

5 Characteristics of people with dementia

5.1 Introduction

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

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

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

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

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

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

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

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

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

5.2 Identification of dementia

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

Survey of Disability, Ageing and Carers

In the 2003 SDAC, long-term health conditions were coded to a classification based on the International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision. A person was considered to have a long-term health condition, such as dementia, if he/she had a disease or disorder which had lasted or was likely to last for at least six months; or a disease, disorder or event (e.g. stroke) which produced an impairment or restriction which had lasted or was likely to last for at least six months.

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

Aged Care Assessment Program

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

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

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

Source: AIHW analysis of the ACAP MDS v2.

National Respite for Carers Program

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

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

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

Source: DoHA analysis of the NRCP MDS.

Community Aged Care Packages and Extended Aged Care at Home

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

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

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

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

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

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

Source: AIHW analysis of CACP and EACH 2002 census.

5.3 Sociodemographic characteristics

Age and sex distribution

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

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

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

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

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

— Nil or rounded to zero.

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

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

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

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

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

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

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

Source: AIHW analysis of the ACAP MDS v2.

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

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

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

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

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

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

Source: AIHW analysis of CACP 2002 census.

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

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

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

— Nil or rounded to zero.

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

Source: AIHW analysis of EACH 2002 census.

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

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

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

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

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

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

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

Source: DoHA analysis of the NRCP MDS.

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

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

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

Country of birth

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

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

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

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

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

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

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

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

Note: See note to Table 5.9.

Source: AIHW analysis of the ACAP MDS v2.

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

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

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

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

Source: AIHW analysis of CACP 2002 census.

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

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

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

— Nil or rounded to zero.

Note: See note to Table 5.9.

Source: AIHW analysis of EACH 2002 census.

Indigenous status

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

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

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

Notes

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

Source: AIHW analysis of the ACAP MDS v2.

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

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

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

Source: DoHA analysis of the NRCP MDS.

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

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

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

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

Source: AIHW analysis of CACP 2002 census.

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

Education

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

Residency

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

accommodation reported dementia, compared with around 1% of those living in households. For those aged 85 years or more, the corresponding figures were 48% and 4%.

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

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

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

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

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

— Nil or rounded to zero.

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

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

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

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

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

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

Source: AIHW analysis of the ACAP MDS v2.

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

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

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

— Nil or rounded to zero.

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

Source: AIHW analysis of CACP 2002 census.

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

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

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

— Nil or rounded to zero.

Source: AIHW analysis of EACH 2002 census.

Living arrangements

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

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

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

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

Notes

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

Source: AIHW analysis of the ACAP MDS v2.

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

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

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

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

Source: AIHW analysis of CACP 2002 census.

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

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

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

— Nil or rounded to zero.

Source: AIHW analysis of EACH 2002 census.

5.4 Nature of the dementia syndrome

Type of dementia

The ACAP MDS v2 records a main health condition and allows up to a further nine health conditions to be recorded by the ACAT at the end of the comprehensive assessment process. Recorded health conditions reflect those that are related to the person's assessed need for

assistance with activities of daily living and social participation. The main condition is the diagnosis with the most impact on the person's need for assistance.

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

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

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

Notes

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

Source: AIHW analysis of the ACAP MDS v2.

The majority (73%) of patients in the study conducted by Brodaty & Gresham (1989) had Alzheimer's disease, 20% had multi-infarct dementia and 7.3% had other forms of dementia. In a study of carers of younger people with dementia, Luscombe et al. (1998) found that 48% had Alzheimer's disease, 24% had Huntington's disease and 28% had other types of dementia.

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

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

Duration

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

Study	Duration of dementia
Brodaty & Hadzi-Pavlovic (1990)	<ul style="list-style-type: none"> • Patients who were still alive at survey had been dementing for about four years (mean 48.2 months, standard deviation 24.4, range 10–97) • Carers had been members of the NSW Alzheimer's Disease and Related Disorders Society for an average of 28.7 months (standard deviation 11.0, range 6–60)
Bindoff et al. (1997)	<ul style="list-style-type: none"> • The duration of disability for those with a dementia-related disorder (5.23 years) was significantly less than that for either those with a physical disability (7.15 years) or an intellectual disability (7.68 years), as some developmental and physical impairments are present at birth or early childhood
Bruce et al. (2002)	<ul style="list-style-type: none"> • Carers' estimates of the first time they consulted a general practitioner (GP) about the dementia ranged from six months to 6.5 years previously (average 1.8 years)
Bruce et al. (2005)	<ul style="list-style-type: none"> • The median duration of memory loss was 24 months (with a range of 17 to 48 months) and the median duration of need for care was 18 months (with a range of 6 to 30 months), although eligible carers were those who had been caring for the care recipient for at least 6 months

Behavioural and psychological symptoms of dementia

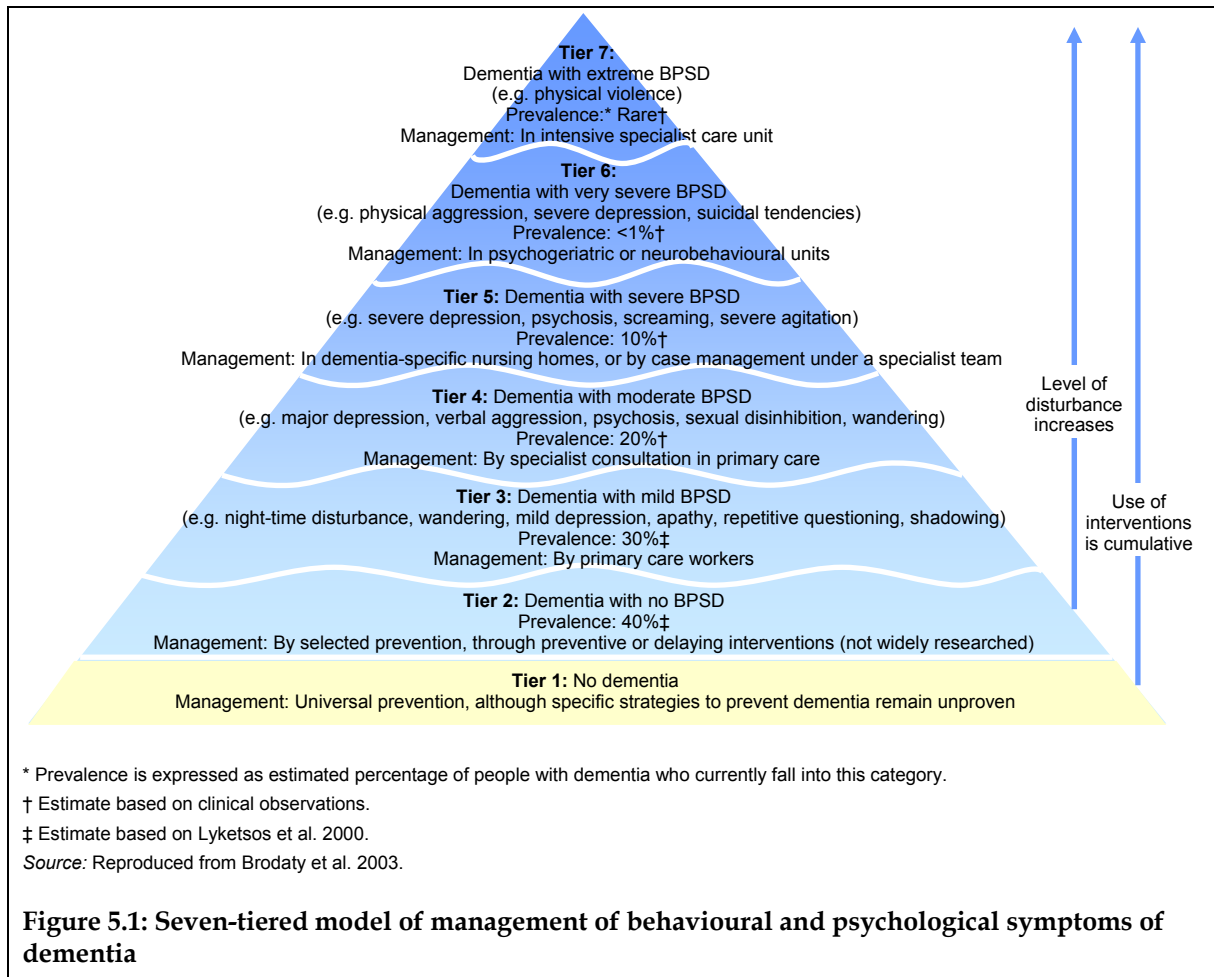
Behavioural and psychological symptoms of dementia (BPSD) is an umbrella term for a heterogeneous group of non-cognitive symptoms that are almost ubiquitous in dementia, including psychosis, depression, agitation, aggression and disinhibition (Brodaty et al. 2003). BPSD may create problems for the individual,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

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

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

BPSD has implications for management. The goals of managing challenging behaviour are to reduce the disruptive effects of the behaviour and/or to ameliorate distress or danger (Bird

et al. 2002). Management strategies include psychosocial approaches, pharmacotherapy and working with carers or nursing staff. Brodaty et al. (2003) proposed a seven-tiered model for the management of behavioural and psychological symptoms of dementia, which indicated that increasing severity of BPSD requires treatment and management in specialised health and care settings (Figure 5.1).



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

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

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

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

Source: Reproduced from Brodaty & Hadzi-Pavlovic 1990.

2. Aggression has been commonly reported in some studies:

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

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

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

4. Carer stress:

For each BPSD surveyed, the evaluation of the Aged Care Innovative Pool Dementia Pilot found that at least 50% of family carers reported a level of distress associated with the symptom. Carers experienced distress from symptoms of a non-aggressive nature as well as from verbal and physical aggression: over 60% of carers with a care recipient who exhibited memory loss, emotional or psychological symptoms, or wandering or intrusive behaviour reported moderate to extreme distress in relation to these symptoms. These results provide strong evidence of an association between BPSD characteristics of care recipients with dementia and psychological symptoms in carers. The study also found a statistically significant association between carer strain and carer psychological symptoms; given the

widely reported association between carer burden and higher rates of institutionalisation of people with dementia, the Pilot data suggest a relationship between the BPSD characteristics and risk of residential placement. Further, some service providers in the Pilot reported that mainstream community care providers are sometimes unwilling to accept people with dementia who exhibit moderate to severe behavioural symptoms, due to difficulties that can arise in providing care such as resisting assistance and occupational health and safety concerns for staff.

5.5 Disability, health and need for assistance

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

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

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

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

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

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

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

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

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

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

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

Need for assistance

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

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

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

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

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

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

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

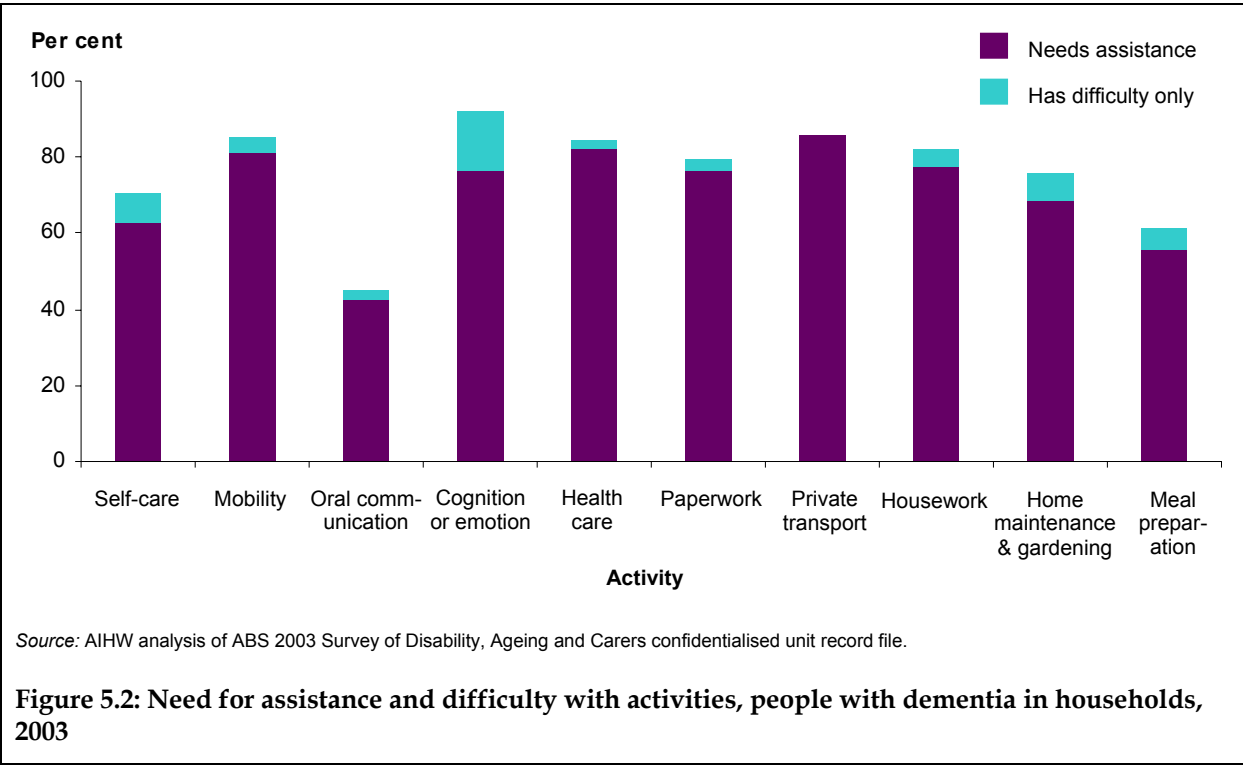
** Estimate has a relative standard error of greater than 50% and is considered too unreliable for general use.

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

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

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

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



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

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

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

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

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

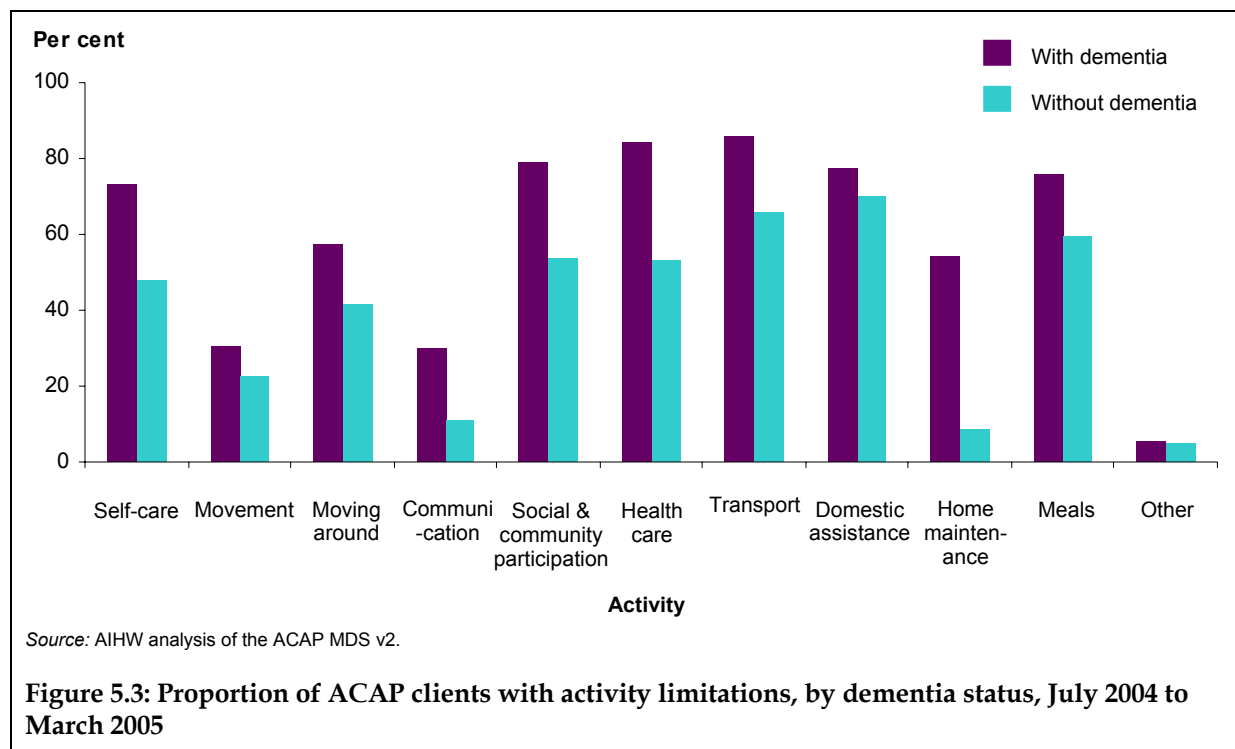
† *Domestic assistance, Meals and Home maintenance* do not apply to those whose usual accommodation setting was in a residential aged care service, hospital or other institutional care setting. For clients living in households, the percentage with limitations in these activities are 90.5%, 89.0% and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

Notes

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

Source: AIHW analysis of the ACAP MDS v2.

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



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

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

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

Notes

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

Source: AIHW analysis of CACP 2002 census.

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

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

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

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

Source: AIHW analysis of EACH 2002 census.

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

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

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

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

Source: AIHW analysis of CACP 2002 census.

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

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

— Nil or rounded to zero.

Source: AIHW analysis of EACH 2002 census.

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

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

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

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

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

Source: Reproduced from Bruce et al. 2005.

Table 5.33: Physical and cognitive impairment

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

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

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

(c) Includes intellectual, communication and psychiatric problems.

Need for assistance with cognition and behaviour

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

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

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

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

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

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

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

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

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

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

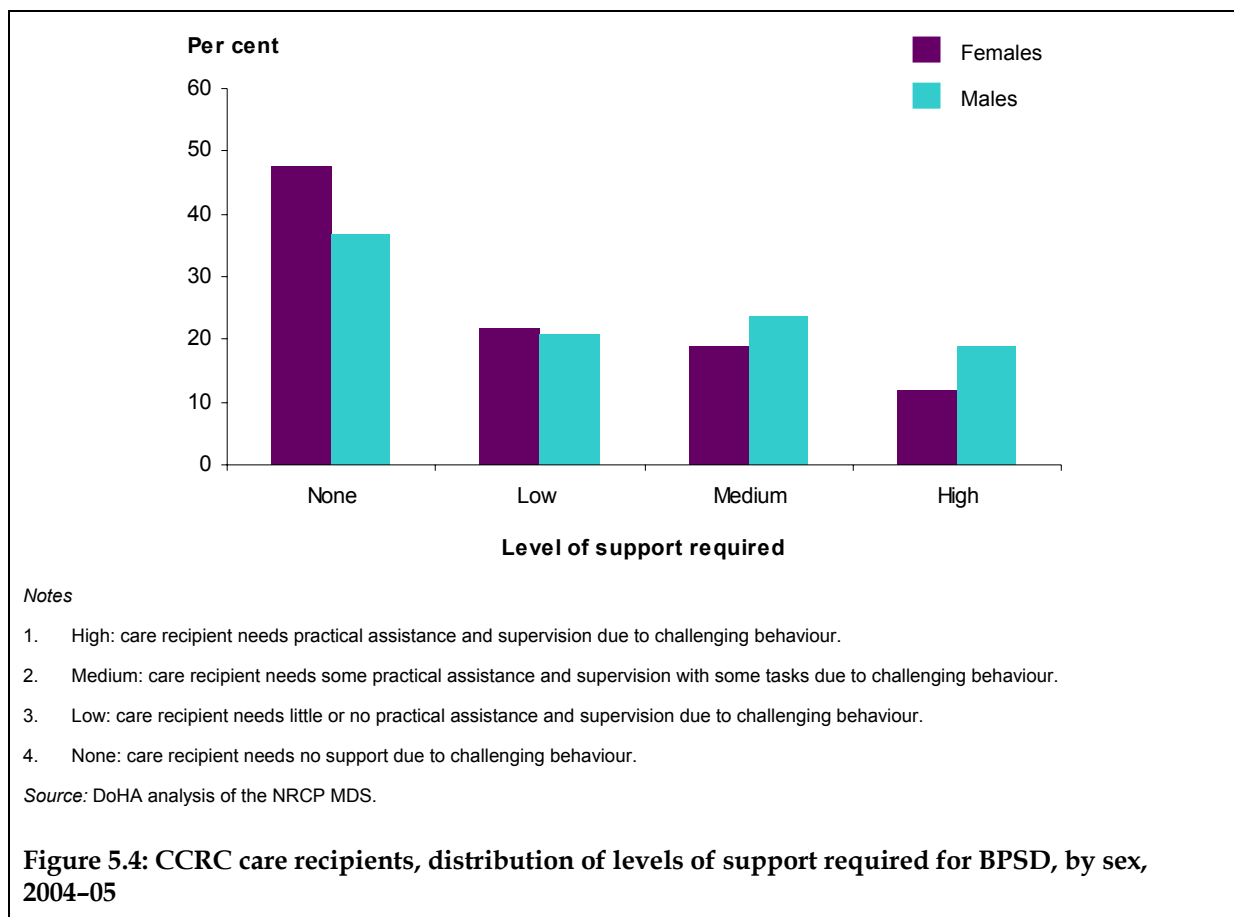
Similar proportions of care recipients registered with a CCRC demonstrate BPSD. In 2004–05, 5,648 CCRC care recipients with dementia (57%) were recorded as having behavioural and psychological symptoms (Table 5.36).

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

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

Source: DoHA analysis of the NRCP MDS.

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



Main health condition

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

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

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

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

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

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

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

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

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

— Nil or rounded to zero.

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

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

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

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

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

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

5.6 Sources of care

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

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

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

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

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

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

— Nil or rounded to zero.

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

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

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

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

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

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

— Nil or rounded to zero.

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

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

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

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

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

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

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

Source: AIHW analysis of the ACAP MDS v2.

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

Carer availability

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

The SDAC defines informal assistance as unpaid help or supervision that is provided to persons with one or more disabilities or to persons aged 60 years and over living in households. It includes only assistance that is provided for one or more of the specified tasks

comprising an activity because of a person's disability or age. Informal assistance may be provided by family, friends or neighbours. Any assistance received from family or friends living in the same household was considered to be informal assistance regardless of whether or not the provider was paid (ABS 2004:75). In 2003, the SDAC identified around 25,800 people with dementia who received informal assistance. This represents around 97% of those with dementia living in households. As previously discussed, the 2003 SDAC tends to identify those people with dementia living in households who have a severe or profound disability.

CACP, EACH and ACAP define a carer similarly as someone such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services (including paid staff in funded group houses), who has been identified as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.

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

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

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

(a) Excludes 196 cases with missing dementia status.

(b) Excludes 8 cases with missing dementia status.

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

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

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

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

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

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

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

Source: AIHW analysis of the ACAP MDS v2.

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

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

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

— Nil or rounded to zero.

Note: Age is at beginning of assessment.

Source: AIHW analysis of the ACAP MDS v2.

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

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

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

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

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

Source: AIHW analysis of CACP 2002 census.

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

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

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

Source: AIHW analysis of CACP 2002 census.

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

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

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

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

Source: AIHW analysis of EACH 2002 census.

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

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

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

— Nil or rounded to zero.

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

Source: AIHW analysis of EACH 2002 census.

5.7 Conclusion

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

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

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