

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

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) BEACH survey 1998–2003 (AIHW/University of Sydney)	Number of prescriptions for dementia-specific drugs dispensed under the PBS & RPBS 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

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

Medication ^(b)	2000–01		2001–02		2003–04	
	Per 100 contacts with dementia (n=351)	Per cent of medications for dementia (n=110)	Per 100 contacts with dementia (n=490)	Per cent of medications for dementia (n=155)	Per 100 contacts with dementia (n=511)	Per cent of medications for dementia (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

Age	Referrals per 100 GP encounters for dementia			Proportion of referrals for dementia		
	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

Type of referral	Referrals per 100 GP encounters for dementia			Proportion of referrals for dementia		
	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
<i>Total</i>	<i>166,912</i>	<i>188,472</i>	<i>208,648</i>
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
<i>Total</i>	<i>31,582</i>	<i>57,517</i>	<i>82,709</i>
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
<i>Total</i>	<i>27,962</i>	<i>25,053</i>	<i>23,663</i>
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
<i>Total</i>	<i>188,472</i>	<i>3,581</i>	<i>192,378</i>
Galantamine			
8536	15,879	337	16,216
8537	41,638	1,182	42,820
<i>Total</i>	<i>57,517</i>	<i>1,519</i>	<i>59,036</i>
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
<i>Total</i>	<i>25,053</i>	<i>177</i>	<i>25,230</i>
Memantine^(b)			
18031	..	7,481	7,481
18032	..	458	458
<i>Total</i>	<i>..</i>	<i>7,939</i>	<i>7,939</i>
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

Reason for ending assessment	With dementia		Without dementia	
	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)

Accommodation setting	Usual accommodation setting		Recommended long-term care 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
<i>Total community setting</i>	<i>84.3</i>	<i>93.4</i>	<i>38.6</i>	<i>58.6</i>
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
<i>Total institutional setting</i>	<i>15.7</i>	<i>6.6</i>	<i>61.4</i>	<i>41.4</i>
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
<i>Not stated/inadequately described</i>	<i>535</i>	<i>10,761</i>	<i>422</i>	<i>11,332</i>

(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

- Components may not add due to rounding.
- 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)

Usual accommodation setting	Recommended long-term care setting										Total	
	Private residence	Independent living in a retirement village	Supported community accommodation	Other community ^(a)	RAC—low care	RAC—high care	Hospital	institutional care	Other			
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	0.1	100.0		
Residential aged care—low level care	0.4	0.1	0.1	0.6	10.8	87.8	0.2	0.1	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	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	0.7	100.0		
Other community ^(a)	33.0	1.0	2.9	6.6	27.7	27.8	0.2	0.8	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	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	0.5	100.0		
Hospital	16.7	0.7	1.3	0.7	19.3	56.0	4.0	1.3	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	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.

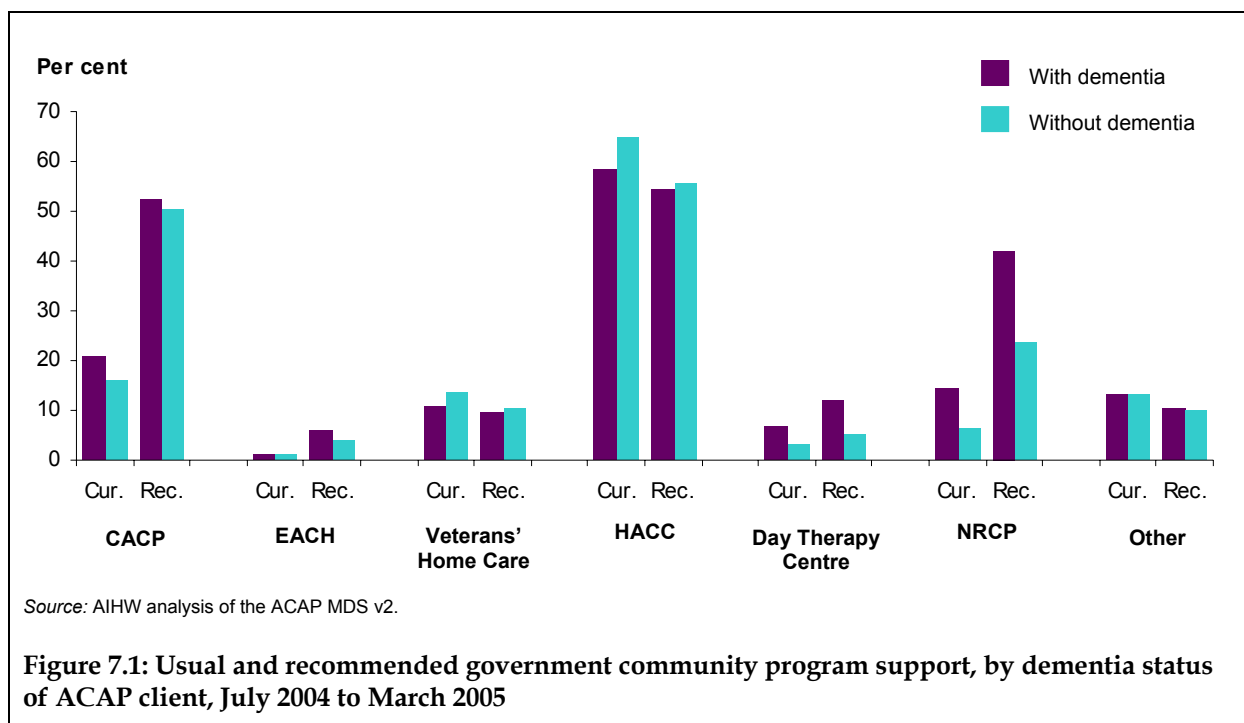


Table 7.15: Usual and recommended government program support, by dementia status of ACAP client living in the community, July 2004 to March 2005

Government program support	Current program support		Recommended 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
<i>Unable to determine or not stated/ inadequately described</i>	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

Program	With dementia		Without dementia		Total	
	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

Sex/age	With dementia		Without dementia		Total		Not stated Number
	Number	Per cent	Number	Per cent	Number	Per cent	
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
<i>Total</i>	<i>1,284</i>	<i>100.0</i>	<i>6,006</i>	<i>100.0</i>	<i>7,290</i>	<i>100.0</i>	<i>57</i>
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
<i>Total</i>	<i>3,300</i>	<i>100.0</i>	<i>14,331</i>	<i>100.0</i>	<i>17,631</i>	<i>100.0</i>	<i>133</i>
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

Type of assistance	With dementia				Without dementia			
	With a carer		Without a carer		With a carer		Without a carer	
	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

Type of assistance	With dementia				Without dementia			
	With carer		Without carer		With carer		Without carer	
	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

Sex/age	With dementia		Without dementia		Total	
	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
<i>Total</i>	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
<i>Total</i>	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

Type of assistance	With dementia ^(a)		Without dementia			
	With a carer		With a carer		Without a carer	
	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
<i>Total</i>	<i>5,646</i>	<i>4,262</i>	<i>2,554</i>	<i>775</i>	<i>2,407</i>	15,644	<i>100.0</i>	<i>38,379</i>	<i>100.0</i>
<i>Percentage of males with dementia in each RCS category</i>	<i>36.1</i>	<i>27.2</i>	<i>16.3</i>	<i>5.0</i>	<i>15.4</i>	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
<i>Percentage of females with dementia in each RCS category</i>									
	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
<i>Percentage of persons with dementia in each RCS category</i>									
	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			
<i>Percentage of permanent residents in each RCS category</i>									
	20.5	24.6	14.6	4.7	35.6	100.0			
<i>Per cent of RCS category with dementia</i>									
	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
<i>Crude rate 60+</i>	<i>3.11</i>	<i>3.19</i>	<i>3.00</i>	<i>3.10</i>	<i>3.03</i>
<i>Age-standardised rate 60+^(b)</i>	<i>3.84</i>	<i>3.90</i>	<i>3.63</i>	<i>3.67</i>	<i>3.57</i>
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
<i>Crude rate 60+</i>	<i>3.19</i>	<i>3.33</i>	<i>3.13</i>	<i>3.14</i>	<i>3.16</i>
<i>Age-standardised rate 60+^(b)</i>	<i>2.94</i>	<i>3.03</i>	<i>2.81</i>	<i>2.79</i>	<i>2.81</i>
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
<i>Crude rate 60+</i>	<i>20.71</i>	<i>20.03</i>	<i>19.26</i>	<i>19.54</i>	<i>20.34</i>
<i>Age-standardised rate 60+^(b)</i>	<i>26.32</i>	<i>25.17</i>	<i>23.90</i>	<i>23.85</i>	<i>24.58</i>
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
<i>Crude rate 60+</i>	<i>27.24</i>	<i>26.09</i>	<i>25.70</i>	<i>25.39</i>	<i>26.41</i>
<i>Age-standardised rate 60+^(b)</i>	<i>24.87</i>	<i>23.36</i>	<i>22.62</i>	<i>22.16</i>	<i>22.90</i>
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.