

16 Ageing, informal care and carers

This chapter presents analyses of the ABS disability survey data related to ageing, informal care and carers. The chapter starts with a brief discussion of the relevant survey definitions and methods of collecting data on informal carers. The first section examines the profile of carers, including age and sex profiles, length of time in the caring role and a comparison of some social and economic characteristics between carer and non-carer populations. This is followed by analyses of the effect of the caring role on carers and their support needs. The trend in de-institutionalisation and its impact on informal care is then discussed.

16.1 Disability survey data on carers

In the 1998 disability survey, information was collected about informal assistance provided by carers and 'primary carers'. A carer was defined as a person, of any age, who provides any informal assistance, in terms of help or supervision, to people with disabilities or long-term conditions, or to people aged 60 years or over. The assistance has to be ongoing, or likely to be ongoing, for at least six months. Where the assistance is provided to a person in a different household, the assistance must relate to 'everyday types of activities', but no specific information on the activities is collected. Where the carer and recipient live in the same household, the assistance must be for one or more activities related to self-care, mobility, communication, health care, housework, meal preparation, paperwork, property maintenance or transport (ABS 1999: 65).

A 'primary carer' was defined as the person, of any age, who provides the most informal assistance to a person with one or more disabilities. The assistance must be ongoing, or likely to be ongoing, for at least six months and must be provided for one or more of the core activities (self-care, mobility or communication) (ABS 1999: 71).

The main differences between a carer and a primary carer are:

- a primary carer must provide 'the most' informal assistance;
- the care recipient of a primary carer must be a person with a disability (as opposed to a person aged 60 or over without a disability as defined in the survey); and
- for a primary carer, the assistance provided must relate to one or more core activities.

This chapter focuses mainly on primary carers, since they are the group of people who provide most assistance to people who have core activity restrictions.

The terms and definitions used to define the person providing most informal care to a person with a disability changed between the 1993 and 1998 surveys, as did the method for identifying carers. In the 1993 disability survey, the 'principal carer' of a person with a disability was the person, aged 15 or over, who provided the most informal care in the areas of self-care, mobility or verbal communication (ABS 1993).

In the 1998 survey, both co-resident and non-co-resident primary carers were identified by a responsible adult in the household, and carer status was then confirmed by the carer in person. In 1993, non-co-resident principal carers were identified in this way, but co-resident principal carers were identified by the recipient of care. As a result of this change, the

number of co-resident primary carers identified in the 1998 survey was estimated at only about 60% of what might have been expected if the 1993 method had been used. In comparison with the 1993 survey data, a higher proportion of primary carers identified in the 1998 survey had care recipients with high-frequency care needs (ABS 1999: 56–57).

16.2 Ageing and profile of informal carers

Age and sex

According to the 1998 disability survey, over 2.3 million people, or 12.6% of the total Australian population, were carers who provided informal assistance to people who needed assistance because of disability or ageing. Of those carers, 450,900 people, or 2.4% of the total population, were primary carers (Tables 16.1 and A16.1).

Females were more likely to be in a caring role than males, and this was particularly true for primary carers. There were 317,300 females, or 3.4% of the total female population, who were primary carers, in contrast to 133,500 males, or 1.4% of the total male population (Table 16.1). Of all people providing care, 56% were females, and 70% of primary carers were females.

The age group in which people were most likely to be involved in a caring role differed for men and women. The peak for women was in the 45–64 age group—24.0% of women in this age group were in a caring role, and 6.6% were a primary carer. The peak for men was in the 65+ age group—22.6% of men in this age group were in a caring role, and 3.8% were a primary carer (Figures 16.1 and 16.2; Table A16.2). The age group 45–64 years accounted for 43% of all primary carers—46% of female primary carers and 42% of male primary carers (Table 16.1).

The impact of population ageing was also reflected in informal care and the carer population. In 1998, there were 96,400 primary carers aged 65 years and over, of whom 62.5% were females (Table A16.1). Primary carers in younger age groups were also noticeable—in 1998, 31,300 primary carers were aged under 30 years. An intensive caring role may have a particular impact on younger carers, in terms of education and career development in an increasingly competitive environment.

Relationship to care recipient

Caring for a spouse is the most common care relationship among adult primary carers. The 1998 disability survey showed that 192,100 primary carers were spouses of their recipients, accounting for 42.9% of primary carers aged 15 years and over. Spouse carers made up about 41.3% of primary carers aged 45–64 years and 75.5% of those aged 65 years and over. The vast majority of son or daughter primary carers were aged under 65 years and 53.9% of them were not living with their parents (Table 16.2).

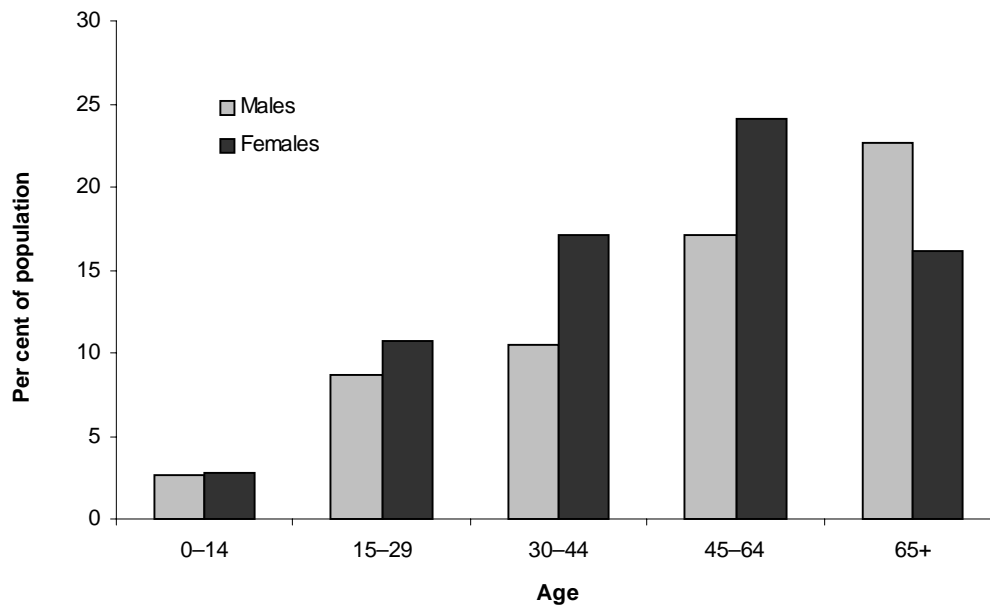
In 1998, 9,700 parent primary carers and 73,000 spouse primary carers were aged 65 years or over. Most ageing parent carers (8,800) were mothers who were living with the son or daughter they cared for (Table 16.2). Ageing parents caring for their son or daughter with a severe or profound core activity restriction often have a different history from people taking on the caring role as a spouse or other relative in later life, because of the long duration of the caring relationship (Madden et al. 1996).

Table 16.1: People living in households: carer status by age by sex (per cent), Australia, 1998^(a)

	Age groups					Total			Total number (^{'000})	Per cent of population
	0-14	15-29	30-44	45-64	65+		0-64	15-64		
Males										
Primary carer	**0.9	*4.6	21.2	46.3	27.1	100	72.9	72.0	133.5	1.4
Carer, not primary	5.8	19.8	22.0	32.5	20.0	100	80.0	74.2	888.4	9.6
Total carer	5.2	17.8	21.9	34.3	20.9	100	79.1	73.9	1,021.9	11.1
Not a carer	23.7	23.5	23.3	20.6	8.9	100	91.1	67.4	8,198.6	88.9
<i>Total</i>	<i>21.7</i>	<i>22.8</i>	<i>23.1</i>	<i>22.1</i>	<i>10.2</i>	<i>100</i>	<i>89.8</i>	<i>68.1</i>	<i>9,220.5</i>	<i>100.0</i>
Females										
Primary carer	**0.5	7.1	31.9	41.6	19.0	100	81.0	80.5	317.3	3.4
Carer, not primary	5.1	19.8	27.1	35.2	12.8	100	87.2	82.1	988.4	10.7
Total carer	4.0	16.7	28.2	36.8	14.3	100	85.7	81.7	1,305.8	14.1
Not a carer	23.3	22.9	22.5	19.1	12.2	100	87.8	64.4	7,943.7	85.9
<i>Total</i>	<i>20.6</i>	<i>22.0</i>	<i>23.3</i>	<i>21.6</i>	<i>12.5</i>	<i>100</i>	<i>87.5</i>	<i>66.9</i>	<i>9,249.5</i>	<i>100.0</i>
Persons										
Primary carer	*0.6	6.3	28.7	43.0	21.4	100	78.6	78.0	450.9	2.4
Carer, not primary	5.5	19.8	24.7	33.9	16.2	100	83.8	78.4	1,876.8	10.2
Total carer	4.5	17.2	25.4	35.7	17.2	100	82.8	78.3	2,327.7	12.6
Not a carer	23.5	23.2	22.9	19.9	10.5	100	89.5	65.9	16,142.3	87.4
Total	21.1	22.4	23.2	21.9	11.4	100	88.6	67.5	18,469.9	100.0

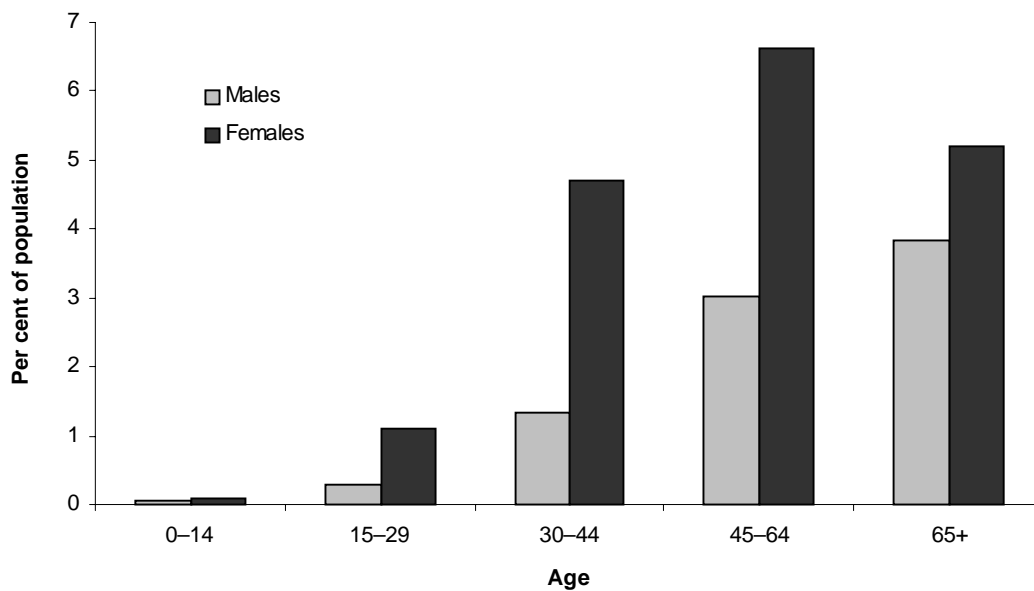
(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: Table A16.1; AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.



Source: Table A16.2.

Figure 16.1: Carers living in households, by sex and age, as a percentage of the population of that sex and age, Australia, 1998



Source: Table A16.2.

Figure 16.2: Primary carers living in households, by sex and age, as a percentage of the population of that sex and age, Australia, 1998

Table 16.2: Primary carers aged 15 years and over: relationship to main recipient of care, by sex and age of primary carer ('000), Australia, 1998^(a)

	Males	Females	Living with main recipient	Not living with main recipient	Total	%
15–44 years						
Partner	14.9	24.3	38.9	n.p.	39.2	24.9
Child	10.5	31.9	20.0	22.4	42.4	26.9
Parent	*4.0	52.1	55.3	n.p.	56.0	35.5
Other	*4.7	15.3	*6.6	13.4	20.1	12.7
Total	34.2	123.6	120.8	36.9	157.7	100.0
45–64 years						
Partner	36.2	43.8	80.0	—	80.0	41.3
Child	16.3	49.5	29.9	35.9	65.8	34.0
Parent	*5.8	22.9	26.1	**2.6	28.7	14.8
Other	*3.6	15.5	*7.9	11.2	19.1	9.9
Total	61.9	131.6	143.9	49.6	193.5	100.0
65 years and over						
Partner	34.7	38.2	72.4	n.p.	73.0	75.5
Child	—	*3.5	n.p.	**2.0	*3.5	*3.6
Parent	n.p.	*8.8	*8.9	n.p.	9.7	10.0
Other	n.p.	9.9	*4.7	*5.8	10.5	10.9
Total	36.3	60.4	87.4	*9.3	96.7	100.0
All ages						
Partner	85.9	106.2	191.2	**0.9	192.1	42.9
Child	26.8	84.9	51.5	60.2	111.7	24.9
Parent	10.7	83.7	90.2	*4.2	94.4	21.1
Other	*8.9	40.8	19.3	30.4	49.7	11.1
Total	132.3	315.6	352.2	95.8	447.9	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
n.p. Not available for publication but included in totals where applicable.
— Nil or rounded to zero.

Source: ABS 1999: Table 32.

Of all primary carers, 39.4% (177,500) had a disability and 9.3% (41,900) had a severe or profound core activity restriction (Table 16.3). Of non-primary carers, 30.9% (59,800) had a disability and 7.3% (137,200) had a severe or profound core activity restriction. These high rates of disability among carers are likely to be due in part to the older age structure of the carer population. However, rates of disability were significantly higher for primary carers than for the total population in the age groups 0–29, 30–44 and 45–64.

Table 16.3: People living in households: carer status by disability status by age, Australia, 1998^(a)

	Age groups				Total
	0-29	30-44	45-64	65+	
Primary carers					
% with disability	29.1	28.5	40.3	55.5	39.4
% with severe or profound core activity restrictions	*8.8	*5.1	9.9	13.8	9.3
Total number ('000)	31.3	129.4	193.7	96.4	450.9
Carers, not primary					
% with disability	15.5	22.5	35.6	57.8	30.9
% with severe or profound core activity restrictions	3.9	6.0	8.2	12.8	7.3
Total number ('000)	474.1	462.8	636.4	303.5	1,876.8
Total population					
% with disability	8.3	13.9	27.3	50.5	18.5
% with severe or profound core activity restrictions	2.8	3.2	6.8	15.5	5.2
Total number ('000)	8,045.4	4,286.5	4,036.2	2,101.8	18,469.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Length of time in the caring role

In 1998, 178,300 primary carers (39.8%) had been in their caring role for at least 10 years. Of those, 59,600 (13.3% of primary carers) had been in their caring role for at least 25 years.

161,300 primary carers (36.0%) spent, on average, 40 hours or more per week providing care. Of these, 22,700 had been caring for at least 25 years (Table 16.4).

Labor force status, income and housing tenure type

Tables 16.5 and A16.3 provide a comparison of some socioeconomic characteristics between primary carers, non-primary carers, and those not involved in care-giving. In 1998, nearly 50% of primary carers aged between 15 and 64 years were not in the labour force, compared to 23% of people who were not in a caring role. Primary carers were much less likely to work full-time (21.6%) than non-carers (51.1%).

Corresponding to the lower labour force participation rate of primary carers, only a third of them reported wages or salary as their principal source of cash income, in contrast to 58.6% of people who were not carers. Nearly half of primary carers relied on a Government pension or allowance as their principal source of income, as compared with 20% of those who were not in a caring role (Tables 16.5 and A16.3).

The data on total cash income indicate that primary carers were more likely to be in lower income quintiles. Income quintiles are calculated by dividing the income distribution for survey respondents into five equal parts. The first quintile contains the 20% of respondents with the lowest incomes and the fifth quintile contains the 20% of respondents with the highest incomes. About 45% of primary carers were in the first or second quintiles,

Table 16.4: Primary carers aged 15 years and over: time spent on caring, Australia, 1998^(a)

Years in caring role	Average weekly hours			Not stated	Total
	<20 hours	20–39 hours	40 hours+		
	Number ('000)				
<2	11.6	*5.1	9.3	**1.5	27.6
2–4	53.8	16.9	35.7	*7.2	113.7
5–9	52.2	20.3	51.4	*4.5	128.5
10–24	51.1	20.7	42.2	*4.7	118.7
25+	26.3	*7.2	22.7	*3.3	59.6
Total	195.0	70.3	161.3	21.3	447.9
	Per cent (sum vertically)				
<2	5.9	*7.3	5.8	**7.0	6.2
2–4	27.6	24.0	22.1	33.8	25.4
5–9	26.8	28.9	31.9	*21.1	28.7
10–24	26.2	29.4	26.2	*22.1	26.5
25+	13.5	*10.2	14.1	*15.5	13.3
Total	100.0	100.0	100.0	100.0	100.0
	Per cent (sum horizontally)				
<2	42.0	*18.5	33.7	**5.4	100.0
2–4	47.3	14.9	31.4	*6.3	100.0
5–9	40.6	15.8	40.0	*3.5	100.0
10–24	43.0	17.4	35.6	*4.0	100.0
25+	44.1	*12.1	38.1	*5.5	100.0
Total	43.5	15.7	36.0	4.8	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: ABS 1999: Table 33.

concentrated mainly in the second quintile, while only about 32% of the non-carer population was in these quintiles—that is, primary carers were over-represented in lower income brackets (Tables 16.5 and A16.3).

Primary carers were more likely to own their home outright than those who were not carers (Table 16.5), probably reflecting the different age distributions of the primary carer and non-carer populations. Of all primary carers, 43% were aged 45–64, in comparison with 20% of non-carers (Table 16.1). In the population as a whole, older people, in particular couples in late adult or older age groups, were the group most likely to own their home without a mortgage (AIHW analysis of 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File).

Table 16.5: People aged 15–64 years living in households, carer status, by income, labour force status and tenure type (per cent), Australia, 1998^(a)

	Carer status				Total
	Primary carer	Carer (not primary)	Total carer	Not a carer	
Labour force status					
Employed full-time workers	21.6	41.4	37.6	51.1	49.1
Employed part-time workers	23.0	21.3	21.6	20.0	20.2
Total employed	44.6	62.7	59.2	71.1	69.3
Unemployed	6.0	7.7	7.4	6.1	6.3
Not in the labour force	49.4	29.6	33.4	22.9	24.4
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Principal source of cash income					
Wages or salary	33.2	49.7	46.5	58.6	56.8
Own business or partnership income	6.1	7.7	7.4	8.3	8.2
Other private income ^(b)	5.5	5.2	5.3	3.9	4.1
Government pension or allowance	49.2	29.7	33.4	20.3	22.2
Not stated ^(c)	5.9	7.8	7.4	8.9	8.7
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Total cash income					
First income quintile ^(d)	18.6	19.2	19.1	20.2	20.0
Second income quintile	26.1	19.0	20.4	12.2	13.4
Third income quintile	24.7	18.4	19.7	16.5	17.0
Fourth income quintile	15.7	21.0	20.0	22.1	21.8
Fifth income quintile	9.9	15.6	14.5	20.9	20.0
Income not known ^(e)	5.0	6.7	6.4	8.1	7.8
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>
Tenure type					
Owner without mortgage	35.2	29.8	30.8	22.9	24.1
Owner with mortgage	34.3	34.8	34.7	37.3	36.9
Public renter	9.6	4.4	5.4	3.2	3.6
Private renter	13.9	13.4	13.5	22.0	20.8
Boarder	*1.7	8.2	7.0	6.1	6.2
Living rent-free	4.3	7.8	7.1	6.9	6.9
Other ^(f)	**0.3	0.8	0.7	0.4	0.4
Not applicable	**0.7	0.8	0.8	1.2	1.3
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Include child support or maintenance, workers compensation, profit or loss from rental property, dividends or interest, superannuation or annuity.

(c) Includes people who report no source of income and main source of income not known.

(d) Includes people with nil income, and no source of income.

(e) Includes refusals.

(f) Includes life tenure schemes and rent/buy or shared equity schemes.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File; Table A16.3.

16.3 Need for and receipt of assistance

Receipt of government pension or benefit

In 1998, 308,200 primary carers aged 15 years and over (69%) were recipients of a government pension or benefit. The most common type of government pension or benefit was a Family Payment or Parenting Allowance, received by 104,600 primary carers (23%), followed by the Age Pension, received by 67,800 primary carers (15%) (Table 16.6). The number of primary carers receiving the Age Pension accounted for about 70% of primary carers aged 65 years and over, meaning that a majority of ageing primary carers were recipients of the Age Pension.

Receipt of support in providing care

The 1998 disability survey shows that about half of all primary carers aged 15 years or more did not receive any assistance in providing care (Table 16.7). While 41.5% of primary carers reported that they did not need any assistance, there were 41,300 (9.2%) who needed assistance but did not receive any, and 70,300 (15.7%) who received assistance but said that they needed further assistance. Some 150,200 primary carers (33.5%) received assistance and did not need further help. Primary carers living in non-capital city regions were less likely to receive assistance than those living in capital cities.

Over 250,000 primary carers (56.2%) reported that a fall-back carer was available. However, there were 160,000 primary carers (35.7%) who did not have a fall-back carer and 36,300 (8.1%) who did not know if a fall-back carer was available (Table 16.7).

In 1998, 59,100 primary carers aged 15 years or over (13.2%) reported that they had used respite care services, such as in-home respite care and day care (Table 16.7). Among the primary carers who had used respite care services, 35,500 had used such services in the last three months and, of those, 15,700 stated that they did not need further services or preferred to provide care without such services. However, 19,800 primary carers who had used respite services in the last three months needed further respite services.

Most primary carers (86.8% or 388,900 people) had never received respite care services. Although the majority of them (345,100) stated that they did not need or want such services, 43,800 primary carers reported that they needed respite services but had never received them (Table 16.7).

16.4 Effects of the caring role on carers

The 1998 survey asked various questions of primary carers regarding the effect of the caring role on their relationships with others, their financial situation and workforce status, and their health and well-being. Table 16.8 shows the effect of the caring role on relationships with friends, the main care recipient, the carer's spouse or partner, and other co-resident family members. Of all primary carers, 55% said that their friendships remained unaffected. However, nearly a quarter said that they had lost or were losing touch with existing friends as a result of the caring role. Regarding their relationship with their main care recipient, 32.7% of primary carers said that they had been brought closer together, while 22.3% said that the relationship had become strained.

Table 16.6: Primary carers aged 15 years and over: receipt of government pension/benefit, Australia, 1998^(a)

	Number ('000)	Per cent
Type of government pension/benefit received		
Age Pension	67.8	15.1
Newstart Allowance/Youth Training Allowance	11.5	2.6
Service Pension ^(b)	17.8	4.0
Disability Support Pension ^(c)	20.7	4.6
Sole Parents Pension	23.8	5.3
Wife Pension/Partner's Allowance	28.0	6.3
Carer Payment	47.8	10.7
Domicillary Allowance/Child Disability Allowance	60.0	13.4
War Widows or Disability Pension ^(b)	9.5	2.1
Family Payment or Parenting Allowance	104.6	23.4
Other benefit ^(d)	33.3	7.4
<i>All receiving government pension/benefit^(d)</i>	<i>308.2</i>	<i>68.8</i>
Does not receive pension/benefit	139.7	31.2
Total^(e)	447.9	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

(b) Department of Veterans' Affairs.

(c) Department of Family and Community Services (Department of Social Security at time of collection).

(d) Includes Mature Age Allowance, Disability Allowance and Widows Pension.

(e) Total may be less than the sum of the components as people may receive more than one pension or benefit.

Source: ABS 1999: Table 35.

Of all primary carers, 45.6% reported that their income was not affected by caring, while 20.6% said that their income had decreased and 25.7% reported extra expenses as a result of the caring role (Table 16.9). Nearly 30% of primary carers reported difficulty meeting living costs. Compared with other age groups, a greater proportion of primary carers aged 30–44 reported negative effects of the caring role on income, living costs and hours worked. Over 10% of primary carers (47,500) reported that they had left their job in order to commence or increase their caring role.

Over a quarter of primary carers said that interrupted sleep affected them in performing daily activities—only 50% of primary carers said that their sleep was not interrupted due to the caring role (Table 16.10). Nearly 30% of primary carers said that their physical or emotional well-being had changed, and 34% said that they frequently felt weary or lacked energy due to their caring role. Over 30% of primary carers frequently felt worried or depressed, and 17% frequently felt angry or resentful, due to their caring role. Over 10% of primary carers had been diagnosed with a stress-related illness.

Table 16.7: Primary carers aged 15 years and over: need and receipt of support in providing care, Australia, 1998^(a)

	Number ('000)			Per cent		
	Capital city	Balance of State/Territory	Total	Capital city	Balance of State/Territory	Total
Need for and receipt of assistance						
Receives assistance:						
Does not need further assistance	98.4	51.9	150.2	34.6	31.7	33.5
Needs further assistance	48.2	22.1	70.3	17.0	13.5	15.7
Does not receive assistance:						
Does not need assistance	112.1	74.1	186.1	39.5	45.2	41.5
Needs assistance	25.4	15.9	41.3	8.9	9.7	9.2
Total	284.0	163.9	447.9	100.0	100.0	100.0
Availability of a fall-back carer						
Available	161.4	90.2	251.6	56.8	55.0	56.2
Not available	98.2	61.9	160.0	34.6	37.8	35.7
Don't know if available	24.5	11.8	36.3	8.6	7.2	8.1
Total	284.0	163.9	447.9	100.0	100.0	100.0
Need for and receipt of respite care						
Received respite care in the last three months:						
Does not need further care	*7.4	*8.3	15.7	*2.6	*5.1	3.5
Needs further care	13.2	*6.5	19.8	4.6	*4.0	4.4
Received respite care, but not in the last three months:						
Does not need care	10.6	*4.6	15.2	3.7	*2.8	3.4
Needs care	*6.2	**2.1	*8.4	*2.2	**1.3	*1.9
<i>Total received respite</i>	<i>37.4</i>	<i>21.5</i>	<i>59.1</i>	<i>13.2</i>	<i>13.1</i>	<i>13.2</i>
Never received respite care:						
Does not need/want care	219.0	126.1	345.1	77.1	76.9	77.0
Needs care	27.6	16.2	43.8	9.7	9.9	9.8
<i>Total never received respite</i>	<i>246.6</i>	<i>142.3</i>	<i>388.9</i>	<i>86.8</i>	<i>86.8</i>	<i>86.8</i>
Total	284.0	163.9	447.9	100.0	100.0	100.0

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: ABS 1999: Table 35.

Table 16.8: Primary carers: effects of the caring role on relationships (per cent), Australia, 1998^(a)

	Age group				Total
	0–29	30–44	45–64	65+	
Effect on friendships					
Friendships unaffected	49.4	51.8	56.3	59.8	55.3
Circle of friends increased	**5.3	*3.2	*2.3	*3.9	3.1
Circle of friends changed	*10.6	15.7	10.4	11.5	12.2
Lost or losing touch with existing friends	*16.3	25.2	27.1	20.5	24.4
NA or not stated	*18.5	*4.1	*3.8	*4.3	5.0
Effect on relationship with main care recipient					
Relationship unaffected	36.5	35.9	38.3	48.7	39.7
Brought closer together	34.8	34.9	32.3	30.0	32.7
Relationship strained	*10.3	25.6	25.4	15.7	22.3
NA or not stated	*18.5	*3.6	*3.9	*5.5	5.2
Effect on relationship with partner					
Relationship unaffected	*23.2	18.6	16.8	*9.1	16.1
Brought closer together	*8.4	*6.2	*4.1	**0.9	4.3
Lack time alone together	**3.0	11.1	7.0	**0.2	6.4
Relationship strained	**2.0	12.2	9.0	**0.4	7.6
NA or not stated	63.4	52.0	63.1	89.4	65.6
Effect on relationship with co-resident family members					
Relationship unaffected	38.4	28.5	29.7	30.9	30.2
Brought closer together	**1.0	8.8	7.0	*6.5	7.0
Less time to spend with them	**8.0	32.0	12.8	*3.9	16.1
Relationship strained	*9.3	14.6	10.4	*4.4	10.3
Relationship changed in other way	**2.3	**1.0	**0.9	**0.5	*1.0
NA or not stated	41.0	15.0	39.2	53.8	35.5
Total number ('000)	31.3	129.4	193.7	96.4	450.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Table 16.9: Primary carers: effects of the caring role on income, living costs and work (per cent), Australia, 1998^(a)

	Age group				Total
	0–29	30–44	45–64	65+	
Effect on financial situation					
Income not affected	52.6	37.0	44.4	57.2	45.6
Income has increased	**3.2	*3.9	*1.6	**1.9	2.4
Income has decreased	**7.3	29.4	23.6	*6.8	20.6
Has extra expenses	*18.4	25.0	26.1	28.1	25.7
NA/not stated	*18.5	*4.6	*4.3	*6.1	5.7
Whether has difficulty with living costs					
Has difficulty	*18.2	36.6	31.4	17.1	28.9
Does not have difficulty	**7.5	17.1	18.0	15.8	16.5
NA/not stated	74.3	46.3	50.6	67.2	54.5
Effect on weekly hours worked					
Unchanged	33.3	35.3	28.8	*2.9	25.4
Reduced	**2.9	14.8	6.7	**0.4	7.4
Increased	**2.5	*3.3	*3.5	**0.5	2.7
NA/not stated	61.3	46.7	61.0	96.3	64.4
Reason left work					
To commence or increase care	**5.6	9.6	15.0	*4.4	10.5
Total number ('000)	31.3	129.4	193.7	96.4	450.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

16.5 Trends in de-institutionalisation

Over recent years there has been a trend towards de-institutionalisation among people with a disability who need ongoing assistance (AIHW 1997b; Wen & Madden 1998a; Madden et al. 1999). The trend is particularly marked for people aged under 30 years. Between 1981 and 1993, there was a large increase in the number of people aged under 65 years with a severe or profound core activity restriction living with their relatives (see Chapter 5).

The 1998 survey data indicate that the trend towards community living has continued (Table 16.11). The proportion of people with a severe or profound core activity restriction living in cared accommodation has steadily decreased from 9.9% in 1981 to 2.6% in 1998. Since 1993, there was an increase of 257,500 people aged 5–64 years with a severe or profound core activity restriction living in households, and a decrease in the number living in cared accommodation (although some of the changes between 1993 and 1998 may be due to changes in survey methods). In 1998, 606,600 people aged 5–64 years with severe or profound core activity restrictions were living in households, while only 20,000 were living in cared accommodation. Most of those living in households were living with their relatives (AIHW 1999a: 256). One of the implications of this trend towards community living is that more people with disabilities are reliant on informal carers to provide the assistance they need.

Table 16.10: Primary carers: effects of the caring role on health and well-being, Australia, 1998^(a)

	Age groups				Total
	0–29	30–44	45–64	65+	
Effect on sleep					
Not interrupted	46.6	44.4	54.6	48.9	49.9
Interrupted, affects activities	*23.0	30.8	22.1	24.5	25.2
Interrupted, does not affect activities	*11.9	20.1	19.0	20.9	19.2
Interrupted, effect not stated	—	**1.1	**0.8	**0.8	*0.8
NA/not stated	*18.5	*3.6	*3.4	*4.8	4.8
Whether physical/emotional well-being has changed					
Has changed	*17.6	38.2	31.2	15.4	28.9
Has not changed	63.9	57.9	64.5	79.8	65.8
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether feels satisfied due to caring role					
Feels satisfied	25.3	25.0	27.7	33.4	27.9
Does not feel satisfied	56.2	71.1	68.0	61.9	66.8
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether frequently feels weary or lacks energy					
Feels weary/lacks energy	*18.5	39.6	36.4	28.6	34.4
Does not feel weary/lack energy	63.1	56.5	59.3	66.6	60.3
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether frequently feels angry or resentful					
Feels angry or resentful	*8.4	19.3	18.9	13.3	17.1
Does not feel angry or resentful	73.2	76.8	76.8	81.9	77.7
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether frequently feels worried or depressed					
Feels worried or depressed	26.9	36.3	32.3	24.2	31.3
Does not feel worried or depressed	54.6	59.7	63.4	71.0	63.4
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Whether has a stress-related illness					
Yes	*8.9	10.1	12.2	7.4	10.3
No	72.7	86.0	83.5	87.8	84.4
NA/not stated	*18.5	*3.9	*4.3	*4.8	5.3
Total number ('000)	31.3	129.4	193.7	96.4	450.9

(a) Estimates marked with ** have an associated relative standard error (RSE) of 50% or more. Estimates marked with * have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.
 — Nil or rounded to zero.

Source: AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File

Table 16.11: People aged 5–64 years and with profound or severe core activity restriction(s), by living arrangements ('000), Australia, 1981, 1988, 1993 and 1998^(a)

Living arrangements	People with severe or profound handicap				
	1981	1988	1993	1998	1998
Households	244.1	302.5	349.1	606.6	606.6
Cared accommodation ^(b)	27.0	24.2	19.2	20.0 ^(inc)	16.4 ^(exc)
Total	271.1	326.7	368.3	626.6	623.0
<i>Proportion in cared accommodation (%)</i>	<i>9.9</i>	<i>7.4</i>	<i>5.2</i>	<i>3.2</i>	<i>2.6</i>

- (a) In the 1981, 1988 and 1993 surveys, three levels of severity of handicap (severe, moderate and mild) were applied to both household and establishment components. In 1993 the severe handicap category was further divided into profound handicap and severe handicap, but the severe handicap category was not applied to the establishment component. In the 1998 survey both the profound and severe core activity restriction categories were applied to the cared accommodation component. To enable comparisons of the four surveys, the 3,600 people with severe core activity restriction in cared accommodation are first included in (inc) and then excluded from (exc) the 1998 results.
- (b) Cared accommodation (1998) and establishments (1981, 1988 and 1993) are defined by ABS as hospitals, nursing homes, hostels, retirement villages and other 'homes'.

Source: AIHW 1999a:256 (Table 7.19).

16.5 Summary

Demographics of the carer population

- In 1998, 450,900 Australians, or 2.4% of the total population, were primary carers of people with a disability. 317,300 females, or 3.4% of the total female population, were primary carers, in contrast to 133,500 males, or 1.4% of the total male population. 96,400 primary carers were aged 65 years or over; of those, 62.5% were females.
- Caring for a spouse was the most common caring relationship among adult primary carers. In 1998, there were 192,100 spouse primary carers, accounting for 42.9% of primary carers aged 15 years and over. Of those primary carers aged 65 years and over, 73,000 (75.5%) were spouses and 9,700 (10.0%) were parents of the main care recipient. Of those primary carers aged between 45 and 64 years, 80,000 (41.3%) were spouses, 65,800 (34.0%) were children and 28,700 (14.8%) were parents of the main care recipient.

Time spent caring

- 59,600 primary carers (13.3%) had been in the caring role for at least 25 years. 161,300 primary carers (36.0%) spent, on average, 40 hours or more per week in providing care; of those, 22,700 had been caring for at least 25 years.

Economic status of the carer population

- In 1998, nearly 50% of primary carers aged between 15 and 64 years were not in the labour force, compared to 23% of non-carers. Only one-third of primary carers aged between 15 and 64 years reported wages or salary as their principal source of cash income, in contrast to nearly 60% of those who were not a carer.

- 308,200 primary carers aged 15 years and over (69%) were recipients of a government pension or benefit. Half of all primary carers aged between 15 and 64 years relied on a pension or benefit as their principal source of income, as compared with 20% of those who were not in a caring role.

Assistance with caring

- Almost half of all primary carers aged 15 years and over received support in providing care. There were 41,300 primary carers (9.2%) who needed assistance but did not receive any help. More than 160,000 primary carers (35.7%) did not have a fall-back carer and 36,300 primary carers (8.1%) did not know if a fall-back carer was available.
- Primary carers living in non-capital city regions were less likely to receive assistance than those living in capital cities.
- 59,100 primary carers aged 15 years or over (13.2%) reported that they had used respite care services. 35,500 had used respite services in the three months prior to the survey, and, of those, 19,800 wanted more respite care. A vast majority of primary carers (86.8%) had never used respite care services; of these, 11% (43,800 primary carers) said that they needed such services.

Effects of the caring role

- Many primary carers reported that the caring role impacted on their relationships with others, their financial situation and workforce status, and their health and well-being. Nearly a quarter said that they had lost or were losing touch with existing friends and 22.3% said that their relationship with the main care recipient had become strained as a result of the caring role. Nearly 30% of primary carers reported difficulty meeting living costs, and 10% had been diagnosed with a stress-related illness.

The trend towards community living

- There is a continuing trend towards community living. In 1998, 606,600 people aged 5–64 years with a severe or profound core activity restriction were living in households, while only 20,000 were living in cared accommodation. One of the implications of this trend is that people with a disability are increasingly reliant on informal carers to provide the assistance they need.