

# 6 Carers of people with dementia

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

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

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of these characteristics can be reasonably considered vulnerable to admission to a residential aged care home (AIHW unpublished).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

## 6.1 What data are available?

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

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

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

## Survey of Disability, Ageing and Carers

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

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

#### ***Informal assistance***

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

#### ***Carer***

*A carer is a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or to older persons aged 60 years and over. This assistance has to be ongoing, or likely to be ongoing, for at least six months. Assistance to a person in a different household relates to 'everyday types of activities', without specific information on the activities. Where the care recipient lives in the same household, the assistance is for one or more of the following activities: cognition or emotion; communication; health care; housework; meal preparation; mobility; paperwork; property maintenance; self-care; or transport.*

#### ***Primary carer***

*A primary carer is a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care).*

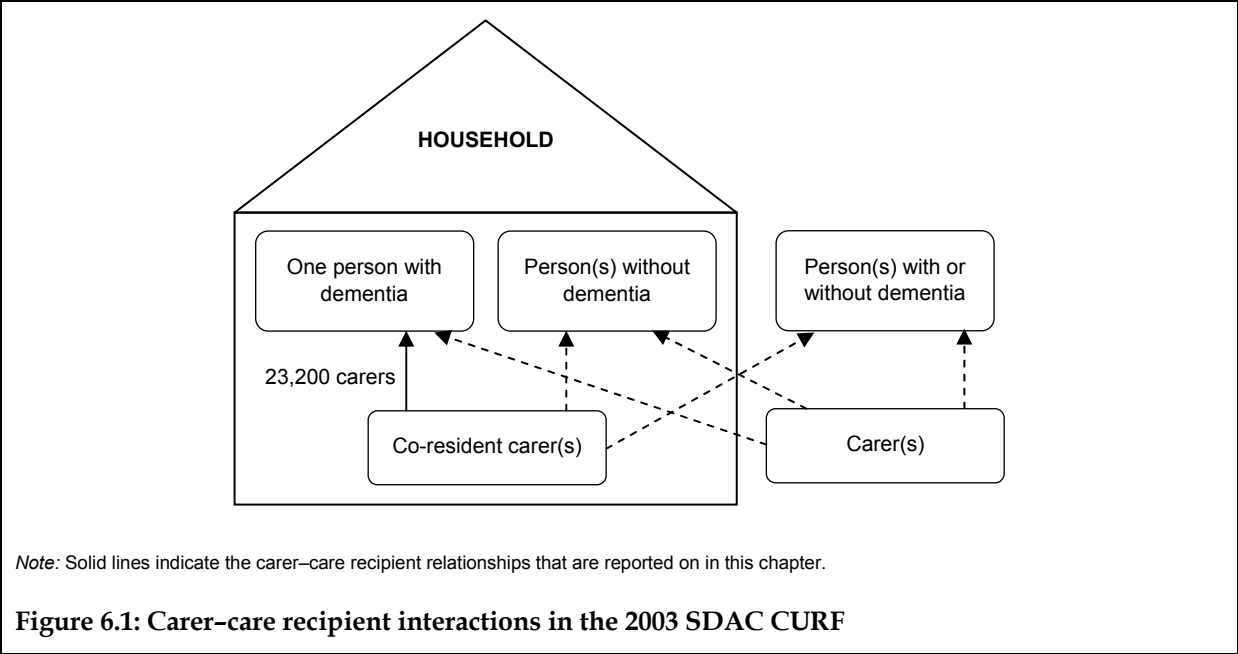
***Confirmed primary carers*** only include persons aged 15 years and over for whom a personal interview was conducted.

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

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

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

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



The SDAC collects demographic information about all co-resident carers, but more detailed information about the caring role is collected by personal interview only about *confirmed*

co-resident *primary* carers (see Box 6.1). The SDAC sample includes only a small number of co-resident and co-resident primary carers of people with dementia. This reduces the reliability of any extrapolation of these numbers to an estimate of the total population of co-resident carers of people with dementia. Therefore, for the purposes of this chapter, most of the analysis will treat the data from the SDAC as a sample, and will not try to extrapolate this to the Australian population.

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

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

## **Administrative data collections**

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

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

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

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

The CACP and EACH census collections included questions on dementia status, carer availability, carer co-residency status and relationship of the carer to the care recipient, as well as assistance needed and service use by the care recipient. However, the censuses were

conducted in 2002 and more recent data of this type are not available from the ongoing program data. A particular limitation in respect of the EACH program is that it was a relatively new and very small program at the time of the census and it is possible that characteristics of caring arrangements for this population have changed as the program has grown in recent years. Current program data do not include information about carers.

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

CACP, EACH and ACAP define a carer similarly as *someone such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services (including paid staff in funded group houses), who has been identified as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.* As information is only collected about one carer, the data items relate to the carer who is identified by the client and/or their carer as providing the most significant amount and type of care and assistance related to the client's capacity to remain living at home.

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

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

## **Australian studies**

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

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

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

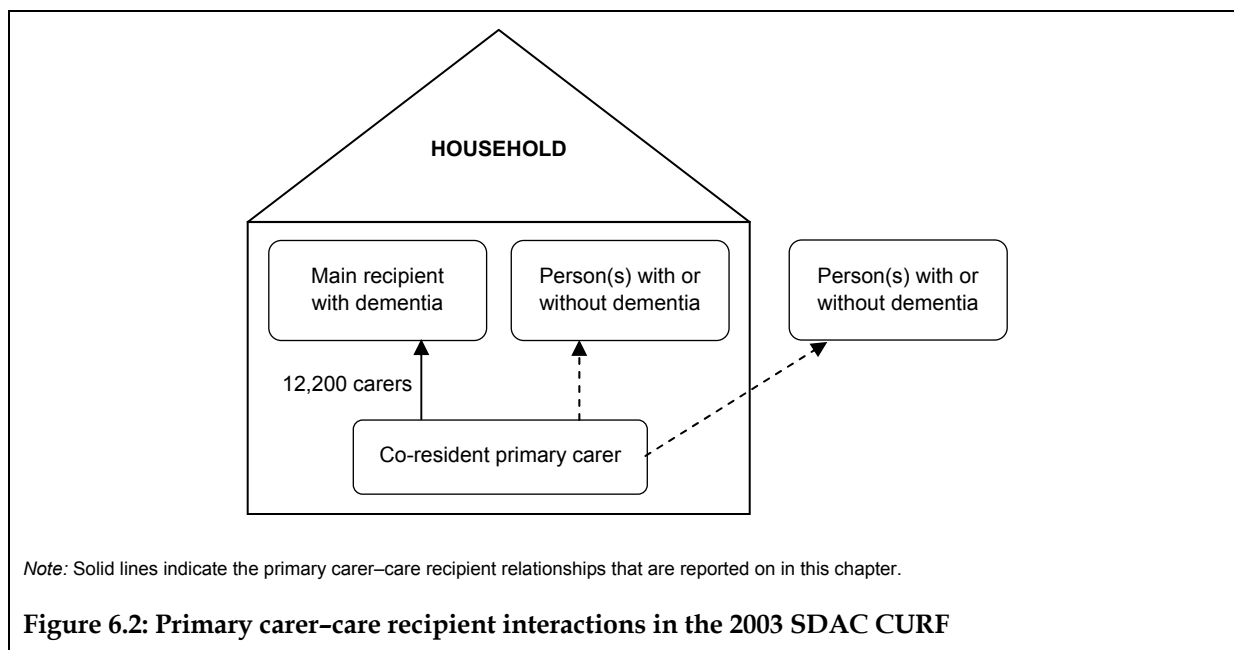
These studies are a valuable contribution to knowledge about carers, and data from these studies have also been included in this chapter. Table A6.1 summarises the published studies whose findings have been reported throughout the chapter. In many cases differences in results may be explained by differences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

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

## **6.2 Carer availability**

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

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



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

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

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

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

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

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

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

## 6.3 Profile of carers

### Age, sex and Indigenous status

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

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

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

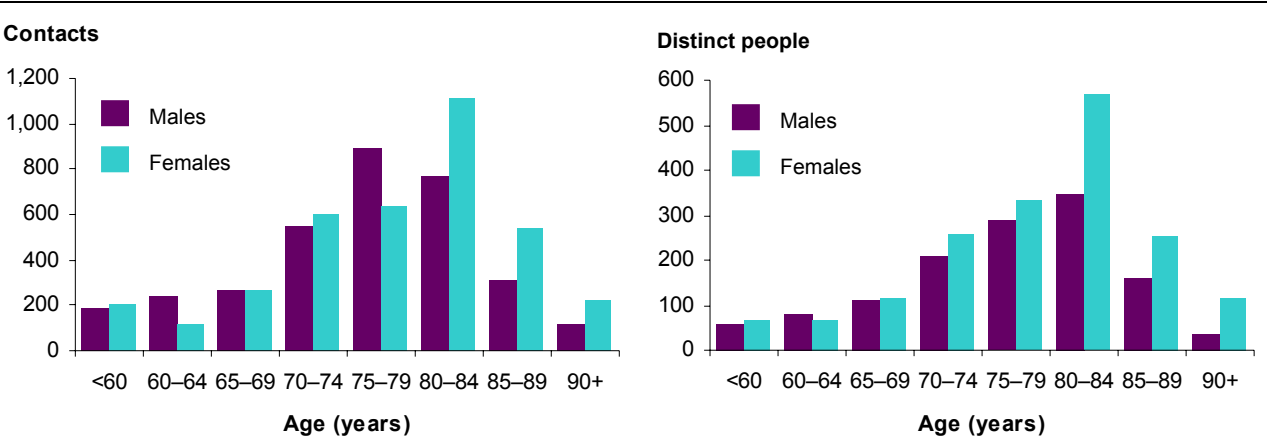
	Carers assisted by a CCRC		Carers of people with dementia		Per cent who care for a person with dementia
	Number	Per cent	Number	Per cent	
<b>Sex</b>					
Males	13,737	23.3	2,826	27.8	20.6
Females	45,227	76.7	7,343	72.2	16.2
<b>Total</b>	<b>58,964</b>	<b>100.0</b>	<b>10,169</b>	<b>100.0</b>	<b>17.2</b>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

Source: DoHA analysis of the NRCP MDS.

Just over half (53%) of carer contacts with Alzheimer’s Australia DESP where a person of concern diagnosed with dementia was identified were female (Figure 6.3). The vast majority of carers were aged over 60 years (95%). Similarly, 55% of distinct people were female and 96% were aged 60 years or over. Carers in contact with Alzheimer’s Australia DESP were



less often female and had an older age profile than NRCP CCRC clients, but this may reflect a larger proportion of non-primary carers in contact with this program.



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

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

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

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

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

The ability to provide more accurate estimates of such basic characteristics of the carer population is important for ensuring that carer support needs may be met in appropriate ways. The age distribution of carers from the SDAC may reflect some bias as a result of the exclusion of non-resident carers. Data from the 1998 SDAC (which did not have the same restrictions on reporting about carers) indicated that carers of the very old were more likely to be non-resident carers (AIHW 2004a). However, we lack the more recent data to confirm whether this is the case with very old people with dementia. In a recent evaluation of

dementia care pilot projects, 45% of carers were a son or daughter (or their partners) of the person with dementia, and almost half of this group did not live with the parent they were caring for. The support needs of older spouse carers and adult children caring for a parent in another household are likely to be different in terms of preferred models of respite care and social support, for example, and the main issues of concern to them may be different.

### Marital status

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

**Table 6.3: Carers’ marital status: comparison across studies**

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

— Nil or rounded to zero.

(a) Excludes carers under 15 years of age.

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

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

### Country of birth and language

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

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

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

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

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

## **Locality/remoteness**

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

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

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

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

significantly affect carer service use, number of respite services used or overall level of use of carer support services.

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

## **Socioeconomic status**

### **Education**

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

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

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

Bruce et al. (2005) noted that carers who had completed less than 10 years of education had significantly lower physical component summary scores. However, education was not associated with any difference in mental component summary scores or self-reported stress.

### **Labour force status**

The labour force status of carers is frequently affected by the caring role (Luscombe et al. 1998) – this is not surprising given the physical, psychological and time demands associated with caring for someone who is severely restricted in daily activities (particularly those with dementia). In addition to the more apparent financial implications of caring and its impact on workforce participation, there are other impacts – paid employment is also a way for carers to get respite from caring and helps to maintain social networks. For those caregivers in the workforce, the demands of caring may have implications for their job – they may have to take jobs with less responsibility or miss training opportunities for promotion, or they may have to reduce working hours or use leave entitlements in order to meet their caring responsibilities.

Most of the available data indicate that carers of people with dementia were either not working or had reduced their hours of work. This partly reflects the age of carers (particularly co-resident carers), and partly the demands associated with caring for someone with dementia.

- No co-resident primary carers of people with dementia identified through the 2003 SDAC were in the labour force. Therefore, analysis of the effect of the caring role on their weekly working hours or time off from work is not possible using this data source.
- In a study of carers of younger people with dementia, Luscombe et al. (1998) found that of the carers working at the time of diagnosis, only 41% retained the same employment status at survey, 54% had retired and 5% had reduced their hours from full-time to part-time; 45% were employed full-time at diagnosis, compared with only 18% at survey.
- Fewer than 11% of carers in the study conducted by Leong et al. (2001) held paid jobs. Among a subsample of 10 carers, three were retired, one was semi-retired, one was receiving a disability pension, three were housewives, and two were unemployed.
- In a study of carers of people with dementia or memory loss, Brodaty et al. (2005) reported that 69% were not working, 11% were working less than 30 hours per week and only 20% were working 30 or more hours per week.
- Schofield et al. (1998b) found that there was no difference between carers of relatives with physical impairment, undiagnosed memory loss or dementia with regard to paid employment – although most carers (61%) were not in paid employment, a significant proportion were (39%).

## Financial status

Data from the 2003 SDAC show that government pensions or allowances were the main source of cash income for the majority (53%) of co-resident carers (excluding those aged less than 15 years), rather than other sources such as wages or salaries or unknown sources. As no co-resident primary carers were in the labour force, none received their main source of cash income from wages or salaries – in fact, 71% received their main source of cash income from government pensions or allowances: 48% of co-resident primary carers reported receiving the Carer Payment.

### **Box 6.2: Income support for carers**

*In addition to general income support, depending on their circumstances, carers may be able to access two government payments: the Carer Payment and the Carer Allowance. People receiving these payments may be caring for more than one person.*

*Carer Payment (adult) is an income support payment for people who are unable to support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail aged. Because it is for people forgoing paid work due to caring responsibilities, relatively few older people receive it. It is set at the same rate as the Age Pension (at the end of 2006, a single person on the maximum rate received \$499.70 a fortnight, and a couple \$834.40 per fortnight) and is subject to the same income and assets tests (Centrelink 2006b). Carer Payment cannot be received as well as another income support payment, and the person being cared for must be receiving a social security pension or payment or satisfy specific income and assets tests. A health professional's report is needed to help establish eligibility.*

*Carer Allowance (adult) is an income supplement payment available to people who provide daily care and attention in a private home to a person who has a disability or severe medical condition or who is frail aged. The Adult Disability Assessment Tool measures the level of care needed by an adult as a result of his or her disability or medical condition and is used to assess medical eligibility for Carer Allowance. Since 1 April 2005, some non-resident carers have also been eligible for this allowance. It is adjusted on 1 January each year, and in 2006 was set at \$94.70 per fortnight (Centrelink 2006a). Carer Allowance is free of income and assets tests and may be paid in addition to Carer Payment or other payments.*

Fewer carers of people with dementia or memory loss in Brodaty et al. (2005) received a pension or benefit (42%). This was comparable to the findings by Helmes et al. (2005) that 41% of carers most commonly reported a pension as their main source of income, followed by income from business (12%), superannuation (16%), salary (27%) and other sources (3.9%).

Bindoff et al. (1997) found that 48% of caregivers received a gross household annual income of less than \$20,000, and 58% lived on less than \$25,000 per annum. Caregivers of intellectually disabled recipients had significantly more income (\$25,000–30,000) than caregivers of people with a physical or dementia-related disability (\$15,000–20,000).

In a study of carers of younger people with dementia, Luscombe et al. (1998) found that only 11% reported no financial problems due to the diagnosis of dementia. The most frequently reported financial problems – reduction in income and loss of carer employment – were more common among carers of people with other dementias than among carers of people with Alzheimer’s disease or Huntington’s disease (Table 6.4). Spouses were more likely to find reduction in income a problem associated with the diagnosis of dementia and parents were the most likely to claim to be financially affected by the person with dementia losing employment, although this difference was not significant. There was no relationship between the number of types of financial problems, or carer or patient age.

**Table 6.4: Proportion of carers reporting causes of financial problems**

	Reduction in income	Loss of carer employment
<b>Type of dementia</b>		
Huntington’s disease	45	5
Alzheimer’s disease	69	31
Other dementias	92	52
<b>Relationship to care recipient</b>		
Spouse	80	52
Parents	45	73
Children	44	11
Other carers	25	50
<b>Total</b>	<b>70</b>	<b>50</b>

Source: Reproduced from Luscombe et al. 1998.

For some carers, financial pressures, such as concern about fees, can be a source of stress (Bruce & Paterson 2000).

**Living arrangements and co-residency status**

Carers of people with dementia are more likely to be co-resident with the recipient with dementia, although the proportion of co-resident carers differs between studies due to methodological differences such as recruitment of participants and eligibility criteria (Table 6.5). For example, Leong et al. (2001) only included carers that were co-resident or lived near the person with dementia and visited regularly. However, most studies found that around 65% of carers were co-resident with the recipient with dementia, although the range was large from 35% to 89%. The rate of carer co-residency is also high for EACH care recipients who are assessed as needing the equivalent of high level residential care.

**Table 6.5: Carer co-residency status: comparison across studies (per cent)**

Data source	Co-resident carer	Non-resident carer	
		Lives alone	Lives with others
ACAP <sup>(a)</sup>			
With dementia	67		33
Without dementia	57		43
CACP <sup>(a)</sup>			
With dementia	52		48
Without dementia	51		49
EACH <sup>(a)</sup>			
With dementia	86		14
Without dementia	82		18
Schofield et al. (1998b) <sup>(b)</sup>			
Dementia	61		39
Undiagnosed memory loss	63		37
Physical impairment	53		47
LoGiudice et al. (1999)	68		32
Leong et al. (2001)	89		11
Low et al. (2002)	35		65
Ward et al. (2003)	86		14
Brodsky et al. (2005)	67	23	11
Bruce et al. (2005)	63		37
Helmes et al. (2005)	65		35

(a) Excludes cases where carer availability or residency status was not reported.

(b) Excludes carers of people with dementia living in residential care.

For comparative purposes, Table 6.5 also includes the co-residency status of those without dementia, where available. Although carers tended to be co-resident with the recipient, regardless of dementia status, this was particularly the case for carers of people with dementia. This may reflect the need for continuous rather than episodic care and supervision by people with dementia. For example, where residency status was reported, the principal or primary carer of ACAP clients diagnosed with dementia was more likely to be a co-resident carer (67%) than a non-resident carer (33%). This was also true for ACAP clients without a dementia diagnosis, although the difference was not as great (57% versus 43%).

Consistent with this, among ACAP clients with a carer, those with dementia were less likely to be living alone (29%) and more likely to be living with family or others than those without dementia (38%). In contrast, among ACAP clients without a carer, those with dementia were more likely to be living alone (82%) than those without dementia (77%). In a study of 26,500 ACAP clients in Victoria, Howe & Kung (2003) note that dementia clients are much less likely to be living in the community alone but equally likely to be living with others, indicating the relatively greater importance of the presence of family caregivers in maintaining individuals with dementia in the community.

Schofield et al. (1998b) noted that significantly more care recipients with dementia were living in residential care, compared with care recipients with undiagnosed memory loss or a

physical impairment. Conversely those recipients with undiagnosed memory loss or physical impairment tended to be living with carers. However, after excluding those living in residential care, a larger proportion of recipients with dementia or undiagnosed memory loss resided with their carer rather than living alone or with others.

However, it should be noted that a considerable proportion of care is also provided by non-resident carers (Sammut 1996). Non-resident carers can have quite different experiences of the caring role to co-resident carers (Schofield et al. 1997, cited in Bruce & Paterson 2000). The needs of carers who do not live with the recipient with dementia are different to those of co-resident carers – as Sammut (1996) suggests, these carers face different pressures and need flexible support.

In an evaluation of dementia care pilot projects (AIHW: Hales et al. 2006), living arrangement was the only variable to show a significant association with client accommodation status at time of discharge from a short-term care pilot. The sample comprised data on 10 clients who were living alone while receiving services and 55 clients who were living with family. Half of those living alone were discharged directly to residential care, compared with 14.5% of clients living with family. Living arrangement is bound up with carer availability since 53 of the 55 clients who were living with family had a co-resident primary carer. Based on the analysis results, the odds of a person who lives alone entering residential aged care on discharge from a Dementia Pilot short-term care project are estimated to be 5.8 times higher than for a person who lives with others.

## **Relationship with the care recipient**

The relationship between a carer and care recipient with dementia is closely associated with the age and sex of the carer, and the age and sex of the recipient. As might be expected, the majority of people with dementia are cared for at home by a spouse or relative (Department of Health 1992, cited in Bruce & Paterson 2000) – usually children or children-in-law. A smaller number of people with dementia are cared for by other relatives such as parents or siblings, or friends or neighbours. However, the experience of a daughter who has young children of her own caring for a mother with dementia is likely to be very different from that of a husband or wife caring for his or her spouse (Herrman 1994). Luscombe et al. (1998) noted that, even in support groups, carers who are young spouses feel different from older spouses or similarly aged children of older people with dementia.

Data from the 2003 SDAC show that 39% of co-resident carers and 65% of co-resident primary carers were a spouse or partner, and 46% of co-resident carers and 30% of co-resident primary carers were children or children-in-law (Table 6.6). That is, co-resident primary carers tended to be spouses or partners while other co-resident carers tended to be children or children-in-law or other relatives.

Around 43% of carers of ACAP clients with dementia were a spouse or partner and 47% were children or children-in-law, compared with 34% spouses or partners and 53% children or children-in-law for carers of ACAP clients without dementia.

Schofield et al. (1998b) found that there was no difference between carers of relatives with physical impairment, undiagnosed memory loss or dementia in regards to relationship with the care recipient – a little over half (54%) were adult offspring (mostly daughters), a quarter were spouses (mostly wives), and 21% were other relatives or friends.

The proportion of carers who are a spouse or partner, or children or children-in-law, appears to be associated with the co-residency status of the carer. For example, Table 6.7 shows that



co-resident carers of ACAP recipients with dementia tended to be a spouse or partner (64%), while non-resident carers were almost always children or children-in-law (81%). This general trend was also noted for carers of ACAP recipients without dementia. Methodological differences between published Australian studies (and in some cases exclusion of non-resident carers) make it difficult to compare the proportions of carers that are spouses or partners, or children or children-in-law, in Table 6.6.

**Table 6.6: Relationship of carer to care recipient status: comparison across studies (per cent)**

Data source	Spouse/partner	Children/children-in-law	Other
SDAC		<b>Per cent</b>	
Co-resident carers	39	46	15
Co-resident primary carers	65	30	5
ACAP <sup>(a)</sup>			
With dementia	43	47	10
Without dementia	34	53	13
CACP <sup>(a)</sup>			
With dementia	33	55	12
Without dementia	31	54	15
EACH			
With dementia	46	51	3
Without dementia	63	31	6
Dementia caregivers training programme	93	3	4
Brodaty & Hadzi-Pavlovic (1990)	62	31	6
Cahill & Shapiro (1993)	62	— —————38—————	—
Bindoff et al. (1997)	38	15	47
Luscombe et al. (1998)	68	†12	†21
Schofield et al. (1998b) <sup>(b)</sup>	25	†54	†21
LoGiudice et al. (1999)	54	†36	†10
Bruce & Paterson (2000)	71	29	—
Bruce et al. (2002)	76	19	5
Low et al. (2002)	16	†63	†21
Ward et al. (2003)	68	26	6
Brodaty et al. (2005)	33	†55	†12
Bruce et al. (2005)	45	52	3
Helmes et al. (2005)	39	†49	†12

† May or may not include children-in-law.

— Nil or rounded to zero.

(a) Excludes cases where relationship of carer to care recipient was not reported. Includes private employees.

(b) Includes carers of people with physical impairment, undiagnosed memory loss or dementia. No differences in regards to relationship between carer and care recipient were found between the three groups.

**Table 6.7: Relationship of carer to care recipient, by co-residency status of carer, ACAP client with dementia**

Relationship of carer to care recipient	Not applicable	Co-resident carer	Non-resident carer	Not stated/inadequately described	Total
Wife/female partner	0	5,165	52	10	5,227
Husband/male partner	5	3,605	36	4	3,650
Mother	0	30	9	0	39
Father	0	15	5	0	20
Daughter	3	2,738	3,679	15	6,435
Son	2	1,266	1,590	9	2,867
Daughter-in-law	1	237	238	0	476
Son-in-law	0	19	16	0	35
Other female relative	2	342	567	6	917
Other male relative	0	136	220	0	356
Female friend/neighbour	0	132	285	2	419
Male friend/neighbour	0	108	116	1	225
Private employee	1	44	40	0	85
Not stated/inadequately described	1,018	331	84	1,160	2,593
Not applicable	6,102	44	70	13	6,229
<b>Total</b>	<b>7,134</b>	<b>14,212</b>	<b>7,007</b>	<b>1,220</b>	<b>29,573</b>

*Notes*

1. A client may have more than one carer. This data element relates to the carer who is identified by the client and/or their carer as providing the most significant amount and type of care and assistance.
2. Some people of Aboriginal or Torres Strait Islander origin attach a different cultural meaning to terms such as 'brother', 'uncle' and 'mother' than the purely biological/social meanings that non-Indigenous people use. In such cases the ACAT recorded the relationship of the carer according to how the client or carer identified that relationship.
3. *Private employee* (not organised by formal services) refers to carers that are personally arranged without the involvement of formal community services. Such carers may be paid directly by the person or a family member or may receive free or subsidised board or lodgings in return for their caring services.

## 6.4 The caring role

The role of primary carers is crucial to maintaining highly dependent people with dementia at home. Carers provide a range of assistance and support with daily activities as well as emotional, financial and practical support. The role of formal services in supplementing care from family becomes critical for people with high care needs living in the community, but it is also important to recognise that the presence of family carers is itself a conduit to the person with dementia receiving formal service intervention.

Pilot services in the Innovative Pool Dementia Pilot were designed for people with high care needs associated with dementia, and a high proportion of recipients had moderate to severe dementia. A number of these pilot services accepted referrals only for people who had access to daily care from family (AIHW: Hales et al. 2006). Judging by this requirement, it may be difficult for a person with dementia who does not have daily access to care from family to access community care services because of the level of risk to the person and to the service provider that is involved in community living, and because it is the service-seeking behaviour of family members that often results in the formal service intervention.

## Motivation to care

The reasons for caring for someone with dementia are complex. The ABS SDAC allowed carers to give more than one reason for taking on a primary caring role. Data from the 2003 SDAC show that a sense of duty to care is one of the most common reasons reported by co-resident primary carers of people with dementia – a large proportion reported that they provided care because they felt an emotional obligation to take on the role (52%) or that it was a family responsibility (48%). Other reasons for taking on the caring role included that they could provide better care than someone else (30%) or no other family or friends were willing or available (35%).

Bruce et al. (2002) also noted that there was a strong sense of duty towards the relative with dementia, and that this drove carers to continue caring for as long as possible without outside help and inhibited carers from discussing problems with their GPs. Interviews of a small subsample of 10 carers in a study conducted by Leong et al. (2001) similarly showed that some family members took on the caring responsibility out of love and concern for the person with dementia, or out of a sense of duty and family obligation. Most took on the caring role because there was no-one else in the family who was willing or available to care for the person (a factor which can also contribute to a sense of duty).

## Assistance provided by carers

As dementia progresses it becomes increasingly difficult for the person with dementia to live independently; consequently, there are increasing demands on the caregiver to provide assistance. The loss of cognitive function means that a person with dementia gradually loses insight into their level of functioning and, over time, becomes unable to seek assistance when assistance is needed. This will tend to reach a point where constant supervision and guidance is required. Memory loss and impaired judgement have implications for medication use and personal and physical safety. In dementia care, the carer provides not only instrumental assistance, but acts as a 'bridge' (terminology used in the Sydney Older Persons Study) to formal services, and provides a critical safety monitoring role.

According to the 2003 SDAC, all people with dementia who were the main recipient of care by a co-resident primary carer were profoundly or severely limited in performing one or more core activities, and sometimes or always needed assistance with that activity (see Box 4.2 for a description of core activity limitations in the SDAC). Accordingly, all co-resident primary carers provided assistance with one or more core activities to their main recipient with dementia (which is consistent with the definition of a primary carer). More specifically, 91% provided assistance with communication, 91% provided assistance with mobility, and 78% provided assistance with self-care.

Furthermore, all co-resident primary carers provided assistance with at least one non-core activity to their main recipient with dementia – in particular, all carers provided assistance with health care, paperwork, housework and meal preparation; 96% provided assistance with transport; 87% provided assistance with property maintenance; and 91% provided assistance with cognition or emotion (the remainder did not state whether they assisted with cognition or emotion).

The ABS definition of a primary carer (see Section 6.1) requires that assistance be provided with core activities. Studies without this definitional limitation provide some insight into the extent to which assistance with ADLs is provided by a broader group of carers of people with dementia. Schofield et al. (1998b) reported that carers of relatives with dementia

reported higher ADL and IADL dependence, and corresponding IADL provision (2.78), than carers of those with undiagnosed memory loss (2.52) or a physical impairment (1.88). Similarly, carers of relatives with an undiagnosed memory loss reported more IADL (but not ADL) dependence and care provision than carers of those with a physical impairment.

Brodady et al. (2005) reported that 29% of carers provided no help with ADLs to the recipient with dementia or memory loss, 43% provided some help and 28% provided most or all help with ADLs. More than half (53%) of carers provided most or all help with IADLs, but 3.7% provided no help, and 14% provided some help.

Carers may continue providing assistance to the recipient with dementia, even after they have entered residential care – the form of care provided usually shifts from meeting daily needs towards giving social and emotional support (Schofield 2001). In a study of rituals of family carers whose relative with dementia had recently entered residential care, Schofield (2001) found that some carers engaged in small caregiving tasks, even when staff normally attended to these chores, giving the carer a sense of a continuing role in their relative's life. However, family carers felt that these tasks were at times directly or indirectly discouraged by caregiving staff. Research on the division of care between staff and family members indicates that confusion may arise about where responsibility for tasks lies when they have both an instrumental and a psychosocial component (Duncan & Morgan 1994, cited in Schofield 2001) – the tasks that were discouraged by caregiving staff were those that fell within this grey area.

## **Time spent caring**

The time demands placed on carers of people with dementia are quite substantial. Because of the progressive nature of most types of dementia, ultimately a person with dementia requires 24-hour care. Draper (2004) notes that many of the behavioural consequences of dementia, such as sleep changes and wandering, require extra supervision from the carer. He states that such behaviour places increasing demands on carers' time and requires them to be vigilant even when they need time to relax.

Data from the 2003 SDAC show that around 65% of co-resident primary carers spend 40 hours or more actively caring or supervising per week – as the majority of co-resident primary carers had only one care recipient, it can be assumed that a large proportion of this time was spent caring for the main recipient with dementia (almost all co-resident carers (87%) and co-resident primary carers (91%) only cared for the recipient with dementia). This is not unexpected, considering almost 96% of main recipients with dementia required continuous (rather than episodic) care from their co-resident primary carer.

Similarly, in a comparative study of carers of relatives with physical impairment, undiagnosed memory loss or dementia, Schofield et al. (1998b) noted that although time spent caring did not differ between the three groups, after excluding those in residential care, over half of the care recipients with dementia were unable to be left alone compared with a quarter of those with undiagnosed memory loss and 13% of physical impairment recipients.

Additionally, Bruce et al. (2005) found that the median number of hours spent caring per week was 28 hours, with a range of 8 to 168 hours per week.

The NRCP also collects information on time spent caring, but these data were not available in time for this report.

## Duration of care

The mean or median duration of care is often reported to be less than five years, reflecting the late age of onset of dementia and its association with increased carer burden as a risk factor for entry into residential care. Methodological and study design differences mean that published estimates of the duration of the caring role vary widely:

- In a retrospective study of carers who were providing care in the community, Cahill & Shapiro (1993) found that the mean duration of care was 47 months.
- Bruce & Paterson (2000) found that the perceived duration of the caring role varied between 4 months and 10 years, with a mean of 2.9 years.
- The length of time since the respondents in the study conducted by Leong et al. (2001) had assumed the role of family carer ranged from 4 months to 20 years, with a mode of 2 years. A subsample of 10 carers included four carers that had been caring for 1–2 years, three for 4 years, two for 6–7 years and one for 20 years.
- Carers in the study by Bruce et al. (2002) estimated that the duration of care was 6 months to 7 years, with an average of 2.3 years (eligible carers were those who had been caring for the care recipient for at least 6 months).

However, it should be noted that mean or median duration of care may be misleading – some carers have been caring for a recipient with dementia for 10 or 20 years.

Data from the 2003 SDAC show that the majority of co-resident primary carers (52%) had been caring for their main recipient with dementia for between 1 and 4 years. However, consistent with Schofield et al. (1998b), over one-fifth (22%) had been caring for their main recipient with dementia for more than 10 years.

In a comparative study of carers of relatives with physical impairment, undiagnosed memory loss or dementia, Schofield et al. (1998b) found that the duration of care exceeded 10 years for 22% of caregivers and under 2 years for 32%. Excluding those whose relatives were in residential care, almost a third had never had a break or had not had a break in over 2 years.

The NRCP also collects information on date the caring role commenced, but the data were not available in time for this report.

## 6.5 Impact of the caring role on carers

Anderson (1987) described the caring role as an ‘unremitting burden’. Much of the literature suggests that the demands placed on caregivers of people with dementia are heavy; they must manage behavioural problems in addition to the care needs of the person with dementia. Observing the gradual decline of a loved one from a competent individual to an incompetent dependant can also be a harrowing experience (Draper 2004), and is likely to add to the burden. High-level dementia care may be different to other types of caring because it involves every aspect of the person: provision of physical, psychological, cognitive and social support. There can also be a high degree of social isolation that impacts on the capacity of the carer to live a participative life.

Numerous researchers have investigated the impact of the caring role for caregivers of people with dementia (for example, Sammut 1996; Brodaty & Gresham 1989; Connell et al. 2001). Carers of people with dementia are at particularly high risk of anxiety and depression as a result of their caring role. Brodaty & Gresham (1989) have summarised some of the

literature on this issue, associating carers with feelings of demoralisation, isolation and psychological distress.

## **Health, wellbeing and carer burden**

Morris et al. (1988) (cited in Henderson & Jorm 1998 and AIHW 2004a) remark that institutionalisation may have more to do with the attitudes and wellbeing of the caregiver than the impairment of the dementia sufferer. The physical and mental wellbeing of carers plays a pivotal role in whether the person with dementia can remain living in the community.

The 2003 SDAC indicated that 46% of co-resident primary carers reported at least one adverse effect due to the caring role. These adverse effects included responses such as frequently feeling angry or resentful about their caring role, having been diagnosed with a stress-related illness, feeling weary or lacking energy or frequently feeling worried or depressed because of the caring role. Around 70% of co-resident primary carers of people with dementia reported that their sleep was frequently or occasionally interrupted due to their caring role. All co-resident carers experiencing interrupted sleep believed that this interfered with their normal daily activities.

In a recent evaluation of dementia pilot projects (AIHW: Hales et al. 2006), two scales were chosen to report on the wellbeing of participating carers (Robinson's (1983) 13-item Caregiver Strain Index, and the 28-item General Health Questionnaire (GHQ)). Data collected for the evaluation confirmed reports from project coordinators and case managers that carers of people referred for pilot services typically presented showing high levels of carer strain. It is thought that most carers had managed for too long without adequate support before approaching the projects. Almost three-quarters of carers scored above the threshold of high carer strain. Anxiety and insomnia were the most frequently reported psychological symptoms. A statistically significant association was found between baseline measures of carer strain and psychological symptoms, confirming that high levels of carer strain are associated with lower levels of psychological wellbeing among primary carers whose care recipients participated in the evaluation.

There is evidence that co-resident carers are more stressed than those whose relative lives elsewhere or in a residential setting (Brodaty & Hadzi-Pavlovic 1990 and Yeatman et al. 1993, cited in Schofield et al. 1998b). However, Schofield et al. (1998b) found that co-resident carers expressed more role satisfaction as well as more resentment than those caring for a relative in residential care, living alone or with another person, regardless of whether they were carers of relatives with physical impairment, undiagnosed memory loss or dementia. Additionally, carers of relatives living alone or with another person reported higher levels of positive affect and life satisfaction than co-resident carers. Helmes et al. (2005) did not find any significant difference in the degree of burden felt by carers who lived with the care recipient with dementia and those who lived separately.

In a comparative study of carers of relatives with dementia, undiagnosed memory loss or a physical impairment, Schofield et al. (1998b) found that resentment was the most effective indicator for predicting burden (combined scores on four measures: negative affect, overload, social support and life satisfaction; followed by increased family conflict, care recipient depression, close relationship and anger). Factors contributing to resentment included low social support, anger, difficulty in behaviour problems and being a carer of a relative with undiagnosed memory loss, rather than a carer of a relative with dementia.

Bruce & Paterson (2000) found that most carers suffered high levels of stress, mainly due to behaviour disturbances and care needs of the dementia sufferers. Problems with health care agencies were also reported by a majority of the carers to be contributors to their distress. General practitioners were perceived to have referred dementia sufferers too late for community care, despite the carer having experienced difficulties for a considerable time period. Carers also complained that too little information was provided about the diagnosis of dementia, how to deal with problem behaviours and how to access support services before and after the assessment procedure.

Leong et al. (2001) investigated areas of significant unmet need perceived as important to family members who were the principal carer of a relative with dementia. The six most frequently reported barrier needs included: to know that someone will provide care when family carer unable to do so; a telephone hot-line; time away from caring duties; ways to deal with stress; time for physical rest; and ways to deal with feelings of being trapped.

Common problems emerging from the interviews of carers in the study conducted by Bruce et al. (2002) included the patients difficult behaviours, their own exhaustion, feeling stressed, and lack of time for person or social activities.

## Social interaction

Leong et al. (2001) stated that the commitment to care for someone with dementia involves major and ongoing sacrifice on the part of the carer – the time involved, the disruption of normal routines and lifestyle, the physical demands of caring on a 24-hour basis, the constant vigilance, and the restrictions on contacts with friends and wider family are just a part of what the caregiving entails.

Common problems reported by carers in the study conducted by Bruce et al. (2002) included lack of time for personal or social activities. LoGiudice et al. (1999) also noted that psychosocial impairment in the health status of carers was greatest in the domains of social interaction and recreations and pastimes. There was significant improvement in the social interaction of carers attending a memory clinic (but not the control group) after 6 months, and this was maintained at 12 months.

Brodsky & Hadzi-Pavlovic (1990) commented that the findings regarding personal contacts were cause for concern, with half of the carers spending time only once a week or less with someone who did not live with them (Table 6.8).

**Table 6.8: Frequency of personal and telephone contacts in the previous two weeks (proportion)**

	Personal contact	Telephone contact
Daily	9	36
2–6 times per week	41	55
Once per week	31	9
Once per fortnight	6	—
Not at all	13	—
<b>Mean number of contacts per week</b>	<b>2.6</b>	<b>5.9 (standard deviation 3.3)</b>
<b>Satisfaction with amount of contact (maximum score of 6)</b>	<b>Modest (mean 3.6, standard deviation 1.8)</b>	<b>Moderate (mean 4.8, standard deviation 1.5)</b>

— Nil or rounded to zero.

Source: Reproduced from Brodsky & Hadzi-Pavlovic 1990.

Comparatively, Gibson (1983) (cited in Brodaty & Hadzi-Pavlovic 1990) reported that 50% of elderly respondents to the Australian Health Survey had at least one personal contact daily, 24% had contacts 3–6 times per week, 20% had 1–2 contacts per week and 6% had no contacts within a month.

Brodaty & Hadzi-Pavlovic (1990) noted caregivers who were in contact with more people from outside their home, and who were more satisfied with the number of people with whom they were in contact, showed fewer psychological symptoms. Thus there were significant negative correlations between GHQ scores and the frequency of personal contacts and satisfaction with the amount of personal contact; and between Zung scores and the frequency of and satisfaction with personal contacts. They suggest that support may be protective. Alternatively, those who were unwell may tend to perceive their supports negatively and as inadequate (i.e. there was contamination of ratings of support by psychological state variables). Similar trends were seen in associations between carer psychological morbidity scores and satisfaction with telephone contacts (but not with the number of telephone contacts), although this did not reach statistical significance.

Bindoff et al. (1997) reported that social and recreational activity was the only one of nine wellbeing measures that significantly differentiated caregivers of people with a dementia-related disorder, intellectual disability or physical disability. Caregivers of those with a dementia-related disorder reported the lowest level of participation, although the majority of the difference in social and recreational activity was between caregivers of those with an intellectual disability and the other two groups.

Distance and physical isolation from family members and friends compounds difficulties carers experience in maintaining relationships and social activities. Brodaty & Hadzi-Pavlovic (1990) found that while 82% of carers had relatives or friends living nearby, 18% had not a single relative or friend within 60 km. Only 68% had at least one child within a 60 km radius, compared to 87% of a group of 1,050 older people (non-carers) living in Sydney (ABS 1983, cited in Brodaty & Hadzi-Pavlovic 1990). A subsample of 10 carers in a study conducted by Leong et al. (2001) reported feeling alone and isolated in their caring role, with lack of support from their families. While in some cases family members and friends had drifted away preferring not to be involved, many had immediate family members living too far away to give practical help.

## Relationship with others

Caring for someone who is old or disabled can also affect the family atmosphere (Schofield et al. 1998b). Data from the 2003 SDAC show that the majority (61%) of co-resident primary carers reported that the caring role had at least one adverse main effect on their relationship with other co-resident family members, friends, spouse or partner, or care recipient with dementia. Adverse effects include responses such as *Less time to spend with them*, *Relationship strained*, or *Lost or losing touch with existing friends*.

Family conflict was identified as an effect of dementia by 41% of carers in a study by Luscombe et al. (1998). Additionally, three-quarters of spouse carers with children reported that their children had suffered psychological or emotional problems as a consequence of dementia in the family and only 8% reported that their children had not encountered **any** problems. Half reported that their children had been in conflict with their affected parent – more often with their affected father than mother and also more often if the affected parent was younger (Table 6.9).



**Table 6.9: Proportion of carers reporting conflict between children and parent with dementia**

	Per cent
<b>Relationship of care recipient to children</b>	
Father	62
Mother	19
<b>Age of care recipient</b>	
<50	79
50–59	48
60–64	36
<b>Total</b>	<b>51</b>

Source: Reproduced from Luscombe et al. 1998.

Children were also more likely to have problems at school or at home if the person with dementia was less than 50 years old. More types of problems in children were associated with both youthfulness in the carer and the patient. The overall number and types of problems faced by children of carers looking after patients from different diagnostic groups were similar, although there was a trend for more frequent Alzheimer's disease carer reports of children with psychological or emotional problems (88%) than Huntington's disease (78%) or other dementias (55%).

Schofield et al. (1998b) found that carers of those with a physical impairment were also less likely to report increasing conflict in the family following the onset of caring compared with carers of those with dementia or undiagnosed memory loss. The groups did not differ on family cohesiveness.

Almost 38% of carers in the study conducted by Bruce & Paterson (2000) reported family friction due to the lack of support from other family members.

## Relationship with care recipient

The 2003 SDAC indicates that the majority of co-resident primary carers (52%) considered that their relationship with the care recipient was unaffected by the care recipient's dementia. This is consistent with the finding that almost 38% of carers in the study conducted by Bruce & Paterson (2000) reported a changed role in their relationship related to the loss of function of the patient.

This same study found that around 29% of carers reported negative premorbid relationships that were exacerbated by dementia (Bruce & Paterson 2000).

In the study conducted by Schofield et al. (1998b), carers of relatives with a physical impairment were more likely to rate the quality of their relationship with a recipient with a physical impairment as very close (71%), compared with carers of those with dementia (53%) or undiagnosed memory loss (52%). On the other hand, 12% of caregivers in the study conducted by Low et al. (2002) rated their relationship with the resident before institutionalisation as somewhat close, 18% as moderately close and 70% as very close.

Schofield et al. (1998b) also found that carers of those with a physical impairment were more likely to rate the level of tension in their relationship with a recipient with a physical impairment as low (62%), compared with carers of those with dementia (49%) or undiagnosed memory loss (41%).

Brodaty & Hadzi-Pavlovic (1990) examined the psychosocial effects of caring on co-resident carers of people with dementia, finding that co-resident carers who are spouses suffer more psychological distress than those who are not spouses.

## **Impact of behavioural and psychological symptoms of dementia**

Evidence of the relationship between challenging behaviours and the impact on carer stress is equivocal. Buono et al. (1999) (cited in AIHW 2004a:24) reported that the main causes of burden in dementia care are the heavy personal care needs, memory loss and behavioural symptoms that can be experienced by the person with dementia. However, an early study by Zarit et al. (1980) found no association between behavioural symptoms and level of carer strain.

Most Australian studies have reported a link between carer burden and the behavioural and psychological symptoms associated with dementia. Brodaty & Hadzi-Pavlovic (1990) found that there was no support for the hypothesis that psychological morbidity in carers was related to total problem behaviours. However, there was modest support for the hypothesis that the level of psychological morbidity (i.e. GHQ score) of carers was associated with demand problem behaviours. No other problem behaviour subscale correlated significantly with either GHQ or Zung depression score. There was a significant interaction between demand and disturbance behaviours and GHQ scores when the carers were the patients' wives.

Around 79% of carers in the study conducted by Bruce & Paterson (2000) reported patient behaviour as a source of stress. Commonest reported behaviours were confusion, argumentative or irritable behaviour, wandering, nocturnal disturbance, constant repetitions and accusations of stealing. Physical or verbal abuse of the carer by the patient, and physical or verbal abuse of the patient by the carer, was reported as a source of stress by 17% and 21% of carers, respectively (although this was not necessarily chronic abusive behaviour).

Similarly, Bruce et al. (2002) reported that common problems for carers emerging from the interviews included the patients' difficult behaviour. Additionally, triggers precipitating referrals from GPs included new behaviours (wandering, incontinence).

Schofield et al. (1998b) noted that a higher proportion of carers of those with a physical impairment (36%) reported it as very easy to cope with their relatives' behaviour, compared with carers of those with dementia (3%) or undiagnosed memory loss (6%), and fewer reported it as very difficult. Carer burden was significantly lower among carers of people with physical impairment, compared with carers of people with dementia or undiagnosed memory loss. Care recipient depression was found to be a significant predictor of burden, and difficulty in coping with problem behaviours was a significant predictor of resentment.

However, Bindoff et al. (1997) noted that carers of people with a dementia-related disorder, an intellectual disability or a physical disability did not differ with regard to cognitive and behavioural coping strategies. Similarly, Ward et al. (2003) found that 76% of all psychological problems and 67% of behavioural ones were labelled as either no problem or only a mild problem by carers. However, tolerance was not without limits and some carers were close to 'burn out': 14 of the 50 had used residential respite care, which is often a prelude to permanent placement. Even experienced carers rarely articulated a strategic plan – when faced with delusions, abuse and repeated questions, carers most commonly stated that they either did nothing or responded gently with reassurance, distraction and orientating information. Ward et al. (2003) suggest that those carers who said they did nothing when faced with resistant, abusive or inappropriate behaviours may actually have

incorporated good preventative strategies so completely into everyday life that they failed to mention them when questioned at interview.

Both Bruce & Paterson (2000) and Schofield et al. (1998b) reported that a firm diagnosis of the care recipient's condition often reduces carer burden. Wood & Rabins (cited in Schofield et al. 1998a and AIHW 2004a) independently maintain that if carers understand the condition they are less inclined to interpret behaviour as offensive or as the product of their own inadequacy.

At least 50% of carers surveyed during the evaluation of Innovative Pool dementia care pilot projects reported some level of distress for each type of BPSD surveyed (AIHW: Hales et al. 2006). Over 60% of carers with a care recipient who exhibited memory loss, emotional or psychological symptoms, and wandering or intrusive behaviour reported moderate to extreme distress as a result of these symptoms. These results confirm the role of BPSD in contributing to carer strain and of the consequent importance of carer support and behaviour management services.

## **Positive aspects of the caring role**

There is a growing body of literature investigating the positive impacts of the caring role (Connell et al. 2001). Such outcomes include enjoyment of the caring role, satisfaction and enhanced self-esteem. Some of the carers in the study conducted by Bruce et al. (2002) expressed pride in their caring role.

However, according to the 2003 SDAC, only 26% of co-resident primary carers reported feeling satisfied due to the caring role – the majority (56%) reported that they were not affected in this way.

Schofield et al. (1998b) reported that although carers of those with dementia or undiagnosed memory loss were more likely to express anger and resentment than carers of those with a physical impairment, the groups did not differ in role satisfaction.

## **6.6 Support networks for carers**

As previously mentioned, many studies only include co-resident carers or primary or principal carers – that is, other people who are part of the network of back-up care, and are important in supporting the complex care needs of people with dementia and in providing support for the carer, are often not included in these studies. However, information about informal support that primary or principal carers receive from family or friends is investigated in a number of studies.

Data from the 2003 SDAC show that almost half (48%) of the co-resident primary carers of people with dementia stated that they did not have a fall-back carer – only 30% reported that they had a fall-back carer, with a smaller number reporting that they did not know whether or not they had a fall-back carer.

- Around 52% of co-resident primary carers of people with dementia reported needing or wanting an improvement or more support in areas such as respite care, financial assistance, physical assistance, emotional support, improvement in own health or other areas of assistance. Respite care was the most commonly reported area that carers needed or wanted an improvement or more support as reported by 26% of co-resident primary carers.

- 57% reported not needing **any** assistance or **further** assistance – 43% reported needing assistance or further assistance (i.e. 30% were already receiving assistance and reported needing further assistance). The majority of co-resident primary carers reported having no unmet need for assistance on weekdays (78%), weekends (74%) or weeknights (87%); overall, 57% reported having no unmet need at any of these times.

While the carers in the study by Brodaty & Hadzi-Pavlovic (1990) may have had access to a confidante, practical help was not always forthcoming – 41% of co-resident primary carers had no main source of assistance. Of carers for whom sufficient data were available for analysis, 33% received (and 26% needed) assistance with shopping, 12% (and 11%) with meals, 30% (and 35%) with housework, 28% (and 17%) with transport, 27% (and 30%) with gardening, and 40% (and 38%) with minor house repairs. Where assistance was received (or needed) it was mostly provided by children once or twice weekly.

Bindoff et al. (1997) noted that the caring role was typically the responsibility of a single caregiver who received limited informal support: 54% reported receiving no help from family members or friends in direct care of the dependant such as feeding, bathing or helping with mobility, and 61% received no indirect help in caring for the dependant such as doing shopping housework or home maintenance. Lack of family support was reported by 38% of carers in the study by Bruce & Paterson (2000).

Of those caregivers who did receive help, as reported by Bindoff et al. (1997), 33% reported almost daily assistance, while 13% reported help six-monthly or less. A majority (68%) rated the quality of this help as good or very good and 11% as very poor. Rating the overall frequency and quality of the help received, 4% reported being very unhappy, 1% were not happy, 27% thought it was okay and 51% were pleased or very pleased. There were no significant differences between caregivers of dependants with a dementia-related disorder, an intellectual disability or a physical disability for any of these variables (Table 6.10).

**Table 6.10: Comparison of informal support for carers of dependants with dementia-related, intellectual and physical disabilities**

	Scale	Disability category		
		Dementia-related disorder	Intellectual disability	Physical disability
Persons providing direct help	0 = no persons, 3 = 5 or more	0.5	0.6	0.6
Persons providing indirect help	0 = no persons, 3 = 5 or more	0.5	0.4	0.4
Frequency of help received	0 = never, 5 = almost daily	2.3	2.7	2.4
Quality of help	0 = very poor, 5 = excellent	3.1	3.9	2.4
Satisfaction with help	0 = very unhappy, 4 = very pleased	2.5	3.0	2.2

Source: Reproduced from Bindoff et al. 1997.

However, in Schofield et al. (1998b), perceived social support was higher for carers of those with a physical impairment in comparison with carers of those with undiagnosed memory loss or dementia.

The most important unmet need reported by carers in the study by Leong et al. (2001) was the need to know that someone would provide care if they became ill and the need to deal with feelings of entrapment. Many did not have back-up arrangements for another member of the family to take over should the principal carers become incapacitated. Most carers in the sample were elderly and almost half reported lack of support from family or other informal sources. Many carers had immediate family members living too far away to be able

to give practical help, and in other cases family members and friends had drifted away, preferring not to be involved, but leaving a vacuum in the support network for the carer.

## 6.7 Formal service use by carers

More detailed information about the use of formal services by people with dementia and their carers is included in Chapter 7. This section examines service use to support carers, such as community services, respite care and counselling.

The major type of assistance provided through community care programs which is designed to directly benefit carers is respite care. In addition, the provision of other assistance types to care recipients (e.g. health care, delivered meals, bathing) provides indirect support to carers by supplementing the amount and type of care they provide to the care recipients. Respite care may be provided in the home, at a centre during the day or overnight, or in a residential service. There are also small cottage services. As well as providing information and support for carers, the National Respite for Carers Program provides respite care. Information about the carers assisted by the program and the care recipients registered in the program is provided in Table 5.14. Use of services provided through this program is discussed in more detail in Chapter 7.

According to the 2003 SDAC, the majority of co-resident primary carers of people with dementia (70%) reported that they had never used respite care. Furthermore, 57% of primary carers stated that they had never received respite care and did not need or want it. This is consistent with ACAP data for nine months during 2003–04 which indicates that 73% of ACAP clients with dementia, for whom use of respite care was applicable, had not used it (Table 6.11). This was slightly less than for ACAP clients without dementia (75%).

The importance of respite care to support carers of people with dementia is indicated by the recommendations for respite care made by ACATs during this period (Table 6.11). While 33% of clients without dementia who had not used respite care were also not recommended for respite care, this was the case for only 15% of clients with dementia. In general, ACAP clients with dementia had higher rates of recommendation for long-term care in a residential aged care or other institutional setting than ACAP clients without dementia. Among ACAP clients for whom respite care recommendations were applicable, 78% of clients with dementia were recommended for some type of respite care, compared with 53% of ACAP clients without dementia.

**Table 6.11: Respite care use at time of assessment and recommended respite care use, ACAP clients, by dementia status, July 2004 to March 2005**

Respite care use	Respite care recommended							Total
	Not applicable <sup>(a)</sup>	Residential	Non-residential	Residential & non-residential	None	Unable to determine	Not stated/inadequately described	
<b>With dementia</b>								
Not applicable <sup>(b)</sup>	3,978	393	6	82	187	54	31	4,731
Residential	1,029	1,505	11	275	97	6	12	2,935
Non-residential	245	312	96	513	31	5	3	1,205
Residential & non-residential	133	114	3	314	8	1	2	575
None	4,372	6,737	318	1,589	2,346	119	98	15,579
Unable to determine	169	99	3	24	27	145	2	469
Not stated/inadequately described	76	166	9	32	245	23	113	664
<b>Total</b>	<b>10,002</b>	<b>9,326</b>	<b>446</b>	<b>2,829</b>	<b>2,941</b>	<b>353</b>	<b>261</b>	<b>26,158</b>
<b>Without dementia</b>								
Not applicable <sup>(b)</sup>	6,126	947	21	730	388	182	199	8,593
Residential	1,781	4,040	18	500	227	52	41	6,659
Non-residential	203	411	168	592	54	3	10	1,441
Residential & non-residential	75	97	2	377	7	1	1	560
None	10,405	21,949	645	2,556	18,032	1,338	385	55,310
Unable to determine	443	203	5	27	130	2,542	51	3,401
Not stated/inadequately described	329	389	24	49	379	297	5,049	6,516
<b>Total</b>	<b>19,362</b>	<b>28,036</b>	<b>883</b>	<b>4,831</b>	<b>19,217</b>	<b>4,415</b>	<b>5,736</b>	<b>82,480</b>

(a) Recorded for people whose recommended long-term care setting is residential aged care, a hospital or other institutional care.

(b) Recorded for people who were permanent residents of residential aged care services, multi-purposes services or centres, Indigenous flexible pilots, hospitals or other institutional settings at the time of assessment.

Note: Residential respite care may be relevant to people with or without carers. Non-residential respite care is only relevant to clients with carers.

Respite care is an important service type provided through the CACP program, and data about respite care use through this program were collected in the 2002 census. Most respite care is used by clients with carers, signifying its important role in carer support (Table 6.12). The mean and median number of hours of respite in the census week was higher for recipients with dementia than those without dementia. Median hours of respite care for those with dementia was 3.0, compared with 2.0 hours for those without dementia (means of 4.0 and 3.0 hours, respectively). CACP recipients with dementia and with a carer were more likely than others to receive respite: 12% of recipients with dementia and a carer received this service, compared with 6% of those without dementia with a carer (Table 6.12).

**Table 6.12: CACP care recipients with and without dementia, use of respite care, by carer status, census week 2002**

	With dementia				Without dementia			
	With a carer		Without a carer		With a carer		Without a carer	
Use of respite care	No.	%	No.	%	No.	%	No.	%
	393	12.0	11	0.9	623	6.0	100	1.1
Amount of respite care (hours)	Mean	Median	Mean	Median	Mean	Median	Mean	Median
	3.9	3.0	5.2	2.5	3.1	2.0	2.3	2.0
Total CACP recipients	<b>3,284</b>	. .	<b>1,179</b>	. .	<b>10,429</b>	. .	<b>9,437</b>	. .

*Note:* The table excludes 1,110 cases. These include both recipients with either carer availability or dementia status missing, as well as those who received no services during census week.

*Source:* AIHW analysis of CACP 2002 census.

Similarly, high levels of non-use of respite care have also been reported by smaller studies, which sometimes also enquired into reasons for non-use. Brodaty et al. (2005) found that 84% of carers did not use respite services, and only 35% of those carers reported needing this service. Perceived lack of need was reported by 65% of carers as the principal reason for non-use of respite services, followed by care recipient's resistance to accepting help from services (12%), not having enquired (9.1%) and lack of knowledge (7.6%).

Low levels of use of respite care were reported in the study conducted by Ward et al. (2003). Only 36% of the care recipients regularly attended day care, and 28% used generic or specialist respite residential care.

Excluding carers of people with dementia in residential settings, Schofield et al. (1998b) found that carers of people with dementia were more likely to both use and need respite care than carers of relatives with physical impairment or undiagnosed memory loss, although the proportions of carers using respite care were low. Around 17% of carers of relatives with dementia used respite care, compared with 11% of carers of those with undiagnosed memory loss and 7% of carers of those with a physical impairment. Similarly, almost half (47%) of carers of those with dementia reported needing respite care, compared with 27% and 19% of carers of those with undiagnosed memory loss or a physical impairment respectively.

Higher rates of respite care use were reported in a study of carers of younger people with dementia (Luscombe et al. 1998) where 33% of carers had used one and 35% had used two or more types of respite care. Carers of people with Huntington's disease tended to use fewer respite services than carers of people with Alzheimer's disease or other dementias. There were no significant differences in the number of respite services used by carer gender, area of residency, relationship to patient or carer age, although the number of respite services used tended to be positively associated with the patient's age. Table 6.13 provides the number of carers that used each type of respite service, and what proportion of these carers rated the service as good.

**Table 6.13: Use of respite services at survey**

Type of service	Number	Per cent	Per cent rated 'good'
Day centre	33	37.5	85
Hospital	25	28.4	68
Nursing home	15	17.0	47
In-home	12	13.6	92
Hostel	10	11.4	70
Other	8	9.1	67
Nil	28	31.8	. .
<b>Total</b>	<b>88</b>	. .	. .

Source: Table reproduced from Luscombe et al. 1998.

Leong et al. (2001) reported that respite care was one of the most frequently mentioned needs, but the experience of study participants at the time was that accessing in-home or institutional respite care at short notice was not usually possible. Respite care was seen as the only opportunity for carers to receive the break they needed for their health and state of mind. Leong et al. (2001) suggested that those caring for people with dementia at home feel a need for a variety of respite services, including day, overnight and weekend care, accessible at short notice – current services need to be more flexible and responsive to the actual needs of those who use them.

The range of respite services and their availability have grown over recent years, due to a number of federal government initiatives directed at increasing respite options for carers. However, data from the SDAC and ACAP suggest that there may still be issues in respect of carers' awareness of respite care options available to them and/or the extent to which carers perceive that respite care services are able to meet their needs appropriately.

## 6.8 Carer support and intervention

The Australian Government offers support and intervention for carers through a number of programs, including the Early Stage Dementia Support and Respite Project, the Dementia Education and Support Program, the Carer Information and Support Program and the National Respite for Carers Program. The last five years have seen a major growth in the availability of respite services, including specific funding through the NRCP for emergency and overnight care for carers of people with dementia.

A number of intervention trials have addressed ways of assisting informal carers of those with dementia – however, as LoGiudice et al. (1999) noted, most trials have evaluated programs which have been specially designed for the project. For example, Brodaty & Gresham (1989) studied patient-carer pairs participating in either a dementia carers' program, memory retraining group or waiting group. At 12 months' follow-up, the carers' program resulted in significantly lower psychological stress among carers than the memory retraining program.

Fewer intervention trials have determined the effectiveness of health services that are already established. LoGiudice et al. (1999) conducted a study of carers and their relatives with mild to moderate cognitive impairment to assess the beneficial effects of a memory clinic for carers. The results demonstrated improved overall psychosocial health-related



quality of life for carers attending the clinic, particularly in the domain of social interaction, which was identified as one of the areas most affected by the caring role.

Vernooij-Dassen et al. (1996) (cited in AIHW 2004a:24-5) found a strong association between carers' sense of competence and the level of agitation and apathy in the care recipient with dementia. They concluded that interventions that help carers recognise, clarify and understand the behaviour of the person with dementia might change the carer's perception of the behaviour. This could increase the carer's sense of competence and so reduce carer burden.

All project coordinators involved in the Innovative Pool dementia care pilots emphasised the importance of engaging primary carers and other family members in care planning (AIHW: Hales et al. 2006). They reported on the need to cater to the needs of different age and lifestyle groups of carers, and reflected on how the characteristics of a carer can influence the level and type of their involvement in care planning and the type of carer support required. It was noted that younger carers are often more confident in negotiating the system of support and interacting with service providers in a care management partnership role. This can potentially reduce the level of ongoing high-level case management from the formal care provider.

Employed younger carers for this particular target group may have a reduced need for social support compared to full-time carers or co-resident older carers. This group generally requires more flexible respite care than is offered by most mainstream services to accommodate paid employment. Older carers and socially isolated carers can benefit from social support and respite services that offer opportunity for social interaction (AIHW: Hales et al. 2006).

Given the imminent high growth in numbers of very old people living in the community, ageing of the baby-boomer population and the estimated doubling in prevalence of dementia with every five years of age over 65, improved awareness of government support programs and community care entry points will ensure formal services continue to play an effective role in early intervention and coordinated support for growing numbers of carers.