

1 Introduction

1.1 Background

The amount of unpaid assistance provided by the family and friends to people with disability who are living in the community has been estimated as the equivalent of almost 1 million full-time employed persons (AIHW 2003). This contribution of the household sector has an imputed value of approximately \$28.8 billion, over \$19.3 billion of which is the estimated value of the work of unpaid carers of older people and younger people with a disability¹ (AIHW 2003: Table 4.24). It is almost double the total government contribution to welfare services (\$10.6 billion; AIHW 2003).

This report is concerned with the work of those who provide care to adults and children who require the assistance of others because of disability, including age-related frailty. Such work is widely referred to as 'informal care'. Use of the adjective 'informal' does not imply that the care provided is thought to be casual or lacking in structure and process. Rather, it is a means of distinguishing the care of a person by family and friends from care that is provided by formal agencies or institutions, paid for by the receiver or provided by (necessarily) trained professionals. Informal care may 'precede, substitute for, or take place along with formal care arrangements.' (NHPF 2002; Gutheil & Chernesky 2001). While informal care can be broadly defined to include non-parental care of children, this report focuses exclusively on the unpaid care provided by family and friends to people of all ages who are restricted in the activities of daily living through disability or age-related frailty.

The type and intensity of support that is provided to a person with long-term health problems or impaired functional status needs to be differentiated from the support that family members exchange in everyday life. The providers of 'care' for a dependent person are a functional subset of the individual's social network that is designated a 'care network' (Keating et al. 2003). This is an important distinction; increasing dependency of frail older people and the relentlessness of caring for a person with long-standing severe or profound activity restriction can, within a short time, exhaust the resources of a social network (Litwin & Auslander 1990). Those providers of unpaid care who emerge from within the social network of a care recipient form a care network. Often, but not always, at the centre of the care network is a 'primary carer'.

While carers have traditionally provided the bulk of care and assistance to those who cannot fully care for themselves, the past two decades have seen a growing awareness of both the importance of their role and the challenges they face. Between 1981 and 1998, the proportion of people with a severe or profound level of activity restriction living in cared accommodation² decreased from 20% to 15% (Australian Institute of Health and Welfare (AIHW) analysis of Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers Confidentialised Unit Record File). As the use of institutional care declined,

1 In the imputation, care of children with a disability is not separated from usual non-parental, unpaid child care.

2 Cared accommodation includes general hospitals, psychiatric hospitals, aged care homes, retirement villages and other 'homes'.

community care programs expanded considerably. So too did the availability of programs specifically aimed at supporting carers, including respite services and income support through the Carer Payment and Carer Allowance (AIHW 2001).

At the same time, a growing body of research has identified the characteristics of carers and the extent of the burden of the caring role. Surveys of carers (e.g. Braithwaite 1990; Schofield et al. 1997a) have consistently identified carers as most likely to be a spouse, mostly wives; an adult offspring, mainly daughters; or a parent, mostly mothers. Carers most frequently live with the person for whom they care and are predominantly among the middle to older age groups.

The 1998 Survey of Disability, Ageing and Carers produced consistent results (ABS 1999a). Among primary carers aged 10 years or over in 1998:

- 70% were women
- 43% were caring for a spouse or partner
- 25% were caring for a parent (including mothers- and fathers-in-law)
- 21% were caring for a son or daughter
- 44% of spouse or partner carers were male
- 69% of primary carers aged 60 or over were caring for a spouse or partner
- 89% were members of the care recipient's immediate family
- 79% lived with their care recipients
- 67% were aged between 25 and 59, and 29% were aged 60 or more.

The 1999 National Survey of Carer Health and Wellbeing provided insight into the demands and pressures experienced by carers. Many carers reported declines in their physical, mental or emotional health as a result of their caring responsibilities (CAA 2000). In addition, nearly 60% reported major negative effects on their life choices including restrictions in their ability to take part in paid work, education or other career opportunities. The Young Carers Research Project (CA 2001) revealed that young carers experience similar negative effects, compounded by systemic lack of recognition of their existence and circumstances.

Carer organisations have been influential in raising the profile of the caring 'workforce' and the rights and needs of carers themselves – their capacity to undertake paid employment, income security, carer health, wellbeing and lifestyle, to name a few. Recognition of the role of family carers in providing valued and sometimes intensive, long-term care and assistance is being increasingly recognised on the policy agenda. Australian Government programs such as Commonwealth Carelink and Commonwealth Carer Resource Centres are aimed at improving the support, education and information available to carers. In 2003 the Australian Government announced additional funding for the support of carers in rural and remote areas. Growth in the number of carers in response to changes in the population age structure over the next three decades highlights the importance of public policy in the area.

This report draws on the results of the 1998 ABS survey and other key studies of Australian carers. The remainder of the introduction outlines the broad demographics of informal care. Chapter 2 discusses the nature and intensity of caring work and its impact on labour force participation and the health and wellbeing of people at the coalface. Chapter 3 examines aspects of social and demographic change that will impact on both the need for informal assistance within the household population and the propensity of people to take on a caring role. This background provides a context for Chapter 4, which presents the results of an AIHW investigation of the effect of certain sociodemographic changes on the availability of

informal care to 2013. Chapter 5 covers the increasing need for care within the household population and discusses the interactions between the use of formal community services and the availability of informal care among recipients of Community Aged Care Packages (generalisation to the wider population of people in receipt of community care are not possible because of limitations in the Home and Community Care and Commonwealth-State/Territory Disability Agreement national minimum data sets).

Concluding remarks in Chapter 6 tie together the threads of earlier chapters to paint a picture of possible trends in an ageing Australia and how these relate to themes in the international literature on informal care.

1.2 A demographic profile of primary carers

The ABS estimates that in 1998 around 2.3 million people provided informal assistance to a person with a disability (ABS 1999a). The term 'carer' loosely refers to anyone who provides ongoing informal assistance to a person with a disability living in the community. However, the literature distinguishes 'principal' or 'primary' carers as those who individually provide the most informal assistance to someone who cannot adequately care for himself or herself because of severe handicap. According to the ABS survey, 19% of all carers in 1998 (approximately 450,900 people) were primary carers. Assuming that the proportion of each age group by sex that comprised carers and remained constant between 1998 and 2002, we can apply the 1998 age- and sex-specific carer rates to population figures for 2002. This produces the distribution of carers by age and sex shown in Figure 1.1, totalling 2.5 million carers including an estimated 490,700 primary carers.

Definitions of 'primary carer' vary but most encompass the dimensions of care intensity and duration. This report adheres to the ABS definition: a primary carer is the person who, of all carers in a support network, provides the most assistance with the core activities of daily living to someone with a disability (Box 1.1).

Although carer numbers based on this definition are the best available national estimates, they could easily underestimate the primary carer population. Notwithstanding this, the ABS survey generates detailed national data on a well-defined group of carers, most of whom provided assistance to someone with a severe or profound activity restriction. This means primary carers identified in the ABS survey assisted their care recipients with at least one of three core activities (ABS 1999a:4):

- self-care – bathing, dressing, using the toilet and managing incontinence
- mobility – moving around at home, getting into or out of a bed or chair, using public transport
- communication – understanding and being understood by others.

Hence, many care recipients could not continue to live in the community without the support of a primary carer.

Box 1.1: ABS Survey of Disability, Ageing and Carers: informal assistance and carers

Informal assistance

Informal assistance is unpaid help or supervision that is provided to a person with one or more disabilities or persons aged 60 years or 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 because they are older. 'Tasks' pertain to a particular type of activity. For example, self-care comprises the tasks of showering and bathing, dressing, eating, toileting and managing incontinence; housework comprises a single task, household chores, examples of which are washing, vacuuming and dusting.

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 persons who are elderly (i.e. aged 60 years or over). The assistance must be ongoing, or likely to be ongoing, for at least 6 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: communication; health care; housework; meal preparation; mobility; paperwork; property maintenance; self-care; transport.

Primary carer

A primary carer is a person of any age who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance must 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).

Source: ABS 1999a: 65, 71

Primary carers typically function within an extensive network of family and social exchange (Howe, Schofield & Herrman 1997). Many are close relatives of the person they care for and it is therefore assumed that they provide assistance without payment. However, unpaid caring work transcends the type of support routinely exchanged within families and wider social groups. Carers who participated in a population-based longitudinal study for the Victorian Carers Program distinguished their role as being 'beyond that of wife, husband, mother, father, daughter, son, sibling and friend' (Schofield et al. 1998a). They related a deeper sense of responsibility that is associated with caring for someone with a disability or long-term health problem.

Age and sex distribution

A primary carer is more likely to be female than male at all ages except 75 years and over (Figure 1.1). The peak age group for women to be in a caring role is 45–64 years. In this age group, 24% of women are carers and approximately 7% are primary carers. Women aged between 35 and 64 years comprise 47% of all primary carers. Men are more likely to be found in a caring role at older ages: 22% of men aged 75 or over are carers and 5% are primary carers.

Over one-half of primary carers aged 25–44 years (32% of all primary carers) had a main recipient of care aged under 45 years; 23% of these carers were caring for someone aged 65 or over. This distribution represents a mix of parent, spouse or partner, and adult offspring carers. In the 45–64 years age group, 36% of primary carers were caring for a person also aged 45–64 years and 44% cared for a person aged 65 years or over, reflecting a mix of mainly partner or spouse, and adult offspring carers. Older primary carers, aged 65 or over,

were predominantly caring for another older person (82%); 17% of older carers were caring for a person aged 25–64 years. This group of primary carers are mostly spouses or partners, or parents of the main care recipient (Table 1.1).

Considering primary carers who had a main care recipient aged 65 years or over in 1998, 17% (35,100) were aged 25–44 years and 43% (85,900) were aged 45–64 years. Thus, over 60% of primary carers who cared for an older person were of working age and 56% of this group did not live with their main care recipient.

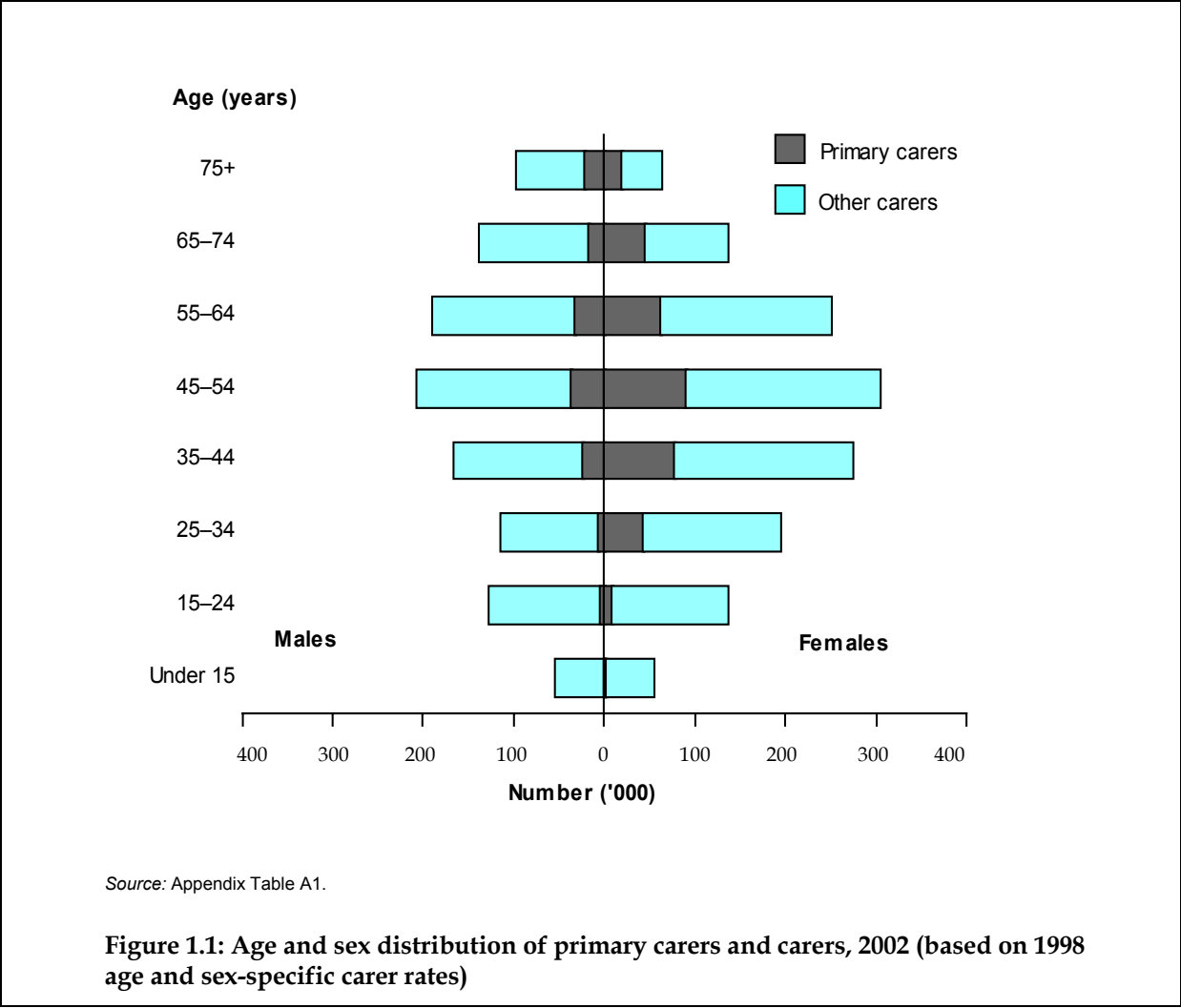


Table 1.1: Co-resident and non-resident primary carers 15 years and over ('000)^(a), age of primary carer by age of main care recipient^(b), 1998

Care recipient	Age of primary carer										Total
	15–24		25–44		45–64		65+		All ages		
	Co-res	Non-res	Co-res	Non-res	Co-res	Non-res	Co-res	Non-res	Co-res	Non-res	
Under 15	**0.6	—	51.2	—	10.4	—	**0.9	—	63.1	—	63.1
15–24	**2.2	—	*6.9	**0.5	*8.1	**1.3	—	—	17.2	**1.8	19.0
25–44	**4.9	—	30.7	**2.8	15.8	**3.1	*5.5	**0.9	56.9	*6.8	63.7
45–64	**3.9	**0.8	10.9	**6.3	65.6	**3.2	10.0	**0.3	90.5	10.7	101.2
65+	—	**1.0	9.6	25.5	44.0	41.9	70.9	*8.1	124.5	76.5	201.0
Total	11.6	**1.8	109.2	35.1	143.9	49.6	87.4	*9.3	352.2	95.8	447.9

(a) The ABS survey enumerates primary carers aged 10 years and over; however, detailed data is available only for those aged 15 and over.

(b) Each primary carer may care for more than one person, but identify one who received the most assistance.

— Nil or rounded to zero.

Source: AIHW 1999: Table A7.6.

Country of birth

Approximately 23% of primary carers in 1998 were born outside Australia (Table 1.2). Age distributions of primary carers by country of birth reflect those of the wider population of overseas-born Australians, associated with post-Second World War waves of migrant intake from Europe and more recent migration from countries in Asia and the Middle East (Paice 2002). About 14% of primary carers originate from non-Anglo countries of birth. One in ten primary carers (43,500) in 1998 said that they used a language other than English to communicate with their main care recipient. ‘

Table 1.2: Primary carers, selected birthplace groups by sex, 1998

Birthplace group	Males		Females		Total	
	'000	Per cent	'000	Per cent	'000	Per cent
Australia/New Zealand ^(a)	98.2	28.3	248.4	71.7	346.6	100.0
UK/Ireland	14.0	33.9	27.4	66.1	41.4	100.0
Europe	14.1	33.4	28.1	66.6	42.1	100.0
Asia	**2.1	**17.9	*9.5	*82.1	11.6	100.0
Middle-East/Northern Africa	**2.6	**43.7	**3.3	**56.3	5.9	100.0
Other	**2.6	**78.7	**0.7	**21.3	3.3	100.0
Total	133.5	0.30	317.3	0.70	450.9	100.0

(a) Includes Oceania and Antarctica.

— Nil or rounded to zero

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

1.3 Relationship and the motivation to care

The relationship between a primary carer and care recipient is closely associated with age. Forty-three percent of primary carers in 1998 were caring for a spouse or partner (Figure 1.2). The vast majority of older carers were spouses or partners of the main care recipient. A higher proportion of primary carers aged under 65 years were parents or children of their care recipient. Over 30% of primary carers aged 45–64 years were caring for a parent (ABS 1999a). Male primary carers in 1998 were mainly spouses and partners or children of their care recipient, whereas female primary carers were more evenly distributed across relationship groups (Table 1.3). Whether a primary carer resides with the care recipient or in a different household depends on their mutual relationship. Most partner and parent primary carers live with their care recipient. Other types of primary carers are less likely to share the same household although, in 1998, 46% and 40% of offspring and other relative or friend primary carers respectively lived with their care recipient.

Relationship history undoubtedly has a bearing on the motivation to care, the impact of a caring role and whether caring can be sustained long term. The ABS carer survey allowed carers to specify one or more reasons for taking on the primary caring role. Frequent responses to the question of motivation included family responsibility (57%), a desire to provide the best possible care (44%), and emotional obligation (39%) (Table 1.4). Spouse and parent carers gave similar patterns of response. They were more likely than offspring carers to report a desire to provide the best possible care (53% and 49% versus 33%). Fifty per cent

or more of each relationship group cited family responsibility as a motivating factor and this was the most frequent response of people caring for a parent (72%).

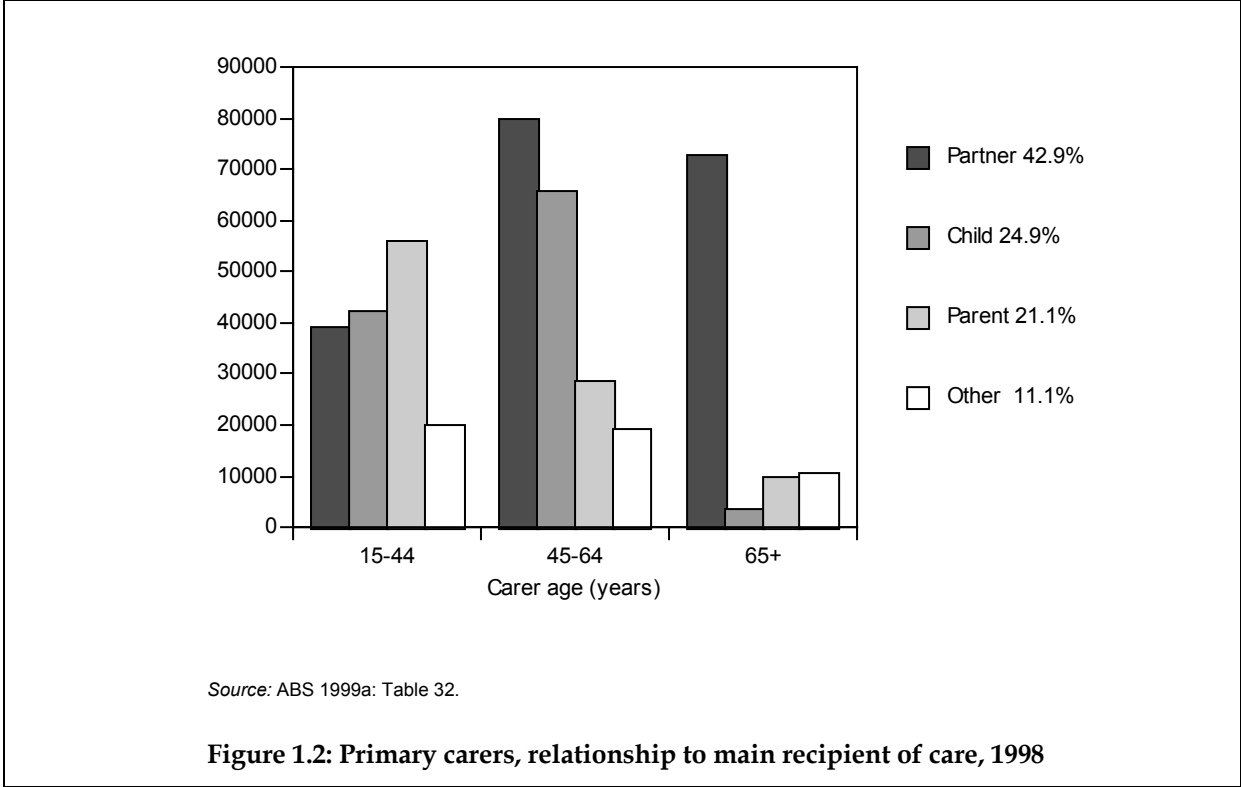


Table 1.3: Primary carer relationship to main recipient of care by sex, 1998

Sex	Spouse/partner		Parent		Child		Other relative/friend		Total	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
Males	85.4	64.0	11.1	8.3	27.8	20.8	*9.2	*6.9	133.5	100.0
Females	108.2	34.1	85.4	26.9	82.9	26.1	40.8	12.9	317.3	100.0
Total	193.6	42.9	96.5	21.4	110.7	24.6	50.0	11.1	450.8	100.0

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

These results suggest that sense of duty is as important a factor among carers with looser kinship ties as it is for spouse and parent carers. Around half of other relative/friend carers cited family responsibility (51%) and emotional obligation (44%) as prime motivating factors. While the literature cites examples of intense caring in the absence of love and affection, relationship history is an important determinant of the impact and outcome of caring for both carer and care recipient (Cahill 1999). In fact, Cahill’s work suggests that female spouse carers and daughter (or daughter-in-law) carers interpret ‘family responsibility’ differently. Wives tend to perceive caring as a natural extension of their marriage relationship. Daughter and daughter-in-law carers more often feel that external factors mean that they had no real

choice but to take on the role of primary carer:

Their motivation seemed shaped by several different structural and contextual constraints including gender, labour market positioning, the availability of others within the kinship network, and commitment to other family care responsibilities (Cahill 1999:243).

Table 1.4: Primary carers aged 15 years or over, reasons for taking on the caring role^(a) by relationship to main recipient of care (per cent), 1998

Reason for taking on caring role ^(a)	Relationship to main recipient of care				Total
	Partner	Offspring	Parent	Other friend or relative	
Can provide better care	52.6	33.3	49.3	24.3	43.9
Family responsibility	49.8	72.4	58.6	50.5	57.4
No other family or friends available	23.5	30.1	17.8	34.6	25.2
No other family or friends willing	11.1	18.6	14.0	21.1	14.7
Emotional obligation	36.8	43.2	35.2	44.1	38.8
Cost of alternative care	26.4	16.7	21.6	*11.7	21.3
No other care arrangements available	9.2	8.9	16.9	*7.4	10.5
No choice	21.2	13.7	35.2	*13.5	21.2
Other reason/not stated	9.4	*7.9	16.4	*14.1	11.0
Persons ('000)	192.1	111.7	94.4	49.7	447.9

(a) Carers may report more than one reason.

Source: AIHW analysis of ABS 1999a: Table 36.

1.4 Labour force participation

Given the time demands of caring for someone who is severely restricted in the activities of daily living, it is hardly surprising that patterns of labour force participation among carers differ from those of the wider population. Carers of working age are less likely than non-carers to be in paid employment. Part-time employment rates are similar for primary carers (23%), non-primary carers (21%) and non-carers (20%). However, carers report lower rates of full-time employment: 22% of primary carers and 41% of non-primary carers in 1998 were employed full-time compared to 51% of non-carers (Table 1.5). To some extent, these results are confounded by differences in the age and sex distribution of carers compared with the general population aged 15 to 64 years. Labour force participation is explored more fully in Chapter 2.

Table 1.5: People aged 15–64 years living in households, carer status by labour force status and source of income (per cent), 1998

	Carer status			Total ('000)
	Primary carer	Carer (not primary)	Not a carer	
Labour force status				
Employed full-time	21.6	41.4	51.1	49.1
Employed part-time	23.0	21.3	20.0	20.2
Total employed	44.6	62.7	71.1	69.3
Unemployed	6.0	7.7	6.1	6.3
Not in the labour force	49.4	29.6	22.9	24.4
Total	100.0	100.0	100.0	100.0
Principal source of cash income				
Wages or salary	33.2	49.7	58.6	56.8
Own business or partnership income	6.1	7.7	8.3	8.2
Other private income	5.5	5.2	3.9	4.1
Government pension or allowance	49.2	29.7	20.3	22.2
Not stated	5.9	7.8	8.9	8.7
Total	100.0	100.0	100.0	100.0

Source: AIHW 2000: Table 16.5.

1.5 Discussion

This brief introduction to the characteristics of people who provide unpaid assistance to those who need help to live in the community reiterates the widely acknowledged fact that informal care is primarily the domain of women in their middle to late years. Gibson's remarks on informal care for the aged are as valid in the context of informal care more generally:

Care of frail and disabled older people in the community is closely predicated on unpaid family labour; predominantly supplied by wives, daughters and daughters-in-law. The role played by formal community-based services and institutional provision should be briefly considered in this context, as popular belief tends to overestimate the role of formal services relative to informal assistance. (Gibson 1998:75–76).

Despite the high number of spouse and partner primary carers, the data depicted in Figure 1.2 and Table 1.3 highlight the importance of inter-generational support to the wellbeing of individuals in contemporary Australian society. The compression of life events brought about by higher rates of participation in post-secondary education, delayed partnering and parenting, and a continuing trend for many young people to remain in, or return to, the family home in their mid- to late 20s mean that many middle-aged primary carers are juggling the demands of caring with other family responsibilities and paid employment. McDonald and Kippen (1999) challenge the myth that 'women in the middle' are those simultaneously caring for young children and aged parents. They suggest that the term more aptly describes women in their pre-retirement years, with adult children and possibly grandchildren, who are also caring for their own parents aged 80 or over. Fine (1999) points out that economic imperative and personal desire of many women to participate in paid

employment will continue to place pressure on families as long as care in the family remains a gendered issue.

Finally, there is the matter of ageing carers. Around 22% of primary carers in 1998 were aged 65 years or over (Table 1.1). Primary carers experience high rates of disability and many report adverse effects of caring work on their physical wellbeing. Age-related frailty compounds the difficulties faced by older carers and can leave many unable to cope with the physical demands of caring for another person. Older men caring for a partner who is severely disabled or frail could be especially challenged by a new-found caring role if earlier life experience has not equipped them to cope with all that caring entails.

Chapter 2 considers the impact of the caring role in more detail, beginning with a description of the main restrictions facing care recipients and consequent demands placed on their carers.

2 Care recipients and the work of carers

2.1 Introduction

Schofield et al. (1997), reporting on a longitudinal study of 976 carers for the Victorian Carers Program, highlight the diversity in caring roles and circumstances. ABS survey data also suggest that it is impossible to generalise about the impact of caring work on carers. Yet common themes have emerged in these and other studies. Many carers of prime working age reduce their hours of employment, or cease work, in order to care. Caring work can have serious adverse effects on carer health and wellbeing. Some carers report a more satisfying relationship with the person they care for, while others associate caring with increased family conflict and a weakening of long standing friendships. This chapter looks at such aspects of caring work, beginning with a discussion of some of the more common reasons that people need a high level of care.

2.2 Disability, ageing and the need for care

In 2002, an estimated 3.7 million people with a disability, as defined broadly by the ABS, were living in households (Table 2.1). Around 1 million of these people, or 5.4% of the household population, had a severe or profound restriction in the areas of self-care, mobility and/or communication, and therefore needed supervision or assistance with core daily activities (Box 2.1). The prevalence of disability increases with age so that one in two persons aged 65 years or over has some form of disability, and one in five older people experiences a severe or profound activity restriction. Although many severely impaired older people live in residential aged care facilities, in 2002 an estimated 369,200 people aged 65 and over with a severe or profound restriction lived in the community. Older Australians accounted for around 35% of the household population with severe or profound restrictions, which also included an estimated 316,700 people aged 45–64 years, 221,900 people aged 15–44 years, and 146,900 children under the age of 15 in 2002 (Table 2.1).

Neither disability nor advanced age automatically implies the need for assistance from another person. Approximately 43% of people with a disability living in households and 54% of older persons (65 years or over) in 1998 reported no need for help beyond that which people routinely exchange (ABS 1999a: Tables 12 and 23). A need for ongoing care typically arises when disability or other long-term condition impairs a person's independence in the core activities of daily living. The ABS definition of severe or profound core activity restriction (or simply, 'severe or profound restriction') is aimed at operationalising this higher level of restriction.

Rates of severe and profound restriction are quite low at ages 65 and below (Table 2.1). For both males and females, rates of severe and profound restriction among people living in households and aged 65 years or over are double those of people aged 45–64 years. At older ages, women are more likely to report a severe or profound restriction than men.

Box 2.1: ABS 1998 Survey of Disability, Ageing and Carers: definitions of core activities and levels of activity restriction

Disability

For ABS survey purposes, a person has a disability if he/she has a condition that restricts everyday activities and lasts for six months or longer. Conditions include, but are not limited to, loss of sensory perception (sight, hearing, speech), chronic pain, respiratory conditions, loss of limb or motor function, learning difficulties, intellectual impairment, mental illness, disfigurement and deformity, and disorders of the nervous system.

Core activities are

- *self-care – bathing or showering, dressing, eating, using the toilet, and managing incontinence*
- *mobility – moving around at home and away from home, getting into or out of a bed or chair, and using public transport*
- *communication – understanding and being understood by others: strangers, family and friends.*

A core activity restriction may be:

- *profound – unable to perform a core activity or always needing assistance*
- *severe – sometimes needing assistance to perform a core activity*
- *moderate – not needing assistance, but having difficulty performing a core activity*
- *mild – having no difficulty performing a core activity but using aids or equipment because of disability.*

Note: Throughout this report, a 'severe or profound core activity restriction' is also referred to as a 'severe or profound restriction'.

Source: ABS 1999a:4.

People with a severe or profound restriction usually require assistance with core daily activities as well as higher level tasks such as housework, shopping, meal preparation and so on. Assistance to those living in the community comes from a variety of sources and over half of the people with a severe or profound restriction in 1998 nominated one person – a primary carer – who provided the most assistance and support. ABS surveys of disability, ageing and carers have collected detailed information on primary carers and the people they care for (ABS 1999a; ABS 1993). Although these care recipients are only a subset of the household population with a severe or profound restriction, their circumstances are most pertinent to a discussion of carers and caring work. This theme is followed in the next section.

Table 2.1: Estimated number of people with a disability living in households by age and sex, 2002^(a) (based on 1998 prevalence rates)

Age/sex	Profound or severe core activity restriction		All with a disability	
	'000	Per cent of age group	'000	Per cent of age group
Males				
0–14	99.2	4.9	197.6	9.7
15–44	106.6	2.5	526.2	12.2
45–64	150.2	6.5	645.5	28.0
65+	135.1	12.2	548.4	49.6
<i>Total</i>	<i>491.1</i>	<i>5.0</i>	<i>1,917.7</i>	<i>19.7</i>
Females				
0–14	47.8	2.5	105.9	5.5
15–44	115.2	2.7	462.2	10.8
45–64	166.7	7.3	624.3	27.2
65+	233.1	16.3	624.1	45.1
<i>Total</i>	<i>562.8</i>	<i>5.7</i>	<i>1,816.5</i>	<i>18.3</i>
Persons				
0–14	146.9	3.7	303.4	7.6
15–44	221.9	2.6	988.8	11.5
45–64	316.7	6.9	1,269.3	27.6
65+	369.2	14.8	1,171.3	47.0
Total	1,054.7	5.4	3,732.8	19.0

(a) People living in households who reported a severe or profound core activity restriction, or any disability, as a proportion of the survey population.

Source: AIHW analysis of ABS 1998 Survey of Disability, Ageing and Carers Confidentialised Unit Record File and ABS preliminary estimates of total population as at 30 June 2002 (Series Q).

Main restrictions and disabling conditions in recipients of care

The need for care is a complex function of potentially many medical and social factors in a person's life. It can rarely be explained merely by age or health condition. The ABS survey recorded information on the activity restrictions and disabling conditions experienced by each person with a severe and profound restriction (in fact, for anyone with a disability). Respondents to the survey identified the activity restriction that occasioned the greatest need for care (main restriction) and the condition associated with the highest level of disability (main disabling condition). This information can be linked to the provision of informal care for people who had a co-resident primary carer. Although not a complete enumeration of care recipients with a primary carer, a profile of the those who were living with their primary carer provides insight into the types of conditions that lead to, or heighten, the need for care.

Some of the more commonly reported main disabling conditions in young care recipients reflect the higher prevalence of intellectual and developmental disorders among younger persons with a severe and profound restriction (AIHW 2000: Tables 14.5, 14.6). Physical

conditions were the most common main conditions in the older age groups (Box 2.2). In terms of main restrictions that affected 5% or more care recipients with a co-resident carer, chronic, recurring pain or discomfort features at all ages; restriction in physical activities or work and incomplete use of feet or legs was reported in all age groups except for under 15 years.

Box 2.2: ABS 1998 Survey of Disability, Ageing and Carers: main disabling conditions and main restrictions in primary carers' recipients of care

The 'main disabling condition' is the condition reported by each care recipient to be associated with most of the problems that he or she experienced. The 'main restriction' is the area of activity that caused most problems for each care recipient. Main disabling conditions and main restrictions are listed below if they were recorded for 5% or more care recipients, by age, who had a co-resident primary carer in 1998 (358,200 care recipients). Main restriction categories of memory loss, reading difficulty and incontinence were excluded from the analysis due to survey data limitations.

Care recipients aged under 15 years

Main disabling conditions: cerebral palsy; attention deficit disorder or hyperactivity; mental retardation or intellectual disability;; autism and related disorders; other developmental disorders.

Main restrictions: slow at learning or understanding; speech difficulties; mental illness; incomplete use of arms or fingers; chronic, recurring pain or discomfort.

Care recipients aged 15–44 years

Main disabling conditions: back problems (dorsopathies); mental retardation or intellectual disability; cerebral palsy, Down's syndrome.

Main restrictions: chronic, recurring pain or discomfort; slow at learning or understanding; restriction in physical activities or work; incomplete use of feet or legs; incomplete use of arms or fingers; nervous or emotional condition; mental illness; loss of hearing.

Care recipients aged 45–64 years

Main disabling conditions: back problems (dorsopathies); arthritis and related disorders; other diseases of the nervous system including transient ischaemic attack; stroke.

Main restrictions: chronic, recurring pain or discomfort; restriction in physical activities or work; incomplete use of feet or legs; incomplete use of arms or fingers; mental illness.

Care recipients aged 65 or over

Main disabling conditions: arthritis and related disorders; stroke; back problems (dorsopathies, sight loss.

Main restrictions: incomplete use of feet or legs; restriction in physical activities or work; chronic, recurring pain or discomfort; loss of sight; breathing difficulties; incomplete use of arms or fingers; loss of hearing; difficulty gripping or holding things.

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

These profiles do not represent the prevalence of conditions and restrictions within the care recipient population generally, since specific conditions and restrictions can also be reported as secondary to a main disabling condition. Rather, data on main conditions and activity restrictions serve to show that many care recipients suffer from complex and chronic conditions with little prospect of marked improvement over time. They highlight a predominance of conditions that are linked with poor mobility and an increasing number of mobility-related conditions with age. Many carers therefore face physical demands which intensify over prolonged periods of caring. Older carers, most of whom are caring for

another older person, are at particularly high risk from the adverse physical consequences of caring for someone with limited mobility.

The predominance of mobility problems in care recipients with a co-resident primary carer emphasises the importance of government programs that provide access to affordable mobility and bathroom aids and training in manual handling procedures for carers. It also follows that primary prevention of mobility restriction and therapies that aim to maintain or increase motor function have the potential to reduce the burden on carers and keep older people at home for longer.

2.3 The nature and intensity of caring work

Within the 1998 household population

- 958,000 people with a severe or profound restriction reported a need for assistance with at least one of ten daily activities³ and two-thirds of these people were aged under 65 years
- 386,700 people with a severe or profound restriction reported a need for assistance with more than one core activity
- 73,000 people required assistance with all three core activities of daily living (AIHW 2000:104–6).

People with a severe or profound restriction aged less than 65 years were more likely than older people to require assistance with three core activities (9% versus 5%). Almost one in four children aged under 15 with a severe or profound restriction needed help with three core activities (AIHW 2000:106). Differences in the type of assistance received by younger and older people with severe or profound restriction reflect both the type of activity restrictions present and stage of life. Family and friends were the main source of assistance to both younger and older groups for all types of activity included in the ABS survey although half of this population received assistance from both carers and formal service providers (Table 2.2). Only 3% of people with a severe or profound restriction relied solely on formal service providers for all types of assistance.

Considering people who received assistance from a co-resident carer in 1998, approximately 65% needed assistance at times with five to nine activities of daily living, 60% always needed help with up to four daily activities and a further 27% always needed help with five or more activities (Table 2.3). These proportions confirm that the need for help arises from disability-related restriction in performing what are to most people routine activities. Youth and old age can compound the need for assistance as seen in similarly high proportions of the youngest and oldest age groups reporting a need for help with 5 or more daily activities (40% and 31% respectively). Thus, the needs of people who rely on the support of a primary carer are more likely to be continuous than episodic.

High demands on primary carers are reflected in the amount of time consumed by caring activities. In 1998, unpaid caring work occupied one in three primary carers aged 15 years or over for 40 or more hours per week (Table 2.4). On average, older carers reported spending more time on caring than younger carers, with one-half of primary carers aged 65 or over indicating that their role involved 40 hours or more per week. The higher caring workload

3 Self-care, mobility, communication, health care, housework, property maintenance, paperwork, meal preparation, transport and guidance (relationship counselling and decision support).

among older carers is associated with a higher rate of co-residency. Co-resident primary carers report higher caring workloads on average than non-resident carers.

Table 2.2: People with a severe or profound core activity restriction living in households in receipt of assistance: main source of assistance by need, 1998

	Under 65 years		65 years and over	
	Number ('000)	Per cent receiving assistance ^(a)	Number ('000)	Per cent receiving assistance ^(b)
Need for assistance				
One of ten daily activities ^(b)	633.4	99.6	324.6	99.6
More than one core activity	264.3	41.5	122.4	37.6
All three core activities	56.0	8.8	17.0	5.2
<i>Total severe or profound</i>	<i>636.0</i>		<i>325.6</i>	
Main source of assistance is a formal service provider				
Self-care	14.5	4.3	17.8	12.6
Mobility	28.6	6.8	22.2	8.6
Communication	18.0	13.6	—	—
Health care	49.8	16.3	95.4	46.6
Housework	18.6	7.6	60.0	27.3
Property maintenance	40.0	13.9	74.9	31.3
Paperwork	*9.0	*7.4	*5.1	*4.8
Meal preparation	*6.0	*5.2	23.7	20.0
Transport	18.9	6.6	22.8	10.4
Main source of assistance is a carer (co-resident and non-resident)				
Self-care	320.0	95.7	123.4	87.4
Mobility	391.8	93.2	235.4	91.4
Communication	114.4	86.4	25.5	100.0
Health care	255.5	83.7	109.2	53.4
Housework	225.4	92.4	160.1	72.7
Property maintenance	248.8	86.1	164.6	68.7
Paperwork	112.2	92.6	101.9	95.2
Meal preparation	109.6	94.8	94.6	80.0
Transport	265.8	93.4	196.1	89.6

(a) As a percentage of people of that age group who received assistance with that particular activity.

(b) Daily activities include three core activities (self-care, mobility and communication) plus health care, housework, property maintenance, paperwork, meal preparation, transport and guidance.

— Nil or rounded to zero.

Source: AIHW 2000: Tables 19.2 and A15.3.

Table 2.3: Main care recipients^(a) with a co-resident primary carer^(b), number of daily activities for which assistance is needed by age, 1998

	Age of main care recipient									
	0-14		15-44		45-64		65+		All ages	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
Number of activities for which assistance is needed										
1-4	32.7	52.2	19.6	25.4	29.2	31.9	24.6	19.6	106.0	29.8
5-9	27.9	44.5	50.0	64.9	60.4	66.0	94.6	75.5	232.8	65.3
10+	—	—	*4.7	*6.1	**0.7	**0.8	*5.2	*4.2	10.6	3.0
Not applicable	**2.1	**3.4	**2.8	**3.6	**1.2	**1.3	**0.8	**0.7	*6.9	*2.0
Total	62.7	100.0	77.0	100.0	91.5	100.0	125.2	100.0	356.4	100.0
Number of activities for which assistance is always needed										
1-4	28.7	45.7	43.6	56.6	62.2	68.0	77.6	62.0	212.1	59.5
5-9	19.9	31.7	15.8	20.6	15.8	17.2	35.4	28.3	86.9	24.4
10+	*5.2	*8.2	**2.2	**2.9	—	—	*3.1	*2.4	10.4	2.9
Not applicable	*9.0	*14.3	15.3	19.9	13.5	14.8	*9.1	*7.3	47.0	13.2
Total	62.7	100.0	77.0	100.0	91.5	100.0	125.2	100.0	356.4	100.0

(a) In cases where a carer provided assistance to more than one person, the care recipient who received the most care was designated the main care recipient i.e. table does not report on all care recipients.

(b) The 1998 ABS Survey of Disability, Ageing and Carers collected information on the needs of all people with a disability, but these can be reliably associated with a carer only when the carer is a co-resident primary carer.

— Nil or rounded to zero.

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

Table 2.4: Primary carers 15 years and over, hours of caring for main care recipient^(a) per week, 1998

Age	Co-resident primary carers									
	<20 hours		20 to 39 hours		40+ hours		Not stated		Total	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
15-44	48.0	39.6	23.5	19.4	42.0	34.6	*7.8	*6.4	121.4	100.0
45-64	48.5	33.4	24.3	16.8	66.9	46.1	*5.3	*3.7	145.0	100.0
65+	21.9	25.1	13.5	15.5	46.7	53.5	*5.2	*6.0	87.3	100.0
All ages	118.4	33.5	61.3	17.4	155.7	44.0	18.3	5.2	353.6	100.0
Age	All primary carers									
	<20 hours		20 to 39 hours		40+ hours		Not stated		Total	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
15-44	77.8	49.3	27.3	17.3	44.3	28.1	*8.5	*5.4	158.0	100.0
45-64	88.5	45.7	28.8	14.9	69.1	35.7	*7.3	*3.8	193.7	100.0
65+	27.1	28.2	15.1	15.7	48.6	50.5	*5.5	*5.7	96.4	100.0
All ages	193.5	43.2	71.2	15.9	162.1	36.2	21.3	4.8	448.1	100.0

(a) A primary carer may care for more than one person with a disability, but nominates one person as the main recipient of care.

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

Three-quarters of primary carers in 1998 had spent at least 5 years in the caring role, and 40% had been caring for at least 10 years (AIHW 2000: Table 16.4). Among those caring for a person aged 15 or over, 177,700 primary carers could not leave their main care recipient for more than a few hours without supervision and 63,800 carers could not leave their care recipient unattended for an hour or more (ABS 1999a: Table 33). Consistent findings emerged from the Victorian Carers Program research (Schofield et al. 1997). Caring time in that study ranged from the minimum qualifying period for inclusion in the study of 4 hours per week to the reported maximum of 168 hours of care provision per week. Twenty-seven per cent of carers reported spending over 100 hours per week in direct care. Duration of care ranged from 1 month to 50 years, with carers of children most likely to have provided care for 5 years or more. The constancy and time-consuming nature of long-term caring have been cited as specific causes of carer stress (CAA 2000:30).

Primary carers provide direct care and assist their care recipients to access formal services. Carers who took part in the 1999 National Survey of Carer Health and Wellbeing (CAA 2000) broadly divided caring time into:

- direct personal care (34%)
- support activities such as organising health services, transport, financial management, laundry and meal preparation (31%)
- supervision to prevent self-harm and harm to others, emotional support and companionship, and arranging activities for the development of children with disabilities (35%).

Data collected in the ABS survey shows that over 60% of co-resident primary carers in 1998 provided assistance with self-care tasks such as dressing, bathing, using the toilet and managing incontinence; 74% assisted with mobility; and 45% assisted with communication (Table 2.5).

Some differences appear in relation to the age of the main care recipient. For example, higher proportions of primary carers with young (under 15) and old (65 or over) care recipients helped with self-care activities than did carers of people in the middle age groups. In contrast, relatively fewer primary carers with young care recipients reported assisting with mobility. A higher proportion of primary carers with care recipients aged under 15 years or 15–44 years assisted with communication than carers of middle-aged and older people. These results reflect age-related patterns of main restrictions and disabling conditions among people with primary carers.

Table 2.5: Primary carers aged 15 years and over, provision of assistance^(a) with core activities of daily living^(b), 1998

	Age of main recipient of care								All ages	
	<15		15–44		45–64		65+			
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
Whether carer usually assists with self-care										
Usually assists	60.5	74.0	68.1	45.4	60.7	66.6	92.0	73.4	281.3	62.8
Does not usually assist	21.2	26.0	81.9	54.6	30.4	33.4	33.2	26.6	166.8	37.2
<i>Total</i>	<i>81.7</i>	<i>100.0</i>	<i>150.0</i>	<i>100.0</i>	<i>91.1</i>	<i>100.0</i>	<i>125.2</i>	<i>100.0</i>	<i>448.1</i>	<i>100.0</i>
Whether carer usually assists with mobility										
Usually assists	40.3	49.3	119.3	79.5	71.8	78.8	101.9	81.4	333.3	74.4
Does not usually assist	41.4	50.7	30.7	20.5	19.3	21.2	23.3	18.6	114.8	25.6
<i>Total</i>	<i>81.7</i>	<i>100.0</i>	<i>150.0</i>	<i>100.0</i>	<i>91.1</i>	<i>100.0</i>	<i>125.2</i>	<i>100.0</i>	<i>448.1</i>	<i>100.0</i>
Whether carer usually assists with communication										
Usually assists	48.7	59.6	76.8	51.2	26.5	29.1	48.5	38.7	200.5	44.7
Does not usually assist	33.0	40.4	73.2	48.8	64.7	70.9	76.7	61.3	247.6	55.3
<i>Total</i>	<i>81.7</i>	<i>100.0</i>	<i>150.0</i>	<i>100.0</i>	<i>91.1</i>	<i>100.0</i>	<i>125.2</i>	<i>100.0</i>	<i>448.1</i>	<i>100.0</i>

(a) The data represent the number of primary carers who assist their main care recipient with core activities. Where a primary carer provides assistance to more than one person, the person who receives the most care is designated the main care recipient.

(b) Self-care (bathing or showering, dressing, eating, using the toilet and managing incontinence); mobility (moving around at home and away from home, getting into or out of a bed or chair, using public transport); communication (understanding and being understood by others—strangers, family and friends) (ABS 1999a).

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

2.4 Impact of the caring role on carers

Many factors influence the impact of the caring role on carers, including the personal characteristics and circumstances of care-giver and receiver, the nature and strength of their relationship, living arrangements, and the level of support available from social networks and formal services. This section considers evidence on the impact of caring on labour force participation and carer health and wellbeing.

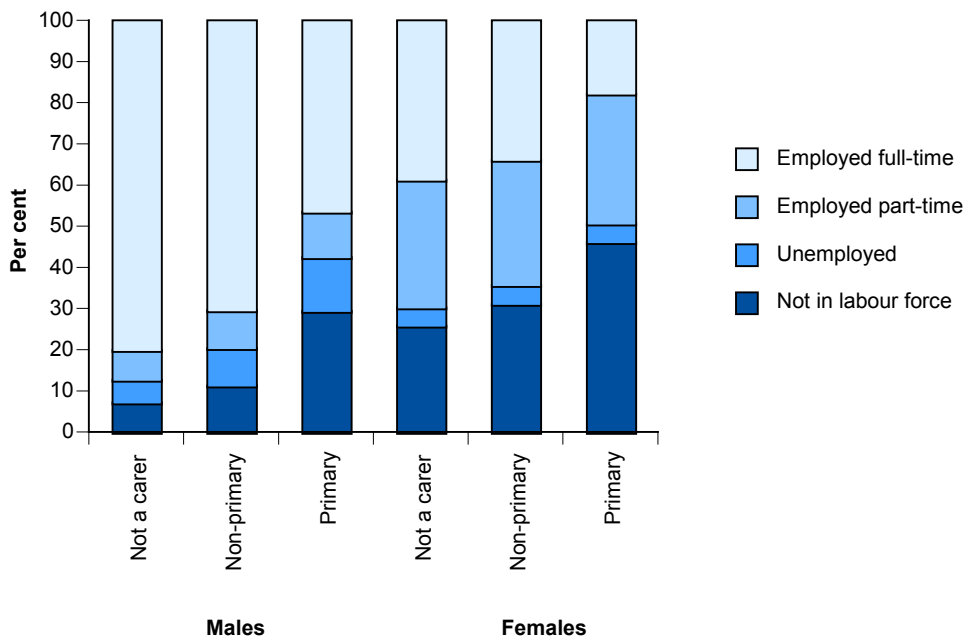
Combining a caring role with paid employment

Chapter 1 reported that employment rates, particularly for full-time employment, are lower for primary carers and carers more generally than for people without caring responsibilities. Given the disparate age and sex structures of the primary carer and general populations, it is more insightful to compare employment rates of carers and non-carers of prime working ages, 25–54 years. This confirms lower labour force participation among primary carers compared to non-carers in the same age group, with reduced participation mainly at the expense of full-time employment (Figure 2.1). Approximately 47% of male primary carers were employed full-time in 1998 versus 80% of men who were not primary carers. Similarly, 18% of female primary carers aged 25–54 years were in full-time paid employment versus 39% of women who were not primary carers.

There were sufficient numbers of female primary carers aged 25–54 years in the sample survey to comment on the relationship between labour force participation and hours of unpaid caring work per week. Due to high sampling error in the estimates for male carers in this age range, the following discussion is confined to patterns of female primary carer employment. Among female primary carers who provided fewer than 20 hours of unpaid assistance, the overall pattern of labour force participation in 1998 was similar to that of non-primary carers (71% and 69% respectively; Figure 2.2). Lower rates of part-time and full-time employment were recorded for female primary carers providing informal assistance of 20 hours or more per week. Among female primary carers aged 25–54 years performing 40 hours or more per week, 30% were employed and 67% were not in the labour force, compared to 70% and 26% respectively of women aged 25–54 without caring responsibilities. In 1998, 31,200 primary carers (6,800 men and 24,400 women) reported being in paid employment while performing 40 hours or more of unpaid caring work per week.

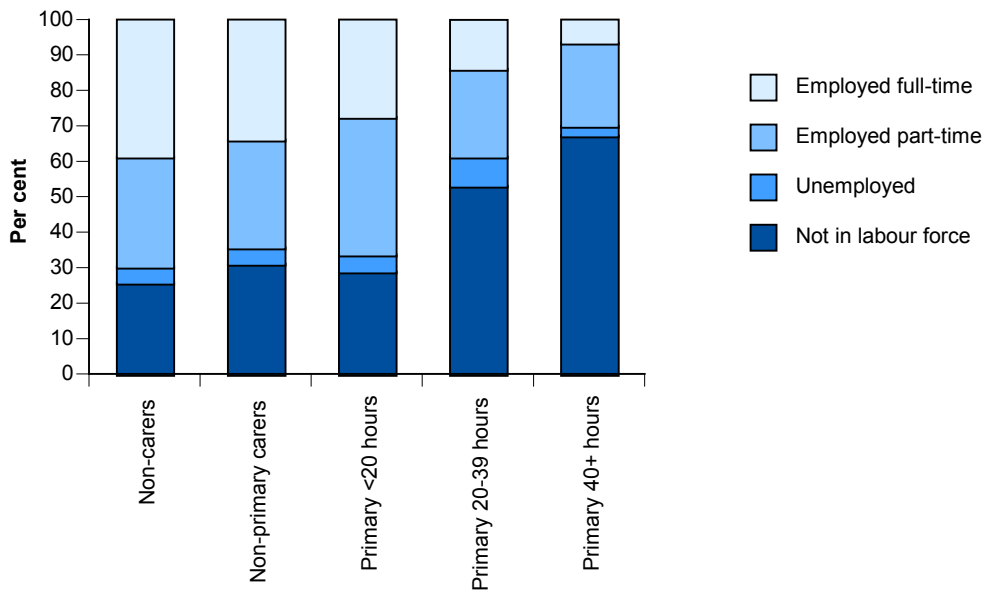
Paid employment is reported to have protective effects for carers by offering respite from the caring role and helping to maintain social networks (Schofield et al. 1997a; Spiess & Schneider 2003; Doty, Jackson & Crown 1998; Turvey & Thomson 1996). Schofield et al. (1998a) identified caring and not having full-time work as significant predictors of major health problems in the past year among primary carers who participated in the Victorian Carers Program study. However, the physical, psychological and time demands of caring place paid employment out of reach for many carers of working age. Table 2.6 summarises income, living costs and employment outcomes reported by primary carers in 1998. Further breakdown of the data by primary carer sex is not possible due to the high sampling error associated with small numbers of male carers in detailed reporting categories. According to the 1998 ABS survey, 11% of primary carers aged 25–54 years and 17% of those aged 55–64 years had left work in order to commence caring or increase their hours of care. Around 21% of employed primary carers had reduced their hours of paid work, and the same proportion of employed carers reported a reduction in income that was directly associated with caring (Table 2.6).

The impact of ceasing or reducing paid employment to perform unpaid caring work can extend well beyond the actual or intended period of caring. Among 108,700 primary carers aged 25–54 years who were not in the labour force at the time of the 1998 ABS survey, 57% (61,600) said that return to work was not relevant and a small proportion (2%) did not anticipate any difficulty. The remaining 47,100 primary carers expected to face problems that could prevent a return to paid employment. Making suitable alternative care arrangements was the most commonly anticipated difficulty in a list that included inflexible work hours, disruption to the care recipient, and loss of skills while caring. However, almost one-third of this group (15,700) cited 'other reasons', suggesting that more research is needed if such problems are to be addressed (AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File). The ability of carers to maintain or return to paid employment will be an increasingly important factor in women's predisposition to provide ongoing unpaid care. Moreover, it will determine the extent to which employed men can take on a greater share of family caring responsibilities.



Source: Appendix Table A2.

Figure 2.1: Persons 25-54 years, labour force status by carer status, 1998



Source: Appendix Table A3.

Figure 2.2: Females 25-54 years, labour force status by caring hours per week, 1998

Table 2.6: Primary carers aged 15 years and over, impact of caring on hours of work, income and living costs (per cent), 1998

	Age group				Total
	15–24	25–54	55–64	65+	
Effect on income					
Income not affected	71.5	39.3	49.2	57.2	45.9
Income has increased	**2.4	*2.8	**2.0	**1.9	2.5
Income has decreased	**5.4	27.2	18.8	*6.8	20.7
Has extra expenses	**16.7	25.5	26.0	28.1	25.8
NA/not stated	**4.0	5.2	**4.0	*6.0	5.2
	100.0	100.0	100.0	100.0	100.0
Effect on living costs					
Difficulty meeting costs	**14.5	34.6	28.3	17.1	29.1
No difficulty meeting costs	**7.6	17.5	16.3	15.8	16.6
NA/not stated	77.9	47.9	55.4	67.2	54.3
	100.0	100.0	100.0	100.0	100.0
Effect on hours of paid work					
Applicable	42.8	51.4	22.4	*3.7	35.8
No effect	*86.4	71.5	64.9	*76.6	71.4
Reduced hours	—	21.8	*22.7	**10.4	20.9
Increased hours	**13.6	*6.7	**12.3	**13.0	7.7
Not applicable	*57.2	48.6	77.6	96.3	64.2
	100.0	100.0	100.0	100.0	100.0
Reason left work					
To commence or increase care	—	11.4	17.2	*4.4	10.6
Total number ('000)	13.6	259.0	79.1	96.4	448.1

— Nil or rounded to zero.

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

Carer health and wellbeing

Primary carers experience high rates of disability and long-term health problems. Of those surveyed in 1998, just over 39% (177,500) had a disability and 9% (41,900) had a severe or profound restriction (Table 3.2). Many primary carers are themselves older people, so that a high rate of disability is not entirely unexpected. Elsewhere, however, the AIHW has reported substantially higher age-specific rates of disability among primary carers (AIHW 2000:141). Many primary carers provide an intense level of support for someone who is severely restricted in their activities, while also coping with their own severe level of physical restriction. The physical and psychological demands of the caring role itself can lead to adverse health outcomes for carers.

The ABS survey asked primary carers to assess the impact of caring on various aspects of physical and emotional wellbeing. High numbers reported on the adverse effects of caring, including a changed overall state of wellbeing (29%); feelings of dissatisfaction (67%); fatigue and weariness (34%); and feelings of worry or depression (31%) (AIHW 2000: Table 16.10).

Many said that caring work had taken a toll on personal relationships. While one in three primary carers felt that caring had strengthened their relationship with the care recipient, 22% said that the relationship was strained. Nearly a quarter of primary carers said that they had lost, or were losing, touch with friends because of caring commitments.

Carers who took part in the 1999 National Survey of Carer Health and Wellbeing reported declines in physical, mental or emotional health as a result of their caring responsibilities (CAA 2000). Providing mobility assistance (lifting, transferring and carrying) presented difficulties for 38% of surveyed long-term carers. Around 60% of carers in the survey reported major negative effects on their life choices including restrictions in their ability to take part in paid work, education or other career opportunities. The survey reported on the emotional and physical demands faced by families caring for children with severe disabilities, highlighting parents' anxiety about the future welfare of their disabled children. Responses to questions about personal wellbeing referred to the physical demands of caring, constant responsibility, and the emotional and psychological impact of behavioural disorders in care recipients as specific causes of carer stress. Although based on a relatively small convenience sample, these results serve to highlight the types of difficulty that primary carers can experience.

The Young Carers Research Project (CA 2001) revealed that many young carers feel a sense of isolation and alienation from their peers because the caring role varies considerably from more typical adolescent experience. Caring responsibilities can interrupt education and make the transition from home to independent living more difficult. Younger carers in the Victorian Carers Program, particularly adult daughters and daughters-in-law, were more negative about their circumstances than older spouse carers (Schofield et al. 1998a).

The same study found that female carers in general experienced more psychological distress and overload than male carers. Self-reported measures of health and wellbeing for female primary carers were compared to those for a representative random sample of women with usual household and parenting responsibilities. Overall, carers reported lower life satisfaction, higher feelings of work overload and poorer self-rated health status.

Relinquishing primary caring responsibilities during the study period was associated with improved life satisfaction, reduced feelings of overload and lower levels of family conflict.

Bergquist and colleagues (1993) highlighted the strain that caring for aged parents can place on people in their fifties and sixties because of competing priorities and family responsibilities. At this stage of life many people experience changing life patterns while continuing to work and provide support to adult children and possibly grandchildren. Two factors said to contribute most to a positive experience of caring for an elderly parent are having the support of other family members and having a sense that there was some choice in the decision to provide care (Millward 1999).

Carers of people with dementia are at particularly high risk of anxiety and depression as a result of their caring role. Morris et al. 1988 (cited in Henderson & Jorm 1998) remark that:

Institutionalisation may have more to do with the attitudes and wellbeing of the caregiver than the impairment of the dementia sufferer.

Dello Buono et al. (1999) 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. Evidence of the relationship between challenging behaviour and carer burden is equivocal. A study by Zarit et al. (1980) found no association between behavioural symptoms and level of carer strain. Vernooij-Dassen et al. (1996) found a strong association between carers' sense of competence and 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.

Australian studies have also revealed a link between carer burden and the behavioural and psychological symptoms associated with dementia (e.g. Bruce & Paterson 2000; Schofield et al. 1998). Schofield and colleagues noted the coincidence between behavioural symptoms and greater functional dependence, both in activities of daily living and in instrumental activities of daily living. Carer burden was significantly lower among carers of people with physical impairment, compared to carers of people with cognitive impairment or memory loss. Depression in carers of people with a psychiatric disorder was mediated by the presence of a carer confidante. Both studies reported that a firm diagnosis of the care recipient's condition often reduces carer burden. Wood and Rabins, cited in Schofield et al. (1998), 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. Hence, there are two aspects to the evaluation of outcomes in the treatment of problem behaviour. One is the impact of intervention on the behaviour itself and the other is whether the intervention has addressed the carer's understanding of, and ability to cope with, the behavioural and psychological symptoms of dementia.

The Australian Government offers such assistance 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 network of Commonwealth Carer Resource Centres and Commonwealth Carer Respite Centres. 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 5 years of age over 65 it will be necessary to increase awareness of government support programs and community care entry points if formal services are to play an effective role in early intervention and coordinated support for growing numbers of carers.

2.5 Discussion

Caring for a person with a severe level of restriction is an intensely demanding experience for many carers. Depending on the age group, one-third to one-half of primary carers spend 40 or more hours per week in the caring role. Some experts predict that the conflicting demands of caring work and paid employment, together with increasing female labour force participation, pose a threat to the availability of carers. Others maintain that women's 'ethic of care', as described by Stohs (1994), is resilient to the economic rewards of employment (Doty, Jackson & Crown 1998:340).

Available data suggests that the ethic of care is alive and well in contemporary Australia, but that relatively higher numbers of women than men respond to needs of family members other than spouses and partners. It is also clear that caring can involve considerable personal and financial sacrifice. Many carers reduce their hours of paid work to care and some face formidable barriers in returning to their former employment status.

Spieß and Schneider (2003) investigated the employment patterns of carers in 12 European countries to show that workplace flexibility is crucial in the early stages of caring. Carers in countries with high levels of community support and well-developed formal services are reportedly more able to adapt their working lives to new caring roles, gradually easing back to earlier patterns of work when support arrangements with formal providers are in place. In

countries with fewer and less coordinated sources of formal support, carers tend to withdraw from the workforce or reduce their hours of paid employment. There is evidence that once these changes are made, earlier work patterns are not recovered when caring ceases.

Spiess and Schneider also refer to the work of Carmichael and Charles who reported on lower average wage rates for carers due to lost productivity and time constraints that force some carers into jobs for which they are over-qualified. A study of the informal costs of dementia care in the United States using national longitudinal data found that caregivers' lost earnings are by far the largest component of the cost of caring (Moore, Zhu & Clipp 2001).

Reduced hours of employment, decreased income and additional costs reported by Australian primary carers aged 25–64 years indicate that there is considerable ground to be gained in improving the capacity of primary carers to cope with the demands of caring and paid employment. The challenge in the years ahead will be for communities to adequately care for growing numbers of carers by providing adequate social and financial support for carers of all ages and promoting flexible workplace arrangements for employed carers. Such measures will help to minimise carer dependency and burnout and the associated negative effects on carers' ability to care.

3 The changing context

3.1 Introduction

The topic of Australia's ageing population has generated debate as to whether informal care will be able to meet the needs of a growing household population with severe or profound levels of activity restriction. The question of how best to design and plan formal welfare services is closely related. Structural and numerical ageing of the population will increase the need for informal care and the continued motivation of families to care for their own is a crucial factor in whether future needs will be met. Historically, care in the community has meant care by the family, and care by the family has meant care by women (Land 1978). Changes in women's lives are therefore at the heart of the issue; higher female labour force participation and lower rates of lifetime partnership are often cited as factors that will reduce the overall availability of informal care. This chapter considers projected changes in the population age structure, living arrangements and labour force participation that could impact on the need for, and availability of, assistance from primary carers.

3.2 Population disability

As noted by Howe and Schofield (1996), 'the underlying determinant of the need for care is the level of disability in the community'. A preliminary comparison of the four disability surveys undertaken by the ABS (1981, 1988, 1993 and 1998) showed that the overall age-standardised rate of severe or profound restriction has increased from 4.0% in 1993 to 5.5% in 1998, while the rate was relatively stable between 1981 and 1993 (ABS 1999a). These increases might be attributable to an increased willingness of people to recognise and describe their disabilities, as well as changes in survey methods and design (Widdowson 1996; AIHW 2001:267). A comprehensive review of international literature on disability trends in 1998 showed evidence that disability rates among older people are decreasing in most industrialised countries, although much of this decline appears to be concentrated at lower levels of disability. In Australia, however, there has been no consistent trend for either declining or increasing disability rates (Waidmann & Manton 1998). AIHW analysis suggests that age structure has been the dominant factor in changing prevalence rates of severe disability since 1993 (AIHW 2000; Wen, Madden & Black 1995).

Based on this evidence, it might be reasonably assumed that the age-and sex- specific rates of disability in the population will remain constant over time. Thus, if the 1998 disability rates continue (that is, if the number of people with a severe or profound restriction per 1,000 persons in each age and sex group in the population stays the same), by 2013 an estimated 1.4 million people aged 10 years or over will have a severe or profound core activity restriction compared to just over 1 million in 2003 (Table 3.1). This projection assumes that recent levels of age-specific rates of disability will continue. Major medical breakthroughs or the emergence of new disabling conditions may alter the number in unforeseen ways.

Rates of disability increase with age, as does the likelihood that an individual will require assistance in at least one area of daily living. Among older people, the rates of severe or profound restriction are quite low until age 75 years. For those aged 65–69 years, for

example, in 1998 only 8% of men and 9% of women were so affected. By ages 75–79 years, however, 19% of men and 25% of women reported this level of restriction, while at ages 80–84 years the rates rise to 24% and 36% for men and women respectively (AIHW 2001). Consideration of the need for care and likely future need for care must therefore take stock of these key factors: the changing age structure of the population and the level of disability in the population.

Estimates of the population with a severe or profound restriction shown in Table 3.1 were derived using population projections supplied to the AIHW by the Department of Treasury (for ages 10 or above only) for consistency throughout this report. These figures differ slightly from projections published in other AIHW reports that are based on ABS population projections. The Treasury population projections were used to produce results reported in Chapter 4 because they afford a detailed level of analysis that is not possible using ABS population projections alone.

Table 3.1: Estimated number of people with a severe or profound core activity restriction, by age and sex ('000), 1998, 2003, 2008, 2013 (based on 1998 prevalence rates)^{(a)(b)}

Age/sex	1998	2003	2008	2013	Per cent change 2003–2008	Per cent change 2003–2013
Males						
10–24	62.2	64.6	66.2	66.5	2.4	2.9
25–44	79.4	81.6	82.5	84.5	1.1	3.5
45–64	137.3	160.1	183.1	195.8	14.4	22.3
65–74	59.6	61.1	67.6	84.0	9.7	36.6
75–84	64.0	78.3	87.6	93.5	11.8	19.4
85+	38.5	51.0	67.5	85.0	32.3	66.7
<i>Total</i>	<i>441.0</i>	<i>497.2</i>	<i>554.5</i>	<i>609.3</i>	<i>11.5</i>	<i>22.5</i>
Females						
10–24	37.9	39.2	39.9	39.9	1.8	1.8
25–44	92.8	94.8	95.3	96.6	0.6	1.9
45–64	149.9	174.1	200.6	216.0	15.2	24.1
65–74	80.6	80.8	86.6	105.2	7.1	30.1
75–84	130.1	150.0	159.7	163.9	6.4	9.2
85+	106.8	132.7	164.1	195.1	23.6	47.0
<i>Total</i>	<i>598.1</i>	<i>671.8</i>	<i>746.3</i>	<i>816.7</i>	<i>11.1</i>	<i>21.6</i>
Persons						
10–24	100.1	103.9	106.2	106.4	2.2	2.5
25–44	172.2	176.4	177.8	181.0	0.8	2.6
45–64	287.2	334.2	383.7	411.9	14.8	23.2
65–74	140.2	142.5	154.2	189.2	8.3	32.8
75–84	194.1	228.4	247.3	257.5	8.3	12.7
85+	145.3	183.7	231.6	280.1	26.0	52.5
Total	1,039.1	1,169.0	1,300.7	1,426.1	11.3	22.0

(a) Treasury 2002 population projections are used for consistency with analysis in Chapter 4 and may differ slightly from ABS projections.

(b) Age- and sex-specific rates of severe and profound restriction recorded in the 1998 ABS Survey of Disability, Ageing and Carers.

Source: Appendix Table A4.

Growth in the number of people with a severe or profound restriction over the next decade will be evident mainly in the 45 years or over age groups. Between 2003 and 2013, the number of people aged 85 years or over with a severe or profound activity restriction is projected to grow by over 50%. Growth in the number of people with a severe or profound restriction at ages 65–84 years is projected to be in the order of 20% over the same period (Table 3.1). The 45–64 years and 85 years and over age groups will account for 30% and 37% respectively of the projected numerical growth in the population with a severe or profound restriction (77,700 at ages 45–64 years and 96,400 at ages 85 years or over). The corollary is that the next 10 years will see increased demand for informal care in the working age population and in the very old population. Moreover, primary carers will be supporting an increasingly dependent population of care recipients.

3.3 Population ageing

Ageing of the aged population—more caring work and older carers

Like other countries in the OECD, Australia has experienced improvements in average life expectancy over the past century and a dramatic downturn in fertility since the post-World War II baby boom. As a result, people aged 65 and over will make up an increasingly higher proportion of the population, from 12% in 2001 to a projected 18% by 2021, and possibly reaching 29% by 2051. A 65-year-old man in 2041 will have a life expectancy of another 18.8 years, up from 15.8 years in 1994–96. For a 65-year old woman, the projected increase is from 18.8 to 22.2 years of additional life (ABS 1998). The older population will also increase numerically as large numbers of people born in the post-Second World War baby-boom era – between 1947 and approximately 1961 – reach age 65 from 2012 onwards. Thus, Australia is making the transition from a period of youth dependency to one of aged dependency.

Ageing primary carers are themselves exposed to age-related risk of frailty and disability. In 1998, 96,700 primary carers (21% of primary carers) were aged 65 years or over. One third of primary carers (146,800) had a specific restriction of one type or another, including 41,900 carers who themselves suffered a profound or severe level of activity restriction (Table 3.2).

Similarly, people with an early onset disability are living longer with implications for their ageing carers, some of whom have been caring for over 25 years (AIHW 2000). Recognising and supporting the needs of older carers will need to be a continuing focus of community care policy in the years ahead.

Table 3.2: Primary carers, disability status by age and sex, 1998

Age	Core activity restriction			All with specific restrictions	All with disability	No disability	All primary carers
	Profound or severe	Moderate	Mild				
Females				Number ('000)			
Under 65	24.5	15.0	28.1	67.6	84.8	172.2	257.0
65 and over	*8.5	11.1	*9.3	28.9	32.0	28.4	60.4
<i>Total</i>	<i>33.0</i>	<i>26.1</i>	<i>37.4</i>	<i>96.4</i>	<i>116.8</i>	<i>200.6</i>	<i>317.4</i>
Males							
Under 65	*4.1	15.0	11.9	31.0	39.2	58.1	97.3
65 and over	*4.8	*7.3	*7.3	19.4	21.5	14.7	36.2
<i>Total</i>	<i>*8.9</i>	<i>22.3</i>	<i>19.2</i>	<i>50.4</i>	<i>60.8</i>	<i>72.7</i>	<i>133.5</i>
Persons							
Under 65	28.6	30.0	40.0	98.6	124.0	230.3	354.3
65 and over	13.3	18.4	16.6	48.3	53.5	43.1	96.6
Total	41.9	48.4	56.6	146.8	177.6	273.3	450.9
Females				Per cent			
Under 65	7.7	4.7	8.9	21.3	26.7	54.3	81.0
65 and over	*2.7	3.5	*2.9	9.1	10.1	8.9	19.0
<i>Total</i>	<i>10.4</i>	<i>8.2</i>	<i>11.8</i>	<i>30.4</i>	<i>36.8</i>	<i>63.2</i>	<i>100.0</i>
Males							
Under 65	*3.1	11.2	8.9	23.2	29.4	43.5	72.9
65 and over	*3.6	*5.5	*5.5	14.5	16.1	11.0	27.1
<i>Total</i>	<i>*6.7</i>	<i>16.7</i>	<i>14.4</i>	<i>37.8</i>	<i>45.5</i>	<i>54.5</i>	<i>100.0</i>
Persons							
Under 65	6.3	6.7	8.9	21.9	27.5	51.1	78.6
65 and over	2.9	4.1	3.7	10.7	11.9	9.6	21.4
Total	9.3	10.7	12.6	32.6	39.4	60.6	100.0

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

Ageing baby-boomers

Over the next two decades, large numbers of baby-boomers in the pre- and early-retirement age groups will increase the community's capacity to deliver informal assistance to the older population. Further beyond, ageing of the baby-boomer generation will result in higher numbers of very old people and corresponding increases in disability-related need for assistance. The population aged 45–64 years is projected to increase from 4.3 million at the 2001 census to 5.6 million by 2011, and growth in the 65–74 year age group will peak between 2008 and 2028. Unprecedented rates of growth in these age groups will skew the age distribution of the older population towards the 'young old' until such time as large numbers of baby-boomers attain age 75 years and older. The population aged 75 years and over will experience high growth in absolute terms between 2018 and 2038, or from 2018 onwards, depending on assumptions about future mortality (McDonald & Kippen 1999:56).

As a result, this latter period is likely to see an increased need for assistance among community-dwelling older people.

The level and type of assistance needed as a result of these demographic changes could vary from the historical precedent. Aged baby-boomers are expected to differ from earlier cohorts of older Australians in a number of respects. Firstly, male and female life expectancies at birth are converging so that in future, couples who stay together or repartner could be better positioned to support each other in old age. The ABS predicts that 48% of people aged 65 years and older in 2021 will be living in couple families (ABS 2001a). Secondly, real average income of older Australians has been increasing over the past two decades, and this trend is likely to continue (Whiteford & Bond 1999:195; Madge 2000:37). Many baby-boomers were at the peak of their earning potential during the favourable wage and investment climate of the 1970s and 1980s. Proportionately more people of this generation could be financially independent in old age.

Following a strategy endorsed by the OECD, Australia has introduced compulsory superannuation to reduce dependency on the Age Pension. In the fourteen years to 1997, retirement scheme membership of retired people aged 45 years and over increased from 38% to 60%. For women, the increase was from 19% to 48%. Together with rising female labour force participation, these measures may have reduced one traditional pool of aged dependants. Superannuation scheme coverage among employees aged 45 years and over with retirement intentions increased from 77% in 1992 to 91% in 1997 (ABS 2000:4).

A trend towards increasing income and wealth in the older population could affect how assistance received is shared between the informal and formal care sectors. Madge (2000) emphasises that the relationship is by no means clear, but proposes that higher retirement incomes among baby-boomers, compared to earlier generations of retirees, might increase demand for formal services among people who wish to remain in their own homes. Obviously this outcome will depend on the baby-boomer's prudential management of their retirement savings. Madge suggests that, overall, the preference of future large numbers of older people to remain at home will reduce the share of the formal sector in aged care.

New retirees with solid asset bases and relatively high retirement incomes could be more mobile and therefore less likely than past generations to remain in the family home. The decision to relocate in retirement will initially impact on baby-boomers' capacity to care for ageing parents and, later, on their prospects as recipients of care. The effect of 'geographic ageing' can be seen in many coastal populations and this trend is extending along the eastern seaboard (ABS 2002). In coastal retirement havens social networks of older people could become increasingly important sources of informal care. Conversely, younger generations have moved away from many rural population centres in search of greater social, educational and employment opportunities. Less than one-third of older people who responded to a survey conducted in a country town received any assistance from their children (Dempsey 1990). The ABS predicts that geographic ageing presents challenges in meeting the needs of older people in many regional centres (ABS 2002).

3.4 Living arrangements and family formation

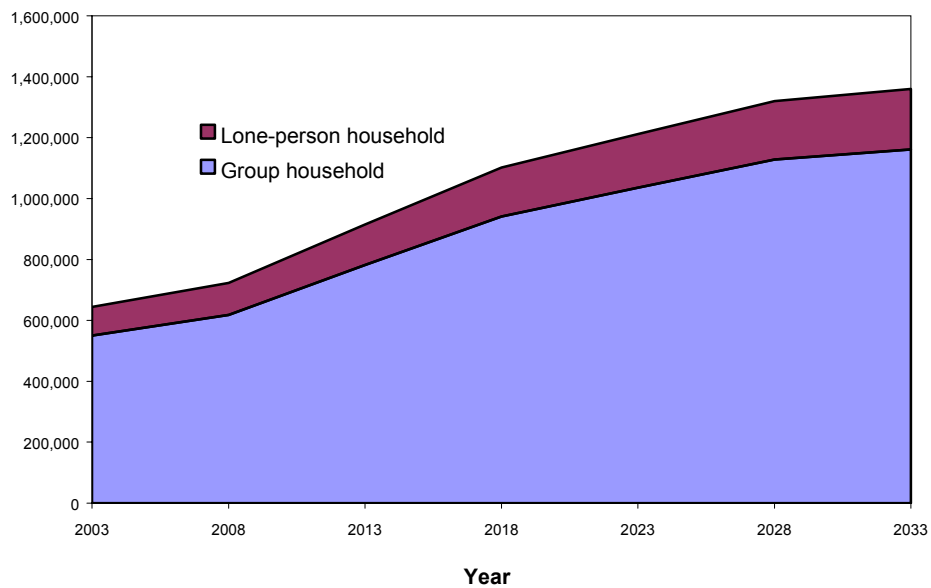
Living alone does not necessarily imply more limited access to informal care. In 1998, 20% of primary carers were providing assistance to a person in another household. However, there is reason to suspect that a 64% increase in the number of people living alone over the past 12 years signals changes in Australian social structure that have implications for informal care

in the community (ABS 2003). Altered living arrangements reflect trends in family formation and social relationships. The overall rate of partnering has fallen and the divorce rate, which has risen from 10.6 divorces per 1,000 married women in the mid-1980s to 12.9 in 2000, are symptoms of trends in widespread relationship breakdown and, possibly, reformation (Weston & Parker 2002:8).

McDonald and Kippen (1999) estimate that the proportion of people aged 45–54 years not living with a partner is now above 20 per cent. They suggest that middle-aged men are especially vulnerable to estrangement from their adult children following family breakdown. Secondly, young people are delaying partnering and parenting decisions. These trends are contributing to increasing rates of voluntary and involuntary childlessness so that about a quarter of women currently in their reproductive years will not bear children. To the extent that an increased propensity to live alone is a result of declining family formation and more fragile relationships, it signals a relatively higher reliance on non-resident carers in the best case, and reduced accessibility to any form of informal care in the worst case.

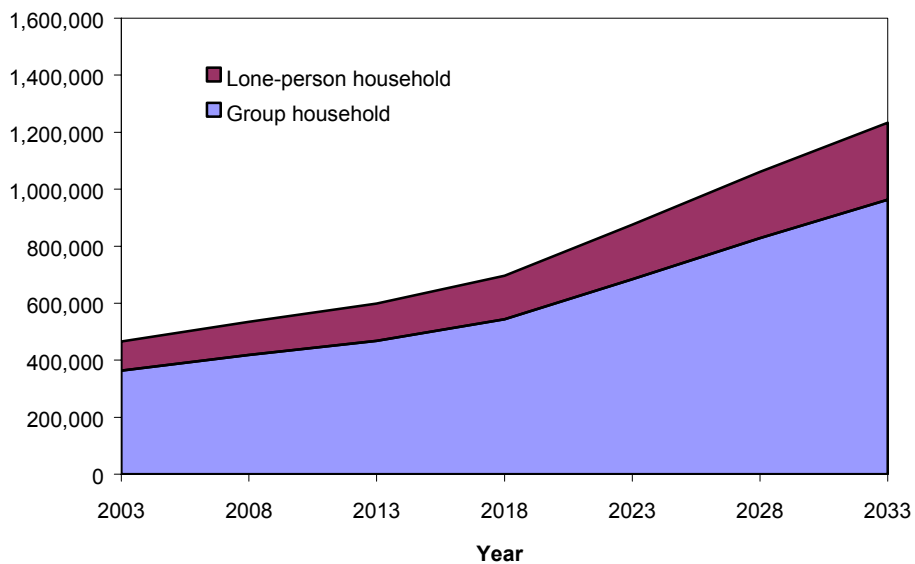
The living arrangements of older people in the community will also impact on the ratio of co-resident (mainly spouses) to ex-household (mainly adult offspring) primary carers of people aged 65 years and over. Among usual residents of private dwellings in 2001, 70% of people aged 65 years or older lived in family or group households (ABS 2001b: Table 3.6 Series B). The likelihood that a person lives alone following the death of a spouse or partner and the risk of serious illness and disability both increase with age. In 1998, people living alone comprised approximately 13% (34,700) of the population aged 45–64 years with a severe or profound restriction, 22% (26,400) of those aged 65–74 years, and 35% (71,600) of those aged 75 years or over (AIHW analysis of 1998 ABS Survey of Disability, Ageing and Carers Confidentialised Unit Record File). The population aged 65 years or older, numbering 2.4 million persons in 2001, is projected to increase to 4.2 million in 2021. One in two older people will be living in a couple family without children and 1.1 to 1.2 million older Australians are projected to be living alone, a 100% increase on the 0.6 million in 2001. Women are more likely than men to live alone at all ages 65 years and over, and the percentage of women living alone increases linearly with age from 65–69 to 80–84 years (Paice 2002). Between 824,000 and 837,000 older people living alone in 2021 will be women (ABS 2001a).

The period 2003 to 2008 will see steady growth in the number of older people living alone. For ages 65 to 74 years, growth in lone-person households will accelerate sharply from 2008 with ageing of the baby-boomer generation. A similar higher rate of growth for the 75 years and over age group will naturally follow around 2018 (figures 3.1 to 3.4).



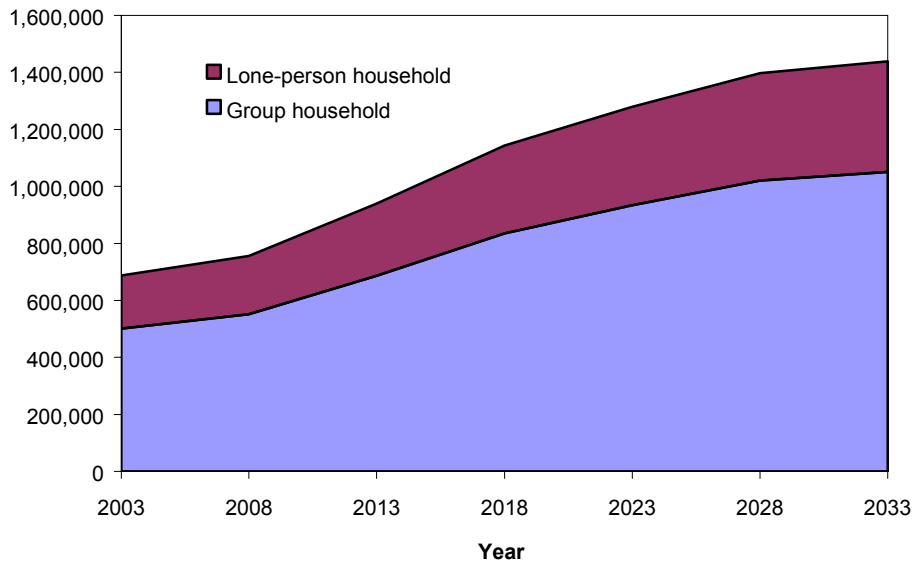
Source: AIHW analysis of ABS 2001b:Table 14.

Figure 3.1: Projected living arrangements of males aged 65–74 years, 2003–2033



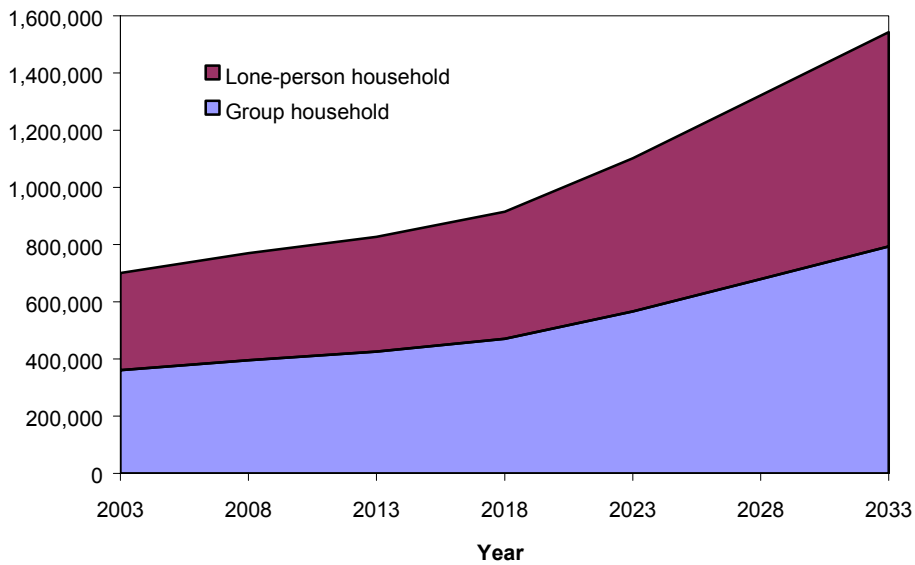
Source: AIHW analysis of ABS 2001b:Table 14

Figure 3.2: Projected living arrangements of males aged 75 years and over, 2003–2033



Source: AIHW analysis of ABS 2001b: Table 14

Figure 3.3: Projected living arrangements of females aged 65–74 years, 2003–2033



Source: AIHW analysis of ABS 2001b: Table 14

Figure 3.4: Projected living arrangements of females aged 75 years and over, 2003–2033

ABS projections of living arrangements to 2021, based on changes in living arrangements between the 1996 and earlier censuses of population and housing, overestimate the number

of older persons living in lone-person households according to the 2001 census. Projected numbers of lone-person households used to construct figures 3.1 to 3.4 were derived by applying 2001 census age- and sex-specific rates of lone-person households to household population projections.

3.5 Combining work and family

Changing attitudes among women towards family and work could alter the gender imbalance among primary carers. After peaking at 3.5 babies per woman in 1961, the total fertility rate in Australia made a dramatic downturn to 1.7 in 2000. Women are starting their families later in life and as a result, or by desire, are having fewer children. Market factors contributing to low fertility include higher levels of educational attainment and labour force participation among women and fluctuating economic cycles that create employment uncertainty (Weston & Parker 2002). Many younger women are choosing against the conventional role of wife and mother that in the past would have required them to leave paid employment to care for children and other family members. It remains to be seen whether changing trends in women's early-life choices will impact on the predisposition to provide care in later life.

Older women are returning to paid employment in higher numbers and remaining employed for longer. At present, however, older working women are more likely than not to work part-time; fewer than 50% of women in each age group from 35–44 to 60–64 years currently work full-time. Increasing female labour force participation since the 1970s is almost entirely due to the uptake of part-time work, and the proportion of women working full-time has declined in most age groups (ABS 2003).

ABS labour force projections to 2016 indicate a sustained increase in female labour force participation, particularly in the age groups 45–54 to 60–64 years, which currently comprise over 40% of female primary carers (Table 3.3). A progressive increase in the pension age for women born on or after 1 July 1949 will prolong the working lives of many women. At ages 45 to 54 years, male and female labour force participation rates are projected to converge from a difference of around 15 percentage points in 2003 to 10 percentage points in 2016.

Table 3.3: Projected labour force participation rate by age (per cent), 2003, 2008, 2013, 2016

	Males							
	15–19	20–24	25–34	35–44	45–54	55–59	60–64	65+
2003	57.1	86.5	92.1	91.6	87.5	71.6	47.6	10.0
2008	56.4	85.7	91.4	90.9	87.0	71.1	47.7	10.3
2013	55.8	85.1	90.8	90.2	86.7	70.8	47.7	10.7
2016	55.4	84.7	90.4	89.8	86.5	70.7	47.7	10.9
	Females							
	15–19	20–24	25–34	35–44	45–54	55–59	60–64	65+
2003	56.9	78.8	71.7	74.4	71.9	45.4	19.5	2.7
2008	56.3	79.1	73.1	75.6	74.3	49.3	21.2	2.8
2013	55.7	79.2	74.1	76.3	75.9	53.3	23.0	2.8
2016	55.4	79.2	74.5	76.6	76.7	55.6	24.0	2.9

Source: ABS 1999c.

3.6 Discussion

Sociodemographic changes that are likely to impact on informal care in the community over the next decade include:

- absolute growth in the numbers of people with a severe and profound restriction requiring care in the community;
- higher numbers of adult offspring carers relative to the number of older people in need of care due to the progression of baby-boomers to pre-retirement and early retirement stages of life;
- increasing need for care from ex-household family members due to changing patterns of family formation and geographic ageing;
- extended working lives, especially for women, which imply increased pressure on many carers at an emotionally vulnerable stage of life;
- older, more dependent care recipients and older primary carers.

While about 65% of people in the community who need a high level of assistance because of severe or profound restriction are aged under 65 years, a substantial increase in the number of older people as a result of ageing baby-boomers, coupled with the higher prevalence of severe and profound restriction at older ages, means that the need for informal care will rise rapidly over the next two decades. The increasing prevalence of dementia in an ageing population will create pressure on institutional care, with likely flow-on effects for informal care in the community. Thus, demand for informal care is likely to increase both in terms of the size of the household population needing assistance and the intensity of caring that is required to support more highly dependent people. The circumstances of older carers will continue to be a concern in this context. In 1998, 96,700 primary carers were aged 65 years and over, including 8,900 parents and 72,400 spouses (AIHW 2000:182).

Female labour force participation is predicted to increase in the pre-retirement age groups, as a result of both the expectations of women and changes to superannuation legislation. However, a high proportion of older employed women work part-time. Australian data are consistent with findings in the United States and Europe. Doty, Jackson and Crown (1998) suggest that part-time work can be a successful strategy for combining a primary caring role with paid employment. In this study, care recipients with three or more impairments in the activities of daily living who had an employed primary carer were found not to be disadvantaged in the amount of caring time per week because, on average, they receive more hours of paid help. The authors propose a non-linear relationship between primary carer hours of paid employment and total hours of care provided to a care recipient. According to their model, hours of care, from an employed primary carer and all other sources combined, increase to a 'pivotal point' of approximately 18 hours per week of primary carer employment time and then decrease as hours of employment increase beyond 18 hours. Reflected in this result is the theory that paid employment protects primary carers against the adverse effects of engulfment in the caring role.

Edelbrock et al. (2003) reported that employed Australian primary carers also substitute formal services for informal care. If working carers have access to flexible working conditions and a range of affordable formal assistance, there is little reason to believe that increased labour force participation among older working women poses a threat to people's willingness to take a lead role in providing and coordinating care. It is perhaps more likely that employed carers retain overall responsibility for the bulk of direct care as well as care planning and decision making for their family member while contracting to formal services

for the necessary substitute or supplementary services. Chapter 4 presents the results of an analysis that examines the sensitivity of future numbers of primary carers to a global change in women's willingness to reduce paid employment for unpaid caring work. The hypothesised rate of increased female labour force participation appears to have less of an impact on the future availability of primary carers than many commentators have predicted. In the longer term, female labour force participation may be a factor in the future availability of carers only insofar as it manifests women's changing role perceptions.

Smaller families, changing attitudes of younger women towards caring, and sustained or increasing rates of relationship breakdown could signal a lower ratio of potential carers to those in need of ongoing assistance by the time younger baby boomers are themselves older Australians. A key question is whether younger working women whose lives have been shaped by the expectation of gender equity will assume prime responsibility for unpaid caring work.