SDAC (AIHW 2004d). The difference in these estimates occurs because the NHS recorded long-term health conditions that were not necessarily related to disability, whereas the SDAC recorded conditions that were more likely to be associated with impairments and activity limitations.

However, differences in prevalence estimates between the two national surveys varied with the type of condition. Some conditions had higher prevalence rates for the 2001 NHS than for the 1998 SDAC (e.g. vision problems, back problems, hearing disorders), while higher rates were reported by the SDAC than the NHS for other conditions (e.g. heart disease and stroke). The relatively lower rates of heart diseases and stroke in the NHS is partly because of the exclusion of persons living in institutions, as a substantial proportion of people with those conditions were living in institutions, and partly because of particular questions included in each survey.

The absence of dementia from the data file of the 2001 NHS means that the prevalence estimates from the two national surveys cannot be compared. However, two features of the SDAC design would suggest that it may be more successful in identifying respondents with dementia than the NHS—the inclusion of people in cared accommodation and the inclusion of all people in selected households who were over the age of 60 years. However, its bias towards recording conditions more likely to be associated with impairments and activity limitations suggests another possible reason for the underestimate of mild and moderate dementia prevalence.

Client surveys

Bettering the Evaluation and Care of Health

BEACH is a survey conducted by the Australian General Practice Statistics and Classification Centre within the Family Medicine Research Centre at the University of Sydney (an AIHW Collaborating Centre). BEACH is an ongoing survey that collects information about patients seen, reasons people seek medical care, problems managed and treatments provided in general practice in Australia. The survey began in April 1998 and involves about 1,000 GPs randomly sampled from Medicare records, each year. One hundred consecutive consultations (including indirect consultations by telephone) which result in a management action are recorded from each GP. The GPs are recruited on a rolling basis; approximately 20 GPs participate each week, 50 weeks a year (AIHW: GPSCU 2005).

BEACH uses a cross-sectional, paper-based data collection system and involves three interrelated data collections: encounter characteristics, GP characteristics and patient characteristics. The **encounter** is the primary unit of analysis; information recorded by the GP at each encounter includes demographic characteristics of the patient, patient reasons for encounter, diagnosis/problems managed and how each of these problems is managed. Data collected about management of each diagnosis/problem managed includes information about medications, procedures, other treatments and counselling, new referrals and admissions, and imaging and pathology ordered.

Additional questions about risk factors or special interest topics may be asked of patients in subsamples of encounters, as part of the Supplementary Analysis of Nominated Data (see AIHW: GPSCU 2005). Specific investigations have been conducted under this program to investigate the prevalence of Alzheimer's disease and other dementias or cognitive impairment in adult general practice patients, and to measure the proportion of general practice patients not diagnosed with dementia who, in the GP's opinion, were likely to have dementia or the early signs of Alzheimer's disease (AIHW: GPSCU 2002). The study also examined difficulties with daily living or behaviour changes in patients not diagnosed with Alzheimer's disease or dementia. This study used a sample of 2,194 encounters (with adults) from 88 GPs in August 2001.

Dementia may be recorded as one of three reasons for encounter or as one of four diagnoses/problems managed, coded using ICPC–2 PLUS. Information about commonly prescribed medications including antidementia drugs is collected and classified according to the Anatomical Therapeutic Chemical group (Britt et al. 2004).

Longitudinal surveys

Longitudinal studies typically follow cohort(s) of people over time thus allowing investigation of causation of the outcome of interest. They are of particular value when the outcome of interest concerns a progressive condition such as dementia. There are a number of Australian longitudinal studies which collect data about dementia. Of these studies, the Australian Longitudinal Study on Women's Health is a national survey, while there are five smaller local area longitudinal studies. Information about these studies is drawn from the stocktake of such studies undertaken by the AIHW in 2004 (AIHW: Logie et al. 2004), also available on the Ageing Research Online website (www.aro.gov.au).

National longitudinal studies

Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health (Women's Health Australia) is a national study providing information on women's health issues. The study began in June 1995 in response to initiatives arising from the National Women's Health Policy. The study is designed to explore factors that influence health among women who are broadly representative of the entire Australian population.

In April 1996, the Health Insurance Commission randomly selected 14,739 women aged 18–23, 12,762 women aged 45–50 and 14,011 women aged 70–75 from the Medicare database. Each age cohort is surveyed once every three years (over a 20-year period), via surveys sent in the mail, to see how each participant's health has changed.

Women's Health Australia collects information about the needs, views, lifestyles, health and factors affecting the health of individual women in Australia. It takes a comprehensive view of all aspects of health throughout women's life spans. In particular, the study assesses:

- physical and emotional health (including wellbeing, major diagnoses, symptoms)
- use of health services (GP, specialists and other visits, access, satisfaction)
- health behaviours and risk factors (diet, exercise, smoking, alcohol, other drugs)
- time use (including paid and unpaid work, family roles and leisure)
- sociodemographic factors (location, education, employment, family composition)
- life stages and key events (such as childbirth, divorce, widowhood).

The study also links social, environmental and personal factors in women's lives to health care use data, by record linkage with the Medicare database.

Alzheimer's disease or dementia was added to the list of diagnosed or treated medical conditions from the second survey of the oldest cohort, although an *Other—please specify* category exists for the younger cohorts. In the second survey, 0.5% of the oldest cohort (aged 73–78 years) reported that they had been diagnosed with (or treated for) Alzheimer's disease or dementia. This increased to 1.1% in the third survey, when the oldest cohort was aged 76–81 years. The oldest cohort is also asked about the presence of poor memory and difficulty concentrating. All cohorts are asked questions about functioning.

The survey also identifies those respondents in the two older cohorts that are carers, but no details of the person they care for (such as dementia status) are collected. Demographic information is collected, and questions are asked about physical and emotional health (including information on a range of signs and symptoms such as pain and stress), difficulties with sleep, service use, sources of income, social support and leisure activities, allowing the impact of the caring role to also be examined.

The longitudinal nature of the survey means that patterns of change at the individual level can be described and analysed, and that casual relationships can be investigated. However, the use of self-reporting (or reporting by proxy), particularly via a mail-out survey, means that dementia and carers of people with dementia are likely to be under-reported.

Local area longitudinal studies

A number of local area longitudinal studies also collect information about dementia. Although these studies are small (compared with the national Australian Longitudinal Study on Women's Health), they frequently include clinical measures and assessments.

Australian Longitudinal Study of Ageing

The Australian Longitudinal Study of Ageing began in 1992, collecting data from 2,087 participants in South Australia. The Centre for Ageing Studies at Flinders University is the unit responsible for the study and for data collection. The study allows assessment of the effects of social, biomedical, psychological, behavioural, economic and environmental factors on changes in health, development of disability, general wellbeing, economic security, use of acute and long-term care services, morbidity, mortality and 'successful' ageing in people aged 70 and over. Data about cognitive functioning along with other information about health and functional status have been collected over the period 1992–2003.

Sydney Older Persons Study

This study began in 1991 with 327 war veterans and widows and 320 non-veterans aged 75 and over. The five stages of the study consist of medical and neurological assessments of the participants, and data collection on health and lifestyle and medication history.

Stage 4 of the study had a particular focus on the cognitive and structural correlates of 'normal' brain ageing, and on the impact of age, environmental factors and illnesses on executive functions in older people. As part of this study stage, 102 community-dwelling individuals aged over 80 years underwent MRI scanning of the brain as well as neurological and neuropsychological assessment. Stage 5 of the study concentrated on subjects who had an MRI scan in stage 4. These people were re-invited to participate in a further MRI scan and neuropsychological assessment.

In a substudy of participants from wave 3, Bennett et al. (2003) found that 78 (26%) had a Clinical Dementia Rating (CDR) score of 1 or above (representing mild, moderate and severe dementia), 95 had a score of 0.5 (questionable dementia or mild cognitive impairment), and 126 had a score of 0 (normal cognition).

Canberra Longitudinal Study of Ageing

The Canberra Longitudinal Study of Ageing is a 12-year study into the health and memory of older people. It aims to identify predictors of memory decline and dementia and provide epidemiological data on mental disorders in older Australians. The sample consists of a single cohort of approximately 1,000 people aged 70 years and over with initial collection in 1990–91, and subsequent waves in 1994, 1998 and 2002.

Interviews incorporated the Canberra Interview for the Elderly which provides diagnoses of dementia and the following cognitive tests: Mini-Mental State Examination (screening test), 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 (measure of cognitive speed), Episodic Memory Test (four short memory tasks) and the Informant Questionnaire on Cognitive Decline.

Korten et al. (1999) found that the main predictors of mortality between waves 1 and 2 were physical ill health and poor cognitive functioning, and that mortality among men was more than twice that of women even after adjusting for a wide range of other variables. The relation with cognitive performance remained when respondents diagnosed with dementia were excluded from the analysis. Age was not a significant covariate once adjustment was made for health and cognitive performance, but was significant if only physical health was controlled—Korten et al. (1999) suggest that cognitive impairment may be a stronger predictor of mortality than age over short periods of time.

For men the physical health predictor was self-rated health, while for women it was disability in activities of daily living. For cognitive functioning, the predictors for men and women were the Symbol-Letter Modalities Test and the MMSE, respectively. This confirms results from other studies that suggest self-rated health is a better predictor of mortality for men than for women, and that a test of mental speed is a good predictor for men (Idler & Benyamini 1997, cited in Korten et al. 1999).

PATH Through Life Project

The Personality and Total Health (PATH) Through Life Project is a 20-year longitudinal study of 7,485 adult community residents randomly selected from the Canberra and Queanbeyan electoral rolls. It aims to investigate the causes of three classes of common mental health problems: anxiety and depression; alcohol and substance abuse; and cognitive ageing and dementia. Neurocognitive assessments by a doctor and MRI scans were used in a substudy of the 60–64-year-old cohort that examined relationships between health and memory and looked at memory change over time. In a substudy of 2,551 subjects aged 60–64 years, Kumar et al. (2005) found that 224 (8.8%) screened positive for mild cognitive impairment. Of these, 112 underwent a detailed assessment and 74% met the criteria for at least one recognised diagnosis of mild cognitive deficit. By predictive regression modelling, the prevalence of any mild cognitive deficit in the population of those aged 60–64 years was 13.7%. The estimated prevalence rates for specific diagnoses were mild cognitive impairment 3.7%, ageing-associated cognitive decline 3.1%, CDR 0.5 2.8%, age-associated memory impairment 1%, other cognitive disorders 0.9% and mild neurocognitive disorder 0.6%.

Most tests in the neuropsychological battery were chosen for their sensitivity to the effects of cognitive ageing: MMSE (cognitive screening instrument), List A of the California Verbal Learning Test (immediate recall and recall after a one minute delay), Digits Backwards from the Weschler Memory Scale (working memory), Symbol Digits Modalities Test (speed of information processing) and simple and choice reaction time tasks. The Spot-the-Word Test was administered as a measure of verbal intelligence, as it does not usually show age-related cognitive deficits.

It has been suggested that greater lifetime oestrogen exposure results in better cognition in later life, particularly in the area of verbal memory. However, in a substudy of 760 naturally postmenopausal women in the 60–64-year-old cohort, Low et al. (2005) found no significant associations between reproductive period and performance on any of the cognitive tests, either before or after controlling for potential confounding variables (such as the small but positive correlation between reproductive period and performance on the Spot-the-Word Test).

Dubbo Study of the Health of the Elderly

The Dubbo Study of the Health of the Elderly is a 15-year biomedical and social science investigation of healthy ageing, service use, delay of disability and age-related diseases such as cardiovascular disease, osteoporosis and dementia. A group of 2,805 non-institutionalised citizens aged 60 and over living in the town of Dubbo were first interviewed in 1988.

The study aims to identify patterns and predictors of mortality, hospitalisation and need for residential care. The Dubbo study also includes questionnaires examining life satisfaction, self-esteem, social involvement and support and family and community contributions. A new phase to the study began in 2000 to investigate how income and assets, government entitlements and informal care services modify expected changes in health or family circumstances in later life.

A unique feature of the Dubbo study was gaining participants’ consent to undertake record linkage to service provider databases including the PBS and Medicare databases.

Recently, McCallum et al. (2005) reported that 44% of nursing home placements were primarily related to dementia, while dementia was a secondary diagnosis in a further 20% of people admitted. At a 16-year follow-up, Simons et al. (2006) reported that of the 1,233 men and 1,572 women initially free of cognitive impairment (measured using the Short Portable Mental Status Questionnaire), 115 men (9.3%) and 170 women (10.8%) had developed dementia. On average, the men developing dementia were 3.5 years older at baseline than their peers without dementia, and the women with dementia were 5.7 older than their peers. Moderate intake of alcohol and daily gardening were found to predict a lower risk of dementia, and daily walking predicted a lower risk of dementia in men. Impaired peak expiratory flow and higher depression score at baseline predicted an increased future risk of dementia. Univariate analysis also suggested that lower educational attainment, prior coronary heart disease, poor self-rated health and physical disability were significant predictors of an increased risk of dementia.

Table 3.1: Summary of data items included across national collections

Collection	Dementia diagnosis status	Type of dementia	Cognitive impairment	Behaviour	Treatments for dementia	Functional impairment	Carer items
Alzheimer's Australia DESP	✓	✓	✓	✓		✓	✓
Medical Benefits Schedule							
Pharmaceutical Benefits Scheme			✓		✓		
National Hospital Morbidity Database		✓	✓				
Aged Care Assessment Program		✓	✓			✓	✓
Home and Community Care Program MDS v2			✓	✓		✓	✓
Community Aged Care Packages Program (census)	✓					✓	✓
Extended Aged Care at Home Program (census)	✓					✓	✓
Resident Classification Scale			✓	✓		✓	
Aged Care Funding Instrument (trial)		✓	✓	✓		✓	
National Respite for Carers Program	✓	✓†		✓		✓	✓
Bettering the Evaluation and Care of Health		✓	✓	✓	✓		
Survey of Disability, Ageing and Carers		✓	✓	✓		✓	✓
National Health Survey		✓†	✓	✓			
Australian Longitudinal Study on Women's Health	✓		✓			✓	✓

✓ The program includes a data item that allows for the collection of this information (though this does not necessarily mean that it is always collected).

✓† Limited information is collected in this area.

Section 2: Dementia data analysis

4 Prevalence, incidence and burden of disease

4.1 Summary

- Almost 175,000 people had dementia in Australia in 2003, and 190,000 in 2006, of whom 64% were female and 81% were aged 75 or older.
- Since dementia prevalence is strongly age-related, the number of cases of dementia is expected to increase to almost 465,000 by 2031, as the population grows and ages.
- Dementia may be classified as 'mild' in about 96,000 people (55%); 'moderate' in 52,000 people (30%); and 'severe' in 26,000 (15%).
- Most people with mild dementia are living in households and most people with moderate or severe dementia are in cared accommodation.
- There were about 37,000 new cases of dementia in 2003 of which 23,000 are female and 14,000 male.
- Most of the 'burden of disease' caused by dementia is due to disability rather than premature death, with disability accounting for about three-quarters of the total disease burden in 2003.

4.2 Prevalence of dementia

The prevalence of dementia is the number of people in the population affected by dementia at a given time. Prevalence estimates for dementia have commonly been based on data from meta-analyses, which combine data from a number of studies that use similar methods to produce better estimates. In Australia, estimates have also been derived from the 1998 and 2003 Surveys of Disability, Ageing and Carers (SDAC). However, there is evidence that these surveys underestimate cases of mild and moderate dementia in both households and, possibly to a lesser extent, in cared accommodation (see Chapter 3 for a discussion of this). For this reason estimates of prevalence of dementia for Australia based on meta-analyses have been preferred to those based on the 2003 SDAC.

Overview of prevalence estimates from meta-analyses

A number of individual epidemiological studies have investigated the prevalence (and incidence) of dementia, and its major subtypes, Alzheimer's disease and vascular dementia. Although these studies generally show similar results such as increasing rates with age, actual prevalence (and incidence) rates vary markedly from one study to another. Methodological effects such as definition of dementia or sample characteristics have substantial effects on the levels reported (Jorm et al. 1987, cited in Wancata et al. 2003).

Meta-analyses pool data from a group of individual studies which have used similar methods, with the aim of producing aggregate estimates with better accuracy than any individual study. These meta-analyses of the prevalence of dementia differ markedly in the number of individual studies included, the level of detail reported and the findings:

- Jorm et al. (1987) analysed data from 22 studies of moderate to severe dementia carried out between 1945 and 1985 across the world. Studies were excluded if they were based on limited psychiatric case registers; did not involve a broad community sample; or did not present rates for all the elderly aged 65 or more. The authors found that whereas the actual prevalence rates differed greatly between studies (due to methodological differences such as case definitions), there was a consistent underlying trend for prevalence rates to increase exponentially with age, with a doubling of the rate every 5.1 years of age up to about 95 years. No difference was found between males and females in the prevalence rate of dementia. Rates for Alzheimer's disease tended to be higher in females and rates for vascular dementia higher in males.
- Hofman et al. (1991) pooled data from 12 methodologically-similar European studies carried out between 1980 and 1990. The selection of studies was based on sufficient sample size; case-finding through direct individual examination; inclusion of both institutionalised and non-institutionalised individuals; and clinical diagnosis of dementia based on Diagnostic and Statistical Manual of Mental Disorders (DSM), Third Edition or equivalent criteria. The dementia prevalence rate nearly doubled with every 5 years of age over 60 years up to 95 years. Sex differences were the same as reported by Jorm et al. (1987).
- Ritchie et al. (1992) analysed data from 13 European, North American and Asian studies of moderate to severe dementia conducted since 1980. By restricting the studies to more recent data using standard diagnostic criteria the authors found much less variability in prevalence rates than Jorm et al. (1987) and Hofman et al. (1991). Their recommended model implied a doubling of the dementia prevalence rate every 6 years of age. No sex comparisons were reported.
- More recently, Ritchie & Kildea (1995) analysed data from nine recent European, North American and Asian studies conducted since the 1980s. The studies all used DSM-III diagnostic criteria, included samples of elderly people over 80 years of age, and used adequate sampling procedures from both community-dwelling and institutionalised populations. The authors modelled a flattened S-shaped curve which implied that prevalence rates levelled out at higher ages, to about 40% at around 95 years. No sex comparisons were reported.
- Fratiglioni et al. (1999) pooled data from 36 population-based prevalence studies of dementia carried out in Europe, North America, Asia and multi-ethnic communities, published between 1990 and 1998. Selection of studies was based on diagnosis of dementia using comparable diagnostic criteria. The dementia prevalence rate increased exponentially with age even at higher ages. No sex comparisons were reported.
- Lobo et al. (2000) pooled data from 11 European population-based studies of mild to severe dementia conducted in the 1990s, as an update to the meta-analyses by Hofman et al. (1991), and Rocca et al. (1991a, 1991b). The selection of studies was based on detection of cases in face-to-face interviews with the subjects and response rates above 80%. In each study, diagnosis of dementia was made according to DSM-III-R criteria, or equivalent criteria such as the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) or Automated Geriatric Examination for Computer Assisted Taxonomy (AGECAT). Prevalence rates differed greatly between studies, which Lobo et al. (2000:S7) suggested 'may reflect differences in sample size, or there may be weak risk factors related to dementia and survival that explain the variation in prevalence at older ages'.

Prevalence rates for dementia nearly doubled with every 5 years of age. In most studies examined by Lobo et al. (2000), the prevalence rate of dementia was found to be higher in females than males, particularly in the older age groups. The prevalence rate of Alzheimer's disease was higher in females than in males in all studies. Under 85 years of age, rates for vascular dementia were higher in males than females but the reverse was true after this age.

- Recently, Access Economics (2005) adopted methodology used by Wancata et al. (2003) and Jorm et al. (2005) and published estimates of the number of people with dementia in Australia based on rates from four meta-analyses. Prevalence rates for those over 60 were estimated by averaging the rates from Jorm et al. (1987), Hofman et al. (1991), Ritchie & Kildea (1995) and Lobo et al. (2000) for each age–sex group.

The age-specific rates for dementia from each of these sources are shown in Table 4.1 together with estimates of the number of Australians aged 65 years or over with dementia in 2003, based on these rates.

Table 4.1: Prevalence rates for dementia estimated from various sources, 2003

	Age group								Total 65+			
Study	**60–64**	**65–69**	**70–74**	**75–79**	**80–84**	**85–89**	**90–94**	**95–99**	**Per cent**	**Number**		
Jorm et al. (1987)	0.7	1.4	2.8	5.6	10.5	20.8	38.6	. .	**6.6**	**167,200**		
Hofman et al. (1991)												
Males	1.6	2.2	4.6	5.0	12.1	18.5	32.1	31.6	*6.3*	*71,200*	**7.4**	**189,100**
Females	0.5	1.1	3.9	6.7	13.5	22.8	32.2	36.0	*8.4*	*117,900*		
Persons	1.0	1.4	4.1	5.7	13.0	21.6	32.2	34.7	**7.3**	**185,800**		
Ritchie et al. (1992)	. .	1.3	2.4	4.4	8.1	14.9	27.3	50.2	**5.3**	**135,700**		
Ritchie & Kildea (1995)	. .	1.5	3.5	6.8	13.6	22.3	31.5	44.5	**7.6**	**193,400**		
Fratiglioni et al. (1999)	0.5	1.5	3.0	6.0	12.0	n.p.	n.p.	n.p.				
Lobo et al. (2000)												
Males	. .	1.6	2.9	5.6	11.0	12.8	22.1		*5.1*	*57,900*	**6.5**	**164,700**
Females	. .	1.0	3.1	6.0	12.6	20.2	30.8		*7.6*	*106,800*		
Persons	. .	0.8	n.p.	n.p.	n.p.	n.p.	28.5		. .	. .		
Ferri et al. (2005)												
EURO A	0.9	1.5	3.6	6.0	12.2	24.8			**7.1**	**181,800**		
WPRO A	0.6	1.4	2.6	4.7	10.4	22.1			**6.0**	**153,400**		
Access Economics (2005)												
Males	1.2	1.7	3.5	5.8	11.8	18.6	31.1	38.1	*6.0*	*67,700*	**7.1**	**180,700**
Females	0.6	1.3	3.3	6.3	12.6	21.5	33.3	40.3	*8.0*	*113,000*		

Notes

1. Age-standardised to the 30 June 2003 population (ABS 2003).
2. Final column includes estimates based on age–sex-specific rates.

Henderson & Jorm (1998) concluded that it is not possible to derive a 'true' prevalence rate from meta-analyses. Further, a 2004 report by the Organisation for Economic Co-operation and Development (OECD) concluded that there is currently no means of disentangling differences in dementia prevalence across countries from methodological differences since methodology is still not reproducible from one study to another (OECD 2004).

The prevalence estimates for Australia derived from the studies presented in Table 4.1 are influenced by the different selection criteria and methods adopted by the meta-analyses. Also, the meta-analyses are not mutually exclusive in terms of the individual studies selected for inclusion. The evidence from the more recent meta-analyses suggests that the prevalence of dementia in Australia in 2003 among Australians aged 65 years or older was between 136,000 and 193,000 (5.3% to 7.6%). Although a prevalence estimate for those aged 65 years or older has not been provided for the study by Fratiglioni et al. (1999), a comparison of the available rates with other studies suggests that it is likely to be within this range.

Estimation of dementia prevalence in this report

In this report, estimates of dementia prevalence in Australia have been derived from the age- and sex-specific rates from one specific meta-analysis, Lobo et al. (2000). The prevalence of the major types of dementia (Alzheimer's disease and vascular dementia) has also been estimated from this meta-analysis. The prevalence of Alzheimer's disease is estimated at 60% of total dementias for men and 75% for women. The corresponding estimate for prevalence of vascular dementia is 40% for men and 25% for women of total dementias.

The decision to use data from the Lobo et al. (2000) meta-analysis as a basis for estimating the prevalence of dementia in Australia was based on the following reasons:

- The meta-analysis is based on population-based studies conducted in the 1990s.
- It provides age- and sex-specific breakdowns for the major subtypes of dementia.
- It is based on studies using DSM-III-R or equivalent criteria (e.g. CAMDEX or AGECAT).
- Nearly all of the studies included in the meta-analysis adopted a two-phase screening design to ascertain dementia (i.e. a cognitive screen of the whole sample followed by clinical examination of all people who screened positive).
- It is a follow-up of the Hofman et al. (1991) meta-analysis of studies conducted in the 1980s by the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) group of researchers, which gave very similar results to the meta-analysis by Jorm et al. (1987).

The meta-analysis reported clear differences in the age-specific prevalence of Alzheimer's disease and vascular dementia, which supports the modelling of the major types of dementia separately. It is not clear whether the sex differences in the rates reported by Lobo et al. (2000) are real or an artefact of differential survival between the sexes and/or methodological differences (Launer et al. 1999).

The prevalence rates for Alzheimer's disease and vascular dementia were adjusted upwards by an age–sex-specific adjustment factor in order to account for 'other' dementia.

The prevalence of dementia in those aged less than 60 years is very low and is more appropriately estimated from cases that come to medical attention rather than from population surveys (Harvey et al. 2003). This UK study identified cases using multiple methods including hospital records and notification by health professionals. This study has been used to estimate prevalence rates of dementia for age groups less than 60.

Based on Lobo et al. (2000) and Harvey et al. (2003), there were an estimated 174,700 people with dementia in Australia in 2003 (Table 4.2). Almost two-thirds of people with dementia (64% or 112,200 people) were female. There were more females than males with dementia from 75 years of age. However, males with dementia outnumbered females with dementia in the younger age groups.

According to these estimates, 44% of people with dementia are aged 75–84 and 37% are aged 85 years and over. The age profile of males with dementia is different from that of females. For example, a higher proportion of males with dementia are aged less than 75 years (30%) than females (13%).

Table 4.2: Prevalence of dementia, by age and sex, 2003

	Rate (%)			Number		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
0–64	0.1	—	0.1	5,500	2,600	8,100
65–74	2.0	1.8	1.9	13,200	12,200	25,400
75–84	7.3	9.3	8.4	28,200	48,100	76,300
85+	17.1	24.9	22.4	15,600	49,300	64,900
65+	**5.0**	**7.8**	**6.5**	57,000	109,600	166,600
Total	**0.6**	**1.1**	**0.9**	**62,500**	**112,200**	**174,700**

— Nil or rounded to zero.

Sources: Based on data from Lobo et al. 2000 and Harvey et al. 2003.

Estimates from Access Economics (2005), which are widely reported in Australia, suggest that there were around 192,000 people with dementia in Australia in 2003. This estimate is higher than the 175,000 people with dementia reported in Table 4.2. However, it should be noted that estimates for those aged 65 years or over from both of these sources fall within the range of estimates reported in Table 4.1.

Prevalence estimates by place of residency

Because of the disabling impact of dementia, a high proportion of people with severe and advanced dementia require full-time care and live in cared accommodation. The Australian Bureau of Statistics (ABS) SDAC is the only national population survey to collect data about people in cared accommodation. As Chapter 3 noted, identification of people with dementia is likely to be more accurate in this component of the survey than in the household component, although people with undiagnosed or early-stage dementia or those whose dementia symptoms are masked by those of other health conditions may not be identified by staff completing the survey. Nevertheless, the SDAC is currently the best source of data about dementia in cared accommodation, and has been used in this report to estimate prevalence in this sector.

The prevalence of dementia by place of residency (cared accommodation or household) is shown in Table 4.3. Of the 175,000 people with dementia, 43% (75,000) live in cared-accommodation (based on the SDAC), and consequently the remaining 57% (99,000 people) live in households. The proportion of people with dementia who live in households decreases with age, with 79% of people with dementia aged between 65 and 74 still living in the community. This proportion decreases to 36% of people with dementia aged 85 and over.

The age profile of people with dementia in cared accommodation is older than for people in households. Almost one-quarter of people with dementia living in households are aged 85 and over, compared with 55% of those in cared accommodation.

Nearly half of males aged 85 and over with dementia still lived in households compared to 32% of females in the same age group. This pattern is reflected across all age groups where a greater proportion of men than women with dementia are still living in households.

Table 4.3: Prevalence of dementia in households and cared accommodation, 2003

Sex/age	Total prevalence	Cared accommodation[(a)]	Household	Per cent living in households
Males				
0–64	5,500	600	4,900	89.7
65–74	13,200	2,300	11,000	83.0
75–84	28,200	7,300	20,900	74.1
85+	15,600	7,900	7,700	49.3
Total	*62,500*	*18,000*	*44,500*	*71.1*
Females				
0–64	2,600	600	2,000	76.1
65–74	12,200	3,000	9,200	75.3
75–84	48,100	20,000	28,100	58.4
85+	49,300	33,600	15,700	31.9
Total	*112,200*	*57,200*	*55,000*	*49.0*
Persons				
0–64	8,100	1,200	6,900	85.3
65–74	25,400	5,300	20,100	79.3
75–84	76,300	27,300	49,000	64.2
85+	64,900	41,500	23,400	36.1
Total	**174,700**	**75,300**	**99,400**	**56.9**

(a) Cared accommodation includes *Accommodation for the retired or aged*, *Home for the aged*, *Home—other*, *Hospital—general* and *Hospital—other*. It is broader in scope than 'Residential aged care' reported in Table 7.27 in Chapter 7.

Source: AIHW analysis of the ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file; Table 4.2.

Stability of age prevalence rates over time

Lobo et al. (2000) reported that the age pattern of the prevalence estimates seemed stable over time, as there was a general similarity between findings in his study and the results based on studies conducted in the previous decade by Hofman et al. (1991), Rocca et al. (1991b) and Rocca et al. (1991a).

Comparison of the 1998 SDAC and 2003 SDAC shows that the overall age-specific dementia prevalence rates changed little over the five years. However, for the age group 85 and over there was a significant decrease from 21.9% to 17.5% (Box 4.1).

For dementia subtypes, Rocca et al. (1991b) reported stable age-specific rates for the prevalence of Alzheimer's disease over 15 years (between 1957 and 1972) for both sexes with the exception of a decrease for women and an increase for men aged 80–89 which resulted in little overall change. The age-specific prevalence rates of vascular dementia also remained relatively stable over 15 years for both sexes, with the exception of declines for both men and women in the 80–89 age group.

Box 4.1: Comparison of 1998 and 2003 SDAC

The overall rate of dementia in the population aged over 65, as estimated from the SDAC, was 4.0% in 2003 compared with 4.3% in 1998 (Table 4.4). For each age group, estimates are a little lower in 2003 with the difference most marked for the 85+ age group (17.5% in 2003 compared with 21.9% in 1998). The rate of dementia in cared accommodation for those aged over 65 was lower in 2003 (3.0%) than in 1998 (3.2%).

The reduction in the cared accommodation rate from 3.2% of the 65+ population in 1998 to 3.0% in 2003 is statistically significant and represents a reduction of 3,000 people with dementia from what it would have been if the rate had remained unchanged. In the cared accommodation segment of the survey the identification of dementia is made by facility staff not by the resident, and survey methods in both years were consistent.

In the future, data from the Aged Care Assessment Program (ACAP) Minimum Data Set (MDS) and the new Aged Care Funding Instrument (ACFI) will be available to more accurately measure changes in dementia in residential aged care.

Table 4.4: Dementia rates from 1998 SDAC and 2003 SDAC, by age and residency

	1998			2003		
Age	Household	Cared accommodation[(a)]	Total	Household	Cared accommodation[(a)]	Total
35–64	—	—	*0.1	—	—	—
65–69	**0.3	0.3	*0.5	**0.2	0.2	*0.4
70–74	*0.9	0.8	1.7	*0.5	0.6	*1.1
75–79	*1.2	2.0	3.2	*1.3	1.7	3.0
80–84	**0.8	6.0	6.8	*1.5	5.0	6.5
85+	4.8	17.1	21.9	*2.8	14.6	17.5
Total 35+	**0.3**	**0.8**	**1.1**	**0.3**	**0.7**	**1.0**
Total 65+	**1.1**	**3.2**	**4.3**	**1.0**	**3.0**	**4.0**

— Nil or rounded to zero.

* 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) Cared accommodation includes *Accommodation for the retired or aged*, *Home for the aged*, *Home—other*, *Hospital—general* and *Hospital—other*.

Source: AIHW analysis of the ABS 1998 and 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

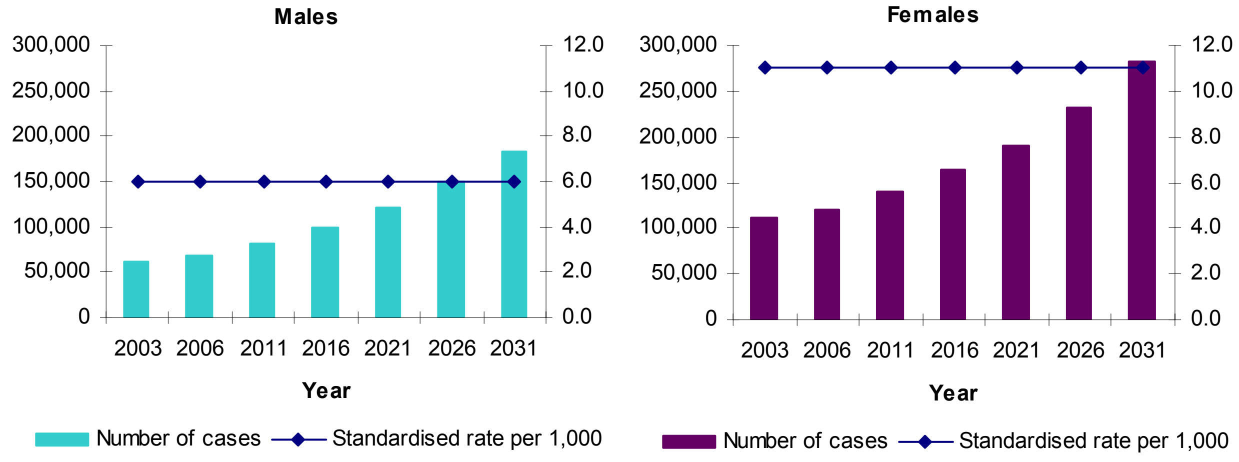
Projections of future prevalence

Between 2003 and 2031, the number of people with dementia is projected to increase from 175,000 to 465,000, an increase of 290,000 persons (Table 4.5 and Figure 4.1). In the eight years to 2011 the number of people with dementia is projected to increase by 27%, in the following decade by 40%, and in the decade to 2031 by 50%. The overall increase is 166%. This expected increase is entirely due to demographic factors, not an increase in the rate of the disease, that is, this increase results from the projected increase in the number of older people over this period and is based on the assumption that prevalence rates for dementia remain stable (Figure 4.1). However, prevalence rates may change as a result of changes in the prevention, detection, management and treatment of the disease.

Table 4.5: Projected number of people with dementia, 2003 to 2031

Sex/age	2003	2006	2011	2016	2021	2026	2031
Males							
0–64	5,500	5,900	6,700	7,100	7,600	7,800	8,000
65–74	13,200	13,900	16,700	20,900	24,100	26,200	28,400
75–84	28,200	30,500	33,000	37,800	47,100	61,000	71,800
85+	15,600	18,300	25,700	34,100	41,800	54,600	74,200
Total	*62,500*	*68,500*	*82,000*	*99,900*	*120,600*	*149,500*	*182,500*
Females							
0–64	2,600	2,900	3,300	3,600	3,800	3,900	4,000
65–74	12,200	12,600	14,900	18,800	22,100	24,200	26,000
75–84	48,100	50,300	51,500	56,400	67,900	87,400	104,100
85+	49,300	55,300	70,300	84,500	96,300	116,100	148,100
Total	*112,200*	*121,000*	*140,000*	*163,300*	*190,100*	*231,600*	*282,200*
Persons							
0–64	8,100	8,800	10,000	10,700	11,400	11,700	12,000
65–74	25,400	26,500	31,600	39,700	46,200	50,300	54,500
75–84	76,300	80,700	84,500	94,200	114,900	148,400	175,900
85+	64,900	73,500	96,000	118,500	138,100	170,700	222,200
Total	**174,700**	**189,600**	**222,000**	**263,200**	**310,600**	**381,100**	**464,700**

For comparative purposes, projections of the number of people with dementia in Australia in 2006, 2010 and 2020 as reported by Access Economics (2005) are 212,500, 242,500 and 332,900, respectively. The projected number of people with dementia in 2030 reported by Access Economics (2005) (465,500 people) is similar to the projected number of people with dementia in 2031 reported in Table 4.5 (464,700 people). Differences between the projections in Table 4.5 and the projections reported by Access Economics (2005) are due to differences in the meta-analyses used to derive prevalence estimates.



Source: Calculations by AIHW based on data from Lobo et al. 2000 and Harvey et al. 2003.

Figure 4.1: Change in prevalence (numbers and standardised rates) for dementia, 2003 to 2031

4.3 Prevalence by severity of dementia

The severity distribution of dementia in Australia has been estimated from the community-based, prospective study of degenerative diseases described by Barendregt & Bonneux (1998). The study included people in cared accommodation. In this study, severity is defined according to the Clinical Dementia Rating (CDR) scale (see Table 4.6) or a Mini-Mental State Exam (MMSE) score. 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 Morris 1993). Impairment is defined as decline from the person's usual level of functioning due to cognitive loss alone for each category, not impairment due to other factors, such as injury or depression. 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.

Table 4.6: Clinical Dementia Rating

Score	Healthy CDR 0	Very mild impairment CDR 0.5	Mild CDR 1	Moderate CDR 2	Severe CDR 3
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 orientated	Fully orientated except for slight difficulty with time relationships	Moderate difficulty with time relationships; orientated for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disorientated in time, often to place	Orientated to person only
Judgement & problem solving	Solves everyday problems and business affairs well; judgement good in relation to past performance	Slight impairment in solving problems, similarities, differences	Moderate difficulty in handling problems, similarities, 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 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		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

Note: Score only as decline from previous usual level due to cognitive loss, not impairment due to other factors.

Source: Reproduced from Morris 1993.

On the basis of severity definitions used in the CDR, Barendregt & Bonneux (1998) reported that 55% of dementia was classified as mild, 30% as moderate and 15% as severe. This overall distribution was applied to the total prevalence of dementia in Australia (Table 4.8), resulting in about 96,000 people with mild dementia, 52,000 with moderate dementia and just over 26,000 people with severe dementia. This is a critical assumption in the calculation of the burden of disease later in this chapter.

Table 4.7: Comparison of severity of dementia impact in the CDR and SDAC

Clinical Dementia Rating			Survey of Disability, Ageing and Carers	
Disease severity	**Definition**	**Estimate**	**Need for assistance**[(a)]	**Definition**
Mild (CDR 0.5–1)	Significant impact on daily activities but still able to undertake daily activities	55%	Mild	The person needs no help & has no difficulty with any of the core activity tasks but may use aids & 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	30%	Profound	The person is unable to do, or always needs help with, a core activity task
Severe (CDR 3)	Permanent supervision required	15%		

(a) Need for assistance is based on limitations with communication, self-care or mobility, which may also be caused by a coexisting condition other than dementia.

Sources: ABS 2004; Barendregt & Bonneux 1998.

In order to estimate the severity distribution of dementia separately for households and cared accommodation, the severity categories of the CDR have been mapped to disability severity measures in the SDAC, the source of data about people with dementia in cared accommodation. Although the SDAC has no disease severity measures, the survey does contain measures of **disability** severity based on need for assistance with core activity limitations. Core activities in the SDAC are personal care, mobility and communication activities (see Box 4.2). Such mapping is possible because the CDR domains include a description of the functional outcomes of dementia of different severity, including personal care. Table 4.7 maps the CDR domain descriptions to the SDAC descriptions of need for assistance with core activities.

Mapping between the CDR and SDAC is not perfect since a person's need for assistance as measured by the SDAC may arise partly because of the presence of another health condition. The two scales also use quite different nomenclature. For example, the 'mild', 'moderate' and 'severe' disability categories in SDAC correspond to the 'mild' domain using CDR. Those who are profoundly disabled according to the SDAC criteria mostly belong in the 'moderate' CDR domain and some belong in the 'severe' CDR domain. 'Moderate' is a serious misnomer for the CDR 2 category. As is shown by Table 4.6, people in the CDR 2 category have such severe memory loss that only highly learned material is retained, they are severely impaired in making judgements or solving problems, they often have no pretence of independent function outside home, and require help with personal care. Most people would describe this situation as 'severe' but the CDR labels it as merely 'moderate'. By contrast, the SDAC category of moderate disability indicates that the person needs no help but has difficulty with a core activity task. It is important to note that the language used in the two scales is therefore not equivalent.

Box 4.2: ABS 2003 Survey of Disability, Ageing and Carers: 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 (communication, mobility or self-care). 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*
- *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 any of the core activity tasks, but:*

- *uses aids or equipment;*
- *cannot easily walk 200 metres;*
- *cannot walk up and down stairs without a handrail;*
- *cannot easily bend to pick up an object from the floor;*
- *cannot use public transport;*
- *can use public transport but needs help or supervision;*
- *needs no help or supervision but has difficulty using public transport.*

Source: ABS 2004:72.

Table 4.8 shows estimates of prevalence of dementia by severity and place of residency based on the results of this mapping and on the severity distribution estimated by Barendregt & Bonneux (1998). The number estimated to have mild dementia (CDR 0.5–1) in cared accommodation is considered roughly equivalent to the number with severe, moderate or mild core activity limitation. Those with profound core activity limitation are allocated to the moderate (CDR 2) or severe (CDR 3) category. The split between moderate (CDR 2) and severe (CDR 3) dementia for the 71,907 people with CDR 2/CDR 3 dementia living in cared accommodation is made according to the proportions from Barendregt & Bonneux (1998) (2/3 moderate and 1/3 severe), resulting in 47,900 people with moderate dementia and 24,000 with severe dementia.

The distribution of severity for people with dementia in households is then allocated to fit with both the cared accommodation severity distribution and the overall severity distribution. For example, 52,400 (30%) of people with dementia have moderate dementia; and 48,900 people in cared accommodation have moderate dementia; therefore 4,400 people with moderate dementia must be living in households.

Table 4.8: Severity of dementia, by sex and residency, 2003

Residency/severity	Males	Females	Persons	Proportion by place of residency	Proportion of total dementia
Cared accommodation[(a)]					
Mild (CDR 0.5–1.0)					
Mild, moderate, severe core activity limitations	900	2,400	3,400	4.5%	1.9%
Moderate (CDR 2)					
Profound core activity limitations (2/3)	11,400	36,500	47,900	63.7%	27.4%
Severe (CDR 3)					
Profound core activity limitations (1/3)	5,700	18,300	24,000	31.8%	13.7%
Total cared accommodation	*18,000*	*57,200*	*75,300*	*100.0%*	*43.1%*
Household					
Mild (CDR 0.5–1.0)					
Mild, moderate, severe core activity limitations	39,000	53,700	92,700	93.2%	53.1%
Moderate (CDR 2)					
Profound core activity limitations (2/3)	4,000	500	4,500	4.5%	2.6%
Severe (CDR 3)					
Profound core activity limitations (1/3)	1,400	800	2,200	2.3%	1.3%
Total household	*44,500*	*55,000*	*99,400*	*100.0%*	*56.9%*
All dementia					
Mild (CDR 0.5–1.0)					
Mild, moderate, severe core activity limitations	40,000	56,100	96,100	55.0%	55.0%
Moderate (CDR 2)					
Profound core activity limitations (2/3)	15,400	37,000	52,400	30.0%	30.0%
Severe (CDR 3)					
Profound core activity limitations (1/3)	7,100	19,100	26,200	15.0%	15.0%
Total dementia	**62,500**	**112,200**	**174,700**	**100.0%**	**100.0%**

(a) Cared accommodation includes *Accommodation for the retired or aged*, *Home for the aged*, *Home—other*, *Hospital—general* and *Hospital—other*.

Based on the method described above, people with mild dementia (CDR 0.5 to 1) comprise 93% of people with dementia living in households. Ninety-six per cent of people with dementia living in cared accommodation have moderate or severe dementia (CDR 2 or 3). Moderate dementia (CDR 2) accounts for 64% of people with dementia in cared accommodation and 3% of people with dementia in households.

4.4 Incidence of dementia

The methodological issues associated with determining estimates of dementia incidence—that is, the number of new cases in a specified period—mean that there are few data sources available in this area. As indicated in earlier discussion in this report, the 2003 SDAC underestimates the prevalence of dementia when symptoms are mild. Clinical assessment is also more difficult for mild cases, and this factor has been surmised to be the reason for discrepancies in estimates obtained across studies (Jorm & Jolley 1998). The number of new dementia cases per year is low and the costs associated with undertaking longitudinal studies in susceptible groups are therefore prohibitively high.

No incidence studies have been undertaken in Australia, but estimates of incidence for Australia have been made using information from overseas epidemiological studies. For example, Access Economics (2005) adopted methodology used by Wancata et al. (2003) and Jorm et al. (2005) and published estimates of the number of incident cases of dementia in Australia based on rates from four meta-analyses. Incidence rates for those over 60 were estimated by averaging the rates from Jorm & Jolley (1998), Gao et al. (1998), Launer et al. (1999) and Fratiglioni et al. (2000) for each age–sex group. Access Economics (2005) estimates that in 2003 there were around 48,900 incident cases of dementia in Australia.

However, this report calculated incidence estimates based on available information about prevalence, duration of illness and mortality over and above background mortality (see AIHW: Mathers et al. 1999:208 for a discussion of this approach). Using this method, it is estimated that in 2003 there were around 37,000 incident cases of dementia in Australia (Table 4.9). (The methods used to derive this estimate are presented in Box 4.3). Incidence rates reported by Access Economics (2005) are higher than those estimated in this report. However, there must be an implausibly high death rate in order for the incidence rates reported by Access Economics (2005) to be consistent with the reported prevalence rates.

Not all of the 37,000 incident cases estimated by the AIHW will be initially visible as people with dementia, as onset usually occurs with mild symptoms. However, as dementia is not reversible, they will over time become part of the visible prevalent population or they will die of other causes. The majority (63% or 23,200) of these were female and 13,800 were male. Incidence increased with age in both males and females, but decreased in those aged 85 years or older.

Table 4.9: Estimated incidence of dementia, by age and sex, 2003

Age	Males	Females	Persons
0–64	1,100	600	1,600
65–74	2,800	2,700	5,400
75–84	6,300	10,100	16,400
85+	3,700	9,900	13,500
Total	**13,800**	**23,200**	**37,100**

Source: AIHW and University of Queensland estimates based on meta-analysis of overseas studies (see Box 4.3).

Box 4.3: Methods used in calculating the incidence of dementia

The incidence estimate for 2003 reported here was derived using a computer software program, DISMOD II (an incidence/prevalence/mortality model). DISMOD was designed primarily to supplement observational data and help disease experts arrive at internally consistent estimates of incidence, prevalence, remission, duration and mortality for the Burden of Disease study. The model assumes no remission and an overall relative risk of mortality of 2.0 for Alzheimer's disease and 3.3 for vascular dementia, which gives an average duration across all ages for both sexes of 4.4 years. For chronic conditions (such as dementia), prevalence information is preferred as an input into DISMOD II as:

- *incidence is more difficult to observe because the date of onset is insidious and progressive; and*
- *comparisons of incidence and prevalence estimates of dementia from meta-analyses are inconsistent (unless an implausibly short duration of two years is assumed with extreme estimates of mortality).*

There have been two recent meta-analyses (Dewey & Saz 2001; Jagger et al. 2000) on prevalent cases of dementia and survival. Prevalent cohort survival data typically arise when prevalent cases are followed either until failure or censoring. Such data are collected as part of what are known as prevalent cohort studies (i.e. some people with dementia at the beginning of the follow-up), commonly through cross-sectional sampling, with follow-up, which is often carried out when time and logistics preclude the possibility of incident cohort studies (Asgharian et al. 2005). Both Jagger et al. (2000) and Dewey & Saz (2001) found an increased risk (relative risk of 2.4–2.6) of mortality in people with dementia. The evidence for differentials in mortality risk by age and sex is not clear (Jagger et al. 2000; Dewey & Saz 2001), and although Dewey & Saz (2001) found that vascular dementia tends to have a higher mortality risk than Alzheimer's disease, this finding was based on four studies and did not necessarily reach statistical significance. These results are not immediately useful due to the limitations inherent in survival studies of prevalent cases, including:

- *the course of the disorder can not be recorded in its entirety because date of onset of disease is not known; and*
- *prevalent cases include a mixture of new and long existing cases which may bias results in either direction).*

As a result the two studies of incident cases and survival (Aguero-Torres et al. 1999 and Helmer et al. 2001), highlighted by the Guehne et al. (2005) review, were considered. Incident studies (i.e. people who were not demented at the beginning of the follow-up and who are prospectively monitored for the incidence or onset of dementia, with follow-up continuing until death) allow more precise statements to be made about the course of the disorder and mortality (Guehne et al. 2005).

The relative risk of death in all dementia of 2.7 (95% CI = 2.1–3.4), in Alzheimer's disease of 2.0 and in vascular dementia of 3.3,was based on the Aguero-Torres et al. (1999) study which controlled for comorbidities. That study was preferred to the results from the Helmer et al. (2001) study as the results were more in keeping with those from prevalent cases; however, it is not clear which study is the most plausible based on the available evidence. An age pattern (based on the Dewey & Saz 2001) finding that the relative risk of death in dementia at age 65 is around 6, whereas by age 85 it has fallen to 2) was built in so that the overall relative risk was in keeping with the Aguero-Torres et al. (1999) result.

Duration is heavily dependent on background mortality and the age distribution of the population. As a result, more emphasis should be placed on relative risks from studies of other contexts rather than durations which are context-specific and hence absolute. The literature on the median survival of all dementia after onset of symptoms appears to converge around 5 years for prevalent cases, with estimates ranging from 3–7 years for Alzheimer's disease and 2–4 years for vascular dementia for several recent studies. Aguero-Torres et al. (1999) calculated a mean survival time of 3.0 years (95% CI = 2.7–3.4) among a sample of 75-year-old demented subjects. Helmer et al. (2001) reported a mean survival time in incident cases of 4.5 years among 65-year-olds. The mean survival time for patients suffering from Alzheimer's disease and vascular dementia from the Aguero-Torres et al. (1999) study was 3.1 (95% CI = 2.8–3.5) and 2.8 (95% CI = 2.2–3.4) years, respectively.

4.5 Burden of disease

Burden of disease analysis is a method for analysing the impact of health conditions and impairments in terms of their mortality and morbidity. The burden of disease approach combines the impact of premature mortality and morbidity in one measure called the disability-adjusted life year (DALY). The premature mortality component is measured in terms of years of life lost (YLL) and the morbidity component in terms of years of life spent living in states of less than full health (years lost due to disability, YLD) (Salmon et al. 2002). The YLD is a measure of the impact of a health condition or impairment in restricting activity and participation.

The burden of disease in Australia for all health conditions has been estimated for 1996 (AIHW: Mathers et al. 1999). The estimates are currently being updated to 2003 and will be published in 2006 by the AIHW and the University of Queensland. While the underlying methodology of burden of disease is standard, the models used for each disease go through considerable development based on literature reviews and expert consultation in order to estimate a model based on a number of parameters—incidence and prevalence, relative risk, mortality and remission. The parameters of the disease model are used in computer modelling software (DISMOD) to produce estimates of the incidence of dementia. More detail on the burden of disease methods is available in AIHW: Mathers et al. (1999).

In this section, the burden of dementia is estimated based on the prevalence of dementia, which is derived from the disease model, and then estimating the severity of the condition or the degree to which quality of life is reduced.

Burden due to premature mortality

In Australia, conditions can be listed on the death certificate as either the underlying or main cause of death, or as an additional or contributing cause of death. The number of deaths with dementia recorded as the underlying cause of death has increased steadily in the period 1997 to 2003 from 3,384 in 1997 to 4,413 in 2003 (Table 4.10). This increase is largely due to population ageing since the age-standardised rate has remained stable over this period for both males and females (Table 4.11).

Table 4.10: Deaths with an underlying cause of dementia, 1997–2003

Sex/age	1997	1998	1999	2000	2001	2002	2003
Males							
0–59	19	23	19	25	26	28	17
60–64	15	21	12	24	23	19	29
65–69	46	45	47	30	36	53	33
70–74	119	86	126	102	104	115	88
75–79	189	205	184	224	204	246	226
80–84	251	287	249	271	283	328	333
85+	457	490	531	502	555	673	693
Total	*1,096*	*1,157*	*1,168*	*1,178*	*1,231*	*1,462*	*1,419*
Females							
0–59	18	20	19	25	17	10	25
60–64	30	19	20	20	11	29	22
65–69	33	44	38	46	32	28	40
70–74	99	100	103	88	109	118	86
75–79	202	241	220	241	236	278	231
80–84	468	434	452	472	455	571	555
85+	1,438	1,360	1,509	1,698	1,757	1,988	2,035
Total	*2,288*	*2,218*	*2,361*	*2,590*	*2,617*	*3,022*	*2,994*
Persons							
0–59	37	43	38	50	43	38	42
60–64	45	40	32	44	34	48	51
65–69	79	89	85	76	68	81	73
70–74	218	186	229	190	213	233	174
75–79	391	446	404	465	440	524	457
80–84	719	721	701	743	738	899	888
85+	1,895	1,850	2,040	2,200	2,312	2,661	2,728
Total	**3,384**	**3,375**	**3,529**	**3,768**	**3,848**	**4,484**	**4,413**

Source: AIHW analysis of the National Mortality Database.

In 2003, age-specific death rates for dementia were low among people aged less than 65 years and more than doubled for each progressive five-year age category, increasing from 10.1 deaths per 100,000 population at 65–69 to 952.3 at 85 years and over (Table 4.11). The age-standardised death rate was greater for women (22.2 per 100,000 population) than for men (18.7 per 100,000 population).

Table 4.11: Death rates per 100,000 people with an underlying cause of dementia, 1997–2003

Sex/age	1997	1998	1999	2000	2001	2002	2003
Males							
0–59	0.2	0.3	0.2	0.3	0.3	0.3	0.2
60–64	4.1	5.6	3.1	6.0	5.6	4.4	6.6
65–69	13.6	13.4	14.1	9.0	10.7	15.4	9.3
70–74	42.2	29.8	42.8	34.0	34.3	37.8	29.1
75–79	99.5	102.1	86.7	102.0	89.7	105.3	93.9
80–84	230.8	259.1	221.1	227.8	220.7	239.2	228.4
85+	715.1	718.3	729.4	647.6	677.5	780.2	770.2
Crude rate	*11.9*	*12.4*	*12.4*	*12.4*	*12.8*	*15.0*	*14.4*
Age-standardised rate[(a)]	*18.6*	*18.9*	*18.3*	*17.4*	*17.4*	*19.8*	*18.7*
Females							
0–59	0.2	0.3	0.2	0.3	0.2	0.1	0.3
60–64	8.2	5.1	5.2	5.0	2.7	6.9	5.1
65–69	9.4	12.6	11.0	13.3	9.2	7.9	10.9
70–74	30.1	30.2	30.9	26.4	32.6	35.4	26.1
75–79	78.8	89.7	78.3	83.8	80.8	94.3	77.4
80–84	260.2	238.4	246.9	248.4	225.5	270.0	250.8
85+	962.8	867.6	908.5	969.4	958.5	1,043.1	1,035.7
Crude rate	*24.6*	*23.6*	*24.8*	*26.8*	*26.8*	*30.6*	*29.9*
Age-standardised rate[(a)]	*21.5*	*20.2*	*20.5*	*21.5*	*20.8*	*23.2*	*22.2*
Persons							
0–59	0.2	0.3	0.2	0.3	0.3	0.2	0.3
60–64	6.2	5.4	4.2	5.5	4.1	5.7	5.9
65–69	11.5	13.0	12.5	11.2	10.0	11.6	10.1
70–74	35.7	30.0	36.5	30.0	33.4	36.6	27.5
75–79	87.6	95.0	81.9	91.7	84.7	99.2	84.8
80–84	249.1	246.2	237.1	240.5	223.6	257.9	241.9
85+	888.6	822.4	853.9	870.7	871.7	961.1	952.3
Crude rate	**18.3**	**18.0**	**18.6**	**19.7**	**19.8**	**22.8**	**22.2**
Age-standardised rate[(a)]	**20.8**	**19.9**	**19.9**	**20.3**	**19.8**	**22.2**	**21.1**

(a) Age-standardised to the 30 June 2001 Australian population.

Source: AIHW analysis of the National Mortality Database.

In 2003, dementia was listed as an additional cause of death on a further 9,820 death certificates. Thus in 2003, dementia was listed as the contributing cause of death (either the underlying cause of death or additional cause of death) on 14,233 death certificates. Only deaths where dementia is the underlying cause of death contribute to the premature mortality component (YLL) of burden of disease.

The YLL is calculated by determining the difference between the age at death and life expectancy for a person of that age as determined by a model life table. The difference is then discounted at a rate of 3% per year to give the YLL. For example, if a person dies at the age of 72 in 2003 and the life expectancy for someone aged 72 in 2003 in the model life table is 84, then the undiscounted years of life lost will be 12 years. The years of life lost discounted at 3% is 10 years.[8]

The 4,413 deaths where dementia was the underlying cause of death resulted in 24,000 years of life lost (Table 4.12). Almost two-thirds of these YLLs (16,000) were for females and 82% were for people over the age of 75.

Table 4.12: Deaths and years of life lost due to dementia as underlying cause of death, 2003

	Deaths			Years of life lost (YLL)		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
0–64	46	47	93	714	907	1,621
65–74	121	126	247	1,273	1,553	2,826
75–84	559	786	1,345	3,675	5,835	9,510
85+	693	2,035	2,728	2,433	7,714	10,147
Total	**1,419**	**2,994**	**4,413**	**8,094**	**16,009**	**24,103**

Sources: Deaths data from Table 4.10; YLL data from Begg et al. 2007 (in press).

Burden due to morbidity

The proposed model for dementia is shown in Table 4.13. The model is for dementia as a progressive illness where the disease progresses from a mild impact where there is significant impact on daily activities, to severe impact where permanent supervision is required. The model is based on 55% of the duration of the disease being in the mild severity phase, 30% in the moderate severity phase and 15% in the severe phase of the disease progression (Table 4.7 and Table 4.13).

Table 4.13: The model used in the burden of disease analysis of dementia, definition and severity weight for different stages of dementia

Disease stages	Severity weight	Definition	% time spent in each stage
Mild	0.27	Significant impact on daily activities but still able to undertake daily activities	0.55
Moderate	0.63	Independent living is not possible without assistance	0.30
Severe	0.94	Permanent supervision required	0.15

Source: Begg et al. 2007 (in press).

The overall YLD lost due to dementia is calculated by multiplying the number of people with dementia (Table 4.8) by the appropriate severity weights according to the severity of dementia (Table 4.13). This shows that, overall, there were 84,000 YLD lost due to dementia in 2003 (Table 4.14). Two-thirds of these healthy years lost were for females and two-thirds were for residents of cared accommodation.

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[8] The YLL is calculated using the formula $YLL = \frac{1 - e^{-0.03\ life\ expectancy}}{0.03}$.

Table 4.14: Prevalent years of life lost to disability, by sex, residency and severity, 2003

Residency/severity	Males	Females	Persons
Cared accommodation			
Mild	256	657	914
Moderate	7,179	23,022	30,201
Severe	5,356	17,175	22,531
Total cared accommodation	*12,791*	*40,854*	*53,645*
Household			
Mild	10,539	14,491	25,030
Moderate	2,512	307	2,819
Severe	1,346	756	2,103
Total household	*14,397*	*15,554*	*29,952*
All dementia			
Mild	10,795	15,148	25,944
Moderate	9,691	23,329	33,019
Severe	6,702	17,931	24,634
Total dementia	**27,188**	**56,408**	**83,597**

Source: AIHW analysis based on YLD data from Begg et al. 2007 (in press).

Because of its disabling rather than fatal nature, dementia has a much greater effect on years of healthy life lost than it has on years of life lost due to premature mortality. The combined effect of premature mortality and burden of disease due to disability can be gauged using DALYs. One DALY is a lost year of 'healthy' life, and is the sum of years of life lost due to premature mortality and years of healthy life lost due to disability. The majority of the burden of disease caused by dementia is due to disability rather than premature death, with disability accounting for around three-quarters of the total burden in 2003 (Table 4.15). Death, however, accounts for a greater proportion of the burden of disease due to dementia for older than younger people; premature death caused about 40% of the burden for people aged 85 and over, but 16% for people aged 65 to 74.

Dementia accounted for 94,000 DALYs in 2003 which is 4% of total DALYs lost due to all diseases (AIHW analysis based on YLL data from Begg et al. 2007). The 25,000 DALYs lost due to dementia by those aged 85 years or more is 12% of total DALYs lost by this age group and is the leading cause of burden for this age group.

Dementia accounted for 70,000 incident years of life lost to disability (incident YLD) which is 5% of total incident YLDs lost due to all diseases (AIHW analysis based on YLD data from Begg et al. 2007). The 15,000 YLDs lost due to dementia by those aged 85 years or more is 28% of total incident YLDs lost by this age group (22% for males and 31% for females), and is the leading cause of burden for this age group. There were 33,000 YLDs lost due to dementia for persons aged between 75 and 84 years of age, representing 21% of total YLDs for all diseases.

Table 4.15: Years of life lost, incident years of life lost to disability and disability-adjusted life years for dementia, by age and sex, 2003

	YLL			Incident YLD			DALY		
Age	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
0–64	714	907	1,621	3,971	2,619	6,590	4,685	3,526	8,211
65–74	1,273	1,553	2,826	6,597	8,681	15,279	7,871	10,235	18,105
75–84	3,675	5,835	9,510	11,020	22,063	33,084	14,695	27,898	42,593
85+	2,433	7,714	10,147	3,962	11,361	15,324	6,395	19,075	25,470
Total	**8,094**	**16,009**	**24,103**	**25,551**	**44,725**	**70,276**	**33,645**	**60,734**	**94,379**

Note: A DALY is a disability-adjusted life year and is calculated by adding the YLL and the incident YLD. Incident YLD is based on incidence estimates for dementia and is lower in magnitude than prevalence YLD shown in Table 4.14.

Source: AIHW analysis based on YLL data from Begg et al. 2007 (in press).

The 94,000 DALYs in 2003 is projected to increase to 236,000 in 2031, a 151% increase (Table 4.16). Most of the increase is for those aged 85 years or more where a 242% increase occurs for the number of DALYs. There is projected to be a 49% increase in dementia DALYS for those aged less than 65 in the period 2003 to 2031.

Table 4.16: Burden of dementia, disability-adjusted life years, projected to 2031

Age	2003	2006	2011	2016	2021	2026	2031	Per cent change 2003–2031
0–64	8,211	8,947	10,153	10,841	11,556	11,902	12,242	49
65–74	18,105	18,919	22,500	28,322	32,968	35,878	38,829	114
75–84	42,593	45,052	47,155	52,597	64,160	82,812	98,197	131
85+	25,470	28,845	37,660	46,501	54,167	66,967	87,184	242
Total	**94,379**	**101,762**	**117,469**	**138,260**	**162,852**	**197,559**	**236,452**	**151**

Source: AIHW analysis based on YLL data from Begg et al. 2007 (in press).

5 Characteristics of people with dementia

5.1 Introduction

This chapter explores what available Australian data reveal about the characteristics of people with dementia (including subpopulations of informal care recipients and formal care program clients). Data are examined in relation to sociodemographic characteristics, details relating to the dementia syndrome, presence and type of coexisting health conditions, extent of disability and need for assistance with daily activities, and the sources of care used by people with dementia. For comparative purposes, information about people without dementia is also included where appropriate.

This chapter focuses on Australian data sources and studies about people with dementia. Although it is recognised that results from international data sources and studies may also be applicable to Australia, this chapter aims to review what information is available in Australia that can be used for planning purposes, and identify its gaps and strengths. A number of data sources are used:

- the ABS 2003 Survey of Disability, Ageing and Carers
- administrative data collections such as 2004–05 ACAP, 2004–05 National Respite for Carers Program (NRCP), 2002 Community Aged Care Packages (CACP) and Extended Aged Care at Home (EACH) censuses and the National Hospital Morbidity Database (NHMD)
- a select number of smaller published Australian studies about carers of people with dementia, which are described in more detail in Chapter 6 and Table A6.1. These studies include information about the circumstances and needs of those people with dementia who receive assistance from family, friends and other sources of informal care.

Data from the Dementia Education and Support Program (DESP) delivered by Alzheimer's Australia is discussed in Chapter 6—services provided by Alzheimer's Australia initially helped carers, although people with dementia have become clients in more recent times.

Where appropriate, the characteristics of informal care recipients (a subset of all people with dementia) will help to understand the role of carers and the needs that they respond to, discussed in the following chapter. For example, certain care recipient characteristics have been identified as predictors of an adverse carer impact in a multinational review, such as severity of the dementia, behavioural disturbance, the gender and age of the care recipient at disease onset and the hours of care required (Torti et al. 2004).[9]

As noted in Chapter 3, administrative data sources are restricted in their coverage to clients of the respective services, and people with mild dementia may not be identified in these populations. Nevertheless, administrative data collections provide information that can

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[9] Carer characteristics which may predict adverse carer impact include the gender and age of the carer, the duration of care giving, the relationship to the patient, the socioeconomic status of the care and their self-rated competence or self-efficiency (Torti et al. 2004).

assist in constructing a profile of an important subpopulation of people with dementia—those receiving assistance through formal services. In addition, compared to sample sizes of most other data sources used in this chapter, the administrative data collections include information about a large number of clients.

Missing data are excluded from the calculation of percentages in tables in this chapter, and the number of cases for which data are missing is reported below the *Total* row in each table. As a consequence of this treatment of missing data, the number of valid cases analysed for any given data source may vary from table to table depending upon which variables are included and the amount of missing data related to each variable.

5.2 Identification of dementia

Chapter 3 of this report discussed the purpose, scope, and collection methodology of the data sources used in this chapter. It also described the type of data collected about dementia and the limitations of each in this respect. Each of the data sources analysed in this chapter includes information designed to identify people with dementia.

Survey of Disability, Ageing and Carers

In the 2003 SDAC, long-term health conditions were coded to a classification based on the International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision. 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 (e.g. stroke) which produced an impairment or restriction which had lasted or was likely to last for at least six months.

As noted in Chapter 3, the SDAC has strengths as a data source about dementia. These include its coverage of people in cared accommodation (e.g. residential aged care), and its inclusion of all people over the age of 60 in selected households. Its limitations arise from the reliance on self- or proxy-report which risks under-reporting of mild dementia in particular, and the bias in reporting of health conditions generally which tends towards identifying those conditions which are associated with disability. The coding of health conditions also restricts the identification of people with dementia, omitting those with alcoholic dementia or dementia in Parkinson's disease (see Chapter 3 for a more detailed discussion).

Aged Care Assessment Program

Dementia may be recorded in the ACAP MDS v2 as a primary health condition that has the greatest impact on the client's need for assistance, or as one of nine other health conditions that impact on the client's need for assistance—codes are based on the Australian modification of the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10-AM). The ACAP data presented in this chapter generally only include details about the most recent assessment for each client that took place between July 2004 and March 2005 (i.e. details about the number of clients during the period rather than the number of assessments). Approximately 108,638 clients had 127,078 assessments between July 2004 and March 2005 (Table 5.1). Around 24% of all clients had dementia, and around 24% of all assessments were for a client with dementia. It is important to note, however, that ACAP clients without dementia also include those clients for whom a health condition was inadequately described or not reported—some of these may have dementia.

Table 5.1: Dementia status of ACAP assessments and clients, July 2004 to March 2005

	Assessments		Clients	
Dementia status	**Number**	**Per cent**	**Number**	**Per cent**
With dementia	30,192	23.8	26,158	24.1
Without dementia	96,886	76.2	82,480	75.9
Total	**127,078**	**100.0**	**108,638**	**100.0**

Source: AIHW analysis of the ACAP MDS v2.

National Respite for Carers Program

NRCP data are collected about people who receive informal care and whose carer is receiving some form of assistance or support through the NRCP. Only limited data from this program were available for this project, due to the constraints of the project's timeframe. The quality of data from this program has been considerably improved over the last 12 months and will be a potentially valuable source of future information about care recipients with dementia. Data from the NRCP show that in 2004–05 9,940 care recipients or 17% of care recipients registered with a Commonwealth Carer Respite Centre (CCRC) had dementia (Table 5.2).

Table 5.2: Care recipients registered with a CCRC, by dementia status, 2004–05

Care recipients registered with a CCRC	Care recipients with dementia	Per cent with dementia
59,849	9,940	16.6

Source: DoHA analysis of the NRCP MDS.

Community Aged Care Packages and Extended Aged Care at Home

As Chapter 3 noted, ongoing administrative data about CACP and EACH clients do not identify people with dementia. The following analyses are therefore based on data collected through the censuses of these programs conducted in 2002. This data has not been subsequently updated. One major limitation of the data is that the EACH program was relatively new at the time of the census with a very small client population. The EACH client population has increased eight-fold since the census and it is possible that the client profile has changed since that time. Although the age, sex and living arrangement profiles of recent EACH clients are broadly similar to those of clients in the EACH census, there are no data available to compare the profiles of clients with dementia. Data from the 2002 census of CACP and EACH programs were included in AIHW (2004f).

At the time of the CACP census, conducted over one week between mid-September and mid-October 2002, there were 904 service outlets on the administrative database with approximately 26,500 CACP clients. Approximately 94% of these service outlets responded, with services being delivered from 759 locations, and data were obtained for 25,439 clients (approximately 96% of estimated clients) (AIHW 2004b). There are currently over 30,500 CACPs.

EACH was established in 2001; at the time of the EACH census conducted over one week in May 2002, there were only 10 providers, located in five jurisdictions, with 288 EACH clients. The response rate by providers was 100% (AIHW 2004e). There are currently about 1,800 EACH packages.

In 2002, almost one in five CACP clients were reported as diagnosed with dementia, while one-third of all EACH clients had been diagnosed with dementia (Table 5.3); 196 CACP clients and 8 EACH clients did not state their dementia status—these clients will be excluded from the subsequent tables.

Table 5.3: CACP and EACH clients with and without dementia, census periods, 2002

	CACP		EACH	
	Number	Per cent	Number	Per cent
With dementia	4,646	18.4	90	32.1
Without dementia	20,597	81.6	190	67.9
Total	**25,243**	**100.0**	**280**	**100.0**
Dementia status not stated	*196*	*. .*	*8*	*. .*

Source: AIHW analysis of CACP and EACH 2002 census.

5.3 Sociodemographic characteristics

Age and sex distribution

The age and sex distribution of people with dementia from a number of meta-analyses is discussed in Chapter 4. In particular, Table 4.3 shows the age and sex distribution of the population with dementia (by residency status) based on the meta-analyses of Lobo et al. (2000) and Harvey et al. (2003). Given the increasing prevalence of dementia with age, it is not surprising that people with dementia are mostly older women—consistent with meta-analyses, more than half of SDAC respondents and ACAP, CACP and EACH clients with dementia were women aged 75 years or older.

Table 5.4: People with dementia, by age and sex, 2003

	Number with dementia			Per cent			Age-specific rates (%)		
Age	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
45–64	**1,800	**800	*2,600	**6.2	**1.1	*2.5	**0.1	—	*0.1
65–69	**1,200	**1,900	*3,100	**4.2	**2.6	*3.1	**0.4	*0.5	*0.4
70–74	*3,800	*3,100	*6,900	*13.1	*4.2	*6.7	*1.3	*0.9	*1.1
75–79	*6,800	*9,200	15,900	*23.4	*12.6	15.7	*2.9	*3.1	3.0
80–84	*5,700	18,100	23,800	*19.8	24.8	23.4	*3.9	8.3	6.5
85+	*9,600	39,900	49,500	33.3	54.7	48.6	10.7	20.6	17.5
Total 65+	*27,100*	*72,200*	*99,300*	*93.8*	*98.9*	*97.5*	*2.4*	*5.2*	*4.0*
Total 45+	**28,900**	**73,000**	**101,900**	**100.0**	**100.0**	**100.0**	**0.8**	**2.0**	**1.4**

* 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.

— Nil or rounded to zero.

Note: The survey reported no people aged under 45 years with dementia.

Source: AIHW analysis of the ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

According to the 2003 SDAC, the majority (72%) of people with dementia were women (Table 5.4). However, only about half of people with dementia who are cared for by a co-resident carer (52%) or a co-resident primary carer (48%) were women (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 majority of people with dementia (72%) were aged 80 years or older. The age profile of males with dementia is different from that of females, with a higher proportion of males (24%) than females (8%) aged less than 75 years. Those cared for by a co-resident carer or a co-resident primary carer appeared to have a younger age profile than the entire population of people with dementia, reflecting the older profile of those living in cared accommodation compared with those living in households.

ACAP clients fall mostly into the old to very old age groups: approximately 80% of clients were aged 75 years or over and over a third of clients were aged 85 years or over. The groups of clients with and without dementia have similar age structures, with only a marginally higher proportion of clients with dementia compared to those without dementia in the 85 years or over age group (Table 5.5).

Table 5.5: ACAP clients with and without dementia, by sex and age at beginning of assessment, July 2004 to March 2005

	With dementia		Without dementia	
Sex/age	**Number**	**Per cent**	**Number**	**Per cent**
Males				
<65	393	4.1	2,866	9.4
65–74	1,290	13.4	5,353	17.6
75–84	4,825	50.1	13,171	43.4
85–94	2,961	30.8	8,340	27.5
95+	159	1.7	638	2.1
Total	*9,628*	*100.0*	*30,368*	*100.0*
Not stated/inadequately described	*3*	. .	*15*	. .
Females				
<65	328	2.0	2,812	5.4
65–74	1,524	9.2	6,806	13.1
75–84	7,648	46.3	22,232	42.7
85–94	6,503	39.4	18,462	35.5
95+	516	3.1	1,746	3.4
Total	*16,519*	*100.0*	*52,058*	*100.0*
Not stated/inadequately described	*4*	. .	*20*	. .
Persons				
<65	721	2.8	5,681	6.9
65–74	2,814	10.8	12,160	14.7
75–84	12,474	47.7	35,407	42.9
85–94	9,467	36.2	26,812	32.5
95+	675	2.6	2,385	2.9
Total	**26,151**	**100.0**	**82,445**	**100.0**
Not stated/inadequately described	*7*	. .	*35*	. .

Note: Cases with known age but missing sex are included in the persons data.

Source: AIHW analysis of the ACAP MDS v2.

Just over 18% of CACP clients reported having a diagnosis of dementia (4,646 clients). Among all CACP clients, 93% were aged 65 and over and 36% were aged 85 and over (Table 5.6). The prevalence of dementia among CACP clients increased with age, rising from 8% in the under 65 age group to 20% in the 75–84 and 85–94 age groups. The proportion with dementia declined to 16% in the 95 and over age group.

CACP clients with dementia showed an older age profile compared with those without dementia. Less than 15% of clients with dementia were under 75 years compared with 24% in this age group for those without dementia. Equivalent proportions of CACP clients with and without dementia (2%) were in the 95 years and over age group.

For all CACP clients, women outnumbered men by a factor of more than two to one (70% were women). There was little difference between men and women for dementia status, with 18% of men and 19% of women diagnosed with dementia. Around 72% of those diagnosed with dementia were female—this is comparable to the proportion of CACP clients without dementia that were female (70%).

Table 5.6: CACP clients with and without dementia, by age and sex, census week 2002

	With dementia			Without dementia		
Sex/age	**Number**	**Per cent (row)**	**Per cent (col.)**	**Number**	**Per cent (row)**	**Per cent (col.)**
Males						
<65	73	9.4	5.7	701	90.6	11.7
65–74	190	14.0	14.8	1,167	86.0	19.4
75–84	573	20.3	44.6	2,252	79.7	37.5
85–94	425	19.5	33.1	1,750	80.5	29.1
95+	23	14.5	1.8	136	85.5	2.3
Total	*1,284*	*17.6*	*100.0*	*6,006*	*82.4*	*100.0*
Age not stated	*11*	*19.3*	. .	*46*	*80.7*	. .
Females						
<65	71	7.5	2.2	882	92.5	6.2
65–74	350	14.0	10.6	2,146	86.0	15.0
75–84	1,534	20.3	46.5	6,006	79.7	41.9
85–94	1,280	20.5	38.8	4,957	79.5	34.6
95+	65	16.0	2.0	340	84.0	2.4
Total	*3,300*	*18.7*	*100.0*	*14,331*	*81.3*	*100.0*
Age not stated	*21*	*17.6*	. .	*98*	*82.4*	. .
Persons						
<65	145	8.4	3.1	1,587	91.6	7.8
65–74	544	14.0	11.8	3,332	86.0	16.3
75–84	2,118	20.3	45.9	8,294	79.7	40.6
85–94	1,715	20.3	37.2	6,754	79.7	33.0
95+	90	15.9	2.0	477	84.1	2.3
Total	**4,612**	**18.4**	**100.0**	**20,444**	**81.6**	**100.0**
Age not stated	*34*	*18.2*	. .	*153*	*81.8*	. .

Note: The table excludes 196 cases with missing dementia status. Cases with known age but missing sex are included in the persons data.

Source: AIHW analysis of CACP 2002 census.

Among all EACH clients, 89% were aged 65 and over and 34% were aged 85 and over (Table 5.7). The prevalence of dementia among EACH clients increased with age. While 15% of clients aged 65–69 had been diagnosed with dementia, this increased to almost one-half for clients aged 85 and over (46% of clients aged 85–94 and 46% of clients aged 95 and over).

Table 5.7: EACH clients with and without dementia, by age and sex, census week May 2002

	With dementia			Without dementia		
Sex/age	**Number**	**Per cent (row)**	**Per cent (col.)**	**Number**	**Per cent (row)**	**Per cent (col.)**
Males						
<65	3	42.9	11.1	4	57.1	5.8
65–74	4	13.8	14.8	25	86.2	36.2
75–84	9	25.7	33.3	26	74.3	37.7
85–94	11	45.8	40.7	13	54.2	18.8
95+	0	—	—	1	100.0	1.4
Total	*27*	*28.1*	*100.0*	*69*	*71.9*	*100.0*
Age not stated	*0*	—	. .	*0*	—	. .
Females						
<65	5	20.8	8.3	19	79.2	16.0
65–74	5	16.1	8.3	26	83.9	21.8
75–84	19	33.9	31.7	37	66.1	31.1
85–94	26	44.8	43.3	32	55.2	26.9
95+	5	50.0	8.3	5	50.0	4.2
Total	*60*	*33.5*	*100.0*	*119*	*66.5*	*100.0*
Age not stated	*2*	*66.7*	. .	*1*	*33.3*	. .
Persons						
<65	8	25.8	9.1	23	74.2	12.2
65–74	9	14.8	10.2	52	85.2	27.5
75–84	28	30.8	31.8	63	69.2	33.3
85–94	38	45.8	43.2	45	54.2	23.8
95+	5	45.5	5.7	6	54.5	3.2
Total	**88**	**31.8**	**100.0**	**189**	**68.2**	**100.0**
Age not stated	*2*	*66.7*	. .	*1*	*33.3*	. .

— Nil or rounded to zero.

Note: The table excludes 8 cases with dementia status missing. Cases with known age but missing sex are included in the persons data.

Source: AIHW analysis of EACH 2002 census.

EACH clients with dementia also showed an older age profile compared with those without dementia. Around 43% of clients with dementia were aged 85–94 and 6% were aged 95 and over, compared with 24% aged 85–94 and 3% aged 95 and over for those not diagnosed with dementia. EACH clients with dementia were more likely to be in the oldest age groups than CACP clients with dementia. For EACH clients, 49% of clients with dementia were 85 years and over. The equivalent proportion for CACP clients was 39%.

Considering all EACH clients, women outnumbered men by a factor of almost two to one (64% were women). Of the EACH care clients diagnosed with dementia, 69% were women. This is higher than the proportion of clients without dementia who were women (63%).

Although the total number of clients was small in this census, Table 5.7 suggests that a higher (or at least equal) proportion of female than male EACH clients had dementia at all ages except in the under 65 age group.

Around 70% of those diagnosed with dementia were female—however, only 60% (63) of those without dementia were female. Similar proportions of clients with a carer were female—the age distribution of those clients with a carer is discussed in Section 5.5.

Data from the NRCP shows that 56% of care recipients with dementia who were registered with a CCRC were female (Table 5.8). The percentage of all care recipients registered with a CCRC that were female was 51%.

Table 5.8: Care recipients registered with a CCRC, by sex and dementia status, 2004–05

	Care recipients registered with a CCRC		Care recipients with dementia		
Sex	**Number**	**Per cent**	**Number**	**Per cent**	**Per cent with dementia**
Males	28,674	49.4	4,290	44.3	15.0
Females	29,331	50.6	5,391	55.7	18.4
Total	**58,005**	**100.0**	**9,681**	**100.0**	**16.7**
Not stated/inadequately described	*1,844*	. .	*259*	. .	*14.0*

Source: DoHA analysis of the NRCP MDS.

Published Australian studies found that the majority of care recipients with dementia were usually female, although this was not the case in all studies (see Table A5.1). The proportion of care recipients that were female ranged from just over 20% to just under 80%.

The age of care recipients with dementia ranged from less than 50 years to over 90 years. This variation was partly the result of methodological differences and study eligibility criteria. For example, the study by Luscombe et al. (1998) required participants to be less than 65 years of age at survey—as might be expected, those with Huntington's disease were younger than those with Alzheimer's disease or other dementias at survey (as well as age at diagnosis).

Caregivers and dependants in the dementia subpopulation in Bindoff et al. (1997) were significantly older than dependants with a physical or intellectual disability, despite attempts to seek older caregivers of physically and intellectually disabled adults and thus match the ages of those caregivers or dependants with those of the dementia group. Physical disability dependants were also found to be significantly older than intellectual disability dependants. Similarly, Schofield et al. (1998b) found that there were proportionately more female care recipients in the dementia group and higher proportions of care recipients with dementia were aged over 70 years.

Country of birth

According to the 2003 SDAC, around 68% or 69,500 of people with dementia were born in Australia (Table 5.9). A further 16% (15,900) were born in non-English-speaking countries and 16% (16,500) from the main overseas English-speaking countries—New Zealand, Ireland, United Kingdom, United States of America, Canada and South Africa.

Table 5.9: Country of birth of people with dementia, 2003

Country of birth	Number	Per cent
Australian-born	69,500	68.2
Main English-speaking countries	15,900	15.6
Non-English-speaking countries	16,500	16.2
Total	**101,900**	**100.0**

Note: Australian-born includes those born in Australian external territories. The *Main English-speaking countries* category for those born overseas comprises people born in New Zealand, Ireland, United Kingdom, United States of America, Canada or South Africa. The *Non-English-speaking countries* category comprises people born in other countries. (Standard Australian Classification of Countries codes for Australia and territories: 1101–1199; NZ: 1201; UK: 2101–2106; Ireland: 2200–2201; Canada: 8102; USA: 8104; South Africa: 9225).

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Around 71% or 17,921 ACAP clients with dementia were born in Australia (Table 5.10). A further 18% (4,525) were born in non-English-speaking countries and 12% (2,923) were from the main English-speaking countries. Similar proportions of ACAP clients without dementia were born in Australia, non-English-speaking countries and the main English-speaking countries.

Table 5.10: Country of birth, by dementia status of ACAP client, July 2004 to March 2005

	With dementia		Without dementia	
Country of birth	Number	Per cent	Number	Per cent
Australian-born	17,921	70.6	56,706	74.0
Main English-speaking countries	2,923	11.5	8,296	10.8
Non-English-speaking countries	4,525	17.8	13,586	17.7
Total	**25,369**	**100.0**	**76,588**	**100.0**
Not stated, unknown or inadequately described	*789*	. .	*3,892*	. .

Note: See note to Table 5.9.

Source: AIHW analysis of the ACAP MDS v2.

Around 66% of CACP clients with dementia were born in Australia (Table 5.11). A further 21% were born in non-English-speaking countries and 13% in the main English-speaking countries. Similar proportions of CACP clients without dementia were born in Australia, non-English-speaking countries and the main English-speaking countries. A higher proportion of CACP clients with a carer were born in non-English-speaking countries than CACP clients without a carer, regardless of dementia status.

Table 5.11: CACP clients with and without dementia, by country of birth, census week 2002

	With dementia		Without dementia	
Country of birth	Number	Per cent	Number	Per cent
Australian-born	3,066	66.3	13,996	68.5
Main English-speaking countries	607	13.1	2,257	11.0
Non-English-speaking countries	954	20.6	4,187	20.5
Total	**4,627**	**100.0**	**20,440**	**100.0**
Not stated, unknown or inadequately described	*19*	. .	*157*	. .

Note: The table excludes 196 cases with missing dementia status. See also note to Table 5.9.

Source: AIHW analysis of CACP 2002 census.

Around 61% of EACH clients with dementia were born in Australia (Table 5.12). A further 28% were born in non-English-speaking countries and 11% in the main English-speaking countries. Similar proportions of EACH clients without dementia were born in Australia, non-English-speaking countries and the main English-speaking countries.

Table 5.12: EACH clients with and without dementia, by country of birth, census week May 2002

	With dementia		Without dementia	
Country of birth	**Number**	**Per cent**	**Number**	**Per cent**
Australian-born	54	60.7	116	61.1
Main English-speaking countries	10	11.2	21	11.1
Non-English-speaking countries	25	28.1	53	27.9
Total	**89**	**100.0**	**190**	**100.0**
Not stated, unknown or inadequately described	*1*	. .	—	. .

— Nil or rounded to zero.

Note: See note to Table 5.9.

Source: AIHW analysis of EACH 2002 census.

Indigenous status

The overwhelming majority of ACAP clients with dementia (99% or 25,072 clients) were non-Indigenous—only around 1% (223) of ACAP clients with dementia were identified as Aboriginal and/or Torres Strait Islander (Table 5.13). Similar proportions of ACAP clients without dementia were identified as Aboriginal and/or Torres Strait Islander.

Table 5.13: Indigenous status, by dementia status of ACAP client, July 2004 to March 2005

	With dementia		Without dementia	
Indigenous status	**Number**	**Per cent**	**Number**	**Per cent**
Aboriginal and/or Torres Strait Islander	223	0.9	1,021	1.3
Neither Aboriginal nor Torres Strait Islander	25,072	99.1	77,472	98.7
Total	**25,295**	**100.0**	**78,493**	**100.0**
Not stated/inadequately described	*863*	. .	*3,987*	. .

Notes

1. This item only relates to whether the person identifies as being of Aboriginal and/or Torres Strait Islander descent.
2. Non-Indigenous status was not taken as the default in the presence of no other evidence.
3. The age benchmark used for service provision and planning within the ACAP is 50 and over for Aboriginal and/or Torres Strait Islander people, compared to 70 and over for the general population.

Source: AIHW analysis of the ACAP MDS v2.

Data from the NRCP show that 1.8% of care recipients with dementia registered with a CCRC were Aboriginal or Torres Strait Islander people (Table 5.14). The percentage of all care recipients registered with a CCRC who were Indigenous was 3.6%. Only a small proportion of people who did not state their Indigenous status are expected to be Aboriginal or Torres Strait Islander (personal communication with DoHA).

Table 5.14: Care recipients registered with a CCRC, by Indigenous status and dementia status, 2004–05

Indigenous status	Care recipients registered with a CCRC		Care recipients with dementia		Per cent with dementia
	Number	Per cent	Number	Per cent	
Indigenous	1,812	3.6	165	1.8	9.1
Non-Indigenous	48,855	96.4	8,970	98.2	18.4
Total	**50,667**	**100.0**	**9,135**	**100.0**	**18.0**
Not stated/inadequately described	*9,183*	. .	*805*	. .	*8.8*

Source: DoHA analysis of the NRCP MDS.

Almost all CACP clients with dementia (97% or 4,468 clients) were non-Indigenous—only around 3% (121) CACP clients with dementia were identified as Aboriginal and/or Torres Strait Islander (Table 5.15). Similar (but marginally higher) proportions of CACP clients without dementia were identified as Aboriginal and/or Torres Strait Islander.

Table 5.15: CACP clients with and without dementia, by Indigenous status, census week 2002

Indigenous status	With dementia		Without dementia	
	Number	Per cent	Number	Per cent
Aboriginal and/or Torres Strait Islander	121	2.6	1,211	6.0
Neither Aboriginal nor Torres Strait Islander	4,468	97.4	19,050	94.0
Total	**4,589**	**100.0**	**20,261**	**100.0**
Not stated/inadequately described	*57*	. .	*336*	. .

Note: The table excludes 196 clients where dementia status was not reported.

Source: AIHW analysis of CACP 2002 census.

According to the 2002 census, no EACH clients were identified as Aboriginal and/or Torres Strait Islander—99% reported that they were non-Indigenous, and Indigenous status was unknown or missing for the remaining 1% of clients.

Education

According to the 2003 SDAC, over half (53%) of people with dementia living in households only completed Year 8 or below or never attended school. Just over a quarter (27%) completed Year 12 or went on to higher education.

Residency

The severity of the disability experienced by people with dementia means that many of those with the condition are eligible for care in residential aged care services. In 2003, only 26,600 people with dementia reported living in households—75,300 people reported to have dementia had been, or were expected to be, living in cared accommodation such as residential aged care services or hospitals for three months or more (Table 5.16). This equates to 74% of all those reporting dementia. For those aged 65 or more, 45% of those in cared accommodation reported dementia, compared with around 1% of those living in households. For those aged 85 years or more, the corresponding figures were 48% and 4%.

People living in households may live in private dwellings or special dwellings such as self-care accommodation for the retired or aged. The majority of people living in cared accommodation (65% or 49,300 people) reported living in a home for the aged and an additional 21% (15,500 people) reported living in accommodation for the retired or aged—the remaining 10,500 people (14%) were living in hospitals or other homes.

Table 5.16: Residency of people with dementia, by age and sex, 2003

	Number with dementia		Number in population		Age-specific rates within accommodation type	
Age	Households	Cared accommodation	Households	Cared accommodation	Households	Cared accommodation
45–64	**1,400	1,200	4,673,400	11,300	—	10.5
65–69	**1,700	1,400	694,800	6,400	**0.2	22.3
70–74	*3,000	3,800	610,300	11,000	*0.5	34.9
75–79	*7,000	9,000	502,500	22,000	*1.4	40.9
80–84	*5,500	18,400	329,300	37,000	*1.7	49.6
85+	*8,000	41,500	196,400	87,200	*4.1	47.6
Total 65+	**25,200**	**74,100**	**2,333,300**	**163,500**	**1.1**	**45.3**
Total 45+	**26,600**	**75,300**	**7,006,700**	**174,800**	**0.4**	**43.1**

* 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.

— Nil or rounded to zero.

Note: Age-specific rates relate to population in households and cared accommodation, respectively.

Source: AIHW analysis of the ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Similar results were obtained from the 1998 survey (see AIHW 2004f): 73,300 people with dementia (or 72%) were living in cared accommodation. For those aged 65 or more, 43% of those in cared accommodation reported dementia, compared with around 1% of those living in households. For those aged 85 years or more, the corresponding figures were 47% and 8%.

Table 5.17 shows that 84% of ACAP clients with dementia lived in a community setting at assessment, mostly in a private residence (73%)—only 16% were in a institutional setting, mostly lower level residential aged care (13%). However, a smaller proportion of ACAP clients with dementia lived in a community setting at assessment than ACAP clients without dementia (93%).

Table 5.17: Usual accommodation setting at the time of ACAP assessment, by dementia status of ACAP client, July 2004 to March 2005

	With dementia		Without dementia	
Usual accommodation setting	**Number**	**Per cent**	**Number**	**Per cent**
Community setting				
Private residence[(a)]	18,666	72.8	58,230	81.2
Independent living within a retirement village	1,501	5.9	5,126	7.1
Supported community accommodation	504	2.0	888	1.2
Other[(b)]	924	3.6	2,750	3.8
Total community setting	*21,595*	*84.3*	*66,994*	*93.4*
Institutional setting				
Residential aged care service — low level care	3,352	13.1	3,707	5.2
Residential aged care service — high level care	481	1.9	656	0.9
Hospital	89	0.3	159	0.2
Other institutional care	106	0.4	203	0.3
Total institutional setting	*4,028*	*15.7*	*4,725*	*6.6*
Total	**25,623**	**100.0**	**71,719**	**100.0**
Not stated/inadequately described	*535*	. .	*10,761*	. .

(a) Includes owned/purchasing, private rentals and public rentals or community housing.

(b) Includes all other types of settings, as well as boarding house/rooming house/private hotel, short-term crisis, emergency or transitional accommodation and public place/temporary shelter.

Source: AIHW analysis of the ACAP MDS v2.

The majority of CACP clients lived in a private residence, mostly a residence that was owned or being purchased, regardless of dementia status (Table 5.18).

Table 5.18: CACP clients with and without dementia, by accommodation type, census week 2002

	With dementia		Without dementia	
Accommodation type	**Number**	**Per cent**	**Number**	**Per cent**
Private	4,122	90.2	18,100	89.3
Owned/purchasing	3,176	69.5	12,361	61.0
Private rental	253	5.5	1,421	7.0
Public rental or community housing	513	11.2	3,711	18.3
Not specified	180	3.9	607	3.0
Independent living within a retirement village	352	7.7	1,730	8.5
Boarding house/ rooming house/ private hotel	28	0.6	161	0.8
Short-term crisis, emergency or transitional accommodation	4	0.1	15	0.1
Public place/temporary shelter	1	—	35	0.2
Other	62	1.4	237	1.2
Total	**4,569**	**100**	**20,278**	**100**
Not stated/inadequately described	*77*	. .	*319*	. .

— Nil or rounded to zero.

Note: The table excludes 196 clients where dementia status was not reported.

Source: AIHW analysis of CACP 2002 census.

A higher proportion of EACH clients with dementia (88%) lived in their own private residence than clients without dementia (78%) (Table 5.19).

Table 5.19: EACH clients with and without dementia, by accommodation type, census week May 2002

Accommodation type	With dementia Number	Per cent	Without dementia Number	Per cent
Private				
Owned/purchasing	79	87.8	149	78.4
Private rental	4	4.4	14	7.4
Public rental or community housing	6	6.7	14	7.4
Independent living within a retirement village	1	1.1	11	5.8
Supported community accommodation	0	—	1	0.5
Other	0	—	1	0.5
Total	**90**	**100.0**	**190**	**100.0**

— Nil or rounded to zero.

Source: AIHW analysis of EACH 2002 census.

Living arrangements

According to the 2003 SDAC, over three-quarters of people with dementia living in private dwellings lived with others rather than living alone (76% or 17,900 people). Similarly, in 2004–05 the majority of ACAP clients with dementia living in the community at assessment were living with family (60%), although a significant proportion (36%) were living alone (Table 5.20). A smaller proportion of ACAP clients with dementia were living alone than ACAP clients without dementia—for ACAP clients without dementia, similar proportions were living with family (49%) and living alone (49%).

Table 5.20: Living arrangements, by dementia status of ACAP client, July 2004 to March 2005

Living arrangements	With dementia Number	Per cent	Without dementia Number	Per cent
Lives alone	7,689	36.1	31,299	47.8
Lives with family	12,851	60.3	32,160	49.1
Lives with others	774	3.6	2,039	3.1
Total	**21,314**	**100.0**	**65,498**	**100.0**
Not stated/inadequately described	*918*	. .	*11,915*	. .
Not applicable[(a)]	*5,067*	. .	*3,926*	. .

(a) Recorded for people who were permanent residents of residential aged care services, multipurpose services or centres, Indigenous flexible pilots, hospital or other institutional settings at the time of assessment.

Notes

1. If the persons' household included both family and non-family members, the person was recorded as living with family. *Living with family* includes de facto and same sex relationships.
2. Where there was difficulty on deciding the living arrangement of a person living in accommodation settings such as boarding houses, group homes or retirement villages, the person was regarded as living alone, unless they were sharing their own private space/room within the premises with a significant other such as a partner, sibling or close friend.
3. If a person was living in a granny flat, they were coded as living alone if the granny flat was a separate dwelling and they did not share their flat with another person.

Source: AIHW analysis of the ACAP MDS v2.

In census week 2002, the majority of CACP clients with dementia were living alone (56%), although a significant number were living with family (42%). A smaller proportion of CACP clients with dementia were living alone than CACP clients without dementia—for CACP clients without dementia, 63% were living alone and over a third (35%) were living with family. A small number of CACP clients lived with others (Table 5.21).

Table 5.21: CACP clients with and without dementia, by living arrangements, census week 2002

	With dementia		Without dementia	
Living arrangements	**Number**	**Per cent**	**Number**	**Per cent**
Lives alone	2,599	56.2	12,839	62.6
Lives with family	1,941	42.0	7,219	35.2
Lives with others	86	1.9	466	2.3
Total	**4,626**	**100.0**	**20,524**	**100.0**
Not stated/inadequately described	*20*	. .	*73*	. .

Note: The table excludes 196 clients where dementia status was not reported.

Source: AIHW analysis of CACP 2002 census.

The majority of EACH clients with dementia were living with family (88%) with the remaining 12% living alone (Table 5.22). A smaller proportion of EACH clients with dementia were living alone than EACH clients without dementia—for EACH clients without dementia, 72% were living with family, one-quarter (26%) were living alone and 2.6% were living with others. Although the majority of EACH clients lived with family, the overwhelming majority (96%) of those without a carer lived alone, regardless of dementia status.

Table 5.22: EACH clients with and without dementia, by living arrangements, census week May 2002

	With dementia		Without dementia	
Living arrangements	**Number**	**Per cent**	**Number**	**Per cent**
Lives alone	11	12.2	49	25.8
Lives with family	79	87.8	136	71.6
Lives with others	0	—	5	2.6
Total	**90**	**100.0**	**190**	**100.0**

— Nil or rounded to zero.

Source: AIHW analysis of EACH 2002 census.

5.4 Nature of the dementia syndrome

Type of dementia

The ACAP MDS v2 records a main health condition and allows up to a further nine health conditions to be recorded by the ACAT at the end of the comprehensive assessment process. Recorded health conditions reflect those that are related to the person's assessed need for assistance with activities of daily living and social participation. The main condition is the diagnosis with the most impact on the person's need for assistance.

In the nine months between July 2004 and March 2005 26,158 ACAP clients reported 26,444 diagnoses of dementia. Around 69% of these clients listed dementia as their main condition. Alzheimer's dementias were the most common diagnoses, making up over half of the dementias recorded (Table 5.23).

Table 5.23: Type of dementia, ACAP client with dementia, July 2004 to March 2005

Type of dementia	Main condition	Main or other condition	Per cent with dementia as main condition
Alzheimer's dementia	10,944	14,193	77.1
Vascular dementia	2,171	3,610	60.1
Dementia in other diseases	639	1,116	57.3
Other dementia	4,454	7,525	59.2
Total	**18,208**	**26,444**	**68.9**

Notes

1. Alzheimer's dementia includes Dementia in Alzheimer's disease, Dementia in Alzheimer's disease with early onset, Dementia in Alzheimer's disease with late onset, Dementia in Alzheimer's disease, atypical or mixed type and Dementia in Alzheimer's disease, unspecified.
2. Vascular dementia includes Vascular dementia, Vascular dementia of acute onset, Multi-infarct dementia, Subcortical vascular dementia, Mixed cortical and subcortical vascular dementia, Other vascular dementia, and Vascular dementia—unspecified.
3. Dementia in other diseases includes Dementia in other disease classified elsewhere, Dementia in Pick's disease, Dementia in Creutzfeldt-Jakob disease, Dementia in Huntington's disease, Dementia in Parkinson's disease, Dementia in HIV disease and Dementia in other specified diseases classified elsewhere.
4. Other dementia includes Other dementia, Alcoholic dementia, Unspecified dementia (includes presenile and senile dementia), and Delirium superimposed on dementia.

Source: AIHW analysis of the ACAP MDS v2.

The majority (73%) of patients in the study conducted by Brodaty & Gresham (1989) had Alzheimer's disease, 20% had multi-infarct dementia and 7.3% had other forms of dementia.

In a study of carers of younger people with dementia, Luscombe et al. (1998) found that 48% had Alzheimer's disease, 24% had Huntington's disease and 28% had other types of dementia.

Of the subjects seen in the study by LoGiudice et al. (1999), 48% fulfilled ICD-10 criteria for Alzheimer's disease, 22% for vascular dementia, 2.2% for alcoholic dementia, 15% for cognitive impairment not meeting criteria for dementia, 11% combined dementia and 2.2% unspecified dementia.

However, Bruce & Paterson (2000) found that many carers were uncertain about the diagnosis of dementia and in some there was uncertainty about whether the diagnosis of Alzheimer's disease had actually been established. Furthermore, several carers were confused about the distinctions between Alzheimer's disease, dementia and age-related memory disturbance.

Duration

A number of small Australian studies, whose primary focus is carers and care recipients with dementia, report data about the length of time someone has had dementia. The duration of dementia reported in these studies ranged from six months to 8 years.

Study	Duration of dementia
Brodaty & Hadzi-Pavlovic (1990)	• Patients who were still alive at survey had been dementing for about four years (mean 48.2 months, standard deviation 24.4, range 10–97) • Carers had been members of the NSW Alzheimer's Disease and Related Disorders Society for an average of 28.7 months (standard deviation 11.0, range 6–60)
Bindoff et al. (1997)	• The duration of disability for those with a dementia-related disorder (5.23 years) was significantly less than that for either those with a physical disability (7.15 years) or an intellectual disability (7.68 years), as some developmental and physical impairments are present at birth or early childhood
Bruce et al. (2002)	• Carers' estimates of the first time they consulted a general practitioner (GP) about the dementia ranged from six months to 6.5 years previously (average 1.8 years)
Bruce et al. (2005)	• The median duration of memory loss was 24 months (with a range of 17 to 48 months) and the median duration of need for care was 18 months (with a range of 6 to 30 months), although eligible carers were those who had been caring for the care recipient for at least 6 months

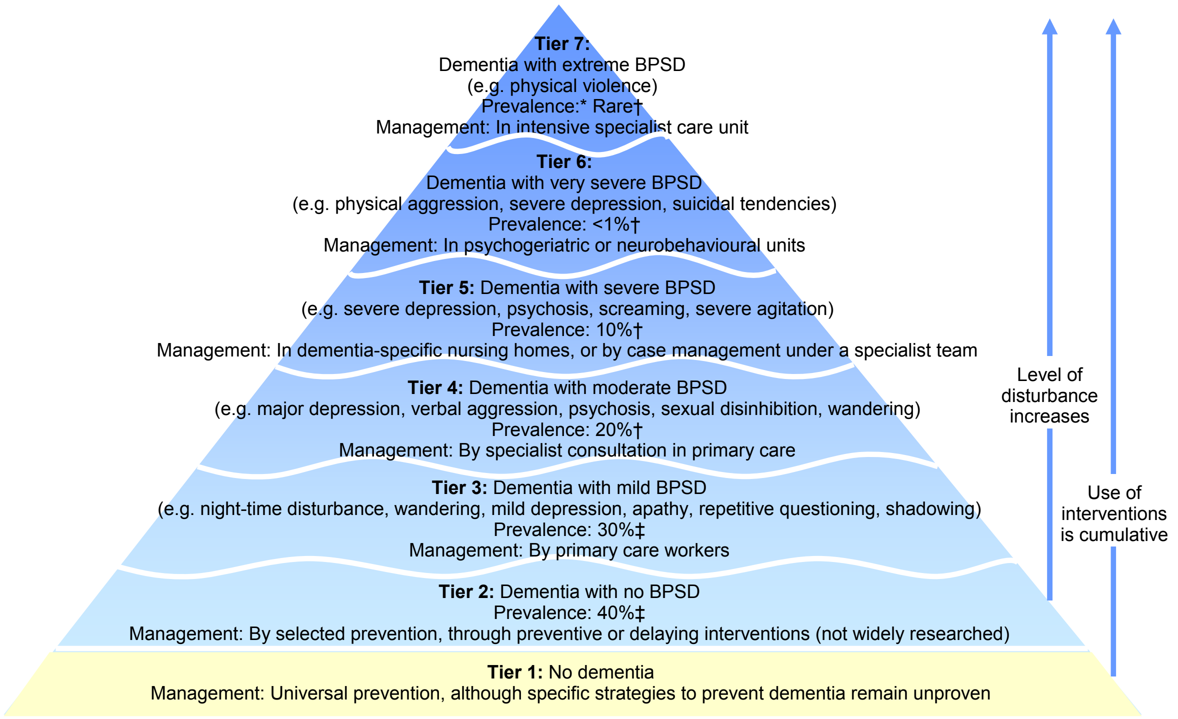
Behavioural and psychological symptoms of dementia

Behavioural and psychological symptoms of dementia (BPSD) is an umbrella term for a heterogeneous group of non-cognitive symptoms that are almost ubiquitous in dementia, including psychosis, depression, agitation, aggression and disinhibition (Brodaty et al. 2003). BPSD may create problems for the individual, the community and health and care workers, and is associated with lowered functional abilities and poorer prognosis, an increased burden on caregivers and nursing-home staff, higher costs of care and earlier institutionalisation. It is not known whether changes in behaviour result from disease-related neurochemical imbalance, from psychological reactions to the cognitive deficits associated with the dementing process or from concomitant physical or psychiatric illness (Baumgarten et al. 1990). Some studies suggest that there is an association between premorbid personality and BPSD (see Low et al. 2002). Quantification of behavioural disturbance is important in determining disease severity and prognosis and has a significant impact on carer stress.

Two issues associated with BPSD include manifestation (e.g. nature, frequency of occurrence and duration of episodes of BPSD) and impact on carers, family, friends or other people. Frequency and duration of challenging behaviour are important indicators of its impact. For example, some types of behaviour may feel disruptive because they occur often (e.g. hiding things, throwing things) and other behaviours may be best defined by how long they last when they do occur, as well as how often they occur (e.g. yelling, screaming or pacing).

Carers, family, friends or other people will vary in terms of the extent to which behaviours are experienced as disrupting or challenging. Challenging behaviour may be described as 'any behaviour associated with the dementing illness which causes distress or danger to the person with dementia and/or others' (Bird 2003). The impact of this behaviour on those around them cannot be simply explained by differences in frequency or the apparently less disruptive behaviour of pacing compared with screaming. The impact of challenging behaviours on the carer is also affected by personal factors, the extent to which modifications to the physical environment have facilitated the management of the behaviour, the development of effective strategies for managing the behaviour, and the nature and type of support available for the carer. For example, wandering at home into a garden without a secure fence is more likely to cause concern that wandering in a secure facility, and training and support may increase a carer's capacity to manage some behaviours more effectively, thereby reducing their disruptive effect.

BPSD has implications for management. The goals of managing challenging behaviour are to reduce the disruptive effects of the behaviour and/or to ameliorate distress or danger (Bird et al. 2002). Management strategies include psychosocial approaches, pharmacotherapy and working with carers or nursing staff. Brodaty et al. (2003) proposed a seven-tiered model for the management of behavioural and psychological symptoms of dementia, which indicated that increasing severity of BPSD requires treatment and management in specialised health and care settings (Figure 5.1).



* Prevalence is expressed as estimated percentage of people with dementia who currently fall into this category.

† Estimate based on clinical observations.

‡ Estimate based on Lyketsos et al. 2000.

Source: Reproduced from Brodaty et al. 2003.

Figure 5.1: Seven-tiered model of management of behavioural and psychological symptoms of dementia

Published Australian studies have examined the range of symptoms and their effects. According to these studies:

1. Multiple behavioural symptoms are common:

- LoGiudice et al. (1999) found that care recipients with dementia had on average 10.5 problem behaviours on the 20-item Clifton Assessment Procedures for the Elderly-Behaviour Rating Scale (CAPE-BRS).
- Brodaty & Hadzi-Pavlovic (1990) found that multiple behavioural symptoms are the rule, especially dependency and demand behaviours; all patients with dementia who were alive at completion of their study exhibited BPSD. Mean scores for patients living at home on the *Problem Behaviour Check List* and subscales are shown in Table 5.24.

Table 5.24: Scores on the total Problem Behaviour Check List and subscales

	Mean score	Standard deviation	Median / possible maximum score
Problem Behaviour Check List (n = 47)	16.2	6.8	Median = 14
Subscales (n = 50–53)			
Dependency	6.3	3.3	6 / 12
Demand	4.2	2.5	3 / 10
Disturbance	2.0	1.9	1 / 8
Disability	2.6	2.6	2 / 8
Wandering	1.1	1.2	0 / 4

Source: Reproduced from Brodaty & Hadzi-Pavlovic 1990.

2. Aggression has been commonly reported in some studies:

- In a study of female primary caregivers, Cahill & Shapiro (1993) found that aggression against caregivers was reported in 89% of cases. Verbal aggression was most prevalent (82%), but more than half (58%) of carers claimed they had been victims of physical aggression including threatening gestures, hitting, kicking, shoving and being struck by flying objects, and 5% experienced sexual aggression. Serious violence was experienced by 26% of carers in the sample.
- Schofield et al. (1998b) found differences in the reports of three groups of carers, depending on whether they were caring for a person with dementia or not. Carers of people with a physical impairment reported fewer instances of aggressive behaviour on the part of the care recipient than carers of people with dementia or undiagnosed memory loss. Carers of people with a physical impairment and no cognitive impairment also reported fewer depressive problems among their care recipients than carers of people with dementia or undiagnosed memory loss.

3. A significant proportion of care recipients experience moderate to severe behavioural symptoms:

- The vast majority of care recipients with dementia or memory loss in a study by Brodaty et al. (2005) displayed behavioural problems: 17% displayed no behavioural symptoms; 35% displayed mild symptoms; 41% displayed moderate symptoms; and 6.4% displayed severe behavioural disturbances, such as severe aggression.
- An evaluation of the Aged Care Innovative Pool Dementia Pilot found that over 64% of care recipients referred for dementia-specific pilot services experienced severe BPSD at time of referral and almost three-quarters experienced at least moderate BPSD (AIHW: Hales et al. 2006).

4. Carer stress:

For each BPSD surveyed, the evaluation of the Aged Care Innovative Pool Dementia Pilot found that at least 50% of family carers reported a level of distress associated with the symptom. Carers experienced distress from symptoms of a non-aggressive nature as well as from verbal and physical aggression: over 60% of carers with a care recipient who exhibited memory loss, emotional or psychological symptoms, or wandering or intrusive behaviour reported moderate to extreme distress in relation to these symptoms. These results provide strong evidence of an association between BPSD characteristics of care recipients with dementia and psychological symptoms in carers. The study also found a statistically significant association between carer strain and carer psychological symptoms; given the widely reported association between carer burden and higher rates of institutionalisation of people with dementia, the Pilot data suggest a relationship between the BPSD characteristics and risk of residential placement. Further, some service providers in the Pilot reported that mainstream community care providers are sometimes unwilling to accept people with dementia who exhibit moderate to severe behavioural symptoms, due to difficulties that can arise in providing care such as resisting assistance and occupational health and safety concerns for staff.

5.5 Disability, health and need for assistance

The impact of a health condition on the population depends on the combination of the prevalence of the health condition and the severity of disability among those with the condition. Dementia does not feature among the most common conditions in the older population, being reported by 4% of people aged 65 and older and by 17% of those with a severe or profound core activity limitation in the 2003 SDAC (Table 5.25). However, dementia is among the health conditions associated with the most severe levels of disability.

For a number of selected health conditions, Table 5.25 measures severity of disability in the older population in terms of:

- the proportion of people with a health condition for whom that condition is their main disabling condition
- the proportion of people with each health condition reporting a severe or profound core activity limitation
- the mean number of conditions reported by people with each health condition.

The selected conditions are examined in people aged 65 years or older in order to account for the increase in the number of comorbid conditions associated with older age. For people aged 65 years or older:

- Those with dementia or Parkinson's disease were much more likely to report that these health conditions were their main disabling conditions than people with other health conditions. Over two-thirds of people with dementia reported that dementia was their main disabling condition (68% or 67,300 people), followed closely by people with Parkinson's disease (66%). The next group of health conditions which people reported as a main disabling condition were arthritis (48%), leg, knee, foot or hip damage from injury or accident (46%), back problems (45%) and cancer (42%).
- Dementia is prominent as the health condition most likely to be associated with a severe or profound core activity limitation—98% of those with dementia (97,300 people) reported a severe or profound core activity limitation. This estimate must be treated with some caution due to the difficulties of identifying people with mild and moderate dementia in population surveys which have been discussed earlier in this report. Other highly disabling conditions identified through the SDAC were problems with speech (87% have a severe or profound core activity limitation) and Parkinson's disease (77%).
- People with dementia reported the third highest mean number of health conditions (5.3 conditions), after those with depression (5.5 conditions) and those with phobic and anxiety disorders (5.3 conditions). Multiple conditions were also associated with nervous tension/stress and head injury/acquired brain damage (5.1 conditions) and leg, knee, foot or hip damage from injury or accident and stroke (4.9 conditions).

Table 5.25: Severity of disability among older people with selected health conditions, 2003

	With health condition					With health condition & profound or severe core activity limitation		
Health condition	**Number**	**% of people aged 65+**	**Number for whom health condition is the main condition**	**% for whom health condition is the main condition**	**Mean number of health conditions**	**Number**	**% of those with the health condition**	**% of people with a profound/severe limitation**
Hypertension	927,500	37.1	242,100	26.1	3.72	210,300	22.7	37.5
Arthritis	893,400	35.8	428,100	47.9	4.01	280,500	31.4	50.0
Total hearing disorders(a)	733,100	29.4	. .	. .	. .	242,600	33.1	43.3
Heart diseases	448,800	18.0	143,900	32.1	4.60	167,000	37.2	29.8
Back problems	408,900	16.4	183,700	44.9	4.43	112,000	27.4	20.0
Diabetes	304,000	12.2	110,700	36.4	4.09	100,300	33.0	17.9
High cholesterol	291,400	11.7	28,100	9.7	4.12	47,500	16.3	8.5
Stroke	252,800	10.1	61,800	24.5	4.87	126,200	49.9	22.5
Osteoporosis	221,900	8.9	67,400	30.4	4.37	85,100	38.3	15.2
Total vision disorders(a)	205,700	8.2	. .	. .	. .	116,200	56.5	20.7
Asthma	176,500	7.1	61,300	34.8	4.25	56,700	32.2	10.1
Head injury/acquired brain damage	133,600	5.4	*6,400	*4.8	5.09	45,400	34.0	8.1
Nervous tension/stress	106,300	4.3	23,900	22.5	5.14	39,700	37.3	7.1
Dementia & Alzheimer's disease	99,300	4.0	67,300	67.8	5.26	97,300	98.0	17.4
Cancer	99,300	4.0	41,400	41.6	4.17	37,600	37.9	6.7
Depression	98,000	3.9	21,400	21.8	5.51	58,400	59.5	10.4
Leg/knee/foot/hip damage from injury/accident	97,300	3.9	44,600	45.8	4.94	49,200	50.5	8.8
Problems with speech(a)	78,000	3.1	. .	. .	. .	67,800	86.9	12.1
Phobic & anxiety disorders	45,500	1.8	10,700	23.5	5.33	27,400	60.3	4.9
Parkinson's disease	26,500	1.1	17,600	66.5	3.93	20,800	78.6	3.7
Any condition	**2,164,800**	**86.7**	. .	. .	**3.27**	**560,900 (22.5% of 65+)**	**25.9**	**100.0**
Total 65+	**2,496,800**	**100.0**	. .	. .	**2.84**		. .	. .

(a) The number of people with hearing disorders, vision disorders and problems with speech was calculated using information about these conditions as well as information about restrictions in these areas.

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

Note: People may have more than one health condition so percentages do not sum to 100.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Need for assistance

The disabling impact of dementia means that people with severe or advanced dementia may require a variety of assistance, including help with activities of daily living (ADLs) related to basic self-care (e.g. bathing, dressing, toileting, getting in and out of bed, continence and feeding). Even those with mild or moderate dementia may require assistance with instrumental activities of daily living (IADLs) central to independent functioning in the community (such as light housework, laundry, meal preparation, grocery shopping, outside mobility, travel, money management, and telephoning). ADLs and IADLs are two basic measures of activity limitation—however, the ADL scale is considered to represent a more basic level of functioning than the IADL scale (AIHW: Wen & Fortune 1999).

The SDAC identifies a range of activities with which assistance is needed by those with a disability or who are frail aged. Certain activities are designated as core activities (self-care, communication and mobility) which are closely aligned with ADLs. Non-core activities include health care, paperwork, transport, housework, property maintenance, meal preparation and cognition or emotion and are similar to IADLs. According to the 2003 SDAC, 98% of people with dementia living in households (26,100 persons) and almost all people with dementia living in cared accommodation (75,200 persons) reported needing assistance with at least one activity (Table 5.26).

Table 5.26: Need for assistance of people with dementia, by residency, 2003

	Households		Cared accommodation	
	Number	**Per cent**	**Number**	**Per cent**
Personal activities[(a)]				
Self-care	16,700	62.8	73,900	98.1
Mobility	21,600	81.3	70,600	93.8
Communication	11,900	44.7	62,800	83.5
Cognition or emotion	20,400	76.6	70,300	93.4
Health care	21,900	82.2	74,700	99.3
Total needing assistance with personal activities[(b)]	*25,800*	*96.9*	*74,900*	*99.5*
Other activities				
Paperwork	20,300	76.5	[(a)]61,400	[(a)]81.6
Private transport[(c)]	22,800	85.8	. .	. .
Housework[(c)]	20,700	77.7	. .	. .
Property maintenance[(c)]	18,200	68.6	. .	. .
Meal preparation[(c)]	14,800	55.7	. .	. .
Total needing assistance with at least one activity[(b)]	**26,100**	**98.3**	**75,200**	**99.8**
Assistance not needed	****500**	****1.7**	****100**	****0.2**
All persons	**26,600**	**100.0**	**75,300**	**100.0**

(a) These activities were only asked of persons with a disability.

(b) Total may be less than the sum of the components as persons may need assistance with more than one activity.

(c) These activities were only asked of persons living in households.

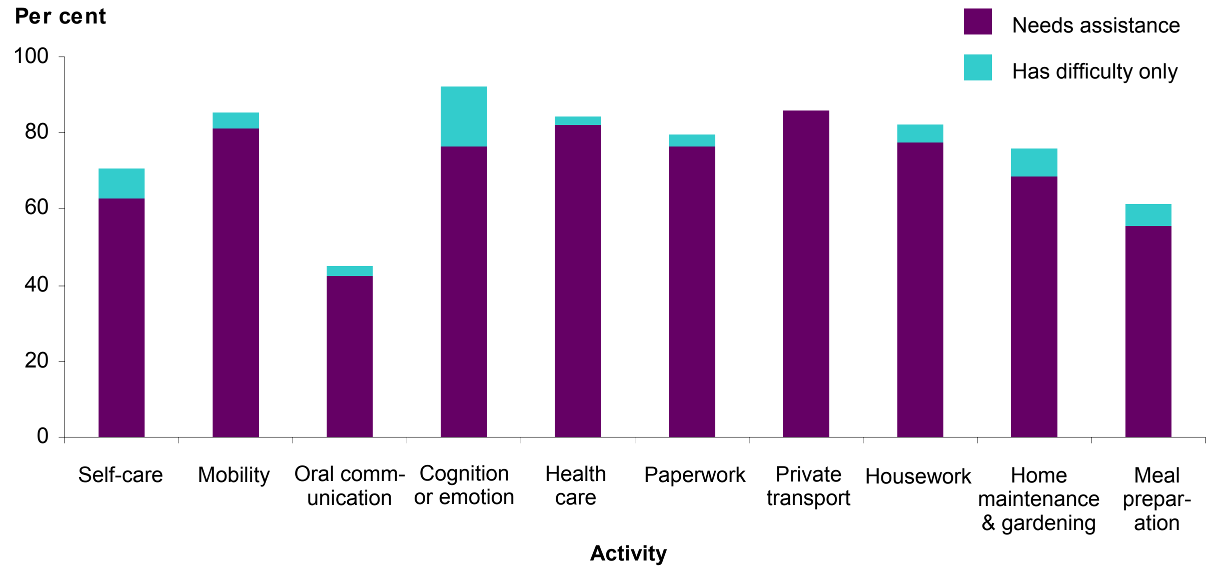
** Estimate has a relative standard error of greater than 50% and is considered too unreliable for general use.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Ninety-seven per cent of people with dementia living in households and almost all people with dementia living in cared accommodation needed assistance with **personal activities**. Health care was the most common personal activity with which people living in households needed assistance (82% needed assistance in this area). This was followed by need for assistance with mobility (81%), cognition or emotion (77%), and self-care (63%). At 42%, assistance with communication was required the least. However, this is still considerably higher than for people without dementia. Other common areas of need included transport (86%), housework (78%) and paperwork (77%).

In cared accommodation, health care was also the most common area of need by those living in households, with 99% needing assistance in this area; this was followed by need for assistance with self-care (98%), mobility (94%) and cognition or emotion (93%). At 84%, assistance with communication was required the least. A higher proportion of people with dementia living in cared accommodation needed assistance with every relevant activity than those living in households.

However, some people with dementia experienced difficulty with activities, but did not necessarily need assistance with these activities. Figure 5.2 shows that, for people with dementia living in households, this was particularly the case in the area of cognition or emotion. Around 92% of people with dementia had difficulty with cognitive or emotional tasks, but only 77% needed assistance with this activity. Data about difficulty with activities are not shown for people with dementia living in cared accommodation, as the vast majority needed assistance with each activity.



Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Figure 5.2: Need for assistance and difficulty with activities, people with dementia in households, 2003

The proportion of people with dementia needing assistance with activities is significantly greater than the proportion of the total population of older people needing assistance with activities (see AIHW 2005b:156–7).

ACAP clients with dementia experience more activity limitations per person than those without dementia. Areas of activity were recorded if the client needed the assistance or supervision of another person, from either formal agencies or informal carers, regardless of whether the assistance was available or not. These categories of assistance are designed to identify severe or profound core activity restriction. The person's need for assistance with activities was reported in relation to their usual accommodation setting. More than one activity can be recorded.

The main activity limitations were the similar for both ACAP clients with dementia and ACAP clients without dementia. For clients with dementia, these were domestic assistance, meals, transport, health care tasks and activities involved in social and community participation (Table 5.27).

Table 5.27: Activity limitations, by dementia status of ACAP client, July 2004 to March 2005

	With dementia		Without dementia	
Activity limitations	**Number**	**Per cent**	**Number**	**Per cent**
Self-care	19,164	73.3	39,595	48.0
Movement activities	8,022	30.7	18,781	22.8
Moving around places at or away from home	14,977	57.3	34,134	41.4
Communication	7,911	30.2	9,050	11.0
Health care tasks	22,030	84.2	43,811	53.1
Transport	22,488	86.0	54,274	65.8
Activities involved in social & community participation	20,726	79.2	44,269	53.7
Domestic assistance	20,186	†77.2	57,880	†70.2
Meals	19,840	†75.8	49,160	†59.6
Home maintenance	14,217	†54.4	39,990	†48.5
Other	1,449	5.5	3,884	4.7
None	346	1.3	3,031	3.7
Unable to determine	294	1.1	7,143	8.7
Not stated/inadequately described	135	0.5	4,792	5.8
Total	**26,158**	**100.0**	**82,480**	**100.0**

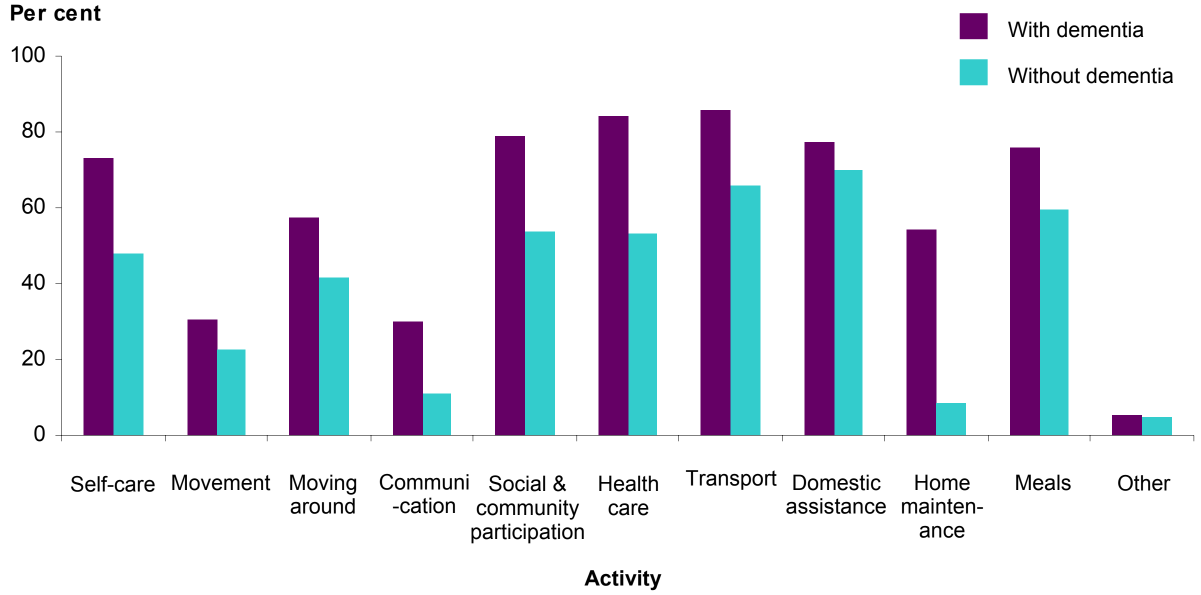
† *Domestic assistance*, *Meals* and *Home maintenance* do not apply to those whose usual accommodation setting was in a residential aged care service, hospital or other institutional care setting. For clients living in households, the percentage with limitations in these activities are 90.5%, 89.0% and 64.0% for clients with dementia and 83.3%, 70.8% and 57.5% for clients without dementia.

Notes

1. Total may be less than the sum of the components as clients may need assistance with more than one activity.
2. If a client independently used an aid (or equipment) to help them with a particular activity, or could independently use such an aid, they were not recorded as needing the help or supervision of another individual.

Source: AIHW analysis of the ACAP MDS v2.

Figure 5.3 shows that all limitations are more prevalent among ACAP clients with dementia than those without. The biggest differences in proportion of ACAP clients with activity limitation between those with and those without dementia occur with health care tasks, activities involved in social and community participation, self-care, transport and communication.



Source: AIHW analysis of the ACAP MDS v2.

Figure 5.3: Proportion of ACAP clients with activity limitations, by dementia status, July 2004 to March 2005

For CACP clients without dementia the proportion requiring self-care assistance was 59%; this is lower than the proportion of clients with dementia requiring such assistance (79%) (Table 5.28). The proportions of clients with and without dementia requiring assistance with mobility were similar—66% and 69%, respectively. Relatively few CACP clients required assistance with communication; however, more clients with dementia required this type of assistance compared with clients without dementia (36% versus 10%). A higher proportion of clients with carers tended to need assistance with each activity, regardless of dementia status.

Table 5.28: CACP clients with and without dementia, core activity in which assistance was needed, census week 2002

	With dementia		Without dementia	
Core activity	**Number**	**Per cent**	**Number**	**Per cent**
Self-care	3,665	78.9	12,161	59.0
Mobility	3,057	65.8	14,156	68.7
Communication	1,689	36.4	2,102	10.2
None	386	8.3	3,448	16.7
Total persons	**4,646**	. .	**20,597**	. .

Notes

1. The table excludes 196 clients where dementia status was not reported.
2. Clients may need more than one type of assistance, and so percentages do not sum to 100.
3. Clients with a self-care limitation sometimes or always needed assistance or supervision with one or more of: eating; showering or bathing; dressing; toileting; or managing incontinence.
4. Clients with a mobility limitation sometimes or always needed assistance or supervision in at least one of the following: maintaining or changing body position; carrying, moving and manipulating objects; getting in or out of a bed or chair; or walking and related activities. Those without other severe or profound mobility limitations but who sometimes or always need assistance using public transport are considered to have a mild mobility limitation.
5. Clients with a communication limitation sometimes or always needed assistance or supervision with understanding others or being understood by others.

Source: AIHW analysis of CACP 2002 census.

Because of targeting, EACH clients have high care needs. All EACH clients, whether with or without dementia, required assistance with self-care tasks, and almost all required assistance with mobility (99% of clients with dementia and 98% of clients without dementia). EACH clients were less likely to require assistance with communication; however, more clients with dementia required this type of assistance (76%), compared with clients without dementia (46%) (Table 5.29). A higher proportion of clients with carers tended to need assistance with each activity.

Table 5.29: EACH clients with and without dementia, core activity in which assistance was needed, by age, census week May 2002

	With dementia		Without dementia	
Core activity	**Number**	**Per cent**	**Number**	**Per cent**
Self-care	90	100.0	190	100.0
Mobility	89	98.9	187	98.4
Communication	68	75.5	88	46.3
Total persons	**90**	. .	**190**	. .

Note: The table excludes 8 clients where dementia status was not reported. See also notes 3, 4 and 5 to Table 5.28.

Source: AIHW analysis of EACH 2002 census.

CACP clients with dementia tended to need assistance with more activities (Table 5.30). In addition, a higher proportion of EACH clients with dementia required assistance with a large number of personal activities (Table 5.31).

Table 5.30: Number of personal activities in which CACP clients sometimes or always need the assistance or supervision of another person, by dementia status, census week 2002

Number of personal activities requiring assistance	With dementia		Without dementia	
	Number	**Per cent**	**Number**	**Per cent**
0	195	4.2	2,147	10.6
1	392	8.5	2,597	12.8
2	550	11.9	3,447	17.0
3	697	15.1	3,419	16.9
4	634	13.8	2,699	13.3
5	591	12.8	2,172	10.7
6	466	10.1	1,439	7.1
7	381	8.3	979	4.8
8	285	6.2	571	2.8
9	155	3.4	409	2.0
10	126	2.7	253	1.2
11	132	2.9	119	0.6
Total	**4,604**	**100.0**	**20,251**	**100.0**
Not stated/inadequately described	*42*	. .	*346*	. .

Note: The table excludes 196 clients where dementia status was not reported.

Source: AIHW analysis of CACP 2002 census.

Table 5.31: Number of personal activities in which EACH clients sometimes or always need the assistance or supervision of another person, by dementia status, census week May 2002

Number of personal activities requiring assistance	With dementia		Without dementia	
	Number	Per cent	Number	Per cent
4	1	1.1	5	2.6
5	1	1.1	7	3.7
6	0	—	7	3.7
7	2	2.2	16	8.4
8	7	7.8	27	14.2
9	18	17.8	45	23.7
10	24	26.7	49	25.8
11	39	43.3	34	17.9
Total	**90**	**100.0**	**190**	**100.0**

— Nil or rounded to zero.

Source: AIHW analysis of EACH 2002 census.

Results from published Australian studies show that people with dementia have higher IADL dependence, and to a lesser extent, higher ADL dependence:

- Schofield et al. (1998b) found that carers of those with dementia reported higher ADL and IADL dependence than the other groups. Similarly, carers of those with undiagnosed memory loss reported more IADL dependence than carers of those with a physical impairment, although the groups did not differ in ADL dependence.
- In a study of carers of people with dementia or memory loss, Brodaty et al. (2005) reported that 24% of care recipients needed no help, 61% needed some help and 15% needed a lot of help with ADLs. In the case of IADLs, 3.7% of care recipients needed no help, 19% needed some help and 99% needed a lot of help.
- Patients with dementia in the study conducted by Helmes et al. (2005) presented with mild functional difficulties—on average, patients had a score of 2.3 (standard deviation = 3.2) on the ADL scale (range = 0–12) and 8.9 (standard deviation = 4.25) on the IADL scale (range = 0–14).
- None of the subjects in the study conducted by LoGiudice et al. (1999) were dependent in more than two activities—39% were ADL dependent and 46% were IADL dependent. Similarly, Bruce et al. (2005) found that the majority of people with dementia were independent in performing basic ADLs, but required assistance with cooking, shopping, managing finances and medications (Table 5.32).

Brodaty et al. (2005) found that the majority of care recipients with dementia or memory loss were moderately or severely physically disabled and had moderate to severe cognitive impairment (Table 5.33). Not surprisingly, Schofield et al. (1998b) found that care recipients with a physical impairment were more physically, and less mentally, impaired than recipients with undiagnosed memory loss or dementia. Care recipients with dementia were more severely mentally disabled than those with undiagnosed memory loss. The frequency of cognitive problems in those with dementia was higher than in those with undiagnosed memory loss or physical impairment.

Table 5.32: Proportion needing ADL and IADL assistance (per cent)

	Supervision only	Assistance/dependence
ADL assistance		
Bathing	8.8	17.6
Toileting	3.3	9.9
Dressing	18.7	17.6
Feeding	7.7	2.2
Grooming	11.0	14.3
Mobility	13.2	8.8
IADL assistance		
Shopping	14.3	63.8
Cooking	9.9	53.9
Finances	11.1	74.4
Medications	29.7	59.4
Housework	9.9	48.4

Source: Reproduced from Bruce et al. 2005.

Table 5.33: Physical and cognitive impairment

Brodaty et al. (2005): Proportion of physical and cognitive disabilities					Schofield et al. (1998b): Mean severity of impairment scores(a)			
	None	Mild	Moderate	Severe		Dementia	Undiagnosed memory loss	Physical impairment
Physical disability	28.4	21.1	18.3	32.1	Physical impairment(b)	10.38	12.43	14.92
Cognitive impairment	—	32.1	33.9	33.9	Mental impairment(c)	12.62	6.63	0.19

(a) A score of 9 = severe impairment, 3 = moderate impairment, 1 = minor impairment and 0 = no impairment.

(b) Includes physical/mobility, coordination, sensory and long-term health problems.

(c) Includes intellectual, communication and psychiatric problems.

Need for assistance with cognition and behaviour

The SDAC collects information from people with a disability about their need for assistance relating to cognition, emotions and behaviour. In 2003, 94% of an estimated 101,900 people with dementia reported a need for assistance with cognitive or emotional tasks (Table 5.34). Most people with dementia in fact need assistance in each of these areas and 62% said they needed help with personal relationships. Over 60% of people with dementia in 2003 recorded a need for behaviour management assistance (Table 5.35).

Table 5.34: People with dementia, estimated number and percentage of people, by stated need for assistance with cognition and emotions, 2003

	Number	Per cent
Whether needs assistance or has difficulty with cognitive or emotional tasks		
Needs assistance or has difficulty with cognitive or emotional tasks	95,200	93.5
Does not need assistance/does not have difficulty with cognitive or emotional tasks	*2,200	*2.2
Assessment of cognitive or emotional support tasks not performed (establishments only)	*3,900	*3.8
Not applicable (heath condition without disability)	**500	**0.5
Total	*101,900*	*100.0*
Whether needs assistance to make decisions or think through problems because of disability		
Needs assistance to make decisions or think through problems	80,600	79.1
Does not need assistance to make decisions or think through problems	*8,400	*8.3
Activity not performed (establishments only)	12,300	12.1
Not applicable (heath condition without disability)	**500	**0.5
Total	*101,900*	*100.0*
Whether needs assistance to cope with feelings or emotions because of disability		
Needs assistance to cope with emotions	72,000	70.7
Does not need assistance to cope with emotions	21,200	20.8
Activity not performed (establishments only)	*8,100	*8.0
Not applicable (heath condition without disability)	**500	**0.5
Total	*101,900*	*100.0*
Whether needs assistance with relationships because of disability		
Needs assistance with relationships	63,300	62.2
Does not need assistance with relationships	27,100	26.6
Activity not performed (establishments only)	10,900	10.7
Not applicable (heath condition without disability)	**500	**0.5
Total	*101,900*	*100.0*
Number of cognitive/emotional tasks for which assistance is needed		
None	10,700	10.5
One	13,300	13.0
Two	21,800	21.4
Three	55,600	54.6
Not applicable (heath condition without disability)	**500	**0.5
Total	*101,900*	*100.0*

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

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

Source: AIHW analysis of the ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Table 5.35: People with dementia, estimated number and percentage of people with behaviour management needs, 2003

Whether needs assistance to manage own behaviour	Number	Per cent
Needs assistance to manage own behaviour	62,900	61.7
Does not need assistance to manage behaviour	*5,900	*5.8
Activity not performed (establishments only)	*6,300	*6.1
Not applicable	26,900	26.4
Total	**101,900**	**100.0**

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

Source: AIHW analysis of the ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

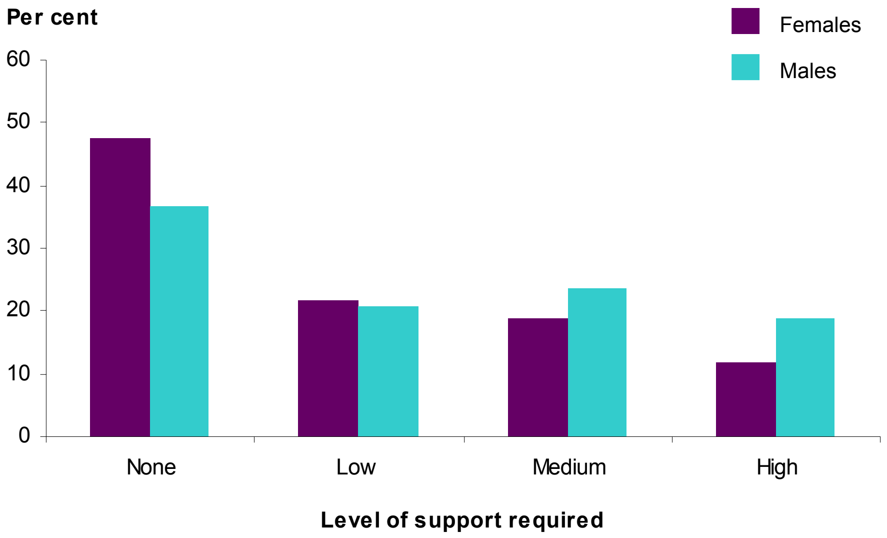
Similar proportions of care recipients registered with a CCRC demonstrate BPSD. In 2004–05, 5,648 CCRC care recipients with dementia (57%) were recorded as having behavioural and psychological symptoms (Table 5.36).

Table 5.36: Dementia status and challenging behaviour of care recipients registered with a CCRC, by sex, 2004–05

	Care recipients with dementia		Care recipients with behavioural symptoms			
Sex	Number	Per cent	Number	Per cent	% with dementia and BPSD	Care recipients with BPSD as a % of all CCRC recipients
Males	4,290	44.3	2,438	44.3	56.8	8.5
Females	5,391	55.7	3,063	55.7	56.8	10.5
Total	**9,681**	**100.0**	**5,501**	**100.0**	**56.8**	**9.5**
Not stated/inadequately described	*259*	. .	*147*	. .	*56.8*	*8.0*

Source: DoHA analysis of the NRCP MDS.

The NRCP data collection also describes the level of support need in relation to a care recipient's BPSD. This rating reflects the carer's perception of the level of support that is needed to manage behavioural and psychological symptoms. It does not imply an assessment process and is a descriptive category only. If the carer is the primary carer of more than one person with care needs, level of support need for BPSD is recorded for each care recipient. More than half of the CCRC care recipients with BPSD were reported to have a need for assistance directly related to this class of symptoms.



Notes

1. High: care recipient needs practical assistance and supervision due to challenging behaviour.
2. Medium: care recipient needs some practical assistance and supervision with some tasks due to challenging behaviour.
3. Low: care recipient needs little or no practical assistance and supervision due to challenging behaviour.
4. None: care recipient needs no support due to challenging behaviour.

Source: DoHA analysis of the NRCP MDS.

Figure 5.4: CCRC care recipients, distribution of levels of support required for BPSD, by sex, 2004–05

Main health condition

As discussed earlier in this section, according to the SDAC, the majority of people with dementia reported that dementia was their main disabling condition. Table 5.37 shows the main health conditions reported by people with dementia from a number of data sources. The meaning of main health condition varies with data collection source:

- The 2003 SDAC asks which long-term condition causes the most problems. Where only one long-term condition is reported, this is the main long-term condition.
- The ACAP MDS v2 records a main condition and allows up to a further nine health conditions to be recorded. The health conditions are recorded at the end of the comprehensive assessment process. Recorded health conditions reflect the health conditions that are related to the person's assessed need for assistance with activities of daily living and social participation. The main condition is the diagnosis with the most impact on the person's need for assistance.
- The principal diagnosis associated with a hospital separation is the diagnosis established after study to be chiefly responsible for the patient's episode of care in hospital. A person with dementia may be admitted to hospital for management of dementia, in which case their record of separation is likely to show dementia as a principal diagnosis, or they may be admitted for some other reason. Where the admission is attributed to a health condition other than dementia, dementia will also be coded on the record as an additional diagnosis if it contributes to the cost of hospital care.

According to the 2003 SDAC and 2004–05 ACAP, over two-thirds of people with dementia or Alzheimer's disease reported that this was their main disabling condition or main health condition (67% and 70%, respectively). Additionally, a further 7.2% of people in the 2003 SDAC reported stroke, head injury/acquired brain damage or Parkinson's disease as their main disabling condition. Collectively, 75% of people with dementia or Alzheimer's disease reported one of these conditions as their main disabling condition.

SDAC respondents with dementia also commonly reported diseases of the circulatory system and diseases of the musculoskeletal system and connective tissue as main health conditions; 9% of ACAP clients reported diseases of the circulatory system as a main health condition. This is not unexpected, considering that conditions such as cardiovascular diseases, arthritis and osteoporosis are common conditions among the older population.

For those in hospital, problems coded to *Factors influencing health status and contact with health services* make up 15.1% of the principal diagnoses for people with dementia (mostly people awaiting admission to an adequate facility elsewhere). In 13% of cases *Dementia and Alzheimer's disease* was the principal diagnosis. Conditions associated with *Injury, poisoning and certain other consequences of external causes* accounted for 14.6% of principal diagnoses. *Diseases of the circulatory system* were the principal cause of hospitalisation in 10.8% of separations with a diagnosis of dementia. These four disease categories were the principal diagnosis for over half (53%) of all hospital separations associated with a diagnosis of dementia in 2003–04.

Table 5.37: Main condition of people with dementia, 2003 SDAC, July 2004 to March 2005 ACAP and 2003–04 NHMD

	SDAC main disabling condition		ACAP main condition				NHMD principal diagnosis	
			With dementia		Without dementia			
Health condition group	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Dementia & Alzheimer's disease	68,800	67.5	18,208	69.6	. .	. .	(a)10,989	(a)13.3
Certain infectious & parasitic disease	—	—	15	0.1	164	0.2	1,595	1.9
Neoplasms (tumours/cancers)	**400	**0.4	433	1.7	4,877	5.9	2,482	3.0
Diseases of the blood & blood forming organs & certain disorders involving the immune system	—	—	52	0.2	450	0.5	821	1.0
Endocrine, nutritional & metabolic disorders	**700	**0.7	464	1.8	3,446	4.2	2,335	2.8
Mental & behavioural disorders (excluding dementia & Alzheimer's disease)	*3,900	*3.8	541	2.1	3,896	4.7	(b)2,398	(b)2.9
Diseases of the nervous system (excluding Alzheimer's disease)	*2,200	*2.2	723	2.8	5,132	6.2	(c)2,376	(c)2.9
Disease of the eye & adnexa	**1,500	**1.5	202	0.8	2,672	3.2	348	0.4
Diseases of the ear & mastoid process	**500	**0.5	67	0.3	584	0.7		
Diseases of the circulatory system	*8,500	*8.4	2,393	9.1	19,156	23.2	8,953	10.8
Diseases of the respiratory system	**1,400	**1.4	361	1.4	4,985	6.0	7,365	8.9
Diseases of the digestive system	**800	**0.8	118	0.5	1,019	1.2	4,556	5.5
Diseases of the skin & subcutaneous tissue	**300	**0.3	55	0.2	499	0.6	1,539	1.9
Diseases of the musculoskeletal system & connective tissue	*10,100	*9.9	755	2.9	11,480	13.9	2,011	2.4
Diseases of the genitourinary system	**400	**0.4	197	0.8	1,378	1.7	4,262	5.1
Pregnancy, childbirth & the puerperium	. .	. .	. .	. .	. .	. .	1	—
Congenital malformations, deformations & chromosomal abnormalities	—	—	22	0.1	58	0.1	14	—
Injury, poisoning & certain other consequences of external causes	**700	**0.6	822	3.1	4,677	5.7	12,071	14.6
Symptoms, signs & abnormal clinical & laboratory findings, not elsewhere classified	**600	**0.6	642	2.5	5,696	6.9	6,170	7.5
Other(d)	**1,000	**1.0	58	0.2	816	1.0	12,520	15.1
Total	**101,900**	**100.0**	**(e)26,158**	**100.0**	**(f)82,480**	**100.0**	**82,806**	**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.

— Nil or rounded to zero.

(a) Includes separations where principal diagnosis is in F01, F03, F051, G30 and G31.

(b) Excludes separations where the principal diagnosis is in F01, F03 or F051.

(c) Excludes separations where the principal diagnosis is in G30 or G31.

(d) Includes *Other conditions which have no ICD-10 equivalent* and *Restriction in physical activity or physical work* (SDAC); *Other health condition not elsewhere specified* (ACAP); and *Factors influencing health status and contact with health services* (NHMD).

(e) Total includes clients where no main health condition diagnosed (3), no formal diagnosis available (15) or main health conditions not stated/inadequately described (12).

(f) Total includes clients where no main health condition diagnosed (322), no formal diagnosis available (655) or main health conditions not stated/inadequately described (10,518).

5.6 Sources of care

The SDAC allows the sources of care for the 26,600 people with dementia living in households to be examined. In 2003, informal care networks of family, friends and neighbours provided much of the assistance received by people with dementia living in the community—57% of assistance with core activities came solely from informal sources; 29% of people receiving help with core activities received assistance from a combination of both informal and formal care providers (Table 5.38). None of those who needed assistance with core activities received such assistance only from formal care providers, such as government organisations and private for-profit and not-for-profit agencies in the community. Fourteen per cent of people with dementia who needed assistance with self-care, mobility and/or communication, received no assistance.

Assistance with communication (100%) and paperwork (92%) were the most likely kinds of assistance to be provided through informal sources for people with dementia living in households with a profound or severe limitation. Health care was the least likely kind of assistance to be obtained only through informal providers (34%), and the most likely kind of assistance to be obtained only through formal providers (19%).

Table 5.38: Source of assistance received by people with dementia living in households with a profound or severe limitation, 2003 (per cent)

Assistance needed	None	Informal only	Formal only	Informal and formal	Number needing assistance
Core activities					
Self-care	20.0	50.8	—	29.2	16,700
Mobility	6.2	63.8	—	30.0	21,600
Communication	—	100.0	—	—	11,900
Total for core activities[(a)]	*14.4*	*56.6*	—	*29.0*	*23,700*
Other activities (in addition to core activity)					
Cognition or emotion	—	75.7	—	*24.3	18,900
Health care	—	*34.1	*18.6	*47.3	20,700
Housework	**3.1	56.1	**2.7	*38.1	20,100
Property maintenance	**1.1	72.5	**4.9	*21.5	17,700
Paperwork	—	92.3	—	**7.7	19,800
Meal preparation	**4.2	*68.4	**1.6	*25.8	14,800
Transport	**2.6	79.0	—	*18.4	20,800

* 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.

— Nil or rounded to zero.

(a) Includes people who need help sometimes or always with at least one core activity. As people may have different sources of care for different activities, these percentages are not simply the average of the percentages for the individual activities.

Note: Components may not add to total due to rounding.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Unmet need occurs when a person does not have sufficient assistance with activities when help is required. The 2003 SDAC provides information on perceptions of unmet need. The area of greatest unmet need was self-care, with 20% of people with dementia living in households with a profound or severe core activity limitation reporting no provider of the assistance needed (Table 5.39). The areas with the highest proportions of people reporting that their need for assistance was fully met were paperwork (97%), meal preparation (91%) and transport (91%).

Table 5.39: People with dementia living in households, whether need for assistance was met, by type of assistance required, 2003 (per cent)

	Extent to which need is met				Number needing assistance
	Fully	Partly	Not at all	Total	
Personal activities[(a)]					
Self-care	62.9	17.1	20.0	100.0	16,700
Mobility	83.9	9.9	6.2	100.0	21,600
Communication	79.4	20.6	—	100.0	11,900
Cognition or emotion	80.9	16.2	2.8	100.0	20,400
Health care	90.2	9.8	—	100.0	21,900
Other activities					
Paperwork	97.4	2.6	—	100.0	20,300
Transport	91.3	1.3	7.5	100.0	22,800
Housework	88.5	8.5	3.0	100.0	20,700
Property maintenance	85.2	13.6	1.1	100.0	18,200
Meal preparation	91.3	4.5	4.2	100.0	14,800

— Nil or rounded to zero.

(a) These activities were only asked of persons with a disability.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

For ACAP clients with dementia, informal assistance was the most common source of assistance for all activities (Table 5.40). For ACAP clients without dementia, informal assistance was the most common source of assistance for all activities except self-care and domestic assistance, where the number receiving informal assistance was roughly equal to the number receiving formal assistance for these activities.

A greater proportion of ACAP clients with dementia than those without dementia relied on informal assistance with activities, for all activities except those involved in social and community participation—for these activities, ACAP clients without dementia were more likely to rely on informal assistance. Conversely, ACAP clients with dementia were less likely than ACAP clients without dementia to rely on formal assistance with all activities except those involved in social and community participation.

Formal assistance is most often used for self-care regardless of dementia status.

Table 5.40: Source of current assistance with activities for ACAP clients, by dementia status

	Formal	Informal	Formal & informal	Total	Number	Not stated/ inadequately described	Not applicable
With dementia							
Self-care	30.1	55.3	14.5	100.0	11,890	2,494	11,774
Movement activities	19.4	68.9	11.7	100.0	3,999	3,825	18,334
Moving around places at or away from home	11.9	76.2	11.9	100.0	9,448	3,021	13,689
Communication	8.9	81.1	10.1	100.0	4,715	3,701	17,742
Activities involved in social & community participation	17.5	63.8	18.7	100.0	14,076	2,105	9,977
Health care tasks	24.5	62.5	12.9	100.0	15,149	1,972	9,037
Transport	10.9	75.2	14.0	100.0	16,170	1,704	8,284
Domestic assistance	29.1	54.9	16.0	100.0	17,428	1,565	7,165
Home maintenance	18.0	75.6	6.5	100.0	11,514	2,491	12,153
Meals	21.8	68.0	10.2	100.0	16,898	1,629	7,631
Other	29.1	65.9	4.9	100.0	1,095	4,459	20,604
Without dementia							
Self-care	43.4	42.4	14.1	100.0	25,918	12,003	44,559
Movement activities	23.8	63.4	12.9	100.0	10,298	14,421	57,761
Moving around places at or away from home	14.6	74.6	10.8	100.0	22,828	12,726	46,926
Communication	14.7	74.2	11.1	100.0	5,726	14,961	61,793
Activities involved in social & community participation	17.1	69.8	13.0	100.0	32,268	10,671	39,541
Health care tasks	39.5	47.1	13.4	100.0	31,414	11,543	39,523
Transport	15.7	69.6	14.7	100.0	42,459	8,956	31,065
Domestic assistance	43.1	42.3	14.6	100.0	49,965	8,301	24,214
Home maintenance	25.6	66.6	7.8	100.0	32,199	10,733	39,548
Meals	30.6	59.9	9.4	100.0	41,016	9,451	32,013
Other	39.5	56.2	4.3	100.0	2,786	15,756	63,938

Source: AIHW analysis of the ACAP MDS v2.

Data on ACAP clients' use of formal services such as government community program support and respite care, as well as recommendations for the use of these services, is included in Chapter 7.

Carer availability

The majority of people with dementia living in households have a carer, particularly those who have a more severe level of disability or dependency. Attempts to estimate the number of people with dementia who receive assistance from an informal carer are complicated by the different definitions of informal care that are used by available data sources.

The SDAC defines informal assistance as unpaid help or supervision that is provided to persons with one or more disabilities or to persons aged 60 years and over living in households. It includes only assistance that is provided for one or more of the specified tasks comprising an activity because of a person's disability or age. 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 (ABS 2004:75). In 2003, the SDAC identified around 25,800 people with dementia who received informal assistance. This represents around 97% of those with dementia living in households. As previously discussed, the 2003 SDAC tends to identify those people with dementia living in households who have a severe or profound disability.

CACP, EACH and ACAP define a carer similarly as 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 as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.

Over three-quarters (77%) of ACAP clients living in households, 56% of CACP clients and 91% of EACH clients reported having a carer (Table 5.41). The high dependency needs of people eligible for the EACH program mean that they require a high level of support to remain in their homes. This support most commonly includes the assistance of family and unpaid carers. However, the ACAP client group includes a wider range of need than the EACH client group, as the program determines eligibility for CACP places and low level residential aged care, as well as EACH places and high level residential care. Therefore, a smaller proportion of ACAP than EACH clients with dementia were reported to have a carer. CACP clients were less likely to have a carer than EACH or ACAP clients.

Table 5.41: ACAP, CACP and EACH clients, by dementia status and carer availability

	With dementia		Without dementia		Total	
Program/carer availability	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
ACAP						
Has a carer	18,586	88.0	46,735	73.5	65,321	77.1
Has no carer	2,545	12.0	16,893	26.5	19,438	22.9
Total	*21,131*	*100.0*	*63,628*	*100.0*	*84,759*	*100.0*
Not applicable	*4,160*	. .	*6,259*	. .	*10,419*	. .
Not stated/inadequately described	*867*	. .	*12,593*	. .	*13,460*	. .
CACP[(a)]						
Has a carer	3,404	73.8	10,727	52.6	14,131	56.5
Has no carer	1,207	26.2	9,673	47.4	10,880	43.5
Total	*4,611*	*100.0*	*20,400*	*100.0*	*25,011*	*100.0*
Not stated	*35*	. .	*197*	. .	*232*	. .
EACH[(b)]						
Has a carer	87	96.7	167	87.9	254	90.7
Has no carer	3	3.3	23	12.1	26	9.3
Total	*90*	*100.0*	*190*	*100.0*	*280*	*100.0*

(a) Excludes 196 cases with missing dementia status.

(b) Excludes 8 cases with missing dementia status.

Note: Not applicable was recorded for people who were permanent residents of residential aged care services, multipurpose services or centres, Indigenous flexible pilots, hospitals or other institutional settings at the time of assessment.

Source: AIHW analysis of the ACAP MDS v2, CACP 2002 census and EACH 2002 census.

Clients diagnosed with dementia were more likely to have a carer than clients without dementia. Around 88% of ACAP clients, 74% of CACP clients and 97% of EACH clients with dementia reported having a carer. In contrast, 73% of ACAP clients, 53% of CACP clients and 88% of EACH clients without dementia reported having a carer.

There were no substantial differences between male and female ACAP clients for carer availability by dementia status (Table 5.42). For both men and women, almost 90%of those with dementia had a carer and approximately three-quarters of those without dementia had a carer.

Table 5.42: ACAP clients with and without dementia, by carer availability and sex, July 2004 to March 2005

	With dementia		Without dementia	
Sex/carer availability	**Number**	**Per cent**	**Number**	**Per cent**
Males				
Has a carer	7,247	89.0	17,622	75.2
No carer	895	11.0	5,802	24.8
Total males	*8,142*	*100.0*	*23,424*	*100.0*
Not stated	*293*	. .	*4,770*	. .
Not applicable	*1,196*	. .	*2,189*	. .
Females				
Has a carer	11,337	87.3	29,106	72.4
No carer	1,649	12.7	11,088	27.6
Total females	*12,986*	*100.0*	*40,194*	*100.0*
Not stated	*574*	. .	*7,817*	. .
Not applicable	*2,963*	. .	*4,067*	. .
Persons				
Has a carer	18,586	88.0	46,735	73.5
No carer	2,545	12.0	16,893	26.5
Total persons	**21,131**	**100.0**	**63,628**	**100.0**
Not stated	*867*	. .	*12,593*	. .
Not applicable	*4,160*	. .	*6,259*	. .

Note: Cases with missing sex are included in the persons data.

Source: AIHW analysis of the ACAP MDS v2.

For all age categories, ACAP clients with dementia were more likely to have a carer than those without dementia (Table 5.43). For all ACAP clients, carer availability was lowest for those under 65 years (83% of those with dementia in this age group had a carer and 67% of those without dementia had a carer) and highest for those aged 95 years and over (89% of those with dementia in this age group had a carer and 80% of those without dementia had a carer).

Table 5.43: ACAP clients with and without dementia, by carer availability and age

Dementia status/age	With a carer		Without a carer		Total		Not stated	Not applicable
	Number	Per cent	Number	Per cent	Number	Per cent		
With dementia								
<65	498	82.9	103	17.1	601	100.0	33	87
65–74	2,154	88.7	275	11.3	2,429	100.0	87	298
75–84	9,233	88.5	1,196	11.5	10,429	100.0	400	1,645
85–94	6,300	87.2	923	12.8	7,223	100.0	325	1,919
95+	394	89.1	48	10.9	442	100.0	22	211
Total with dementia	*18,579*	*88.0*	*2,545*	*12.0*	*21,124*	*100.0*	*867*	*4,160*
Age not stated	*7*	*100.0*	*0*	—	*7*	*100.0*	*0*	*0*
Without dementia								
<65	2,881	67.4	1,396	32.6	4,277	100.0	954	450
65–74	6,728	71.7	2,657	28.3	9,385	100.0	2,083	692
75–84	20,145	72.6	7,584	27.4	27,729	100.0	5,517	2,161
85–94	15,611	76.1	4,906	23.9	20,517	100.0	3,745	2,552
95+	1,351	79.6	346	20.4	1,697	100.0	292	396
Total without dementia	*46,716*	*73.4*	*16,887*	*26.6*	*63,603*	*100.0*	*12,591*	*6,251*
Age not stated	*19*	*76.0*	*6*	*24.0*	*25*	*100.0*	*2*	*8*

— Nil or rounded to zero.

Note: Age is at beginning of assessment.

Source: AIHW analysis of the ACAP MDS v2.

There were no substantial differences between male and female CACP clients for carer availability by dementia status (Table 5.44). For both men and women, approximately three-quarters of those with dementia had a carer and approximately one-half of those without dementia had a carer.

For all age categories, CACP clients with dementia were more likely to have a carer than those without dementia (Table 5.45). For all clients, carer availability was lowest for those under 65 years (64% of those with dementia in this age group had a carer and 46% of those without dementia had a carer) and highest for those aged 95 years and over (76% of those with dementia in this age group had a carer and 56% of those without dementia had a carer).

Table 5.44: CACP clients, by dementia status, carer availability and sex, census week 2002

	With dementia		Without dementia	
Sex/carer availability	**Number**	**Per cent**	**Number**	**Per cent**
Males				
Has a carer	935	72.6	3,213	53.5
No carer	353	27.4	2,789	46.5
Total males	*1,288*	*100.0*	*6,002*	*100.0*
Not stated	*7*	. .	*50*	. .
Females				
Has a carer	2,449	74.4	7,457	52.2
No carer	844	25.6	6,828	47.8
Total females	*3,293*	*100.0*	*14,285*	*100.0*
Not stated	*28*	. .	*144*	. .
Persons				
Has a carer	3,404	73.8	10,727	52.6
No carer	1,207	26.2	9,673	47.4
Total persons	**4,611**	**100.0**	**20,400**	**100.0**
Not stated	*35*	. .	*197*	. .

Note: The table excludes 196 cases with missing dementia status. Cases with missing sex are included in the persons data.

Source: AIHW analysis of CACP 2002 census.

Table 5.45: CACP clients with and without dementia, by carer availability and age, census week 2002

	With a carer		Without a carer		Total		
Dementia status/age	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Not stated**
With dementia							
<65	92	64.3	51	35.7	143	100.0	2
65–74	395	73.0	146	27.0	541	100.0	3
75–84	1,552	73.8	550	26.2	2,102	100.0	16
85–94	1,270	74.7	431	25.3	1,701	100.0	14
95+	68	75.6	22	24.4	90	100.0	0
Total with dementia	*3,377*	*73.8*	*1,200*	*26.2*	*4,577*	*100.0*	*35*
Age not stated	*27*	*79.4*	*7*	*20.6*	*34*	*100.0*	*0*
Without dementia							
<65	721	46.1	844	53.9	1,565	100.0	22
65–74	1,618	49.0	1,681	51.0	3,299	100.0	33
75–84	4,338	52.8	3,884	47.2	8,222	100.0	73
85–94	3,702	55.3	2,989	44.7	6,691	100.0	63
95+	263	55.5	211	44.5	474	100.0	3
Total without dementia	*10,642*	*52.6*	*9,609*	*47.4*	*20,251*	*100.0*	*194*
Age not stated	*85*	*57.0*	*64*	*43.0*	*149*	*100.0*	*3*

Note: The table excludes 196 cases with missing dementia status. Cases with known age but missing sex are included in the persons data.

Source: AIHW analysis of CACP 2002 census.

For EACH clients without dementia, men were more likely to have a carer (97% compared with 83% for women) (Table 5.46). However, for EACH clients with dementia, carer availability was equally high for both men and women (96% and 97%, respectively).

Table 5.46: EACH clients with and without dementia, by carer availability and sex, census week May 2002

	With dementia		Without dementia	
Sex/carer availability	**Number**	**Per cent**	**Number**	**Per cent**
Males				
Has a carer	26	96.3	67	97.1
No carer	1	3.7	2	2.9
Total males	*27*	*100.0*	*69*	*100.0*
Females				
Has a carer	60	96.8	99	82.5
No carer	2	3.2	21	17.5
Total females	*62*	*100.0*	*120*	*100.0*
Persons				
Has a carer	87	96.7	167	87.9
No carer	3	3.3	23	12.1
Total persons	**90**	**100.0**	**190**	**100.0**

Note: The table excludes eight cases with missing dementia status. Cases with missing sex are included in the persons data.

Source: AIHW analysis of EACH 2002 census.

Table 5.47 shows that it was only among the very oldest EACH clients with dementia—aged 85 and over—that clients without a carer are evident. For clients without dementia, carer availability varied across age groups, averaging 88% across all groups.

Table 5.47: EACH clients with and without dementia, by carer availability and age, census week May 2002

Dementia status/age	With a carer		Without a carer		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
With dementia						
<65	8	100.0	0	—	8	100.0
65–74	9	100.0	0	—	9	100.0
75–84	28	100.0	0	—	28	100.0
85–94	36	94.7	2	5.3	38	100.0
95+	4	80.0	1	20.0	5	100.0
Total with dementia	*85*	*96.9*	*3*	*3.4*	*88*	*100.0*
Without dementia						
<65	21	91.3	2	8.7	23	100.0
65–74	44	84.6	8	15.4	52	100.0
75–84	55	87.3	8	12.7	63	100.0
85–94	41	91.1	4	8.9	45	100.0
95+	5	83.3	1	16.7	6	100.0
Total without dementia	*166*	*87.8*	*23*	*12.2*	*189*	*100.0*
Total persons	**251**	**90.6**	**26**	**9.4**	**277**	**100.0**

— Nil or rounded to zero.

Note: The table excludes 11 cases with either age or dementia status missing.

Source: AIHW analysis of EACH 2002 census.

5.7 Conclusion

- Given the increasing prevalence of dementia with age and longer life expectancy for females, it is not surprising that people with dementia are mostly older women—more than half of SDAC respondents and of ACAP, CACP and EACH clients with dementia were women aged 75 years or older. While the majority of people with dementia were born in Australia, a significant minority were born overseas in non-English-speaking countries (16% of SDAC respondents and 18% of clients receiving an aged care assessment).
- According to the SDAC, the majority of people with dementia live in cared accommodation such as homes for the aged. Administrative data collections predominantly collect data from people living in households. Data from both the SDAC and ACAP MDS indicate that the majority of people with dementia living in households, lived with others (usually family) rather than living alone. A smaller proportion of those with dementia lived alone than those without dementia.
- Alzheimer's disease was the most common diagnosis of dementia, followed by vascular dementia.
- People with dementia have higher dependence in IADLs (and to a lesser extent, higher dependence in ADLs) than those without dementia. Almost all people with dementia required assistance with at least one activity (and with at least one personal activity).

Those with dementia experienced more activity limitations than those without dementia, and a larger proportion of people with dementia required assistance with each activity than those without dementia. People with dementia were less likely to require assistance with communication than with other activities—however, a larger proportion of those with dementia required this type of assistance compared with those without dementia.

- The majority of people with dementia needed assistance with activities such as making decisions or thinking through problems, coping with feelings or emotions, relationships, managing their behaviour or with cognitive or emotional tasks. Additionally, multiple behavioural symptoms (including aggression) appear to be common; a significant proportion of care recipients experience moderate to severe behavioural symptoms; and a significant proportion of carers experience distress associated with behavioural symptoms of the people for whom they care.
- Among the older population, dementia is more likely than other conditions to be associated with a severe or profound core activity limitation in self-care, mobility or communication, to be a main disabling condition and to be associated with multiple health conditions.
- Informal sources of care provided much of the assistance received by people with dementia living in households. The majority of people with dementia living in households have a carer, particularly people who have a more severe level of disability or dependency. Those with dementia were more likely to have a carer than those without dementia.

6 Carers of people with dementia

Caring can be broadly defined as providing assistance and support in response to a need arising in the family or community. As such, it can be provided by workers employed in community service organisations or by volunteers in such organisations. However, the vast majority of care for people who need help in their daily activities is provided by family and friends. This ranges from emotional support through financial and practical assistance to supervision and assistance with personal care and other activities for extended periods. This type of care, which is characteristically free of charge, is referred to as 'informal care', and the providers of informal care are referred to as 'carers' for the purposes of this chapter (see AIHW 2003b:65–120 for a discussion of informal care). Use of the adjective 'informal' does not imply that the care provided is thought to be casual or lacking in structure or process. Rather, it is a means of distinguishing the care of a person by family or friends, from care that is provided by formal agencies or institutions, paid for by the receiver or provided by trained professionals.

Carers are family members or friends who provide support to children or adults who have a disability, mental illness, chronic condition or are frail aged and unable to look after themselves (DoHA 2002b). This chapter explores the characteristics of carers of people with dementia and aspects of the caring role, including the impact of the caring role and the carer's use of services. The chapter also identifies gaps in our knowledge, at a national level, about different groups of carers.

Because of dementia's place as one of the leading causes of disease burden, a particular concern associated with the ageing of the population is the increase in the number and proportion of the older population with dementia, and the associated need for both community and residential care (AIHW 2003b:291). Risk factors for entry into residential aged care include: not having a carer; being 80 years or over (or 60 years or over if Aboriginal and/or Torres Strait Islander); having dementia; having a severe or profound core activity limitation; or living alone. Any person who has four or more of these characteristics can be reasonably considered vulnerable to admission to a residential aged care home (AIHW unpublished). Therefore, it is particularly important to understand the circumstances and support needs of carers of people with dementia and the caring role, if people with dementia are to have the option to remain living in the community.

6.1 What data are available?

The review and analysis of data about carers in this report supports the conclusion of Schofield et al. (1996:160) that 'There is limited knowledge about caregivers in Australia in general. Comprehensive data on the prevalence of caregiving are not yet available. Most studies of carers have tended to be small scale and unrepresentative, with study samples often drawn from a client list of a major service provider'. Herrman (1994:12) reiterates 'most research work is focused on families in contact with specialist services or support organisations, and we know that many carers do not know about or seek help'. Additionally, the precise definition of a carer varies between data sources, making comparison of data difficult.

This chapter attempts to make use of the limited Australian data about carers of people with dementia, using data from the 2003 SDAC, administrative data collections and smaller published Australian studies of carers. For comparative purposes, information about carers of people without dementia is also included where appropriate. The results from this analysis provide some information about carers which is useful for policy and planning purposes. Of perhaps more importance, however, is that there are significant gaps and inconsistencies in the data which limit our capacity to answer questions such as:

- Who are the primary carers of people with dementia and what are the important needs for support in these groups? How might this change in an ageing population?
- What kind of back-up care arrangements are currently supporting primary carers, and how might these be affected by population ageing?

Survey of Disability, Ageing and Carers

The ABS SDAC is the source of national population data about carers. For this survey, carers of people with dementia include those who provide informal assistance to people with dementia living in households (see Box 6.1). The definition of a carer is restricted by the requirements that the carer has provided or will provide care for a certain amount of time and that they provide assistance with specified types of activities. This relatively restricted definition of carers will result in underestimates of the number of people providing care and assistance to people with dementia and/or to their primary carers.

Box 6.1: ABS 2003 Survey of Disability, Ageing and Carers: informal assistance and carers

Informal assistance

Informal assistance is unpaid help or supervision that is provided to persons with one or more disabilities or to persons aged 60 years and over living in households. It includes only assistance that is provided for one or more of the specified tasks comprising an activity because of a person's disability or age. Informal assistance may be provided by family, friends or neighbours. Any assistance received from family or friends living in the same household is considered to be informal assistance regardless of whether or not the provider is paid.

Carer

A carer is a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or to older persons aged 60 years and over. This assistance has to be ongoing, or likely to be ongoing, for at least six 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; housework; meal preparation; mobility; paperwork; property maintenance; self-care; or transport.

Primary carer

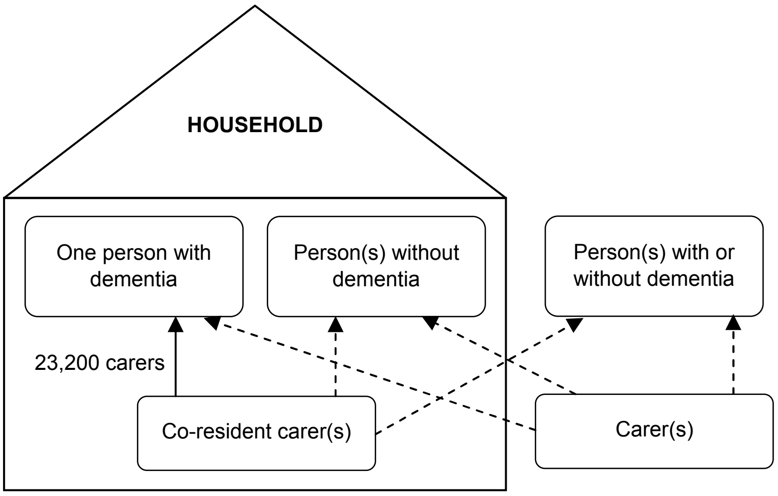
A primary carer is a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care). ***Confirmed primary carers*** *only include persons aged 15 years and over for whom a personal interview was conducted.*

Source: ABS 2004a:71, 75, 77.

Informal care arrangements can be complex. A carer may provide help or supervision for more than one person with dementia, and a person with dementia may receive assistance from more than one carer. Some carers live in the same household with the care recipient, and may be the primary carer for that person while also providing support and assistance to someone living outside the household. The 2003 SDAC identifies 25,800 people with dementia living in households and receiving informal assistance. But the complexities of informal care relationships and arrangements mean that this estimate does not also provide an indication of the number of carers providing this assistance.

This report is unable to describe and analyse this rich set of caring arrangements partly because of the structures of the SDAC files available for analysis. The SDAC Confidentialised Unit Record File (CURF) is the unit record data file that is released by the ABS for use by researchers and analysts. Due to the way the CURF is structured, only the number of co-resident carers and co-resident primary carers can be estimated and only their experiences described.

Co-resident carers are those who live in the same household as the recipient of their care. Some people with dementia received informal assistance from more than one co-resident carer (and/or from carers who did not live in the same household). However, the 2003 CURF only identifies one person with dementia per household as receiving informal assistance from a carer. This also means that each co-resident carer only provided assistance for one person with dementia in the household; this does not exclude the possibility that they also provided assistance to a co-resident recipient without dementia, or to recipients who lived in another household, regardless of whether or not they had dementia (Figure 6.1). Therefore the SDAC CURF does not permit us to estimate the total number of carers providing assistance to people with dementia. Analysis of SDAC data in this report is therefore restricted to co-resident carers. This is an important limitation—as people get older they are more likely to be living alone than with others, and information about non-resident carers is therefore very useful.



Note: Solid lines indicate the carer–care recipient relationships that are reported on in this chapter.

Figure 6.1: Carer–care recipient interactions in the 2003 SDAC CURF

The SDAC collects demographic information about all co-resident carers, but more detailed information about the caring role is collected by personal interview only about *confirmed* co-resident *primary* carers (see Box 6.1). The SDAC sample includes only a small number of co-resident and co-resident primary carers of people with dementia. This reduces the reliability of any extrapolation of these numbers to an estimate of the total population of co-resident carers of people with dementia. Therefore, for the purposes of this chapter, most of the analysis will treat the data from the SDAC as a sample, and will not try to extrapolate this to the Australian population.

Furthermore, as already discussed, the SDAC will under-report on numbers of carers because of the limitations of the survey in identifying people with dementia. These limitations will also affect estimates of carer numbers, although the extent of the underestimate is difficult to determine. It is also important to note that as most carers of people with dementia identified in the SDAC are caring for those in the more severe stages of dementia, the characteristics of their caring role will be different to the characteristics of the broader group caring for people across all stages of dementia.

In summary, the SDAC data only permit this report to describe the experience of co-resident primary carers, with limited reporting possible about other co-resident carers. There are no national comprehensive data that report the number, characteristics and needs of people providing care to those with dementia living in the community.

Administrative data collections

A number of administrative data collections include data about carers of people with dementia, including the 2002 CACP and EACH censuses, the ACAP MDS, Alzheimer's Australia DESP, and the NRCP data set. Data from these programs have been included where possible in this chapter.

Administrative data collections are restricted in coverage to program clients. Consequently they cannot be used to provide an estimate of the total number of carers of people with dementia or to describe the experiences and needs of all carers. However, this information can assist in constructing a profile of carers of people with dementia in contact with these services.

The CACP, EACH and ACAP data collections include information about the primary or principal carer as part of the process of collecting information about the care recipient. These collections therefore do not provide information about all carers of the care recipient, and generally only collect information about the carer that is directly relevant to the care recipient—that is, additional information about the caring role (such as the impact of caring for more than one care recipient) is not collected.

In contrast, Alzheimer's Australia DESP and the NRCP collect information about all carers in contact with these services, and can explore aspects of the caring role in further detail. Additionally, the NRCP collects information about the carer–care recipient interaction in respect of all of the carer's care recipients. These data collections have the potential to be a useful source of information about carers of people with dementia in Australia in contact with these services, but only limited information was available (or relevant) for inclusion in this chapter in the timeframe available for this project. However, compared to sample sizes of most other data sources used in this chapter, the administrative data collections include information about a large number of clients.

The CACP and EACH census collections included questions on dementia status, carer availability, carer co-residency status and relationship of the carer to the care recipient, as well as assistance needed and service use by the care recipient. However, the censuses were conducted in 2002 and more recent data of this type are not available from the ongoing program data. A particular limitation in respect of the EACH program is that it was a relatively new and very small program at the time of the census and it is possible that characteristics of caring arrangements for this population have changed as the program has grown in recent years. Current program data do not include information about carers.

The ACAP MDS includes information that predominantly relates to the client's characteristics and circumstances, but also includes items on carer availability, carer co-residency status and relationship of the carer to the care recipient.

CACP, EACH and ACAP define a carer similarly as *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 as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.* As information is only collected about one carer, the data items relate to the carer who is identified by the client and/or their carer as providing the most significant amount and type of care and assistance related to the client's capacity to remain living at home.

Alzheimer's Australia collects information from contacts with DESP, many of whom are carers of people with dementia. Data items included in the data dictionary about carer status include type of carer, age and sex, main language spoken at home, requirement for an interpreter, locality/remoteness, dementia diagnosis status of the person of concern and relationship to the person of concern. The person of concern is usually a person with symptoms of dementia or memory loss cared for by the carer in contact with Alzheimer's Australia DESP. Information about age, country of birth, proficiency in English and Indigenous status is not collected (or recorded) on a routine basis, and there is too much missing data for it to be useful for analysis. Additional information about carer assistance and carer overall need is collected, but these data items do not appear in the data dictionary. Carers are defined broadly as *those people who provide any level of support or assistance (social, emotional, psychological, physical, personal care, supervisory) to another person who has any level of memory loss, confusion, disorientation, behavioural change or any sequelae of dementia or cognitive impairment*. Professional/service providers (including volunteers) are defined separately.

The NRCP collects information about carers assisted by the program, which include carers of people with dementia. The NRCP defines a carer as *a person such as a family member, friend or neighbour, who provides regular and sustained care and assistance to another person without payment other than a pension or benefit*. The definition excludes all care services such as care or assistance provided by paid workers or volunteers arranged by formal services. Significant efforts over the last year have been made to improve the quality and comprehensiveness of information collected through the NRCP data set. This improved data was unavailable in time for inclusion in this report but represents a potentially rich source of information about carers for future analysis.

Australian studies

Schofield et al. (1996) noted that most studies of carers have tended to be small scale and unrepresentative, with study samples often drawn from a client list of a major service provider. Furthermore, many studies only include co-resident carers or primary or principal carers—so that other people who are part of the network of back-up care, and are important in supporting the complex care needs of people with dementia and in providing support for the carer, are often not included in these studies. In addition, response rates may be low or carers may be unwilling or unable to provide information about particular variables.

Many smaller Australian studies focus on a specific issue with regard to carers—for example, the behavioural and psychological symptoms of dementia or the effects of interventions on carers' psychosocial health. These studies are not designed to provide a detailed profile of carers of people with dementia in Australia, and often use international typologies of carers to guide their research.

The largest of these studies is the Victorian Carers' Program, which involved contacting over 26,000 households and screening for anyone in the household that was a carer—976 identified carers were interviewed. The program comprised a longitudinal survey and a range of promotion interventions—a number of papers have used data collected by this program, including Schofield et al. (1998b) and Brodaty et al. (2005). However, Victorian Carers' Program is not national and was conducted over 10 years ago (in 1993). The program identified carers by asking if anyone in the household took the main responsibility in caring for someone who was aged or had a long-term illness, disability or other problem. Some respondents identified themselves as carers of people in residential aged care facilities—these people are not included in the definition of a carer used by the administrative data collections or the SDAC.

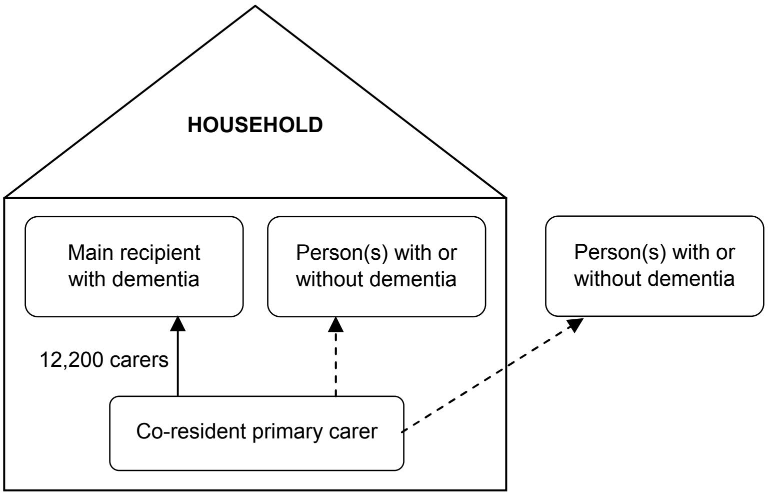
These studies are a valuable contribution to knowledge about carers, and data from these studies have also been included in this chapter. Table A6.1 summarises the published studies whose findings have been reported throughout the chapter. In many cases differences in results may be explained by differences in methodology—for example, carers referred to specialist services might be expected to be experiencing higher levels of burden than those in community samples. Although this report is not intended to reconcile these differences, comment will be made where appropriate.

The following sections in this chapter draw on available data from all these sources to provide a profile of carers of people with dementia in Australia. Improved data to support a more comprehensive profile are important to planning for carer support or for care provision for people with dementia.

6.2 Carer availability

According to the 2003 SDAC, there were 25,800 people with dementia living in households and receiving informal assistance. The SDAC also indicates there were 23,200 (± 7,800) carers who provided assistance to a co-resident person with dementia (see Figure 6.1).

Around 12,200 of these carers were also primary carers (Figure 6.2), and considered the person with dementia their main recipient of care (this number does not include primary carers whose main recipient of care was not the co-resident recipient with dementia). The majority of co-resident primary carers (10,900 carers) were a primary carer only (i.e. they were not also a non-primary carer to another person in need of assistance).



Note: Solid lines indicate the primary carer–care recipient relationships that are reported on in this chapter.

Figure 6.2: Primary carer–care recipient interactions in the 2003 SDAC CURF

However, a considerable proportion of care is also provided by non-resident carers (Sammut 1996). The 2003 SDAC CURF does not permit an analysis of the numbers of people providing care for someone with dementia who does not live in the same household. However, the SDAC also indicates that approximately 65% of carers of people with dementia are co-resident (see *Living arrangements and co-residency status* section below). Assuming the estimate of 23,200 co-resident carers of people with dementia represents 65% of carers, this suggests that there may be approximately 35,900 carers of people with dementia in Australia identified according to ABS definitions. This equates to about four carers for every three people with dementia living in households who receive informal assistance (who are mostly severely or profoundly disabled). This estimate of carer numbers is still an underestimate for the reasons discussed above.

Table 6.1: Alzheimer's Australia DESP carer contacts and distinct people, by dementia diagnosis status of person of concern, 2003–04

	Contacts		Distinct people	
Dementia diagnosis status	**Number**	**Per cent**	**Number**	**Per cent**
Diagnosed	9,590	55.9	4,237	50.4
Being assessed	513	3.0	210	2.5
Symptoms present	2,340	13.6	1,530	18.2
Assessed not diagnosed	118	0.7	71	0.8
Unknown	131	0.8	117	1.4
Not recorded	4,451	26.0	2,236	26.6
Total	**17,143**	**100.0**	**8,401**	**100.0**

Source: Applied Aged Care Solutions analysis of the Alzheimer's Australia DESP database.

In 2003–04, 12,133 people made 22,085 carer contacts with Alzheimer's Australia DESP; 13,462 of these contacts were by principal carers, 5,888 were by secondary carers and 4,477 were by general carers. Considering only carer contacts where a person of concern was also listed in the group (usually a family group), there were 17,143 carer contacts by 8,401 people

(Table 6.1). Of those reporting a dementia diagnosis status for the person of concern, 76% carer contacts and 69% distinct people were a carer of a person of concern who had been diagnosed with dementia.

The NRCP CCRCs assisted 59,342 carers in 2004–05, of whom 10,195 (17%) were carers of people with dementia (Table 5.14). Of the 59,849 care recipients registered with a NRCP CCRC, 9,940 (17%) were recipients with dementia (Table 5.2).

6.3 Profile of carers

Age, sex and Indigenous status

Across all of the studies considered, it seems to be consistently the case that carers of people with dementia are mostly older women—however, a significant proportion of care is also provided by men. According to the 2003 SDAC, 45% of co-resident carers of people with dementia were men and 55% were women. The majority (71%) of male carers were aged under 65 years of age; the number of female carers aged under 65 years (48%) was approximately equal to the number aged over 65 years. Of co-resident **primary** carers, 29% were men and 71% were women. Two-thirds (67%) of male carers were aged over 65 years of age; the number of female carers aged under 65 years (45%) was approximately equal to the number aged over 65 years.

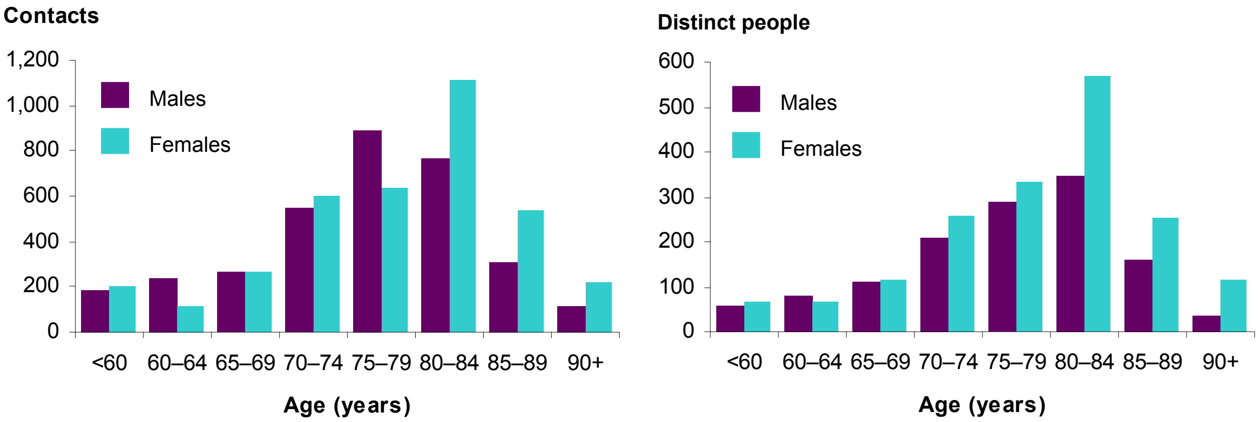
Data from the NRCP show that 72% of carers of people with dementia assisted by a CCRC were female (Table 5.14). The percentage of all carers assisted by a CCRC that were female was 77%.

Table 6.2: Carers assisted by a CCRC, by sex, Indigenous status and dementia status, 2004–05

	Carers assisted by a CCRC		Carers of people with dementia		Per cent who care for a person with dementia
	Number	Per cent	Number	Per cent	
Sex					
Males	13,737	23.3	2,826	27.8	20.6
Females	45,227	76.7	7,343	72.2	16.2
Total	**58,964**	**100.0**	**10,169**	**100.0**	**17.2**
Not stated/inadequately described	*378*	. .	*26*	. .	*6.9*
Indigenous status					
Indigenous	1,648	3.3	162	1.8	9.8
Non-Indigenous	48,359	96.7	9,066	98.2	18.7
Total	**50,007**	**100.0**	**9,228**	**100.0**	**18.5**
Not stated/inadequately described	*9,339*	. .	*967*	. .	*10.4*

Source: DoHA analysis of the NRCP MDS.

Just over half (53%) of carer contacts with Alzheimer's Australia DESP where a person of concern diagnosed with dementia was identified were female (Figure 6.3). The vast majority of carers were aged over 60 years (95%). Similarly, 55% of distinct people were female and 96% were aged 60 years or over. Carers in contact with Alzheimer's Australia DESP were less often female and had an older age profile than NRCP CCRC clients, but this may reflect a larger proportion of non-primary carers in contact with this program.



Source: Applied Aged Care Solutions analysis of the Alzheimer's Australia DESP database.

Figure 6.3: Age distribution of carers of people with dementia contacting Alzheimer's Australia DESP, by sex, 2003–04

Table A6.2 shows the age and sex distribution of carers of people with dementia in the published Australian studies. These studies found that the majority of carers of people with dementia were female, although the precise proportion varied between just over 50% to fewer than 80%, depending on methodological differences and eligibility criteria. The age of carers of people with dementia ranged from less than 30 years to over 90 years. However, the average age for each study was between 50 and 70 years. Overall, just under 70% of carers of people with dementia appear to be female and were on average just over 60 years of age. This is fairly consistent with results from the 2003 SDAC and NRCP.

There are no conclusive data about whether carers of people with dementia are older than other carer groups. Bindoff et al. (1997) noted that although attempts were made to seek older caregivers of physically and intellectually disabled adults for the study, it was not possible to match the ages of those caregivers or dependants with those of the dementia group. Thus, caregivers and dependants in the dementia group in that study were significantly older. However, Schofield et al. (1998b) found that there were no differences between carers of relatives with physical impairment, undiagnosed memory loss or dementia in regards to age or sex.

There are some data from the NRCP about the Indigenous status of carers: 1.8% of carers of people with dementia assisted by a CCRC were Aboriginal or Torres Strait Islander (Table 6.2). The percentage of all carers assisted by a CCRC who were Indigenous was 3.3%. Only a small proportion of people who did not state their Indigenous status are expected to be Aboriginal or Torres Strait Islander.

The ability to provide more accurate estimates of such basic characteristics of the carer population is important for ensuring that carer support needs may be met in appropriate ways. The age distribution of carers from the SDAC may reflect some bias as a result of the exclusion of non-resident carers. Data from the 1998 SDAC (which did not have the same restrictions on reporting about carers) indicated that carers of the very old were more likely to be non-resident carers (AIHW 2004a). However, we lack the more recent data to confirm whether this is the case with very old people with dementia. In a recent evaluation of dementia care pilot projects, 45% of carers were a son or daughter (or their partners) of the person with dementia, and almost half of this group did not live with the parent they were caring for. The support needs of older spouse carers and adult children caring for a parent in another household are likely to be different in terms of preferred models of respite care and social support, for example, and the main issues of concern to them may be different.

Marital status

Around three-quarters of carers of people with dementia participating in the studies listed in Table 6.3 were married or in de facto relationships. Bindoff et al. (1997) found that similar proportions of carers of people with dementia and carers of people with an intellectual disability were married (a higher rate of 84% among carers of people with an intellectual disability may reflect the younger age distribution of carers in this group). Similarly, Schofield et al. (1998b) found that there was no difference between carers of relatives with physical impairment, undiagnosed memory loss or dementia in regards to marital status.

Table 6.3: Carers' marital status: comparison across studies

<table>
<tr><th>Data source</th><th>Married/de facto</th><th>Widowed</th><th>Divorced/separated</th><th>Single</th></tr>
<tr><td>SDAC</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Co-resident carers[(a)]</td><td>67%</td><td colspan="2">16%</td><td>18%[(b)]</td></tr>
<tr><td>Co-resident primary carers</td><td>83%</td><td colspan="2">(9%)</td><td>(9%)</td></tr>
<tr><td>Bindoff et al. (1997)</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Dementia-related disorder</td><td colspan="2">76%</td><td>9%</td><td>15%</td></tr>
<tr><td>Intellectual disability</td><td colspan="2">84%</td><td>11%</td><td>5%</td></tr>
<tr><td>Physical disability</td><td colspan="2">75%</td><td>5%</td><td>20%</td></tr>
<tr><td>Schofield et al. (1998b)[(c)]</td><td>76%</td><td colspan="3">24%</td></tr>
<tr><td>Brodaty et al. (2005)</td><td>74%</td><td>—</td><td>—</td><td>26%</td></tr>
<tr><td>Helmes et al. (2005)</td><td>77%</td><td>6%</td><td>16%</td><td>2%</td></tr>
</table>

— Nil or rounded to zero.

(a) Excludes carers under 15 years of age.

(b) Includes carers that have never married—may include carers in de facto relationships.

(c) Includes carers of people with physical impairment, undiagnosed memory loss or dementia. No differences in regards to marital status were found between the three groups.

Country of birth and language

Many people in the community are carers in one way or another. For example, parents care for children, children for their ageing parents, and spouses and other family members for each other. Some cultural groups see 'normal' caring of this kind as extending further than others. It is likely that carers' responses are shaped by country and culture—therefore, carers' responses to behavioural and psychological symptoms of dementia might vary greatly from one social and cultural setting to another (Ward et al. 2003). However, the response will also be affected by factors personal to the carer and the recipient, by the social and physical setting, by the nature of the disability and by social policies and available services (Herrman 1994).

As noted by AIHW: Rowland & Karmel (2004), the older population born in non-English-speaking countries is projected to increase more quickly and age more rapidly than the older Australian-born population. This, in turn, will have an impact on the demand and type of services required by carers of people with dementia.

The majority of carers of people with dementia are born in Australia and mainly speak English at home (or speak English as a first language). Data from the 2003 SDAC show that 63% of co-resident carers and 57% of co-resident primary carers were born in Australia. Of people born overseas, around 70% were born in countries other than the main English-speaking countries. Almost three-quarters (74%) of co-resident primary carers usually communicated with the care recipient in English.

Ninety-eight per cent of carer contacts with Alzheimer's Australia DESP mainly spoke English at home. Similarly, 98% of distinct people mainly spoke English at home, consistent with the proportion of people that did not require an interpreter (99%). This higher percentage perhaps reflects the lower likelihood of people from non-English-speaking backgrounds contacting mainstream programs for assistance or advice.

These findings are consistent with the results from smaller studies. Bruce & Paterson (2000) found that English was a second language for 8% of those interviewed (however, over 20% of those who declined to be interviewed spoke English as a second language). Brodaty et al. (2005) reported that 81% of carers of people with dementia or memory loss were from English-speaking backgrounds and 19% were from non-English-speaking backgrounds. A smaller proportion of carers from non-English-speaking backgrounds were service users than carers from English-speaking backgrounds, although the difference between the two groups was not found to be significant.

Locality/remoteness

There is considerable variation in results from the various studies and data sources about the regional localities where carers are living. These variations reflect differences in coverage of the population between the surveys and studies.

The 2003 SDAC and Alzheimer's Australia DESP data suggest that most carers of people with dementia live in metropolitan areas of Australia, a pattern reflecting the regional distribution of the Australian population. However, it is also possible that carers' residential patterns partially reflect altered arrangements in order to better access support services. Data from the 2003 SDAC show that 63% of co-resident carers and 74% of co-resident primary carers lived in major cities in Australia. However, the 2003 SDAC only collected information from those living in rural and urban areas—those living in remote or sparsely settled areas in Australia were not covered by the survey.

Sixty-nine per cent of carer contacts with Alzheimer's Australia DESP lived in major cities in Australia, with a further 25% living in inner regional Australia and 5.4% living in outer regional Australia. Similarly, 73% of distinct people lived in major cities in Australia, with a further 20% living in inner regional Australia and 6% living in outer regional Australia. Less than 1% of contacts or distinct people lived in remote regions of Australia.

On the other hand, only 44% of carers recruited for the study by Luscombe et al. (1998) lived in metropolitan areas. Carers living in non-metropolitan areas were more likely (44%) to report that long travel was a problem when seeking a diagnosis of dementia, compared with carers living in metropolitan areas (13%). However, area of residence was not found to significantly affect carer service use, number of respite services used or overall level of use of carer support services.

Similarly, Brodaty et al. (2005) reported in their study that 55% of carers of people with dementia or memory loss lived in metropolitan areas.

Socioeconomic status

Education

Half of the carers of people with dementia have not completed secondary education, though this does not appear to be specific to carers of people with dementia. Data from the 2003 SDAC show that over half (51%) of co-resident carers of people with dementia had not completed Year 12 or a higher level of educational attainment (excluding those aged less than 15 years).

Studies by Brodaty et al. (2005) and Helmes et al. (2005) both reported that the majority of carers of people with dementia or memory loss had no tertiary qualifications (76% and 73% respectively).

Similarly, the mean education level of carers of people with a physical, intellectual or dementia-related disability in the study conducted by Bindoff et al. (1997) was completion of Year 10 or 11—there was no significant difference in mean education level between the three groups. Overall, 24% had completed Year 9, 18% had completed Year 10, 10% had matriculated and 15% had completed university studies. Schofield et al. (1998b) also found that there was no difference between carers of relatives with physical impairment, undiagnosed memory loss or dementia in regards to education—a third had completed secondary education.

Bruce et al. (2005) noted that carers who had completed less than 10 years of education had significantly lower physical component summary scores. However, education was not associated with any difference in mental component summary scores or self-reported stress.

Labour force status

The labour force status of carers is frequently affected by the caring role (Luscombe et al. 1998)—this is not surprising given the physical, psychological and time demands associated with caring for someone who is severely restricted in daily activities (particularly those with dementia). In addition to the more apparent financial implications of caring and its impact on workforce participation, there are other impacts—paid employment is also a way for carers to get respite from caring and helps to maintain social networks. For those caregivers in the workforce, the demands of caring may have implications for their job—they may have to take jobs with less responsibility or miss training opportunities for promotion, or they may have to reduce working hours or use leave entitlements in order to meet their caring responsibilities.

Most of the available data indicate that carers of people with dementia were either not working or had reduced their hours of work. This partly reflects the age of carers (particularly co-resident carers), and partly the demands associated with caring for someone with dementia.

- No co-resident primary carers of people with dementia identified through the 2003 SDAC were in the labour force. Therefore, analysis of the effect of the caring role on their weekly working hours or time off from work is not possible using this data source.
- In a study of carers of younger people with dementia, Luscombe et al. (1998) found that of the carers working at the time of diagnosis, only 41% retained the same employment status at survey, 54% had retired and 5% had reduced their hours from full-time to part-time; 45% were employed full-time at diagnosis, compared with only 18% at survey.
- Fewer than 11% of carers in the study conducted by Leong et al. (2001) held paid jobs. Among a subsample of 10 carers, three were retired, one was semi-retired, one was receiving a disability pension, three were housewives, and two were unemployed.
- In a study of carers of people with dementia or memory loss, Brodaty et al. (2005) reported that 69% were not working, 11% were working less than 30 hours per week and only 20% were working 30 or more hours per week.
- Schofield et al. (1998b) found that there was no difference between carers of relatives with physical impairment, undiagnosed memory loss or dementia with regard to paid employment—although most carers (61%) were not in paid employment, a significant proportion were (39%).

Financial status

Data from the 2003 SDAC show that government pensions or allowances were the main source of cash income for the majority (53%) of co-resident carers (excluding those aged less than 15 years), rather than other sources such as wages or salaries or unknown sources. As no co-resident primary carers were in the labour force, none received their main source of cash income from wages or salaries—in fact, 71% received their main source of cash income from government pensions or allowances: 48% of co-resident primary carers reported receiving the Carer Payment.

Box 6.2: Income support for carers

In addition to general income support, depending on their circumstances, carers may be able to access two government payments: the Carer Payment and the Carer Allowance. People receiving these payments may be caring for more than one person.

Carer Payment (adult) is an income support payment for people who are unable to support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail aged. Because it is for people forgoing paid work due to caring responsibilities, relatively few older people receive it. It is set at the same rate as the Age Pension (at the end of 2006, a single person on the maximum rate received $499.70 a fortnight, and a couple $834.40 per fortnight) and is subject to the same income and assets tests (Centrelink 2006b). Carer Payment cannot be received as well as another income support payment, and the person being cared for must be receiving a social security pension or payment or satisfy specific income and assets tests. A health professional's report is needed to help establish eligibility.

Carer Allowance (adult) is an income supplement payment available to people who provide daily care and attention in a private home to a person who has a disability or severe medical condition or who is frail aged. The Adult Disability Assessment Tool measures the level of care needed by an adult as a result of his or her disability or medical condition and is used to assess medical eligibility for Carer Allowance. Since 1 April 2005, some non-resident carers have also been eligible for this allowance. It is adjusted on 1 January each year, and in 2006 was set at $94.70 per fortnight (Centrelink 2006a). Carer Allowance is free of income and assets tests and may be paid in addition to Carer Payment or other payments.

Fewer carers of people with dementia or memory loss in Brodaty et al. (2005) received a pension or benefit (42%). This was comparable to the findings by Helmes et al. (2005) that 41% of carers most commonly reported a pension as their main source of income, followed by income from business (12%), superannuation (16%), salary (27%) and other sources (3.9%).

Bindoff et al. (1997) found that 48% of caregivers received a gross household annual income of less than $20,000, and 58% lived on less than $25,000 per annum. Caregivers of intellectually disabled recipients had significantly more income ($25,000–30,000) than caregivers of people with a physical or dementia-related disability ($15,000–20,000).

In a study of carers of younger people with dementia, Luscombe et al. (1998) found that only 11% reported no financial problems due to the diagnosis of dementia. The most frequently reported financial problems—reduction in income and loss of carer employment—were more common among carers of people with other dementias than among carers of people with Alzheimer's disease or Huntington's disease (Table 6.4). Spouses were more likely to find reduction in income a problem associated with the diagnosis of dementia and parents were the most likely to claim to be financially affected by the person with dementia losing employment, although this difference was not significant. There was no relationship between the number of types of financial problems, or carer or patient age.

Table 6.4: Proportion of carers reporting causes of financial problems

	Reduction in income	Loss of carer employment
Type of dementia		
Huntington's disease	45	5
Alzheimer's disease	69	31
Other dementias	92	52
Relationship to care recipient		
Spouse	80	52
Parents	45	73
Children	44	11
Other carers	25	50
Total	**70**	**50**

Source: Reproduced from Luscombe et al. 1998.

For some carers, financial pressures, such as concern about fees, can be a source of stress (Bruce & Paterson 2000).

Living arrangements and co-residency status

Carers of people with dementia are more likely to be co-resident with the recipient with dementia, although the proportion of co-resident carers differs between studies due to methodological differences such as recruitment of participants and eligibility criteria (Table 6.5). For example, Leong et al. (2001) only included carers that were co-resident or lived near the person with dementia and visited regularly. However, most studies found that around 65% of carers were co-resident with the recipient with dementia, although the range was large from 35% to 89%. The rate of carer co-residency is also high for EACH care recipients who are assessed as needing the equivalent of high level residential care.

Table 6.5: Carer co-residency status: comparison across studies (per cent)

		Non-resident carer	
Data source	**Co-resident carer**	**Lives alone**	**Lives with others**
ACAP[(a)]			
With dementia	67	33	
Without dementia	57	43	
CACP[(a)]			
With dementia	52	48	
Without dementia	51	49	
EACH[(a)]			
With dementia	86	14	
Without dementia	82	18	
Schofield et al. (1998b)[(b)]			
Dementia	61	39	
Undiagnosed memory loss	63	37	
Physical impairment	53	47	
LoGiudice et al. (1999)	68	32	
Leong et al. (2001)	89	11	
Low et al. (2002)	35	65	
Ward et al. (2003)	86	14	
Brodaty et al. (2005)	67	23	11
Bruce et al. (2005)	63	37	
Helmes et al. (2005)	65	35	

(a) Excludes cases where carer availability or residency status was not reported.

(b) Excludes carers of people with dementia living in residential care.

For comparative purposes, Table 6.5 also includes the co-residency status of those without dementia, where available. Although carers tended to be co-resident with the recipient, regardless of dementia status, this was particularly the case for carers of people with dementia. This may reflect the need for continuous rather than episodic care and supervision by people with dementia. For example, where residency status was reported, the principal or primary carer of ACAP clients diagnosed with dementia was more likely to be a co-resident carer (67%) than a non-resident carer (33%). This was also true for ACAP clients without a dementia diagnosis, although the difference was not as great (57% versus 43%).

Consistent with this, among ACAP clients with a carer, those with dementia were less likely to be living alone (29%) and more likely to be living with family or others than those without dementia (38%). In contrast, among ACAP clients without a carer, those with dementia were more likely to be living alone (82%) than those without dementia (77%). In a study of 26,500 ACAP clients in Victoria, Howe & Kung (2003) note that dementia clients are much less likely to be living in the community alone but equally likely to be living with others, indicating the relatively greater importance of the presence of family caregivers in maintaining individuals with dementia in the community.

Schofield et al. (1998b) noted that significantly more care recipients with dementia were living in residential care, compared with care recipients with undiagnosed memory loss or a physical impairment. Conversely those recipients with undiagnosed memory loss or physical impairment tended to be living with carers. However, after excluding those living in residential care, a larger proportion of recipients with dementia or undiagnosed memory loss resided with their carer rather than living alone or with others.

However, it should be noted that a considerable proportion of care is also provided by non-resident carers (Sammut 1996). Non-resident carers can have quite different experiences of the caring role to co-resident carers (Schofield et al. 1997, cited in Bruce & Paterson 2000). The needs of carers who do not live with the recipient with dementia are different to those of co-resident carers—as Sammut (1996) suggests, these carers face different pressures and need flexible support.

In an evaluation of dementia care pilot projects (AIHW: Hales et al. 2006), living arrangement was the only variable to show a significant association with client accommodation status at time of discharge from a short-term care pilot. The sample comprised data on 10 clients who were living alone while receiving services and 55 clients who were living with family. Half of those living alone were discharged directly to residential care, compared with 14.5% of clients living with family. Living arrangement is bound up with carer availability since 53 of the 55 clients who were living with family had a co-resident primary carer. Based on the analysis results, the odds of a person who lives alone entering residential aged care on discharge from a Dementia Pilot short-term care project are estimated to be 5.8 times higher than for a person who lives with others.

Relationship with the care recipient

The relationship between a carer and care recipient with dementia is closely associated with the age and sex of the carer, and the age and sex of the recipient. As might be expected, the majority of people with dementia are cared for at home by a spouse or relative (Department of Health 1992, cited in Bruce & Paterson 2000)—usually children or children-in-law. A smaller number of people with dementia are cared for by other relatives such as parents or siblings, or friends or neighbours. However, the experience of a daughter who has young children of her own caring for a mother with dementia is likely to be very different from that of a husband or wife caring for his or her spouse (Herrman 1994). Luscombe et al. (1998) noted that, even in support groups, carers who are young spouses feel different from older spouses or similarly aged children of older people with dementia.

Data from the 2003 SDAC show that 39% of co-resident carers and 65% of co-resident primary carers were a spouse or partner, and 46% of co-resident carers and 30% of co-resident primary carers were children or children-in-law (Table 6.6). That is, co-resident primary carers tended to be spouses or partners while other co-resident carers tended to be children or children-in-law or other relatives.

Around 43% of carers of ACAP clients with dementia were a spouse or partner and 47% were children or children-in-law, compared with 34% spouses or partners and 53% children or children-in-law for carers of ACAP clients without dementia.

Schofield et al. (1998b) found that there was no difference between carers of relatives with physical impairment, undiagnosed memory loss or dementia in regards to relationship with the care recipient—a little over half (54%) were adult offspring (mostly daughters), a quarter were spouses (mostly wives), and 21% were other relatives or friends.

The proportion of carers who are a spouse or partner, or children or children-in-law, appears to be associated with the co-residency status of the carer. For example, Table 6.7 shows that co-resident carers of ACAP recipients with dementia tended to be a spouse or partner (64%), while non-resident carers were almost always children or children-in-law (81%). This general trend was also noted for carers of ACAP recipients without dementia. Methodological differences between published Australian studies (and in some cases exclusion of non-resident carers) make it difficult to compare the proportions of carers that are spouses or partners, or children or children-in-law, in Table 6.6.

Table 6.6: Relationship of carer to care recipient status: comparison across studies (per cent)

Data source	Spouse/partner	Children/children-in-law	Other
SDAC		**Per cent**	
Co-resident carers	39	46	15
Co-resident primary carers	65	30	5
ACAP[(a)]			
With dementia	43	47	10
Without dementia	34	53	13
CACP[(a)]			
With dementia	33	55	12
Without dementia	31	54	15
EACH			
With dementia	46	51	3
Without dementia	63	31	6
Dementia caregivers training programme	93	3	4
Brodaty & Hadzi-Pavlovic (1990)	62	31	6
Cahill & Shapiro (1993)	62	38	
Bindoff et al. (1997)	38	15	47
Luscombe et al. (1998)	68	†12	†21
Schofield et al. (1998b)[(b)]	25	†54	†21
LoGiudice et al. (1999)	54	†36	†10
Bruce & Paterson (2000)	71	29	—
Bruce et al. (2002)	76	19	5
Low et al. (2002)	16	†63	†21
Ward et al. (2003)	68	26	6
Brodaty et al. (2005)	33	†55	†12
Bruce et al. (2005)	45	52	3
Helmes et al. (2005)	39	†49	†12

† May or may not include children-in-law.

— Nil or rounded to zero.

(a) Excludes cases where relationship of carer to care recipient was not reported. Includes private employees.

(b) Includes carers of people with physical impairment, undiagnosed memory loss or dementia. No differences in regards to relationship between carer and care recipient were found between the three groups.

Table 6.7: Relationship of carer to care recipient, by co-residency status of carer, ACAP client with dementia

Relationship of carer to care recipient	Not applicable	Co-resident carer	Non-resident carer	Not stated/ inadequately described	Total
Wife/female partner	0	5,165	52	10	5,227
Husband/male partner	5	3,605	36	4	3,650
Mother	0	30	9	0	39
Father	0	15	5	0	20
Daughter	3	2,738	3,679	15	6,435
Son	2	1,266	1,590	9	2,867
Daughter-in-law	1	237	238	0	476
Son-in-law	0	19	16	0	35
Other female relative	2	342	567	6	917
Other male relative	0	136	220	0	356
Female friend/neighbour	0	132	285	2	419
Male friend/neighbour	0	108	116	1	225
Private employee	1	44	40	0	85
Not stated/inadequately described	1,018	331	84	1,160	2,593
Not applicable	6,102	44	70	13	6,229
Total	**7,134**	**14,212**	**7,007**	**1,220**	**29,573**

Notes

1. A client may have more than one carer. This data element relates to the carer who is identified by the client and/or their carer as providing the most significant amount and type of care and assistance.
2. Some people of Aboriginal or Torres Strait Islander origin attach a different cultural meaning to terms such as 'brother', 'uncle' and 'mother' than the purely biological/social meanings that non-Indigenous people use. In such cases the ACAT recorded the relationship of the carer according to how the client or carer identified that relationship.
3. *Private employee* (not organised by formal services) refers to carers that are personally arranged without the involvement of formal community services. Such carers may be paid directly by the person or a family member or may receive free or subsidised board or lodgings in return for their caring services.

6.4 The caring role

The role of primary carers is crucial to maintaining highly dependent people with dementia at home. Carers provide a range of assistance and support with daily activities as well as emotional, financial and practical support. The role of formal services in supplementing care from family becomes critical for people with high care needs living in the community, but it is also important to recognise that the presence of family carers is itself a conduit to the person with dementia receiving formal service intervention.

Pilot services in the Innovative Pool Dementia Pilot were designed for people with high care needs associated with dementia, and a high proportion of recipients had moderate to severe dementia. A number of these pilot services accepted referrals only for people who had access to daily care from family (AIHW: Hales et al. 2006). Judging by this requirement, it may be difficult for a person with dementia who does not have daily access to care from family to access community care services because of the level of risk to the person and to the service provider that is involved in community living, and because it is the service-seeking behaviour of family members that often results in the formal service intervention.

Motivation to care

The reasons for caring for someone with dementia are complex. The ABS SDAC allowed carers to give more than one reason for taking on a primary caring role. Data from the 2003 SDAC show that a sense of duty to care is one of the most common reasons reported by co-resident primary carers of people with dementia—a large proportion reported that they provided care because they felt an emotional obligation to take on the role (52%) or that it was a family responsibility (48%). Other reasons for taking on the caring role included that they could provide better care than someone else (30%) or no other family or friends were willing or available (35%).

Bruce et al. (2002) also noted that there was a strong sense of duty towards the relative with dementia, and that this drove carers to continue caring for as long as possible without outside help and inhibited carers from discussing problems with their GPs. Interviews of a small subsample of 10 carers in a study conducted by Leong et al. (2001) similarly showed that some family members took on the caring responsibility out of love and concern for the person with dementia, or out of a sense of duty and family obligation. Most took on the caring role because there was no-one else in the family who was willing or available to care for the person (a factor which can also contribute to a sense of duty).

Assistance provided by carers

As dementia progresses it becomes increasingly difficult for the person with dementia to live independently; consequently, there are increasing demands on the caregiver to provide assistance. The loss of cognitive function means that a person with dementia gradually loses insight into their level of functioning and, over time, becomes unable to seek assistance when assistance is needed. This will tend to reach a point where constant supervision and guidance is required. Memory loss and impaired judgement have implications for medication use and personal and physical safety. In dementia care, the carer provides not only instrumental assistance, but acts as a 'bridge' (terminology used in the Sydney Older Persons Study) to formal services, and provides a critical safety monitoring role.

According to the 2003 SDAC, all people with dementia who were the main recipient of care by a co-resident primary carer were profoundly or severely limited in performing one or more core activities, and sometimes or always needed assistance with that activity (see Box 4.2 for a description of core activity limitations in the SDAC). Accordingly, all co-resident primary carers provided assistance with one or more core activities to their main recipient with dementia (which is consistent with the definition of a primary carer). More specifically, 91% provided assistance with communication, 91% provided assistance with mobility, and 78% provided assistance with self-care.

Furthermore, all co-resident primary carers provided assistance with at least one non-core activity to their main recipient with dementia—in particular, all carers provided assistance with health care, paperwork, housework and meal preparation; 96% provided assistance with transport; 87% provided assistance with property maintenance; and 91% provided assistance with cognition or emotion (the remainder did not state whether they assisted with cognition or emotion).

The ABS definition of a primary carer (see Section 6.1) requires that assistance be provided with core activities. Studies without this definitional limitation provide some insight into the extent to which assistance with ADLs is provided by a broader group of carers of people with dementia. Schofield et al. (1998b) reported that carers of relatives with dementia reported higher ADL and IADL dependence, and corresponding IADL provision (2.78), than carers of those with undiagnosed memory loss (2.52) or a physical impairment (1.88). Similarly, carers of relatives with an undiagnosed memory loss reported more IADL (but not ADL) dependence and care provision than carers of those with a physical impairment.

Brodaty et al. (2005) reported that 29% of carers provided no help with ADLs to the recipient with dementia or memory loss, 43% provided some help and 28% provided most or all help with ADLs. More than half (53%) of carers provided most or all help with IADLs, but 3.7% provided no help, and 14% provided some help.

Carers may continue providing assistance to the recipient with dementia, even after they have entered residential care—the form of care provided usually shifts from meeting daily needs towards giving social and emotional support (Schofield 2001). In a study of rituals of family carers whose relative with dementia had recently entered residential care, Schofield (2001) found that some carers engaged in small caregiving tasks, even when staff normally attended to these chores, giving the carer a sense of a continuing role in their relative's life. However, family carers felt that these tasks were at times directly or indirectly discouraged by caregiving staff. Research on the division of care between staff and family members indicates that confusion may arise about where responsibility for tasks lies when they have both an instrumental and a psychosocial component (Duncan & Morgan 1994, cited in Schofield 2001)—the tasks that were discouraged by caregiving staff were those that fell within this grey area.

Time spent caring

The time demands placed on carers of people with dementia are quite substantial. Because of the progressive nature of most types of dementia, ultimately a person with dementia requires 24-hour care. Draper (2004) notes that many of the behavioural consequences of dementia, such as sleep changes and wandering, require extra supervision from the carer. He states that such behaviour places increasing demands on carers' time and requires them to be vigilant even when they need time to relax.

Data from the 2003 SDAC show that around 65% of co-resident primary carers spend 40 hours or more actively caring or supervising per week—as the majority of co-resident primary carers had only one care recipient, it can be assumed that a large proportion of this time was spent caring for the main recipient with dementia (almost all co-resident carers (87%) and co-resident primary carers (91%) only cared for the recipient with dementia). This is not unexpected, considering almost 96% of main recipients with dementia required continuous (rather than episodic) care from their co-resident primary carer.

Similarly, in a comparative study of carers of relatives with physical impairment, undiagnosed memory loss or dementia, Schofield et al. (1998b) noted that although time spent caring did not differ between the three groups, after excluding those in residential care, over half of the care recipients with dementia were unable to be left alone compared with a quarter of those with undiagnosed memory loss and 13% of physical impairment recipients.

Additionally, Bruce et al. (2005) found that the median number of hours spent caring per week was 28 hours, with a range of 8 to 168 hours per week.

The NRCP also collects information on time spent caring, but these data were not available in time for this report.

Duration of care

The mean or median duration of care is often reported to be less than five years, reflecting the late age of onset of dementia and its association with increased carer burden as a risk factor for entry into residential care. Methodological and study design differences mean that published estimates of the duration of the caring role vary widely:

- In a retrospective study of carers who were providing care in the community, Cahill & Shapiro (1993) found that the mean duration of care was 47 months.
- Bruce & Paterson (2000) found that the perceived duration of the caring role varied between 4 months and 10 years, with a mean of 2.9 years.
- The length of time since the respondents in the study conducted by Leong et al. (2001) had assumed the role of family carer ranged from 4 months to 20 years, with a mode of 2 years. A subsample of 10 carers included four carers that had been caring for 1–2 years, three for 4 years, two for 6–7 years and one for 20 years.
- Carers in the study by Bruce et al. (2002) estimated that the duration of care was 6 months to 7 years, with an average of 2.3 years (eligible carers were those who had been caring for the care recipient for at least 6 months).

However, it should be noted that mean or median duration of care may be misleading—some carers have been caring for a recipient with dementia for 10 or 20 years.

Data from the 2003 SDAC show that the majority of co-resident primary carers (52%) had been caring for their main recipient with dementia for between 1 and 4 years. However, consistent with Schofield et al. (1998b), over one-fifth (22%) had been caring for their main recipient with dementia for more than 10 years.

In a comparative study of carers of relatives with physical impairment, undiagnosed memory loss or dementia, Schofield et al. (1998b) found that the duration of care exceeded 10 years for 22% of caregivers and under 2 years for 32%. Excluding those whose relatives were in residential care, almost a third had never had a break or had not had a break in over 2 years.

The NRCP also collects information on date the caring role commenced, but the data were not available in time for this report.

6.5 Impact of the caring role on carers

Anderson (1987) described the caring role as an ‘unremitting burden’. Much of the literature suggests that the demands placed on caregivers of people with dementia are heavy; they must manage behavioural problems in addition to the care needs of the person with dementia. Observing the gradual decline of a loved one from a competent individual to an incompetent dependant can also be a harrowing experience (Draper 2004), and is likely to add to the burden. High-level dementia care may be different to other types of caring because it involves every aspect of the person: provision of physical, psychological, cognitive and social support. There can also be a high degree of social isolation that impacts on the capacity of the carer to live a participative life.

Numerous researchers have investigated the impact of the caring role for caregivers of people with dementia (for example, Sammut 1996; Brodaty & Gresham 1989; Connell et al. 2001). Carers of people with dementia are at particularly high risk of anxiety and depression as a result of their caring role. Brodaty & Gresham (1989) have summarised some of the literature on this issue, associating carers with feelings of demoralisation, isolation and psychological distress.

Health, wellbeing and carer burden

Morris et al. (1988) (cited in Henderson & Jorm 1998 and AIHW 2004a) remark that institutionalisation may have more to do with the attitudes and wellbeing of the caregiver than the impairment of the dementia sufferer. The physical and mental wellbeing of carers plays a pivotal role in whether the person with dementia can remain living in the community.

The 2003 SDAC indicated that 46% of co-resident primary carers reported at least one adverse effect due to the caring role. These adverse effects included responses such as frequently feeling angry or resentful about their caring role, having been diagnosed with a stress-related illness, feeling weary or lacking energy or frequently feeling worried or depressed because of the caring role. Around 70% of co-resident primary carers of people with dementia reported that their sleep was frequently or occasionally interrupted due to their caring role. All co-resident carers experiencing interrupted sleep believed that this interfered with their normal daily activities.

In a recent evaluation of dementia pilot projects (AIHW: Hales et al. 2006), two scales were chosen to report on the wellbeing of participating carers (Robinson's (1983) 13-item Caregiver Strain Index, and the 28-item General Health Questionnaire (GHQ)). Data collected for the evaluation confirmed reports from project coordinators and case managers that carers of people referred for pilot services typically presented showing high levels of carer strain. It is thought that most carers had managed for too long without adequate support before approaching the projects. Almost three-quarters of carers scored above the threshold of high carer strain. Anxiety and insomnia were the most frequently reported psychological symptoms. A statistically significant association was found between baseline measures of carer strain and psychological symptoms, confirming that high levels of carer strain are associated with lower levels of psychological wellbeing among primary carers whose care recipients participated in the evaluation.

There is evidence that co-resident carers are more stressed than those whose relative lives elsewhere or in a residential setting (Brodaty & Hadzi-Pavlovic 1990 and Yeatman et al. 1993, cited in Schofield et al. 1998b). However, Schofield et al. (1998b) found that co-resident carers expressed more role satisfaction as well as more resentment than those caring for a relative in residential care, living alone or with another person, regardless of whether they were carers of relatives with physical impairment, undiagnosed memory loss or dementia. Additionally, carers of relatives living alone or with another person reported higher levels of positive affect and life satisfaction than co-resident carers. Helmes et al. (2005) did not find any significant difference in the degree of burden felt by carers who lived with the care recipient with dementia and those who lived separately.

In a comparative study of carers of relatives with dementia, undiagnosed memory loss or a physical impairment, Schofield et al. (1998b) found that resentment was the most effective indicator for predicting burden (combined scores on four measures: negative affect, overload, social support and life satisfaction; followed by increased family conflict, care recipient depression, close relationship and anger). Factors contributing to resentment included low social support, anger, difficulty in behaviour problems and being a carer of a relative with undiagnosed memory loss, rather than a carer of a relative with dementia.

Bruce & Paterson (2000) found that most carers suffered high levels of stress, mainly due to behaviour disturbances and care needs of the dementia sufferers. Problems with health care agencies were also reported by a majority of the carers to be contributors to their distress. General practitioners were perceived to have referred dementia sufferers too late for community care, despite the carer having experienced difficulties for a considerable time period. Carers also complained that too little information was provided about the diagnosis of dementia, how to deal with problem behaviours and how to access support services before and after the assessment procedure.

Leong et al. (2001) investigated areas of significant unmet need perceived as important to family members who were the principal carer of a relative with dementia. The six most frequently reported barrier needs included: to know that someone will provide care when family carer unable to do so; a telephone hot-line; time away from caring duties; ways to deal with stress; time for physical rest; and ways to deal with feelings of being trapped.

Common problems emerging from the interviews of carers in the study conducted by Bruce et al. (2002) included the patients difficult behaviours, their own exhaustion, feeling stressed, and lack of time for person or social activities.

Social interaction

Leong et al. (2001) stated that the commitment to care for someone with dementia involves major and ongoing sacrifice on the part of the carer—the time involved, the disruption of normal routines and lifestyle, the physical demands of caring on a 24-hour basis, the constant vigilance, and the restrictions on contacts with friends and wider family are just a part of what the caregiving entails.

Common problems reported by carers in the study conducted by Bruce et al. (2002) included lack of time for personal or social activities. LoGiudice et al. (1999) also noted that psychosocial impairment in the health status of carers was greatest in the domains of social interaction and recreations and pastimes. There was significant improvement in the social interaction of carers attending a memory clinic (but not the control group) after 6 months, and this was maintained at 12 months.

Brodaty & Hadzi-Pavlovic (1990) commented that the findings regarding personal contacts were cause for concern, with half of the carers spending time only once a week or less with someone who did not live with them (Table 6.8).

Table 6.8: Frequency of personal and telephone contacts in the previous two weeks (proportion)

	Personal contact	Telephone contact
Daily	9	36
2–6 times per week	41	55
Once per week	31	9
Once per fortnight	6	—
Not at all	13	—
Mean number of contacts per week	**2.6**	**5.9 (standard deviation 3.3)**
Satisfaction with amount of contact (maximum score of 6)	**Modest (mean 3.6, standard deviation 1.8)**	**Moderate (mean 4.8, standard deviation 1.5)**

— Nil or rounded to zero.

Source: Reproduced from Brodaty & Hadzi-Pavlovic 1990.

Comparatively, Gibson (1983) (cited in Brodaty & Hadzi-Pavlovic 1990) reported that 50% of elderly respondents to the Australian Health Survey had at least one personal contact daily, 24% had contacts 3–6 times per week, 20% had 1–2 contacts per week and 6% had no contacts within a month.

Brodaty & Hadzi-Pavlovic (1990) noted caregivers who were in contact with more people from outside their home, and who were more satisfied with the number of people with whom they were in contact, showed fewer psychological symptoms. Thus there were significant negative correlations between GHQ scores and the frequency of personal contacts and satisfaction with the amount of personal contact; and between Zung scores and the frequency of and satisfaction with personal contacts. They suggest that support may be protective. Alternatively, those who were unwell may tend to perceive their supports negatively and as inadequate (i.e. there was contamination of ratings of support by psychological state variables). Similar trends were seen in associations between carer psychological morbidity scores and satisfaction with telephone contacts (but not with the number of telephone contacts), although this did not reach statistical significance.

Bindoff et al. (1997) reported that social and recreational activity was the only one of nine wellbeing measures that significantly differentiated caregivers of people with a dementia-related disorder, intellectual disability or physical disability. Caregivers of those with a dementia-related disorder reported the lowest level of participation, although the majority of the difference in social and recreational activity was between caregivers of those with an intellectual disability and the other two groups.

Distance and physical isolation from family members and friends compounds difficulties carers experience in maintaining relationships and social activities. Brodaty & Hadzi-Pavlovic (1990) found that while 82% of carers had relatives or friends living nearby, 18% had not a single relative or friend within 60 km. Only 68% had at least one child within a 60 km radius, compared to 87% of a group of 1,050 older people (non-carers) living in Sydney (ABS 1983, cited in Brodaty & Hadzi-Pavlovic 1990). A subsample of 10 carers in a study conducted by Leong et al. (2001) reported feeling alone and isolated in their caring role, with lack of support from their families. While in some cases family members and friends had drifted away preferring not to be involved, many had immediate family members living too far away to give practical help.

Relationship with others

Caring for someone who is old or disabled can also affect the family atmosphere (Schofield et al. 1998b). Data from the 2003 SDAC show that the majority (61%) of co-resident primary carers reported that the caring role had at least one adverse main effect on their relationship with other co-resident family members, friends, spouse or partner, or care recipient with dementia. Adverse effects include responses such as *Less time to spend with them*, *Relationship strained*, or *Lost or losing touch with existing friends*.

Family conflict was identified as an effect of dementia by 41% of carers in a study by Luscombe et al. (1998). Additionally, three-quarters of spouse carers with children reported that their children had suffered psychological or emotional problems as a consequence of dementia in the family and only 8% reported that their children had not encountered **any** problems. Half reported that their children had been in conflict with their affected parent—more often with their affected father than mother and also more often if the affected parent was younger (Table 6.9).

Table 6.9: Proportion of carers reporting conflict between children and parent with dementia

	Per cent
Relationship of care recipient to children	
Father	62
Mother	19
Age of care recipient	
<50	79
50–59	48
60–64	36
Total	**51**

Source: Reproduced from Luscombe et al. 1998.

Children were also more likely to have problems at school or at home if the person with dementia was less than 50 years old. More types of problems in children were associated with both youthfulness in the carer and the patient. The overall number and types of problems faced by children of carers looking after patients from different diagnostic groups were similar, although there was a trend for more frequent Alzheimer's disease carer reports of children with psychological or emotional problems (88%) than Huntington's disease (78%) or other dementias (55%).

Schofield et al. (1998b) found that carers of those with a physical impairment were also less likely to report increasing conflict in the family following the onset of caring compared with carers of those with dementia or undiagnosed memory loss. The groups did not differ on family cohesiveness.

Almost 38% of carers in the study conducted by Bruce & Paterson (2000) reported family friction due to the lack of support from other family members.

Relationship with care recipient

The 2003 SDAC indicates that the majority of co-resident primary carers (52%) considered that their relationship with the care recipient was unaffected by the care recipient's dementia. This is consistent with the finding that almost 38% of carers in the study conducted by Bruce & Paterson (2000) reported a changed role in their relationship related to the loss of function of the patient.

This same study found that around 29% of carers reported negative premorbid relationships that were exacerbated by dementia (Bruce & Paterson 2000).

In the study conducted by Schofield et al. (1998b), carers of relatives with a physical impairment were more likely to rate the quality of their relationship with a recipient with a physical impairment as very close (71%), compared with carers of those with dementia (53%) or undiagnosed memory loss (52%). On the other hand, 12% of caregivers in the study conducted by Low et al. (2002) rated their relationship with the resident before institutionalisation as somewhat close, 18% as moderately close and 70% as very close.

Schofield et al. (1998b) also found that carers of those with a physical impairment were more likely to rate the level of tension in their relationship with a recipient with a physical impairment as low (62%), compared with carers of those with dementia (49%) or undiagnosed memory loss (41%).

Brodaty & Hadzi-Pavlovic (1990) examined the psychosocial effects of caring on co-resident carers of people with dementia, finding that co-resident carers who are spouses suffer more psychological distress than those who are not spouses.

Impact of behavioural and psychological symptoms of dementia

Evidence of the relationship between challenging behaviours and the impact on carer stress is equivocal. Buono et al. (1999) (cited in AIHW 2004a:24) reported that the main causes of burden in dementia care are the heavy personal care needs, memory loss and behavioural symptoms that can be experienced by the person with dementia. However, an early study by Zarit et al. (1980) found no association between behavioural symptoms and level of carer strain.

Most Australian studies have reported a link between carer burden and the behavioural and psychological symptoms associated with dementia. Brodaty & Hadzi-Pavlovic (1990) found that there was no support for the hypothesis that psychological morbidity in carers was related to total problem behaviours. However, there was modest support for the hypothesis that the level of psychological morbidity (i.e. GHQ score) of carers was associated with demand problem behaviours. No other problem behaviour subscale correlated significantly with either GHQ or Zung depression score. There was a significant interaction between demand and disturbance behaviours and GHQ scores when the carers were the patients' wives.

Around 79% of carers in the study conducted by Bruce & Paterson (2000) reported patient behaviour as a source of stress. Commonest reported behaviours were confusion, argumentative or irritable behaviour, wandering, nocturnal disturbance, constant repetitions and accusations of stealing. Physical or verbal abuse of the carer by the patient, and physical or verbal abuse of the patient by the carer, was reported as a source of stress by 17% and 21% of carers, respectively (although this was not necessarily chronic abusive behaviour).

Similarly, Bruce et al. (2002) reported that common problems for carers emerging from the interviews included the patients' difficult behaviour. Additionally, triggers precipitating referrals from GPs included new behaviours (wandering, incontinence).

Schofield et al. (1998b) noted that a higher proportion of carers of those with a physical impairment (36%) reported it as very easy to cope with their relatives' behaviour, compared with carers of those with dementia (3%) or undiagnosed memory loss (6%), and fewer reported it as very difficult. Carer burden was significantly lower among carers of people with physical impairment, compared with carers of people with dementia or undiagnosed memory loss. Care recipient depression was found to be a significant predictor of burden, and difficulty in coping with problem behaviours was a significant predictor of resentment.

However, Bindoff et al. (1997) noted that carers of people with a dementia-related disorder, an intellectual disability or a physical disability did not differ with regard to cognitive and behavioural coping strategies. Similarly, Ward et al. (2003) found that 76% of all psychological problems and 67% of behavioural ones were labelled as either no problem or only a mild problem by carers. However, tolerance was not without limits and some carers were close to 'burn out': 14 of the 50 had used residential respite care, which is often a prelude to permanent placement. Even experienced carers rarely articulated a strategic plan—when faced with delusions, abuse and repeated questions, carers most commonly stated that they either did nothing or responded gently with reassurance, distraction and orientating information. Ward et al. (2003) suggest that those carers who said they did nothing when faced with resistant, abusive or inappropriate behaviours may actually have incorporated good preventative strategies so completely into everyday life that they failed to mention them when questioned at interview.

Both Bruce & Paterson (2000) and Schofield et al. (1998b) reported that a firm diagnosis of the care recipient's condition often reduces carer burden. Wood & Rabins (cited in Schofield et al. 1998a and AIHW 2004a) independently maintain that if carers understand the condition they are less inclined to interpret behaviour as offensive or as the product of their own inadequacy.

At least 50% of carers surveyed during the evaluation of Innovative Pool dementia care pilot projects reported some level of distress for each type of BPSD surveyed (AIHW: Hales et al. 2006). Over 60% of carers with a care recipient who exhibited memory loss, emotional or psychological symptoms, and wandering or intrusive behaviour reported moderate to extreme distress as a result of these symptoms. These results confirm the role of BPSD in contributing to carer strain and of the consequent importance of carer support and behaviour management services.

Positive aspects of the caring role

There is a growing body of literature investigating the positive impacts of the caring role (Connell et al. 2001). Such outcomes include enjoyment of the caring role, satisfaction and enhanced self-esteem. Some of the carers in the study conducted by Bruce et al. (2002) expressed pride in their caring role.

However, according to the 2003 SDAC, only 26% of co-resident primary carers reported feeling satisfied due to the caring role—the majority (56%) reported that they were not affected in this way.

Schofield et al. (1998b) reported that although carers of those with dementia or undiagnosed memory loss were more likely to express anger and resentment than carers of those with a physical impairment, the groups did not differ in role satisfaction.

6.6 Support networks for carers

As previously mentioned, many studies only include co-resident carers or primary or principal carers—that is, other people who are part of the network of back-up care, and are important in supporting the complex care needs of people with dementia and in providing support for the carer, are often not included in these studies. However, information about informal support that primary or principal carers receive from family or friends is investigated in a number of studies.

Data from the 2003 SDAC show that almost half (48%) of the co-resident primary carers of people with dementia stated that they did not have a fall-back carer—only 30% reported that they had a fall-back carer, with a smaller number reporting that they did not know whether or not they had a fall-back carer.

- Around 52% of co-resident primary carers of people with dementia reported needing or wanting an improvement or more support in areas such as respite care, financial assistance, physical assistance, emotional support, improvement in own health or other areas of assistance. Respite care was the most commonly reported area that carers needed or wanted an improvement or more support as reported by 26% of co-resident primary carers.

- 57% reported not needing **any** assistance or **further** assistance—43% reported needing assistance or further assistance (i.e. 30% were already receiving assistance and reported needing further assistance). The majority of co-resident primary carers reported having no unmet need for assistance on weekdays (78%), weekends (74%) or weeknights (87%); overall, 57% reported having no unmet need at any of these times.

While the carers in the study by Brodaty & Hadzi-Pavlovic (1990) may have had access to a confidante, practical help was not always forthcoming—41% of co-resident primary carers had no main source of assistance. Of carers for whom sufficient data were available for analysis, 33% received (and 26% needed) assistance with shopping, 12% (and 11%) with meals, 30% (and 35%) with housework, 28% (and 17%) with transport, 27% (and 30%) with gardening, and 40% (and 38%) with minor house repairs. Where assistance was received (or needed) it was mostly provided by children once or twice weekly.

Bindoff et al. (1997) noted that the caring role was typically the responsibility of a single caregiver who received limited informal support: 54% reported receiving no help from family members or friends in direct care of the dependant such as feeding, bathing or helping with mobility, and 61% received no indirect help in caring for the dependant such as doing shopping housework or home maintenance. Lack of family support was reported by 38% of carers in the study by Bruce & Paterson (2000).

Of those caregivers who did receive help, as reported by Bindoff et al. (1997), 33% reported almost daily assistance, while 13% reported help six-monthly or less. A majority (68%) rated the quality of this help as good or very good and 11% as very poor. Rating the overall frequency and quality of the help received, 4% reported being very unhappy, 1% were not happy, 27% thought it was okay and 51% were pleased or very pleased. There were no significant differences between caregivers of dependants with a dementia-related disorder, an intellectual disability or a physical disability for any of these variables (Table 6.10).

Table 6.10: Comparison of informal support for carers of dependants with dementia-related, intellectual and physical disabilities

		Disability category		
	Scale	**Dementia-related disorder**	**Intellectual disability**	**Physical disability**
Persons providing direct help	0 = no persons, 3 = 5 or more	0.5	0.6	0.6
Persons providing indirect help	0 = no persons, 3 = 5 or more	0.5	0.4	0.4
Frequency of help received	0 = never, 5 = almost daily	2.3	2.7	2.4
Quality of help	0 = very poor, 5 = excellent	3.1	3.9	2.4
Satisfaction with help	0 = very unhappy, 4 = very pleased	2.5	3.0	2.2

Source: Reproduced from Bindoff et al. 1997.

However, in Schofield et al. (1998b), perceived social support was higher for carers of those with a physical impairment in comparison with carers of those with undiagnosed memory loss or dementia.

The most important unmet need reported by carers in the study by Leong et al. (2001) was the need to know that someone would provide care if they became ill and the need to deal with feelings of entrapment. Many did not have back-up arrangements for another member of the family to take over should the principal carers become incapacitated. Most carers in the sample were elderly and almost half reported lack of support from family or other informal sources. Many carers had immediate family members living too far away to be able to give practical help, and in other cases family members and friends had drifted away, preferring not to be involved, but leaving a vacuum in the support network for the carer.

6.7 Formal service use by carers

More detailed information about the use of formal services by people with dementia and their carers is included in Chapter 7. This section examines service use to support carers, such as community services, respite care and counselling.

The major type of assistance provided through community care programs which is designed to directly benefit carers is respite care. In addition, the provision of other assistance types to care recipients (e.g. health care, delivered meals, bathing) provides indirect support to carers by supplementing the amount and type of care they provide to the care recipients. Respite care may be provided in the home, at a centre during the day or overnight, or in a residential service. There are also small cottage services. As well as providing information and support for carers, the National Respite for Carers Program provides respite care. Information about the carers assisted by the program and the care recipients registered in the program is provided in Table 5.14. Use of services provided through this program is discussed in more detail in Chapter 7.

According to the 2003 SDAC, the majority of co-resident primary carers of people with dementia (70%) reported that they had never used respite care. Furthermore, 57% of primary carers stated that they had never received respite care and did not need or want it. This is consistent with ACAP data for nine months during 2003–04 which indicates that 73% of ACAP clients with dementia, for whom use of respite care was applicable, had not used it (Table 6.11). This was slightly less than for ACAP clients without dementia (75%).

The importance of respite care to support carers of people with dementia is indicated by the recommendations for respite care made by ACATs during this period (Table 6.11). While 33% of clients without dementia who had not used respite care were also not recommended for respite care, this was the case for only 15% of clients with dementia. In general, ACAP clients with dementia had higher rates of recommendation for long-term care in a residential aged care or other institutional setting than ACAP clients without dementia. Among ACAP clients for whom respite care recommendations were applicable, 78% of clients with dementia were recommended for some type of respite care, compared with 53% of ACAP clients without dementia.

Table 6.11: Respite care use at time of assessment and recommended respite care use, ACAP clients, by dementia status, July 2004 to March 2005

	Respite care recommended							
Respite care use	**Not applicable[(a)]**	**Residential**	**Non-residential**	**Residential & non-residential**	**None**	**Unable to determine**	**Not stated/ inadequately described**	**Total**
With dementia								
Not applicable[(b)]	3,978	393	6	82	187	54	31	4,731
Residential	1,029	1,505	11	275	97	6	12	2,935
Non-residential	245	312	96	513	31	5	3	1,205
Residential & non-residential	133	114	3	314	8	1	2	575
None	4,372	6,737	318	1,589	2,346	119	98	15,579
Unable to determine	169	99	3	24	27	145	2	469
Not stated/ inadequately described	76	166	9	32	245	23	113	664
Total	**10,002**	**9,326**	**446**	**2,829**	**2,941**	**353**	**261**	**26,158**
Without dementia								
Not applicable[(b)]	6,126	947	21	730	388	182	199	8,593
Residential	1,781	4,040	18	500	227	52	41	6,659
Non-residential	203	411	168	592	54	3	10	1,441
Residential & non-residential	75	97	2	377	7	1	1	560
None	10,405	21,949	645	2,556	18,032	1,338	385	55,310
Unable to determine	443	203	5	27	130	2,542	51	3,401
Not stated/ inadequately described	329	389	24	49	379	297	5,049	6,516
Total	**19,362**	**28,036**	**883**	**4,831**	**19,217**	**4,415**	**5,736**	**82,480**

(a) Recorded for people whose recommended long-term care setting is residential aged care, a hospital or other institutional care.

(b) Recorded for people who were permanent residents of residential aged care services, multi-purposes services or centres, Indigenous flexible pilots, hospitals or other institutional settings at the time of assessment.

Note: Residential respite care may be relevant to people with or without carers. Non-residential respite care is only relevant to clients with carers.

Respite care is an important service type provided through the CACP program, and data about respite care use through this program were collected in the 2002 census. Most respite care is used by clients with carers, signifying its important role in carer support (Table 6.12). The mean and median number of hours of respite in the census week was higher for recipients with dementia than those without dementia. Median hours of respite care for those with dementia was 3.0, compared with 2.0 hours for those without dementia (means of 4.0 and 3.0 hours, respectively). CACP recipients with dementia and with a carer were more likely than others to receive respite: 12% of recipients with dementia and a carer received this service, compared with 6% of those without dementia with a carer (Table 6.12).

Table 6.12: CACP care recipients with and without dementia, use of respite care, by carer status, census week 2002

	With dementia				Without dementia			
	With a carer		Without a carer		With a carer		Without a carer	
Use of respite care	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
	393	12.0	11	0.9	623	6.0	100	1.1
Amount of respite care (hours)	**Mean**	**Median**	**Mean**	**Median**	**Mean**	**Median**	**Mean**	**Median**
	3.9	3.0	5.2	2.5	3.1	2.0	2.3	2.0
Total CACP recipients	**3,284**	. .	**1,179**	. .	**10,429**	. .	**9,437**	. .

Note: The table excludes 1,110 cases. These include both recipients with either carer availability or dementia status missing, as well as those who received no services during census week.

Source: AIHW analysis of CACP 2002 census.

Similarly, high levels of non-use of respite care have also been reported by smaller studies, which sometimes also enquired into reasons for non-use. Brodaty et al. (2005) found that 84% of carers did not use respite services, and only 35% of those carers reported needing this service. Perceived lack of need was reported by 65% of carers as the principal reason for non-use of respite services, followed by care recipient's resistance to accepting help from services (12%), not having enquired (9.1%) and lack of knowledge (7.6%).

Low levels of use of respite care were reported in the study conducted by Ward et al. (2003). Only 36% of the care recipients regularly attended day care, and 28% used generic or specialist respite residential care.

Excluding carers of people with dementia in residential settings, Schofield et al. (1998b) found that carers of people with dementia were more likely to both use and need respite care than carers of relatives with physical impairment or undiagnosed memory loss, although the proportions of carers using respite care were low. Around 17% of carers of relatives with dementia used respite care, compared with 11% of carers of those with undiagnosed memory loss and 7% of carers of those with a physical impairment. Similarly, almost half (47%) of carers of those with dementia reported needing respite care, compared with 27% and 19% of carers of those with undiagnosed memory loss or a physical impairment respectively.

Higher rates of respite care use were reported in a study of carers of younger people with dementia (Luscombe et al. 1998) where 33% of carers had used one and 35% had used two or more types of respite care. Carers of people with Huntington's disease tended to use fewer respite services than carers of people with Alzheimer's disease or other dementias. There were no significant differences in the number of respite services used by carer gender, area of residency, relationship to patient or carer age, although the number of respite services used tended to be positively associated with the patient's age. Table 6.13 provides the number of carers that used each type of respite service, and what proportion of these carers rated the service as good.

Table 6.13: Use of respite services at survey

Type of service	Number	Per cent	Per cent rated 'good'
Day centre	33	37.5	85
Hospital	25	28.4	68
Nursing home	15	17.0	47
In-home	12	13.6	92
Hostel	10	11.4	70
Other	8	9.1	67
Nil	28	31.8	. .
Total	**88**	. .	. .

Source: Table reproduced from Luscombe et al. 1998.

Leong et al. (2001) reported that respite care was one of the most frequently mentioned needs, but the experience of study participants at the time was that accessing in-home or institutional respite care at short notice was not usually possible. Respite care was seen as the only opportunity for carers to receive the break they needed for their health and state of mind. Leong et al. (2001) suggested that those caring for people with dementia at home feel a need for a variety of respite services, including day, overnight and weekend care, accessible at short notice—current services need to be more flexible and responsive to the actual needs of those who use them.

The range of respite services and their availability have grown over recent years, due to a number of federal government initiatives directed at increasing respite options for carers. However, data from the SDAC and ACAP suggest that there may still be issues in respect of carers' awareness of respite care options available to them and/or the extent to which carers perceive that respite care services are able to meet their needs appropriately.

6.8 Carer support and intervention

The Australian Government offers support and intervention for carers through a number of programs, including the Early Stage Dementia Support and Respite Project, the Dementia Education and Support Program, the Carer Information and Support Program and the National Respite for Carers Program. The last five years have seen a major growth in the availability of respite services, including specific funding through the NRCP for emergency and overnight care for carers of people with dementia.

A number of intervention trials have addressed ways of assisting informal carers of those with dementia—however, as LoGiudice et al. (1999) noted, most trials have evaluated programs which have been specially designed for the project. For example, Brodaty & Gresham (1989) studied patient–carer pairs participating in either a dementia carers' program, memory retraining group or waiting group. At 12 months' follow-up, the carers' program resulted in significantly lower psychological stress among carers than the memory retraining program.

Fewer intervention trials have determined the effectiveness of health services that are already established. LoGiudice et al. (1999) conducted a study of carers and their relatives with mild to moderate cognitive impairment to assess the beneficial effects of a memory clinic for carers. The results demonstrated improved overall psychosocial health-related quality of life for carers attending the clinic, particularly in the domain of social interaction, which was identified as one of the areas most affected by the caring role.

Vernooij-Dassen et al. (1996) (cited in AIHW 2004a:24–5) found a strong association between carers' sense of competence and the level of agitation and apathy in the care recipient with dementia. They concluded that interventions that help carers recognise, clarify and understand the behaviour of the person with dementia might change the carer's perception of the behaviour. This could increase the carer's sense of competence and so reduce carer burden.

All project coordinators involved in the Innovative Pool dementia care pilots emphasised the importance of engaging primary carers and other family members in care planning (AIHW: Hales et al. 2006). They reported on the need to cater to the needs of different age and lifestyle groups of carers, and reflected on how the characteristics of a carer can influence the level and type of their involvement in care planning and the type of carer support required. It was noted that younger carers are often more confident in negotiating the system of support and interacting with service providers in a care management partnership role. This can potentially reduce the level of ongoing high-level case management from the formal care provider.

Employed younger carers for this particular target group may have a reduced need for social support compared to full-time carers or co-resident older carers. This group generally requires more flexible respite care than is offered by most mainstream services to accommodate paid employment. Older carers and socially isolated carers can benefit from social support and respite services that offer opportunity for social interaction (AIHW: Hales et al. 2006).

Given the imminent high growth in numbers of very old people living in the community, ageing of the baby-boomer population and the estimated doubling in prevalence of dementia with every five years of age over 65, improved awareness of government support programs and community care entry points will ensure formal services continue to play an effective role in early intervention and coordinated support for growing numbers of carers.

7 Use of health and aged care services

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 need for assistance with daily living in connection with health conditions and age, the availability of social resources, personal preferences and cultural influences, financial resources, education and level of access to services. A conceptual model that is often used to characterise and investigate the use of formal services, including health care and long-term care services, in older populations proposes that service use is determined by societal factors, services system factors, and a set of factors relating to the person: individual need, enabling and predisposing factors (Andersen 1995; Andersen & Newman 1973). Dementia, as an important determinant of the use of formal services, poses special challenges in this context, both in terms of services system factors and individual factors. Increased understanding of the range of services that is needed by, available to and used by people with dementia and their carers is currently an area of policy and research priority. This chapter examines the data that are available to portray the use of health care, community care, and residential aged care programs by people with dementia and their carers.

The natural course of dementia can have a profound effect on decisions surrounding the timing and pathways of formal service intervention. Chapter 4 showed that dementia has a far greater effect on years of healthy life lost due to disability than on years of life lost due to premature mortality: in 2003 an estimated 24,100 years of life were lost due to deaths with an underlying cause of dementia, compared with an estimated 84,000 years of healthy life lost due to the disabling nature of dementia. Therefore, most of the service use that is associated with dementia is concerned with reducing the impact of disability on individuals with dementia and their families. Dementia and Alzheimer's disease are among a number of health conditions that individually are associated with high rates of long-term institutional care. Most people with advanced dementia live in cared accommodation (see Chapter 5), reflecting the difficulties of living alone and the heavy burden involved in caring for a family member with advanced dementia. 'Dementia care pathways' is commonly used as a generic descriptor for the trajectory that dementia takes, from the early signs of memory loss often through to full dependency in daily activities, and which is characterised by the receipt of assistance from family and friends and the use of one or all of health care services, community care services and residential care services for dementia care, in different amounts at different times by different people. 'Pathways' implies that people will navigate the service system differently, according to their needs and circumstances; 'dementia pathways' implies that there are dementia-specific aspects of the receipt and delivery of care.

Existing administrative, census and survey data do not, however, provide a comprehensive picture of the potentially many different pathways of dementia care over time, at least not at a national level. The identification of people with dementia in national program data varies from no identification at all to identification using different methods. Then there is the issue that people with dementia, like all older people in receipt of assistance, may access a range of services and it is not always possible to merge records of service use from different data sources to provide a complete longitudinal view of service use and transitions pertaining to the progression of dementia. As a condition that is most prevalent at older ages, dementia typically occurs alongside other age-related conditions which also give rise to need for assistance. There is thus the added complexity that a service episode for a person with dementia can occur in three main contexts:

1. Service is sought and received because the person has dementia—for example, a person attends a general practitioner because of the impact of dementia on daily living.
2. Service is sought for some other reason but the service episode is impacted 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.
3. Service is incidental and mostly unrelated to the presence of dementia—for example, a person with dementia was receiving home help services due to a physical condition, long before they experienced the effects of dementia and the diagnosis of dementia has as yet not altered the level or type of home help received.

Public policy interest in the use of health and aged care services associated with dementia can be focused on the extent to which people with dementia and their carers are part of the target groups of various programs and services, but may also be concerned with the extent to which the use of programs is dementia-care specific. These different, both important aspects of service use by people with dementia and their carers are relevant to service development and workforce planning and for understanding the present and potential future impact of dementia across the range of relevant programs that relates to managing the care needs of people at different stages of dementia in different service delivery settings.

This chapter looks at the use of major health and aged care programs from both perspectives, where possible, and highlights gaps in the data that currently limit our understanding of dementia care pathways. Data sources used for this exercise are described in Chapter 3 and are summarised in Table 7.1 with respect to the types of services discussed.

Presently, it is not possible to give a complete coverage of service use by people affected by dementia, mainly because of the limited available data. Most notably:

- Programs that deliver multidisciplinary, diagnostic and therapeutic services for people with cognitive impairment operate in some states and territories but national data on comparable services are not readily available (e.g. Cognitive, Dementia and Memory Service Clinics in Victoria).
- Hospital outpatient services used by people with dementia are not identified.
- Any dementia-specific services, including support services for carers of people with dementia, that are funded and operated by state and territory governments (as opposed to national aged care and carer support programs) are not identified.
- Information on the use of services funded by the Home and Community Care (HACC) program by people with dementia is not currently available. HACC is the largest program for the delivery of community care to frail older people and younger people with a disability. People with dementia-related need for assistance and family carers of such people are included in the HACC target population and dementia-specific initiatives are funded under the HACC program (see for example Victorian Government Department of Human Services 2004). Data on client levels of dependency, including dementia status, are not recorded in the HACC Minimum Data Set Version 1.[10] A HACC dependency pilot survey of almost 1,000 clients conducted in Victoria in 2002 revealed

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[10] Dependency data items have been adopted for HACC MDS Version 2. These data were not available for this report.

that 5.2% were reported to have dementia (4% of clients aged 65–74 years and 10% of clients aged 85 years or more; Victorian Government Department of Human Services 2004). Were this proportion to apply to the national HACC client population, there would have been around 35,400 HACC clients with dementia in 2003–04.[11]

- HACC assessment agencies perform assessments of people with dementia who are referred for HACC services. These are not represented here under Assessment Services due to HACC data limitations.
- Psychogeriatric Care Units are not reported here.

Table 7.1: Service categories and related programs reported in Chapter 7

Service category/program	Data sources (owner/custodian)	Scope
Medical services		
General practice patient encounters	Bettering the Evaluation and Care of Health (BEACH) survey 1998–2003 (AIHW/University of Sydney) Medicare Benefits Schedule A1 claims data (Medicare Australia)	Population estimates of GP encounters for the management of dementia derived using age–sex-specific encounter rates in the BEACH survey
General practice referrals to specialists & other services	BEACH survey 1998–2003 (AIHW/University of Sydney) Medicare Benefits Schedule (MBS) A1 claims data (Medicare Australia)	Population estimates of referrals for the management of dementia derived using age–sex-specific referral rates in the BEACH survey
Pharmacy services	Pharmaceutical Benefits Scheme (PBS) & Repatriation Pharmaceutical Benefits Scheme (RPBS) (Medicare Australia)	Number of prescriptions for dementia-specific drugs dispensed under the PBS & RPBS
	BEACH survey 1998–2003 (AIHW/University of Sydney)	Prescriptions for other drugs used to manage dementia & its symptoms
Assessment services		
Aged Care Assessment Program	ACAP MDS (DoHA)	ACAT recommendations by dementia status of ACAP clients
Community care services		
Dementia Education & Support Program	DESP Database (Alzheimer's Australia)	
Community Aged Care Packages	CACP census 2002 (AIHW)	CACP clients in 2002 by dementia status & type of assistance
Extended Aged Care at Home	EACH census 2002 (AIHW)	EACH clients in 2002 by dementia status & type of assistance
National Respite for Carers Program	NRCP MDS (DoHA)	
Residential aged care services		
Residential Aged Care Program	Survey of Disability, Ageing & Carers (ABS)	Cared accommodation component of the survey, by dementia status & care category approximated by a mapping of survey questions to items on the Resident Classification Scale funding instrument
Hospital services—admitted patients	National Hospital Morbidity Database (AIHW)	Hospital separations with a diagnosis code for dementia

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[11] HACC serviced 707,207 clients nationwide in 2003–04 (DoHA 2004a: Table A3). Age groups 65–79 and 80+ made up similar proportions in the HACC client population and in the Victorian HACC dependency pilot study.

Summary

In 2003 an estimated 175,000 people in Australia had some type of dementia and 83,000 of this group experienced dementia of such severity that they always or sometimes needed assistance with basic daily activities (27,000 in households and 56,000 in high level residential aged care). The use of services by people with dementia, in relation to the programs listed above, is summarised in Table 7.2. Approximately 68,000 permanent residents with dementia in aged care facilities collectively used 24.7 million residential aged care bed-days. People with dementia accounted for 1.4 million patient days for 83,000 hospital separations. An estimated 450,000 GP–patient encounters, 83,000 GP-ordered pathology services, 42,000 referrals by GPs to other health care providers and 10,000 GP-ordered imaging services in 2003 were for the diagnosis and management of dementia.

Table 7.2: Services provided for people with dementia

Year	Service	Number
2003	GP encounters[(a)]	450,000
2003	Imaging services[(a)]	10,000
2003	Pathology services[(a)]	82,500
2003	Referrals[(a)]	42,000
2003–04	Hospital bed-days	1.4 million
2003–04	Hospital separations	82,800
2003	Residential aged care services	67,650 permanent residents with dementia
2003	Residential aged care bed-days	24.7 million
	HACC services	unknown
2004–05	ACAP clients	35,000
2002	CACP clients	4,600
2002	EACH clients	90
2003–04	Pharmaceuticals—dementia-specific[(b)]	285,000
2003	Pharmaceuticals—other[(c)]	90,000

(a) Services provided to manage dementia only. GPs also provided or ordered additional services for people with dementia to manage their other conditions. Encounters data derived using age-specific rates of dementia from BEACH, extrapolated to A1 Medicare claims data for each age group, with an additional adjustment for non-Medicare paid encounters by their age distribution.

(b) Prescriptions for dementia-specific pharmaceuticals on PBS/RPBS and private scripts.

(c) Pharmaceuticals prescribed by a GP to manage dementia. Specialist prescriptions not included.

7.1 General practice

Consulting a doctor is the second most common health-related service intervention for Australians, after the use of medications (ABS 1997). The key role of general practitioners in the diagnosis and management of dementia is well recognised in Australia and overseas (see for example Bruce et al. 2002; Brodaty et al. 1994, cited in Downs 1996) and the Royal Australian College of General Practitioners has endorsed guidelines for the care of general practice patients with dementia (Bridges-Webb & Wolk 2003). Diagnosis is a main element of dementia care in general practice but doctors and practice nurses are involved in a variety of functions: identifying patients who have a suspected dementing illness; excluding (and treating) treatable causes; referring patients to specialist services for further diagnosis;

providing information about diagnosis and prognosis of dementia; assessing the carer's ability to cope; providing information about available services and benefits; helping with access to a range of support services; providing support to family carers; and attending to the medical needs of people with dementia and their carers (Downs 1996).

Diagnosis is not always straightforward because of the insidious onset and progression of the condition, and many GPs face 'legitimate anxieties' in diagnosis and management of dementia (Brodaty et al. 1994, cited in Downs 1996). A person in the early stages of dementia may be able to continue to function well for some time without formal assistance (or additional formal assistance), particularly if there is support from family. But over time a series of important questions arise that may rely on a medical diagnosis of dementia or Alzheimer's disease, such as access to dementia-specific drugs, use of motor vehicles, personal safety, management of personal finances, and access to community services. Diagnosis can lead to understanding and acceptance among relatives and friends of the person's functional impairments. Early detection and management of comorbidities is particularly important when dementia is present; left untreated, other conditions such as arthritis and depression have been found to cause excess disability in approximately 60% of people with dementia (McLean 1993, cited in Downs 1996). Yet many cases of dementia are identified late in the disease following a medical or carer crisis (Bruce et al. 2002; Downs 1996). People may delay seeking a formal diagnosis of dementia if cognitive decline is disguised by the effects on daily living of other health conditions, if it is attributed to normal ageing, or as a result of lack of acceptance and stigmatisation of dementia.

The clinical activities of GPs are the subject of the ongoing BEACH survey, described in Chapter 3. BEACH is the main source of information about dementia care in general practice. BEACH data highlight the important links between general practitioners and other health and community care providers, including, but not limited to, geriatricians and Aged Care Assessment Teams (ACATs). In BEACH, the content of a doctor–patient encounter is described in terms of the problems managed and the management techniques applied to each of these problems (Box 7.1). Up to three patient reasons for encounter (RFEs) and up to four diagnoses or problems may be recorded for a single encounter.

Box 7.1: Using the BEACH database

In analysing the BEACH database, the GP–patient encounter is the primary unit of analysis. Proportions (%) are only used when describing the distribution of an event that can arise only once at a consultation (e.g. patient characteristics such as age and sex or consultation characteristics such as Medicare item number), or to describe the distribution of events within a class of events (e.g. problem A as a percentage of total problems). Rates per 100 encounters are used when an event can occur more than once at the consultation (e.g. patient reasons for encounter, problems managed or medications). Rates per 100 problems are also sometimes used when a management event can occur more than once per problem managed. In general, the following results present the number of observations (n), the rate per 100 encounters and the 95% confidence intervals (CIs).

GP–patient encounters for the management of dementia, 1998–2004

On the basis of all of the data collected through the BEACH survey over the first six years from 1998, dementia was managed by GPs at a rate of 0.43 per 100 GP–patient encounters (95% CI: 0.42–0.45), fluctuating from 0.34 per 100 encounters in 2000–01 to 0.51 per 100 encounters in 2003–04 (Table 7.3). The dementia was described as 'Alzheimer's disease/dementia' in about 21% of these encounters, and as 'dementia' in 76% of these encounters. Within the dementia group, the condition labelled Alzheimer's disease/dementia was managed at a rate of between 0.07 and 0.13 per 100 encounters.

The management rate of dementia rate increased with patient age, from 0.01 per 100 encounters for people aged 0–64 years, to 0.06 per 100 encounters for people aged 65–74 years and up to 0.36 per 100 encounters for people aged 75 years or over. As would be expected from the prevalence of dementia in the population, an overwhelming majority (84%) of GP–patient encounters involving the management of dementia were for people aged 75 years or over, with around 13% being for people aged 65 to 74 years. Just 3% of GP–patient encounters for dementia management over the period 1998–99 to 2003–04 were for people aged less than 65 years.

Even if a patient has dementia, the condition may not be managed in every one of the GP–patient encounters and hence will not be captured in BEACH data. A substudy in BEACH was conducted in 2001 to estimate the prevalence of dementia among general practice patients (see Box 7.2).

Box 7.2: Dementia prevalence among general practice patients

Estimates of the prevalence of dementia among GP patients are drawn from a single substudy in BEACH, conducted as one part of the Supplementary Analysis of Nominated Data (SAND) program. In SAND, a section of the recording form investigates aspects of patient health or health-care delivery in general practice not covered by the consultation-based information. Different questions are asked of the patient in each sample period.

Specific investigations have been conducted under this program to investigate the prevalence of Alzheimer's disease and other dementias in adult general practice patients—that is, among people aged 18 and over—and to measure the proportion of general practice patients not diagnosed with Alzheimer's or other dementia who (in the GP's opinion) were likely to have dementia or the early signs of Alzheimer's. The proportion of the undiagnosed patients who had taken a Mini Mental Health Assessment (MMHA) was also explored (AIHW: GPSCU 2002).

This study used a sample of 2,194 encounters with adults from 88 GPs collected in 2001. The prevalence of diagnosed Alzheimer's disease in this adult general practice patient population was 1.6% (95% CI: 0.0–4.4), and the prevalence of diagnosed dementia was 2.4% (95% CI: 0.0–5.4).

Of adult patients not diagnosed with dementia, 4.2% displayed cognitive impairment, 4.9% encountered difficulties with daily living and 5.6% experienced behavioural changes. All three of the above symptoms were displayed by 1.4% of patients, 2.7% had two of the three symptoms, and 5.0% displayed one symptom.

A MMHA had been used for 2.4% of the 2,046 adult patients without dementia, including Alzheimer's, for whom a response to this question was provided. Use of a MMHA was rare (0.9% assessed) for patients with no symptoms of dementia, but more common (51.7% assessed) with patients who had all three dementia symptoms.

GPs were asked whether it was likely that patients without diagnosed dementia actually had signs of dementia or early Alzheimer's. GPs indicated that 59 patients (2.9%) were likely to have dementia not yet diagnosed, and 20 patients (1.0%) were likely to have early Alzheimer's not yet diagnosed. Combined, GPs indicated that 63 patients (3.1%) were likely to have undiagnosed dementia or early Alzheimer's.

Overall, of the 2,098 adult patients with data available, 52 (2.5%) had diagnosed dementia, and a further 59 (2.8%, 95% CI: 0.0–6.5) were thought likely to have undiagnosed dementia. More than half of these patients were aged 75 years or more. By far the majority of these expressed opinions were based on clinical opinion rather than on results of a MMHA.

Patient characteristics

Table 7.3 shows the age and sex of patients for whom dementia was managed in each of the years 1998–99 to 2003–04. Patients managed for dementia were more likely to be aged 75 years and over and were more likely to be female than male.

Table 7.3: Characteristics of the patients at dementia encounters, 1998–99 to 2003–04

Survey year	1998–99	1999–00	2000–01	2001–02	2002–03	2003–04	1998–2004
Number of dementia encounters in BEACH database	409	451	344	480	419	511	2,614
Sex of patient							
Males	34.5%	27.8%	31.7%	31.8%	29.3%	27.7%	30.3%
Females	65.5%	72.2%	68.3%	68.2%	70.7%	72.3%	69.7%
Age group							
0–64	3.7%	4.2%	4.1%	1.7%	3.3%	3.1%	3.3%
65–74	15.2%	12.6%	12.2%	12.3%	11.9%	12.9%	12.9%
75+	81.2%	83.1%	83.7%	86.0%	84.7%	84.0%	83.9%
Type of dementia							
Alcoholic dementia	0.2%	0.9%	0.0%	0.2%	0.2%	0.4%	0.3%
Alzheimer’s disease/dementia	18.1%	16.0%	20.3%	26.3%	26.5%	18.0%	20.8%
Dementia	77.3%	79.6%	74.4%	71.5%	70.9%	79.6%	75.7%
Senile dementia	4.4%	3.5%	5.2%	2.1%	2.4%	2.0%	3.1%
Total BEACH encounters	98,400	104,700	99,900	98,300	100,800	98,877	602,100
Dementia encounters per 100 encounters	0.42	0.43	0.34	0.49	0.42	0.51	0.43

Note: Missing data removed in calculation of rates.

Source: AIHW analysis of BEACH data.

Management

Management of a condition during an encounter can involve a number of strategies. In BEACH, management data include medications prescribed, advice given for over-the-counter medications and other medications supplied by the GP. Details for each medication comprise brand name, form (where required), strength, regimen, status (if new medication for this condition for this patient) and number of repeat prescriptions. Non-pharmacological management includes counselling and procedures, new referrals, and orders for pathology and imaging (Table 7.4).

Table 7.4: General practice service use for people managed for dementia, 2003–04

	Males	Females	Total attendances
GP–patient encounters for dementia	140	370	511
Rate per 100 encounters for dementia			
Referrals to specialists	14.0	7.3	9.1
Imaging	1.6	2.4	2.2
Pathology	16.8	18.6	17.9
Prescriptions (any)	70.6	55.7	60.3

Note: Total attendances data include a small number of cases where gender is unknown.

Source: AIHW analysis of BEACH database for the period April 2003 to March 2004.

In 2003–04, medications were prescribed at a rate of 60.3 medications per 100 GP–patient encounters for management of dementia (similarly, rates of 31.3 and 31.6 per 100 encounters were recorded in 2000–01 and 2001–02 respectively). Between 2000–01, when antidementia medications became available on the PBS, and 2003–04 there has been a twofold increase in the prescription of antidementia medications (Table 7.5). Over the same period, there has been a decrease in the prescription of other drugs such as antipsychotics, anxiolytics, sedatives and hypnotics, while the rate of prescription for analgesics and antidepressants has increased. The rate of prescription per 100 GP encounters for dementia management shown in BEACH suggests about 90,000 PBS/RPBS GP prescriptions were filled in 2003 in Australia.

Table 7.5: Most commonly prescribed medications[(a)], 2000–01 to 2003–04

	2000–01		2001–02		2003–04	
	Per 100 contacts with dementia	Per cent of medications for dementia	Per 100 contacts with dementia	Per cent of medications for dementia	Per 100 contacts with dementia	Per cent of medications for dementia
Medication[(b)]	(n=351)	(n=110)	(n=490)	(n=155)	(n=511)	(n=160)
Antidementia drugs	5.7	18.2	11.0	34.8	10.8	35.0
Antipsychotics	12.0	38.2	9.2	29.0	7.9	25.6
Anxiolytics	2.3	7.3	3.1	9.7	1.5	5.0
Antidepressants	2.0	6.4	1.2	3.9	2.7	8.8
Sedatives & hypnotics	1.4	4.5	1.2	3.9	0.8	2.5
Other analgesics & antipyretics	0.6	1.8	1.0	3.2	1.5	5.0
Other medications	7.4	23.6	4.9	15.5	5.6	18.1

(a) This is number of prescriptions written and does not count repeats authorised as part of that prescription.

(b) Medications are classified by Anatomical Therapeutic Chemical group.

Sources: AIHW analysis of BEACH data; WHO Collaborating Centre for Drug Statistics Methodology 1998.

Referrals to other health care providers

In 2003–04, there were nine referrals from a GP to a health care provider for every 100 GP–patient encounters for dementia (Table 7.6). GP referral to other health care providers is twice as likely for males (14 per 100 encounters) as for females (7 referrals per 100 encounters) with dementia. There were a greater number of referrals, in absolute terms, for people in the older age groups and for females: 81% of referrals were for patients aged 75 years or over. This is consistent with the exponential increase in the prevalence of dementia with age, and with the older age structure of the female population.

Table 7.6: Number of referrals by GPs to other health care providers for people managed for dementia, by age and sex, 2003–04

	Referrals per 100 GP encounters for dementia			Proportion of referrals for dementia		
Age	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
<65	0.7	0.5	0.6	5.0	7.4	6.4
65–74	2.1	0.8	1.2	15.0	11.1	12.8
75+	11.2	5.9	7.3	80.0	81.5	80.9
Total	**14.0**	**7.3**	**9.1**	**100.0**	**100.0**	**100.0**

Note: There were no referrals of people diagnosed with dementia who were aged less than 25 from a GP to another health care provider.

Source: AIHW analysis of BEACH database.

Almost a third of referrals made by GPs for patients being managed for dementia or suspected dementia were to geriatricians (30%); 13% of referrals were to an ACAT; 11% were referrals to a neurologist; and 11% were referrals to a hospital (Table 7.7). These data reveal that referrals made by GPs in the management of dementia are primarily referrals for medical services.

Table 7.7: Number of referrals by GPs to other health care providers per 100 GP–patient encounters for people managed for dementia, by type of referral, 2003–04

	Referrals per 100 GP encounters for dementia			Proportion of referrals for dementia		
Type of referral	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
Referral to geriatrician	4.9	1.9	2.7	35.0	25.9	29.8
Referral for aged care assessment	1.4	1.1	1.2	10.0	14.8	12.8
Referral to hospital	2.1	0.5	1.0	15.0	7.4	10.6
Referral to neurologist	1.4	0.8	1.0	10.0	11.1	10.6
Referral to physician	—	0.5	0.4	—	7.4	4.3
Referral to clinic/centre	1.4	—	0.4	10.0	—	4.3
Referral to nursing home	0.7	0.3	0.4	5.0	3.7	4.3
Referral to psychologist	—	0.5	0.4	—	7.4	4.3
Referral to psychiatrist	0.7	0.3	0.4	5.0	3.7	4.3
Referral to home nursing	—	0.3	0.2	—	3.7	2.1
Referral to specialist (type of specialist not specified)	—	0.3	0.2	—	3.7	2.1
Referral to speech therapist	0.7	—	0.2	5.0	—	2.1
Referral to diabetes clinic	—	0.3	0.2	—	3.7	2.1
Referral to respite care	0.7	—	0.2	5.0	—	2.1
Referral, not elsewhere classified	—	0.5	0.4	—	7.4	4.3
All referrals to health care providers	**14.0**	**7.3**	**9.1**	**100.0**	**100.0**	**100.0**

— Nil or rounded to zero.

Source: AIHW analysis of BEACH database.

Pathology and imaging services

The majority of pathology services requested by GPs for people being managed for dementia were full blood counts (19%), B12 tests (12%) and urine microscopy, culture and sensitivity tests (11%) (Table 7.8). Pathology tests were requested for 18% of GP–patient encounters for dementia management. These results reflect the activity of GPs directed at excluding possible causes of temporary cognitive impairment, such as nutrient deficiency, electrolyte imbalance and urinary tract infection. The rate of ordering of pathology in the BEACH data suggests that there were approximately 82,500 pathology services ordered by GPs for the management of dementia in Australia in 2003.

Table 7.8: Number of pathology services requested by GPs for people managed for dementia, by type of pathology service, 2003–04

	Pathology services per 100 GP consultations for dementia			Proportion of pathology services for dementia		
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**
Full blood count	2.8	3.8	3.5	16.7	20.3	19.4
B12 test	2.1	2.2	2.1	12.5	11.6	11.8
Urine MC&S test	0.7	2.4	1.9	4.2	13.0	10.8
TSH test	1.4	1.4	1.3	8.3	7.2	7.5
Liver function test	1.4	1.1	1.2	8.3	5.8	6.5
Electrolytes & liver function tests	0.7	1.1	1.0	4.2	5.8	5.4
U&E test	1.4	0.8	1.0	8.3	4.3	5.4
Folate (red cell) test	1.4	0.8	1.0	8.3	4.3	5.4
Thyroid function test	1.4	0.8	1.0	8.3	4.3	5.4
Syphilis serology test	0.7	0.5	0.6	4.2	2.9	3.2
ESR test	—	0.8	0.6	—	4.3	3.2
EUC test	—	0.5	0.4	—	2.9	2.2
Other lab test for the neurological system	0.7	0.3	0.4	4.2	1.4	2.2
Electrolytes test	—	0.3	0.2	—	1.4	1.1
Multiple biochemical analysis test	0.7	—	0.2	4.2	—	1.1
Calcium phosphate test	—	0.3	0.2	—	1.4	1.1
Iron studies test	—	0.3	0.2	—	1.4	1.1
Test—homocysteine	0.7	—	0.2	4.2	—	1.1
Valproate test	—	0.3	0.2	—	1.4	1.1
Glucose test	—	0.3	0.2	—	1.4	1.1
HBA1c test	—	0.3	0.2	—	1.4	1.1
Creatinine test	—	0.3	0.2	—	1.4	1.1
Test, BUN	—	0.3	0.2	—	1.4	1.1
Prostate specific antigen test	0.7	—	0.2	4.2	—	1.1
All pathology tests	**16.8**	**18.6**	**17.9**	**100.0**	**100.0**	**100.0**

MC&S: microscopy, culture and sensitivity; TSH: thyroid stimulating hormone; U&E: urea and electrolytes; ESR: erythrocyte sedimentation rate; EUC: electrolyte, urea, creatinine; HBA1c: glycosylated haemoglobin, BUN: blood urea nitrogen.

— Nil or rounded to zero.

Source: AIHW analysis of BEACH database.

In 2003–04, GPs requested imaging services for people with dementia at a rate of 3 per 100 patient encounters (Table 7.9). Almost 60% of these imaging services were for computed tomography (CT) scans of the brain. The rate of ordering of imaging services in the BEACH data suggests that there were approximately 10,000 imaging services ordered by GPs for the management of dementia in Australia in 2003.

Table 7.9: Number of imaging services for people managed for dementia, by type of imaging service, 2003–04

	Imaging services per 100 GP encounters for dementia			Proportion of imaging services for dementia		
	Males	**Females**	**Persons**	**Males**	**Females**	**Persons**
Chest x-ray	—	0.8	0.6	—	23.1	17.6
CT scan of the abdomen	0.7	—	0.2	25.0	—	5.9
CT scan of the brain	1.4	2.2	1.9	50.0	61.5	58.8
CT scan of the head	0.7	0.5	0.6	25.0	15.4	17.6
All imaging	**2.8**	**3.5**	**3.3**	**100.0**	**100.0**	**100.0**

— Nil or rounded to zero.

Source: AIHW analysis of BEACH database.

7.2 Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme

Data from the PBS and RPBS show the number of **prescriptions** for dementia-specific drugs that were dispensed under the two schemes from 2002–03 to 2004–05 (Table 7.10). Three dementia-specific anticholinesterases are funded under the PBS/RPBS for the treatment of mild to moderately severe Alzheimer's disease: Donepezil Hydrochloride (Aricept), Galantamine Hydrobromide (Reminyl) and Rivastigmine Hydrogen tartrate (Exelon).

Anticholinesterases, also called cholinesterase inhibitors, are designed to improved cognitive function by increasing levels of acetylcholine, a chemical messenger involved in memory, judgement and other thought processes. Acetylcholine is released by certain brain cells to carry messages to other cells. After a message reaches the receiving cell, various other chemicals, including one called acetylcholinesterase, break acetylcholine down so it can be recycled. Alzheimer's disease damages or destroys cells that produce and use acetylcholine, reducing amounts available to carry messages. A cholinesterase inhibitor slows the breakdown of acetylcholine by blocking the activity of acetylcholinesterase. By maintaining acetylcholine levels, the drug may help compensate for the loss of functioning brain cells (Alzheimer's Association USA 2006).

The PBS/RPBS subsidises the cost of these drugs when prescribed to a person who has had a diagnosis of Alzheimer's disease confirmed by specialist/consultant physician. Subsidy is subject to specified clinical criteria based on the MMSE, Alzheimer's Disease Assessment Scale, cognitive subscale (ADAS-Cog) and CIBIC scale. PBS data on dementia-specific drugs therefore cover prescriptions for people with dementia in Alzheimer's disease, not other types of dementia, and whose level of cognition falls within a certain range.

In 2004–05, there were 315,020 prescriptions under the PBS/RPBS for the anticholinesterases Donepezil, Galantamine and Rivastigmine. This represents an increase in the number of prescriptions for these drugs from 2002–03 (226,456 prescriptions) and 2003–04 (271,042 prescriptions). In particular, the number of prescriptions for Donepezil and Galantamine has increased over this period; the number of prescriptions for Rivastigmine has decreased.

Prescriptions for Donepezil make up the majority of all prescriptions for anticholinesterases dispensed under the PBS/RPBS (66% in 2004–05), followed by Galantamine (26%) and Rivastigmine (8%).

Table 7.10: Number of PBS/RPBS prescriptions for dementia-specific drugs, 2002–03 to 2004–05

Drug name & item number	2002–03	2003–04	2004–05
Donepezil			
8495	51,837	54,558	55,632
8496	115,075	133,914	153,016
Total	*166,912*	*188,472*	*208,648*
Galantamine			
8536	10,520	15,879	15,448
8537	21,062	41,638	54,470
8756	. .	. .	2,478
8770	. .	. .	2,905
8771	. .	. .	6,404
8772	. .	. .	1,004
Total	*31,582*	*57,517*	*82,709*
Rivastigmine			
8497	6,507	5,231	4,396
8498	9,857	9,117	8,654
8499	4,744	4,215	4,064
8500	6,287	5,981	5,752
8563	567	509	797
Total	*27,962*	*25,053*	*23,663*
Total	**226,456**	**271,042**	**315,020**

Note: Galantamine item numbers 8756, 8770, 8771 and 8772 were not available on the PBS in 2002–03 and 2003–04.

In 2003–04, 284,583 prescriptions for dementia-specific drugs were issued. Of these, 271,042 were from the PBS or RPBS and a further 13,216 were private prescriptions (Table 7.11). Donepezil is prescribed in 69% of all prescriptions for dementia-specific drugs.

Table 7.11: Number of prescriptions for dementia-specific drugs, by source, 2003–04

Drug name & item number	PBS/RPBS	Private prescriptions[(a)]	Total prescriptions
Donepezil			
8495	54,558	1,286	55,855
8496	133,914	2,295	136,523
Total	*188,472*	*3,581*	*192,378*
Galantamine			
8536	15,879	337	16,216
8537	41,638	1,182	42,820
Total	*57,517*	*1,519*	*59,036*
Rivastigmine			
8497	5,231	155	5,386
8498	9,117	11	9,128
8499	4,215	11	4,226
8500	5,981	0	5,981
8563	509	0	509
Total	*25,053*	*177*	*25,230*
Memantine[(b)]			
18031	. .	7,481	7,481
18032	. .	458	458
Total	. .	*7,939*	*7,939*
Total	**271,042**	**13,216**	**284,583**

(a) These data were produced by the Drug Utilisation Subcommittee, Pharmaceutical Benefits Branch, Medical and Pharmaceutical Services Division, Department of Health and Ageing.

(b) Memantine was not available on the PBS in 2003–04.

Box 7.3: Dosage information, by drug name and item number

Donepezil

8495 – Tablet 5mg (maximum quantity 28)
8496 – Tablet 10mg (maximum quantity 28)

Galantamine

8536 – Tablet 4mg (base) (maximum quantity 56)
8537 – Tablet 8mg (base) (maximum quantity 56)
8756 – Tablet 12mg (base) (maximum quantity 56)
8770 – Capsule 8mg (base) (prolonged release) (maximum quantity 28)
8771 – Capsule 16mg (base) (prolonged release) (maximum quantity 28)
8772 – Capsule 24mg (base) (prolonged release) (maximum quantity 28)

Rivastigmine

8497 – Capsule 1.5mg (base) (maximum quantity 56)
8498 – Capsule 3mg (base) (maximum quantity 56)
8499 – Capsule 4.5mg (base) (maximum quantity 56)

8500 – Capsule 6mg (base) (maximum quantity 56)
8563 – Oral solution 2mg (base) per mL, 120mL
Memantine
18031 – Tablet 10mg (maximum quantity 56)
18032 – Solution 10mg/mL

7.3 Aged Care Assessment Program

ACATs are multi-disciplinary teams located in each state and territory that are responsible for determining eligibility for admission to residential aged care facilities and for CACPs and EACH packages. ACATs may also recommend a range of other services, including services funded by the HACC program, the NRCP, and Veterans' Home Care, although they do not determine eligibility for these programs and access to these other programs usually involves assessment by program service agencies. People seek ACAT assessment when they require advice, referral or some assistance in managing their ongoing care in the community, or for seeking residential placement. ACATs make recommendations on long-term accommodation setting and sources of assistance for community living. A person may be referred to an ACAT by a GP, by a community service agency, by hospital staff, by a family member or friend, or may self-refer.

A client may or may not follow the ACAT recommendation—this will depend on a number of factors relating to individual circumstances, preferences and service availability. Often, however, ACAT assessment is the first step to changing the level of care and is triggered by increased need or change in the usual provision of care at home. Patterns of recommended changes to accommodation setting by dementia status of ACAP clients are interesting in that they reveal higher proportions of clients with dementia than those without dementia being recommended for higher levels of care and for care in a setting other than the client's usual accommodation at time of assessment.

At the time of reporting, the latest ACAP data available for analysis covered assessments recorded between July 2004 and March 2005. Almost a quarter of assessments recorded in this period were for a client with dementia (Table 7.12).

Table 7.12: Reason for ending assessment, by dementia status of client, July 2004 to March 2005

	With dementia		Without dementia	
Reason for ending assessment	**Assessments**	**Clients**	**Assessments**	**Clients**
Assessment complete—care plan developed to the point of effective referral	28,880	25,242	77,940	68,852
Assessment incomplete[(a)]	784	467	12,326	8,582
Other reason	178	139	4,467	3,289
Not stated/inadequately described	350	310	2,153	1,757
Total	**30,192**	**26,158**	**96,886**	**82,480**

(a) Includes clients who withdrew, died or transferred to another ACAT, and clients whose medical condition or functional status was unstable and required acute care, medical attention or rehabilitation care before comprehensive assessment.

Source: AIHW analysis of the ACAP MDS v2.

ACAP clients fall mostly into the old to very old age groups: approximately 80% of clients were aged 75 years or over and over a third of clients were aged 85 years or over (see Table 5.5). The groups of clients with and without dementia have similar age structures, with only a marginally higher proportion of clients with dementia compared to those without dementia in the 85 years or over age group. Thus, there is no reason to attribute differences in ACAT recommended long-term accommodation setting to age.

Usual and recommended accommodation setting

Most ACAP clients were living in the community at the time of assessment, though a higher proportion of clients with dementia (15%) were living in residential aged care facilities compared to clients without dementia (6%) (Table 7.13). In comparing ACAT recommendations of change in long-term care settings it is therefore more useful to cross-tabulate usual accommodation setting by recommended accommodation setting, as in Table 7.14 (clients with missing or inadequately described usual or long-term accommodation setting are excluded).

Table 7.13: Usual and recommended accommodation setting, by dementia status of ACAP client, July 2004 to March 2005 (per cent)

	Usual accommodation setting		Recommended long-term care setting	
Accommodation setting	**With dementia**	**Without dementia**	**With dementia**	**Without dementia**
Community setting				
Private residence[(a)]	72.8	81.2	35.8	52.5
Independent living in a retirement village	5.9	7.1	1.7	3.2
Supported community accommodation	2.0	1.2	0.7	1.0
Other[(b)]	3.6	3.8	0.6	1.4
Total community setting	*84.3*	*93.4*	*38.6*	*58.6*
Institutional setting				
Residential aged care—low level care	13.1	5.2	22.3	20.0
Residential aged care—high level care	1.9	0.9	39.1	20.3
Hospital	0.3	0.2	0.1	0.6
Other institutional care	0.4	0.3	0.1	0.1
Total institutional setting	*15.7*	*6.6*	*61.4*	*41.4*
Per cent (non-missing values)	**100.0**	**100.0**	**100.0**	**100.0**
Number (non-missing values)	**25,623**	**71,719**	**25,736**	**71,148**
Not stated/inadequately described	*535*	*10,761*	*422*	*11,332*

(a) Includes owned/purchasing, private rentals and public rentals or community housing.

(b) Includes all other types of settings (as well as boarding house/rooming house/private hotel, short-term crisis, emergency or transitional accommodation and public place/temporary shelter for usual accommodation setting).

Notes

1. Components may not add due to rounding.
2. Recommended long-term care setting is recorded at the end of a comprehensive assessment for all comprehensive assessments that have ended with development of a care plan for the client (i.e. complete assessments).

Source: AIHW analysis of the ACAP MDS v2.

Noteworthy differences in ACAT recommended long-term care settings by client dementia status include:

- Considering ACAT clients with dementia who were living in private residences at time of assessment (18,405 clients with valid data), 45.9% of recommendations were for continuation of usual accommodation—52.6% of assessments concluded with a recommendation for residential aged care. The corresponding proportions of ACAT recommendations for clients without dementia were 61.3% (private residence) and 35.6% (residential aged care).
- ACAT assessments for people living in independent living units in retirement villages were more likely to conclude with a recommendation for residential aged care if the client had dementia than if the client did not have dementia. Of 1,478 clients with dementia, 63.8% were recommended residential aged care. In contrast, clients without dementia who were living in independent living units (4,873 with valid data) were less likely to be recommended residential aged care (48.7%). The higher proportions of recommendations for residential aged care among people living in retirement villages (with or without dementia), compared with people living in private residences, may be related to the lower availability of care from family for older people in retirement villages (see AIHW: Hales et al. 2006).
- People with dementia living in low level residential care were more likely than people without dementia in low level residential care to be recommended for high level residential care (87.8% versus 75.8% respectively).

Table 7.14: ACAT assessment outcomes for long-term care setting, by usual accommodation setting and dementia status of ACAP client, July 2004 to March 2005 (per cent of non-missing values)

	Recommended long-term care setting								
Usual accommodation setting	**Private residence**	**Independent living in a retirement village**	**Supported community accommodation**	**Other community[(a)]**	**RAC—low care**	**RAC—high care**	**Hospital**	**Other institutional care**	**Total**
With dementia									
Private residence	45.9	0.4	0.5	0.5	23.3	29.3	0.1	—	100.0
Independent living in a retirement village	13.5	21.8	0.8	0.1	39.6	24.2	0.0	—	100.0
Supported community accommodation	2.0	0.4	11.1	0.8	20.6	65.1	0.0	—	100.0
Other community[(a)]	26.8	0.9	1.5	3.3	26.4	40.8	0.1	0.2	100.0
Residential aged care—low level care	0.4	0.1	0.1	0.6	10.8	87.8	0.2	0.1	100.0
Residential aged care—high level care	3.9	—	—	—	6.2	88.7	1.3	—	100.0
Hospital	6.9	—	—	2.3	16.1	73.6	1.1	—	100.0
Other institutional care	4.8	1.0	1.0	1.9	12.4	69.5	—	9.5	100.0
Total (non-missing values)	**35.4**	**1.6**	**0.7**	**0.6**	**22.3**	**39.1**	**0.1**	**0.1**	**100.0**
Without dementia									
Private residence	61.3	1.0	0.7	0.8	18.9	16.7	0.5	—	100.0
Independent living in a retirement village	17.3	32.4	0.7	0.6	34.2	14.5	0.3	—	100.0
Supported community accommodation	4.1	1.1	24.2	2.3	33.8	33.7	0.1	0.7	100.0
Other community[(a)]	33.0	1.0	2.9	6.6	27.7	27.8	0.2	0.8	100.0
Residential aged care—low level care	0.8	0.3	0.2	0.8	21.0	75.8	1.0	0.1	100.0
Residential aged care—high level care	6.9	0.2	0.2	2.2	11.7	74.0	4.4	0.5	100.0
Hospital	16.7	0.7	1.3	0.7	19.3	56.0	4.0	1.3	100.0
Other institutional care	12.1	2.2	1.1	1.1	15.9	53.3	—	14.3	100.0
Total (non-missing values)	**52.5**	**3.2**	**1.1**	**1.1**	**20.6**	**20.9**	**0.6**	**0.1**	**100.0**

(a) Includes all other types of settings (as well as boarding house/rooming house/private hotel, short-term crisis, emergency or transitional accommodation and public place/temporary shelter for usual accommodation setting).

— Nil or rounded to zero.

Notes

1. Recommended long-term care setting is recorded at the end of a comprehensive assessment for all comprehensive assessments that have ended with development of a care plan for the client (i.e. complete assessments).
2. Table excludes cases with not stated/inadequately described information on accommodation setting.

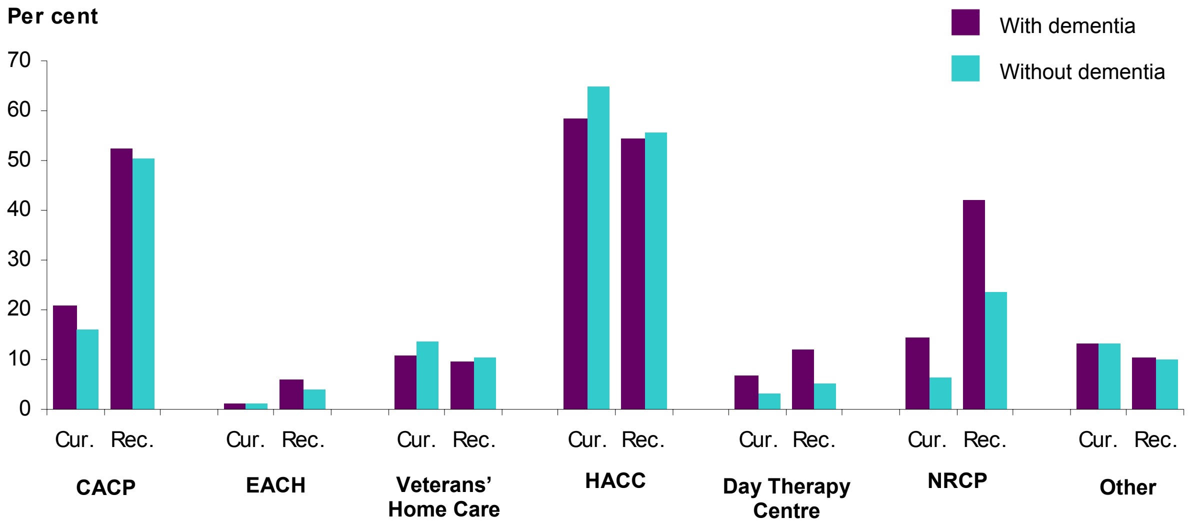
Source: Table A7.1.

Current and recommended community-based government program support

As well as making recommendations on long-term care setting, ACATs recommend the type of government program support that community-based clients are eligible for, and would potentially benefit from, based on their assessed needs and their access to assistance from family and friends. Take-up of recommendations ultimately depends on a number of factors and may not translate to actual service use; however, ACAT approvals determine eligibility for CACP and EACH packages and in making recommendations for assistance from these and other programs, ACATs help to influence the uptake of formal assistance.

Approximately equal proportions of community-based clients with and without dementia were not receiving government program support at the time of their ACAT assessment (Table 7.15: 43% and 42% respectively). Current use of the range of programs is not too dissimilar between the with-dementia and without-dementia groups (Table 7.15 and Figure 7.1). Around 80% of clients using support programs at assessment were using CACP and HACC, regardless of dementia status.

Apart from a substantially higher proportion of recommendations for NRCP support given to people with dementia (31.9%) compared to those without (17.7%), the patterns of recommended government program support do not differ markedly.



Source: AIHW analysis of the ACAP MDS v2.

Figure 7.1: Usual and recommended government community program support, by dementia status of ACAP client, July 2004 to March 2005

Table 7.15: Usual and recommended government program support, by dementia status of ACAP client living in the community, July 2004 to March 2005

	Current program support		Recommended program support	
Government program support	**With dementia**	**Without dementia**	**With dementia**	**Without dementia**
		Number		
Community Aged Care Packages	2,419	5,726	4,625	16,377
Extended Aged Care at Home	140	482	517	1,341
Home and Community Care (including Community Options/Linkages)	6,787	23,372	4,829	18,008
Veterans' Home Care	1,278	4,867	855	3,374
Day Therapy Centre (Commonwealth funded)	797	1,207	1,058	1,726
National Respite for Carers Program	1,665	2,347	3,710	7,623
Other	1,533	4,712	920	3,201
None	8,791	26,228	2,792	10,754
Total[(a)]	**20,417**	**62,324**	**11,644**	**43,168**
Unable to determine or not stated/ inadequately described	*654*	*12,690*	*520*	*13,161*
		Per cent (of valid data)		
Community Aged Care Packages	11.8	9.2	39.7	37.9
Extended Aged Care at Home	0.7	0.8	4.4	3.1
Home and Community Care (including Community Options/Linkages)	33.2	37.5	41.5	41.7
Veterans' Home Care	6.3	7.8	7.3	7.8
Day Therapy Centre (Commonwealth funded)	3.9	1.9	9.1	4.0
National Respite for Carers Program	8.2	3.8	31.9	17.7
Other	7.5	7.6	7.9	7.4
None	43.1	42.1	24.0	24.9
Total[(a)]	**100.0**	**100.0**	**100.0**	**100.0**

(a) Sum of components may not add to total—clients may have used or be recommended more than one program.

Note: Table excludes people who were permanent residents of residential aged care services, multi-purpose services or centres, Indigenous flexible pilots, hospitals or other institutional settings at the time of assessment (current program support) or people whose recommended long-term care setting is residential aged care, a hospital or other institutional care (recommended program support).

Source: Table A7.2.

Respite care is an important element of supporting primary carers to help older people remain at home and the differential results in ACAT recommendations for NRCP reflect the fact that most people with moderate to severe dementia who are assessed by ACATs are living at home with a carer or with assistance from non-resident carers, and that dementia care imposes a high need for respite.

Another difference in the patterns of recommendation is seen in relation to people assessed by ACATs who were not receiving government program support at the time of assessment. Excluding records with an unknown ACAT recommendation, source data in Table A7.2 indicates that:

- For clients with dementia who were not accessing community-based services at time of assessment, almost half (49.3%) of ACAT recommendations were for an institutional care setting.
- For clients without dementia who were not accessing community-based services at time of assessment, around a third (32.9%) of ACAT recommendations were for an institutional care setting.

In summary, ACAT assessment is a key service milestone for older people in general. Patterns of ACAT recommendations highlight that people with dementia are accessing a similar range of aged care programs to older people without dementia, for community and residential care. ACATs have a role in the diagnosis of dementia in addition to acting as a point of referral to formal services funded through a range of government programs (AIHW: Hales et al. 2006, which describes ACAT experiences in the diagnosis of dementia and behavioural and psychological symptoms of dementia). Data from the ACAP highlight the need for respite care among people with dementia and their carers and suggest that many people with dementia are recommended for residential aged care without having ever received government program support in the community. These results possibly reflect a lack of awareness among older people and their carers of the range of assistance available and the function of ACAT assessment in helping to make services available, and perhaps a failure of health care providers to make earlier referrals to community services or to follow-up on actions taken by patients and their carers to obtain assistance.

7.4 Community care

As dementia progresses, the affected person needs increasing support in daily living. Some people with dementia will have already been receiving assistance from formal services before the diagnosis of dementia is received, due to other health conditions and/or age-related frailty. This assistance may be in the form of community or residential aged care that, over time, changes in type or intensity due to the progression of dementia. Others will rely wholly on their social network, often with a primary carer at home, up to the point where assistance from formal services is sought and received to supplement the care provided by family and friends. Still others may never use formal services for assistance with daily living, or may access formal services for respite care only. Section 7.3 showed that ACAT assessment is a gateway to the receipt of formal services or to a change in formal service use. In this section we consider the recorded use of community-based services by people with dementia.

The 2003 SDAC identified 101,900 people with dementia, of whom 26,600 were living in households. Nearly all (98%) of people living in households who were identified as having dementia needed assistance in core activities (self-care, mobility and communication). Recall from Chapter 5 that around 57% of the household population with dementia received assistance from relatives and friends without supplementation from formal services; 29% received both formal and informal assistance; and 14% were not receiving assistance. Formal assistance in fact can come from a range of sources, funded privately or through government programs. This section is concerned with the use of government-funded community care programs by people with dementia. At this point in time, the available national data support mainly cross-sectional program-based perspectives of service use. Analysis of linked data is a more recent development that as yet has not extended to dementia care pathways (see AIHW: Karmel 2005 for an example of early work in this area). This means that there is limited insight into the parallel use of multiple community care programs and services or change in service use by individuals over time. While national program and survey data highlight the heavy use of formal and informal assistance by people with dementia, there are some indications from smaller studies that people with dementia-related high care needs living in the community access assistance through multiple programs and that formal service arrangements tend to be fluid (AIHW: Hales et al. 2006).

Community care programs offer a range of assistive services, including information, counselling and referral services and instrumental assistance. Some are dementia-specific, whilst others fall into the category of generic community aged care (but may have a dementia-specific focus because of the expertise of staff providing the service, for example). The use of some of the main programs with data available for analysis is described below.

Dementia Education and Support Program (Alzheimer's Australia)

People with dementia and their carers may be referred to or may themselves find out about the DESP, which is delivered by Alzheimer's Australia. DESP provides support, education, and short-term counselling to people with dementia and their families and carers. Services include the provision of a national 1800 Helpline, face to face and telephone counselling, facilitation of carer support groups, carer education programs, and the provision of education and information resources. The mix of services funded varies from state to state.

In 2003–04, there were 17,000 contacts associated with over 8,000 distinct people of concern (Box 7.4 defines DESP 'contacts'). Half of the distinct people of concern had been diagnosed with dementia, 18% had symptoms and 2.5% were being assessed. For more than a quarter (27%) the dementia status for the person of concern was not recorded.

On average, there were two contacts for each person of concern (Table 7.16). People being assessed had the highest rate of contact (2.4 contacts per person per year) and those with an unconfirmed diagnosis had the lowest rate (1.1 contacts per person per year), although since the rate is so much lower it could be that dementia status had changed prior to any subsequent contact with the program.

Table 7.16: Dementia Education and Support Program contacts[(a)] and distinct people[(b)] of concern, by dementia status, 2003–04

Dementia status of person of concern	Contacts[(a)]		Distinct people of concern[(b)]		Contacts per person of concern
	Frequency	Per cent	Frequency	Per cent	
Diagnosed	9,590	55.9	4,237	50.4	2.26
Being assessed	513	3.0	210	2.5	2.44
Symptoms	2,340	13.7	1,530	18.2	1.53
Assessed not diagnosed	118	0.7	71	0.9	1.66
Unknown	131	0.8	117	1.4	1.12
Not recorded	4,451	26.0	2,236	26.6	1.99
Total	**17,143**	**100.0**	**8,401**	**100.0**	**2.04**

(a) A contact is counted for phone calls, letters and meetings with persons requiring the expert support from program staff. A contact is defined by the unit of service or episode, not the number of people involved in the discussion.

(b) The number of distinct people recorded in this table therefore reflects the number of people of concern associated with a carer (all types) who made a contact with the service in this period.

Box 7.4: Use of the DESP data set for reporting service use by people with dementia

All persons receiving any level of assistance through the DESP can be described by the generic term 'client'. The primary focus of the DESP data set is on clients such as principal carers, secondary carers, persons of concern (those with dementia) and service providers/professionals.

A contact is recorded when some form of interaction between a DESP staff member and a client occurs, and includes some interaction regarding information about dementia or caring-related issues.

Client contacts are not counted for limited interactions (e.g. telephone messages; very brief discussions of around 2–3 minutes), staff meetings and internal discussions, but is counted for interactions requiring expert support of program staff. A contact is defined by each episode or service provided and may involve more than one person. For example, a group discussion with 10 people would be counted as one contact but 10 people contacts. The number of ***distinct people of concern*** *therefore reflects the number of people (who may have dementia) associated with a carer (all types) who made a contact with the service.*

Community Aged Care Packages and Extended Aged Care at Home

CACP and EACH are currently the two main programs for the delivery of community care packages. The CACP program targets older people living in the community with care needs equivalent to at least low level residential aged care. EACH targets older people living at home with care needs equivalent to high level residential aged care. ACAT approval is required to be able to access either program.

Program data for CACP and EACH do not identify clients with dementia. In 2002, the AIHW conducted two censuses to collect information in a snapshot week of CACP and EACH clients (AIHW 2004b and AIHW 2004e), which recorded the dementia status of clients and their service profiles. Using census data it is possible to identify which clients had dementia but it is not possible to confirm that all of the services received were needed because of dementia. Care packages are mainly received by people aged 75 years or over, with a high proportion of clients aged 85 years or over. Any number of conditions may contribute to a need for and use of formal services.

The types of assistance available from a CACP may include help with personal hygiene, social support, transport to appointments, food services and gardening. On 30 June 2004, 25,722 people aged 65 years or over were registered CACP clients (AIHW 2005c). The 2002 CACP census reported results covering 25,439 clients aged 65 years or over.

EACH packages offer a higher level of care than a CACP, in terms of the weekly hours of assistance that can be accessed, and a more comprehensive range of types of assistance. In addition to the services offered by a typical CACP package, an EACH client may be able to receive nursing care, allied health care and rehabilitation services. In 2003–04, over 900 EACH packages were available through 56 approved service providers. The 2002 EACH census was conducted shortly after establishment of the EACH Program (in 2001) and recorded only 288 EACH clients. The profile of EACH clients and their service activity may have changed as the program matured.

In 2002, almost one in five CACP clients was reported as having been diagnosed with dementia. Also, one-third of all EACH clients had been diagnosed with dementia (Table 7.17). Details on the characteristics and care needs of clients of the CACP and EACH programs, with and without dementia, are provided below.

Table 7.17: CACP and EACH clients with and without dementia, census periods, 2002

	With dementia		Without dementia		Total	
Program	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
EACH	90	32.1	190	67.9	280	100.0
CACP	4,646	18.4	20,597	81.6	25,243	100.0

Note: Dementia status was not stated for eight (3%) of EACH clients and 196 (1%) of CACP clients.

Source: AIHW analysis of CACP and EACH 2002 censuses.

Community Aged Care Packages

CACP clients with dementia showed a slightly older age profile than clients without dementia (Table 7.18). Less than 15% of clients with dementia were aged under 75 years compared with 24% of clients in this age group without dementia. Equivalent proportions of CACP clients with and without dementia (2%) were in the 95 years and over age group.

Table 7.18: CACP clients with and without dementia, number of clients by age and sex, census week 2002

	With dementia		Without dementia		Total		Not stated
Sex/age	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**	**Number**
Males							
<65	73	5.7	701	11.7	774	10.6	5
65–74	190	14.8	1,167	19.4	1,357	18.6	6
75–84	573	44.6	2,252	37.5	2,825	38.8	17
85–94	425	33.1	1,750	29.1	2,175	29.8	28
95+	23	1.8	136	2.3	159	2.2	1
Total	*1,284*	*100.0*	*6,006*	*100.0*	*7,290*	*100.0*	*57*
Females							
<65	71	2.2	882	6.2	953	5.4	6
65–74	350	10.6	2,146	15.0	2,496	14.2	13
75–84	1,534	46.5	6,006	41.9	7,540	42.8	62
85–94	1,280	38.8	4,957	34.6	6,237	35.4	42
95+	65	2.0	340	2.4	405	2.3	10
Total	*3,300*	*100.0*	*14,331*	*100.0*	*17,631*	*100.0*	*133*
Persons							
<65	145	3.1	1,587	7.8	1,732	6.9	11
65–74	544	11.8	3,332	16.3	3,876	15.5	20
75–84	2,118	45.9	8,294	40.6	10,412	41.6	81
85–94	1,715	37.2	6,754	33.0	8,469	33.8	70
95+	90	2.0	477	2.3	567	2.3	11
Total	**4,612**	**100.0**	**20,444**	**100.0**	**25,056**	**100.0**	**193**

Note: The table excludes 190 cases with missing age. Cases with known age but missing sex are included in the persons data.

Source: AIHW analysis of CACP 2002 census.

CACP clients receive a range of different services appropriate to their needs. In general, only small differences exist between the median hours of weekly service and median numbers of ancillary services of clients with and without dementia (Table 7.19). The main difference in cross-sectional service profiles of the two groups is an average of one additional hour of respite care per week delivered to people with dementia.

In terms of total hours of service per week, excluding ancillary services not recorded in time-based units, CACP clients with dementia received a median of 6.0 hours in the census week (mean 6.9 hours), which was half an hour more on average than the median of 5.5 hours for clients without dementia (mean 5.9 hours).

Table 7.19: Mean and median service units (hours or number of events), by type of assistance received by CACP clients with and without dementia, census week 2002

	With dementia		Without dementia	
	Mean	**Median**	**Mean**	**Median**
Type of assistance		**Hours**		
Personal care	2.4	2.0	2.3	2.0
Domestic assistance	2.0	2.0	2.3	2.0
Social support	2.6	2.0	2.1	1.5
Other food services	1.8	1.5	1.7	1.3
Respite care	4.0	3.0	3.0	2.0
Rehabilitation	1.4	1.0	1.4	1.0
Home maintenance	0.9	0.8	1.1	1.0
Case management	1.0	0.8	0.9	0.8
Total hours	**6.9**	**6.0**	**5.9**	**5.5**
Ancillary services		**Number**		
Delivered meals	5.7	5.0	6.2	5.0
Linen deliveries	2.1	2.0	1.9	1.0
Transport one-way trips	3.0	2.0	2.9	2.0

Notes

1. The table excludes 196 clients where dementia status was not reported.
2. Amounts of type of assistance relate only to those receiving that assistance. Consequently, the sum of the mean number of hours of assistance received across types does not equal the total number of hours of assistance received.

Source: AIHW analysis of CACP 2002 census.

CACP clients with dementia and with a carer were more likely than those without dementia to receive respite (12% of clients with dementia and a carer received this service compared with 6% of those without dementia with a carer (Table 7.20). The availability of a carer is not observed to greatly affect the total number of hours of formal assistance received (Table 7.21).

Table 7.20: Number and percentage of CACP clients with and without dementia, by type of assistance and carer status, census week 2002

	With dementia				Without dementia			
	With a carer		Without a carer		With a carer		Without a carer	
Type of assistance	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Personal care	2,192	66.7	795	67.4	5,983	57.4	4,396	46.6
Domestic assistance	2,489	75.8	1,019	86.4	8,669	83.1	8,482	89.9
Social support	1,985	60.4	846	71.8	5,853	56.1	6,225	66.0
Other food services	1,112	33.9	505	42.8	2,912	27.9	2,679	28.4
Respite care	393	12.0	11	0.9	623	6.0	100	1.1
Rehabilitation	70	2.1	19	1.6	312	3.0	182	1.9
Home maintenance	339	10.3	179	15.2	1,606	15.4	1,857	19.7
Case management	2,609	79.4	959	81.3	7,892	75.7	6,812	72.2
Ancillary services								
Delivered meals	673	20.5	361	30.6	1,921	18.4	2,296	24.3
Linen deliveries	30	0.9	13	1.1	80	0.8	112	1.2
Transport one-way trips	1,058	32.2	530	45.0	3,288	31.5	4,067	43.1
Total CACP clients	**3,284**	. .	**1,179**	. .	**10,429**	. .	**9,437**	. .

Note: The table excludes 1,110 cases. These include both clients with either carer availability or dementia status missing, as well as those who received no services during census week.

Source: AIHW analysis of CACP 2002 census.

Table 7.21: Amount of assistance for CACP clients with and without dementia, by type of assistance and carer status, census week 2002

	With dementia				Without dementia			
	With carer		Without carer		With carer		Without carer	
Type of assistance	**Mean**	**Median**	**Mean**	**Median**	**Mean**	**Median**	**Mean**	**Median**
	Hours							
Personal care	2.5	2.0	2.3	1.8	2.4	2.0	2.1	1.8
Domestic assistance	2.0	2.0	2.1	2.0	2.3	2.0	2.3	2.0
Social support	2.7	2.0	2.4	2.0	2.0	1.5	2.1	1.8
Other food services	1.8	1.5	1.8	1.5	1.7	1.3	1.6	1.0
Respite care	3.9	3.0	5.2	2.5	3.1	2.0	2.3	2.0
Rehabilitation	1.5	1.0	1.0	0.8	1.4	1.0	1.3	1.0
Home maintenance	0.9	0.8	0.9	0.5	1.1	1.0	1.1	1.0
Case management	1.0	0.8	1.1	0.8	0.9	0.5	1.0	0.8
Total hours	**6.8**	**6.0**	**7.0**	**6.3**	**6.0**	**5.5**	**5.9**	**5.3**
Ancillary services	**Number**							
Delivered meals	5.4	5.0	6.2	6.0	5.8	5.0	6.5	6.0
Linen deliveries	2.0	2.0	2.2	2.0	2.1	1.0	1.8	1.0
Transport trips	2.9	2.0	3.3	2.0	2.8	2.0	3.0	2.0

Note: The table excludes 1,110 cases. These include both clients with either carer availability or dementia status missing, as well as those who received no services during census week.

Source: AIHW analysis of CACP 2002 census.

Extended Aged Care at Home

The prevalence of dementia among EACH clients increases with age (Table 7.22). While approximately 15% of clients aged 65–74 years had been diagnosed with dementia, this increased to almost one-half for clients aged 85 years or over.

EACH clients with dementia showed an older age profile than those without dementia (Table 7.22). Just under half (49%) of EACH clients with dementia in 2002 were aged 85 years or over, compared with 27% of clients without dementia.

Table 7.22: EACH clients with and without dementia, number of clients, by age group and sex, census week May 2002

	With dementia		Without dementia		Total	
Sex/age	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Males						
<65	3	11.1	4	5.8	7	7.3
65–74	4	14.8	25	36.2	29	30.2
75–84	9	33.3	26	37.7	35	36.5
85–94	11	40.7	13	18.8	24	25.0
95+	0	—	1	1.4	1	1.0
Total	*27*	*100.0*	*69*	*100.0*	*96*	*100.0*
Females						
<65	5	8.3	19	16.0	24	13.4
65–74	5	8.3	26	21.8	31	17.3
75–84	19	31.7	37	31.1	56	31.3
85–94	26	43.3	32	26.9	58	32.4
95+	5	8.3	5	4.2	10	5.6
Total	*60*	*100.0*	*119*	*100.0*	*179*	*100.0*
Persons						
<65	8	9.1	23	12.2	31	11.2
65–74	9	10.2	52	27.5	61	22.0
75–84	28	31.8	63	33.3	91	32.9
85–94	38	43.2	45	23.8	83	30.0
95+	5	5.7	6	3.2	11	4.0
Total	**88**	**100.0**	**189**	**100.0**	**277**	**100.0**

— Nil or rounded to zero.

Note: The table excludes 11 cases with either age or dementia status missing. Cases with missing sex are included in the persons data.

Source: AIHW analysis of EACH 2002 census.

Like CACP clients, EACH clients receive a range of different services in different amounts according to their needs. Most of these services are measured according to the number of hours provided during the census week. However, meals, linen deliveries and transport trips are counted according to number of service events. Comparison of the weekly median hours or number of service events shows little difference between levels of service for clients with and without dementia (Table 7.23).

The mean figures differ somewhat from the median figures, indicating that some individuals received substantially more or less of a service type than most, thus skewing the mean away from the median. This is a more noticeable effect in small numbers of clients.

When the number of hours of service provided is added over all service types, clients with dementia received a median of 17.9 hours in the week (mean of 17.6 hours). This was just half an hour less than the median number of hours of assistance in the week for clients without dementia (median of 18.4 and mean of 17.8). These results reflect the high care needs of all clients in the EACH program.

Table 7.23: Average weekly hours of assistance and number of events, by type of assistance and dementia status, census week May 2002

	With dementia		Without dementia	
	Mean	**Median**	**Mean**	**Median**
Type of assistance		**Hours**		
Personal care	8.8	9.0	9.5	9.0
Domestic assistance	2.2	2.0	2.4	2.0
Social support	2.5	2.0	2.9	2.0
Other food services	3.0	2.5	3.7	3.5
Respite care	5.0	4.0	4.6	4.0
Rehabilitation	1.8	1.8	2.1	1.8
Home maintenance	1.3	1.3	1.2	1.0
Case management	1.8	1.5	1.5	1.5
Allied health	0.9	0.8	1.4	1.0
Nursing	1.9	1.0	2.1	1.3
Total hours	**17.6**	**17.9**	**17.8**	**18.4**
Ancillary services for EACH		**Number**		
Delivered meals	4.6	5.0	5.7	7.0
Linen deliveries	1.3	1.0	1.1	1.0
Transport one-way trips	3.2	4.0	2.9	2.0

Notes

1. The table excludes eight cases with dementia status missing and six cases where clients were on leave and so did not receive any services during census week.
2. Amounts of type of assistance relate only to those receiving that assistance. Consequently, the sum of the mean number of hours of assistance received across types does not equal the total number of hours of assistance received.

Source: AIHW analysis of EACH 2002 census.

Family and other carers also contribute to the care and support of EACH clients in the home. There were insufficient cases to enable a comparison of amount of services provided to clients with dementia who do not have a carer, a result which is itself indicative of the difficulty of providing services in the home to people with dementia who do not have access to care from relatives and friends. In most areas of assistance, similar proportions of clients with or without dementia who had a carer received assistance. EACH clients with dementia were more likely to use respite care services (53% for those with dementia and with a carer) compared with the proportion without dementia receiving this service (37% of those without dementia and with a carer) (see Tables 7.25 and 7.26).

On average, among clients with a carer, those with and without dementia received a similar number of hours assistance during census week. However, those without dementia on average received about one more delivered meal during the census week per person than those with dementia (mean of 5.8 compared with 4.7 meals). EACH clients without dementia and without a carer received slightly more domestic assistance and other food services, and slightly less social support, delivered meals, rehabilitation and nursing care, compared with those with a carer (Table 7.24).

Table 7.24: EACH clients with and without dementia, types of therapies and ancillary services provided, by carer status, census week May 2002

	With dementia[(a)]		Without dementia			
	With a carer		With a carer		Without a carer	
Type of assistance	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Personal care	79	92.9	146	89.6	22	95.7
Domestic assistance	51	60.0	108	66.3	22	95.7
Social support	43	50.6	84	51.5	5	21.7
Other food services	32	37.6	53	32.5	13	56.5
Respite care	45	52.9	61	37.4	†	†
Rehabilitation	16	18.8	41	25.2	3	13.0
Home maintenance	6	7.1	19	11.7	0	—
Case management	73	85.9	148	90.8	22	95.7
Allied health	7	8.2	22	13.5	7	30.4
Nursing	47	55.3	88	54.0	14	60.9
Ancillary services						
Delivered meals	7	8.2	12	7.4	8	34.8
Linen deliveries	7	8.2	9	5.5	3	13.0
Transport one-way trips	6	7.1	16	9.8	†	†
Total EACH clients[(a)]	**85**	. .	**163**	. .	**23**	. .

(a) Three EACH clients with dementia did not have a carer. These have been excluded from the table as they do not allow accurate comparisons to be made.

† Fewer than three people received this service.

— Nil or rounded to zero.

Notes

1. The table excludes eight cases with dementia status missing and six cases where clients were on leave and so did not receive any services during census week.
2. Clients may receive more than one type of assistance, and so percentages do not sum to 100.

Source: AIHW analysis of EACH 2002 census.

Indications in the CACP and EACH census data are that clients with dementia who have a primary carer are more likely to use respite care services than clients who do not have dementia (with a primary carer). Among CACP clients, there are differences in the average service levels per week, mainly due to higher respite care hours on average, according to whether a client has dementia or not. Around 90% of CACP clients in the 2002 census week received under 10 hours of formal service per week from their CACP provider. Higher levels of respite care (an average of 2 hours per client per week) imply a reduced level of instrumental assistance, which may be an issue for carers who are experiencing carer strain associated with dementia care. In the EACH census data there are no marked differences in average hours of service per week for clients with and without dementia, nor in the average hours of respite care delivered per client during the census week. The results most likely reflect a greater homogeneity in need for formal assistance among clients with ACAT approval for high level residential care or equivalent, compared to the larger number of clients and range of levels of need for assistance among CACP clients. Of course, the infancy of the EACH program at the time of the census also needs to be taken into account.

Use of EACH by people with dementia will be encouraged by the implementation of EACH Dementia places. The EACH Dementia Program was announced in the 2005 Federal Budget as part of the initiative *Helping Australians with dementia, and their carers – making dementia a National Health Priority*. EACH Dementia consists of 2,000 new flexible care places to be allocated over three years:

- 667 packages to be released in 2005–06
- 667 packages to be released in 2006–07 (indicative releases)
- 666 packages to be released in 2007–08 (indicative releases).

EACH Dementia packages are aimed at those at the highest end of the community care continuum. EACH Dementia packages will provide the same full range of services that 'general purpose' EACH packages provide. The first three years of the EACH Dementia program have been designated a 'developmental' period; additional specific services and approaches related to the special needs of the clients will therefore be considered (DoHA 2005a:3).

Service use data for CACP and EACH described above do not include measures of case management time. Care package services, such as CACP and EACH services, are distinguished by their packaging of multiple types of assistance according to individual needs with overall case management and service coordination. It has been found that servicing clients with high dementia-related needs involves both a higher case management load than is more generally required in community care and more highly skilled care assistants, especially workers with dementia-specific expertise (AIHW: Hales et al. 2006).

National Respite for Carers Program

The aim of the NRCP is to contribute to the support and maintenance of caring relationships between carers and their dependent family members or friends by facilitating access to information, respite care and other support appropriate to their individual needs and circumstances, and those of the persons for whom they care. The program funds respite services, Commonwealth Carer Respite Centres (which provide information on respite services and assistance to arrange respite), Commonwealth Carer Resource Centres (which provide information to carers about services available to them), and the National Carer Counselling Program.

Respite care may be provided in the home, in a variety of community settings such as at a centre during the day, or in a residential setting. ACAT assessment is not required for people accessing respite through the NRCP; there are, however, assessment procedures within the program with a focus on the relative needs of primary carers and the people for whom they care ('care recipients'). An ACAT assessment is necessary for people wanting respite care in aged care facilities.

In 2004–05 the CCRCs assisted around 59,000 carers. Of those, 17% (10,000) were caring for someone with dementia (Table 7.25). Women account for 76% of carers assisted by the CCRCs. Of those who care for a person with dementia, 72% were female.

Table 7.25: Carers assisted by, and care recipients registered with, a CCRC, by sex and dementia status, 2004–05

Sex	Carers assisted by CCRCs	Carers for people with dementia	% of carers who care for a person with dementia	Care recipients registered with CCRCs	Care recipients with dementia	% with dementia
Males	13,737	2,826	20.6	28,674	4,290	15.0
Females	45,227	7,343	16.2	29,331	5,391	18.4
Not stated/ inadequately described	378	26	6.9	1,844	259	14.0
Total (calculated)	**59,342**	**10,195**	**17.2**	**59,849**	**9,940**	**16.6**

Source: DoHA analysis of the NRCP MDS.

Respite care through the NRCP (or HACC, for example) may be the only formal assistance used by a person with dementia and their carer, but the NRCP has also been found to provide a valuable adjunct source of assistance to community-based people with high-level dementia-related needs who receive formal assistance through other programs, including CACP and EACH (AIHW: Hales et al. 2006). The NRCP allows providers to deliver respite care with some flexibility, through direct service and brokerage arrangements, sourcing the best available form of respite to suit the needs of individuals with dementia and their carers.

While ACAT approval is not required to access NRCP-funded services, ACATs will often refer assessed clients and their carers to NRCP service providers. An AIHW report on the national evaluation of the Aged Care Innovative Pool Dementia Pilot revealed that respite care can be an important means by which formal assistance is introduced to a person with dementia and is often a key to helping family members to continue with provision of care at home (AIHW: Hales et al. 2006). Yet it was found that many carers of people with dementia (or moderate to severe cognitive impairment) are not aware of the agencies that provide information and support to carers. Among 118 carers who responded to specific questions about these services:

- 59% had never heard of or contacted Commonwealth Carelink
- 55% had never heard of or contacted a Commonwealth Carer Resource Centre
- 49% had never heard of or contacted a Commonwealth Carer Respite Centre
- 59% had never heard of or contacted the Dementia Helpline (1800 Freecall number).

There are in fact many reasons, not just lack of awareness of services, that contribute to non-use of respite care and other types of formal assistance. Some of these are peculiarly associated with the nature of dementing illnesses. For example, a person with moderate to severe dementia may be resistant to receiving care from outsiders or being left with a person other than their primary carer. Carers may reject formal assistance even though they feel a need for the support if they are concerned that the care recipient with dementia will not be happy being cared for by others or if there is a fear that behavioural symptoms will be exacerbated in the process (AIHW: Hales et al. 2006). The experience of service providers and carers in the Aged Care Innovative Pool Dementia Pilot suggests that dementia presents special challenges to carers' use of assistive services such as respite care.

Responses from carers to questions about their use of respite care services in the Survey of Disability, Ageing and Carers provide some insight into reasons for not using respite care, but our understanding of the issues (covered comprehensively by questions in the survey) is hampered by high sampling errors associated with small sample sizes. A main issue is that detailed information on carers and care recipients with dementia is available only where the carer is a co-resident primary carer. This, combined with low sample sizes in the older household population, means that the richness of questions about service use in the survey is not fully exploited.

The data which are available points to carer and care recipient factors in the non-use of respite care services, in situations where there is an identified need for respite (Table 7.26).

Table 7.26: Co-resident primary carers of people with dementia living in households, estimated number of carers, by recent use of respite care services, 2003

Main reason never used respite care	Number	Per cent
Has used respite care	*3,600	*30.7
Used respite care in the last three months	*2,900	*25.2
Used respite care but not in the last three months	**600	**5.5
Never used respite care	*8,100	69.3
Does not need service	*4,900	*41.6
Available services not suited to needs	—	—
Recipient does not want service	**2,000	*17.3
Carer does not want service	**1,000	**8.2
Other reason	**300	**2.2
Total	**11,700**	**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.

— Nil or rounded to zero.

Source: AIHW analysis of the ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

7.5 Residential aged care

When a person with need for assistance can no longer manage or be managed at home, they may enter a residential aged care facility. Certain aspects of dementia care have been reported to contribute to an elevated risk of use of residential care among older people. LoGiudice et al. (1997:316) concluded that:

> *There seems to be a large gap in the ability to service adequately the needs of those with dementia living at home, so that residential care becomes the only option…It may be possible to target a subgroup of this population that may benefit from innovative home care schemes in an attempt to avoid institutionalisation. It is imperative, however, that alternative options do not subsequently place extra financial or social costs on carers.*

The implied link between the use of residential care in relation to dementia care and the cost to carers of community-based alternatives is an important one to make. The study of dementia care in Australia by LoGiudice and colleagues found that people caring for a person with dementia experienced a significant increase in psychological morbidity and carer burden over the study period, whereas, on average, psychological morbidity among spouse carers of people without cognitive impairment decreased over time. Chapter 6, in addressing the topic of family carers of people with dementia, highlights that sense of relationship and family obligation is a primary motivator for provision of care at home. Indeed, it is not uncommon for carers, particularly older carers providing assistance to a spouse, to be unwilling to separate their caring role from their relationship to the care recipient (and may therefore continue to regard their role as wife, husband, or partner, not carer). A need for high-level ADL assistance arises in connection with many health conditions; however, severe dementia involves not only high ADL impairment but a loss of personhood that can disrupt interpersonal relationships and undermine motivation as a foundation of caring relationships within families (Mittelman et al. 1993).

Supporting the claims of the extra burden on carers associated with dementia care in community settings are findings of increased dependency, hence increased costs relating to dementia care for people in aged care facilities and hospitals (see for example Gallo et al. 2000 and Kavanagh et al. 1993) and the higher levels of skill needed by community care workers in the field of dementia care (AIHW: Hales et al. 2006).

Dementia is the most common primary diagnosis made by ACATs in Australia (Lincoln Gerontology Centre 2002:36) and is associated with high rates of admission to permanent residential care. Administrative data on residents in aged care facilities accredited by the Australian Government are recorded in the Aged and Community Care Management Information System (ACCMIS). In addition, the ABS SDAC samples people in residential aged care facilities as part of the cared accommodation component of the survey. In 2003, 5,000 residents were sampled, or about 1 in 30 residents. The survey also provides information about disease and disability. While ACCMIS records all users of residential services, it does not contain diagnosis information, leaving the SDAC as the main source of information about people with dementia in residential care facilities. As noted in Chapter 3, the prevalence of dementia in these settings is likely to be more accurate than in the household component of the survey, although people who have undiagnosed or early-stage dementia, or whose dementia symptoms are masked by the symptoms of other health conditions and disabilities, may not be identified.

Following implementation of the new funding instrument for residential aged care (the ACFI), a record of morbidity will be kept allowing more accurate analysis of illness and disability in residential aged care settings.

Currently, the Resident Classification Scale (RCS) is the instrument used for setting residential care subsidy rates according to determined levels of resident dependency (RCS 1 to 8). This report has taken estimates of the numbers of people in residential aged care with dementia from the SDAC and allocated them across the 8 RCS categories based on a mapping of questions from the RCS to questions on the cared accommodation component of the SDAC (Box 7.5). This method gives a more accurate allocation of residents with dementia across the 8 RCS categories than that reported by AIHW in 2004 (AIHW 2004f).

Box 7.5: Mapping from RCS questions to SDAC

The 20 questions from the RCS questionnaire were mapped to questions from the 2003 SDAC. From this mapping an estimate was made of the likely response to the RCS questions. A weight was applied to each response to these mapped SDAC questions which when added provided a proxy RCS score (SDAC-RCS score). The distribution of the SDAC-RCS score was adjusted to fit as closely as possible the distribution of the RCS scores from the RCS file. This provided the cut off points for the SDAC-RCS between each level on the RCS scale and an estimated RCS classification for each record in the SDAC. Hence, the level of funding could be attributed to each record in the SDAC and to the main cause of disability recorded in the SDAC.

In 2003, the SDAC identified 67,650 people in permanent residential aged care with dementia and Alzheimer's disease (Table 7.27), comprising 48% of the permanent resident population (as at June 2003). There are more than three times as many females as males (52,000 females compared to 16,000 males) in residential aged care with dementia and Alzheimer's disease. For other diseases there are only twice as many females (48,000) as males (23,000). Eighty-three per cent of people with dementia and Alzheimer's disease in residential aged care (56,000 people) were in high care settings (RCS 1–RCS 4) and over half (56%) were aged over 85 years.

The age profile of people with dementia in residential aged care is different for males and females: 30% of males with dementia in residential aged care are less than 80 years of age compared with 17% of females in the same age range. Nearly 60% of females in residential aged care are over 85 years of age.

The age profile for people with dementia is slightly older than that for all permanent residents: 23% of male residents are aged less than 75 but this is true for only 14% of males with dementia. Similarly, 10% of all female residents are aged less than 75 and this compares with 6% of females with dementia.

A person with dementia is also more likely to be in high level care (RCS 1–RCS 4): 83% of people with dementia require high care compared with 64% of all permanent residents. The proportion of each RCS level for people with dementia decreases from 72% in RCS 1 to 46% in RCS 4 and only 23% of low level aged care is for people with dementia.

Thirty-six per cent of males with dementia in residential aged care are in RCS 1 and 27% in RCS 2. For females with dementia, 29% are in RCS 1 and 31% in RCS 2.

Table 7.27: Dementia and Alzheimer's disease in residential aged care, by RCS category, 2003

Sex/age	RCS 1	RCS 2	RCS 3	RCS 4	RCS 5–RCS 8	Total(a)	% total dementia	Total permanent residents(b)	% total permanent residents
Males with dementia									
<65	154	52	148	0	48	**402**	2.6	3,123	8.1
65–69	121	91	96	60	120	**488**	3.1	2,208	5.8
70–74	459	360	173	0	268	**1,260**	8.1	3,909	10.2
75–79	885	663	366	159	425	**2,498**	16.0	6,591	17.2
80–84	1,418	1,132	725	149	489	**3,913**	25.0	8,482	22.1
85+	2,609	1,964	1,045	407	1,057	**7,082**	45.3	14,066	36.7
Total	*5,646*	*4,262*	*2,554*	*775*	*2,407*	**15,644**	*100.0*	*38,379*	*100.0*
Percentage of males with dementia in each RCS category	*36.1*	*27.2*	*16.3*	*5.0*	*15.4*	**100.0**			

(continued)

Table 7.27 (continued): Dementia and Alzheimer's disease in residential aged care, by RCS category, 2003

Sex/age	RCS 1	RCS 2	RCS 3	RCS 4	RCS 5–RCS 8	Total[(a)]	% total dementia	Total permanent residents[(b)]	% total permanent residents
Females with dementia									
<65	171	83	122	0	173	**549**	1.1	2,915	2.9
65–69	194	152	190	0	223	**759**	1.5	2,145	2.1
70–74	347	644	343	0	562	**1,896**	3.6	4,803	4.8
75–79	1,184	1,663	971	340	1,380	**5,538**	10.6	11,695	11.6
80–84	3,061	3,909	2,594	846	2,195	**12,605**	24.2	22,397	22.2
85+	9,932	9,890	5,277	1,087	4,472	**30,658**	59.0	56,717	56.3
Total	14,888	16,341	9,497	2,274	9,006	**52,006**	100.0	100,672	100.0
Percentage of females with dementia in each RCS category	*28.6*	*31.4*	*18.3*	*4.4*	*17.3*	**100.0**			
Persons with dementia									
<65	325	135	270	0	221	**951**	1.4	6,038	1.9
65–69	315	243	286	60	343	**1,247**	1.8	4,353	3.0
70–74	806	1,004	516	0	830	**3,156**	4.7	8,712	7.3
75–79	2,069	2,326	1,337	499	1,805	**8,036**	11.9	18,286	15.8
80–84	4,479	5,041	3,319	995	2,684	**16,518**	24.4	30,879	23.5
85+	12,541	11,854	6,322	1,494	5,529	**37,740**	55.8	70,783	48.4
Total with dementia	**20,535**	**20,603**	**12,051**	**3,049**	**11,413**	**67,650**	**100.0**	**139,051**	**100.0**
Percentage of persons with dementia in each RCS category	*30.4*	*30.5*	*17.8*	*4.5*	*16.9*	**100.0**			
Total permanent residents	**28,470**	**34,213**	**20,255**	**6,558**	**49,555**	**139,051**			
Percentage of permanent residents in each RCS category	20.5	24.6	14.6	4.7	35.6	**100.0**			
Per cent of RCS category with dementia	*72.1*	*60.2*	*59.5*	*46.5*	*23.0*	***48.7***			

— Nil or rounded to zero.

(a) Population with dementia in residential aged care is derived from analysis of the ABS 2003 Survey of Disability, Ageing and Carers.

(b) Total permanent residents of residential aged care (AIHW 2004h).

7.6 Hospitals—admitted patient services

Hospital separations

Data relating to hospital use in Australia are available from the National Hospital Morbidity Database. The database provides information on the characteristics of admitted patients, including diagnosis and procedures, for each **separation** from hospital by financial year of separation. A record is included for each separation, not for each patient, thus patients who separated more than once in the year have more than one record in the database.

A person with dementia may be admitted to hospital for management of dementia, in which case their record of separation is likely to show dementia as a principal diagnosis, or they may be admitted for some other reason. The principal diagnosis is the diagnosis established after study to be chiefly responsible for the patient's episode of care in hospital. Where the admission is attributed to some other health condition, dementia will also be coded on the record as an additional diagnosis if it contributes to the cost of hospital care.

Box 7.6: ICD-10-AM diagnosis codes for dementia

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

G30 – Alzheimer's disease

G31 – Other degenerative diseases of nervous system, not elsewhere classified

Dementia as a principal diagnosis

In 2003–04, dementia was reported as the principal diagnosis on 10,989 hospital separations, or 0.2% of total hospital separations (Table 7.28). This represents an increase of 727 hospital separations (or 7%) over the 10,117 separations recorded for 1999–00.

For all years examined, the number of separations for patients with a principal diagnosis of dementia peak in the 80–84 years and 85–89 years age groups. There were approximately 10 times as many separations with a principal diagnosis of dementia for patients aged 85 years or over as there were for those 60 years of age or under. Overall, there were more separations for women with a principal diagnosis of dementia than for men (55% of separations for patients with a principal diagnosis of dementia were for women in 2003–04). There were almost twice as many separations for female patients with a principal diagnosis of dementia aged 85 and over as there were for males in this age group.

The higher number of separations for female than male patients is due to the higher number of females among older patients (75 years and over)—at all ages men have higher age-specific rates of hospital separation with a principal diagnosis of dementia than women (Table 7.29). Age-specific rates of hospital separation with a principal diagnosis of dementia were highest in age groups 85–89 years and 90–94 years for both men and women in 2003–04.

Age-standardised rates adjust crude rates of hospital separations to take account of different age structures, both between the sexes and in different years. Crude separation rates are similar for men and women; however, the age-standardised rate for women (2.8 separations per 1,000 women aged 60 years or over in 2003–04) is lower than that for men (3.6 separations per 1,000 men aged 60 years or over). The age-standardised rate of hospital separations with a principal diagnosis of dementia remained fairly stable between 1999–00 and 2003–04 at around 3.1 separations per 1,000 persons aged 60 years and over.

Table 7.28: Separations with principal diagnosis of dementia[(a)], by age and sex, 1999–00 to 2003–04

Sex/age	1999–00	2000–01	2001–02	2002–03	2003–04
Males					
0–59	127	129	108	114	120
60–64	130	113	116	154	148
65–69	270	271	271	260	232
70–74	590	610	586	621	513
75–79	1,040	1,079	955	1,055	1,135
80–84	1,160	1,268	1,274	1,364	1,367
85–89	961	974	895	959	989
90–94	245	319	370	337	360
95+	42	53	67	60	92
Total	*4,565*	*4,816*	*4,642*	*4,924*	*4,956*
Females					
0–59	104	100	101	92	135
60–64	110	103	72	108	108
65–69	193	205	169	166	174
70–74	475	506	526	482	501
75–79	1,052	1,126	1,081	1,021	1,060
80–84	1,454	1,543	1,465	1,585	1,752
85–89	1,550	1,480	1,423	1,431	1,434
90–94	512	700	691	748	707
95+	102	152	168	183	162
Total	*5,552*	*5,915*	*5,696*	*5,816*	*6,033*
Persons					
0–59	231	229	209	206	255
60–64	240	216	188	262	256
65–69	463	476	440	426	406
70–74	1,065	1,116	1,112	1,103	1,014
75–79	2,092	2,205	2,036	2,076	2,195
80–84	2,614	2,811	2,739	2,949	3,119
85–89	2,511	2,454	2,318	2,390	2,423
90–94	757	1,019	1,061	1,085	1,067
95+	144	205	235	243	254
Total	**10,117**	**10,731**	**10,338**	**10,740**	**10,989**

(a) ICD-10-AM diagnosis codes F00, F01, F02, F03, F051, G30 and G31. Principal diagnosis G31 included only when additional diagnosis of dementia is recorded.

Note: Separations with missing data on patient age and/or sex are included in the relevant totals.

Source: AIHW analysis of the National Hospital Morbidity Database.

Table 7.29: Age-specific rates of hospital separation with a principal diagnosis of dementia[(a)] per 1,000 persons, by sex, 1999–00 to 2003–04

Sex/age	1999–00	2000–01	2001–02	2002–03	2003–04
Males					
60–64	0.33	0.28	0.28	0.36	0.33
65–69	0.81	0.81	0.80	0.74	0.64
70–74	1.99	2.02	1.93	2.05	1.70
75–79	4.82	4.83	4.15	4.46	4.65
80–84	10.03	10.27	9.61	9.67	9.12
85–89	17.45	16.79	14.77	15.29	15.28
90–94	15.21	18.45	19.87	17.10	17.03
95+	11.01	12.44	14.00	11.46	16.01
Crude rate 60+	*3.11*	*3.19*	*3.00*	*3.10*	*3.03*
Age-standardised rate 60+[(b)]	*3.84*	*3.90*	*3.63*	*3.67*	*3.57*
Females					
60–64	0.28	0.26	0.17	0.25	0.25
65–69	0.56	0.59	0.48	0.46	0.47
70–74	1.42	1.51	1.58	1.46	1.53
75–79	3.70	3.89	3.69	3.45	3.53
80–84	7.81	7.89	7.10	7.34	7.77
85–89	13.60	12.50	11.64	11.47	11.31
90–94	11.70	14.95	13.84	14.27	12.86
95+	8.15	11.38	11.56	11.70	9.65
Crude rate 60+	*3.19*	*3.33*	*3.13*	*3.14*	*3.16*
Age-standardised rate 60+[(b)]	*2.94*	*3.03*	*2.81*	*2.79*	*2.81*
Persons					
60–64	0.31	0.27	0.23	0.31	0.29
65–69	0.68	0.70	0.64	0.60	0.55
70–74	1.69	1.76	1.74	1.74	1.61
75–79	4.19	4.30	3.89	3.90	4.03
80–84	8.66	8.81	8.08	8.26	8.31
85–89	14.86	13.91	12.68	12.75	12.65
90–94	12.65	15.89	15.48	15.05	14.01
95+	8.82	11.64	12.16	11.64	11.27
Crude rate 60+	*3.15*	*3.27*	*3.07*	*3.12*	*3.10*
Age-standardised rate 60+[(b)]	*3.29*	*3.36*	*3.12*	*3.14*	*3.10*

(a) ICD-10-AM diagnosis codes F00, F01, F02, F03, F051, G30 and G31. Principal diagnosis G31 included only when additional diagnosis of dementia is recorded.

(b) Direct standardisation using the standard Australian population at 30 June 2001.

Note: Age–sex-specific rates are based on ABS population estimates for 31 December of each year.

Sources: Table 7.28 and ABS 2003.

One measure of resource use by admitted patients is the number of days spent in hospital. Dementia—or other health conditions—can contribute to the cost of treatment in hospital in a number of ways, one of which is to increase length of stay beyond that which would occur on average for treating the main condition (i.e. where dementia is an additional diagnosis). Also, in considering the impact of dementia as a reason for admission to hospital, it is insightful to examine the average number of days that a person admitted for dementia management spends in hospital (Box 7.7).

Box 7.7: Calculation of admitted patient days

In the National Hospital Morbidity Database, ***patient days*** *provide information on the length of stay of patients and are calculated as the difference between the separation date and admission date, less any leave days. Same-day patients are allocated a length of stay of one day. As the database contains records for patients separating from hospital during the year, this definition means that not all patient days reported will have occurred in the reporting period (1 July to 30 June) and, therefore, cannot be used to calculate accurate financial year-based activity estimates based on patient days. It is expected, however, that patient days for patients who separated during the financial year, but who were admitted in the previous financial year, would be counterbalanced by the patient days for patients in hospital at the end of the financial year who will separate in the following reporting period, and for whom data will be reported in the data collection for the next financial year.*

The 10,989 separations with a principal diagnosis of dementia in 2003–04 accounted for 289,816 patient days, or 1.5% of all patient days. This compares with dementia as a principal diagnosis accounting for 0.2% of total separations. Clearly dementia separations have a much longer length of stay than the average separation. Taking into account all separations, including same-day separations, there were 0.5 hospital separations per 1,000 persons in 2003–04 for patients whose admission was chiefly attributed to dementia (principal diagnosis), with an average of 26.4 patient days per episode.

Approximately 87% of separations with a principal diagnosis of dementia involved overnight or longer stays (just 1,398 out of 10,989 separations in 2003–04 were same-day separations). When same-day separations are excluded, patients admitted to hospital with a principal diagnosis of dementia stayed in hospital for an average of a month (30 days; Table 7.30). The average (mean) length of stay for all patients in Australian hospitals in 2003–04, excluding same-day separations, was 8.6 days (all ages).

The median length of stay for patients admitted for at least an overnight hospital stay with a principal diagnosis of dementia was 14 days (50th percentile), compared to the mean of 30 days. The large difference between the mean and median can be explained by a small group of patients with dementia who remained in hospital for extended periods of months or years. Again excluding same-day separations, 75% of separations for patients with a principal diagnosis of dementia involved hospital stays of 28 days or less. For 5% of overnight separations, patients with a principal diagnosis of dementia stayed two months or longer (78 days or more). These 5% of separations accounted for 13% of patient days (37,000 patient days) for people with a principal diagnosis of dementia.

Table 7.30: Length of hospital stay, patient days and separations, by dementia diagnosis (excluding same-day separations), 2003–04

	Separations	Total patient days	Mean length of stay	Percentile 5th	 25th	 50th	 75th	 95th
	Number	Days	Days			Days		
Principal diagnosis of dementia	9,591	288,418	30.1	3	7	14	28	78
Other principal diagnosis	60,540	1,085,691	17.9	2	5	9	18	47
Any diagnosis of dementia, including principal diagnosis	70,131	1,374,109	19.6	2	5	10	20	51
All separations, all diagnoses (excluding same-day)	**3,129,725**	**19,871,746**	**8.6**	**2**	**3**	**5**	**9**	**26**

Source: AIHW analysis of the National Hospital Morbidity Database.

Dementia—any diagnosis

Patients admitted to hospital are assigned a principal diagnosis and can also be assigned a number of additional diagnoses. Additional diagnoses are conditions or complaints either coexisting with the principal diagnosis or arising during the episode of care. Usual practice is to assign additional diagnoses for conditions that are found to contribute to the resource consumption of the hospital episode of care. Therefore, counts of separations with any given additional diagnosis do not necessarily measure the number of separations for hospital patients who have that condition. Particularly in the case of separations with admission on the same day, hospital separations with an additional diagnosis of dementia might not accurately reflect the number of separations for patients where dementia was present. They do, however, provide a measure of the number of separations for which dementia was thought to contribute significantly to the cost of care and are therefore more likely to be patients with moderate or severe dementia.

In 2003–04, dementia was reported either as a principal or additional diagnosis for 82,806 hospital separations, or 1.2% of total hospital separations (Table 7.31).

In all five years, the number of separations for patients with dementia either as a principal or additional diagnosis increased with age and peaked in the 80–84 years and 85–89 years age groups. Overall, there were more separations for women with dementia either as a principal or additional diagnosis (60% of all separations for patients with dementia in the year 2003–04) than for men. Below the age of 75 years, more hospital separations were attributed to men with dementia than to women. For patients 75 years and over, however, separations for women outnumbered those for men and the difference was more pronounced with increasing age.

Crude rates of hospital separation with a diagnosis of dementia for the population aged 60 years and over suggest that the separation rate is higher for women (26.4 per 1,000 women aged 60 years and over in 2003–04) than for men (20.3 per 1,000 men in 2003–04) (Table 7.31). To a large extent this is because the female population is considerably older than the male population. To take account of different age structures in the male and female populations, the crude rate of hospital separations with a dementia diagnosis—principal or additional—were age-standardised to the national population as at 30 June 2001. The results show that rates of hospital separation with a diagnosis of dementia are similar for men and women, with men having slightly higher rates than women at all ages (age-standardised rates of 24.6 and 22.9 per 1,000 men and women aged 60 years or over, respectively, in 2003–04; Table

7.32). The overall age-standardised rate of hospital separation recorded with a dementia diagnosis was slightly lower in 2002–03 than in 1999–00, and slightly higher in 2003–04 than in 2002–03. Differences over time can relate to the actual number of admitted patients with dementia but may also be due to changes in clinical coding practice.

Table 7.31: Separations with a principal or additional diagnosis of dementia, by age and sex, 1999–00 to 2003–04

Sex/age	1999–00	2000–01	2001–02	2002–03	2003–04
Males					
0–59	666	651	572	569	653
60–64	619	625	548	614	657
65–69	1,429	1,199	1,250	1,326	1,244
70–74	3,654	3,407	3,173	3,203	3,087
75–79	6,544	6,529	6,062	6,351	6,927
80–84	7,602	7,876	7,975	8,478	9,194
85–89	7,171	6,678	6,726	6,872	7,574
90–94	2,168	2,614	2,818	2,907	3,188
95+	408	487	549	577	626
Total	*30,261*	*30,066*	*29,673*	*30,897*	*33,150*
Females					
0–59	497	393	412	363	439
60–64	490	429	411	513	500
65–69	1,027	972	958	986	1,016
70–74	3,205	3,041	2,824	2,786	2,926
75–79	7,796	7,299	7,301	7,102	7,588
80–84	11,986	11,700	11,927	12,439	13,408
85–89	14,896	13,267	13,331	12,979	13,847
90–94	5,772	7,001	7,182	7,439	7,836
95+	1,402	1,842	1,926	2,022	2,095
Total	*47,071*	*45,944*	*46,272*	*46,629*	*49,655*
Persons					
0–59	1,163	1,044	984	932	1,092
60–64	1,109	1,054	959	1,127	1,157
65–69	2,456	2,171	2,208	2,312	2,260
70–74	6,859	6,448	5,997	5,989	6,013
75–79	14,340	13,828	13,363	13,453	14,515
80–84	19,588	19,576	19,902	20,917	22,602
85–89	22,067	19,945	20,057	19,851	21,421
90–94	7,940	9,615	10,000	10,346	11,024
95+	1,810	2,329	2,475	2,599	2,721
Total	**77,332**	**76,012**	**75,946**	**77,533**	**82,806**

(a) ICD-10-AM diagnosis codes F00, F01, F02, F03, F051, G30.

Note: Separations with missing data on patient age and/or sex are included in the relevant totals.

Source: AIHW analysis of the National Hospital Morbidity Database.

Table 7.32: Age-specific rates of hospital separation with a principal or additional diagnosis of dementia[(a)] per 1,000 persons, by age and sex, 1999–00 to 2003–04

Sex/age	1999–00	2000–01	2001–02	2002–03	2003–04
Males					
60–64	1.58	1.53	1.30	1.42	1.47
65–69	4.29	3.59	3.68	3.79	3.44
70–74	12.31	11.30	10.45	10.57	10.23
75–79	30.36	29.26	26.34	26.84	28.40
80–84	65.73	63.81	60.17	60.08	61.31
85–89	130.20	115.11	110.97	109.59	117.03
90–94	134.60	151.22	151.33	147.48	150.77
95+	107.00	114.35	114.69	110.24	108.96
Crude rate 60+	*20.71*	*20.03*	*19.26*	*19.54*	*20.34*
Age-standardised rate 60+[(b)]	*26.32*	*25.17*	*23.90*	*23.85*	*24.58*
Females					
60–64	1.25	1.07	0.99	1.21	1.14
65–69	2.97	2.81	2.73	2.74	2.73
70–74	9.61	9.10	8.47	8.42	8.91
75–79	27.46	25.20	24.91	23.97	25.28
80–84	64.38	59.83	57.81	57.60	59.44
85–89	130.72	112.06	109.07	104.00	109.21
90–94	131.92	149.51	143.84	141.97	142.49
95+	112.06	137.96	132.50	129.31	124.77
Crude rate 60+	*27.24*	*26.09*	*25.70*	*25.39*	*26.41*
Age-standardised rate 60+[(b)]	*24.87*	*23.36*	*22.62*	*22.16*	*22.90*
Persons					
60–64	1.42	1.30	1.15	1.31	1.30
65–69	3.62	3.20	3.20	3.25	3.08
70–74	10.88	10.15	9.41	9.44	9.54
75–79	28.71	26.96	25.54	25.24	26.68
80–84	64.90	61.37	58.73	58.58	60.19
85–89	130.55	113.07	109.70	105.87	111.85
90–94	132.64	149.97	145.87	143.47	144.79
95+	110.88	132.25	128.09	124.53	120.74
Crude rate 60+	**24.27**	**23.32**	**22.74**	**22.70**	**23.61**
Age-standardised rate 60+[(b)]	**25.53**	**24.17**	**23.18**	**22.89**	**23.61**

(a) ICD-10-AM diagnosis codes F00, F01, F02, F03, F051 and G30.

(b) Direct standardisation using the standard Australian population at 30 June 2001.

Note: Age–sex-specific rates are based on ABS population estimates for 31 December of each year.

Source: AIHW analysis of the National Hospital Morbidity Database, Table 7.31 and ABS 2003.

Overall, patients with either a principal or additional diagnosis of dementia accounted for a total of 1,386,784 patient days—or 6.9% of all patient days—in 2003–04.

There were 11,277 separations for patients with dementia as either the principal or additional diagnosis who were admitted and separated from hospital on the same day in 2003–04. When same-day separations are excluded, patients admitted to hospital with any diagnosis of dementia stayed in hospital for an average of 20 days per separation, approximately 10 days less than the average for patients with a principal diagnosis of dementia (Table 7.30). Median length of stay calculated from separations for patients with a principal or additional diagnosis of dementia was 10 days; 75% of separations for patients with a diagnosis of dementia (either principal or additional) were for periods of 20 days or less. Patient stays were 51 days or more for 5% of separations of patients with a diagnosis of dementia.

Taking into account all separations, including same-day separations, there were 4.1 hospital separations per 1,000 persons in the Australian population in 2003–04 for patients where dementia occasioned admission to hospital or contributed to the cost of treatment (any diagnosis), with an average of 20 patient days per episode.

Table 7.33 shows the length of stay associated with a principal diagnosis of dementia in 2003–04. There were 1.4 million patient days for people with dementia in 2003–04 with an average length of stay of nearly 17 days per separation. Only a principal diagnosis of *Factors influencing health status and contact with health services* results in a longer length of stay per separation (33.5 days) than a principal diagnosis of dementia (26.4 days) for separations with a diagnosis of dementia. This will be due in part to dementia patients waiting to be transferred to appropriate long-term accommodation like a residential aged care facility.

Projected number of hospital separations with dementia in the year 2031

Projected numbers of such separations in 2031 were calculated using age-specific rates of separation with a principal diagnosis or additional diagnosis of dementia recorded in 2003–04 and ABS population projections by sex and five-year age groups to 85 years or over. Based on 10,734 hospital separations with a principal diagnosis of dementia in 2003–04, there will be around 30,400 such separations in 2031 assuming that age-specific rates of hospital use for the management of dementia remain the same. Whereas in 2003–04 there were 81,714 hospital separations for people with a principal or additional diagnosis of dementia, it is projected that there will be 238,700 such separations in 2031 due to population ageing. These results point to a quadrupling of hospital separations for people with dementia over the next 25 years, due solely to population ageing. Numbers of hospital admissions for the medical management of dementia (i.e. where dementia is the principal diagnosis) will increase by a factor of three, also due to population ageing, and assuming that major changes in the medical management of dementia do not occur in the projection period. Greater use of community-based memory clinics in lieu of admitted patient services, for example, would potentially affect numbers of hospital admissions.

Assuming an average length of stay of 26.4 days for separations with a principal diagnosis of dementia, in 2031 there could be as many as 802,600 patient days attributed to patients admitted to hospital for the management of dementia (compared with 289,816 patient days in 2003–04). Counting separations coded with a principal or additional diagnosis of dementia, the projected 238,700 separations in 2031 would equate to around 4,774,000 patient days for admitted patients with dementia (including same-day separations and assuming an average of 20 days per separation); in 2003–04 this figure was 1,386,784 days.

Projected increases in the number of separations and patient days associated with patients with a principal diagnosis of dementia logically reflect rising health system costs for the treatment of dementia in hospitals as the population ages. Projected increases in the number of hospital separations and patient days including principal **or** additional diagnosis of dementia imply two increasing cost components:

- increases in the use of admitted patient services and associated costs for the management of dementia in hospitals
- cost increases due to the fact that many more older people with dementia will be using hospital services in future years for the treatment of other conditions and dementia as a coexistent health condition impacts on patient recovery and provision of care.

Table 7.33: Length of stay, by principal diagnosis (ICD-10-AM chapter) for all separations that included a diagnosis of dementia, 2003–04

ICD-10 chapter	Separations	Patient days	Average length of stay	Lower 95% CI	Upper 95%CI
Certain infectious & parasitic diseases	1,595	17,908	11.23	10.56	11.90
Neoplasms	2,482	30,630	12.34	11.71	12.98
Diseases of the blood & blood-forming organs & certain disorders involving the immune mechanism	821	6,032	7.35	6.55	8.14
Endocrine, nutritional & metabolic diseases	2,335	26,402	11.31	10.73	11.89
Mental & behavioural disorders	2,398	80,437	33.54	16.89	50.19
Dementia & Alzheimer's disease	10,989	289,816	26.37	23.91	28.84
Diseases of the nervous system	2,376	35,128	14.78	13.04	16.52
Diseases of the eye, adnexa, ear & mastoid process	348	1,744	5.01	3.65	6.37
Diseases of the circulatory system	8,953	98,122	10.96	10.65	11.27
Diseases of the respiratory system	7,365	71,909	9.76	9.34	10.18
Diseases of the digestive system	4,556	36,766	8.07	7.78	8.36
Diseases of the skin & subcutaneous tissue	1,539	18,458	11.99	10.52	13.47
Diseases of the musculoskeletal system & connective tissue	2,011	25,270	12.57	11.92	13.21
Diseases of the genitourinary system	4,262	43,475	10.20	9.62	10.78
Pregnancy, childbirth & the puerperium	1	5	5.00	. .	. .
Congenital malformations, deformations & chromosomal abnormalities	14	237	16.93	5.57	28.29
Symptoms, signs & abnormal clinical & laboratory findings, not elsewhere classified	6,170	48,471	7.86	7.56	8.15
Injury, poisoning & certain other consequences of external causes	12,071	135,950	11.26	10.99	11.53
Factors influencing health status & contact with health services	7,886	234,030	29.68	26.80	32.56
Person awaiting admission to adequate facility elsewhere other than residential aged care	209	16,895	80.84	36.49	125.19
Person awaiting admission to residential aged care	4,425	169,099	38.21	35.58	40.85
Total separations	**82,806**	**1,386,784**	**16.75**		

Notes

1. Includes separations where principal diagnosis is in F01, F03 or F051.
2. Excludes separations where the principal diagnosis is in F01, F03 or F051.
3. Excludes separations where the principal diagnosis is in G30 or G31.

8 Expenditure on dementia

Traditionally, expenditure on dementia has been estimated by examining the total health and care costs incurred for people with dementia as their main health condition, regardless of the cost impact of any other health conditions experienced by the individual (e.g. the total hospital costs for a person hospitalised because of dementia or the residential aged care subsidy for a person whose main condition is dementia).

This report presents updated estimates for 2003 using this method (see Table 8.2). However, the report also presents the results of a different approach to estimating expenditure that takes account of the presence of other health conditions. This approach results in estimates of expenditure that can be attributed to the dementia condition and its impact on the cost of care rather than the total care cost of people with dementia as their main condition.

According to the ABS SDAC, older people with dementia have an average of 5.26 health conditions per person (see Chapter 5, Table 5.22), while people with dementia living in permanent residential aged care have an average of 5.1 health conditions per person (Table 8.5). The expenditure estimates presented in this chapter assume that all of a person's health conditions contribute to the cost of their care.

This approach results in only a portion of the expenditure for people whose main health condition is dementia being allocated against dementia. Part of their expenditure is allocated to other comorbid conditions. However, it takes account of expenditure on people who have dementia, but whose main condition is a different health condition. For example, this method measures the cost impact of having dementia for admitted hospital patients who are admitted for another reason. This recognises that, for this patient, dementia is likely to result in higher care needs while in hospital.

In this report, we have referred to the traditional method of calculating expenditure as the 'Main condition cost allocation method'; the alternative approach is referred to as the 'Multiple conditions cost allocation method'. The Multiple conditions cost allocation method has been used to estimate expenditure that can be attributed to dementia for:

- residential aged care, using data from the ABS SDAC which extensively sampled people in residential aged care and collected comprehensive information about residents' comorbid conditions
- hospital services, using data about principal and additional diagnoses recorded for admitted patients.

Expenditure on medical services is only for GP consultations which occurred for the management of dementia. Medical services received by people with dementia which related to the management of other health conditions were excluded. Similarly, expenditure on pharmaceuticals is limited to those prescribed for the treatment and management of dementia.

This chapter also provides an estimate of expenditure on people with dementia using the ACAP and other community care programs. These expenditure estimates have been based on the proportion of program expenditure incurred for program clients with dementia using the Main condition cost allocation method.

8.1 Health and aged care system expenditure on dementia for 2003

Total health and aged care system expenditure for dementia in 2003 is estimated at $1.4 billion (Table 8.1). The majority is in the residential aged care sector where $993 million was attributed to dementia. Admitted patient expenditure of $149.3 million, pharmaceutical expenditure of $72.8 million and out-of-hospital medical service expenditure of nearly $20 million are also attributed to people with dementia. Expenditure for program support from HACC, EACH, Veterans' Home Care, CACP and ACAP is estimated to be $135 million.

Table 8.1: Health and aged care system expenditure for dementia and Alzheimer's disease, 2003

Health and aged care sector	**$ million**
Admitted patient services	149.3
Hospital services for non-admitted patients	unknown
Unreferred (GP) services[(a)]	10.0
Pathology & imaging services[(a)]	4.1
Specialist services[(a)]	5.4
Pharmaceuticals requiring a prescription[(b)]	72.8
Residential aged care	992.8
Community care—2003–04[(c)]	*134.6*
Veterans' Home Care	4.6
HACC	45.9
CACP	67.7
ACAP	11.5
EACH	5.0
Total	**1,369.2**

(a) Expenditure for the out-of-hospital medical services is for the year ending March 2004.

(b) Includes expenditure for all drugs prescribed by GPs for the management of dementia, and antidementia drugs prescribed by specialists. Does not include expenditure for other drugs prescribed by specialists for dementia management. Includes patient contribution to the cost of drugs. Private and under co-payment pharmaceuticals included as well as PBS/RPBS drugs.

(c) Community care includes ACAP, Veterans' Home Care, HACC, CACP and EACH. Expenditure listed here is for 2003–04 financial year.

Comparison of methods used for these estimates and for previous estimates

The Multiple conditions cost allocation method is different from the traditional methodology used to calculate previous expenditure methods:

1. The inclusion of estimates of costs for people with an additional diagnosis of dementia in hospitals, not just the principal diagnosis, has increased the estimate by $68 million to $149 million in 2003.
2. The main change in method occurred for the residential aged care sector where the new method estimates the costs imposed by the dementia itself, rather than the total costs of caring for residents whose designated main condition was dementia. This results in a large reallocation of residential aged care costs between conditions (Table 8.3). Hearing loss and mental health are allocated a greater proportion and dementia, mobility and

stroke a lower proportion. The cost imposed by dementia itself is $1.0 billion compared to the costs of caring for residents whose main problem is dementia of $1.6 billion.

These new methods mean that the estimates for 2003 cannot be compared with estimates published in AIHW (2004f) and AIHW (2005d).

Table 8.2: Comparison of the Multiple conditions cost allocation method with the Main condition allocation method ($ million)

Health and aged care sector	Main condition allocation (old) method	Multiple conditions cost allocation (new) method
Admitted patient—principal diagnosis	81	81
Admitted patient—additional diagnosis	Not estimated	68
Total cost of care for people with dementia ***as the main condition*** *in residential aged care (old method)*	1,598	. .
Residential aged care—costs of care due to dementia for all residents with dementia (new method)	. .	993
Other sectors[(a)]	227	227
Total	**1,906**	**1,369**

(a) Other sectors includes: unreferred services, pathology, imaging, specialist, pharmaceuticals and community care services. Methods used to estimate expenditure in these sectors have not changed.

Under the Multiple conditions cost allocation method, the $1,598 million in expenditure for people with a main condition of dementia is attributed to each disease group: $726 million is allocated to dementia and $872 million is allocated to the seven other disease groups.

This new method of estimating costs in residential aged care results in different allocation between the different conditions (Table 8.3). The share of total expenditure decreases for dementia and Alzheimer's disease ($605 million), cardiovascular disease (stroke and other diseases) ($134 million), diseases causing problems with mobility ($100 million) and Parkinson's disease ($70 million), and increases for hearing loss ($274 million), mental conditions ($80 million) and other conditions ($554 million).

Table 8.3: Comparison of residential aged care expenditure allocation using the multiple conditions and main condition methods

	Expenditure ($m)			Proportions of total residential aged care expenditure	
Condition groups	Main condition method (old)	Multiple conditions method (new)	Difference between Main condition method & Multiple conditions method	Main condition method (old)	Multiple conditions method (new)
Dementia & Alzheimer's disease	1,598	993	605	38%	24%
Stroke	445	335	110	11%	8%
Mobility	752	652	100	18%	16%
Mental	380	460	–80	9%	11%
Other cardiovascular disease	200	176	24	5%	4%
Hearing loss	28	303	–274	1%	7%
Parkinson's disease	156	87	70	4%	2%
Other conditions	612	1,166	–554	15%	28%
Total	**4,171**	**4,171**	**0**	**100%**	**100%**

8.2 Residential aged care services

Government funding in the form of the residential care subsidy is paid to approved providers for providing residential care for residential aged care services. It comprises a basic subsidy plus supplements for special needs and less any reduction specific to the resident's circumstances (DoHA 2005c:Chapter 6). The residential care subsidy is paid according to the level of care needed and in 2003 ranged from $41,038 (RCS 1) to $8,773 (RCS 7). There is no funding for RCS 8 residents.

There were 139,051 permanent residents of residential aged care facilities at 30 June 2003. Basic funding for permanent residents in the calendar year 2003 was $4.2 billion. Additionally, supplements totalling $600 million[12] were paid in 2003. Reductions for income-tested fees for 2003 totalled $210 million. The supplements include concessional supplements, charge exempt supplement, oxygen and enteral supplement, pensioner supplement and conditional adjustments.

This analysis uses questions related to need for assistance from the SDAC to rank SDAC respondents according to their need for assistance in areas similar to those used in assessing a residential aged care residents classification (see also Chapter 7, Box 7.5). This ranked list is divided proportionally according to the actual RCS distribution to model the RCS categories. These modelled RCS categories are used throughout the analysis.

According to the SDAC, those 139,000 permanent residents had 753,081 long-term conditions. The number of conditions per person ranged from 8.4 in Residential Classification Scale 1 (RCS 1) to 3 conditions per permanent resident in RCS 7 (Table 8.4).

Table 8.4: Number of conditions in residential aged care, by modelled RCS level, RCS 1–RCS 8, 2003

		Number of conditions			
Modelled RCS classification	Permanent residents	Residents with dementia	Number of other conditions	All conditions	Conditions per person
RCS 1	28,470	20,535	217,447	237,982	8.4
RCS 2	34,213	20,603	176,760	197,363	5.8
RCS 3	20,255	12,051	86,468	98,519	4.9
RCS 4	6,558	3,049	28,914	31,963	4.9
RCS 5	15,474	5,872	63,953	69,825	4.5
RCS 6	14,969	3,718	54,042	57,760	3.9
RCS 7	17,698	1,646	51,582	53,228	3.0
RCS 8	1,414	177	6,263	6,440	4.6
Total RCS 1–8	**139,051**	**67,650**	**685,430**	**753,081**	**5.4**

It is estimated from the SDAC that there were 67,650 people with dementia living in residential aged care and, of these, 45,425 had dementia recorded as the main problem. These 67,650 residents with dementia made up 45% of people in residential aged care, and for 30% out of this 45% (two-thirds) dementia was the main problem for which assistance was needed. Although the SDAC may somewhat underestimate the number with dementia,

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[12] Calculated assuming that subsidy paid in June 2003 for the permanent resident population at 30 June 2003 was the average for the whole year (i.e. $50 million in subsidies paid in June 2003 extrapolated across 12 months).

particularly those with mild dementia, this will not markedly affect the cost estimates, as the costs of care for those with milder dementia are unlikely to be significant.

Table 8.5: Number of conditions for permanent residents for whom the main condition is dementia or Alzheimer's disease, by modelled RCS level, 2003

Modelled RCS classification	Permanent residents with dementia as main condition	Number of additional conditions	Total number of conditions when main condition is dementia	Conditions per person
RCS 1	12,948	82,866	95,839	7.4
RCS 2	13,693	58,679	72,372	5.3
RCS 3	8,212	21,967	30,180	3.7
RCS 4	2,209	5,339	7,548	3.4
RCS 5	4,415	10,879	15,294	3.5
RCS 6	2,603	5,365	7,968	3.1
RCS 7	1,166	1,645	2,812	2.4
RCS 8	177	190	368	2.1
Total RCS 1–8	**45,425**	**186,929**	**232,379**	**5.1**

Previous methods have estimated the cost of dementia as the total costs of care for residents with dementia as the main problem. This would only be a correct estimation method if dementia was the only condition that caused a need for assistance. Table 8.5 shows, that, for a person with dementia as the main condition for which assistance is required, the average number of conditions for which assistance is needed is 5.1. So a person with dementia will typically need assistance in a wide range of areas, and only some of that need for assistance will be due to dementia-induced problems. They may need assistance with mobility due to a stroke they have experienced. They may need assistance in communication both because of hearing loss and dementia. In the method developed for this project, only the assistance for problems due to the dementia is counted.

While dementia is often considered to be a so-called 'tipping condition'—that is, the condition that causes the movement from home care to residential care—data identifying the 'tipping condition' for residents are not available. Similarly, data are unavailable about the relative severity of a resident's comorbid conditions. In this analysis there is no assumption made about the reason a person is in residential aged care, and the problem recorded as the main problem is treated no differently than any of the other conditions listed.

Health conditions[13] 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 is grouped with hip damage from injury in the group 'Conditions affecting mobility'. The eight groups are listed in Table 8.6 (and Table A8.1 for a list of conditions). 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 (i.e. the disease group is an on/off variable and does not count more than once the multiple conditions within each group).

A regression model was established using all possible combinations of the eight condition groups. The dependent variable was the RCS score with more than 200 independent

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[13] High cholesterol and hypertension have been left out of this analysis since they do not add significantly to the need for care.

variables being the combinations of conditions. The model has 207 degrees of freedom, an F value of 13.36 (Pr > F = 0.0001) and an adjusted R^2 of 0.39.

From this model a predicted RCS score is generated for each combination of the condition-groups which provides an average RCS score and hence level of funding for each set of conditions within the model.

Comparisons could then be made between sets of conditions with dementia and the same set of conditions without dementia and the impact of the dementia on that set of conditions in terms of change in RCS score and associated level of funding ascertained. For example, the result for a resident with dementia, stroke and mobility problems is compared with the result for a resident with just stroke and mobility. The level of funding needed to care for the problems brought about by dementia is the difference between the level of funding for the group of conditions without dementia and the level of funding for the group of conditions plus dementia. Using this method, a cost of dementia is allocated to each person in the SDAC according to the conditions listed for that person.

Table 8.6: Condition groups for medical conditions from the SDAC

Condition group	ABS codes
CG1. Dementia & Alzheimer's disease	511, 605
CG2. Stroke	923
CG3. Conditions affecting mobility	1301, 1303, 1306, 1307, 1399, 1802, 1804, 707, 612, 607, 1904
CG4. Mental health	500, 512, 513, 521, 522, 599
CG5. Other cardiovascular disease	910, 913, 914, 919, 929, 508
CG6. Hearing loss	803, 804, 810, 811, 899
CG7. Parkinson's disease	604
CG8. Other conditions[(a)]	All codes not mentioned above excluding 404 & 922

(a) High cholesterol (404) and hypertension (922) have been excluded from this analysis because they do not add significantly to the need for care.

From this analysis, dementia is the most expensive condition group ($993 million), followed by mobility ($652 million) and mental health conditions ($460 million) (Table 8.7).

Table 8.7: The amount of basic funding, by condition groups and modelled RCS classification ($ million)

	Modelled residential classification scale classification							
Condition group	RCS 1	RCS 2	RCS 3	RCS 4	RCS 5	RCS 6	RCS 7	Total
CG1. Dementia	329	331	190	43	65	29	8	993
CG3. Mobility	215	193	107	31	51	35	19	652
CG4. Mental	164	147	65	21	32	20	11	460
CG2. Stroke	112	115	53	16	19	12	6	335
CG6. Hearing	106	98	52	9	20	10	7	303
CG5. Other cardiovascular disease	64	56	28	7	14	5	2	176
CG7. Parkinson's disease	26	32	18	3	3	3	1	87
CG8. Other conditions	377	366	178	54	94	64	34	1,166
Total	**1,393**	**1,339**	**691**	**183**	**299**	**178**	**88**	**4,171**

Funding for care of the 45,425 people in aged care facilities with dementia where dementia is recorded as the main problem is $1.6 billion (Table 8.8). This is more than twice the $681 million in funding for people whose dementia is **not** their main condition. The proportion of this $1.6 billion in funding that is estimated to be due to dementia is nearly 45% ($726 million) with the remaining $872 million allocated to the other 187,000 conditions (Table 8.5). The distribution across all conditions is shown in Figure 8.1. The number of conditions recorded for people whose main condition is dementia, 5.1 conditions per person, is lower than for all permanent residents (5.4). The number of conditions per person with the main condition being dementia ranges from 7.4 in RCS 1 to 2.1 in RCS 8 (Table 8.5).

Table 8.8: Expenditure for dementia in residential aged care where dementia is recorded as the main problem

Modelled RCS classification	Residents with dementia as their main condition	Proportion of residents where main condition is dementia	Funding for people with dementia as main condition ($ million)	Expenditure for dementia when dementia is the main condition ($ million)	Expenditure for other conditions when dementia is the main condition ($ million)
RCS 1	12,948	0.45	601	234	367
RCS 2	13,693	0.40	556	236	320
RCS 3	8,212	0.41	247	141	105
RCS 4	2,209	0.34	58	34	24
Total high care	*37,063*	*0.41*	*1,461*	*645*	*816*
RCS 5	4,415	0.29	95	54	40
RCS 6	2,603	0.17	34	21	13
RCS 7	1,166	0.07	8	6	2
RCS 8	177	0.13	0	0	0
Total RCS 1–8	**45,425**	**0.33**	**1,598**	**726**	**872**

Figure 8.1 shows that whether dementia is the main or an additional condition does not impact greatly on the distribution, across condition groups, of expenditure for people with dementia in residential aged care. For residents with dementia, dementia has the greatest allocation of expenditure—45% if dementia is the main condition and 40% if dementia is **not** the main condition. Stroke, Parkinson's disease and 'other conditions' show a small increase in the proportion of expenditure allocated when dementia is **not** the main condition.

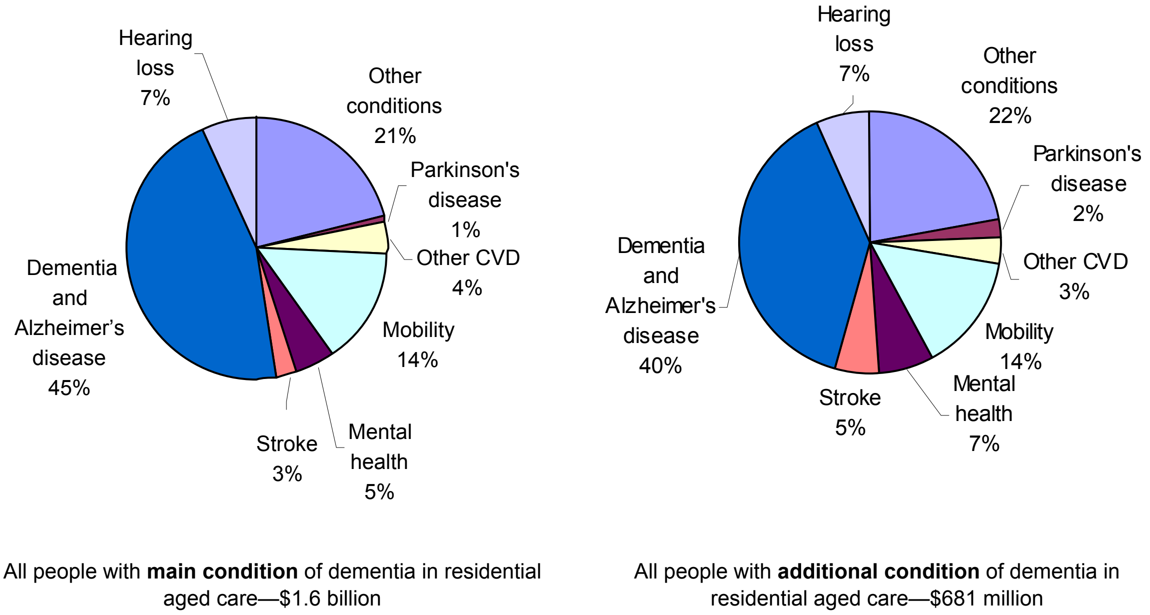

Figure 8.1: Distribution of expenditure, by condition groups according to main condition for people with dementia in residential aged care

If all residents with dementia are considered, not just those whose main problem is dementia, the funding for care due to dementia is just under $1 billion, with $3.2 billion being for care due to other conditions (Table 8.9).

Table 8.9: Funding for care due to dementia and other conditions in residential aged care where dementia is recorded as a problem, 2003

Modelled RCS classification	Permanent residents	Permanent residents with dementia	Proportion of residents who have dementia	Funding for care due to dementia ($ million)	Funding for care due to other conditions ($ million)
RCS 1	28,470	20,535	0.72	329	1,064
RCS 2	34,213	20,603	0.60	331	1,008
RCS 3	20,255	12,051	0.59	190	502
RCS 4	6,558	3,049	0.46	43	140
Total high care	*89,496*	*56,237*	*0.63*	*892*	*2,715*
RCS 5	15,474	5,872	0.38	65	234
RCS 6	14,969	3,718	0.25	29	149
RCS 7	17,698	1,646	0.09	8	80
RCS 8	1,414	177	0.13	0	0
Total RCS 1–8	**139,051**	**67,650**	**0.49**	**993**	**3,178**

Residents’ contributions to residential aged care

The costs of residential aged care services are mostly funded by governments, with some funding from residents’ contributions.

Government funds are allocated to aged care homes to cover the full costs of care that residents require in 20 areas of need—areas of toileting, personal hygiene, mobility, assistance with eating and drinking, nursing procedures, and so on. The residents' contributions cover the remaining costs which are the normal costs of living—such as food, board and cleaning. It is assumed that the normal costs of living are not due to any health conditions or problem. Therefore these costs are not allocated by health condition.

Thus the only costs allocated by health condition are those costs funded by government subsidy.

In 2003–04 residential aged care subsidies were $5,336.0 billion, basic daily care resident contributions were $1,411.8 million and income-tested resident contributions were $119.2 million (AIHW 2005b:188). Supplements for people in residential aged care in 2003 were approximately $50 million per month or $600 million per year.

Funding for dementia and Alzheimer's disease in residential aged care in 2003 was $993 million (Table 8.10): 78% of this funding was for females and 59% was for people aged 85 and over. Over 90% of funding for dementia and Alzheimer's disease was in high level residential aged care, with RCS 2 (33.3%) and RCS 1 (33.1%) allocated the greatest proportion of the overall funding.

Table 8.10: Funding allocated to dementia and Alzheimer's disease in residential aged care facilities, by age and sex, 2003 ($ million)

	High level residential aged care ($ million)				Total high level residential aged care	Total residential aged care
Sex/age	**RCS 1**	**RCS 2**	**RCS 3**	**RCS 4**	**RCS 1–4**	**RCS 1–7**
Males						
45–49	0.3	0.0	0.0	0.0	0.3	0.3
50–54	0.0	0.0	0.0	0.0	0.0	0.0
55–59	0.3	0.7	0.6	0.0	1.6	1.6
60–64	1.9	0.3	0.5	0.0	2.8	2.9
65–69	1.3	1.2	0.8	0.7	4.0	5.1
70–74	6.8	4.4	2.6	0.0	13.8	16.8
75–79	9.5	8.1	7.0	1.9	26.6	30.3
80–84	21.5	14.9	12.5	2.5	51.3	55.9
85+	43.8	27.3	16.6	3.9	91.6	100.8
Total	*85.3*	*57.1*	*40.6*	*9.0*	*192.0*	*213.7*
Females						
45–49	0.0	0.0	0.0	0.0	0.0	0.1
50–54	1.2	0.0	0.6	0.0	1.8	2.1
55–59	0.3	0.8	1.4	0.0	2.5	3.1
60–64	1.1	0.6	0.1	0.0	1.8	2.2
65–69	1.9	2.8	2.2	0.0	6.8	9.4
70–74	5.7	9.8	5.0	0.0	20.6	25.4
75–79	19.5	23.3	15.3	4.9	63.0	72.2
80–84	50.4	62.2	37.8	12.0	162.5	182.8
85+	163.2	174.1	86.8	16.7	440.9	481.9
Total	*243.3*	*273.6*	*149.2*	*33.6*	*699.8*	*779.1*
Persons						
45–49	0.3	0.0	0.0	0.0	0.3	0.5
50–54	1.2	0.0	0.6	0.0	1.8	2.1
55–59	0.6	1.5	2.0	0.0	4.1	4.8
60–64	3.0	0.9	0.6	0.0	4.6	5.1
65–69	3.2	4.0	3.0	0.7	10.9	14.5
70–74	12.5	14.3	7.5	0.0	34.3	42.2
75–79	28.9	31.5	22.4	6.8	89.5	102.4
80–84	71.9	77.1	50.3	14.4	213.8	238.6
85+	207.0	201.4	103.4	20.7	532.5	582.7
Total	**328.6**	**330.7**	**189.8**	**42.6**	**891.8**	**992.8**

8.3 Hospital services

There were nearly 83,000 separations from hospital for people with dementia in 2003–04: 11,000 were admitted with a principal diagnosis of dementia at a cost to the health system of $81.6 million. There were 72,000 admissions with an additional diagnosis of dementia where it is estimated that dementia was responsible for $69 million of hospital costs. Therefore the total admitted patient expenditure due to dementia or Alzheimer's disease was $150.5 million.

People with dementia may be admitted to hospitals for their dementia or for another condition. When the main reason for admission to hospital is dementia (principal diagnosis of dementia or Alzheimer's disease), a Diagnosis Related Group code will be allocated to that separation. In this analysis, the public hospital weighted cost per Diagnosis Related Group is applied to any separation where the principal diagnosis is dementia or Alzheimer's disease.

When a patient is admitted and an additional diagnosis of dementia is recorded (principal diagnosis is a condition other than dementia but a diagnosis of dementia is recorded on the record), then it is assumed that the care needed by the patient is affected by the patient having dementia. The analysis of expenditure for care due to dementia in residential aged care has shown that the average amount of funding attributed to people with dementia or Alzheimer's disease in residential aged care is $40.20 per day ($992.8 million divided by 24.7 million bed-days). Since care is more expensive in hospitals, the cost of caring for dementia in aged care has been increased by 50% — that is, a cost of $60.30 has been applied per bed-day in hospital for dementia when dementia is not the principal diagnosis.

Using this method, admitted patient expenditure for people with a principal diagnosis of dementia or Alzheimer's disease was $81.6 million in 2003–04 (Table 8.11). There was a steady increase from $62.9 million in 1999–00. In 2003–04, admitted patient expenditure for females was $44.7 million (55%) and for males $36.9 million (45%); $23.2 million (28%) was for patients aged between 80 and 84 years and $27.5 million (34%) for patients 85 years and over.

The admitted patient expenditure due to dementia or Alzheimer's disease (regardless of principal diagnosis) was $150.5 million in 2003–04 (Table 8.12). This was a steady increase from $130.8 million in 1999–00. In 2003–04, admitted patient expenditure for females was $87.1 million (58%) and $40.6 million (27%) was for patients aged between 80 and 84 years old.

For admitted patients with a principal diagnosis of dementia or Alzheimer's disease the average length of stay was 26 days, the average cost per separation was $7,429 and the average cost per bed-day was $282 (Table 8.13). When a patient with dementia was admitted for a reason other than dementia, the average length of stay was 15 days. With the cost attributed to caring for the dementia estimated at $60.30 per day, the average cost per separation was $921.

Table 8.11: Hospital expenditure due to a principal diagnosis of dementia or Alzheimer's disease during a hospital stay, 1999–00 to 2003–04, ($ million)

Sex/age	1999–00	2000–01	2001–02	2002–03	2003–04	2003[(a)]
Males						
0–59	0.9	1.0	0.9	0.9	0.9	0.9
60–64	0.8	0.9	0.9	1.2	1.1	1.2
65–69	1.7	2.0	2.0	1.9	1.8	1.9
70–74	3.7	4.4	4.3	4.7	3.8	4.3
75–79	6.5	7.9	7.0	7.9	8.5	8.2
80–84	7.2	9.3	9.3	10.2	10.2	10.2
85–89	5.9	7.1	6.5	7.2	7.3	7.3
90–94	1.5	2.3	2.7	2.5	2.7	2.6
95+	0.3	0.4	0.5	0.4	0.7	0.6
Total	*28.5*	*35.4*	*33.9*	*37.0*	*36.9*	*37.0*
Females						
0–59	0.7	0.8	0.8	0.7	1.0	0.9
60–64	0.7	0.8	0.5	0.8	0.8	0.8
65–69	1.2	1.6	1.2	1.2	1.4	1.3
70–74	3.0	3.7	3.9	3.6	3.7	3.7
75–79	6.6	8.3	7.8	7.7	7.9	7.8
80–84	9.0	11.2	10.6	11.8	13.0	12.4
85–89	9.6	10.8	10.3	10.7	10.5	10.6
90–94	3.1	5.1	5.0	5.5	5.1	5.3
95+	0.6	1.1	1.2	1.3	1.2	1.3
Total	*34.4*	*43.3*	*41.2*	*43.4*	*44.7*	*44.1*
Persons[(b)]						
0–59	1.5	1.8	1.7	1.6	1.9	1.8
60–64	1.5	1.6	1.4	2.0	2.0	2.0
65–69	2.9	3.6	3.2	3.2	3.1	3.2
70–74	6.6	8.1	8.1	8.3	7.5	7.9
75–79	13.1	16.2	14.8	15.6	16.3	16.0
80–84	16.2	20.5	19.9	22.1	23.2	22.7
85–89	15.5	17.9	16.8	17.8	17.8	17.8
90–94	4.7	7.4	7.6	8.1	7.8	8.0
95+	0.9	1.5	1.7	1.8	1.9	1.9
Total	**62.9**	**78.6**	**75.2**	**80.4**	**81.6**	**81.0**
Inflation adjusted[(c)]	**72.0**	**87.1**	**80.7**	**83.4**	**81.6**	**82.5**

(a) Estimated expenditure for the 2003 calendar year.

(b) Includes expenditure for admitted patients whose gender is unknown.

(c) Total admitted patient expenditure adjusted to 2003–04 dollars using the hospital/nursing home care deflator (AIHW 2005d).

Source: AIHW analysis of the National Hospital Morbidity Database and the National Public Hospital Establishments Database.

Table 8.12: Hospital expenditure due to any diagnosis of dementia or Alzheimer's disease during a hospital stay, 1999–00 to 2003–04 ($ million)

Sex/age	**1999–00**	**2000–01**	**2001–02**	**2002–03**	**2003–04**	**2003[(a)]**
Males						
0–59	2.3	2.0	1.6	1.8	2.0	1.9
60–64	1.3	1.5	1.4	1.8	1.9	1.9
65–69	3.7	3.1	3.3	3.6	2.9	3.3
70–74	7.0	7.3	7.1	7.0	6.4	6.7
75–79	11.4	13.3	12.0	13.1	13.8	13.5
80–84	13.1	15.3	15.7	16.9	16.9	16.9
85–89	11.2	12.4	12.1	12.4	13.3	12.9
90–94	3.2	4.5	5.1	5.1	5.1	5.1
95+	0.5	0.7	0.9	0.8	1.1	1.0
Total	*53.7*	*60.1*	*59.1*	*62.5*	*63.4*	*63.0*
Females						
0–59	2.4	1.3	1.6	3.0	2.7	2.9
60–64	1.7	1.0	1.0	1.3	1.4	1.4
65–69	2.1	2.6	2.2	2.6	2.3	2.5
70–74	5.6	6.1	6.8	6.1	6.1	6.1
75–79	13.0	14.5	14.2	13.6	14.2	13.9
80–84	18.9	21.4	21.6	22.3	23.7	23.0
85–89	24.0	21.9	21.3	21.5	22.6	22.1
90–94	7.5	11.3	11.5	12.0	11.5	11.8
95+	1.8	3.1	2.8	3.0	2.8	2.9
Total	*77.1*	*83.2*	*82.8*	*85.5*	*87.1*	*86.3*
Persons[(b)]						
0–59	4.7	3.3	3.1	4.8	4.6	4.7
60–64	3.1	2.6	2.3	3.0	3.3	3.2
65–69	5.8	5.6	5.5	6.2	5.2	5.7
70–74	12.6	13.4	13.9	13.1	12.5	12.8
75–79	24.5	27.8	26.1	26.7	28.0	27.4
80–84	32.0	36.7	37.3	39.3	40.6	40.0
85–89	35.2	34.3	33.4	33.9	35.9	34.9
90–94	10.6	15.8	16.6	17.1	16.6	16.9
95+	2.3	3.8	3.7	3.9	3.9	3.9
Total	**130.8**	**143.3**	**141.9**	**148.1**	**150.5**	**149.3**
Inflation adjusted[(c)]	**149.7**	**158.8**	**152.3**	**153.5**	**150.5**	**152.0**

(a) Estimated expenditure for the 2003 calendar year.

(b) Includes expenditure for admitted patients whose gender is unknown.

(c) Total admitted patient expenditure adjusted to 2003–04 dollars using the hospital/nursing home care deflator (AIHW 2005d).

Source: AIHW analysis of the National Hospital Morbidity Database and the National Public Hospital Establishments Database.

Table 8.13: Hospital costs allocated to dementia, by number of separations and bed-days where dementia or Alzheimer's disease is recorded as a diagnosis during a hospital stay, 2003–04

	Principal diagnosis—Dementia and Alzheimer's disease						Additional diagnosis was dementia or Alzheimer's disease but principal diagnosis was not					
Sex/age	Separations	Bed-days	Expenditure ($ million)	Bed-days per separation	Cost per separation	Cost per bed-day ($)	Separations	Bed-days	Expenditure ($ million)	Bed-days per separation	Cost per separation	Cost per bed-day ($)
Males												
0–59	119	15,916	0.9	134	7,663	57	534	16,770	1.0	31	1,894	60
60–64	148	6,067	1.1	41	7,577	185	509	12,668	0.8	25	1,501	60
65–69	232	7,856	1.8	34	7,587	224	1,012	18,004	1.1	18	1,073	60
70–74	510	14,001	3.8	27	7,421	270	2,577	42,048	2.5	16	984	60
75–79	1,135	27,983	8.5	25	7,452	302	5,792	84,740	5.1	15	882	60
80–84	1,367	34,234	10.2	25	7,449	297	7,827	107,222	6.5	14	826	60
85–89	989	24,213	7.3	24	7,373	301	6,585	95,826	5.8	15	877	60
90–94	360	7,094	2.7	20	7,386	375	2,828	38,480	2.3	14	820	60
95+	92	948	0.7	10	7,530	731	534	7,231	0.4	14	817	60
Total	*4,952*	*138,312*	*36.9*	*28*	*7,444*	*267*	*28,198*	*422,989*	*25.5*	*15*	*905*	*60*
Females												
0–59	135	11,056	1.0	82	7,632	93	304	26,058	1.6	86	5,169	60
60–64	108	1,855	0.8	17	7,738	450	392	8,232	0.5	21	1,266	60
65–69	174	6,019	1.4	35	7,929	229	842	14,256	0.9	17	1,021	60
70–74	501	15,368	3.7	31	7,475	244	2,425	36,954	2.2	15	919	60
75–79	1,060	23,877	7.9	23	7,429	330	6,528	100,428	6.1	15	928	60
80–84	1,752	40,680	13.0	23	7,447	321	11,656	169,496	10.2	15	877	60
85–89	1,433	35,749	10.5	25	7,345	294	12,414	191,858	11.6	15	932	60
90–94	707	13,500	5.1	19	7,261	380	7,129	101,158	6.1	14	856	60
95+	162	3,320	1.2	20	7,174	350	1,933	25,489	1.5	13	795	60
Total	*6,032*	*151,424*	*44.7*	*25*	*7,416*	*295*	*43,623*	*673,929*	*40.6*	*15*	*932*	*60*
Total persons	**10,984**	**289,736**	**81.6**	**26**	**7,429**	**282**	**71,822**	**1,097,048**	**66.1**	**15**	**921**	**60**

Source: AIHW analysis of the National Hospital Morbidity Database and the National Public Hospital Establishments Database.

8.4 Medical services

Data from the general practitioners' survey, Bettering the Evaluation of Care and Health (BEACH), were used to allocate private medical services by disease for both GPs and specialists. The BEACH survey collects information about the number of people who have seen their GP about dementia and who are referred to specialists because of their dementia. It is estimated, using this data, that there were 484,500 GP attendances in which dementia was managed and 43,600 out-of-hospital specialist attendances for dementia nationally in 2003–04. Expenditure for out-of-hospital medical services in 2003–04 was estimated as $19.5 million (Table 8.14). Of this expenditure $10 million was for GP services, $5.4 million for specialist services, $2.7 million for pathology and $1.4 million for imaging. Two-thirds of this expenditure was for females and more than three-quarters was for people aged 75 or older.

People with dementia often have other conditions which are also managed by the GP. The expenditure below does not relate to these other conditions but only to attendances where dementia is managed.

Table 8.14: Out-of-hospital medical expenditure for dementia and Alzheimer's disease, 2003–04[(a)] ($ million)

Sex/age	Unreferred attendances	Imaging	Pathology	Other medical	Total out-of-hospital medical expenditure
Males					
0–64	0.2	—	—	0.3	0.5
65–74	0.5	—	—	0.8	1.3
75–84	1.3	0.4	0.3	1.0	2.9
85+	1.0	0.1	0.4	0.4	1.9
Females					
0–64	0.2	0.1	—	0.3	0.5
65–74	0.7	0.1	0.4	0.6	1.8
75–84	3.0	0.5	0.6	0.7	4.8
85+	3.1	0.3	0.9	1.4	5.7
Persons					
0–64	0.4	0.1	—	0.6	1.1
65–74	1.2	0.1	0.4	1.4	3.2
75–84	4.3	0.8	0.9	1.6	7.7
85+	4.0	0.4	1.4	1.8	7.5
Total	**10.0**	**1.4**	**2.7**	**5.4**	**19.5**

— Represents zero or less than $50,000.

(a) Year ending March 2004.

Source: AIHW analysis of BEACH and the AIHW disease expenditure database.

8.5 Pharmaceuticals

There was a steep increase (38%) in the use of dementia-specific drugs between 2002–03 and 2004–05, from $35.4 million to $48.8 million. Donepezil had the lion's share, $32.4 million (67%) in 2004–05, though this share dropped in the three years of analysis from 74% in 2002–03. The proportion of Galantamine increased from 14% in 2002–03 to 26% in 2004–05.

Table 8.15: Benefit paid for dementia-specific drugs on the PBS and RPBS prescribed by GPs and specialists, 2002–03 to 2004–05 ($)

Drug name and item number	2002–03	2003–04	2004–05
Donepezil			
8495	8,253,261	8,655,315	8,807,902
8496	17,819,601	20,750,350	23,666,782
Total	*26,072,862*	*29,405,664*	*32,474,683*
Galantamine			
8536	1,636,474	2,468,560	2,072,519
8537	3,255,450	6,445,656	8,445,330
8756	. .	. .	463,332
8770	. .	. .	400,787
8771	. .	. .	978,870
8772	. .	. .	186,608
Total	*4,891,925*	*8,914,216*	*12,547,446*
Rivastigmine			
8497	1,057,656	857,891	714,121
8498	1,558,096	1,440,867	1,367,177
8499	736,892	653,861	630,152
8500	974,826	927,167	891,039
8563	93,725	82,537	129,551
Total	*4,421,195*	*3,962,322*	*3,732,040*
Total	**35,385,982**	**42,282,203**	**48,754,169**

Note: Galantamine item numbers 8756, 8770, 8771 and 8772 were not available on the PBS in 2002–03 and 2003–04.

Source: Department of Health and Ageing unpublished.

Of the $42.3 million for prescribed antidementia drugs in 2003–04 (Table 8.15), $27.7 million (65%) were prescribed by a GP (Table 8.16). The remaining 35% were prescribed by specialists. Other GP-prescribed prescriptions for dementia such as antipsychotics and antidepressants accounted for a government benefit paid of $10.8 million. Antidementia drugs ($27.7 million) and antipsychotics ($8.6 million) contributed 95% of the total benefit paid for GP-prescribed drugs for dementia patients.

Table 8.16: PBS/RPBS benefit paid for drugs prescribed to manage dementia by GPs[(a)], 2003–04

ATC[(b)] group	ATC[(b)] group name	Benefit paid[(c)] ($)
N06D	Antidementia drugs	27,671,015
N05A	Antipsychotics	8,618,623
N05B	Anxiolytics	29,497
N06A	Antidepressants	713,503
N05C	Sedatives & hypnotics	9,205
N02B	Other analgesics & antipyretics	25,057
	Other GP-prescribed drugs	1,289,769
Total benefit paid		**38,356,668**

(a) Prescriptions written by specialists are not included in this analysis.

(b) Anatomical Therapeutic Chemical classification system.

(c) Benefit paid for antidementia drugs is based on PBS data (number of scripts and cost per script). The benefit paid for all other drug groups listed is derived from BEACH (number of scripts) and PBS data (cost per ATC drug group).

Source: AIHW analysis of BEACH and PBS data.

8.6 Community care services

The data on the cost of dementia for community care programs are inadequate or non-existent. However, using a number of broad assumptions an indication of the costs involved can be obtained.

Home and Community Care

In an analysis of 14,000 community care clients over 60 years of age, Silver Cross WA reported about 3% had a diagnosis of dementia, 5% showed functional pointers of cognitive loss and another 2% had 'behaviour problems/memory loss/confusion' recorded on the notes (personal communication 17 November 2005). An estimate of 5% (3% with diagnosis and half of those with cognitive loss) is applied to the total HACC funding to provide an estimate for HACC funding for people with dementia.

Of the total HACC funding for 2003–04 ($917.1 million), the amount allocated to dementia is $45.9 million.

Aged Care Assessment Program

Around 23.7% of ACAP clients have a primary diagnosis of dementia. Using this proportion to estimate the cost of dementia to assessment for aged care services, around $11.5 million (0.237 × $48.4 million) of funding for the ACAP in 2003–04 can be attributed to dementia.

CACP and EACH programs

While the CACP and EACH 2002 censuses collected information on dementia status, they did not collect unit level costs for particular services, nor did they record the cost of providing a package to a particular client. Consequently, the cost of dementia to these programs must also be estimated. However, data on the amount of particular services provided to clients were collected. Using these it is possible to get an indication of the cost of dementia to these programs.

From census data, it is estimated that 18% of CACP clients had dementia and that these people received 22% of the total hours of service provided under Community Aged Care Packages. For EACH, clients with dementia accounted for 32% of both clients and hours of service provided. Using the percentage of hours of service used by people with dementia to estimate the cost of dementia to the two programs, the cost of dementia to government in 2003–04 was approximately $5.0 million for EACH and $67.7 million for CACP. While these estimates take into account the different total hours of service provided to people with and without dementia, they do not allow for differential mix of service types by people with and without the disorder, nor are costs to users included. They also assume that dementia is the reason why services are required.

8.7 Projected expenditure

Expenditure is projected to 2030–31. Total expenditure due to dementia is projected to grow by 225% between 2003 and 2030–31. This growth is due to the ageing of the population and the total growth of the Australian population in this period. It assumes no growth in the age-specific rate of dementia, and no change in the intensity with which dementia is treated.

Table 8.17: Projected expenditure for dementia, 2003 to 2030–31 ($ million)

	Admitted patient	All out-of-hospital medical	Pharmaceutical prescriptions	Residential aged care	Other care	Total health expenditure
2003	149	20	73	993	135	1,369
2005–06	159	21	77	1,058	143	1,458
2010–11	193	25	94	1,317	174	1,804
2015–16	238	31	116	1,625	214	2,224
2020–21	292	38	142	1,973	263	2,708
2025–26	373	48	179	2,524	337	3,461
2030–31	473	61	226	3,267	427	4,454

9 Strengths and limitations of dementia data

9.1 Introduction

All governments in Australia increasingly recognise the importance of responding to the growing prevalence and impact of dementia with coordinated and well-targeted initiatives. Effective policy and program responses to the needs of people with dementia and their carers require a solid evidence base to inform their development and evaluation. A number of initiatives funded in the 2005 Federal Budget will make important contributions to building this evidence base, including the Dementia Research Mapping project, the Dementia website, the Dementia Collaborative Research Centres and the Dementia Research Grants.

Consistent and comprehensive data about dementia are a basic building block for research, policy development and planning, program monitoring and evaluation, and developing, testing and implementing improvements in the delivery of treatment and care. When considering what kind of information and data would constitute an evidence base for policy research, three questions arise:

- What use will be made of the information and the data?
- Who will use the information and data?
- What questions are important to each end user of the data?

A fundamental requirement is that the data should help to measure the need for services, treatment and care.

This chapter summarises the limitations and strengths of the data analysed in earlier chapters in this report. Its focus is on population, service use and epidemiological data.

The remaining chapters of this report then examine dementia-relevant data elements in existing population and health and aged care service data collections for their consistency and comparability with each other. Chapter 12 recommends data elements for further development that would be designed to increase the comprehensiveness and consistency of information collected about dementia, including in terms of case identification.

9.2 Limitations of existing data

Identifying people with dementia

Chapter 3 describes existing collections and the information they include about dementia. People with dementia are not identified at all in a number of relevant collections. In particular, data from the HACC, EACH, CACP and residential aged care programs do not include any identifier for dementia. This will improve in future with the development and implementation of the ACFI in residential aged care and with the implementation of EACH

Dementia places. In addition, HACC MDSv2 will collect some information about memory problems, confusion and behavioural problems. It is important that consistency of data collected and reported about dementia is achieved as these developments occur.

In those collections where dementia is identified, it is not identified in a consistent way. This is discussed in more detail in Chapter 11 and has been apparent in data reporting in earlier chapters of this report. Dementia identification may be constrained by the data collection context—for example, as a long-term health condition lasting six months or more which restricts everyday activity (SDAC); a health condition that impacts on the client's need for assistance (ACAP); a diagnosed health condition that is either chiefly responsible for a hospital episode, or coexistent with such a condition (hospital morbidity data).

Dementia is sometimes identified as a result of self-report or proxy-report (SDAC), sometimes on the basis of specialist diagnosis which usually includes scores on assessment tests (PBS). Some collections directly query whether a diagnosis of dementia is present (NRCP, CACP/EACH census), while others do not seek this level of confirmation (SDAC).

It is, however, important to note that there are real difficulties in collecting data on dementia. There may never be consistent and high quality data on early-stage dementia as long as problems are manageable, diagnosis delayed, treatment approaches are few and stigma remains. Further difficulties in identifying people with dementia, particularly at very old ages, arise because symptoms of co-existing health conditions mask those of dementia.

These difficulties will always affect data collected by self- or proxy-report in surveys such as the SDAC. Even in the cared accommodation component, there may be impediments to obtaining a diagnosis of dementia—is there value in doing so if it is possibly the outcome of another disease process, or if the person is too unwell to take appropriate medications? However, the introduction of the ACFI in residential aged care may lead to improved identification in that sector, with resulting improvements in the cared accommodation component of the SDAC.

The diagnosis of dementia, its definition and classification are still subject to considerable development and evolution. There is a significant amount of research being undertaken which throws new light on, or raises new questions about, previously accepted understanding in this area. Definitions and classifications are basic tools which underpin the development and collection of consistent data across collections and over time. While these tools continue to be subject to a high degree of change and/or reflect current difficulties of diagnosing dementia, data collected will be necessarily less comprehensive, consistent and/or authoritative than would be the case otherwise.

Non-reporting of collected data

In considering the comprehensiveness of information, there would appear to be potential to increase this on the basis of already collected information. In obtaining and analysing data for this report, the AIHW became aware of potentially useful information gathered in some programs which is not reported as part of the minimum data set. The most obvious instance of this were the questions about symptoms of cognitive impairment, which are included on the Aged Care Client Record completed by ACATs but not required to be reported as part of the national minimum data set (e.g. ACAP).

The NHS does not code Alzheimer's disease or other dementias to a separate diagnostic category. Currently it is collapsed into the category of *Organic mental health problems* or *Symptoms and signs involving cognition, perceptions, emotional state and behaviour* under *Mental* *health and behavioural problems*. The value of the information collected for the purposes of identifying people with dementia is therefore lost.

Non-collection of some data that are relevant

In addition, this project found that the data that are reported and available for analysis are sometimes inconsistent with what appears to be available from data dictionaries (e.g. the Dementia Education and Support Program data). This creates the impression that more or different data are available than is in fact the case.

This problem is not just one of non-reporting of collected information, but of non-collection at all. Non-collection may reflect the practicalities and relevance of some of these data items, and may signal the need to review their inclusion in data collections and dictionaries. In other cases, it may indicate a need to improve training of data collectors to ensure that relevant information is obtained.

Little national longitudinal or linked data

The analysis possible for this report has been based on a service contact perspective and on cross-sectional population data. As Chapter 3 discussed, Australia has a number of relatively small longitudinal surveys which identify people with dementia. The Australian Longitudinal Survey of Women's Health will gradually collect more national level data about older women with dementia. Longitudinal data or linked data facilitates a person-centred analysis of change over time, an important consideration with a progressive condition such as dementia.

A person-centred view with the potential to track individuals over time permits consideration of issues such as progression of the condition, effectiveness of treatment and interventions, changes in symptoms such as behaviour, changes in carer circumstances, continuity and coordination of care and service provision.

There should be serious consideration and support given to linking existing databases to facilitate such analysis. Linking ACAP, residential aged care, pharmaceutical and hospital data would enormously strengthen Australia's capacity to report on the incidence and prevalence of dementia. Linked data also have the potential to address a range of issues which are relevant to service providers and consumers as well as policy analysts. For example, by linking ACAP, residential aged care, PBS and MBS data, it would be possible to explore issues such as the use of medical services by people with dementia in residential aged care and assess whether residents are being given sufficient and appropriate medical care.

Study design issues

There are a number of characteristics of current collection methodologies which contribute to the limitations of data about dementia.

Sample size in national ABS surveys is relatively small for the purpose of identifying people with conditions with low prevalence in the general population. Oversampling of older people living in households would improve the reliability of the estimates available from this source, since dementia is much more highly prevalent at these older ages.

While the SDAC cared accommodation component represents one of the areas of strength in Australian data, it is nevertheless relatively thin in terms of data about the sociodemographic characteristics of residents.

The **reliance on self-report or proxy-reporting** is particularly problematic for any condition where the individual's cognitive functioning is impaired, where the diagnosis process can be prolonged and uncertain and where stigma may result in a reluctance to identify. It contributes to the underestimate of mild and moderate dementia in the household population through the SDAC.

Limited data about carers

As Chapter 6 noted, the majority of data about carers are from small-scale local studies based on samples of carers who have come into contact with a service. The SDAC provides adequate data about the population of carers overall, but sample sizes severely restrict the rigour and quality of the data about carers of people with dementia. In particular, there is little data about back-up or secondary carers, which results in an inadequate understanding of the complete network of care and of some of the supportive informal arrangements that contribute to an individual caregiver's capacity to cope with their caring role.

In the course of this project, there have been questions raised about the extent to which the report should focus on carers, since issues affecting them are not necessarily dementia-specific. There have been a couple of small-scale comparative studies undertaken which compare the experience of carers of people with dementia with the experience of other carers. There is an important issue to explore further, as these studies suggest there may be some areas in which carers of people with dementia have different experiences and may need different types of support. This kind of research may require a purpose-designed study which links existing administrative data and obtains additional qualitative information from carers.

9.3 Strengths of data

While a number of limitations of existing dementia data have been documented in this report, Australian data do exhibit some strengths, which provide a solid basis for further developments. There is a strong commitment to collecting good data in Australia, and well-developed infrastructure for developing and implementing data standards.

Compared with many other countries, Australia has **a considerable amount of relevant data**, as evidenced by the analysis provided in earlier chapters. In respect of health service use, data from the NHMD, the BEACH survey and the PBS together contribute to a reasonably comprehensive profile of dementia patients.

In addition, a number of Australian collections identify cases of dementia through a **formal diagnosis or assessment** which is more robust than the self-report methodology. The PBS may require MMSE scores, and the trial ACFI also collects data about assessment scores.

As mentioned above, the SDAC includes people living in **cared accommodation.** This survey component is particularly important when examining conditions which are most prevalent at older ages and which frequently result in entry to residential aged care. When used in conjunction with the administrative residential aged care data, it is possible to compare characteristics and dependency of residents with dementia with those of residents without dementia. The development of the **ACFI** will considerably improve the data available about dementia in residential aged care.

9.4 Future directions

Four major strategies would contribute to the improvement of data about dementia in Australia on the basis of the analysis undertaken in this report:

- First, **better and earlier diagnosis** of people with dementia.
- Second, **improved consistency of identification** of people with dementia in all data collections. This issue is discussed further in later chapters of this report.
- Third, agreement about the **extent of information to be collected**, taking account of the purpose and context of data collection activity. This issue is also explored further in later chapters.
- Finally, a change in focus from services-focused data to person-focused data through **data linkage** (subject to appropriate ethical and privacy considerations), and development and analysis of **longitudinal data**. Pursuing this strategy would provide data useful to the full range of stakeholders, (consumers and service providers, as well as policy analysts and service planners). It would facilitate analysis of health and care pathways of individuals, of interactions between the health and care systems and of the impact on outcomes of health and care services. Data linkage would, over time, also provide further impetus to improve the consistency with which dementia is identified in various datasets.

Section 3: Dementia data development

10 Developing dementia data standards

10.1 Purpose

This section of the report aims to provide a guide for improving national dementia data in ways that will inform future policy and planning by improving its consistency and comprehensiveness.

This chapter discusses principles and requirements of data development which adhere to recognised data standards. It examines the constraints affecting the collection of data in terms of the context and possible collections methods, including the issue of who provides information, which is of particular relevance for dementia data.

An earlier chapter in the report (Chapter 3) reviewed the scope, purpose and collection context of a number of national data collections, and identified the amount and nature of dementia-relevant data elements included in each collection. Issues associated with existing dementia data were further revealed in the data analysis that comprised section 2 of this report and which were summarised in Chapter 9. Chapter 11 reviews and compares dementia data elements across a selection of relevant data sources in more detail.

Chapter 12 identifies three levels of data elements that would be suitable for inclusion in a range of data collections. The purpose of this report is not to define or prescribe a definitive set of data elements for collection about dementia but to outline key themes and options for potential data elements useable in a wide range of collections. If these data elements are used as a standard 'menu', and if context and purpose are taken into account, this will promote greater consistency and comparability across the field, and improved data quality in many collections.

10.2 Principles of data development

The following policy, planning, provision and performance considerations should guide the development of dementia data elements:

1. Policy considerations: the data elements should reflect and be consistent with policy issues with relation to dementia.
2. Planning considerations: the data elements should also support decisions about the allocation of resources and funding. When fully developed, they should include clear and concise statements about who should deliver what, to whom and where.
3. Provision: data elements should also describe the provision of services that has occurred. These should relate to both policy and planning.
4. Performance: data elements should allow analysis of how well the planning and delivery achieved the policy outcomes. This information should be able to inform policy, evaluation and research.

In determining the type and 'minimum' level of information required to meet reporting requirements about dementia the following principles were considered. These principles guide decisions about whether a data element is recommended for collection and provide a basis for assessing the suitability of elements selected. These principles should also guide the further development of dementia data:

- *Consistency of data specifications with relevant and available national and international standards*

  This is important in order to avoid duplication of effort and the development of conflicting standards. Data sets that are based on a single set of agreed definitions and standards are more likely to have a high degree of consistency with each other and reduce data development time and cost. The quality of data, including its consistency and comparability, is enhanced when the proper standards are available for that data. The cost of not creating data standards may be high and can include loss of information with staff changes, data redundancy, data conflicts, liability, misapplications, and decisions based upon poorly documented data.

- *Minimisation of burden on respondents*

  Data development should also support the collection and provision of standardised information as a by-product of service providers' administrative practice. This will also improve data accuracy and completeness. Surveys should also be designed with a view to collecting the required information with minimum impost on respondents.

- *Compatibility of data collection and reporting requirements across settings*

  This avoids situations where the same data has to be counted or reported differently for different programs.

- *Data must be relevant and meaningful to respondents including service providers*

  Data should provide statistics that support service planning, or provide information necessary for the care and treatment of individuals and the support of their families and carers. They must take account of relevant needs of providers, feasibility and appropriateness of data collection, and current scientific knowledge and technological capacity.

- *Data requirements should take account of usual practice in service delivery*

  Where data are collected from service providers, it is important that data collections describe what actually happens in practice. They need to have practical utility (e.g. support client care). Data specifications should not constrain users or force them to operate in a way that does not reflect usual practice. Where possible, data development should be based on data that service providers already want or need to collect about clients and service provision.

- *Privacy and confidentiality provisions should be adhered to*

  The data development process must ensure that data that are recommended will be collected, disseminated, secured and used in such a way as to protect the privacy and confidentiality of any individual and/or organisation to which it may refer.

The collection methodology and the context of data capture are other considerations when selecting and specifying data elements. Part 10.4 contains a discussion of the constraints that impact upon the collection of dementia data elements and further explores this theme.

10.3 Data standards

Data standards describe the expected meaning and acceptable representation of data for use within a defined context. Adherence to data standards ensures there is mutual understanding of the meaning of underlying concepts between different parties, and promotes consistency and comparability of data for analysis and interpretation.

Descriptions of data (metadata) are defined in the International Standards Organisation/ International Electrotechnical Commission (ISO/IEC) 11179 standard that includes six parts (Box 10.1) (ISO/IEC 2004). These metadata standards allow information to be consistently defined, so that information can be compared across different service delivery settings and sectors and between service level data and population data. The need for consistency of meaning is vital to facilitate information sharing among primary and secondary users of the data. Much of the work involved in establishing a data collection is in the development of data standards to ensure comparability and consistency of the data collected and produced from the collection. The development of data standards is not something that is done at the end of the data development process. It is part of the data development process and carries on throughout the life of the data collection.

Box 10.1: Component parts of the ISO/IEC 11179 standard

Part 1: Framework – introduces *and discusses fundamental ideas of data elements, value domains, data element concepts, conceptual domains, and classification schemes essential to the understanding of this set of standards and provides the context for associating the individual parts of ISO/IEC 11179.*

Part 2: Classification *– provides a conceptual model for managing classification schemes. There are many structures used to organise classification schemes and there are many subject matter areas that classification schemes describe. So, this Part also provides a two-faceted classification for classification schemes themselves.*

Part 3: Registry Metamodel and Basic Attributes *– specifies a conceptual model for a metadata registry. It is limited to a set of basic attributes for data elements, data element concepts, value domains, conceptual domains, classification schemes, and other related classes, called administered elements. The basic attributes specified for data elements in ISO/IEC 11179-3:1994 are provided in this revision.*

Part 4: Formulation of Data Definitions *– provides guidance on how to develop unambiguous data definitions. A number of specific rules and guidelines are presented in ISO/IEC 11179-4 that specify exactly how a data definition should be formed. A precise, well-formed definition is one of the most critical requirements for shared understanding of an administered element; well-formed definitions are imperative for the exchange of information. Only if every user has a common and exact understanding of the data element can it be exchanged trouble-free.*

Part 5: Naming and Identification Principles *– provides guidance for the identification of administered elements. Identification is a broad term for designating, or identifying, a particular data element. Identification can be accomplished in various ways, depending upon the use of the identifier. Identification includes the assignment of numerical identifiers that have no inherent meanings to humans; icons (graphic symbols to which meaning has been assigned); and names with embedded meaning, usually for human understanding, that are associated with the data element's definition and value domain.*

Part 6: Registration *– provides instruction on how a registration applicant may register a data element with a central Registration Authority and the allocation of unique identifiers for each data element. Maintenance of administered elements already registered is also specified in this document.*

This report uses and refers to national data standards as described in Australian data standards. National health, community services and housing data standards are contained in the National Health Data Dictionary (NHDD) (National Health Data Committee 2004a), the

National Community Services Data Dictionary (NCSDD) (AIHW 2004g) and the National Housing Assistance Data Dictionary (NHADD) respectively (AIHW 2006b). The dictionaries provide a menu of standard data elements, from which a data collection can be specified.

Under the National Health Information Agreement and the National Health Information Standards Plan for Australia, the NHDD is the authoritative source of health data definitions used in Australia where national consistency is required.

The NCSDD is the reference on agreed data definitions and information standards of relevance to the community services sector. The NCSDD is an initiative under the National Community Services Information Agreement and all signatories to the Agreement have agreed to use the NCSDD as the authoritative source of information about endorsed metadata for use in data collections in the community services field.

The NHADD is the authoritative source of housing data definitions where national consistency is required or desired and it sets out agreed data definitions, classifications and standards developed under the National Housing Data Agreement and the Agreement on National Indigenous Housing Information.

These dictionaries contain the agreed specification of the meaning and representation of individual components of data that have been endorsed for use by the relevant national information authority. That is, each metadata element in the national dictionaries has been endorsed as a national data standard. The dictionaries are also intended to assist a much broader audience (e.g. service providers in developing their own data collections, and information systems, and researchers in either analysing data and/or developing surveys).

As part of the data development process, classification schemes such as the International Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) (NCCH 2002b), the International Classification of Functioning and Disability (ICF) (WHO 2001) and the International Classification of Primary Care Version 2, Plus (ICPC-2 Plus) (Britt 1997) can contribute toward semantic interoperability, that is, the ability to exchange data such that there is a mutual understanding of the precise meaning of the data and the context in which that meaning is valid. These are official terminological systems that are used to classify data and that are recognised and endorsed by national or international bodies.

In addition, METeOR, or the Metadata Online Registry, has been developed by the AIHW as the its online registry of nationally endorsed data standards and for the health, community services and housing assistance sectors. Data standards presented in the NCSDD and NHDD have been restructured for METeOR in line with the latest version of the international standard for metadata registries.

10.4 Constraints that impact upon the collection of dementia data elements

The scope of this project has been to identify data elements which are desirable for improving the amount and type of information available about dementia. While this project has attempted to take account of the constraints arising from the data collection context, these considerations will become even more important in the further development and implementation of these data elements in collections.

Both the feasibility and/or appropriateness of introducing new data elements to an existing collection or introducing the same data element across multiple existing collections is influenced by a number of factors. The development of data elements for inclusion in collections involves a mix of 'top-down' and 'bottom-up' approaches. That is, the inclusion of data elements needs to be driven by management and policy requirements but should also be mindful of the operational constraints on the systems and people who need to record and process data.

Data needed to support secondary (or downstream) information purposes (e.g. reporting, policy, governance, decision support) should be derivable from primary data (point of service delivery data). The challenge for data development is to ensure that operational systems designed to support direct care are also capable of generating standard data as a by-product of the care process, to be used for downstream purposes.

When new data elements are introduced, care should be taken to minimise the burden on data collectors. If the collection of a data element takes significant time or resources, the quality of the data are likely to be compromised if resources and time are limited. This consideration applies not only to service providers but also to population surveys of different types.

To reduce the burden on data recorders in services, and to improve data accuracy, the introduction of data elements should support the collection and provision of standardised information as a by-product of service providers' administrative practice. If the collection of data is used to manage the service it is more likely to be seen as relevant. Data elements that are administrative by-products and can be collected as part of normal processes are more likely to be collected accurately. Data that are not relevant to service delivery or a by-product of service should as far as possible not be collected through routine data collection methods, but through other data collection methods, for example, one-off surveys.

Whether or not a data element can be included in a collection also depends on the scope and purpose of the collection, that is, what population and establishments are included in the collection and what services are provided by the data collector. For example, data elements about type of dementia and type of medications taken are probably not appropriate for collection by a service providing domestic assistance services, but would be relevant for a residential aged care provider or hospital.

The timing and the frequency of data collection can also influence the appropriateness of including some data elements. The data may be collected continuously as a by-product of administrative processes or as part of a one-off survey. In order to monitor change over time it is necessary to collect the same data concerning a person of interest at intervals. The interval of time should be enough that changes can be detected without the need to collect the element too frequently. In addition, some data elements may not be appropriately collected through an initial contact or needs assessment, but may be better collected at a later stage in the service process.

The amount of time needed to collect the data is an important consideration. A data collector who is experiencing time pressures may not be able to dedicate enough time to glean accurate information. The use of closed-end questions, clear question wording and useful instructions are all common ways of ensuring that data collection can occur efficiently.

The physical location where data collection occurs may also have an impact on either the appropriateness of seeking information, or the respondent's ability to respond honestly. For example, collecting information about potentially sensitive topics, such as how a carer is feeling or managing, can be influenced by the level of privacy or intrusion during the collection process.

The skills and knowledge of the data collector may also have a bearing on the quality of the information gathered. If the collection of accurate information is dependent on specific knowledge and skills, the collection of quality information will be compromised if this is missing.

Any data development activity in relation to dementia data needs to recognise that there are very real issues that affect its collection and quality. There is currently no cure for dementia and treatment approaches are few. Diagnosis is difficult, especially since dementia is a secondary complication for a number of other diseases (e.g. stroke and other cardiovascular diseases, diabetes, Parkinson's disease and acquired immunodeficiency syndrome (AIDS)). In this context, and particularly while there continues to be stigma associated with dementia, there may be little incentive to seek and/or provide a diagnosis. A diagnosis may also not be obtained while any problems remain manageable, or the symptoms of dementia are masked by symptoms of comorbid health conditions. While these factors remain, it is possible that the availability and quality of data about early-stage dementia will continue to be poor. In other words, improving dementia data is not simply a technical process, but will also depend on changes in diagnosis and assessment practices.

10.5 Who provides the information?

Practical difficulties can be encountered in recording reliable information about people with cognitive impairment including dementia. Self-reported health and disability data are provided by either the person in scope for the collection or by a professional, family member or caregiver. In either situation, the accuracy and reliability of the information provided may be compromised by factors such as poor memory, misunderstanding of questions or differing perceptions. These problems affect all data collection activities, but are of particular concern for collection of data about dementia:

> *The nature of dementia as a degenerating condition involving cognitive impairment is perceived as a major barrier, since memory, reasoning and speech and language difficulties militate against understanding and self-report although these may still be appropriate for people in the early stages of dementia (Bond 1999:572).*

Cognitive decline, manifest for example in progressive memory loss and/or difficulty in communicating with others, presents a real limitation on the reliability of information provided by the person with dementia, especially during more advanced stages of dementia. As a consequence, professionals and carers are often called on in health and disability surveys to provide proxy information about the health and functional status of people with dementia.

Studies of proxy-reporting have shown that agreement between subjects and caregivers is greater for easily observable, objective elements and less for more subjective measures. Without validity testing it is difficult to know how proxy-reports vary from self-reports; however, a number of factors influence the accuracy of the information collected. A study of differences between elderly subjects with and without dementia and their caregivers revealed that the agreement between self- and caregiver reports decreased with the severity of dementia (Ostbyte et al. 1997). In this study the authors noted that 'some characteristic of the caregivers other than their formal relationship to the subject (e.g. amount of time spent with the subject or even the "quality" of the relationship) could influence agreement more strongly'. The relationship of the reporter, whether the relationship is professional or personal, to the subject of interest can also affect the accuracy of the data collected.

A review of proxy-reporting in the Statistics Canada National Population Health Survey found that the reasons for proxy-reporting fall into two categories, necessity and convenience (Shields 2004). Understanding why the information is collected by proxy is necessary to identify factors that may also influence accuracy. Finally, there may be greater agreement between subjects and proxy reporters where the proxy reporter is careful to understand and present the subject's own responses as far as possible, rather than reporting their own judgements about a subject.

Given the significance of reporter details for dementia data, this report proposes that data elements on self-report or proxy-reporting should be considered for inclusion in relevant data collections, providing an indication of the accuracy and reliability of the data.

11 Comparison and mapping of data items

The scope, purpose and collection context of the data collections described in Chapter 3 in part influences the amount and nature of dementia-related data items included in each collection. This chapter examines these data items in more detail and discusses their comparability between collections.

11.1 Identifying people with dementia and cognitive impairment

This report has already noted that consistent ways of identifying people with dementia and cognitive impairment is a critical requirement for data development in this area. Section 2 of this report illustrates the limitations of existing data collections in this regard, and the resulting differences that arise in prevalence estimates from the variety of definitions and identification approaches used.

Existing data collections vary with respect to the type and amount of data collected which is used to identify people with dementia (Table 11.1, with more detail in Tables 11.4–11.8). Most collect multiple types of information which could be used to assist with the identification of people with dementia and cognitive impairment, including data about whether there is a confirmed diagnosis (diagnosis status), type of dementia, whether there is evidence of cognitive impairment and/or behavioural symptoms, and whether or which dementia-specific treatments are used. Table 11.1 indicates the amount and nature of the information currently collected.

Table 11.1: Number and type of data items used to identify people with dementia and/or cognitive impairment

Number of data items collected	Collections	Type of data items
1 data item	CACP & EACH census	Diagnosis status
	NHS	Dementia as one of the health conditions classified as *organic mental health problems*
2 data items	NRCP	Diagnosis status, behavioural symptoms
	ALSWH	Diagnosis of Alzheimer's disease or dementia, cognitive impairment
	Residential aged care (RCS questions), HACC MDS v2	Cognitive impairment, behavioural symptoms
	PBS	Cognitive impairment, prescription of dementia-specific medication
	NHMD, BEACH	Cognitive impairment, type of dementia
3 data items	Residential aged care (trial ACFI), SDAC, ACAP	Cognitive impairment, type of dementia, behavioural symptoms
4 data items	DESP	Cognitive impairment, diagnosis status, type of dementia, behavioural symptoms

ACAP: Aged Care Assessment Program, ACFI: Aged Care Funding Instrument, ALSWH: Australian Longitudinal Study of Women's Health, BEACH: Bettering the Evaluation and Care of Health, CACP: Community Aged Care Packages, DESP: Dementia Education & Support Program. EACH: Extended Aged Care at Home, HACC: Home and Community Care, MDS: Minimum Data Set, NHMD: National Hospital Morbidity Database, NHS: National Health Survey, NRCP: National Respite for Carers Program, PBS: Pharmaceutical Benefits Scheme, RCS: Resident Classification Scale, SDAC: Survey of Disability, Ageing and Carers.

Three collections rely on a single data item to identify people with dementia and cognitive impairment:

- Two of these (CACP and EACH census collections) obtain information about dementia diagnosis only with a simple yes/no response category. One (NHS) obtains information about health conditions including dementia, which assumes or implies there is a diagnosis, although, as already noted, dementia is not coded separately hence precluding identification of people with dementia through the collections.

Seven collections obtain two data items that can be used to identify people with dementia or cognitive impairment:

- In six of these collections, a data item about cognitive impairment is used mostly in combination with data about dementia type (NHMD, BEACH), or behavioural symptoms (RCS questions in residential aged care, HACC MDS Version 2).
- Two collections use information about diagnosis status, combined with data about behavioural symptoms (NRCP) or cognitive impairment (ALSWH).
- Programs designed to provide care for people with dementia are more likely to include data items about behavioural symptoms, since these are usually directly related to the need for and level of care, and have a severe impact on carer stress. As mentioned, the NRCP also obtains information about diagnosis status, while the current RCS questions and HACC MDS v2 also include data items about observed areas of cognitive impairment such as memory problems.
- Data about prescription or use of dementia-specific medication can also be used to identify cases of people with dementia. These data are available through the PBS collection and the BEACH survey.

The current trial version of the ACFI, the Australian Bureau of Statistics (ABS) SDAC and the ACAP include three data items: cognitive impairment, dementia type, and behavioural symptoms.

Alzheimer’s Australia DESP data collection includes the most comprehensive suite of items, including diagnosis status, type of dementia, cognitive impairment and challenging behaviour.

The variety of data item types reflects the multi-dimensional nature of the dementia syndrome. At the same time, the primacy of cognitive impairment as the defining feature of dementia is reflected in the use of items about cognitive impairment in nine of the current data collections examined here. Type of dementia is collected in seven collections. While type of dementia implies there is a diagnosis, diagnosis status is separately collected by five collections, as are data about behavioural symptoms.

Cognitive impairment

Although items about cognitive impairment feature heavily, there is no consistent approach across data collections in respect of the type of data collected (see Table 11.6 at end of chapter). The items vary in the domains they cover, the questions used, the response categories and measurements, the temporal context and the assessment environment. As a result of these variations, it is difficult to find a reference point upon which to compare data elements across collections.

Three overall approaches can however be discerned. The first approach involves the collection of data about decline, or evidence of impairment, in specific cognitive domains.

The RCS includes questions on understanding and communication. However, the most common domain reported is memory function (DESP, HACC, ALSWH, ACAP). ALSWH also asks about difficulty concentrating, and ACAP data domains cover a range of mental functions based on the International Classification of Functioning, Disability and Health (ICF).

This general approach is consistent with that used in the ICF Body Functions domain. Chapter 1 on mental functions identifies a range of specific cognitive functions which may be impaired (Box 11.1). Three of these domains are suggested by the ICF for minimum information systems about cognition—attention, memory and high-level cognitive functioning.

Box 11.1: ICF mental functions

Global mental functions

b110	*Consciousness functions*
b114	*Orientation functions*
b117	*Intellectual functions*
b122	*Global psychosocial functions*
b126	*Temperament and personality functions*
b130	*Energy and drive functions*
b134	*Sleep functions*
b139	*Global mental functions, other specified and unspecified*

Specific mental functions

b140	*Attention functions (sustaining attention, shifting attention, dividing attention, sharing attention)*
b144	*Memory functions (short-term memory, long-term memory, retrieval of memory)*
b147	*Psychomotor functions*
b152	*Emotional functions*
b156	*Perceptual functions*
b160	*Thought functions*
b164	*Higher-level cognitive functions (abstraction, organisation and planning, time management, cognitive flexibility, insight, judgement, problem-solving)*
b167	*Mental functions of language*
b172	*Calculation functions*
b176	*Mental function of sequencing complex movements*
b180	*Experience of self and time functions*
b189	*Specific mental functions, other specified and unspecified*
b198	*Mental functions, other specified*
b199	*Mental functions, unspecified*

The second approach involves the collection of data about screening or assessment tools used to identify cognitive impairment and the resulting score:

- This type of data is collected by the PBS which obtains results of the Mini-Mental State Examination (MMSE) or Alzheimer's Disease Assessment Scale, cognitive subscale (ADAS-Cog) before and after initial therapy. The ACFI is trialling the collection of scores from the Psychogeriatric Assessment Scales, General Practitioner Assessment of

Cognition and the Rowland Universal Dementia Assessment Scale. Data about scores from the MMSE are also sometimes available from the ACAT Aged Care Client Record, although not reported as part of the MDS.

The third general approach consists of constructing categories that describe the manifestations or outcomes of cognitive impairment across a range of activities, for example, '*needs cues or prompting to make decisions – short-term memory loss*' or '*disorientation to time and place is likely*' (ACFI).

- This approach is used by the current trial ACFI. It is also used by the SDAC which collects data on whether assistance is needed with:
    - cognitive or emotional skills
    - making decisions and problem solving
    - coping with feelings or emotions.

Dementia diagnosis status

As already noted in this report, there is a lack of consistency between major classification tools in the definition of dementia and the operationalised diagnostic criteria. However, obtaining an accurate diagnosis of dementia and dementia-related conditions is important for people with dementia and their family and carers. Difficulties in obtaining a diagnosis can lead to complications in the provision of care and delays in obtaining appropriate treatment. A data item about dementia diagnosis status (i.e. whether the person of concern has a confirmed diagnosis) represents an efficient and relatively straightforward way for collections to identify people with dementia.

Table 11.4 describes the diagnosis status data items which are included in five collections, three of which are community care data sets (EACH and CACP census collections and NRCP). The two census collections record the service provider's knowledge about whether the client has been diagnosed with dementia by an ACAT or medical practitioner. NRCP data are based on a report by the carer that a medical practitioner has diagnosed the care recipient as having dementia. All three collections use the same value domains (yes, no, not stated/inadequately described).

The ALSWH also includes a question about whether the respondent had been diagnosed with or treated for Alzheimer's disease or dementia in the last three years, with response options consisting of 'yes' or 'no response'.

The most comprehensive type of diagnostic information is collected by the DESP data collection. The data item about dementia diagnosis status includes value domains which indicate whether or not the person of concern is being assessed for dementia, or has not been assessed but shows symptoms of dementia or memory loss. It therefore combines diagnostic status information and some information about the possible presence of cognitive impairment. Further information is also collected by DESP about the profession which provided the diagnosis and the date of the diagnosis.

Type of dementia

Information about type of dementia is usually collected in lieu of information about diagnosis status. If type of dementia is known, then it can be assumed that there is a confirmed diagnosis. This item is described consistently across the data collections and the value domains are mostly based on ICD-10. The BEACH data are classified using ICPC-2 Plus (see Table 11.5).

However, the level of detail among the value domains used varies. The NHS collects information about dementia as a long-term health condition, but collapses it into the category of '*organic mental health problems*' under '*mental and behavioural problems*'. This results in a significant loss of information. The SDAC also collapses categories of long-term health condition so that only 'dementia' and 'Alzheimer's disease' are clearly and unambiguously identified, again reducing information available about other types of dementia.

Administrative data sets collect information about type of dementia in order to serve the purposes of the service or program, so that the data items have different meanings:

- as a principal or additional diagnosis contributing to the cost of a hospital episode (NHMD)
- as a primary health condition or other health condition that has an impact on the person's need for assistance with activities of daily living and social participation (ACAP)
- a documented diagnosis that is relevant to current care needs (ACFI)
- reasons for general practitioner (GP) encounter and diagnosis or problems managed by the GP (BEACH).

11.2 Severity of dementia and cognitive impairment

There are no data items in these collections that directly report on the concept of severity of dementia. *Date of diagnosis* collected in the DESP dataset provides an indication of the length of time the person of concern has known they have the condition, and may provide an indication of the stage of dementia they are likely to have reached.

However, the main way in which severity can be assessed is through information about the functional and behavioural outcomes for the person of concern. Functional outcomes include both cognitive functioning and functioning in daily activities. These outcomes are interrelated. Dementia is characterised by cognitive decline, the extent of which will impact over time on the affected person's ability to perform daily activities and to participate in family and community life. In a significant proportion of people with dementia, cognitive impairment also affects their emotional and psychological wellbeing, and their capacity to communicate and interact with others and to regulate their behaviour. These declines manifest as behavioural disturbances and, with functional and cognitive decline, are indictors of severity of the syndrome.

Extent of cognitive impairment

There are a number of ways in which the extent or severity of cognitive impairment is collected in the collections reviewed in this chapter (see Table 11.6). A common approach is to rely on scales of self- or proxy-reported assessments of severity. However, the scales are based on different concepts:

- ALSWH is based on **frequency of occurrence** (never, rarely, sometimes, often).
- ACFI records a scale of **degree of impairment** (no, mild, moderate, severe), which is based on observations about difficulty and/or independence and/or symptoms of cognitive decline.

- DESP records a scale of **degree of memory impairment** (no, minor, moderate, major, severe), which is based on problems experienced compared to previous levels of memory.
- The RCS uses a four-point scale to denote the **level of supervision and care required** because of the impairment.
- **Scores on cognitive screening or assessment tools** are collected by the PBS and the trial ACFI.
- Binary responses are used to simply denote the presence of cognitive impairment by HACC (yes/no in respect of memory problems or confusion). The SDAC also uses a binary response, but in this case about whether the person needs assistance with cognitive skills. Needing assistance denotes a higher level of severity than simply the presence of the impairment.

Extent of behavioural and psychological symptoms of dementia

Six collections include some data items about the behavioural and psychological symptoms of dementia (BPSD) (see Table 11.7 at end of chapter). There is substantial evidence that the presence of BPSD contributes significantly to carer stress and the cost of care and supervision in residential settings.

Once again there is little consistency in how the data are collected. The DESP contact data set identifies particular types of challenging behaviours which may be identified through contact discussions (e.g. anxiety, repetitive speech, depression, wandering). Information about the frequency or severity of these behaviours is not collected.

The RCS questions similarly list a number of BPSDs, but also indicate how much care is required because of the behaviours. The behaviours included in the list are less comprehensive than for DESP but are mappable to the latter (Table 11.2). This is also the case for the ACFI which focuses on three domains—problem wandering, physical and verbal behaviour, and depression and anxiety; and the ACAP which allows unhappiness, irritability and anger, restlessness and agitation, physical violence and hostility to be recorded as one of ten health conditions. The ACFI records information about the frequency with which the behaviour occurs.

Both NRCP and HACC report information only at a broad level in relation to behavioural problems (HACC) or challenging behaviour (NRCP). For NRCP the definition requires that the behaviour is aggressive, disruptive, agitated or offensive and hence leads to a requirement for support. The data domains describe the level of support required because of the behavioural problems.

Only three collections include items to measure the severity of BPSD, all on a different basis. The ACFI collects information about the frequency with which the problem behaviour occurs. NRCP and RCS scales are based on self- or proxy-reports about the level of care or support required because of the behaviours. HACC and DESP only record the presence of behaviours, while the SDAC again records whether the person needs assistance to manage behaviour, feelings or emotions. ACAP only records the behaviours as health conditions if they have an impact on the person’s need for assistance with activities of daily living and social participation.

Table 11.2: Comparison of BPSD across relevant data collections

DESP	RCS	ACAP	ACFI	SDAC	HACC MDS v2	NRCP
Anxiety/panic/phobias	Emotional dependence	Unhappiness (worries nos)	Depression & anxiety	Manage own behaviour Cope with feelings & emotions	Behavioural problems	Challenging behaviour
Depression/hopelessness						
Constantly complaining/ irritability/demanding		Irritability & anger				
Wandering & disruptive	Problem wandering or intrusive behaviour		Problem wandering			
Generally agitated/ unsettled/restless		Restlessness & agitation				
Inappropriate dress/ disrobing						
Repetitive speech/ repetitious mannerisms						
Threatened or actual physical aggression	Physically aggressive	Physical violence Hostility	Physical & verbal behaviour			
Verbally noisy/screeching/ screaming	Verbally disruptive or noisy					
Resistive to personal care help						
Hiding/hoarding things						
Inappropriate sexual behaviour						
Delusional behaviour/ imaginary voices/noises						
Excessively suspicious/ paranoid behaviour						
Substance abuse						
Threats of self-harm	Danger to self or others					
	Other behaviour					

Extent of functional limitation

The extent of limitation experienced by the person of concern in performing daily activities is collected by a number of existing collections (Table 11.9). These measures are indicative of an individual's capacity for independent living, their need for assistance and support, the type of support required and the possible impact on carers and service providers.

Data collected by ACAP and the CACP and EACH census collections are consistent with and mappable to each other and to the SDAC, which is based on the ICF. This consistency facilitates comparison between the client population and the general population.

The CACP and EACH census collections are limited to data about core activity limitations (self-care, mobility and communication). Severity in core activity limitations is measured by how often the person needs assistance with those activities (always, sometimes, never), and where difficulty is experienced and/or aids and equipment used.

ACAP includes a wider range of activity limitations covering both advanced activities of daily living (ADLs) such as transport, health care tasks, domestic assistance, and home maintenance as well as basic ADLs to do with self-care and mobility. The ACAP data set records activity limitations where the person needs the help or supervision of another person. Where the core activity limitations are recorded, this is interpreted to be equivalent to having a severe or profound limitation comparable with the SDAC measure.

The SDAC itself includes a broad range of activity types, including self-care activities, communication and mobility activities. However, the range of activities also includes instrumental activities of daily living (IADLs) such as paperwork, meal preparation, and household chores. The key measure of severity is how often the person needs the assistance of another person in those activities, along with items about the frequency of the need for assistance.

Concepts of difficulty or problems associated with undertaking daily activities underpin the severity measures used in ALSWH and DESP. The latter collection is restricted to information about personal care support, while the others collect information about a more comprehensive range of activities. ALSWH also measures severity using the concept of needing the help of another person, based variously on how often the help was needed ('occasionally'), needing the help with more difficult tasks, or simply that help was needed in the last month.

The HACC MDS Version 2 includes both IADLs and ADLs in its functional categories, and severity is measured by the extent to which assistance is needed for the performance of those activities. The RCS focuses on activities and tasks which have most bearing on the cost of residential care, (IADLs are not represented), with severity measured by the extent of care or supervision involved. The ACFI is similarly focused on activities and tasks which are of relevance to care in a residential setting, and IADLs such as paperwork, managing money and housework are not included.

NRCP differs from all other collections by using a scale (low, moderate, high) to measure the level of need for support by the care recipient.

11.3 Environmental factors

The recognition of environmental factors as fundamental to functioning and disability is an important development in the conceptualisation of disability in the ICF. Environmental factors 'make up the physical, social and attitudinal environment in which people live and conduct their lives' (WHO 2001:10). Environmental factors can have the effect of improving or hindering an individual's body function (e.g. medications), ability to execute an activity (e.g. with the use of aids), and/or their participation in society. Different environments may have a different impact on the same individual with a given health condition (AIHW 2003c).

Environmental factors are clearly an important element in the extent to which a person with dementia is able to remain living in their home, through the availability of a carer. Certain treatment options may reduce the symptoms of dementia in the early stages. Carer support and training potentially increases the care management approaches available for carers, possibly improving their capacity to respond to challenging behaviour. The design of appropriate physical environments can be used to reduce the possible negative impact of problem wandering or other challenging behaviours.

Carers

The availability of a carer greatly influences the ability of a person with dementia to remain at home safely, and carer stress has been found to be a critical factor in decisions to move into the residential care sector. As a result, a number of support programs for people with dementia are also aimed at supporting carers in their role. Information about carers, and particularly measures of the impact of the caring role, are therefore critical for the delivery of current services and future service planning.

Data items on carer availability or carer status, co-residency status, relationship of carer to care recipient and carer demographics are obviously fundamental to understanding the carer–care recipient dyad. Table 11.3 shows which collections include these data items. The scope of this report is to primarily focus on data items which are specific (or particularly relevant) to dementia: hence this chapter does not compare these data items across collections.

Table 11.3: Comparison of data sources collecting core information about carers

Collection	Carer availability	Carer co-residency status	Relationship of carer to care recipient	Carer status	Carer demographics
CACP	✓	✓	✓		
EACH	✓	✓	✓		
ACAP	✓	✓	✓		
HACC	✓	✓	✓		
NRCP	(all are recipients)	✓	✓	✓	✓
SDAC	(whether receives informal assistance)	✓	✓	✓	✓
ALSWH	✓			✓	✓
DESP	(some)		✓	✓	✓

Alzheimer's Australia DESP, NRCP, ALSWH and SDAC ask questions directly of the carer and therefore provide demographic information as well as information about impact of the caring role and interaction with the care recipient. Although ALSWH and SDAC also collect a range of information about the health and wellbeing of carers, whether a carer is caring for someone with dementia cannot always be (if at all) determined.

Measures that are relevant to the impact of the caring role are collected by Alzheimer's Australia DESP, HACC MDS v2, NRCP, ALSWH and SDAC. These measures include number of care recipients, frequency and duration of care provision, overall carer need and measures of the health and wellbeing of the carer. These data items, as well as data items about formal and informal support, are included in Tables 11.10a–11.10e. Tables including further data items about carer health and wellbeing, income and financial situation, paid work, social support and relationships, respite care and assistance provided are included in Tables A11.1–A11.7.

Services and treatments

Many formal services and/or service types available to people with dementia or cognitive decline are not specific to this population. Residential aged care is targeted at frail older people no longer able to live in the community. Service types, such as information, counselling or advocacy which may be provided by organisations such as Alzheimer's

Australia who target people with (suspected) dementia, are also provided by other programs targeting a wider population (e.g. HACC, NRCP).

The major dementia-specific treatment which is included in this set of data collections is dementia-specific medications which are available through the PBS. The PBS includes information about the nature of these drugs and the number of prescriptions for them. The BEACH survey also reports information about medications prescribed by GPs.

11.4 Conclusion

In summary, existing data collections include a wide array of information which is relevant to the identification, treatment and care of people with dementia and the support of carers and family members. However, in many areas there is inconsistency between collections in terms of what type of data is collected, and there is only limited comparability of definitions and value domains. International classifications such as the ICD-10 and ICF have been used as standards in some areas, notably type of dementia and functional impairment. The general picture however is one of fragmentation and inconsistency of approach to identifying people with dementia or cognitive impairment and the severity of the associated impairments.

Table 11.4: Mapping of dementia-related data items in Australian dementia-relevant collections: Dementia diagnosis

DESP	CACP census	EACH census	NRCP	ALSWH
Data item: Dementia diagnostic status **Definition:** Dementia diagnostic status of the person of concern **Data domain:** Diagnosed with dementia Being formally assessed for dementia Not assessed but symptoms of dementia/memory loss Assessed—dementia not diagnosed Unknown	**Data item:** Dementia status **Definition:** Whether or not the care recipient has been diagnosed with dementia (by an ACAT or medical practitioner) to the knowledge of staff of the service outlet **Data domain:** Yes No Not stated/inadequately described	**Data item:** Dementia status **Definition:** Whether or not the care recipient has been diagnosed with dementia (by an ACAT or medical practitioner) to the knowledge of staff of the service outlet **Data domain:** Yes No Not stated/inadequately described	**Data item:** Dementia **Definition:** A report by the carer that a medical practitioner has diagnosed the person he or she cares for as having dementia. **Data domain:** Yes No Not stated/inadequately described	**Question:** In the last 3 years have you been diagnosed with or treated for… **Options include:** Alzheimer's disease or dementia **Response**: Yes (or no response) **Notes:** Option only exists for older cohort in surveys 2, 3 & 4 although an 'Other—please specify' category exists for the younger & mid-age cohorts
Data item: Diagnosis by whom **Definition:** Category of professional providing the dementia diagnosis **Data domain:** General practitioner Psychogeriatric/Aged Psychiatry Services Team Behavioural Support Unit/Behavioural Advisory Service Aged Care Assessment Team/Services Neurologist Psychogeriatrician/Psychiatrist Geriatrician Memory clinic/Cognitive, Dementia & Memory Service/Other diagnostic service Other (specify in notes)			***Data item:*** *Care recipient's primary disability* ***Definition:*** *A record of the primary disability, impairment or condition of the care recipient causing the most difficulty to the person.* ***Data domain includes:*** *Acquired brain injury* *Neurological (including epilepsy & Alzheimer's disease)*	
Data item: Date of dementia diagnosis **Definition:** This item describes the date on which the person of concern was diagnosed with dementia **Data domain:** MM/YYYY				

Table 11.5: Mapping of dementia-related data items in Australian dementia-relevant collections: Type of dementia

DESP	NHMD	ACAP	ACFI	BEACH	SDAC	*NHS*
Data item: Type of dementia **Definition:** Type of dementia as reported by the carer or person of concern **Data domain:** Dementia of unspecified type Alzheimer's disease Vascular dementia Mixed dementia Frontal lobe dementia Lewy body dementia Alcoholic dementia (e.g. alcohol-related brain damage) Other dementia (dementia type not described in this list) Unknown	**Data items:** Principal diagnosis, Additional diagnosis **Data domain:** Valid codes from ICD-10-AM (4th edition)— Dementia in Alzheimer's disease Vascular dementia Dementia in other diseases classified elsewhere Unspecified dementia Delirium superimposed on dementia Alzheimer's disease	**Data items:** Primary health condition, Other health condition **Definition:** The diagnosed disease(s) or disorder(s) that have an impact on the person's need for assistance with ADLs—up to 10 health conditions can be recorded. The condition listed first is the one with the greatest impact on the person's need for assistance with ADLs & social participation. Codes are based on the ICD-10 (modified for Version 2.0 & comparable to the SDAC codes) **Data domain includes:** Dementia in Alzheimer's disease Dementia in Alzheimer's disease with early onset Dementia in Alzheimer's disease with late onset Dementia in Alzheimer's disease, atypical or mixed type Dementia in Alzheimer's disease, unspecified Vascular dementia Vascular dementia of acute onset Multi-infarct dementia Subcortical vascular dementia Mixed cortical & subcortical vascular dementia Other vascular dementia Vascular dementia—unspecified Dementia in other disease classified elsewhere Dementia in Pick's disease Dementia in Creutzfeldt-Jakob disease Dementia in Huntington's disease Dementia in Parkinson's disease Dementia in human immunodeficiency virus (HIV) disease Dementia in other specified diseases classified elsewhere Other dementia Alcoholic dementia Unspecified dementia (includes presenile & senile dementia) Delirium superimposed on dementia	**Data item:** Mental & behavioural diagnosis **Data domain:** No diagnosed disorder currently impacting on functioning Dementia Alzheimer's disease Vascular dementia Dementia in other diseases Other dementias Delirium Psychoses, mood disorders (e.g. depression) Neurotic, stress-related, somatoform disorders Intellectual & developmental disorders Other mental & behavioural disorders **Data item:** Medical diagnosis **Data domain includes:** Huntington's disease Parkinson's disease Other diseases of the nervous system Cerebrovascular disease Stroke Amnesia	**Data items:** Reasons for encounter (up to 3) & Diagnosis/problems managed (up to 4) **Data domain:** ICPC–2 Plus codes include symptoms & complaints & diagnoses— Dementia Alzheimer's disease Dementia, alcoholic Dementia, senile	**Data items:** Type of long-term condition reported, Conditions producing main disability, Main condition **Data domain:** Codes based on ICD-10 & include— Dementia Alzheimer's disease	***Data item:** Long-term condition* ***Data domain:** ABS codes based on ICD-10, ICPC-2 Plus & ICD-9* ***Notes:** While the NHS collects information about dementia as a long-term health condition it is collapsed into the category of **Organic mental health problems** under **Mental & behavioural problems***

Table 11.6: Mapping of dementia-related data items in Australian dementia-relevant collections: Cognitive impairment

DESP	PBS	NHMD	ACAP	HACC	RCS
Data item: Memory impairment **Definition:** The level of memory impairment of the person of concern (as compared to previous levels?) **Data domain:** No discernible problems Minor problems Moderate problems Major problems Severe problems	**Data item:** Baseline results of the MMSE or ADAS-Cog prior to initial therapy & results of evaluations after initial therapy	**Data items:** Principal diagnosis, Additional diagnosis **Data domain:** Valid codes from ICD-10-AM (4th edition)— Cognitive disorder not otherwise specified Age-related cognitive decline	**Data item:** Body function impairments **Definition:** The physiological or psychological functions of the person's body where significant deviation from the norm or loss of function is experienced & affects the person's need for assistance with ADLs or social participation—codes based on the ICF **Data domain under heading of *Mental functions* includes:** Consciousness functions Orientation functions Intellectual functions Energy & drive functions Sleep functions Memory functions Psychomotor functions Emotional functions Thought functions Other **Data items:** Primary health condition, Other health condition **Definition:** The diagnosed disease(s) or disorder(s) that have an impact on the person's need for assistance with ADLs—up to 10 health conditions can be recorded. The condition listed first is the one with the greatest impact on the person's need for assistance with ADLs & social participation. Codes are based on the ICD-10 (modified for Version 2.0 & comparable to the SDAC codes) **Data domain includes:** Disorientation (confusion) Amnesia (memory disturbance, lack or loss)	**Data items:** Functional status, Functional status—additional items **Definition:** The extent to which the person is able to perform selected ADLs; & whether they have memory or behavioural problems **Data sub-items:** Memory problems or confusion **Data domain:** Yes No Not stated/inadequately described **Data sub-items:** Communication **Data domain:** No Yes, sometimes Yes, always Not stated/inadequately described **Notes:** The client is asked questions about all activities except Memory problems or confusion & Behavioural problems—ratings for these questions are based on other available information	**Data items:** Understanding & undertaking living activities Social & human needs—care recipient Social & human needs—family & friends Communication **Data domain:** A to D, where *A* means virtually no intervention is required & *D* indicates extensive care involvement

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Table 11.6 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Cognitive impairment

ACFI	BEACH	SDAC	NHS	ALSWH
Data item: Cognitive skills **Data domain:** No impairment Mild impairment Moderate impairment Severe impairment	**Data items:** Reasons for encounter (up to 3) & Diagnosis/problems managed (up to 4) **Data domain:** ICPC–2 Plus codes include symptoms & complaints & diagnoses under 17 chapters including— Psychological (includes dementia, memory disturbance & limited function/disability)	**Data item:** Whether needs assistance or has difficulty with cognitive or emotional skills **Data domain:** Not applicable Needs assistance or has difficulty with cognitive or emotional tasks Does not need assistance or have difficulty with cognitive or emotional tasks Assessment of cognitive or emotional tasks not performed (establishments only) or too young to assess **Data item:** Whether needs assistance to make decisions or think through problems because of disability **Data domain:** Not applicable Needs assistance to make decisions or think through problems Does not need assistance to make decisions or think through problems Activity not performed (establishments only) **Data item:** Whether needs assistance to cope with feelings or emotions because of disability **Data domain:** Not applicable Needs assistance to cope with emotions Does not need assistance to cope with emotions or too young to measure Activity not performed (establishments only) **Data item:** Number of cognitive/emotion tasks for which assistance is needed because of disability **Data domain:** 0→ 6, Not applicable **Notes:** Above data items asked of people with a disability (excluding people with a non-restricting disfigurement or deformity only)	**Data item:** Long-term condition **Data domain:** ABS codes based on ICD-10, ICPC-2 Plus & ICD-9— Symptoms & signs involving cognition, perceptions, emotional state & behaviour	**Question:** In the last 12 months have you had any of the following? **Options include:** Poor memory, Difficulty concentrating **Response:** Never, Rarely, Sometimes, Often **Notes:** Asked of the older cohort in survey 1 (similar questions asked in surveys 2, 3 & 4) **Question:** Compared with when you were in your twenties, how good are you at… **Options include:** Remembering the name of a person just introduced to you? Recalling the telephone numbers or other numbers that you use on a daily or weekly basis? Recalling where you put objects (such as keys) in your home? Remembering specific facts from a newspaper or magazine article you have just finished reading? Remembering the item(s) you intend to buy when you arrive at the shops? In general, how would you describe your memory compared to when you were in your 20s? **Response**: Much better now Somewhat better now About the same Somewhat worse now Much worse now **Notes:** Asked of the older cohort in surveys 3 & 4 & the mid age cohort in survey 4

Table 11.7: Mapping of dementia-related data items in Australian dementia-relevant collections: Behaviour

DESP	ACAP	HACC	RCS	ACFI	NRCP	BEACH	SDAC
Data item: Key issues & discussion areas **Definition:** Service provided (by whatever approach) to the client **Data sub-items include:** Challenging behaviour **Data domain:** Anxiety/panic/phobias Depression/hopelessness Constantly complaining/irritability/ demanding Wandering & disruptive Generally agitated/unsettled/restless Inappropriate dress/disrobing Repetitive speech/repetitious mannerisms Threatened or actual physical aggression Verbally noisy/screeching/ screaming Resistive to personal care help Hiding/hoarding things Inappropriate sexual behaviour Delusional behaviour/ imaginary voices/noises Excessively suspicious/ paranoid behaviour Substance abuse Threats of self-harm	**Data items:** Primary health condition, Other health condition **Definition:** The diagnosed disease(s) or disorder(s) that have an impact on the person's need for assistance with ADLs—up to 10 health conditions can be recorded. The condition listed first is the one with the greatest impact on the person's need for assistance with ADLs & social participation. Codes are based on the ICD-10 (modified for Version 2.0 & comparable to the SDAC codes) **Data domain includes:** Restlessness & agitation Unhappiness (worries not otherwise specified) Irritability & anger Hostility Physical violence	**Data item:** Functional status **Definition:** The extent to which the person is able to perform selected ADLs; & whether they have memory or behavioural problems **Data sub-items:** Behavioural problems **Data domain:** Yes No Not stated/inadequately described **Notes:** The client is asked questions about all activities except Memory problems or confusion & Behavioural problems—ratings for these questions are based on other available information	**Data items:** Verbally disruptive or noisy Problem wandering or intrusive behaviour Emotional dependence Physically aggressive Other behaviour Danger to self or others **Data domain:** A to D, where *A* means virtually no intervention is required & *D* indicates extensive care involvement	**Data items:** Problem wandering, Physical & verbal behaviour **Data domain:** Does not occur Occurred at least once in a week Occurred daily Occurred daily & with more than one episode in any one day of a week	**Data item:** Challenging behaviour **Definition:** A report by the carer concerning the level of support that is required because the type of behaviour exhibited by the care recipient is aggressive, disruptive, agitated or offensive **Data domain:** High level of support required for behaviour Medium level of support required for behaviour Low level of support required for behaviour No level of support required for behaviour No challenging behaviour Not stated/inadequately described	**Data items:** Reasons for encounter (up to 3) & Diagnosis/problems managed (up to 4) **Data domain:** ICPC–2 Plus codes include symptoms & complaints & diagnoses under 17 chapters including— Social problems	**Data item:** Whether needs assistance to manage own behaviour because of disability **Data domain:** Not applicable Needs assistance to manage behaviour Does not need assistance to manage behaviour or too young to measure Activity not performed (establishments only) **Notes:** Asked of people aged 0–14 with a disability living in households (excluding people with a non-restricting disfigurement or deformity only) & persons with a disability living in health establishments **Data item:** Whether primary carer usually assists or guides main recipient of care to manage behaviour **Data domain:** Not applicable Usually assists or guides with management of behaviour Does not usually assist or guide with management of behaviour Not stated **Data item:** Reasons for inability to use some or all forms of public transport **Data domain includes:** Cognitive difficulties Behavioural problems **Notes:** Asked of people aged 5 or over with a disability (excluding people with a non-restricting disfigurement or deformity only) or aged 60 years or over living in households

Table 11.8: Mapping of dementia-related data items in Australian dementia-relevant collections: Treatments

PBS
Data item: Alzheimer's disease identified by the prescription of PBS-funded antidementia medications **Data domain:** Donepezil Hydrochloride Galantamine Hydrobromide Rivastigmine Hydrogen tartrate

Table 11.9: Mapping of dementia-related data items in Australian dementia-relevant collections: Functional impairment *(excluding cognitive impairment or changes in behaviour)*

DESP	ACAP	HACC	CACP census	EACH census
Data item: Personal care assistance **Definition:** The degree of personal care support provided to the person of concern (as compared to previous levels?) **Data domain:** No discernable problems Minor problems Moderate problems Major problems Severe problems	**Data item:** Activity limitations Definition: The activities in which the help or supervision of another individual is needed by the person, as assessed by the ACAT **Data domain:** Self-care Movement activities Moving around places at or away from home Communication Health care tasks Transport Activities involved in social & community participation Domestic assistance Meals Home maintenance Other None Unable to determine Not stated/inadequately described **Data item:** Body function impairments **Definition:** The physiological or psychological functions of the person's body where significant deviation from the norm or loss of function is experienced & affects the person's need for assistance with ADLs or social participation—includes 63 codes based on the ICF **Data domain headings:** Mental functions Sensory functions Voice & speech functions Functions of the cardiovascular, haematological, immunological & respiratory systems Functions of the digestive, metabolic & endocrine systems Genitourinary & reproductive functions Neuromusculoskeletal & movement-related functions Functions of the skin & related structures	**Data items:** Functional status, Functional status—additional items **Definition:** The extent to which the person is able to perform selected ADLs **Data sub-items:** Housework, Transport, Shopping, Medication, Money, Walking, Bathing/showering, Dressing, Eating, Toileting **Data domain:** Without help With some help Completely unable Not stated/inadequately described **Data sub-items:** Communication, Getting out of bed/moving around **Data domain:** No Yes, sometimes Yes, always Not stated/inadequately described	**Data item:** Core activity limitations **Definition:** The core activities in which the help or supervision of another individual is needed by the person, as assessed by staff of the service outlet **Data domain:** Eating Showering/bathing Dressing Toileting Managing incontinence Maintaining or changing body position Carrying, moving or manipulating objects related to the tasks of daily living Getting in or out of bed or chair Walking & related activities Using public transport (e.g. buses, trains) Understanding or making oneself understood by others None Not stated/inadequately described	**Data item:** Core activity limitations **Definition:** The core activities in which the help or supervision of another individual is needed by the person, as assessed by staff of the service outlet **Data domain:** Eating Showering/bathing Dressing Toileting Managing incontinence Maintaining or changing body position Carrying, moving or manipulating objects related to the tasks of daily living Getting in or out of bed or chair Walking & related activities Using public transport (e.g. buses, trains) Understanding or making oneself understood by others No assistance needed from another person in any of these areas Not stated/inadequately described

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Table 11.9 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Functional impairment *(excluding cognitive impairment or changes in behaviour)*

RCS	ACFI	NRCP	SDAC	ALSWH
Data items: Personal hygiene Toileting Medication Technical & complex nursing procedures Therapy Bowel management Bladder management Social & human needs—care recipient Other services Meals & drinks Mobility Social & human needs—family & friends Communication **Data domain:** A to D, where *A* means virtually no intervention is required & *D* indicates extensive care involvement	**Data items:** Eating & drinking Mobility Personal hygiene Toileting **Data domain:** Independent Supervision Physical assistance **Data item:** Continence **Data domain:** Frequency Management program **Data item:** Medication **Data domain:** Supervision Physical assistance Daily administer controlled drug Daily administer injection **Data item:** Technical & complex nursing procedures **Data domain:** Number & frequency of procedures	**Data item:** Care recipient's level of need **Definition:** A statement depicting the level of need for, & type of support required by the care recipient **Data domain:** High (no additional factors) High (plus additional factors) Moderate (no additional factors) Moderate (plus additional factors) Low (no additional factors) Low (plus additional factors) Not stated/ inadequately described	Many data items on functional impairment—examples are below **Data item:** Broad activity groups—Mobility, Self-care, Oral communication, Health care, Cognitive or emotional tasks, Household chores, Home maintenance or gardening, Meal preparation, Paperwork, Private transport **Data sub-item:** Broad area of activity where assistance is required or difficulty is experienced **Data domain:** Yes, No **Data sub-item:** Grouped frequency of need for assistance or supervision **Data domain:** Not applicable Less than once a month One to three times a month Once a week Two to six times a week Once a day Twice a day Three to five times a day Six or more times a day Not known **Data sub-item:** Number of times per day, week or month needs assistance or supervision **Data domain:** Continuous	**Question:** Do you regularly need help with daily tasks because of long-term illness, disability or frailty (e.g. personal care, getting around, preparing meals etc)? **Response:** Yes, No **Notes:** Asked of the mid age & older cohorts (similar question asked of the younger cohort) **Questions:** In the last month have you needed help from another person to carry out any of these activities? In the last month have you had any difficulty (for example, needing to take extra time, changing the activity or using a device to help you) in completing any of these activities? **Options:** Grooming (e.g. brushing hair, applying make-up) Eating (e.g. cutting meat, lifting glass or cup, opening milk carton) Bathing or taking a shower Dressing your upper body Dressing your lower body Getting up from a chair Walking inside the house Using the toilet Shopping for personal items or groceries Doing light housework (e.g. cleaning, washing-up) Doing heavy housework (e.g. vacuuming, yard work) Managing money (e.g. writing cheques or keeping accounts) Preparing meals Taking medications Using the telephone Doing leisure activities or hobbies **Response:** Yes, No No difficulty, Some difficulty, Unable to do **Notes:** Asked of the older cohort in survey 4

Table 11.10a: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(number of care recipients)*

HACC MDS v2	NRCP	SDAC	ALSWH
Data item: Carer for more than one person **Definition:** Whether or not a primary carer is providing assistance on a regular & sustained basis to more than one care recipient **Data domain:** Yes No Not stated/inadequately described	**Data item:** Number of care recipients **Definition:** A record of those carers who are caring for more than one person who requires help (with self-care, mobility or communication) due to a disability or with a disability as a consequence of ageing or illness **Data domain:** Carer of one person Carer of two people Carer of three people Carer of more than three people Not stated/inadequately described	**Data item:** Number of recipients of care **Data domain:** Not applicable One care recipient Two care recipients Three or more care recipients ***Data item:*** *Carer status* ***Data domain:*** *Not applicable* *Primary & other carer* *Primary carer only* *Unconfirmed primary carer* *Carer, but not primary carer* *Principal carer only* *Not a carer* ***Data item:*** *Place of residence of recipient(s) of care* ***Data domain:*** *Not applicable* *Carer lives with each recipient of care* *Carer does not live with any recipient of care* *Carer lives with at least one recipient of care & does not live with at least one recipient of care*	**Question:** How many people with a long-term illness, disability or frailty do you regularly provide care for? **Response:** One person Two people More than two people **Notes:** Asked of the mid age cohort in surveys 2, 3 & 4 & the older cohort in survey 2 ***Question:*** *Do you regularly provide care or assistance (e.g. personal care, transport) to any other person because of their long-term illness, disability or frailty?* ***Options:*** *Yes, for someone who lives with me* *Yes, for someone who lives elsewhere* *No, I do not provide care* ***Response:*** *Yes (or no response)* ***Notes:*** *Asked of the older cohort in surveys 2, 3 & 4 (similar question asked of the mid age cohort in surveys 2, 3 & 4)*

Table 11.10b: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(frequency and duration of care)*

DESP	**NRCP**	**SDAC**		**ALSWH**
Information collected on date care commenced	**Data item:** Time spent caring **Definition:** An indicator of the average amount of time the carer spends caring each week **Data domain:** Less than 20 hours per week 20 to 39 hours per week 40 hours or more per week Not stated/inadequately described **Data item:** Date caring role commenced **Definition:** The date on which the carer's role as primary carer or other carer, commenced **Data domain:** Valid month/year date	**Data item:** Number of hours per week primary carer spends actively caring or supervising **Data domain:** Not applicable Less than 20 hours 20 to less than 40 hours 40 hours or more Not stated **Data item:** Weekly hours of care main recipient of care receives from primary carer **Data domain:** Not applicable Less than 20 hours 20 to less than 40 hours 40 hours or more Not stated **Data item:** Duration of care provision (number of years primary carer provided to main recipient of care) **Data domain:** Not applicable Does not know Less than one year 1–4 years 5–9 years 10–14 years 15–19 years 20–24 years 25–29 years 30–34 years 35 years or more	**Data item:** Length of time caring because of condition **Data domain:** Not applicable 1 year 2 years 3 years 4 years 5 years 6 years 7 years 8 to 9 years 10 years 11 to 15 years 16 to 20 years 21 to 30 years 31 years or more Less than one year **Notes:** Asked of primary carers **Data item:** Whether main recipient of care needs episodic or continuous care from primary carer **Data domain:** Not applicable Needs continuous care Needs episodic care	**Question:** How often do you provide this care or assistance? **Response:** Every day Several times a week Once a week Once every few weeks Less often **Notes:** Asked of the mid age cohort in surveys 2, 3 & 4 & the older cohort in survey 2 **Question:** How much time do you usually spend providing such care or assistance on each occasion? **Response:** All day & night All day All night Several hours About an hour **Notes:** Asked of the mid age cohort in surveys 3 & 4 & the older cohort in survey 2 (similar question asked of the mid age cohort in survey 2)

Table 11.10c: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(overall carer need)*

DESP	NRCP	SDAC	
Data item: Carer overall need **Data domain:** Low Moderate High **Data item:** Emergency contact **Definition:** The nature of the contact made by the client, whether by telephone or in person, in terms or urgency **Data domain:** Emergency contact (or no response)	**Data item:** Carer need **Definition:** The level of need for support at the time of contact, experienced by the carer in terms of the vulnerability of the carer **Data domain:** High need Moderate need Low need Not stated/inadequately described	**Data item:** Whether primary carer needs improvement or more support to assist in caring role **Data domain:** Not applicable Needs an improvement or more support Does not need an improvement or more support Not stated **Data item:** Type of support or improvement most desired by primary carer to assist in carer role **Data domain:** Not applicable More respite care More financial assistance More physical assistance More emotional support Improvement in own health Other Does not need an improvement or more support Not stated **Data item:** Primary carer need & receipt of assistance to care for main recipient of care **Data domain:** Not applicable Receives assistance & does not need further assistance Receives assistance & needs further assistance Does not receive assistance & needs assistance Does not receive assistance & does not need assistance	**Data item:** Whether primary carer has unmet need for assistance on weekdays **Data domain:** Not applicable Unmet need for assistance on weekdays No unmet need for assistance on weekdays **Data item:** Whether primary carer has unmet need for assistance on weekends **Data domain:** Not applicable Unmet need for assistance on weekends No unmet need for assistance on weekends **Data item:** Whether primary carer has unmet need for assistance on weeknights **Data domain:** Not applicable Unmet need for assistance on weeknights No unmet need for assistance on weeknights

Table 11.10d: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(carer health and wellbeing)*

DESP	SDAC		ALSWH
Data item: Key issues & discussion areas **Definition:** Service provided) by whatever approach) to the client **Dada sub-items include:** Coping & mental health **Data domain:** Stress/anxiety Feelings of anger/frustration/ aggression Symptoms of depression Loss & grief issues Spirituality No time for leisure pursuits/ pleasant events	**Data item:** Whether primary carer feels satisfied due to caring role **Data domain:** Not applicable Feels satisfied due to caring role Does not feel satisfied due to caring role Not stated **Data item:** Whether primary carer feels weary or lacks energy due to caring role **Data domain:** Not applicable Feels weary or lacks energy due to caring role Does not feel weary or lack energy due to caring role Not stated **Data item:** Whether primary carer frequently feels angry or resentful due to caring role **Data domain:** Not applicable Frequently feels angry or resentful due to caring role Does not frequently feel angry or resentful due to caring role Not stated **Data item:** Whether primary carer frequently feels worried or depressed due to caring role **Data domain:** Not applicable Frequently feels worried or depressed due to caring role Does not frequently feel worried or depressed due to caring role Not stated **Data item:** Whether primary carer has had a stress-related illness due to caring role **Data domain:** Not applicable Has been diagnosed with a stress-related illness due to caring role Has not been diagnosed with a stress-related illness due to caring role Not stated	**Data item:** Whether primary carer's physical or emotional wellbeing has changed due to caring role **Data domain:** Not applicable Physical or emotional wellbeing has changed due to caring role Physical or emotional wellbeing has not changed due to caring role Not stated **Data item:** Whether primary carer's sleep is interrupted frequently or occasionally due to caring role **Data domain:** Not applicable Sleep interrupted frequently due to caring role Sleep interrupted occasionally due to caring role Sleep is not interrupted due to caring role Not stated Sleep interrupted due to caring role but frequency not stated **Data item:** Whether primary carer's interrupted sleep interferes with normal daily activities **Data domain:** Not applicable Sleep interrupted frequently interferes with normal daily activities Sleep interrupted frequently does not interfere with normal daily activities Sleep interrupted frequently interference with normal daily activities not stated Sleep interrupted occasionally interferes with normal daily activities Sleep interrupted occasionally does not interfere with normal daily activities Sleep interrupted occasionally interference with normal daily activities not stated Sleep interrupted but frequency or interference not stated Sleep is not interrupted Not stated	**Question:** How much of the time during the past 4 weeks… **Options:** Did you feel full of life? Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt calm & peaceful? Did you have a lot of energy? Have you felt down? Did you feel worn out? Have you been a happy person? Did you feel tired? **Response:** All of the time Most of the time A good bit of the time Some of the time A little of the time None of the time **Question:** Do you have any of these sleeping problems? **Options:** Waking up in the early hours of the morning Lying awake for most of the night Taking a long time to get to sleep Worry keeping you awake at night Sleeping badly at night None of these problems **Response:** Yes (or no response) **Notes:** Asked of the older cohort in surveys 2, 3 & 4 & the mid age cohort in survey 4 **Question:** In general, would you say your health is… **Response:** Excellent Very good Good Fair Poor **Question:** Compared to one year ago, how would you rate your health in general now? **Response:** Much better now than one year ago Somewhat better now than one year ago About the same as one year ago Somewhat worse now than one year ago Much worse now than one year ago

Table 11.10e: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(formal and informal support)*

DESP	NRCP	SDAC	ALSWH
Data item: Current services **Definition:** The primary type of assistance received in the last 2 weeks by the principal carer or person of concern from Commonwealth, state, local government or private services **Data domain:** No formal services Home-based supports Home nursing care/domiciliary nursing Personal care Allied health care/paramedical Food services Delivered meals Domestic assistance Maintenance/modification Social support Day supports Day hospital/rehabilitation centre Centre-based day care Respite support Respite—home Respite—residential Community packages Community options/Linkages/COPS Aged care packages Community teams Aged Care Assessment Team/Service Aged Psychiatry/Psychogeriatric Team Alzheimer's Association service Support Group Counselling Education/training Other service Carer's Association service Support group/counselling/other Home modifications Home modification/security Other service	**Data item:** Current use of formal services **Definition:** The current pattern of formal service used by the carer **Data domain:** Is receiving one or more formal services (on a regular, intermittent or occasional basis) that are primarily focused on meeting the needs of the carer Is receiving one or more formal services (on a regular, intermittent or occasional basis) that are primarily focused on meeting the needs of the care recipient Is receiving a 'package' of formal services—more than one service (case managed or coordinated) which is primarily focused on meeting the carer's needs Is receiving a 'package' of formal services—more than one service (case managed or coordinated) which is primarily focused on meeting the care recipient's needs Is not receiving services that are either focused on meeting the needs of the carer or the care recipient Not stated/inadequately described	**Data item:** Whether main recipient of care has a fall-back informal carer **Data domain:** Not applicable Has a fall-back informal carer Does not have a fall-back informal carer Don't know	**Question:** Which of the following groups have you sought advice or help from in the last 6 months? **Options:** Food services (e.g. Meals on Wheels) Nursing or community health services Respite services (in-home, day centre or inpatient) Homemaking services (e.g. home care service, laundry service) Home maintenance services (e.g. odd jobs, gardening) Counselling or other mental health services Ambulance service Social groups (e.g. CWA, Senior Citizen's Centre, craft or exercise groups, church groups) Support & advisory groups (e.g. Arthritis Foundation, Pensioner Advisory Service, Older Women's network) None of the groups **Response:** Yes (or no response) **Notes:** Asked of the older cohort in survey 3 (similar questions asked of the older cohort in surveys 2 & 4)
Data item: Counselling support summary **Definition:** Describing the level of counselling support provided **Data domain:** Information, advice & support—practical aspects Empathetic listening & emotional support Counselling Structured therapy	**Data item:** Informal support **Definition:** The informal support provided to the carer by people outside the carer/care recipient relationship **Data domain:** Wife/female partner Husband/male partner Mother Father Daughter Son Daughter-in-law Son-in-law Other relative—female Other relative—male Friend/neighbour—female Friend/neighbour—male No informal support Not stated/inadequately described	**Data item:** Whether fall-back carer lives with main recipient of care **Data domain:** Not applicable Fall-back carer lives with main recipient Fall-back carer does not live with main recipient Does not have a fall-back carer/does not know	**Question:** Do you have any paid help with domestic work (e.g. housework, ironing)? **Response:** Yes, No **Notes:** Asked of the mid age cohort in survey 2
		Data item: Relationship of fall-back carer to main recipient of care **Data domain:** Not applicable Spouse or partner Father Mother Son Daughter Son-in-law Daughter-in-law Other male relative Other female relative Friend or neighbour (male) Friend or neighbour (female) Does not have a fall-back carer or does not know	
		Data item: Relationship of main source of assistance to primary carer **Data domain:** Not applicable Spouse or partner Father Mother Son Daughter Father-in-law Mother-in-law Other male relative Other female relative Friend or neighbour (male) Friend or neighbour (female) Formal provider Has no main source of assistance	
		Data item: Whether primary carer's main source of assistance is a co-resident **Data domain:** Not applicable Co-resident Not a co-resident Has no main source of assistance	

12 Improving dementia data

The differences in purpose and operational context of the data collections reviewed in Chapter 11 have produced varying approaches to the collection of data about dementia and cognitive impairment. Data development in this area also reflects the complexity of the syndrome of dementia, variations in its progression and manifestations among different types of dementia, and developments in clinical research and care practice. The purpose of this report is not to define or prescribe a definitive set of data elements for collection about dementia, but to present options for potential data elements that could be used in a wide range of collections. If these elements are used as a standard 'menu', and if context and purpose are taken into account, this will promote greater consistency and comparability across the field, and greater quality in many collections.

12.1 Data development methodology

Data development concerns the building and/or improvement of a data collection for a specific purpose, irrespective of how the data are collected. For this project the data development process was overseen and guided by the National Dementia Data Analysis and Development Reference Group.

The Reference Group was guided by considerations of the relative importance of the data element for supporting policy and practice designed to assist people with dementia and their carers. In addition, the Reference Group took account of other data development criteria such as feasibility of collection and consistency with existing data standards. The recommended data elements were developed with reference to both existing data elements collected in Australia and priorities in dementia research. Where possible, existing data elements that are included in collections described in Chapter 11 have been used.

The Reference Group considered the intended applications of the information collected by the data elements, and this guided the selection of value domains for new data elements. The value domains that were included were selected to be exhaustive, mutually exclusive and internally consistent.

The theme concerned with the impact on carers is not only of relevance to dementia data. However, as Chapters 6 and 7 both observe, there is some evidence which suggests that caring for someone with dementia can be a different experience in many respects from caring for people with other types of disabilities or long-term conditions. For this reason, this report makes recommendations about possible data elements in this area.

Elements about sociodemographic characteristics of people with dementia and their carers are assumed to be already included in relevant collections and they are not proposed here. Similarly, data elements about activity and participation limitations (e.g. mobility, self-care, shopping) are clearly critical for assessing the care and support needs of people with dementia and their family and carers. However, the scope of this project did not extend to this area of data collection and the report does not propose specific data elements. The ICF provides a well-developed classificatory framework for the collection of data items about functioning.

The menu is focused on elements of relevance to dementia or cognitive decline. The proposed data elements are grouped within the following categories:

1. Identification of cognitive impairment and dementia
2. Cognitive impairment and dementia diagnosis information
3. Current behaviour related to dementia and its impact on care
4. Coexisting health conditions
5. Impact of caring
6. Reporter details.

Table 12.1: Framework for proposed dementia data elements

<table>
<tr>
<td rowspan="4">**6 Reporter details**
6.1: Reporter status
6.2: Relationship of proxy reporter to person of interest</td>
<td colspan="2">**1 Identification of cognitive impairment and dementia**
1.1: Identification of cognitive impairment
1.2: Identification of a diagnosis of dementia</td>
</tr>
<tr>
<td>**2 Cognitive impairment and dementia diagnosis information**
2.1: Type of dementia
2.2: Date of first formal diagnosis
2.3: Medical Professional who first identified cognitive impairment or diagnosed dementia
2.4: Severity of dementia
2.5: Treatment with medication for cognitive impairment due to dementia
2.6: Treatment with medication for behavioural and psychological symptoms of dementia</td>
<td>**3 Current behaviour related to dementia and its impact on care**
3.1: Nature of current challenging behaviour
3.2: Frequency of occurrence of current challenging behaviour
3.3: Duration of episodes of current challenging behaviour
3.4: Disruption due to current challenging behaviour
3.5: Stress experienced as a result of current challenging behaviour</td>
</tr>
<tr>
<td colspan="2">**4 Coexisting health conditions**
4.1: Coexisting health conditions</td>
</tr>
<tr>
<td colspan="2">**5 Impact of caring**
5.1: Impact of care measure</td>
</tr>
</table>

This report recommends data elements for three dementia data collection levels, which differ in terms of the amount and complexity of elements included. The categorisation of elements into levels is not intended to be prescriptive but provides an indication of how information collected about people with dementia and their carers can be structured. Categorisation to any of the levels depends primarily on the underlying purpose and nature of the collection and the extent to which people with dementia and/or their carers are a significant proportion of the population of interest. Information about proxy-reporting is an overarching theme that applies to all levels because it can provide an indication of the accuracy of the information at any level.

The data elements may be collected on one occasion only, such as when a person accesses an emergency service, or at intervals depending on the nature and purpose of the collection.

12.2 Dementia data collection levels

Level 1: Essential data elements

In this level not all subjects about whom data are collected will have dementia. This level of dementia data is appropriate for collections or surveys that require an estimate of the population experiencing dementia or cognitive impairment and an indication of the accuracy of the reported data. These collections do not necessarily focus on dementia, and any relevant population may either include only a relatively small number of people with dementia, or more detailed information about the dementia syndrome is not required for effective and appropriate service delivery. Data elements about reporter details are included in this level because of their importance in assessing the accuracy of information. The data elements included in this level are:

- *Identification of cognitive impairment or dementia*
  - 1.1: Identification of cognitive impairment
  - 1.2: Identification of a diagnosis of dementia

- *Reporter details*
  - 6.1: Reporter status
  - 6.2: Relationship of proxy reporter to person of interest

Level 2: Highly desirable data elements

The subjects for these data elements are people with dementia. This level is appropriate for collections which require more detailed information about the syndrome itself. This may be for research reasons, or because a service population includes a significant proportion of people with dementia, and information about their condition is necessary to ensure appropriate treatment, care and services. Examples of such service collections might be the NRCP and ACAP.

Level 2 data elements include those in Level 1, with the addition of:

- *Cognitive impairment or dementia diagnosis information*
  - 2.1: Type of dementia
  - 2.2: Date of first formal diagnosis
  - 2.3: Medical professional who first identified cognitive impairment or diagnosed dementia
  - 2.4: Severity of dementia

Level 3: Desirable data elements

For a comprehensive picture of the population experiencing dementia, it is recommended that the whole suite of elements be used, including data elements at this level and the previous two levels. This level is appropriate for collections focusing on people with dementia, for example researchers or programs who deliver dementia-specific services. They may also be collected in contexts where a significant proportion of the service population have dementia, or are considered to be at risk of developing dementia, and this more detailed information is required for appropriate treatment and care management.

At the same time, there needs to be discretion in the use of these additional data elements, even in dementia-specific programs. The collection of any suite of data elements must be appropriate for the purpose of the service being provided and the characteristics of the clients, and feasible in the service setting and context.

Level 3 data elements include those in Level 1 and Level 2, with the addition of:

- *Cognitive impairment or dementia diagnosis information*
  - 2.5: Treatment with medication for cognitive impairment due to dementia
  - 2.6: Treatment with medication for behavioural and psychological symptoms of dementia
- *Current behaviour related to dementia and its impact on care*
  - 3.1: Nature of current challenging behaviour
  - 3.2: Frequency of occurrence of current challenging behaviour
  - 3.3: Duration of episodes of current challenging behaviour
  - 3.4: Disruption due to current challenging behaviour
  - 3.5: Stress experienced as a result of current challenging behaviour
- *Coexisting conditions*
  - 4.1: Coexisting health conditions
- *Measuring the impact of caring*
  - 5.1: Impact of care measure

12.3 Proposed data elements

The data elements in this framework can be used to improve the comparability of data collected in existing collections and in epidemiological research. The data elements are based on relevant national data standards where these are available or appropriate. Most importantly, they provide a description of the experience of dementia, which is generally unavailable from most existing national collections, and which is essential for a whole-of-a-person approach to assisting people with dementia.

The proposed data elements aim to be independently valid yet related to each other, and appropriate to the general context and scope of a range of data collection instruments and contexts.

Each data element stands alone to provide crucial information on an aspect of dementia, but the data elements together provide a more detailed account of the experience of people with dementia and their carers. They may also be used to monitor changes, over successive collection periods.

A data element is a basic unit of identifiable and definable information. The data elements in this chapter include a name, a definition, value domains and sometimes a guide for use.

- Each data element has a definition attached that expresses the essential nature of the data element and its differentiation from other data elements.
- A value domain provides a set of permissible values by which a data element can be implemented. Some elements include definitions of the value domains.

- The guide for use includes additional comments or advice on the interpretation or application of the value domains. Not all elements include a guide for use and none include detailed information about collection methodology. This is because the guide for use and the collection methodology are specific to the collection in which the element is included.

In this chapter, existing scales used by clinicians have been used as the basis of value domains for some data elements. The advantage of this approach is that the value domains are consistent with existing practice. However, this approach can be problematic.

The settings that scales are used in, and the experience and qualification of the users, can influence the accuracy of the information collected. If these scales are to provide the basis for data element value domains, it may be necessary to ensure that people collecting this data have adequate training in the use of the scales. Similarly if other information or tools are required to calculate the score, these should be available to anyone using the data element. This is especially important if the data element is used as part of a research study.

Scales can provide a starting point for measurement but users should be mindful that scales may be updated. If an update results in a change to the value domains or the essential meaning of the data element, the data element should be updated with a new version number and the commencement date of the new version should be recorded.

Many scales originate overseas and the language may not be 'Australian English'. For example, the Cohen Mansfield Agitation Inventory refers to 'Inappropriate robing/disrobing' which are not terms used in Australia. Terms can be substituted as long as the essential meaning is not compromised.

Identification of cognitive impairment or dementia

The following data elements are proposed to capture the range of information relevant to the identification of dementia and cognitive impairment.

Cognitive impairment is an indicator of possible dementia, particularly when the diagnostic process has not been undertaken or completed or is not conclusive. It is recognised that there are states of memory and other cognitive impairments that fall short of criteria for a diagnosis of dementia (Henderson 1994b). The criteria for cognitive impairment and dementia are closely linked, and there can be similar behavioural and functional outcomes.

Cognitive impairment is also associated with conditions other than dementia, including intellectual disability, closed head injury and discrete brain injury which is not progressive, as well as with depression or other reversible health conditions.

Cases of cognitive impairment due to intellectual disability should be excluded from collection. Intellectual disability is associated with impairment of intellectual functions, with limitations in a range of daily activities and with restriction in participation in various life areas. *Support may be needed throughout life, the level of support tending to be consistent over a period of time but may change in association with changes in life circumstances* (AIHW 2004g, italics added).

This data element is designed to collect information about cognitive impairments that would be considered to be a physical disability. Physical/diverse disability is associated with the presence of an impairment, which may have diverse effects within and among individuals. Included in this broad category is the subcategory *Acquired brain injury* which is used to describe multiple disabilities arising from damage to the brain acquired after birth. It can occur as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease, and so on. Effects include deterioration in cognitive, physical, emotional or independent functioning (AIHW 2004g).

These guidelines mean that someone with Down Syndrome would be excluded from the collection, until they subsequently develop dementia which causes a decline in their cognitive functioning beyond what had existed before. The guide for use outlines inclusion and exclusion guidelines to specify the collection criteria.

A number of screening and assessment tools are available to identify the presence of cognitive impairment (see Chapter 2 for a discussion of some of these). The data element capturing information about cognitive impairment simply records whether there is evidence of cognitive impairment. The value domain of a data element does not replace clinical judgement but can record the outcome of the assessment.

Similarly, *Identification of a diagnosis of dementia* allows for the collection of information that reflects the outcome of the process of diagnosing dementia.

Data element 1.1: Identification of cognitive impairment

Definition: *The presence of cognitive impairment in the person of interest.*

Value domains:

Definite

Probable

None

Unknown

Guide for use: *Cognitive impairment is impairment in one or more mental functions that comprise cognition. These functions include short-term memory (learning skills) or long-term memory, executive function (abstract thinking, judgement, problem solving) or other higher cortical function (aphasia, apraxia, agnosia, constructional abilities, calculation).*

If the person of interest has dementia, the code Yes should be selected and dementia diagnosis should also be collected.

Inclusions: *Any person whose cognitive functioning has been impaired as a result of acquired brain injury due to events such as accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, or degenerative neurological disease. This includes a person with pre-existing impairment of cognitive functioning, which had been stable and can be due to any cause, who has experienced a decline from a previous level of cognitive functioning.*

Exclusions: *Any person with cognitive impairment who has not experienced a decline from a previous level of cognitive functioning, including people with intellectual disabilities.*

Value meanings:

Definite: Presence should be coded where evidence of cognitive impairment is available based on the results of an assessment conducted by a medical practitioner.

Probable: The person of interest has not been assessed and the presence of cognitive impairment has not been definitively established but observations of behaviour and capacity in the person of interest by another person with a long-standing close relationship with the person of interest suggest impairment of cognitive functioning.

None: There is no suggestion of cognitive impairment based on the result of an assessment or the observed behaviour or capacity in the person of interest by another person with a long-standing close relationship with the person of interest.

Unknown: No information about cognitive impairment is available.

Source: National Dementia Data Analysis and Development Reference Group.

Data element 1.2: Identification of a diagnosis of dementia

Definition: *The presence of a diagnosis of dementia in the person of interest.*

Value domains:

Yes

No

Unknown

Guide for use: *Presence should be coded where a diagnosis of dementia is confirmed by a medical practitioner.*

Source: National Dementia Data Analysis and Development Reference Group.

Cognitive impairment or dementia diagnosis and treatment

The following data elements are proposed to capture a wider range of information about the diagnosis of dementia, the type of dementia which the diagnosis reveals, its severity and pharmaceutical treatments being used.

Type of dementia

The inclusion of the data element *Type of dementia* allows for the differentiation of aetiology which can impact on the manifestation, management and progress of the condition. It also reflects the information that the person of interest, family member, carer or friend is given at the time of initial diagnosis.

Data element 2.1: Type of dementia

Definition: *A code set representing the aetiology of dementia.*

Value domains:

Alzheimer's disease

Vascular dementia

Mixed dementia

Lewy body dementia

Frontal lobe dementia (includes Pick's disease)

Dementia in alcohol abuse (e.g. alcohol-related brain damage)

Dementia in other substance abuse

Dementia in Huntington's disease

Dementia in Parkinson's disease

Dementia in HIV disease

Dementia in Creutzfeldt-Jakob disease

Dementia of unspecified type

Other dementia of a type not listed above

Unknown type

Source: National Dementia Data Analysis and Development Reference Group, based on ICD-10-AM.

Date of first formal diagnosis

Date of first formal diagnosis is included to support the estimation of the length of time the person of concern has had dementia. In some circumstances it can also be used to calculate the length of time prior to admission to residential care and the duration of the caring role. Collecting the date of diagnosis is preferable to collecting data about the number of years that have elapsed since diagnosis, which changes yearly. Date only needs to be collected once, and it allows a more precise calculation of time.

A diagnosis is defined as the decision reached, after assessment, of the nature and identity of the disease or condition in a patient (National Health Data Committee 2004b). The diagnostic process includes the use of recognised and accepted assessment and diagnostic tools by a medical practitioner who is experienced in their use and interpretation. The diagnostic process results in a formal diagnosis. This does not mean that a definitive diagnosis always results from the diagnostic process but that the process should have been undertaken in order to arrive at a diagnosis.

This data element is intended to be collected for people who have been diagnosed with dementia. It is expected that the amount of information collected about the diagnosis is likely to increase and improve over time. In the past there has been reluctance on the part of some medical practitioners to initiate the diagnostic process because it was felt that there was no benefit in knowing, there was a fear of provoking distress, it was felt that the diagnosis would be difficult for the person to understand or that no benefit could be gained by the person being diagnosed. There is growing recognition of the value of both diagnosing dementia and informing the person and their family carers of their diagnosis, which will improve the amount and reliability of information about dementia diagnosis.

The date of diagnosis may be the date on which a conclusive diagnosis of dementia was determined, but this is not necessarily the date on which the diagnosis was relayed to the person of interest, their family member, carer or friend. The difference between the two dates is unlikely to be great and it is the provision of a diagnosis that is the most relevant to the person and/or another person. In addition, the person and/or other people are unlikely to be provided with the date on which a conclusive diagnosis was achieved and this date could be difficult to identify because of the number of investigations that would occur before a definitive (or close to) diagnosis was achieved.

On some occasions the diagnosis is not conveyed to the person of interest but is provided initially to another person. A survey of carers of people with dementia that was conducted in 1990 revealed that the diagnosis was given to the respondent alone in 65% of cases in the first instances and to the respondent and patient together in 21% of cases (Brodaty et al. 1990). A more recent consumer medication study revealed that the diagnostic information was provided to the carer, the person with dementia or another person (Alzheimer's Australia 2005a). In order to support the collection of accurate and comprehensive information, the date of diagnosis should therefore be the first date on which either the person of interest, their family member, carer or friend was provided with a diagnosis of dementia.

The data element *Date of first formal diagnosis* cannot always be fully completed, with missing information about the day or month of diagnosis. Where possible it is desirable to collect the full date of diagnosis and include guidelines for data collectors about how to deal with missing data (e.g. if the respondent only knows the month and year of diagnosis). When date is an estimated or default value, national health and community services collections typically use 0101 or 0107 or 3006 as the estimate or default for DDMM. Whatever approach is chosen for dealing with missing data, it should be documented and used consistently.

The collection of this information can also be accompanied by an additional data element, *Date accuracy indicator* (METeOR identifier 294429) which is an indicator of the accuracy of the components of a reported date. The concurrent collection of *Date accuracy indicator* would provide an indication of improvement in the accuracy of date of diagnosis information over time.

Data element 2.2: Date of first formal diagnosis

Definition: *The date on which a person of interest, family member, carer or friend is first provided with a diagnosis of dementia.*

Value domains:

DDMMYYYY

Guide for use: *The date of the first formal diagnosis marks the occasion when a medical practitioner first provides a diagnosis of dementia to a person, family member, carer or friend based on the outcome of a formal diagnostic process.*

A formal diagnosis is defined as a 'decision reached, after assessment, of the nature and identity of the disease or condition in a patient'. The diagnostic process includes the use of recognised and accepted assessment or diagnostic tools by a medical practitioner who is experienced in their use and interpretation.

If a medical practitioner subsequently revises the type of dementia, this does not influence the date of the first formal diagnosis.

Source: National Dementia Data Analysis and Development Reference Group, based on METeOR identifier 270544.

Medical professional who first identified cognitive impairment or diagnosed dementia

The data element *Medical professional who first identified cognitive impairment or diagnosed dementia* identifies the professional occupation of the person who diagnosed dementia (not the role of the person). This is because the role refers to functions, tasks or responsibilities, whereas the profession refers to the vocation or occupation, which is more appropriate in this case.

Data element 2.3: Medical professional who first identified cognitive impairment or diagnosed dementia

Definition: *The professional occupation of the person that identified cognitive impairment or diagnosed dementia in the person of interest.*

Value domains:

General practitioner

Specialist physician

Geriatrician

Psychogeriatrician or Psychiatrist

Neurologist

Other

Unknown

Guide for use: *A formal diagnosis is defined as the decision reached, after assessment, of the nature and identity of the disease or condition in a patient. The diagnostic process includes the use of recognised and accepted assessment and diagnostic tools by a Medical Practitioner who is experienced in their use and interpretation.*

Source: National Dementia Data Analysis and Development Reference Group.

Severity of dementia

A data element that collects information about the severity of dementia has been included because of the importance of information about the extent of the condition and the impact it has on the person with dementia and those caring for them. The severity of dementia can be measured using any of a number of severity scales currently in use. For example, the Global Deterioration Scale (GDS) is used to assess severity and comprises part of a clinical rating system called the GDS staging system (Reisberg et al. 1982). There are three independent measures included: the GDS, the Brief Cognitive Rating Scale and the Functional Assessment Staging Measure.

A consistently used severity scale would allow the collection of nationally comparable data about dementia severity. Developing a data element for this concept, however, needs to take account of the diversity of approaches used by clinicians and care providers to ascertain severity. Two options to achieve this include the development of a data element whose value domains are mappable to a range of severity scales, or the development and implementation of a data element based on an agreed nationally consistent standardised approach to measuring severity.

The Clinical Dementia Rating (CDR) scale is an example of a scale that could be used as the basis of a data element. It describes six domains: memory, orientation, judgement and problem solving; community affairs; home and hobbies; and personal care (Hughes et al. 1982, Morris 1993). The severity categories are *Healthy*, *Questionable dementia*, *Mild dementia*, *Moderate dementia* and *Severe dementia*. It is usually administered by clinicians in the setting of detailed knowledge of the individual patient. Clinicians using this tool require training in its use. A scoring algorithm is used to calculate the severity of dementia. The CDR requires that the assessor determine the score only if it is due to cognitive loss, but this could be difficult to determine. If one domain of the score cannot be completed due to characteristics other than cognitive impairment, this would influence the outcome of the score.

Whatever scoring system is used as the basis of a data element, the element is not the assessment tool; it records the result of the assessment or evaluation. The user guide should specify that a value cannot be allocated without the use of the assessment tool and/or calculation of the algorithm used to derive a result.

Data element 2.4 presented below is based on the CDR. There is some research which suggests that there may be value in adding an additional category of *Advanced dementia* (characterised by complete dependence on carers for all aspects of daily living and with no semblance of memory function) (Draper 2004). Further, most dementia severity scales include a value for no dementia—'no cognitive decline' (GDS) or 'healthy' (CDR scale). This reflects that the scales are used to detect both the presence and severity of the disorder. The proposed data element below is intended to be collected about people with dementia so no value for normal has been included.

The AIHW considers that this data element should be the subject of further work and consultation with clinicians and care providers in order to determine the most appropriate basis for an agreed national data element.

Data element 2.4: Severity of dementia

Definition: *A code set representing the extent of the dementia.*

Value domains:

- *Very mild*
- *Mild*
- *Moderate*
- *Severe*

Guide for use: *This data element should be based on the assessment of a clinician who has had training in the use of the Clinical Dementia Rating scale based on a detailed knowledge of the person of interest.*

Source: Based on Hughes et al. 1982 and Morris 1993.

Treatment with medication

The data elements that describe treatment with medication for dementia are proposed to capture information relevant to medication usage in people with dementia. Pharmacological interventions for people with dementia are most commonly prescribed to manage behavioural and psychological symptoms and other effects of cognitive impairment. These pharmaceuticals are not limited to cholinesterase inhibitors but include antipsychotic medication that is prescribed to manage behavioural problems.

The collection of information about medication for cognitive impairment allows for the analysis of usage of commonly prescribed medication to assist cognition. Because the range of currently available medications is limited, the proposed data element (2.5) names individual medications. Together with the information about *Type of dementia* it would be possible to identify changing prescribing patterns, reflecting the expansion of usage of antidementia medication for vascular and Lewy Body dementia.

The data elements that deal with medication usage include a value domain '*No medication taken*'. This is to ensure the relevance of the data element for the whole population whether or not they are taking medication, and is intended to improve the accuracy of the data and their application. If a decision is made to collect this data element, it should be collected for all people in the collection, not only those taking medication. Collecting the information about the whole population will enable the estimation of medication usage rates for the total population. If the question is only completed for persons who take medication there would be uncertainty about whether those who had not responded were not taking medication, or they chose not to answer or they were not asked the question. The ambiguity of a simple 'no' response (sometimes called the 'flavours of null') can influence the accuracy and completeness of the data collected. The proposed data elements aim to minimise the adverse influences on aggregated data as much as possible.

The wording of the proposed data elements asks about what medication is being taken as opposed to what medication is prescribed. This recognises that although medication can be prescribed, it is not necessarily taken. Similarly, it allows for the inclusion of complementary medications.

The collection of the name of the medication in data element 2.5 ensures that the lowest level of granularity is available. It can then be aggregated for analysis and reporting and could be allocated to classes of the Anatomical Therapeutic Chemical (ATC) classification system if required. If only aggregated information is collected it cannot be disaggregated to identify specific medications. This approach also supports the most common way in which medication usage is ascertained (i.e. 'What medicines, tablets or drugs are you taking?').

This list only includes currently prescribed medication. As newer medication becomes available it would need to be coded initially to the *Other medication* value. When introducing the data element to a specific collection, the guide for use should specify that this is the approach to be taken. A review of the *Other* category should be undertaken at defined intervals. This category usually comprises 5–10% of responses. Once the percentage of response in this category rises above an agreed level, the specified medications that have been recorded should be reviewed and if necessary the value domains should be updated.

Complementary medications (also known as 'traditional' or 'alternative' medicines) are not separately included in the list of medications, but this does not preclude collection of this information in the *Other* category. The same approach to incorporating this information into changes to the data element can be used.

Data element 2.5: Treatment with medication for cognitive impairment due to dementia

Definition: *The medication, if any, the person of interest is currently taking to manage cognitive impairment.*

Value domains:

No medication taken

Donepezil (Aricept)

Galantamine hydrobromide (Reminyl)

Rivastigmine (Exelon)

Memantine (Ebixa)

Other medication (please specify)

Not stated/inadequately described

Source: National Dementia Data Analysis and Development Reference Group.

Data element 2.6 records information about the class of medication rather than the individual trade names of medications. This is because a wider range of possible medications are available for the treatment of behavioural and psychological symptoms. The use of this data element requires allocation of the medication to a category, which can increase time and burden for those who are reporting the data. A list of commonly used medication and the classes they belong too should be included in the guide for use to allow data collectors to allocate medication to a specified class.

The categories that are currently included in the data element 2.6 are restricted to those in the Psycholeptics and Psychoanaleptics levels (pharmacological/therapeutic subgroup) within the Nervous system group of the ATC classification. More detail is available at lower levels of the classification. The ATC has been endorsed by the National Health Information Group for inclusion in the Australian Family of Health and Related Classifications, and as a national health data standard for reporting on therapeutic drug use.

Data element 2.6: Treatment with medication for behavioural and psychological symptoms related to dementia

Definition: *The class of medication, if any, the person of interest is currently taking to manage behavioural and psychological symptoms of dementia.*

Value domains:

No medication taken
Psycholeptic
Antipsychotics (typical and atypical)
Anxiolytics
Hypnotics and sedatives
Psychoanaleptics
Antidepressants
Psychostimulants and nootropics
Psycholeptics and psychoanaleptics in combination
Antidementia drugs
Other medication (please specify)
Not stated/inadequately described

Source: ATC classification.

Current behaviour related to dementia and its impact on care

Challenging behaviour is described as 'any behaviour associated with the dementing illness which causes distress or danger to the person with dementia and/or others' (Bird 2003). An integral part of the description is the impact the behaviour has on the person with dementia and on others, not only the type of behaviour. A description of current behaviour is insufficient on its own. The person with dementia and care providers will vary in terms of the extent to which behaviours are experienced as disrupting or challenging. Training and support for carers may also increase their capacity to manage some behaviours more effectively, thereby reducing their disruptive effect. At the same time, caregiver attributes and behaviour may contribute to behavioural and psychological symptoms in the person with dementia (Sink et al. 2006).

Quantification of behavioural disturbance is important in determining disease severity and prognosis and has a significant impact on carer stress. It is not known whether changes in behaviour result from disease-related neuro-chemical imbalance, from psychological reactions to the cognitive deficits associated with the dementing process or from concomitant physical or psychiatric illness (Baumgarten et al. 1990). The data element *Nature of current challenging behaviour* (3.1) does not encompass the psychological causes of the behaviour, but the manifestation.

It is recommended that detailed information about the nature of psychological symptoms experienced by the person with dementia, including depression and anxiety, is collected using the data element *Coexisting health conditions* (4.1) that is described later in this chapter.

The goals of managing challenging behaviour are to reduce the disruptive effects of the behaviour and/or amelioration of distress or danger (Bird et al. 2002). Management strategies include psychosocial approaches, pharmacotherapy, and education and support for carers or nursing staff.

The impact of the behaviour on the person with dementia, family members, carers, friends or other people determines whether it is considered challenging rather than the behaviour itself and may lead to referral to specialist services for help. Additionally the impact of the behaviour depends on the environment and setting in which it occurs; wandering at home into a garden without a secure fence is more likely to cause concern that wandering in a secure facility.

The guide for use for the data element *Nature of current challenging behaviour* defines current behaviour as 'any behaviour occurring over the previous four weeks'. This definition of 'current' could exclude people who manifest challenging behaviour very infrequently but some constraint on the period over which the behaviour is occurring is usually required in order to capture reliable information about behaviour of concern to family members, carers or health and care workers. A further difficulty with this proposed time period is that it may result in the capture of information about behaviours which are occurring in response to significant changes in the person's environment (e.g. entry to residential aged care, or loss of a carer). On the one hand, these behavioural responses may be atypical of the individual's usual pattern and the collected information may not be regarded as useful for understanding the impact of dementia. On the other hand, any such behaviour requires a care and/or treatment response at the time and may be typical of the individual's response to stressful situations.

The primary focus of the data elements below is to collect a range of information about current challenging behaviour from the perspective of those around them, particularly carers. The inclusion of the data elements *Frequency of occurrence of current challenging behaviour* (3.2) and *Duration of episodes of current challenging behaviour* (3.3) reflects that the frequency and duration of challenging behaviour are important indicators of its impact.

It may not be appropriate to collect both *Frequency of occurrence of current challenging behaviour* and *Duration of episodes of current challenging behaviour*. Some types of behaviour may feel disruptive because they occur often (e.g. hiding things, throwing things). Other behaviours are best defined by how long they last when they do occur, as well as how often they occur. Yelling, screaming or pacing are examples. Both data elements are included here. However, the appropriateness of collecting either or both will depend on the nature of the behaviour manifested.

If the appropriate set of data elements is used they can describe the multifaceted nature of challenging behaviour and assist in understanding the reasons why carers and family members find the behaviour distressing and disruptive. This can be used to guide the development and provision of appropriate information, support and assistance to those caring for people with dementia who manifest these behaviours. Collection at different intervals would facilitate monitoring changes in behaviour and its impact over time, although these would not be sufficient for evaluation purposes.

Collecting information about the frequency of behaviour is most useful if it can be collected in respect of each behaviour. The matrix in Table A12.1 is an example of how this could be achieved.

Data element 3.1 is based on the Cohen-Mansfield Agitation Inventory. Other scales and inventories of challenging behaviours also exist, such as the Dementia Behaviour Disturbance Scale (Baumgarten et al. 1990) and the Problem Behaviour Checklist (Brodaty & Hadzi-Pavlovic 1990). No single existing scale was considered by the National Dementia Data Analysis and Development Reference Group to be completely satisfactory. The Cohen-

Mansfield Agitation Inventory is widely used, including by the trial ACFI, and hence has been proposed as the basis of data element 3.1. One limitation of the Cohen-Mansfield inventory is that it doesn't give any measure of severity or impact. Further work is required to develop this data element, including issues associated with interpretation and weighting of responses to individual items.

Data element 3.1: Nature of current challenging behaviour

Definition: *The challenging behaviour the person exhibits.*

Value domains:

Does not exhibit challenging behaviour
Verbal aggression
Hitting
Grabbing
Tearing things
Pushing
Biting
Spitting
Physical sexual advances
Pacing
Inappropriate robing/disrobing
Performing repetitive mannerisms
Trying to get to a different place
Handling things inappropriately
Throwing things
General restlessness
Constant requests for attention
Repetitious sentences/questions
Complaining
Negativism
Making strange noises
Screaming
Verbal sexual advances
Hiding things
Hoarding things
Other
Not stated/inadequately described

Guide for use: *Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others (Bird 2003).*

Current behaviour includes any behaviour occurring over the previous four weeks.

Source: National Dementia Data Analysis and Development Reference Group, based on Cohen-Mansfield Agitation Inventory.

Data element 3.2: Frequency of occurrence of current challenging behaviour

Definition: *How often a person exhibits challenging behaviour due to dementia.*

Value domains:

Not applicable

Less than once a week, but still occurring

Once or twice a week

Several times a week (three or more)

Once or twice a day

Several times a day (three or more)

Several times an hour (two or more)

Other

Not stated/inadequately described

Guide for use: *Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others (Bird 2003).*

Current behaviour includes any behaviour occurring over the previous four weeks.

Source: National Dementia Data Analysis and Development Reference Group, based on Cohen-Mansfield Agitation Inventory.

Data element 3.3: Duration of episodes of current challenging behaviour

Definition: *The average number of minutes, from start to finish, that a person exhibits challenging behaviour due to dementia.*

Value domains:

Not applicable

Number (MMMM)

Not stated/inadequately described

Guide for use: *Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others (Bird 2003).*

Current behaviour includes any behaviour occurring over the previous four weeks.

Source: National Dementia Data Analysis and Development Reference Group.

The above data elements can be used to describe the characteristics of challenging behaviour. However, the extent to which such behaviour contributes to distress for the person with dementia, family members and carers is highly variable. The impact of this behaviour cannot be simply explained by differences in frequency or the apparently less disruptive behaviour of pacing compared with screaming. The impact of challenging behaviours is also affected by personal factors, the extent to which modifications to the physical environment have facilitated the management of the behaviour, the development of effective strategies for managing the behaviour, and the nature and type of support and education available for the carer.

In order to understand the impact of challenging behaviours, it is also necessary to collect data which specifically focus on the extent to which the carer finds the behaviour stressful or disruptive (Caldwell & Bird 2004). As discussed earlier, these data elements record subjective measures of the impact.

Data element 3.4: Disruption due to current challenging behaviour

Definition: *The extent of disruption to usual activities that results from the challenging behaviour.*

Value domains:

Not disruptive
Mildly disruptive
Moderately disruptive
Very disruptive
Extremely disruptive

Guide for use: *Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others (Bird 2003).*

Current behaviour includes any behaviour occurring over the previous four weeks.

Source: National Dementia Data Analysis and Development Reference Group, based on Caldwell & Bird 2004.

Data element 3.5: Stress experienced as a result of current challenging behaviour

Definition: *The extent of stress experienced by a family member, carer, friend or other person in response to challenging behaviour.*

Value domains:

No stress
Little stress
Moderate stress
High stress
Extreme stress

Guide for use: *Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others (Bird 2003).*

Current behaviour includes any behaviour occurring over the previous four weeks.

Source: National Dementia Data Analysis and Development Reference Group, based on Caldwell & Bird 2004.

Coexisting health conditions

Chapter 5 reported data which reveal that people with disabilities and dementia have a higher average number of comorbidities compared with others. The existence of comorbid conditions has implications for the diagnosis, treatment and care management of people with dementia.

A coexisting condition is one that exists at a point in time, usually the time when the information is collected. These conditions include pre-existing conditions, conditions that have become evident after the diagnosis and conditions that have arisen because of dementia or the care received for dementia.

Data item 4.1: Coexisting health conditions

Definition: *Coexisting diseases and conditions that have been diagnosed by a clinician and are currently being treated, including mental health conditions, and other diseases, illnesses or conditions.*

Value domains:

No coexisting health condition
Certain infectious and parasitic diseases
Neoplasms
Diseases of the blood and blood-forming organs and certain disorders involving the immune system
Endocrine, nutritional and metabolic disorders
Mental and behavioural disorders
Diseases of the nervous system
Diseases of the eye and adnexa
Diseases of the ear and mastoid process
Diseases of the circulatory system
Diseases of the respiratory system
Diseases of the digestive system
Diseases of the skin and subcutaneous tissue
Diseases of the musculoskeletal system and connective tissue
Diseases of the genitourinary system
Certain conditions originating in the perinatal period
Symptoms, signs and abnormal clinical and laboratory findings not otherwise specified
Injury, poisoning and certain other consequences of external causes

Guide for use: *The presence of a coexisting health condition may indicate a need to engage other clinical support.*

Source: Based on ICD-10-AM.

The presence of a coexisting health condition may indicate a need to engage other clinical support. The list of health conditions that are included in the data element that is proposed is not extensive or detailed enough to reflect the intricacies of clinical management but merely provides an indication of the need for additional care, not the specific nature of that care. Although the list includes some conditions that are risk factors for dementia, accurate identification of risk factors is more suited to the collection of detailed medical histories rather than by the use of this data element.

Health conditions can be either self-diagnosed or diagnosed by a clinician. In this data element self-reported health conditions are excluded to enhance the reliability of the information collected. Health conditions are included if they are currently being treated, and excluded if they occurred in the past and are no longer current or being treated, for example, postnatal depression.

The coexisting conditions are grouped into the chapter headings of the ICD. This classification was used in order to maximise the comparability of information collected about health conditions across collections. It is used as the basis of health condition collection in the Australian Bureau of Statistics collections.

Only the chapter headings are included in the data element; the suggested list of conditions based on the ACAP code list for *Health condition – short* is included in Table A12.2 (AIHW

2002a). The contents of the list are not exhaustive and may not meet the data needs of all agencies. It can be expanded within the existing chapter structure to meet the needs of individual collections, particularly in respect of conditions and symptoms which are integral to dementia.

For example, anxiety and depression are particularly common amongst people with dementia. Between 30% and 50% of people with Alzheimer's disease have depression and similar rates occur in other types of dementia (Olin et al. 2002). Some symptoms of depression such as sleep disturbance, apathy, lethargy and decreased concentration are common to dementia, and may result in certain types of behaviour (e.g. negativism or general restlessness) which would be captured through the data element *Nature of current challenging behaviours.* These conditions are included in the Mental and Behavioural disorders chapter of the ICD-10 (*psychoses and depression/mood affective disorders; phobic and anxiety disorders).* It is important to collect information about the presence of these conditions at a sufficient level of detail through the data element *Coexisting health conditions.* However, care should be taken to only record depression or anxiety if they have been diagnosed by a medical practitioner, using tools specific to assessing depression in people with dementia such as the Cornell Scale for Depression.

Measuring the impact of caring

The provision of care by the family and friends of people with dementia constitutes the largest care sector for people with dementia. This is not unique to people with dementia. However, there is increasing recognition that the provision of treatment and care for people with dementia needs to acknowledge the part carers play. Service provision needs to include both carers and people with dementia—people in care relationships—and there is growing evidence that support for carers is an essential component in the provision of care and treatment for the person with dementia (AIHW: Hales et al. 2006). Indeed some services, such as those provided by Alzheimer's Australia, initially helped carers; people with dementia became clients in more recent times. Understanding the impact of caring is critical to understanding how carers can be supported.

Although data about the impact of caring is not a dementia-specific data requirement, the inclusion of such data elements is recommended for any level 3 collection. These data elements should go beyond the information collected by data element 3.5 *Stress experienced as a result of current challenging behaviour*, which does not capture the overall impact of the caring role. This would particularly be the case where behavioural disturbances are either absent or infrequent (which may be the case in 'advanced' stages of dementia as described by Draper 2004:66). Similarly, if the behaviours occur but do not cause the carer to feel stress, other aspects of their caring role such as feelings of isolation or financial disadvantage may contribute to carer stress.

Chapter 6 discussed research suggesting that caregivers of those with an intellectual disability reported significantly more positive components of caregiving than the caregivers of those with a dementia-related disorder, and carers of those with dementia or undiagnosed memory loss were more likely to express anger and resentment than carers of those with a physical impairment. Research in the United States by Clipp & George (1993) (cited in Parks & Novielli 2000) suggests that caring for someone with dementia is associated with a higher level of stress than caring for someone with functional impairment from another type of chronic illness. Data collected through the inclusion of these data elements will contribute to better understanding whether and in what ways the needs of this group of carers differ from those of other carers (e.g. carers of people with an intellectual disability).

Caring for a person with dementia can cause adverse impacts on the carer although not all carers experience caring negatively. 'Carer burden' is a term that has been used to describe the negative impacts on carers and been defined as 'the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults' (George & Gwyther 1986:253, cited in Vitaliano et al. 1991:67). The impact of caring is not restricted to family members but includes anyone who provides care. The stress of caring is a widely recognised risk factor for entry to a long-term residential aged care facility and for formal service use in general. The stress that can arise from caring is recognised as causing psychiatric and physical consequences. Depression and anxiety are the most commonly observed psychiatric conditions observed in carers, whilst activation of the hypothalamic-pituitary-adrenal axis and impaired immune function in older caregivers, and increased systolic blood pressure in carers who had ceased employment, were observed. In addition carers are at an increased risk of injury due to the physical demands of caring (Volicer 2005).

Amongst carers who experience stress, the impact has been defined as both objective burden (e.g. disruption of family life) and subjective burden (e.g. caregiver response to the situation). Objective burden reflects disruption to finances, role, family life, supervision and neighbour relations, whilst subjective burden refers to feeling embarrassed, overloaded, trapped and resentful and excluded (Thompson & Doll 1982, cited in Vitaliano et al. 1991). Not all caregivers experience both types of burden nor would they necessarily use the word burden to define the impact of their role, but measures that capture the impact of caring should ideally be able to capture both objective and subjective burden. Subjective measures are harder to collect even when collected with a standardised measurement tool (AIHW 2003a).

Predictors of an adverse carer impact identified in a multinational review include the care recipient characteristics such as severity of the dementia, behavioural disturbance, the gender and age of the care recipient at disease onset and the hours of care required. Carer characteristics include the gender and age of the carer, the duration of caregiving, the relationship to the patient, the socioeconomic status of the care and their self-rated competence or self-efficiency (Torti et al. 2004).

There are a number of possible scales of carer stress or carer burden which would be appropriate for use in collecting such information. This project does not recommend any particular scale for use. Its recommendations are limited to the following:

- Data elements about the impact of care should be included at least in Level 3 collections.
- The data element(s) should be based on a reputable and validated instrument that covers a range of possible impacts.
- The data element(s) should be mappable to the ABS SDAC, thus facilitating comparison with the general population of carers.
- Reporting should include an overall score of carer stress, along with scores on individual items making up the scale or instrument used.
- The same scale should be used for repeat measures as appropriate to monitor change over time.

Two widely used scales used for measuring caregiver burden are the Zarit Burden Interview and the Caregiver Strain Index (CSI).

The Zarit Burden Interview is a 22-element self-reported inventory that examines burden associated with functional and behavioural impairments and the home care situation, and includes questions such as: 'Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?' and 'Do you feel your health has suffered because of your involvement with your relative?' (Zarit et al. 1980). The elements are worded subjectively focusing on the affective response of the caregiver (Vitaliano et al. 1991). A high score correlates with higher level of burden.

The CSI was developed using responses from 85 individual carers of older patients who had returned home after hospitalisation for a major episode of illness or surgery (Robinson 1983). In this 13-element self-report scale, scoring is dichotomous and subjective burden can be inferred through the endorsement of certain elements (Vitaliano et al. 1991). It is included in the Australian Government Department of Veterans' Affairs outcome measurement guidelines and in the Queensland Ongoing Needs Identification assessment guidelines.

Experience in the Aged Care Innovative Pool dementia and disability services evaluation conducted by the AIHW suggested that service providers often feel more comfortable requesting caregivers to complete the CSI than the Zarit Burden Interview (AIHW: Hales et al. 2006). A positive screen (7 or more elements positive) on the CSI indicates a need for more in-depth assessment to facilitate appropriate intervention.

Table 12.2: Caregiver Strain Index

Here is a list of things that other people have found to be difficult when caring for someone who needs support. Please circle YES if they apply to you or NO if they do not apply to you.	
1. My sleep is disturbed (e.g. because the person I care for is in and out of bed or wanders around all night)	YES / NO
2. It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help)	YES / NO
3. It is a physical strain (e.g. because of lifting in and out of chair; effort of concentration is required)	YES / NO
4. It is confining (e.g. helping restricts my free time or I cannot go visiting)	YES / NO
5. There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)	YES / NO
6. There have been changes in personal plans (e.g. had to turn down a job; could not go on holiday)	YES / NO
7. There have been other demands on my time (e.g. from other family members)	YES / NO
8. There have been emotional adjustments (e.g. because of severe arguments)	YES / NO
9. Some behaviour is upsetting (e.g. incontinence, trouble remembering things, or accusing people of taking things)	YES / NO
10. It is upsetting to find the person I care for has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)	YES / NO
11. There have been work adjustments (e.g. because of having to take time off)	YES / NO
12. It is a financial strain	YES / NO
13. Feeling completely overwhelmed (e.g. because of worry about the person I care for; concerns about how I will manage)	YES / NO
Total score (count YES responses)	

Source: Robinson 1983.

A data item on the effect of the caring role on carer wellbeing was proposed in a related project (*Australian incontinence data analysis and development*) (AIHW 2006a). The item is modelled on selected relevant data items collected in the ABS SDAC. Each of the values in the value domain is drawn from questions directed to primary carers in the SDAC, and concern the carer's physical and emotional response to the caring role, and the effect of the caring role on their relationship with the person being cared for, other family members and friends.

A similar data element might also be considered for the collection of information about the impact of caring for a person with dementia with the inclusion of additional value domains:

- No effect of caring role (to cater for carers who do not experience effects on their physical and emotional wellbeing)
- Other effect of caring role on physical and emotional wellbeing
- Not stated/inadequately described.

Box 12.1: Dementia—effects on carer physical and emotional wellbeing

Definition: *The effects on a carer's physical and emotional wellbeing associated with assisting a person to manage their dementia.*

Example value domains:

Feels weary or lacks energy due to caring role
Sleep frequently interrupted due to caring role
Feels worried or depressed due to caring role
Feels angry or resentful due to caring role
Relationship with person being cared for affected due to caring role
Relationships with other family members affected due to caring role
Relationships with friends affected due to caring role
Other effects
No effect due to caring role
Not stated/inadequately described

Source: Based on ABS Survey of Disability, Ageing and Carers.

Finally, screening tools such as the 28-item General Health Questionnaire (e.g. GHQ-28) could be used to collect data on the mental health of carers. However, this tool is focused on subjective aspects of carer stress and does not include items relating to disruptions to work, relationships and family life.

The AIHW considers that a data element to collect information about the effect of the caring role on carers of people with dementia should be the subject of further work and consultation with care providers and clinicians in order to determine the most appropriate basis for an agreed national data element.

Reporter details

As discussed earlier, understanding the source of reported information provides an indication of the accuracy of the information collected. Gradual decline is a key characteristic of dementia and the nature and extent of the decline can only be appreciated if the proxy reporter has known and been able to observe the person with dementia for some time.

In addition to the data element *Reporter status* (6.1), one other element is proposed: *Relationship of proxy reporter to person of interest* (6.2). This element captures information that can provide an indication of the accuracy of the reported information based on the nature of the relationship between the reporter and the person of interest.

Data element 6.1: Reporter status

Definition: *The source of reported information regarding the person of interest.*

Example value domains:

Self-reported
Reported by another person (proxy reporter)
Not stated/inadequately described

Guide for use: *If another person reports on behalf of the person of interest, that person is a proxy reporter.*

Source: National Dementia Data Analysis and Development Reference Group.

Data element 6.2: Relationship of proxy reporter to person of interest

Definition: *The nature of the relationship between the proxy reporter and the person of interest.*

Example value domains:

Clinician/Medical practitioner
Care worker
Spouse or partner
Family member other than spouse or partner
Friend or neighbour
Other
Not stated/inadequately described

Source: National Dementia Data Analysis and Development Reference Group.

12.4 Recommendations for future data development

This report reviewed Australian data collections to determine the nature and extent of data about dementia that are currently collected in Australia, and to guide the development of draft data elements for possible inclusion in future collections.

This chapter proposes 14 data elements that may be used to collect information on the prevalence, type, severity, behavioural manifestations and impact of dementia among Australians, and the types of medications they use to manage their dementia. The chapter also recommends that data about the impact of caring should be included in collections. Data about functional limitations is clearly also of importance. However, the focus of this project was on dementia-specific data. It is assumed that data about functional impairment and other relevant sociodemographic characteristics are already (or will be) collected.

Further work is required to develop these data elements, particularly in respect of dementia severity and impact on carers. As research, treatment and management modalities and the provision of care in the field of dementia change, new information needs may also become evident. These might include the capacity to collect the outcomes of screening and assessment tools and information about new medications or psychosocial interventions. The project to develop the Dementia Outcomes Measurement Suite being undertaken over the next year will be an important part of the next stage of developments in this area.

Appendix: Expenditure method

The 20 questions from the residential classification scale questionnaire were mapped to questions from the ABS Survey of Disability Ageing and Carers. From this mapping an estimate was made of the likely response of each SDAC person to the RCS questions. A proxy RCS score (SDAC-RCS score) is calculated by applying a response weight to the likely response and summing the response weights for the mapped SDAC questions. The distribution of the SDAC-RCS score was adjusted to fit as closely as possible the distribution of the RCS scores from the RCS file. This provided the cut-off points for the SDAC-RCS between each level on the RCS scale—e.g. the highest scoring 20% allocated to category 1, the next 25% to category 2 and so on in line with the distribution from the RCS.

The conditions[14] recorded in the SDAC were allocated across eight categories grouped according to similarities in the likely need for assistance for the condition. These eight groups are listed in Table 8.6 (and Table A8.1 for a list of conditions). Each group was only counted once, which means that someone who has two conditions that are allocated to the same group only has one of them counted (i.e. the disease group is an on/off variable and does not count multiple conditions within each group). For each record, each condition group is given either a '1' or a '0' and an 8-digit condition list is generated which depends on the value for each condition group. Figure A8.1 shows the derivation of the 'condition list' from the 'condition groups 1–8' for a person with dementia or Alzheimer's disease, one or more mental health problems, one or more communication problems and one or more other conditions.

A regression model was established using all possible combinations of the condition list variable. In this model the dependent variable is the RCS score and there are 239 independent variables representing the combinations of conditions. The model has 207 degrees of freedom, an F value of 13.36 (Pr > F = 0.0001) and an adjusted R^2 of 0.39.

From the model a predicted RCS score is generated for each combination of the condition groups which provides an average RCS score and hence level of funding for each independent variable within the model.

Comparisons were then made between sets of conditions with dementia and the same set of conditions without dementia and the impact of the dementia on that set of conditions in terms of change in RCS score and associated level of funding ascertained. For example, the result for dementia, stroke, mobility and communication is compared to the result for stroke, mobility and communication. If the group of conditions with which to compare does not feature in the data set, then the last (eighth) digit of the condition list is changed and a comparison is made with the new condition list. If this does not reveal a match, then the second last (seventh) digit is changed. For example, the condition list '10001010' needs to be compared with condition list '00001010'. If this does not exist in the data set, then the eighth digit is changed and the comparison is made with the condition list '00001011'. In turn if this does not exist in the data set, then the seventh digit is changed and the comparison with '00001000' is used to determine the impact of dementia.

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[14] High cholesterol and hypertension have been left out of this analysis since they do not add significantly to the need for care.

The level of funding for dementia is the difference between the level of funding for the group of conditions without dementia and the level of funding for the group of conditions plus dementia. Using this method, a cost of each disease group is allocated to each record in the SDAC according to the conditions listed for that record. The total allocated cost is scaled to the total basic funding for each RCS group.

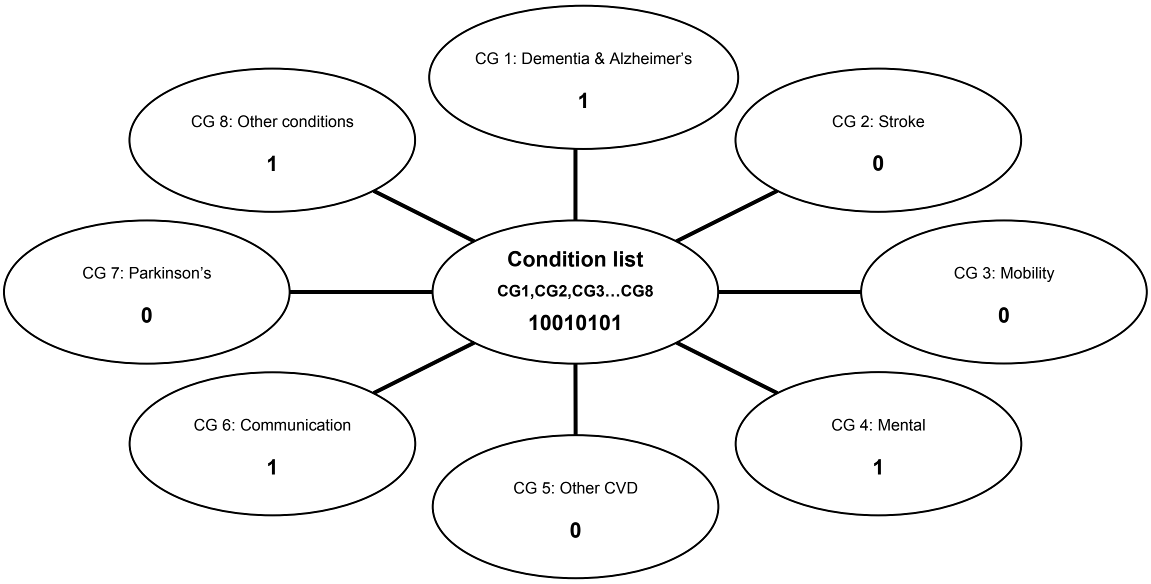

Figure A8.1: Derivation of the condition list from the condition group variable for a residential aged care resident with dementia or Alzheimer's disease, one or more mental health problems, one or more communication problems and one or more other conditions

Appendix tables

Table A5.1: Summary of published Australian studies: age and sex distribution of care recipients

	Age			Sex	
Study	**Range**	**Mean (std dev)**	**Other details**	**% female**	**% male**
Victorian Carers' Program					
Schofield et al. (1998b)			Includes recipients >50		
Dementia			93% >70	77	23
Undiagnosed memory loss			76% >70	60	40
Physical impairment			77% >70	68	32
Brodaty et al. (2005)			30% 53–73, 45% 74–82 & 25% >83		
Dementia caregivers' training programme	49–79	70.2 (6.5)	Eligible patients <80	48	52
Brodaty & Hadzi-Pavlovic (1990)	51–91	72.2 (8.3)	Numbers are for patients who were alive at survey	54	46
Bindoff et al. (1997)					
Dementia		76.2 (12.5)			
Intellectual disability		23.5 (7.8)			
Physical disability		54.2 (25.4)			
Luscombe et al. (1998)			Eligible recipients <65		
Alzheimer's disease		56.5 (5.8)		51	49
Huntington's disease		46.3 (10.5)		39	61
Other dementias		54.5 (8.4)		24	76
LoGiudice et al. (1999)				57	43
Control		77.5 (8.6)		61	39
Memory clinic		72.9 (7.9)		52	48
Bruce & Paterson (2000)	57–93	79		46	54
Leong et al. (2001)					
Schofield (2001)					
Bruce et al. (2002)					
Low et al. (2002)	49–95	82.9 (7.8)		74	26
Ward et al. (2003)	62–93	79.7		48	52
Bruce et al. (2005)					
Helmes et al. (2005)	55–96	78.49 (8.56)		63	37

Table A6.1: Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Victorian Carers' Program	1993	94% of 26,000 randomly selected Victorian households agreed to answer the screening question	Do you or does anyone in your household take the **main** responsibility in caring for someone who is aged or has a long-term illness, disability or other problem?		Included both co-resident & non-resident carers & carers of people in residential care	Of the self-identified carers, 976 (78%) participated in an extensive telephone interview
Schofield et al. (1998b): *Carers of people aged over 50 with physical impairment, memory loss & dementia: a comparative study*				Subsample included caregivers of people aged over 50 years with physical impairment, memory loss or dementia		Subsample included 196 carers of those with physical impairment, 182 carers of those with memory loss & 117 carers of those with dementia
Brodaty et al. (2005): *Why caregivers of people with dementia & memory loss don't use services*			Principal carers	Subsample included caregivers of people with dementia or memory loss	Subsample included caregivers of people living in the community	109 carers
Dementia caregivers' training programme Brodaty & Gresham (1989): *Effect of a training programme to reduce stress in carers of patients with dementia* Brodaty & Peters (1991): *Cost effectiveness of a training program for dementia carers* Brodaty et al. (1997): *The Prince Henry Hospital dementia caregivers' training programme*		Subjects were recruited by referral or publicity & the programs were conducted in a Sydney hospital		Mild to moderate dementia Aged less than 80 years old Could understand English Did not wander & were not aggressive	Eligible patients lived at home with their carer	96 patient–carer pairs—33 in the dementia carers' program, 31 in the memory retraining group & 33 in the wait list group

(continued)

Table A6.1 (continued): Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Brodaty & Hadzi-Pavlovic (1990): *Psychosocial effects on carers of living with persons with dementia*		Sampled from list of NSW Alzheimer's Disease & Related Disorders Society members			Included both co-resident & non-resident carers as well as carers of people in institutions—only co-resident carers completed all 3 sections of the survey	146 usable questionnaires—112 were carers of a person with dementia who was still alive & 53 carers lived with the person with dementia
Cahill & Shapiro (1993): *'I think he might have hit me once': aggression towards caregivers in dementia care*	September 1990 – March 1991	Recruited in the Brisbane metropolitan area	Female, primary caregivers	Dementia	Retrospective study while carers were providing care in the community	39 caregivers
Bindoff et al. (1997): *Caregivers of family members with dementia & disability: a comparative study of wellbeing*		Tasmania			Dependent was co-resident	72 family caregivers: 20 of physically disabled & 19 of intellectually disabled dependants & 22 of a dependant with a dementia-related disorder
Luscombe et al. (1998): *Younger people with dementia: diagnostic issues, effects on carers & use of services*		Recruited through support groups of the Alzheimer's Association & Huntington's Disease Association of Australia & clinician referrals		Dementia, excluding AIDS-related dementia Less than 65 years of age when surveyed		102 eligible carers
LoGiudice et al. (1999): *Do memory clinics improve the quality of life of carers? A randomized pilot trial*		Recruited through various sources: local GPs; local community services including district nursing service; council services & ACATs; & advertising in local newspapers & carer groups	One **principally** responsible for providing or coordinating resources required by the person, who was in personal contact with the care recipient at least weekly	Mild to moderate cognitive impairment with >6 month history of memory loss & intellectual decline & MMSE <24 Independent mobility & intact basic self-hygiene	Community dwelling subjects	50 subjects & their carers—4 withdrew consent for participation after randomisation & one withdrew after initial interview

(continued)

Table A6.1 (continued): Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Bruce & Paterson (2000): *Barriers to community support for the dementia carer: a qualitative study*	January 1996 – June 1997	Carers of people who had been seen by members of the WA Fremantle ACAT		Dementia	Co-resident carers—12 had relinquished care at the time of interview	24 carers
Leong et al. (2001): *Needs of family carers of elderly people with dementia living in the community*		Recruited through the community health nursing service of a regional Area Health Service in eastern Australia & dementia support group meetings run in several locations in the region	**Principal** carer at least 3 months Aged over 18 years Related to person with dementia Able to communicate in English	Dementia	Sharing residence or living nearby to person with dementia	94 valid responses—a purposive subsample of ten carers were interviewed
Schofield (2001): *Rituals of visiting people with dementia in residential care*			Family members who had been **primarily** responsible for the care of a relative with dementia	Dementia	Person with dementia had recently entered long-term residential care	25 carers
Bruce et al. (2002): *Communication problems between dementia carers & general practitioners: effect on access to community support services*	1 September 1999 – 30 April 2000	Carers of patients referred for the first time to the WA Fremantle ACAT by their GP	Carers had been in the caring role for at least 6 months	Dementia	Live-in carers of people living in the community	21 carers & 19 referring GPs
Low et al. (2002): *A study of premorbid personality & behavioural & psychological symptoms of dementia in nursing home residents*		11 nursing homes in eastern Sydney	Caregiver visited resident at least weekly	Dementia & depression &/or psychosis	Subjects resided in nursing homes	58 informal caregivers (57 returned questionnaires)

(continued)

Table A6.1 (continued): Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Ward et al. (2003): *Family carers' responses to behavioural & psychological symptoms of dementia*		Identified in a survey of mental disorder in general practice or referred by local aged mental health services		Dementia	Included both co-resident & non-resident carers	50 family carers
Bruce et al. (2005): *Physical disability contributes to caregiver stress in dementia caregivers*	April–December 2001	Subjects who had been referred by their family physicians for the first time for formal support services or memory evaluation	**Primary** caregivers caring for relatives with verified dementia for at least 6 months	Dementia	Included both co-resident & non-resident carers	91 caregivers
Helmes et al. (2005): *Individual differences in the experience of burden in caring for relatives with dementia: role of personality & mastery*		Participants were recruited from the Royal Perth Hospital Memory Clinic, advertisement in the local press & other clinical services in the hospital	Carer had to score 23 or above on the MMSE	Dementia	Included both co-resident & non-resident carers Most carers resided in their own home	51 people with dementia & their carers
AIHW: Hales et al. (2006): *National evaluation of the Aged Care Innovative Pool Dementia Pilot: final report*	2004	Care recipients & their family carers participating in the Innovative Pool Dementia Pilot projects		ACAT approval for residential aged care (usually high level residential care) Cognitive impairment that made a significant contribution to the need for care	Included both co-resident & non-resident carers & carers of people in residential care	249 care recipient & 219 family carers

Table A6.2: Summary of published Australian studies: age and sex distribution of carers

	Age			Sex	
Study	**Range**	**Mean (std dev)**	**Other details**	**% female**	**% male**
Victorian Carers' Program					
Schofield et al. (1998b)			>70% 35–64	75	25
Dementia					
Undiagnosed memory loss					
Physical impairment					
Brodaty et al. (2005)			4.6% 0–34, 35% 35–49, 30% 50–64 & 30% ≥65	73	27
Dementia caregivers' training programme		67.7 (8.2)		54	46
Brodaty & Hadzi-Pavlovic (1990)	29–85	60.2 (13.3)		79	21
Bindoff et al. (1997)	28–82	55 (13.17)		76	24
Dementia		61.1 (12.8)		73	27
Intellectual disability		50.6 (9.7)		84	16
Physical disability		49.4 (12.9)		75	25
Luscombe et al. (1998)		51.7 (12.5)		75	25
Alzheimer's disease					
Huntington's disease					
Other dementias					
LoGiudice et al. (1999)			Most were elderly	78	22
Control		60.7 (12.6)		80	20
Memory clinic		61.4 (14.0)		76	24
Bruce & Paterson (2000)	36–85	69	63% >70	67	33
Leong et al. (2001)	45–97	65.5 (11.5)	Eligible carers >18 69% ≥60	>67	<33
Schofield (2001)	Mid 30s to late 80s			68	32
Bruce et al. (2002)	43–83	68		52	48
Low et al. (2002)	34–84	61 (± 11.6)		54	46
Ward et al. (2003)	42–92	69	Most were elderly	64	36
Bruce et al. (2005)	38–85	Median 62	Bimodal distribution of ages	71	29
Helmes et al. (2005)	31–85	61.1 (14.0)		71	29

Table A7.1: Usual and recommended accommodation setting of ACAP clients, by dementia status, July 2004 to March 2005

	Recommended long-term care setting									
Usual accommodation setting	**Private residence**	**Independent living in a retirement village**	**Supported community accommodation**	**Other community[(a)]**	**RAC—low level care**	**RAC—high level care**	**Hospital**	**Other institutional care**	**Total**	**Not stated/ inadequately described**
With dementia										
Private residence	8,442	77	84	91	4,293	5,392	18	8	18,405	261
Independent living in a retirement village	200	322	12	2	585	357	0	0	1,478	23
Supported community accommodation	10	2	55	4	102	322	0	0	495	9
Other community[(a)]	244	8	14	30	241	372	1	2	912	12
RAC—low level care	13	3	2	19	353	2,882	6	3	3,281	71
RAC—high level care	18	0	0	0	29	414	6	0	467	14
Hospital	6	0	0	2	14	64	1	0	87	2
Other institutional care	5	1	1	2	13	73	0	10	105	1
Total	**8,938**	**413**	**168**	**150**	**5,630**	**9,876**	**32**	**23**	**25,230**	**393**
Not stated/inadequately described	*246*	*13*	*7*	*8*	*82*	*148*	*1*	*1*	*506*	*29*
Without dementia										
Private residence	33,595	525	400	458	10,361	9,141	300	26	54,806	3,424
Independent living in a retirement village	842	1,581	32	28	1,667	708	14	1	4,873	253
Supported community accommodation	34	9	202	19	282	281	1	6	834	54
Other community[(a)]	835	26	74	167	702	703	6	20	2,533	217
RAC—low level care	29	9	7	28	720	2,602	34	5	3,434	273
RAC—high level care	41	1	1	13	70	442	26	3	597	59
Hospital	25	1	2	1	29	84	6	2	150	9
Other institutional care	22	4	2	2	29	97	0	26	182	21
Total	**35,423**	**2,156**	**720**	**716**	**13,860**	**14,058**	**387**	**89**	**67,409**	**4,310**
Not stated/inadequately described	*2,225*	*114*	*31*	*314*	*457*	*526*	*59*	*13*	*3,739*	*7,022*

RAC Residential Aged Care.

(a) Includes all other types of settings (as well as boarding house/rooming house/private hotel, short-term crisis, emergency or transitional accommodation and public place/temporary shelter for usual accommodation setting).

Note: Recommended long-term care setting is recorded at the end of a comprehensive assessment for all comprehensive assessments that have ended with development of a care plan for the client (i.e. complete assessments).

Source: AIHW analysis of the ACAP MDS v2.

Table A7.2: Government community program support at time of assessment and recommended government program support, by dementia status of ACAP client, July 2004 to March 2005

	Recommended government community program support										
Government community program support at assessment	**Not applicable(a)**	**CACP**	**EACH**	**HACC**	**Veterans' Home Care**	**Day Therapy Centre**	**NRCP**	**Other**	**None**	**Total(b)**	**Not stated/ inadequately described**
With dementia											
Not applicable(c)	4,705	75	6	36	3	12	46	24	363	5,012	75
CACP	1,189	1,074	89	171	16	71	296	64	111	2,386	33
EACH	44	38	48	19	2	7	21	5	3	138	2
HACC	2,787	1,429	202	3,122	184	325	1,360	275	306	6,739	48
Veterans' Home Care	529	224	40	179	546	63	237	68	61	1,264	14
Day Therapy Centre	267	169	31	227	53	414	299	37	39	787	10
NRCP	614	314	86	558	77	225	937	102	41	1,651	14
Other	613	357	67	343	84	67	312	418	116	1,518	15
None	4,278	1,558	103	1,201	170	325	1,232	250	2,010	8,672	119
Total(b)	**13,727**	**4,574**	**515**	**4,755**	**846**	**1,048**	**3,660**	**898**	**2,715**	**25,206**	**298**
Not stated/inadequately described or unable to determine	*267*	*51*	*2*	*74*	*9*	*10*	*50*	*22*	*77*	*432*	*222*
Without dementia											
Not applicable(c)	6,426	199	17	140	22	13	74	61	532	7,120	346
CACP	1,970	3,386	233	484	57	133	563	161	284	5,621	105
EACH	126	162	168	74	12	19	44	11	16	476	6
HACC	6,880	5,875	502	12,303	603	684	3,153	1,102	1,056	22,925	447
Veterans' Home Care	1,369	1,173	86	924	2,374	140	626	300	222	4,806	61
Day Therapy Centre	271	330	36	445	139	666	342	90	42	1,192	15
NRCP	620	582	132	927	146	200	1,471	150	60	2,329	18
Other	1,399	1,264	139	1,264	331	170	725	1,551	398	4,625	87
None	8,207	5,091	297	4,018	558	466	2,424	831	8,498	24,924	1304
Total(b)	**25,329**	**16,138**	**1,329**	**17,685**	**3,331**	**1,705**	**7,509**	**3,109**	**10,238**	**67,723**	**2,067**
Not stated/inadequately described or unable to determine	*822*	*239*	*12*	*323*	*43*	*21*	*114*	*92*	*516*	*1,596*	*11,094*

(a) Recorded for people whose recommended long-term care setting is residential aged care, a hospital or other institutional care.

(b) Sum of components may not add to total—clients may have used or be recommended more than one program.

(c) Recorded for people who were permanent residents of residential aged care services, multi-purposes services or centres, Indigenous flexible pilots, hospitals or other institutional settings at the time of assessment.

Source: AIHW analysis of the ACAP MDS v2.

Table A8.1: Condition weights for each ABS CURF code applied to SDAC data for allocation of residential aged care funding allocation to conditions

ABS CURF code	Condition	Condition group[(a)]	ABS CURF code	Condition	Condition group[(a)]
100	Certain infectious & parasitic diseases	8	910	Heart disease	5
204	Breast cancer	8	913	Angina	5
205	Prostate cancer	8	914	Myocardial infarction (heart attack)	5
299	Other neoplasms (tumours/cancers)	8	919	Other heart diseases	5
300	Diseases of the blood & blood-forming organs & certain disorders involving the immune system	8	922	Hypertension (high blood pressure)	Not included
401	Disorders of the thyroid gland	8	923	Stroke	2
402	Diabetes	8	929	Other diseases of the circulatory system	5
404	High cholesterol	Not included	1002	Bronchitis/bronchiolitis	8
499	Other endocrine/nutritional & metabolic disorders	8	1003	Respiratory allergies (excluding allergic asthma)	8
500	Mental & behavioural disorders nfd	4	1004	Emphysema	8
511	Dementia	1	1005	Asthma	8
512	Schizophrenia	4	1099	Other diseases of the respiratory system	8
513	Depression/mood affective disorders (excluding postnatal depression)	4	1101	Stomach/duodenal ulcer	8
521	Phobic & anxiety disorders	4	1102	Abdominal hernia (except congenital)	8
522	Nervous tension/stress	4	1103	Enteritis & colitis	8
530	Intellectual & developmental disorders nec	8	1104	Other diseases of the intestine	8
531	Mental retardation/intellectual disability	8	1199	Diseases of the digestive system	8
532	Autism & related disorders (including Rett's syndrome & Asperger's syndrome)	8	1202	Skin allergies (Dermatitis & Eczema)	8
595	Attention deficit disorder/hyperactivity	8	1299	Other diseases of the skin & subcutaneous tissue	8
596	Speech impediment	8	1301	Arthritis & related disorders	3
599	Other mental & behavioural disorders	4	1303	Back problems (dorsopathies)	3
604	Parkinson's disease	7	1304	Repetitive strain injury/occupational overuse syndrome	8
605	Alzheimer's disease	1	1306	Other soft tissue/muscle disorders (including Rheumatism)	3
607	Multiple sclerosis	3	1307	Osteoporosis	3

(continued)

Table A8.1 (continued): Condition weights for each ABS CURF code applied to SDAC data for allocation of residential aged care funding allocation to conditions

ABS CURF code	Condition	Condition group[(a)]	ABS CURF code	Condition	Condition group[(a)]
608	Epilepsy	8	1399	Other diseases of the musculoskeletal system & connective tissue	3
609	Migraine	8	1401	Kidney & urinary system (bladder) disorders (except incontinence)	8
611	Cerebral palsy	8	1405	Menopause disorders	8
612	Paralysis	3	1499	Other diseases of the genitourinary system	8
699	Other diseases of the nervous system	8	1600	Congenital malformations, deformations & chromosomal abnormalities	8
703	Retinal disorders/defects	8	1701	Breathing difficulties/shortness of breath	8
704	Glaucoma	8	1704	Pain nfd	8
707	Sight loss	3	1705	Unspecified speech difficulties	8
799	Other diseases of the eye & adnexa	8	1799	Other symptoms/signs & abnormal clinical & laboratory findings nec	8
802	Diseases of the middle ear & mastoid	8	1801	Head injury/acquired brain damage	8
803	Diseases of the inner ear (except noise induced deafness)	6	1802	Arm/hand/shoulder damage from injury/accident	3
804	Tinnitus	6	1804	Leg/knee/foot/hip damage from injury/accident	3
810	Deafness/hearing loss	6	1808	Complications/consequences of surgery & medical care nec	8
811	Deafness/hearing loss—noise induced	6	1899	Other injury/poisoning & certain other consequences of external causes	8
812	Deafness/hearing loss—congenital	8	1904	Restriction in physical activity or physical work	3
899	Other diseases of the ear & mastoid process	6	1907	Other 2003 codes which have no ICD-10 equivalent	8

(a) Condition group refers to the list: 1. Dementia and Alzheimer's disease; 2. Stroke; 3. Mobility; 4. Mental; 5. Other cardiovascular disease; 6. Communication; 7. Parkinson's disease; and 8. Other conditions.

Table A11.1: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(carer health and wellbeing)*

ALSWH		
Question: During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups? **Response:** Not at all Slightly Moderately Quite a bit Extremely **Question:** During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives etc.)? **Response:** All of the time Most of the time Some of the time A little of the time None of the time **Question:** During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? **Options:** Cut down on the amount of time you spent on work or other activities Accomplished less than you would like Didn't do work or other activities as carefully as usual **Response:** Yes, No **Question:** During the past 4 weeks, have you had any of the following problems with your work (including your work outside the home & housework) or other regular daily activities as a result of your physical health? **Options:** Cut down on the amount of time you spent on work or other activities Accomplished less than you would like Were limited in the kind of work or other activities Had difficulty performing the work or other activities (e.g. it took extra effort) **Response:** Yes, No **Question:** In the last 3 years have you been told by a doctor that you have… **Options include:** Depression Anxiety/nervous disorder **Response:** Yes (or no response) **Notes:** Asked of the older cohort in surveys 2, 3 & 4 (similar questions asked of the younger & mid age cohorts in surveys 2, 3 & 4)	**Question:** In the last 12 months, have you had any of the following… **Options include:** Headaches/migraines Severe tiredness Difficulty sleeping Depression Anxiety **Response:** Never, Rarely, Sometimes, Often **Notes:** Asked of the mid age cohort in survey 2 (similar questions asked of the younger cohort, mid age cohort in surveys 1, 3 & 4 & older cohort) **Question:** Please indicate how often you have felt this way during the last week… **Options:** I was bothered by things that don't usually bother me I had trouble keeping my mind on what I was doing I felt depressed I felt that everything I did was an effort I felt hopeful about the future I felt fearful My sleep was restless I was happy I felt lonely I could not 'get going' I felt terrific **Response:** Rarely or none of the time (less than 1 day) Some or a little of the time (1–2 days) Occasionally or a moderate amount of the time (3–4 days) Most or all of the time (5–7 days) **Notes:** Asked of the younger & mid age cohorts in surveys 2, 3 & 4 (similar question asked of the older cohort in survey 2) **Question:** During the past 4 weeks have you taken any medications… **Options include:** For nerves/anxiety/worries For stress (difficulty coping) To help you sleep For tiredness/fatigue For depression **Response:** Yes, No **Notes:** Asked of the mid age cohort in surveys 3 & 4 (similar questions asked of the younger cohort in surveys 3 & 4, mid age cohort in surveys 1 & 2 & older cohort in surveys 1, 2 & 3)	**Question:** During the past 4 weeks, how many different types of medication (e.g. tablets or medicine) have you used which were… **Options include:** Prescription medication for your nerves (e.g. valium, serapax, ducene etc.) Prescription medication to help you sleep (e.g. normison, mogadon etc.) Prescription medication for depression (e.g. prozac, aropax etc.) **Response:** One, Two, Three, Four or more (or no response) **Notes:** Asked of the younger cohort in survey 2 **Question:** Over the last 12 months, how stressed have you felt about the following areas of your life… **Options:** Own health Health of other family members Work/employment Living arrangements Study Money Relationship with parents Relationship with partner/spouse Relationship with children Relationship with other family members Anything else (please specify) **Response:** Not applicable Not at all stressed Somewhat stressed Moderately stressed Very stressed Extremely stressed **Notes:** Asked of the mid age cohort in survey 1 (similar questions asked of the younger cohort, mid age cohort in surveys 2, 3 & 4 & older cohort in surveys 1 & 2) **Questions:** In the past week, have you been feeling that life isn't worth living? In the past 6 months, have you ever deliberately hurt yourself or done anything that you knew might have harmed or even killed you? **Response:** Yes, No **Notes**: Asked of the younger cohort in surveys 2, 3 & 4 & the mid age cohort in surveys 3 & 4

Table A11.2: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(income and financial situation)*

DESP	NRCP	SDAC	
Data item: Pension status **Definition:** Whether or not the person of concern is in receipt of an income support payment from the Commonwealth Government in the form of a government pension or benefit **Data domain:** No government pension or benefit Aged Pension Veterans' Affairs Pension Disability Support Pension Carer Payment (formerly carer pension) Carer Allowance (formerly DNCB) Unemployment-related benefits Other government pension or benefit Unknown **Data item:** Key issues & discussion areas **Definition:** Service provided) by whatever approach) to the client **Data sub-items include:** Financial matters **Data domain:** Financial planning Carer benefits/entitlements Aged care facility costs	**Data item:** Government pension/benefit status **Definition:** Statement by a person of receipt of an income support payment from the Commonwealth Government in the form of a pension or benefit **Data domain:** Aged Pension Veterans' Affairs Pension Disability Support Pension Carer Payment (pension) Unemployment-related benefits Other government pension or benefit No government pension or benefit Carer Allowance Not stated/inadequately described	**Data item:** Main effect of caring role on primary carer's financial situation **Data domain:** Not applicable Income not affected Income has increased Income has decreased Has extra expenses Not stated **Data item:** Whether primary carer has difficulty meeting everyday costs as a result of caring role **Data domain:** Not applicable Has difficulty meeting everyday living costs Does not have difficulty meeting everyday living costs Not stated **Data item:** Whether primary carer usually pays significant proportion of living costs of main recipient of care **Data domain:** Not applicable Regularly pays a large part of living costs Does not regularly pay a large part of living costs Not stated	**Data item:** Primary carer awareness of Carer Payment **Data domain:** Not applicable Receives Carer Payment Does not receive Carer Payment but has looked at eligibility Does not receive Carer Payment & has not looked at eligibility Has not looked at eligibility **Data item:** Main reason primary carer has not looked at eligibility for Carer Payment **Data domain:** Not applicable Not heard of it Pride Would not be eligible Dual eligibility (eligible for conflicting payment type) Not necessary Does not think of self as a carer Other Currently receiving it Looked at eligibility but does not receive it **Data item:** Main reason looking at eligibility by primary carer did not lead to receipt of Carer Payment **Data domain:** Not applicable Did not meet requirements for eligibility Dual eligibility (eligible for conflicting payment type) Changed mind or decided not necessary Other Currently receiving Carer Payment

(continued)

Table A11.2 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(income and financial situation)*

ALSWH		
Question: How do you manage on the income you have available? **Response:** It is impossible It is difficult all the time It is difficult some of the time It is not too bad It is easy **Notes:** Asked of the younger cohort in surveys 1, 3 & 4 & the mid age & older cohorts **Question:** What is the average gross (before tax) income that you (& your household) receive each week, including wages, salary, pensions & allowances? **Options:** Self Household (include self) **Response:** No income $1–$119 ($1–$6,239 annually) $120–$299 ($6,240–$15,999 annually) $300–$499 ($16,000–$25,999 annually) $500–$699 ($26,000–$36,999 annually) $700–$999 ($37,000–$51,999 annually) $1,000–$1,499 ($52,000–$77,999 annually) $1,500 or more ($78,000 or more annually) Don't know Don't want to answer Household income is the same as mine **Notes:** Asked of the mid age cohort in survey 3 (similar questions asked of the younger cohort in surveys 2, 3 & 4 & the mid age cohort in survey 2)	**Question:** How many people (including yourself) are dependent on this household income? **Response:** (Continuous) **Notes:** Asked of the younger cohort in surveys 2, 3 & 4 & the mid age cohort in surveys 2 & 3 **Question:** Are there people who do not live with you who are dependent on this household income? **Response:** No Yes, one Yes, more than one **Notes:** Asked of the mid age cohort in survey 3 (similar question asked of the mid age cohort in survey 4) **Question:** Which of the following are sources of income for you & your spouse? **Options:** Wage or salary Own business/farm/partnership Superannuation or other private income Government pension or allowance **Response:** Yes (or no response) **Notes:** Asked of the mid age cohort in survey 2 (similar questions asked of the older cohort in surveys 2 & 3)	**Question:** Which of the following are sources of income for you & your spouse or partner (if you have one)? **Options:** Age Pension Superannuation Partner allowance & Wife pension Carer Payment or Carer Allowance Disability Support Pension Widow allowance (including Widow B pension) War widow's pension Overseas pension Veterans' service pension Veterans' disability pension Veterans' TPI Income from interest, dividends or rent Income from own business or partnership Other government pension or allowance Other income **Response:** Yes (or no response) **Notes:** Asked of the older cohort in survey 4 **Question:** If you are retired, what are the source of your retirement funding? If you are not retired, or have never been in paid work, what do you expect to be the sources for funding your retirement? **Options:** Age Pension/Service Pension/Widow's Pension/War Widow's Pension Other government pension or allowance Lump sum superannuation payout A pension or annuity purchased with superannuation or some other funds Income from savings & investments (such as shares & property) Income from a business Income or pension from your spouse/partner Financial support from family Other sources (please specify) Don't know **Response:** Yes (or no response) **Notes:** Asked of the mid age cohort in survey 4

Table A11.3: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(paid work)*

NRCP	**SDAC**	
Data item: Paid employment participation **Definition:** A record of the person's statement concerning their current participation in the paid workforce **Data domain:** Full-time Part-time Casual Seasonal Not in paid employment Not stated/inadequately described	**Data item:** Whether worked just before commencing caring for main recipient of care **Data domain:** Not applicable Worked prior to caring role Did not work prior to caring role Primary carer permanently unable to work	**Data item:** Main reason left work just before commencing caring role **Data domain:** Not applicable To commence care To increase care Retired Became eligible for pension/benefit Other
	Data item: Number of weekly hours primary carer was employed before commencing care for main recipient of care **Data domain:** Not applicable (Continuous) Did not have job prior to caring role	**Data item:** Main reason had to leave work to care for main recipient of care **Data domain:** Not applicable No alternative care arrangements available Financial considerations/cost of alternative care arrangements Unable to change working arrangements Emotional obligations Preferred to care full-time Other
	Data item: Effect on weekly hours worked in all jobs by primary carer since commencing caring role **Data domain:** Not applicable Weekly hours worked are unchanged Weekly hours worked are reduced Weekly hours worked are increased	**Data item:** Whether would like to be employed while caring for main recipient of care **Data domain:** Not applicable Would like to work full-time Would like to work part-time Would not like to work
	Data item: Increase in weekly hours worked since commencing caring role **Data domain:** (Continuous)	**Data item:** Main perceived barrier to re-entering workforce while caring **Data domain:** Not applicable No alternative care arrangements available Disruption to main recipient of care Difficulty in arranging working hours Loss of skills from being out of workforce Age Other difficulty No difficulties expected
	Data item: Reduction in weekly hours worked since commencing caring role **Data domain:** (Continuous)	
	Data item: Whether primary carer needs time off work at least once a week because of caring for main recipient **Data domain:** Not applicable Needs time off work at least once a week Needs time off work but not once a week Does not need time off work Unemployed or not in the labour force, excluding those permanently unable to work Permanently unable to work	
	Data item: Whether has ever had to leave work for at least 3 months to care for main recipient of care **Data domain:** Not applicable Has had to leave work for at least 3 months Has not had to leave work for at least 3 months	

(continued)

Table A11.3 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(paid work)*

ALSWH			
Question: Which of the following best describes your main current employment status? **Options:** In full-time paid work In part-time or casual paid work Work without pay (e.g. in a family business) Home duties only—no paid work Studying—no paid work Unemployed—looking for work Unpaid voluntary work Retired Unable to work due to sickness or injury Other (please specify) **Response:** Yes (or no response) **Notes:** Asked of the mid age cohort in survey 1 (similar questions asked of the younger cohort in survey 1 & the mid age cohort in survey 4) **Question:** How many hours do you normally spend in all your paid jobs each week? **Response:** 1–15 hours 16–24 hours 25–34 hours 35–40 hours 41–48 hours 49 hours or more **Notes:** Asked of those in the younger & mid age cohorts in survey 1 that were in full-time, part-time or casual paid work (similar question asked of the mid age cohort in survey 2) **Questions:** Do you normally do paid shift work? Do you normally do paid work at night? Is your home your normal (paid work) work-place? **Response:** Yes, No **Notes:** Asked of those in the younger & mid age cohorts in survey 1 that were in full-time, part-time or casual paid work (similar questions asked of the mid age cohort in survey 2)	**Question:** Do you normally do any of the following kinds of paid work? **Options:** Paid shift work Paid work at night Paid work from home Self employment Paid work in more than one job Casual paid work (work in a job which doesn't provide holiday pay or sick leave) Paid work involving none of the above I don't do any paid work **Response:** Yes (or no response) **Notes:** Asked of the younger cohort in survey 3 & mid age cohort in survey 4 (similar questions asked of the younger cohort in surveys 2 & 4 & mid age cohort in survey 3 **Question:** How secure or insecure do you feel about your paid job or jobs? **Response:** I worry all the time about losing my job Sometimes I worry about losing my job I rarely or never worry about losing my job Don't know **Notes:** Asked of those in the younger cohort in surveys 3 & 4 that were in paid work **Question:** Are you happy with the number of hours of paid work you do? **Response:** Yes, happy as is No, would like to do more No, would like to do less **Notes:** Asked of the younger cohort in surveys 2, 3 & 4	**Question:** What is the main reason you would like to do fewer hours of paid work? **Response:** Child care Other family reasons Health reasons Would like more time for leisure/for myself/to do other things **Notes:** Asked of those in the younger cohort in survey 2 that would like to do less hours of paid work **Question:** What is the main reason you do not do more hours of paid work? **Response:** Can't find a suitable job (e.g. with right hours/suits my skills/nearby) Child care Other family reasons Health reasons My spouse/partner prefers I don't work (more) Language difficulties **Notes:** Asked of those in the younger cohort in survey 2 that would like to do more hours of paid work **Question:** Do you consider yourself to be completely retired from the paid workforce, partly retired or not retired at all? **Options:** I am not retired at all (currently working or planning to return to work) I am partially retired (have cut down on hours of work or changed type of job as a way of retiring gradually) I am completely retired from paid work (within the last 20 years) I gave unpaid work over 20 years ago (& do not intend to return to work) I have never been in paid work **Response:** Yes (or no response) **Notes:** Asked of the mid age cohort in survey 4 **Question:** When did you retire or give up work? **Response:** (Continuous) **Notes:** Asked of those in the mid age cohort in survey 4 that were retired or gave up work within the last 20 years	**Question:** At what age do you expect to retire (completely) from the paid workforce? **Response:** (Continuous) Do not expect to ever retire Don't know **Notes:** Asked of those in the mid age cohort in survey 4 that were not retired or were partially retired **Question:** If you had the choice, at what age would you like to retire (completely) from the paid workforce? **Response:** (Continuous) Do not want to ever retire Don't know **Notes:** Asked of those in the mid age cohort in survey 4 that were not retired or were partially retired **Question:** Indicate how important each of the following might be in your decision about when to retire (completely) from the workforce… **Options:** Reaching the eligibility age for an old age (or service) pension The ability to access other government pensions or benefits The ability to access superannuation funds Being retrenched or made redundant The stresses & pressures of your job A declining interest in work Financial security The number of people for whom you need to provide financial support When your partner retires Your personal health or physical abilities The need to care for your spouse or another family member The desire for a different lifestyle **Response:** Not important Of limited importance Important Very important Don't know **Notes:** Asked of those in the mid age cohort in survey 4 that were not retired or were partially retired

Table A11.4: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(other)*

SDAC	ALSWH		
Data item: Why primary carer took on the caring role (multiple response) **Data domain:** Not applicable Could provide better care than someone else Family responsibility No other family or friends available No other family or friends willing Emotional obligation Alternative care too costly No other care arrangements available Had no other choice Other reason Not stated	**Question:** Are you happy with your share of the following tasks & activities? **Options:** Domestic work (shopping, cooking, cleaning etc.) Child care Caring for another adult (who is elderly/disabled/sick) Other household work (gardening, home/car maintenance) **Response:** Happy the way it is Would like other family members to do more Would prefer another arrangement Not applicable (don't do this) **Notes:** Asked of the younger & mid age cohorts in survey 1 (similar questions asked of the younger cohort in surveys 3 & 4, mid age cohort in survey 4 & older cohort in survey 1) **Questions:** How often do you feel rushed/pressured/too busy? How often do you feel you have time on your hands that you don't know what to do with? **Response:** Every day A few times a week About once a week About once a month Never **Notes:** Asked of the younger cohort in survey 1 & the mid age & older cohorts in surveys 1 & 2 (similar questions asked of younger cohort in surveys 2, 3 & 4 & the mid age cohort in surveys 3 & 4) **Question:** Compared to 5 years ago, do you now feel… **Response:** More rushed/pressured/busy About the same Less rushed/pressured/busy **Notes:** Asked of the mid age & older cohorts in survey 1	**Question:** Which of the following events have you experienced? **Options include:** Major decline in health of spouse or partner Major decline in health of other close family member or friend Decreased income **Response:** In the last 12 months 1–2 years ago More than 2 years ago (Or no response) **Notes:** Asked of the mid age cohort in survey 2 (similar questions asked of the mid age cohort in surveys 1, 3 & 4 & the older cohort in survey 1) **Question:** This question is about events you may have experienced in the last 3 years **Options include:** Major decline in health of spouse or partner Major decline in health of other close family member or friend Decreased income Spouse/partner moving into hostel/institution (institutionalised care) **Response:** Yes (or no response) **Notes:** Asked of the older cohort in surveys 2, 3 & 4 **Question:** How happy are you with the amount of time you spend in the following aspects of your life? **Options:** In paid work In active leisure (e.g. sport, art, drama, music) In passive leisure (e.g. reading, TV, writing letters) Studying Doing voluntary work In religious activities Sleeping Alone **Response:** Happy the way it is Would like to do more Would like to do less Not applicable (don't do this) **Notes:** Asked of the younger, mid age & older cohorts in survey 1	**Question:** In the last week, how much time in total did you spend doing the following things? **Options:** Full-time paid work Permanent part-time paid work Casual paid work Home duties (own/family home) Work without pay (e.g. family business) Looking for work Unpaid voluntary work Active leisure (e.g. walking, exercise, sport) Passive leisure (e.g. TV, listening to music, reading, relaxing) Studying Socialising Using a computer (for work, study or hobbies) **Response:** I don't do this activity 1–15 hours 16–24 hours 25–34 hours 35–40 hours 41–48 hours 49 hours or more **Notes:** Asked of the mid age cohort in survey 3 (similar questions asked of younger cohort in surveys 2, 3 & 4 & the mid age cohort in survey 4) **Question:** In general, are you satisfied with what you have achieved in your life so far in the areas of… **Options:** Work/career/study Family relationships Partner/closest personal relationship Friendships Social activities **Response:** Very satisfied Satisfied Dissatisfied Very dissatisfied **Notes:** Asked of younger, mid age & older cohorts in the first survey (similar questions asked of the younger & mid age cohorts in surveys 2, 3 & 4)

Table A11.5: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(social support and relationships)*

SDAC	ALSWH	
Data item: Main effect of caring role on primary carer's relationship with main recipient of care **Data domain:** Not applicable Relationship unaffected Brought closer together Relationship strained Not stated	**Question:** Does it seem that your family & friends (i.e. people who are important to you) understand you? **Response:** Hardly ever Some of the time Most of the time **Notes:** Asked of the younger & mid age cohorts in survey 1 & the older cohort in surveys 1 & 2	**Question:** How often is each of the following kind of support available to you if you need it? **Options:** Someone to help you if you are confined to bed Someone you can count on to listen to you when you need to talk Someone to give you good advice about a crisis Someone to take you to the doctor if you need it Someone who shows you love & affection Someone to have a good time with Someone to give you information to help you understand a situation Someone to confide in or talk to about yourself or your problems Someone who hugs you Someone to get together with for relaxation Someone to prepare your meals if you are unable to do it yourself Someone whose advice you really want Someone to do things with to help you get your mind off things Someone to help with daily chores if you are sick Someone to share your most private worries & fears with Someone to turn to for suggestions about how to deal with a personal problem Someone to do something enjoyable with Someone who understands your problems Someone to love & make you feel wanted **Response:** None of the time A little of the time Some of the time Most of the time All of the time **Notes:** Asked of the younger cohort in survey 4 & the mid age cohort in surveys 2 & 4 (shorter question asked of the younger cohort in surveys 2 & 3 & the mid age cohort in survey 3)
Data item: Main effect of caring role on primary carer's relationship with other co-resident family members **Data domain:** Not applicable Relationships unaffected Brought closer together Less time to spend with them Relationships strained Relationships affected in another way Has no other co-resident family members Not stated	**Question:** Can you talk about your deepest problems with at least some of your family & friends? **Response:** Hardly ever Some of the time Most of the time **Notes:** Asked of the younger & mid age cohorts in survey 1 & the older cohort in surveys 1, 2 & 3	
Data item: Main effect of caring role on primary carer's relationship with spouse or partner **Data domain:** Not applicable Relationship unaffected Brought closer together Lack time alone together Relationship strained Has no spouse or partner Not stated	**Question:** Other than members of your family, how many persons in your local area do you feel you can depend on or feel very close to? **Response:** None 1–2 people More than 2 people **Notes:** Asked of the younger, mid age & older cohorts in survey 1 (similar question asked of the older cohort in surveys 2, 3 & 4)	
Data item: Main effect of caring role on the primary carer's friendships **Data domain:** Not applicable Friendships unaffected Circle of friends has increased Circle of friends has changed Lost or losing touch with existing friends Not stated	**Questions:** Do people help you to do odd jobs? Do people lend you small things (e.g. sugar, screwdriver etc.)? Do people lend you small amounts of money? Do people give you information or advice? Do people help you if you call upon them to do so unexpectedly? Do people lend you valuable things? Do people help you, for example, when you are sick, when you have transport problems or when you need them to accompany you somewhere? **Response:** Yes, No, I don't need help with this **Notes:** Asked of the older cohort in survey 2 (similar question asked of the older cohort in survey 3)	
Data item: Whether primary carer able to use public transport when accompanied by main recipient of care **Data domain:** Not applicable Not able to use public transport Able to use with difficulty Able to use without difficulty Able to use but difficulty not stated Does not need or want to use public transport Not stated		

Table A11.6: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(respite care)*

NRCP	SDAC		
Data items about respite services booked, respite services purchased, respite hours purchased & cost of respite services purchased for: Commonwealth approved aged care homes residential respite services State/territory funded disability care homes residential respite services Community residential respite services Other residential respite services Community respite services In-home respite services Individualised respite services Indirect respite services	**Data item:** Primary carer use of respite care **Data domain:** Not applicable Used respite care in the last 3 months Used respite care but not in the last 3 months Never used respite care **Data item:** Type of respite care used in last 3 months (multiple response) **Data domain:** Used a day-care centre in the last 3 months Used in-home respite in the last 3 months Used residential respite in the last 3 months Used respite service other than day-care centre, in-home or residential in the last 3 months Has used respite care but not in the last 3 months Has never used respite care Not applicable **Data item:** Whether primary carer used a day-care centre in the last 3 months **Data domain:** Not applicable Used a day-care centre in the last 3 months Has used respite care in the last 3 months but not a day-care centre Has used respite care but not in the last 3 months Has never used respite care **Data item:** Whether primary carer used in-home respite in the last 3 months **Data domain:** Not applicable Used in-home respite in the last 3 months Has used respite care in the last 3 months but not in-home respite Has used respite care but not in the last 3 months Has never used respite care **Data item:** Whether primary carer used residential respite care in the last 3 months **Data domain:** Not applicable Used residential respite in the last 3 months Has used respite care in the last 3 months but not residential respite Has used respite care but not in the last 3 months Has never used respite care	**Data item:** Whether primary carer used other respite service in the last 3 months **Data domain:** Not applicable Used respite service other than day-care centre, in-home or residential in the last 3 months Has not used respite service other than day-care centre, in-home or residential in the last 3 months Used respite care, but not in the last 3 months Has never used respite care **Data item:** Primary carer need & receipt of respite care for main recipient of care **Data domain:** Not applicable Received respite care in last 3 months & does not need it further Received respite care in last 3 months but needs it further Did not receive respite care in last 3 months & does not need it Did not receive respite care in last 3 months but needs it Has never received respite care & does not need or want it Has never received respite care but needs it **Data item:** Main reason primary carer did not use respite care in the last 3 months **Data domain:** Not applicable Does not need it Not available in area Available respite not suited to needs No affordable respite available Main recipient of care does not want it Carer prefers not to use it Other reason Used respite in the last 3 months Has never used respite care **Data item:** Main reason primary carer has never used respite care **Data domain:** Not applicable Does not need service Respite care services not available in area Available services not suited to needs No affordable services available Recipient does not want service Carer does not want service Other reason Has used respite care	**Data item:** Whether primary carer has unmet need for respite care on weekdays (at least once a month) **Data domain:** Not applicable Needs respite care on weekdays at least once a month Needs respite care on weekdays less than once a month Needs respite care but not on weekdays Does not need or want respite care **Data item:** Whether primary carer has unmet need for respite care on weekends (at least once a month) **Data domain:** Not applicable Needs respite care on weekends at least once a month Needs respite care on weekends less than once a month Needs respite care but not on weekends Does not need or want respite care **Data item:** Whether primary carer has unmet need for respite care on weeknights (at least once a month) **Data domain:** Not applicable Needs respite care on weeknights at least once a month Needs respite care on weeknights less than once a month Needs respite care but not on weeknights Does not need or want respite care **Data item:** Whether primary carer has unmet need for respite care on short notice or on an irregular basis **Data domain:** Not applicable Needs respite care at short notice or on irregular basis Needs respite care but not at short notice or on irregular basis Does not need or want respite care

Table A11.7: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role *(assistance provided)*

SDAC	
Data item: Whether primary carer usually accompanies main recipient of care when going out **Data domain:** Not applicable Usually has to accompany main recipient Does not usually have to accompany main recipient Main recipient does not leave home	**Data item:** Whether carer provides assistance with… **Data sub-items:** Cognitive & emotional needs; Communication; Health care; Home maintenance or gardening tasks; Household tasks; Meal preparation; Mobility; Private transport; Reading & writing; Self-care **Data domain:** Not applicable Usually assists with… Does not assist with… Not stated
Data item: Whether primary carer usually assists main recipient of care… **Data sub-item:** To make or maintain relationships; Coping with feelings or emotions; Decision making or problem solving; Financial management; Footcare; Gardening; Health care other than footcare; Heavy housework; Home maintenance; Laundry; Letter writing; Light housework; Manipulating limbs or exercising; Meal preparation; Manage behaviour **Data domain:** Not applicable Usually assists with… Does not usually assist with… Not stated	**Data item:** Whether possible primary carer usually assists main recipient of care with… **Data sub-items:** Communication tasks; Mobility tasks; Self-care tasks; Communication with strangers; Getting in & out of bed or chair; Bathing or showering; Cognitive or emotional tasks; Communication tasks; Dressing; Eating or feeding; Health care tasks; Household tasks; Managing incontinence; Mobility tasks; Moving about the house; Moving around away from home; Paperwork tasks; Property maintenance tasks; Self care tasks; Toileting; Transport tasks; Communication with family & friends **Data domain:** Not applicable Usually assists with… Does not usually assist with…
Data item: Whether primary carer usually assists or supervises main recipient of care in using public transport **Data domain:** Not applicable Usually supervises or assists with using public transport Does not usually supervise or assist with using public transport Main recipient of care does not use public transport	
Data item: Whether primary carer usually drives main recipient of care in private transport **Data domain:** Not applicable Usually has to drive main recipient of care Does not usually have to drive main recipient of care Main recipient of care does not leave home	

Table A12.1: Collection matrix for challenging behaviour and frequency of occurrence

	Frequency of occurrence							
Behaviour	**Never**	**Less than once a week, but still occurring**	**Once or twice a week**	**Several times a week (three or more)**	**Once or twice a day**	**Several times a day (three or more)**	**Several times an hour (two or more)**	**Not applicable**
Cursing or verbal aggression								
Hitting								
Grabbing								
Tearing things								
Pushing								
Biting								
Spitting								
Physical sexual advances								
Pacing								
Inappropriate robing/disrobing								
Performing repetitive mannerisms								
Trying to get to a different place								
Handling things inappropriately								
Throwing things								
General restlessness								
Constant requests for attention								
Repetitious sentences/questions								
Complaining								
Negativism								
Making strange noises								
Screaming								
Verbal sexual advances								
Hiding things								
Hoarding things								
Other								

Table A12.2: Coexisting health conditions

Certain infectious and parasitic diseases
Tuberculosis
HIV/acquired immunodeficiency syndrome (AIDS)
Other infections and parasitic diseases
Neoplasms
Colon cancer
Lung cancer
Skin cancer
Breast cancer
Prostate cancer
Brain cancer
Hodgkin’s disease
Lymphoma
Leukaemia
Other malignant tumour
Other neoplasms
Diseases of the blood and blood-forming organs and certain disorders involving the immune system
Anaemia
Haemophilia
Immunodeficiency disorder (except AIDS)
Other diseases of the blood and blood-forming organs and certain disorders involving the immune system
Endocrine, nutritional and metabolic disorders
Disorders of the thyroid gland
Diabetes
Obesity
High cholesterol
Other endocrine, nutritional and metabolic disorders
Mental and behavioural disorders
Psychoses and depression/mood affective disorders
Schizophrenia
Depression/mood affective disorders (excluding postnatal depression)
Other psychoses
Neurotic, stress-related and somatoform disorders
Phobic and anxiety disorders
Nervous tension/stress
Obsessive-compulsive disorder
Other neurotic, stress-related and somatoform disorders
Intellectual and developmental disorders
Down’s syndrome
Intellectual disability
Autism and related disorders (including Rett’s syndrome and Asperger’s syndrome)
Other developmental disorders

(continued)

Table A12.2 (continued): Coexisting health conditions

Mental and behavioural disorders (continued)
Other mental and behavioural disorders
Mental disorders due to alcohol and other psychoactive substance use
Eating disorders
Adult personality and behavioural disorders
Attention deficit disorder/hyperactivity
Speech impediment
Diseases of the nervous system
Meningitis and encephalitis (excluding 'viral')
Huntington's disease
Motor neurone disease
Parkinson's disease
Brain disease/disorders—acquired
Multiple sclerosis
Epilepsy
Migraine
Muscular dystrophy
Cerebral palsy
Paralysis
Chronic/postviral fatigue syndrome
Other diseases of the nervous system (including transient cerebral ischaemic attacks)
Diseases of the eye and adnexa
Corneal disorders/defects
Cataracts
Retinal disorders/defects
Glaucoma
Refraction and accommodation disorders
Visual disturbances
Sight loss
Other diseases of the eye and adnexa
Diseases of the ear and mastoid process
Diseases of external ear
Diseases of middle ear and mastoid
Diseases of inner ear (except noise-induced deafness)
Tinnitus
Deafness/hearing loss
Other diseases of the ear and mastoid process

(continued)

Table A12.2 (continued): Coexisting health conditions

Diseases of the circulatory system
Heart disease
Rheumatic fever/chorea with heart disease
Rheumatic heart disease
Angina
Myocardial infarction (heart attack)
Other heart diseases
Diseases of the circulatory system
Rheumatic fever/chorea without heart disease
Hypertension (high blood pressure)
Stroke
Arterial or aortic aneurysm
Hypotension (low blood pressure)
Peripheral vascular disease
Other diseases of the circulatory system
Diseases of the respiratory system
Influenza and pneumonia
Bronchitis/bronchiolitis
Respiratory allergies (excluding allergic asthma)
Emphysema
Asthma
Asbestosis
Other diseases of the respiratory system
Diseases of the digestive system
Dental caries/gum disease
Stomach/duodenal ulcer
Abdominal hernia (except congenital)
Enteritis and colitis
Other diseases of the intestine
Diseases of the peritoneum
Diseases of the liver
Other diseases of the digestive system
Diseases of the skin and subcutaneous tissue
Skin and subcutaneous tissue infections
Skin allergies (dermatitis and eczema)
Other diseases of the skin and subcutaneous tissue
Diseases of the musculoskeletal system and connective tissue
Arthritis and related disorders
Deformities of joints/limbs—acquired
Osteoporosis
Other acquired deformities of the musculoskeletal system and connective tissue
Other disorders of the musculoskeletal system and connective tissue

(continued)

Table A12.2 (continued): Coexisting health conditions

Diseases of the genitourinary system
Kidney and urinary system (bladder) disorders (except incontinence)
Renal failure
Stress/urinary incontinence
Prostate disorders
Breast disorders
Menopause disorders
Other diseases of the genitourinary system
Certain conditions originating in the perinatal period
Congenital malformations, deformations and chromosomal abnormalities
Spina bifida
Deformities of joints/limbs—congenital
Other chromosomal abnormalities
Congenital brain damage/malformation
Other congenital malformations and deformations
Symptoms, signs and abnormal clinical and laboratory findings not otherwise specified
Breathing difficulties/shortness of breath
Bowel/faecal incontinence
Headaches
Pain not further defined
Unspecified speech difficulties
Malaise and fatigue
Blackouts, fainting, convulsions not elsewhere classified
Incontinence not further defined
Insomnia not further defined
Other symptoms and signs not elsewhere classified
Injury, poisoning and certain other consequences of external causes
Head injury/acquired brain damage
Arm/hand/shoulder damage from injury/accident
Amputation of the finger/thumb/hand/arm
Leg/knee/foot/hip damage from injury/accident
Amputation of toe/foot/leg
Poisoning/toxic side effects
Allergies—food
Complications/consequences of surgery and medical care not elsewhere classified
Other injury, poisoning and consequences of external causes

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