

Carers in Australia

**Assisting frail older people and people
with a disability**

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Carers in Australia

**Assisting frail older people and people
with a disability**

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Preface

This report is a joint initiative of the Australian Institute of Health and Welfare (AIHW) and the Australian Government Department of Health and Ageing. It was principally authored by Cathy Hales, with significant contributions from Diane Gibson, Frieda Rowland, Paula Laws and Anne Jenkins.

The motivation for an exposition on carers in Australia came from an AIHW project that analysed the likely impact of social trends on future numbers of primary carers (Jenkins et al. 2003). Building on this earlier work, the present report uses data from the 1998 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers to present a picture of informal care in contemporary Australia – who are the primary carers, who do they assist, and what does caring involve? It explores the impact of caring work and patterns of formal service use with informal care.

The findings of this report are based on national data that were 5 years old at the time of writing. However, results from the survey are in close agreement with smaller scale Australian studies and international research on carers and caring. Differences in methodology between the 1998 survey and earlier ABS surveys render time series analysis problematic. Analysis of the data from the 2003 ABS Survey of Disability, Ageing and Carers, due for release in late 2004, will provide a basis for comparison with the projections contained in this report.

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
CACP	Community Aged Care Packages
CSTDA	Commonwealth State/Territory Disability Agreement
EACH	Extended Aged Care at Home
HACC	Home and Community Care
OECD	Organisation for Economic Co-operation and Development
*	Estimate has an associated relative standard error of between 25% and 50% and should be interpreted with caution.
**	Estimate has an associated relative standard error of 50% or more and should be interpreted with caution.

Summary

Broadly speaking, primary carers are the main source of ongoing assistance to people in the community who are unable to adequately care for themselves because of a severe or profound restriction in performing core activities of daily living. This level of activity restriction can be associated with early- and late-onset disability and/or age-related frailty. The assistance received from a primary carer helps many such people to avoid or delay long-term care in an institutional setting. To exercise a preference to stay at home, most people who need assistance rely heavily on family and friends. To describe this type of care as 'informal' is somewhat of a misnomer as there is nothing casual about taking primary responsibility for another person's welfare. Rather, the term 'informal care' is used to reflect the fact that the care is provided according to the dictionary definition 'without ceremony'. It is not arranged or regulated in any formal sense by government, non-government or volunteer organisations. While informal care can be interpreted 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.

In 1998, only 3% of people who reported an ongoing need for assistance with core daily activities of self-care, mobility and communication relied solely on formal services. The vast majority received assistance from both unpaid carers and formal services. Recent years have seen a number of policy initiatives to support the pivotal role of family carers in Australia's welfare system. To quote the 1996 Respite Review Report

Carers have played, and always will play, a significant role in community care...the achievement of government policy objectives in aged and community care rests on the extent to which the relationship between the carer and the person cared for can be sustained without unacceptable costs to either (DHFS 1996).

Main findings

Who are the *primary carers*?

1. Primary carers are people who mostly care for a person with a severe level of disability. Consistent with earlier ABS surveys, the 1998 Survey of Disability, Ageing and Carers revealed that caring for a person with a severe or profound core activity restriction (hereafter abbreviated to severe or profound restriction) in a community setting is a predominantly female occupation. Men and women are more equally represented among carers of people with any level of disability (estimated at 2.5 million carers in 2002), than among primary carers (estimated at 490,700 primary carers in 2002). In 1998, 70% of primary carers were women.
2. In terms of relationship, 43% of primary carers aged 10 years or over in 1998 were caring for a spouse or partner; 25% were caring for a parent; and 21% were parents caring for a son or daughter with a disability. The remaining 11% of primary carers were other relatives or friends. Over 50% of primary carers in 1998 cited family responsibility as a reason for taking on the caring role. A similar proportion of partner and parent carers said that they could offer the best available care for their family member, confirming a widespread preference for care in the community.

3. Overall, 79% of primary carers in 1998 lived with their care recipient; the rate of co-residency among primary carers of people aged 65 years or over is somewhat lower (62%).

Demands and consequences of caring work

4. Over one-half of primary carers spend 20 or more hours per week in the caring role and over one-third spend 40 or more hours per week on unpaid caring work. 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.
5. Detailed data collected by the ABS on co-resident primary carers in 1998 revealed that 60% of care recipients always needed assistance with between one and four activities of daily living and a further 24% always needed assistance with between five and nine activities of daily living. Among young care recipients with a co-resident carer, intellectual and developmental disorders were the most common main disabling conditions. Physical conditions including impaired use of feet or legs, recurring pain or discomfort and restriction in physical activities or work were the more common disabling conditions among older care recipients with a co-resident carer. Growing numbers of frail aged care recipients over the coming decades highlight the importance of training in manual handling procedures for carers and access to mobility and bathroom aids.
6. The intensity of a caring role is reflected in substantially lower labour force participation among working-age carers compared to non-carers of the same age. Not surprisingly, there is evidence of an inverse relationship between primary carer labour force participation and weekly hours of caring work.
7. Negative consequences of a primary caring role reported by primary carers in 1998 include reduced hours of paid employment and resignation from positions of employment (21% and 11% respectively of primary carers aged 15–64), lower overall life satisfaction and a reduced feeling of wellbeing, and increased feelings of fatigue and depression.

The changing context of informal care

8. Structural and numerical ageing of the population signals higher demand for primary carers and heightens concern about the circumstances of a growing number of older carers. 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 activity 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 (an increase of 77,700 persons aged 45–64 years and 96,400 persons aged 85 years or over). In 1998, 21% of primary carers were aged 65 years or over and 9% of all primary carers suffered a severe or profound restriction in the activities of self-care, communication, or mobility. Among primary carers aged 45–64 years in 1998, 28,700 were parents caring for a son or daughter with a disability. Becoming unable to care can cause significant anxiety and practical difficulties for older carers in particular.
9. High growth in the number of people aged 45–64 years over the next 10 years – the baby-boomer generation – offers the potential of increased numbers of family carers for

community-dwelling older people. Historically, primary carers in this age group have been mostly a spouse or partner (41%) or a child (34%) of their main care recipient (ABS 1999a). Future provision of informal care to people aged 45 to 64 years, in particular, could prove vulnerable to higher rates of relationship breakdown than has been evident in previous generations.

Impact of social trends on the need for and availability of primary carers

10. Based on 1998 age- and sex-specific rates of severe and profound core activity restriction, the number of people aged 10 years or over in need of ongoing assistance with the core daily activities of self-care, mobility and communication is projected to increase by approximately 257,100 persons (22%) between 2003 and 2013 (Table 3.1).
11. A baseline scenario posited in this report assumes that 1998 levels of permanent cared accommodation and proportions of primary carers by age, sex, living arrangement category and labour force participation category prevail to 2013. Assuming all other factors are held constant, in 2013 the ratio of primary carers to the population in need of assistance from a primary carer will have declined from the ratio observed in 1998. This is despite a marked increase in the absolute number of primary carers (from 450,900 in 1998 to a projected 573,900 in 2013; Table 4.11). Thus the baseline scenario produces a care ratio that declines from 43 primary carers per 100 persons with a severe or profound restriction in 1998 to around 40 primary carers per 100 persons with a severe or profound restriction in 2013.
12. Conceivably, the projected increase in the household population with a severe or profound restriction will draw a proportionate response, rendering 1998 age- and sex-specific carer rates less relevant. No attempt has been made to model this possibility owing to the difficulty in estimating how demand-led supply might change over the next decade.
13. A 10% to 30% decrease in the proportion of women aged 25 to 59 years who are willing to reduce paid employment to take on a role as primary carer over the 15-year projection period from 1998 to 2013 is unlikely to have a marked impact on the availability of primary carers to 2013. Effectively, the outcome of a 20% decrease in the willingness of women to substitute time spent providing unpaid care for time in paid employment would be the same as if 1998 carer rates are sustained throughout the period. This is projected to produce around 40 primary carers per 100 persons with a severe or profound restriction in core activities by 2013, down from 43 per 100 in 1998. Such a result is driven by high growth in the age groups from which large numbers of primary carers are traditionally sourced. Baby-boomers who survive the projection period will age from between 37 and 51 years in 1998 to between 52 and 66 years in 2013. In 1998, women aged between 35 and 64 accounted for 65% of all female primary carers (ABS 1999a: Table 28). Growth in these traditional primary carer age groups drives increases in the number of primary carers over the next 10 years. This high growth counteracts the effect of a moderate reduction in the proportion of working-age women who are willing to reduce paid work to care compared with the situation in 1998.
14. Most of the increase in female labour force participation since the 1970s has been in part-time employment (ABS 2003). Studies of the relationship between hours of employment and hours of unpaid caring performed by female primary carers have shown that part-time work and substitution of formal assistance for reduced hours of informal care is a successful strategy for many employed primary carers. Flexible working hours, access to a range of affordable formal support services and being able to share the load with other

family members will prove to be the key to women continuing in their caring roles and offer potential for more working men to accept a higher profile in family caring activity.

15. An increase in the proportion of older spouse and partner carers in the order of 20% by 2013 could offset projected growth in the number of people with a severe or profound activity restriction to maintain the 1998 situation of 43 primary carers per 100 persons with a severe or profound restriction. This scenario projection assumes that at least one partner in most intact older couple relationships is both well enough and competent to care for the other should the need arise.
16. Results of the 1998 ABS survey revealed that a sense of being able to provide the best possible care and family obligation underpinned many people's decision to take on a primary caring role. Thus, factors that are most likely to reduce demand-led supply would appear to include increasing rates of relationship breakdown, estrangement of parents from adult children, reduced family formation among young adults and widespread altered role perceptions among women – the traditional carers. A 64% increase in lone person households over the past 12 years and predictions that this trend is set to continue offers some evidence that these factors are indeed having an impact on Australian society (ABS 2003). If such factors contrived to effect a 20% decline in the proportion of primary carers by age, sex, labour force participation category (for the working age population) and living arrangement category (for the older population) over the next decade, there will be a substantial shortfall in the number of primary carers relative to 1998. According to a scenario projection in this report, there would then be around 32 primary carers per 100 persons with a severe or profound activity restriction in 2013, compared to 43 carers per 100 persons with a severe or profound activity restriction in 1998.
17. Lower ratios of primary carers to persons with a severe or profound restriction do not necessarily signal higher numbers of people with unmet need for assistance because affordable, accessible formal services can substitute for a primary carer. Moreover, in 1998, one in five primary carers cared for more than one person in need of ongoing assistance, so that a ratio of the number of primary carers to persons with a severe or profound restriction underestimates the number of people receiving assistance from a primary carer. By definition, primary carers provide assistance to a highly dependent group of care recipients. Less intense care from a wider network of carers could be problematic for people who require constant supervision and assistance with core daily activities. Given the intensity of caring work performed by primary carers in 1998, considerable resources from wider social networks and formal services would be required to compensate for a lower ratio of primary carers to persons in need of assistance.

Interplay of informal care and use of formal services

18. According to the 1998 ABS survey, 46% of people with a severe or profound restriction received assistance only from family and/or friends, 48% received assistance from family and friends supplemented by formal services and 3% received assistance only from formal services (3% of people with severe or profound activity restriction reported that they received no assistance). These figures underscore the importance of family carers as the main providers of welfare assistance and highlight the interplay of formal services and informal care in the community care model.
19. A cross-sectional comparison of the use of formal services measured in the 2002 census of Community Aged Care Packages (AIHW 2004a) revealed that a similar proportion of

clients aged 65 years and over with a primary carer to those without a primary carer made use of most available services. Most clients used domestic assistance services irrespective of primary carer availability, and the proportion of clients who used this type of service was consistent across age groups 65–74, 75–84 and 85 years or over. A higher proportion of clients with a carer used personal care services (59% versus 49% of clients without a carer). This result supports a finding from the national Aged Care Assessment Program (LGC 2002:55) that people with high levels of dependency in core daily activities are more commonly able to remain in their homes if they have a primary carer.

At least one in two clients used food services (delivered meals and/or meal preparation), irrespective of carer availability, and use of these services was more common among older clients. A higher proportion of the older clients (75 years or over) without a carer used social support services than clients with a carer in the same age group. It has been observed in the Aged Care Assessment Program that Aged Care Assessment Team recommendations for low-level residential care for people who live alone are often based on psychosocial needs as much as functional dependency; living with others helps people to remain in the community until they require high-level care (LGC 2002:55).

20. Limited data were available for an examination of the interplay between formal and informal care in this report. Recent developments in the Commonwealth State/Territory Disability Agreement and Home and Community Care data collections will facilitate this type of analysis in the future to determine if similar patterns of service utilisation hold for the wider population of people with an unpaid primary carer, including younger people with a disability.

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.

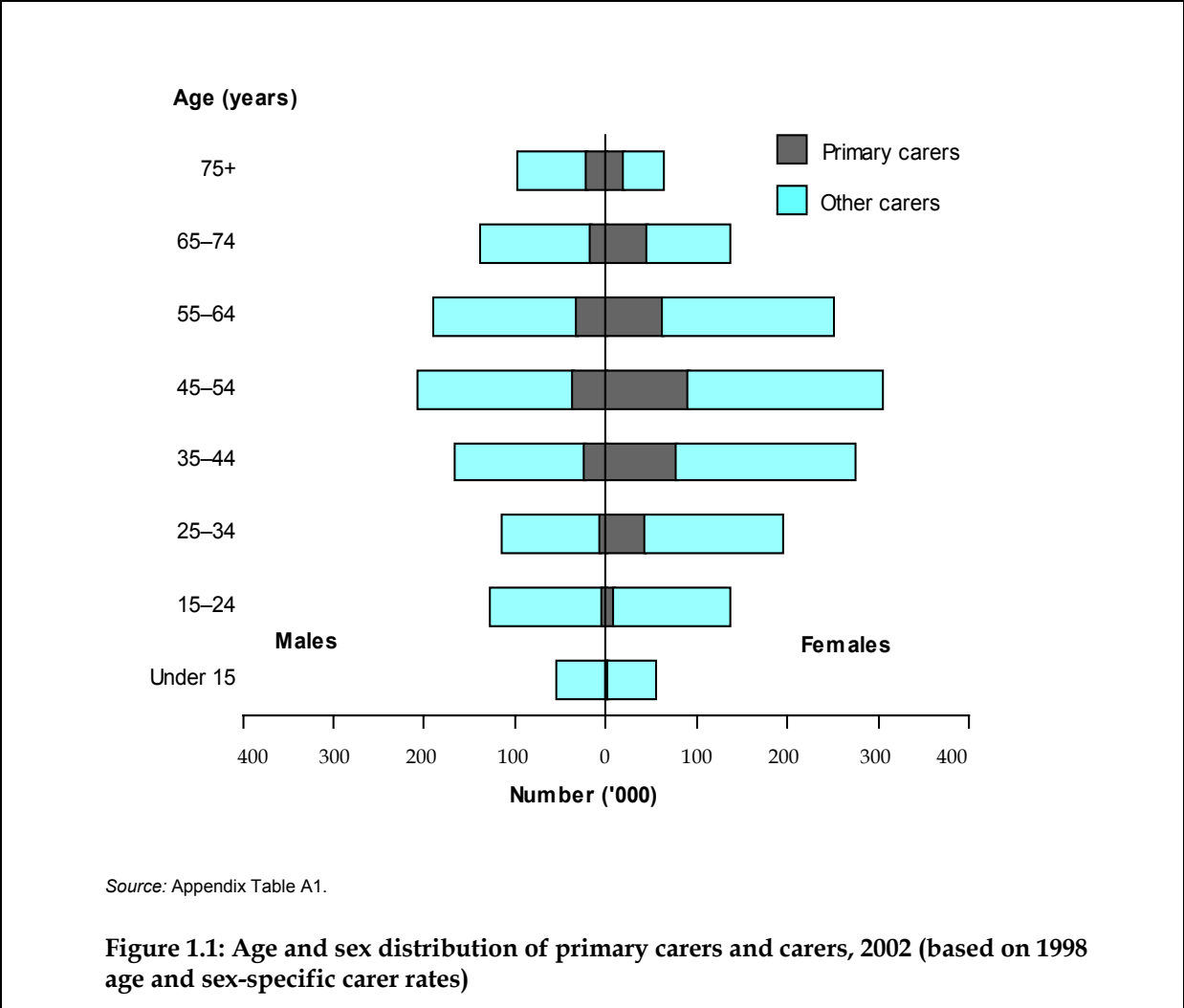


Table 1.1: Co-resident and non-resident primary carers 15 years and over ('000)^(a), age of primary carer by age of main care recipient^(b), 1998

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%).

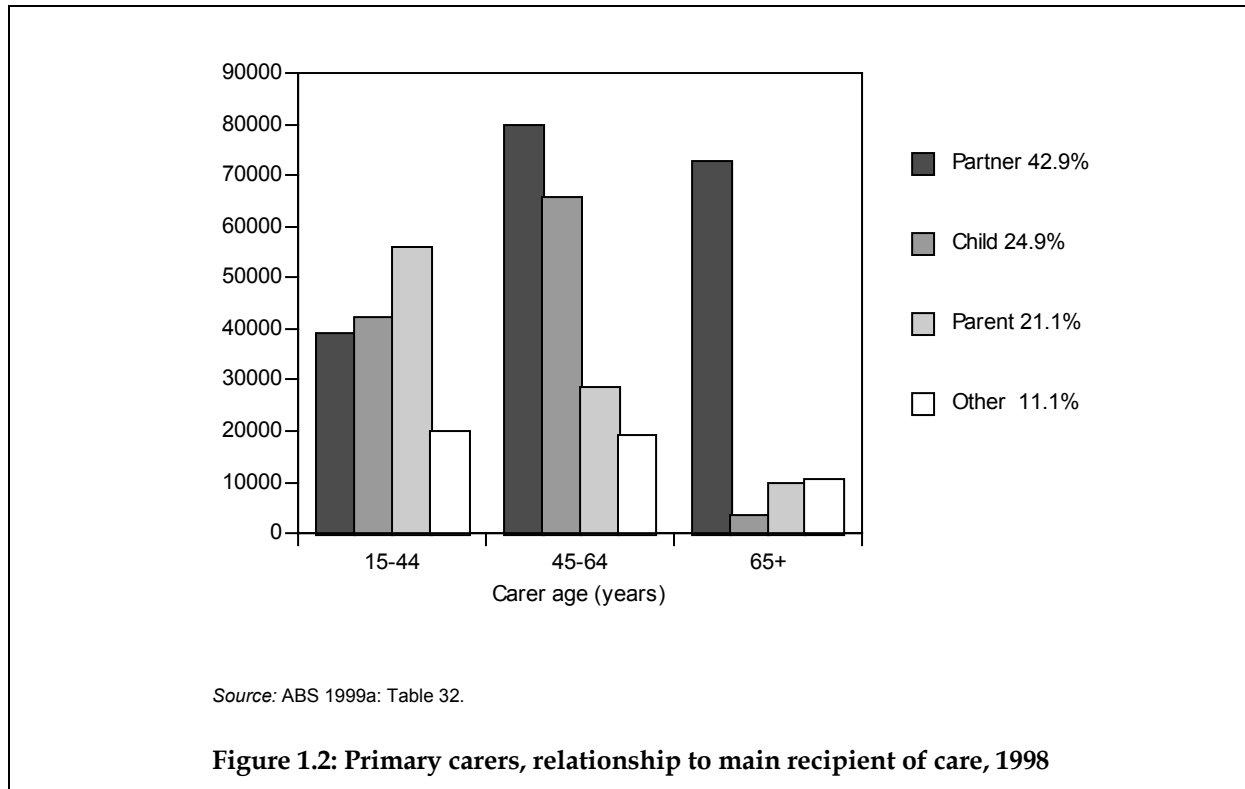


Table 1.3: Primary carer relationship to main recipient of care by sex, 1998

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.

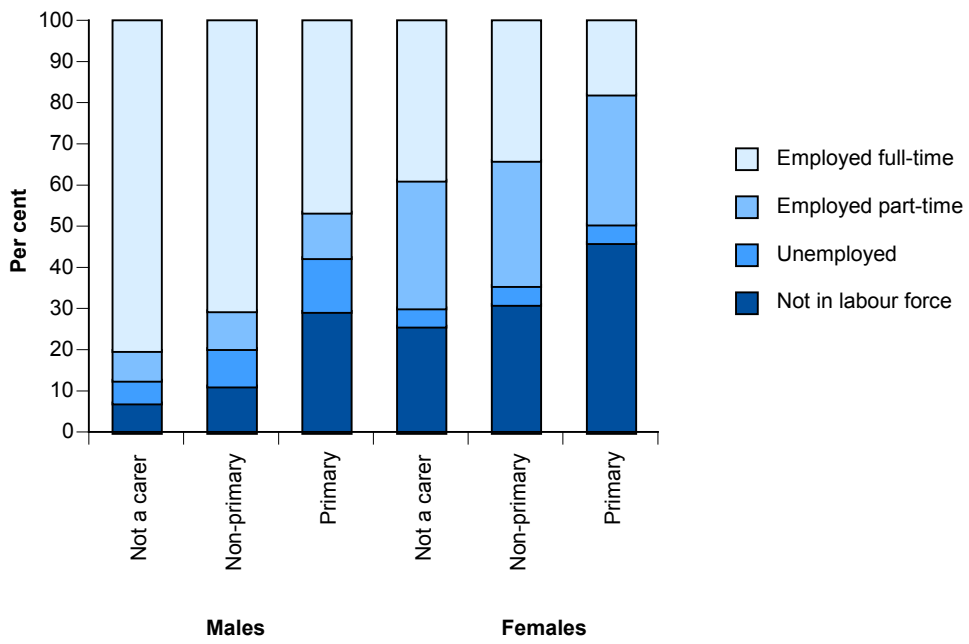
Combining a caring role with paid employment

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.

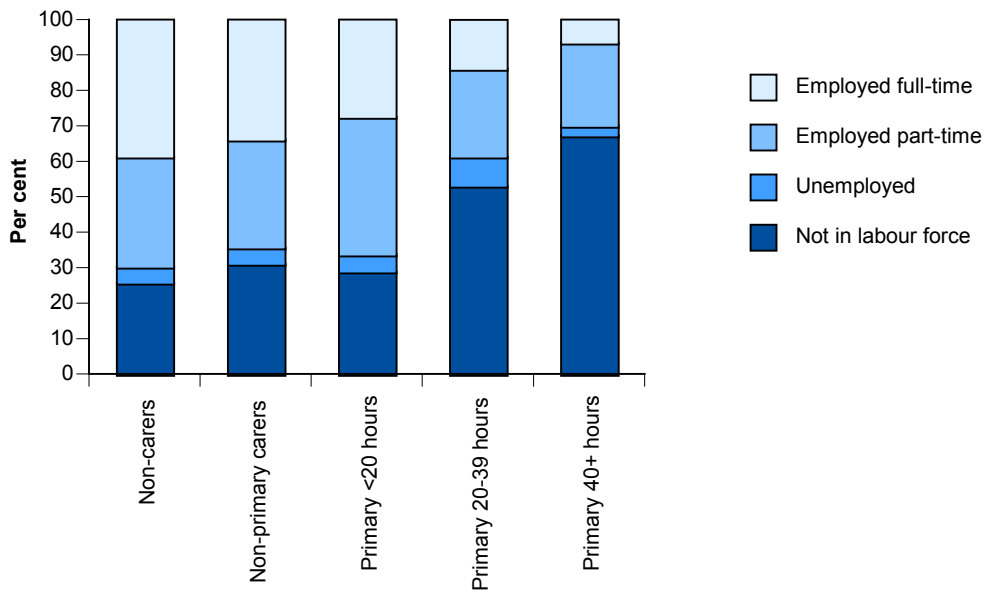
Paid employment is reported to have protective effects for carers by offering respite from the caring role and helping to maintain social networks (Schofield et al. 1997a; Spiess & Schneider 2003; Doty, Jackson & Crown 1998; Turvey & Thomson 1996). Schofield et al. (1998a) identified caring and not having 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

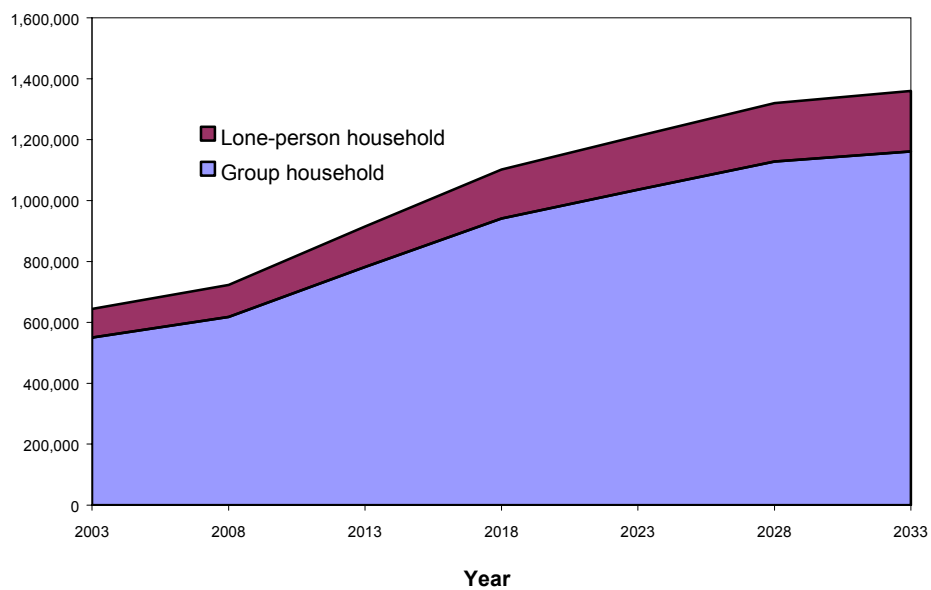
Living alone does not necessarily imply more limited access to informal care. In 1998, 20% of primary carers were providing assistance to a person in another household. However, there is reason to suspect that a 64% increase in the number of people living alone over the past 12 years signals changes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

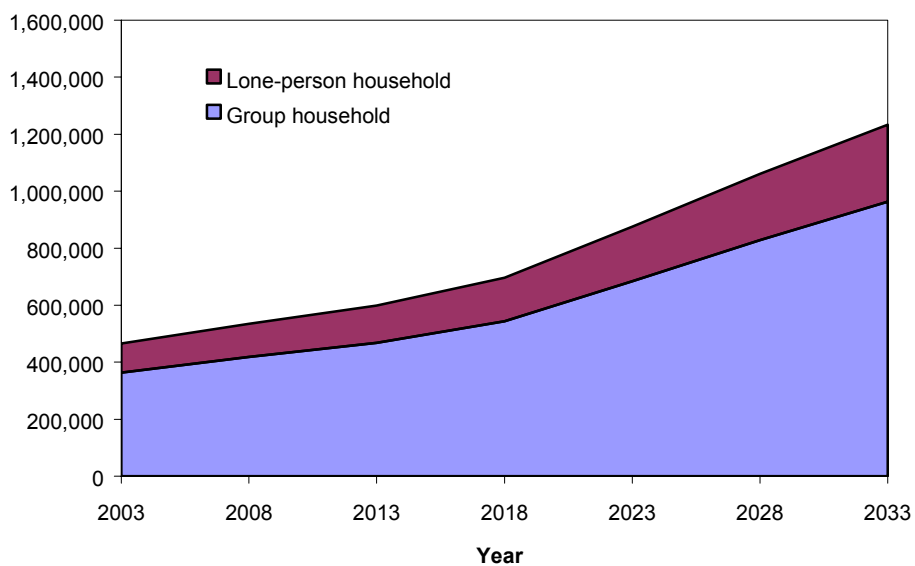
The living arrangements of older people in the community will also impact on the ratio of co-resident (mainly spouses) to ex-household (mainly adult offspring) primary carers of people aged 65 years and over. Among usual residents of private dwellings in 2001, 70% of people aged 65 years or older lived 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).



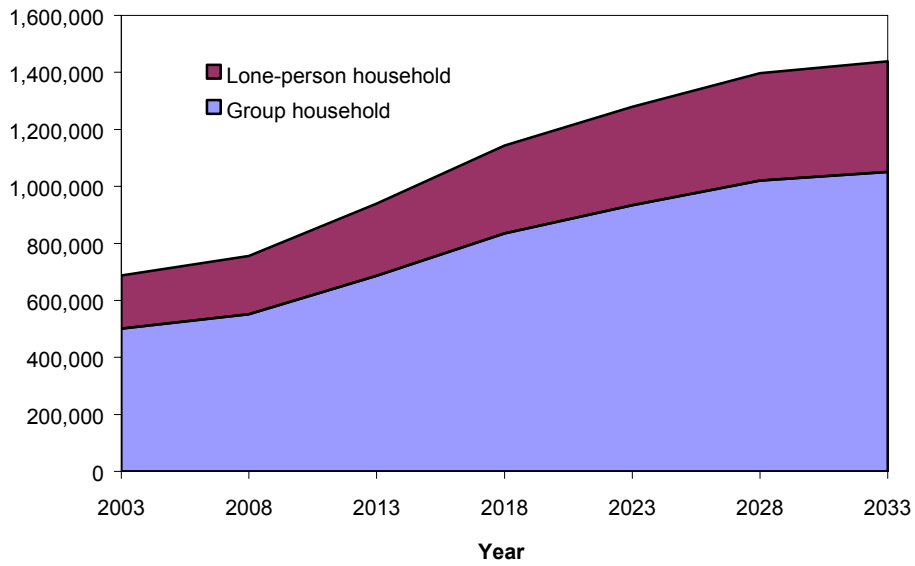
Source: AIHW analysis of ABS 2001b:Table 14.

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



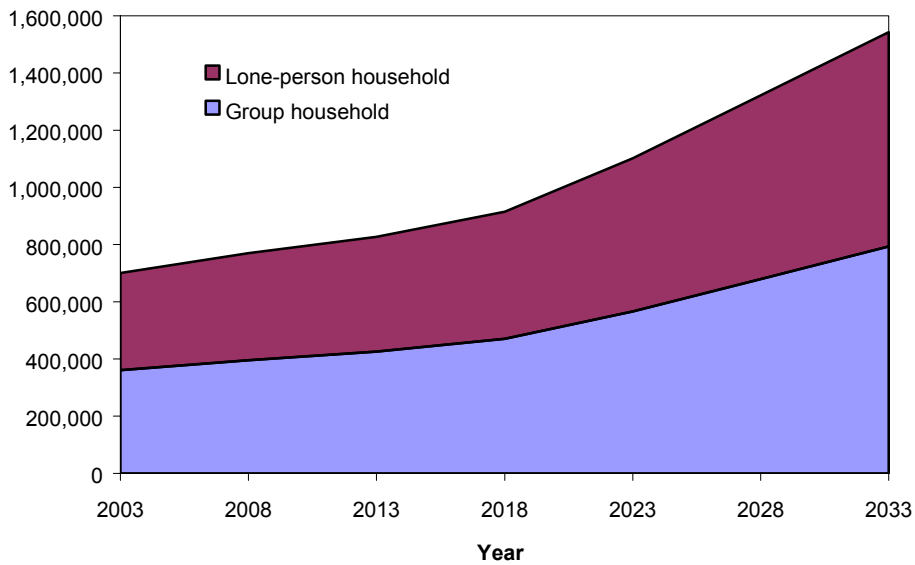
Source: AIHW analysis of ABS 2001b:Table 14

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.

4 Scenario projections 2003–2013

4.1 Background

A review of United Kingdom literature by Pickard et al. (2000) identified a number of reasons for anticipating a potential decline in the availability of informal care. These include the social changes touched on in Chapter 3, such as the changing structure of the population, rising childlessness, decline in family size, changing living arrangements, shifts in the perceptions of family obligation and commitment, rising divorce rates and rising female employment rates. Many of these trends are evident in the Australian context however; characteristics of the Australian situation compared to that of other developed nations offer greater optimism. Although fertility rates are currently declining, the impact of fewer children per family on informal care capacity may not be seen until the baby-boomers replace their parents at the top of the population pyramid around 2040. In Australia, the post-Second World War 'baby boom' was notably later and longer than many other countries, thus delaying this decline in family size. The 1990–91 Mid Term Review of the Aged Care Reform Strategy concluded that this factor and sustained immigration would contribute to continued growth in the availability of potential carers for some three decades (DHHCS 1991:13).

There remains some evidence of a decreasing rate of informal care, at least in terms of the number of primary carers. Population estimates for the number of carers in Australia were obtained from national surveys conducted in 1993 and 1998 by the ABS. Changes in the methodology for the identification of carers who lived with their care recipients cast some doubt on the validity of comparing the results for these two surveys. Nevertheless, there was a small decrease over time in the number of carers reported in the two surveys and this decrease was more marked among non-resident carers (for whom the methodology did not change) than among co-resident carers.

While hypotheses about the future availability of carers abound, there is inadequate quantitative information on which to make an informed judgment. This chapter presents the results of an AIHW analysis designed to isolate the impact of certain factors on future numbers of primary carers (Jenkins et al. 2003). The analysis did not aim to forecast the future supply of informal care based on the likely effects of a complex milieu of relevant variables, nor was it designed to resolve the debate around the influence of the range of social changes on future carer availability. Its main contribution is to quantify the potential impact of particular social changes should they occur in the context of current demographic trends and under a set of reasonable assumptions. In particular, the project explored the consequences of:

- a continuation of the 'status quo', incorporating demographic and labour market participation trends that were discernible in 1998
- an overall decline in the willingness to care among men and women of all ages
- a decrease in the number of carers that could result from a reduced willingness of women to reduce their hours of paid employment to take on a caring role
- an increase in the number of carers that could result from higher numbers of co-resident spouses and partners.

The projections serve to illustrate future situations that could occur if certain assumptions apply over the projection period (from the observed situation in 1998 to 2003, 2008, and 2013). The scenarios include a future 'baseline propensity to care' scenario, which is calculated as the estimated number of carers that will be available given population growth and projected changes in the population composition with respect to changing labour force participation trends in the working-age population and changing patterns of living arrangement in the older population (presence of a spouse or partner). Baseline carer rates, are, therefore, the proportions of primary carers observed in 1998 for each age group by sex, labour force participation category for the working-age population, and living arrangement category for the population aged 60 years and over. Projections of carer numbers under this scenario are driven by projected changes in the age and sex composition of the population, and projected changes in living arrangement at older ages and workforce participation in the working-age population throughout the projection period. The 'baseline propensity to care' scenario, using 1998 rates, is not necessarily intended to represent the most likely outcome. Rather, it provides a point of reference if current patterns continue and against which the effects of other changes can be compared.

4.2 Approach

Supply and demand based projections

Pickard et al. (2000) notes that two approaches to projecting future levels of informal care dominate the fairly small base of quantitative research in this field. Both have their origins in economic models. In one approach, projections of informal care are demand-led, insofar as the need for care drives the projections of the informal care that is required. In the other approach, projections of informal care are supply-led, in that projections of informal care are determined by how much will be supplied. It is the supply side issues, in terms of the likely future availability of carers, which are of most concern for long-term care planning.

To propose that the supply of informal care bears little relation to the demand for care would be to take an extreme theoretical position. This would imply that the drivers of social change will act to reduce the number of carers regardless of the growing needs of those affected by disability or illness. Nevertheless, it has been observed that many people with considerable care needs do not have a primary carer. In 1998, an estimated 1 million people experienced a severe or profound restriction and the ABS survey estimated approximately 450,900 primary carers, 20% of whom provided assistance to more than one person. However, Chapter 5 highlights the fact that carers, including primary carers, supported approximately 94% of people with a severe or profound restriction. Clearly, the relationship between the need for assistance and availability of informal care is complex and multifaceted. Informal care is sourced from social networks that might or might not include a primary carer. Moreover, informal care can be provided at differing levels depending on the type of help required. For example, Parker and Lawton (1994) observed that help with personal or physical tasks is more likely to come from within the household. The extent to which self-reported receipt of assistance might underestimate the need for assistance, simply because the help received is integral to interpersonal relationships and long-term living arrangements, is unknown.

It is beyond the scope of this report to resolve the debate surrounding the nature of the relationship between the need for, and availability of, informal care. However, some observations about how demand might alter over the projection period and assumptions

about how this may affect supply are warranted. The projections of the supply of informal care in the future that are presented in this chapter are based on the number of people responding to the care needs of others by acting in a primary care role in 1998, with future projections based on specified changes in certain variables. Thus, the projections are based on conditions and characteristics that have resulted in the population of carers evident in 1998, including the prevalence of disability. In assuming that disability prevalence remains constant over the next decade, a key factor that could in reality influence supply is held constant in the scenarios presented here.

Projection methodology

It would be optimal to base projections of the future availability of carers on the findings of a time series analysis. Using time series data, the trend observed over a previous period is extrapolated over a future period, taking into account change in other variables. Three techniques based on this methodology were considered: macrosimulation, dynamic microsimulation or the propensity method⁴. In each case, however, insufficient or inadequate data were available to support the use of the technique.

Although carers in the 1993 and 1998 ABS surveys are conceptually the same, the methods used to collect the data were different. The same method was used to identify people who cared for someone outside the household but different methods were involved in identifying carers who cared for someone within the household. In 1998, any responsible adult in the household was asked if there was a carer living in the household. If a carer was identified, he or she was asked a series of questions to determine if they cared for someone inside or outside the household. This method was used in 1993 to identify carers in the household who were caring for someone outside the household. To identify co-resident carers, however, any responsible adult was asked if there was someone with a disability in the household and, if so, the person with the disability was asked a series of questions to identify their carer. If the person identified was another member of the household, then that person was interviewed to determine if he or she was indeed a primary carer.

This difference in survey methodology makes the carer populations measured in 1993 and 1998 incomparable. Further, the 1993 survey resulted in a very small number of carers aged 70 and over and a high number of employed male carers, both of which were considered to be unrepresentative of the carer population. Of the two, the 1998 survey is considered to have generated more reliable estimates of the age distribution of carers and the proportion of employed males who are carers.

The significantly different carer distributions in 1993 and 1998 and the unreliable components of the 1993 survey data mean that projection methods based on time series data cannot be used. A scenarios approach was therefore adopted to overcome data limitations and produce a number of projections based on different assumptions.

The scenarios approach

This chapter looks at alternative scenarios of the availability of primary carers in 2003, 2008 and 2013. The basis for the projections are the findings of the 1998 ABS Disability, Ageing and Carers Survey, specifically, the estimated carer rates that it generated. Carer rates refer

4 See glossary for brief descriptions of these projection techniques.

to the number of carers per 1,000 population in a specific category, such as the number of male carers per 1,000 males aged 60 to 64 years who are living with a spouse or partner. In using a scenarios approach, carer rates were applied to projected populations for 2003, 2008 and 2013. Projected populations take into account the changing age and sex distribution of the population and any other variable that is to stratify the population figures. Carer rates and population projections must be available for the same population subgroups because the projections are calculated by multiplying the matrix of population projections by a corresponding matrix of carer rates. Hence, the level of detail that can be incorporated into the projections depends on the availability of population projections at that level of detail that can be used to derive appropriate carer rates.

While it is not difficult to obtain carer rates and population projections for the same groupings of age and sex, for other variables of interest the methodology becomes more complex. For the specific questions that were addressed in this analysis, carer rates and population projections were required to be further broken down by labour force status, and living arrangement. A limitation of very detailed breakdown is that small estimates from the ABS Survey of Disability, Ageing and Carers are subject to high sampling error. To overcome this problem, carer rates for some groups (particularly in relation to male carers) were combined for improved reliability.

4.3 Measures and data sources

Carers

The 1998 ABS Survey of Disability, Ageing and Carers collected information about informal assistance provided by carers according to ABS definitions of 'carer' and 'primary carer' (see Box 1.1)⁵. The main differences between a carer and a primary carer are:

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

The projections presented in this chapter relate only to primary carers, since this is the group that provides the most assistance to people with core activity restrictions. Further, information on carers' demographic and labour force characteristics, the care they give, the support they receive, their relationship with the care recipient and the impact of the caring role on their lives is gathered comprehensively for this group and less so, or not at all, for non-primary carers. In this chapter, the terms 'carer', and 'primary carer' are used interchangeably. Scenario projections, therefore, describe possible future outcomes in the size of the same population of carers discussed in chapters 1 and 2.

Carers included in the analysis are those aged 10 years and over. Methodological constraints have precluded the examination of carers aged less than 10 years. However, as the Young Carers Research Project has noted, 'In Australia, young carers have been identified by

5 Further information regarding the methodology used in the Survey of Disability, Ageing and Carers can be obtained from ABS 1999a.

services as being as young as 6 years of age, and just under half of young carers are below 18 years of age' (DFaCS 2002:10).

Age, sex and labour force participation

Population projections by age and sex supplied by the Department of Treasury were used in conjunction with the 1998 ABS survey to project the number of carers in each age group by sex. Labour force projections, also provided by the Department of Treasury and consistent with those used in the Intergenerational Report (Costello 2002) are used in the scenarios for which labour force participation is included as a factor in the projection. These labour force projections assume that past trends of increasing female labour force participation and decreasing male labour force participation will continue but taper off as they approach each other. Age-specific population projections for the working-age population were further broken down into labour force participation categories of employed and unemployed/not in the labour force for males and full-time employed, part-time employed and unemployed/not in the labour force for females. The full-time/part-time separation could not be used for males, due to unstable carer rates in certain age groups within these labour force categories.

The ABS Survey of Disability, Ageing and Carers identifies the labour force status of carers, including whether those who are employed work full-time (35 hours or more per week) or part-time (less than 35 hours per week). For the scenario analysis, it was necessary to define 'working-age', conventionally defined as ages 15–64 years, to be between 25 and 59 years, due to high sampling error in estimated carer rates by labour force participation at younger and older ages.

Living arrangement: co-resident spouse or partner

Population projections by living arrangement category were taken from the ABS household and family projections report and are based on the three previous censuses of population and housing (ABS 1999b). The ABS household and family projections were calculated using the propensity method where an assumed proportional distribution of characteristics is applied to population projections by age and sex. This method assumes that trends over the past three censuses accurately reflect underlying changes in living arrangement characteristics, and that this trend will continue to 2013.

In the ABS household and family projections report, living arrangement combines the concepts of 'relationship in the household', 'family type' and 'household type'. Household types include 'family households', 'group households' and 'lone-person households'. Family types include 'couple family with children', 'couple family without children', 'one-parent family' and 'other families'. For couple families without children, two relationships are defined, which are 'husband, wife or partner' and 'other related individual'. For the purpose of the projections reported here, the family types 'couple family with children' and 'couple family without children' with the relationship 'husband, wife or partner' were the categories of interest. ABS projections for all other living arrangement categories were collapsed into one category, identified as 'Other living arrangement'.

The 1998 ABS survey identifies the relationship of the carer to the care recipient and identifies whether carers are usually living with the main care recipient. The relationship category of 'spouse or partner' is the relationship category of interest, in conjunction with co-

resident status. For compatibility with the ABS living arrangement projection categories, other relationships and living arrangement categories were collapsed into one.

The Treasury population projections do not contain living arrangement data. For each age and sex category of the Treasury population projections, population proportions projected by the ABS to be in each living arrangement were applied.

An additional assumption was of equal numbers of males and females with a spouse or partner. This was necessary, as the projected ABS living arrangement categories do not provide this data by sex. While the number of same-sex partners is considered to be small, accurate estimates are not available for the period of interest. In addition, same-sex couples are not included as spouses and partners in the ABS Survey of Disability, Ageing and Carers.

4.4 Construction of future scenarios

Scenario projections were calculated separately for three broad age groups, 10–24 years, 25–59 years and 60 years or over. In the youngest group, sex is the only factor in the projection model because more detailed projections involving age and labour force participation category would be susceptible to the effects of unreliable carer estimates from the survey data. In the middle age range, projections were made for every combination of age (25–34, 35–44, 45–54 and 55–59 years), sex, and labour force participation category as previously outlined (see 4.3: Age, sex and labour force participation). Therefore, each scenario for this population group automatically incorporates projected changes in the age and sex structure, and changing patterns of labour force participation in the population at these ages. For the older population (60 years or over), presence of a co-resident spouse or partner was considered a more salient factor in determining primary carer availability than labour force participation. Hence, for this group projections were made for every combination of 5-year age group up to 80 years and over, sex, and living arrangement (co-resident spouse/partner or ‘other living arrangement’). Since age, sex and living arrangement form the axes of the projections in the older age group, changing patterns in the age and sex structure of the older population and projected trends in living arrangements are automatically included in the scenario projections.

A ‘baseline propensity to care’ scenario was constructed for each age group, 10–24 years, 25–59 years, and 60 years or over. This scenario applies 1998 carer rates by projection category to the projected population in that category for each of the projection years 2003, 2008 and 2013. In this way, projected population changes with regard to age, sex, labour force participation (at ages 25–59 years) and living arrangement (at ages 60 years and over) drive the baseline projections. The ‘baseline propensity to care’ scenario assumes that the ratio of carers to non-carers in each projection category defined by sex, age group and labour force status or living arrangement, estimated from results of the 1998 ABS Survey of Disability, Ageing and Carers, holds throughout the projection period. This is not presented as necessarily the most likely outcome in informal care, but as a baseline against which to compare projections from other future scenarios.

Scenarios other than the baseline propensity to care scenario were constructed to separately consider questions concerning the willingness of women to reduce hours of paid employment in order to care, an increase in older spouse or partners, and an overall decline in the propensity to provide care. The following projection scenarios present a range of plausible future patterns concerning the availability of carers in each broad age group.

Future scenarios for carers aged 10–24 years

Two scenarios for the 10–24 year age group are common to the other two age groups: the baseline propensity to care scenario and the overall decreasing propensity to care scenario. The results of these two scenarios are combined, as appropriate, with the scenario projections for the 25–59 years and 60 years and over age groups.

Baseline propensity to care scenario

In the baseline scenario, 1998 rates of male and female carers aged 10–24 years were applied to projected populations for this age group. No further breakdown by labour force status or living arrangement was undertaken due to the data limitations discussed above. Projections of carers aged 10–24 years using male and female baseline propensities are compatible with scenarios for the other age groups that assume baseline propensity to care in this younger age group.

Decreasing propensity to care scenario

For the decreasing propensity to care scenario, the rates of carers among males and females in this age group were discounted to achieve a 20% decrease by 2013. This assumption is compatible with the decreasing propensity to care scenario for the 25–59 years and 60 years or over age groups.

Future scenarios for carers aged 25 to 59 years

Factors included in all scenario projections for the 25–59 years age group include age, sex and labour force participation category. Baseline projections for this age group were calculated on the basis of these factors alone. Two other scenarios for this age group describe further assumptions that could impact on the propensity to care in the working-age population, over and above projected population changes with respect to the baseline factors.

Baseline propensity to care scenario

The first scenario for the 25–59 years age group assumes that 1998 patterns of care continue, in relation to each age, sex and labour force participation category in the model. This is the baseline propensity to care scenario, in which the driving forces in the projection model are assumed to be the changing age and sex structure of the population and changing patterns of labour force participation. These include the increasing labour force participation of women that is reflected in the projected population of women in full-time and part-time employment in 2003, 2008 and 2013. According to this scenario, it is assumed that successive cohorts of people aged 25–59 years will respond to the care needs of others by becoming primary carers with the same propensity to care (taking into account age, sex and labour force status) in the future as they did in 1998. This scenario of ‘baseline propensity to care’ is used as a baseline against which other scenarios will be compared for the younger carers. The scenario is not necessarily proposed as the most likely outcome but rather as a starting point from which the effect of other changes can be assessed.

Women's career preference scenario

A second scenario assumes that, over the projection period, 20% fewer women in this age group relative to the proportion in 1998 will be prepared to leave work or reduce the number of hours of employment in order to undertake primary carer responsibilities. In 1998, an estimated 22,800 (7%) female primary carers had reduced the number of hours of paid employment, or resigned from a paid position, in order to provide care. According to this scenario this proportion will reduce linearly over the 15-year projection period by up to 20% in 2013. The 1998 patterns of care (baseline propensity scenarios) are assumed to continue, in relation to each age, sex and labour force participation category for all other groups including the 10-to 24-years age group, men aged 25-59 years, and the 60 years and over age group. While the proportion of 20% is chosen arbitrarily, it demonstrates the impact on the supply of carers if there is a significant decrease in the willingness of women to leave work or decrease their work hours to take on the caring role.

Decreased propensity to care scenario

The third scenario assumes a linear decrease of up to 20% by 2013 in the proportion of people aged 25-59 years who are carers in each age group within this range, and across sex and labour force participation categories. While it is not possible currently to quantify the change in the availability of carers that has been occurring over time, there is some indication that the direction of the trend may be towards a decline, at least among non-co-resident carers. This scenario projects the number of carers in future years given what might be considered a pessimistic outlook in which there is an overall decline in willingness or ability to care. The proportion of 20% has been selected to reflect this outlook while remaining within the bounds of what might reasonably be expected given current knowledge.

Future scenarios for carers aged 60 and over

Scenarios for future availability of primary carers aged 60 years or over all recognise age, sex and the availability of a co-resident spouse or partner as the main factors in the projections. Labour force status is not explicitly modelled in the scenarios for older carers.

Baseline propensity to care scenario

The baseline scenario for older carers assumes that 1998 patterns of care continue in relation to each age, sex and living arrangement category in the model and so constitutes the 'baseline propensity to care' scenario for older people. The driving forces in the projection model are the changing age and sex structure of the population in this age group, and changing patterns of living arrangement in terms of the presence of a co-resident spouse or partner.

According to this scenario, it is assumed that successive cohorts of people aged 60 years or over will respond to the care needs of others by becoming primary carers in the same proportions (according to age, sex and living arrangement) in the future as they did in 1998. This scenario is not necessarily proposed as the most likely outcome but a baseline against which other scenarios for this older age group can be compared.

Converging life expectancies scenario

The second scenario for the older population assumes linear increase of up to 20% in the proportion of spouse or partner carers over the 15-year period as a result of improving male longevity. Although 20% is chosen arbitrarily, it demonstrates the impact on the supply of carers if there is a significant increase in the proportion of co-resident spouse or partner carers. This increase is a plausible scenario in future years given increases in healthy life expectancy and the consequent probability that more spouses or partners will be available to care for people with a severe or profound restriction. It was assumed that 1998 patterns of care continue in relation to age and sex for older people who are not living with a spouse or partner. The scenario takes into account projected demographic changes in age, sex and living arrangement which are incorporated in the underlying population projections.

Decreasing propensity to care scenario

The final scenario for the future of caring in the older population assumes a linear decrease of up to 20% over the projection period in the proportion of older carers across all age, sex and living arrangement categories, taking into account projected demographic changes in these categories. As mentioned in relation to the decreased propensity to care scenario for the 25–59 years age group, it is not currently possible to quantify the trend over time in relation to carer availability but there is some indication of a decline, at least among non-co-resident carers. This scenario replicates the decreasing propensity to care scenarios for the 10–24 and 25–59 years age groups, as it examines carer availability under the assumption that the proportion of older carers decreases to a notable degree over time.

4.5 Outline of the projection analysis

This section presents the projection results for each scenario. Some results from the 1998 ABS survey that are particularly relevant in this context are presented first, including the population estimates for the variables of age, sex, living arrangement (co-resident spouse or partners) and labour force status. This is followed by the presentation and discussion of future scenarios of informal care for 2003, 2008 and 2013. This section is divided into three parts corresponding to the following age groups:

- carers aged 10–24 years
- carers aged 25–59 years, where labour force participation is used, in conjunction with age and sex, to drive the model
- carers aged 60 years and over, where living arrangement, again in conjunction with age and sex, is employed as the basis for the projection.

The full set of tables for the scenarios, by age and sex, are contained in an AIHW information paper (Jenkins et al. 2003).

4.6 Informal care in 1998

Chapter 1 presented a demographic profile of the 450,900 primary carers in 1998. This population forms the baseline for comparison of each of the projection scenarios. To recap on the main points, the 1998 ABS Survey of Disability, Ageing and Carers revealed that 70% of primary carers were women and an estimated 79% of all primary carers lived with the main

recipient of care. An estimated 301,700 primary carers (67%) were aged between 25 and 59 years and another 132,800 carers were aged 60 years or over (29%). Male carers had an older age structure than female carers, with 59% of male carers aged 25–59 years and 36% aged 60 years or over, compared to 70% and 27% of female carers respectively. Eighty per cent of parents who were carers for their child lived with that child. Carers who were children, students or siblings all lived with the recipient of their care. Carers who cared for friends were less likely to live with the care recipient (19%). These trends were similar for both sexes (Table A6).

It is recognised that it would be desirable to project carer availability by carer relationship to the recipient and whether the recipient lives with the carer. This is not possible due to small estimates for carers not living with the recipient and the problem of finding an appropriate base for a carer rate when the caring population is split by a characteristic of the person for whom they care. It is, however, possible to look at this breakdown in 1998 (see Table A6).

Carers aged 25–59 years in 1998

A much lower proportion of carers (48%) aged 25–59 years in 1998 were employed compared to the same age group in the total population (78%; ABS 1999c). This is not surprising given the demanding nature of the caring role as discussed in Chapter 3. Of male carers aged 25–59 years, 55% were employed, compared with 46% of female carers in this age group (Table 4.1).

Table 4.1: Primary carers aged 25–59 years, by age, sex and labour force participation, 1998

Age/sex	Full-time	Part-time	U & NILF ^(a)	Total carers
Females				
25–34	*5,400	12,100	23,500	41,000
35–44	10,900	29,400	33,700	74,000
45–54	17,500	19,700	42,500	79,800
55–59	**1,900	*5,300	21,000	28,200
<i>Total 25–59</i>	<i>35,700</i>	<i>66,600</i>	<i>120,700</i>	<i>223,100</i>
Males				
		Employed^(b)	U & NILF	Total carers
25–34		*3,900	*2,600	*6,500
35–44		12,600	10,300	22,900
45–54		20,200	14,600	34,900
55–59		*6,700	*7,800	14,500
<i>Total 25–59</i>		<i>43,300</i>	<i>35,300</i>	<i>78,700</i>
Persons				
		Employed	U & NILF	Total carers
25–34		21,400	26,100	47,500
35–44		52,900	44,000	96,900
45–54		57,500	57,200	114,600
55–59		13,900	28,800	42,700
Total 25–59		145,700	156,000	301,700

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to produce reliable estimates.

Source: Jenkins et al. (2003: Table 2).

The majority (79%) of employed male carers aged 25–59 years were in full-time employment. The corresponding proportion for female carers was 35%.

Carers aged 60 years or over in 1998

The majority of carers aged 60 years or over lived with and cared for a spouse or partner (68%). Male carers in this age group were more likely to be caring for a spouse or partner than their female counterparts (88% compared with 57% of female carers). Anecdotally, women take on a wider range of caring roles than men and this is supported by the higher proportion of older female carers who were caring for someone other than their spouse or partner. Only a small proportion of older carers who lived with a spouse or partner were aged 80 years or more (11%; Table 4.2). This is hardly surprising, given that carers aged 80 years or over can become incapable of caring, they or the care recipient might die, or the care recipient might move into residential aged care.

Table 4.2: Primary carers aged 60 years or over, by age, sex and whether they live with a care recipient who is a spouse or partner, 1998

Carer age/sex	Relationship to care recipient		Total
	Spouse or partner in same household	Other ^(a)	
Females			
60–79	44,700	34,900	79,600
80+	*3,300	**1,300	*4,600
<i>Total 60+</i>	<i>48,100</i>	<i>36,100</i>	<i>84,200</i>
Males			
60–79	36,400	*5,700	42,200
80+	*6,400	—	*6,400
<i>Total 60+</i>	<i>42,900</i>	<i>*5,700</i>	<i>48,600</i>
Persons			
60–79	81,200	40,600	121,800
80+	9,800	**1,300	11,000
Total 60+	90,900	41,800	132,800

(a) Includes parent, child, other relative or friend in the same or a different household, or spouse/partner in a different household.

— There were no carers in the survey sample in this category.

Source: Jenkins et al. (2003: Table 3).

4.7 Projection results

Projected carers aged 10 to 24 years

Baseline propensity to care scenario

If carer rates remain at 1998 levels by age and sex, primary carers aged 10–24 years will increase in number from an estimated 16,900 in 2003 to around 17,300 by 2013.⁶ This represents a 6% increase over the 15-year projection period from 1998 (Table 4.3). By 2013, 10,600 of the 17,300 carers will be female.

Table 4.3: Estimated and projected carers aged 10–24 years using 1998 carer rates, by sex, 1998, 2003, 2008 and 2013

Sex	1998	2003	2008	2013
Females	10,100	10,400	10,600	10,600
Males	*6,200	6,500	6,600	6,700
Persons	16,300	16,900	17,300	17,300

Source: Jenkins et al. (2003: Table 4).

Decreasing propensity to care scenario

If carer rates decrease by up to 20% over the 15-year period, an estimated 15,800 carers aged between 10 and 24 years in 2003 will decrease to 13,800 by 2013 (Table 4.4). By 2013, 8,500 (62%) of the 13,800 carers will be female.

Table 4.4: Estimated and projected carers aged 10–24 years given decreasing carer rates (20%), by sex, 1998, 2003, 2008 and 2013

Sex	1998	2003	2008	2013
Females	10,100	9,700	9,200	8,500
Males	*6,200	6,100	5,800	5,300
Persons	16,300	15,800	15,000	13,800

Source: Jenkins et al. (2003: Table 5).

Projected carers aged 25 to 59 years

Baseline propensity to care scenario

The variables under examination in the scenarios for carers aged 25–59 are age, sex, and labour force participation category with the distinction between full-time and part-time

⁶ All projections are based on Treasury population projections for 2003, 2008 and 2013, by age and sex.

employment for women. In the baseline propensity to care scenario for this age group, the number of primary carers is projected to increase from 301,700 in 1998 to 361,600 carers in 2013 (Table 4.5). This increase is solely due to projected changes in the age and sex structure of the population and changing patterns of labour force participation in conjunction with 1998 primary carer rates. In this scenario, 265,200 of the 361,600 carers in 2013 will be women. Of these, 121,900 (46%) will be unemployed or not in the labour force, 91,900 will be working part-time and 51,400 will be working full-time. Of the projected 96,400 male carers in 2013, 43,400 will be unemployed or not in the labour force and 53,000 will be employed.

Table 4.5: Estimated and projected carers aged 25–59 years using 1998 carer rates, by sex and labour force status, 1998, 2003, 2008 and 2013

Sex/labour force	1998	2003	2008	2013
Females				
Full-time	35,700	42,500	48,300	51,400
Part-time	66,600	77,200	86,200	91,900
U & NILF ^(a)	120,700	123,400	122,700	121,900
<i>Total</i>	<i>223,100</i>	<i>243,100</i>	<i>257,200</i>	<i>265,200</i>
Males				
Employed ^(b)	43,300	47,700	51,800	53,000
U & NILF ^(a)	35,300	39,300	41,100	43,400
<i>Total</i>	<i>78,700</i>	<i>87,000</i>	<i>92,900</i>	<i>96,400</i>
Persons				
Employed	145,700	167,500	186,300	196,300
U & NILF ^(a)	156,000	162,700	163,800	165,300
Total	301,700	330,100	350,100	361,600

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to be reliable.

Source: Jenkins et al. (2003: Table 6).

Women's career preference scenario

The trend towards greater workforce participation by women, particularly those in the later stages of life, has raised concerns about the impact on the availability of carers. The 1998 ABS survey shows that an estimated 22,800 female carers (7% of female carers) had either reduced the number of hours of paid employment, or resigned from a paid position, in order to care. A key question is whether, in future, women will be less likely to do so and how this might affect the number of primary carers. This possibility was examined by considering the case in which, compared to 1998 proportions, by 2013 up to 20% fewer women will be prepared to reduce their hours of work in order to take up the role as a carer. It is further assumed that this group will not be prepared to undertake a primary care role at all. Carer rates for other projection categories pertaining to the population aged 25 to 59 years are those of the baseline propensity to care scenario, i.e. the 1998 carer rates in each projection category apart from employed women.

The number of female carers in each labour force category is projected to increase despite the 20% reduction in willingness to reduce paid employment (Table 4.6). These increases are the

result of projected population growth by age, sex and labour force participation outweighing the scenario effect.

There are projected to be 121,000 female carers unemployed or not in the labour force in 2013, 51,100 working full-time and 87,800 working part-time. Thus, if 20% fewer women are willing to reduce their hours of work to care than was the case in 1998, there will be 356,200 carers aged 25–59 years in 2013 instead of the 361,600 carers projected under the baseline propensity to care scenario for this age group. The projected 5,400 fewer carers aged 25 to 59 years in 2013 represent a reduction of only 1.5% from the baseline scenario. This projection suggests that a substantial drop in the willingness of women to take on a primary carer role because they are not prepared to forgo paid work is unlikely to have a marked impact on the availability of carers to 2013.

To examine the sensitivity of this scenario, projections were also calculated assuming 10% and 30% decreases in the proportion of women who leave work or reduce hours of work to care. This did not notably affect the total number of carers (Jenkins et al. 2003: tables A10 and A11).

Table 4.6: Estimated and projected primary carers aged 25–59 years given a decrease (20%) in the proportion of women who reduce their hours of work to care, by sex and labour force, 1998, 2003, 2008 and 2013

Sex/labour force	1998	2003	2008	2013
Females				
Full-time	35,700	42,400	48,100	51,100
Part-time	66,600	76,100	83,600	87,800
U & NILF ^(a)	120,700	123,100	122,100	121,000
<i>Total</i>	<i>223,100</i>	<i>241,500</i>	<i>253,800</i>	<i>259,900</i>
Males				
Employed ^(b)	43,300	47,700	51,800	53,000
U & NILF ^(a)	35,300	39,300	41,100	43,400
<i>Total</i>	<i>78,700</i>	<i>87,000</i>	<i>92,900</i>	<i>96,400</i>
Persons				
Employed	145,700	166,200	183,500	191,800
U & NILF ^(a)	156,000	162,400	163,200	164,500
Total persons	301,700	328,500	346,700	356,200

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to be reliable.

Source: Jenkins et al. (2003: Table 7).

Decreasing propensity to care scenario

The third scenario for the population aged 25 to 59 years assumes a decrease of up to 20% by 2013 in carer rates by age, sex, and labour force participation category. In this scenario, population growth offsets the 6.7% decline in propensity to care between 1998 and 2003 to realise an increase in carers in this age group from 301,700 to 308,100 (Table 4.7). Thereafter, the decreasing propensity to care results in decreasing numbers of carers aged 25–59 years, to 303,400 in 2008 and 289,300 in 2013. This scenario projects 12,400 fewer carers in this age group in 2013 than there were in 1998. Compared to the baseline propensity to care scenario

for this age group, the decreasing propensity to care scenario projects 72,300 fewer carers in 2013.

To examine the sensitivity of this scenario, the projections were also calculated assuming a 10% and 30% decrease in carer rates. Estimates of the number of available carers varied considerably under these alternative conditions. A 30% decrease in carers aged between 25 and 59 years in each projection category (age by sex by labour force participation) would result in approximately 253,100 carers in 2013, whereas a smaller decrease of 10% would result in 325,400 carers aged 25 to 59 years in 2013 (Jenkins et al. 2003 tables A15 and A16).

Table 4.7: Estimated and projected primary carers aged 25–59 years given decreasing carer rates (20%), by sex and labour force status, 1998, 2003, 2008 and 2013

Sex/labour force	1998	2003	2008	2013
Females				
Full-time	35,700	39,700	41,900	41,100
Part-time	66,600	72,100	74,700	73,500
U & NILF ^(a)	120,700	115,100	106,400	97,500
<i>Total</i>	<i>223,100</i>	<i>226,900</i>	<i>222,900</i>	<i>212,200</i>
Males				
Employed ^(b)	43,300	44,500	44,900	42,400
U & NILF ^(a)	35,300	36,700	35,600	34,700
<i>Total</i>	<i>78,700</i>	<i>81,200</i>	<i>80,500</i>	<i>77,100</i>
Persons				
Employed	145,700	156,300	161,500	157,000
U & NILF ^(a)	156,000	151,800	142,000	132,300
Total	301,700	308,100	303,400	289,300

(a) U & NILF is the sum of the categories unemployed and not in the labour force.

(b) Male labour force participation is not split into full- and part-time because the relative standard errors in the part-time categories were too high to be reliable.

Source: Jenkins et al. (2003: Table 8).

Projected carers aged 60 years or over

Baseline propensity to care scenario

The baseline scenario for the population aged 60 years or over assumes that the 1998 carer rate within each 5-year age interval by sex and living arrangement (co-resident spouse or partner versus 'other') is sustained throughout the 15-year projection period. A projected increase from 132,800 carers aged 60 years or over in 1998 to 195,100 in 2013 would result from projected changes in the age, sex and living arrangement composition of the older population (Table 4.8).

The population of older people is growing substantially in size, which results in a larger number of older carers – 145,700 carers aged 60 or over in 2003, or a 10% increase on the estimated number in 1998. The number of male carers increases faster than the number of female carers, reflecting a more rapid rise in the older male population. The number of male carers aged 60 years or over is projected to have increased by 14% between 1998 and 2003.

Table 4.8: Estimated and projected carers aged 60 years or over given 1998 carer rates, by sex and whether they live with a care recipient who is a spouse or partner, 1998, 2003, 2008 and 2013

Sex/relationship	1998	2003	2008	2013
Females				
Spouse or partner	48,100	52,900	60,000	69,800
Other ^(a)	36,100	37,600	43,700	52,600
<i>Total</i>	<i>84,200</i>	<i>90,500</i>	<i>103,700</i>	<i>122,400</i>
Males				
Spouse or partner	42,900	48,600	55,700	63,800
Other ^(a)	*5,700	*6,600	*8,000	*8,900
<i>Total</i>	<i>48,600</i>	<i>55,200</i>	<i>63,700</i>	<i>72,700</i>
Persons				
Spouse or partner	90,900	101,500	115,700	133,600
Other ^(a)	41,800	44,200	51,700	61,500
Total	132,800	145,700	167,400	195,100

(a) Includes parent, child, other relative and friend, in the same or a different household, or spouse or partner in a different household.

Source: Jenkins et al. (2003: Table 9).

Converging life expectancies scenario

This scenario assumes an increase in the proportion of co-resident spouses and partners aged 60 years or over who are carers, whilst 1998 patterns of care are assumed to continue for carers whose relationship with the care recipient falls into the 'other' category (and other age groups). As is the case in all scenarios, changes in the number of carers also reflect increasing population size at these ages, and changes in the age and sex structure of the population that are implicit in the underlying population projections for 2003, 2008 and 2013. It is plausible that, as spouses or partners are one of the most willing groups of carers, an increase in the number of couples at older ages will mean higher rates of spouse and partner carers. If this was to amount to a linear increase throughout the projection period, reaching 20% by 2013, then it is expected that there will be 221,800 primary carers aged 60 years or over in 2013, compared with 195,100 under baseline propensity to care conditions for this age group (Table 4.9).

To examine the sensitivity of this scenario, the projections were also calculated assuming 10% and 30% increases in the proportion of spouse/partner carers, which would vary the 2013 projection from 208,400 to 235,200 carers respectively (Jenkins et al. 2003 tables A23 and A24).

Table 4.9: Estimated and projected carers aged 60 years or over given an increase in the proportion of spouse/partner carers (20%), by sex and whether they live with a care recipient who is a spouse or partner, 1998, 2003, 2008 and 2013

Sex/relationship	1998	2003	2008	2013
Females				
Spouse or partner	48,100	56,400	68,000	83,800
Other ^(a)	36,100	37,600	43,700	52,600
<i>Total</i>	<i>84,200</i>	<i>94,000</i>	<i>111,700</i>	<i>136,400</i>
Males				
Spouse or partner	42,900	51,800	63,100	76,500
Other ^(a)	*5,700	*6,600	*8,000	*8,900
<i>Total</i>	<i>48,600</i>	<i>58,400</i>	<i>71,100</i>	<i>85,400</i>
Persons				
Spouse or partner	90,900	108,300	131,100	160,300
Other ^(a)	41,800	44,200	51,700	61,500
Total	132,800	152,400	182,800	221,800

(a) Includes parent, child, other relative and friend, in the same or a different household, or spouse or partner in a different household.

Source: Jenkins et al. (2003: Table 10).

Decreasing propensity to care scenario

The final scenario for the older population assumes a linear decrease in all carer rates over the projection period at ages 60 and over, reaching a 20% decrease by 2013. The decrease applies to the projected population in each projection category in 2003, 2008 and 2013. The scenario implicitly models the changing age and sex composition of the older population, and altered patterns of living arrangement throughout the 15-year projection period. If an across-the-board 20% decrease in the propensity to care were to occur by 2013, there would be 156,100 carers aged 60 years or over in 2013, compared with 195,100 in the baseline propensity to care scenario (tables 4.8 and 4.10). Thus, a 20% decrease in the propensity to care among older carers by age, sex and living arrangement would result in 39,000 fewer carers than if rates remained at 1998 levels by age, sex and living arrangement for this age group.

To examine the sensitivity of this scenario, the projections were also calculated assuming 10% and 30% decreases in carer rates by projection category. Estimates of the number of carers vary considerably under these alternative conditions, from 136,500 for a 30% decrease in rates to 175,600 for a 10% decrease in rates (Jenkins et al. 2003 tables A28 and A29).

Table 4.10: Estimated and projected carers aged 60 years or over given a decrease in carer rates (20%), by sex and whether they live with a care recipient who is a spouse or partner, 1998, 2003, 2008 and 2013

Sex/relationship	1998	2003	2008	2013
Females				
Spouse or partner	48,100	49,400	52,000	55,800
Other ^(a)	36,100	35,100	37,900	42,100
<i>Total</i>	<i>84,200</i>	<i>84,400</i>	<i>89,900</i>	<i>97,900</i>
Males				
Spouse or partner	42,900	45,300	48,300	51,000
Other ^(a)	*5,700	*6,200	*6,900	*7,100
<i>Total</i>	<i>48,600</i>	<i>51,500</i>	<i>55,200</i>	<i>58,100</i>
Persons				
Spouse or partner	90,900	94,700	100,200	106,900
Other ^(a)	41,800	41,300	44,800	49,200
Total	132,800	136,000	145,100	156,100

(a) Includes parent, child, other relative and friend, in the same or a different household, or spouse or partner in a different household.

Source: Jenkins et al. (2003: Table 11).

4.8 Projected total carer pools

The scenarios presented so far have provided projections of the number of available carers for the age groups 10–24 years, 25–59 years and 60 years or over. The total pool of available carers at each of the future projection years can be calculated by combining these scenarios where appropriate.

Projections from the baseline propensity to care scenario for each age group were summed to generate the projected total carer pool under consistent assumptions of baseline propensity to care. Likewise, projections from the decreasing propensity to care scenario for each age group were combined to produce an overall decreasing propensity to care scenario. The projected total carer pool for the women's career preference scenario was calculated as the sum of that scenario projection for the population aged 25–59 years and baseline propensity to care projections for the 10–24 years and 60 years or over age groups. Baseline propensity to care projections for the 10–24 years and 25–59 years age groups were also used in conjunction with the converging life expectancies projections for the 60 years and over age group to generate a total carer pool for that scenario. In this way, the difference between the projected total carer pools for the baseline propensity to care scenario and any one of the other scenarios measures the possible effect of the type and degree of change described by the other scenario. Every scenario incorporates projected population changes with respect to age, sex, labour force participation (for the 25–59 years age group), and living arrangement (for the 60 years or over age group) since these are incorporated into the underlying population projections for 2003, 2008 and 2013. Consequently, differences in the total carer pools of the baseline scenario and each of the other scenarios measure change that is over and above that which is due to demographic and labour force trends throughout the projection period.

Table 4.11 summarises the projected total carer pool in 2013 for each combined scenario. Combined baseline propensity to care projections are the likely outcome if caring rates remain at 1998 levels within each projection category for each of the broad age groups, but the age, sex, labour force participation and living arrangements of the population change in line with current population projections. In other words, the population continues to age, labour force participation rates for women increase, and, at older ages, there is an increasing proportion of intact marriages owing to improving male longevity. The results of this scenario show that in 2013 there would be 573,900 primary carers in a population with a projected 1.4 million persons with a severe or profound restriction⁷. In 2013, on the basis of this baseline propensity to care scenario, there would be around 40 primary carers to 100 persons with a severe or profound restriction (i.e. a care ratio of 0.40). This compares to the 1998 survey estimate of 43 primary carers to 100 persons with a severe or profound restriction, or a care ratio of 0.43.

Table 4.11: Estimated and projected primary carers aged 10 years and over, by sex, 1998, 2003, 2008 and 2013^(a)

Scenario	1998	2003	2008	2013
Males				
Baseline propensity to care	133,500	148,700	163,200	175,700
Overall decreasing propensity to care	n.a.	138,800	141,400	140,600
Women's career preference	n.a.	148,700	163,200	175,700
Converging life expectancies	n.a.	151,900	170,600	188,500
Females				
Baseline propensity to care	317,300	344,000	371,600	398,200
Overall decreasing propensity to care	n.a.	321,100	322,000	318,600
Women's career preference	n.a.	342,400	368,100	392,900
Converging life expectancies		347,600	379,600	412,200
Persons				
Baseline propensity to care	450,900	492,700	534,800	573,900
Overall decreasing propensity to care	n.a.	459,900	463,500	459,200
Women's career preference	n.a.	491,100	531,300	568,600
Converging life expectancies	n.a.	499,500	550,200	600,700

(a) Differences between the total carer pools of the baseline and other scenarios may vary from differences seen in the age-specific scenario projections to within 100 carers. This is due to rounding.

Source: Tables 4.3–4.10; Table A5 (1998).

The overall decrease in propensity to care scenario, which combines the decreasing propensity to care projections across the three age groups, assumes that carer rates within each projection category decrease linearly over the projection period, up to a 20% decrease by 2013. Again, the previously described age, sex, living arrangement and labour force participation rates continue to change in line with population projections. The projections under this scenario might be considered a 'worst case' scenario, in which the decline in carer availability occurs across all ages, for both sexes and across all categories of living

⁷ Numbers of persons with a severe or profound restriction were projected by applying the 1998 rate of people with a severe or profound restriction by age and sex to the projected total populations for 2003, 2008 and 2013 supplied by the Department of Treasury (Jenkins et al. 2003: Table A1).

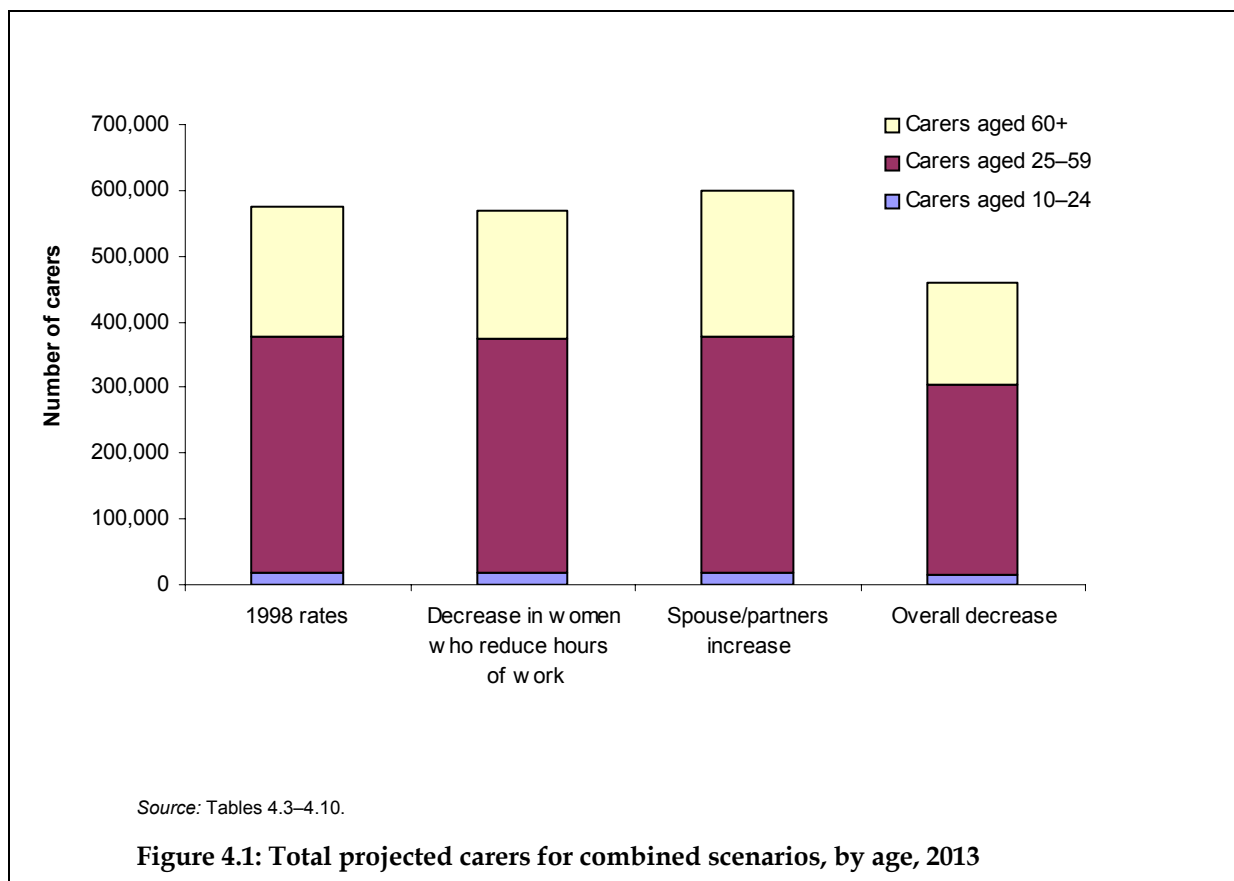
arrangement and labour force participation. In this scenario, the total number of carers in 2013 is projected to be 459,200, compared to an estimated 450,900 carers in 1998, and a projected 573,900 in 2013 under baseline propensity to care conditions throughout the projection period. In this instance, the ratio of carers to people with a severe or profound restriction would be around 32 to 100 (0.32) in 2013, compared with 43 to 100 (0.43) in 1998, or 40 to 100 (0.40) in 2013 if 1998 caring rates are sustained.

Two other scenarios were considered. One assumes that there will be an increase in the proportion of older spouses and partners who will undertake the caring role (the converging life expectancies scenario). This scenario was calculated on the basis of an increase in the rate of co-resident spouses and partners aged 60 years or over who take on a caring role. The increase is assumed to be linear throughout the projection period, reaching a 20% increase in each projection category (5-year age interval, sex, and living arrangement) by 2013. This scenario projects a total of 221,800 carers aged 60 years or over in 2013 (Table 4.9). In combination with the baseline propensity to care projections for people aged under 60 years, the result is a projected 600,700 carers aged 10 years and over in 2013. Under these conditions, the 2013 care ratio is expected to be 42 primary carers to every 100 persons with a severe or profound restriction (0.42).

Finally, the analysis explored the possibility that women will be less willing in the future to reduce their hours of paid work to care, the so-called 'women's career preference scenario'. The calculation focuses on female carers aged 25 to 59 years. It estimates the impact of a reduction in their willingness to reduce paid employment based on the 1998 proportions who were willing to do so. The decrease is linear throughout the projection period, reaching a 20% decrease in the rate by 2013. Combined with baseline propensity to care projections for age groups 10–24 years and 60 years and over, this scenario yields a total of 568,600 carers in 2013, equating to a ratio of 40 carers to every 100 persons with a severe or profound restriction (i.e. a care ratio of 0.40).

Compared with the baseline propensity to care scenario that applies 1998 rates in all projection categories across the three main age groups, only the overall decrease in propensity to care scenario shows a marked impact on the number of primary carers to 2013 (Figure 4.1). According to this projection, there would be 114,700 fewer carers than if carer rates remain at 1998 levels and the projected population changes in regard to age, sex, labour force participation and living arrangement occur. The scenario with the least impact on the number of carers in 2013 is that of a reduced willingness of women to give up paid employment to care. Under an assumption of a 20% decrease by 2013 in the proportion of women who are prepared to do so, there would be possibly be as little as 5,400⁸ fewer carers in 2013 than if 1998 carer rates by projection category are sustained throughout the projection period. It should be remembered that the population projections themselves reflect a continuing increase in female labour force participation and take stock of the relationship between propensity to care and full-time or part-time female employment. The women's career preference scenario models an effect over and above trends in female labour force participation. Significantly, over this particular 15-year projection period, ageing baby-boomers move into age groups that have traditionally registered high proportions of primary carers. For this reason, conclusions based on a comparison of the scenario projections with informal care in 1998 should be viewed in the context of this demographically unique period in time.

8 Rounding to the nearest 100 carers in the calculation of the total carer pool increases the difference of 5,300 carers reported in the women's career preference scenario under Projected carers 25–59 years.



4.9 Conclusion

This chapter presents projections of the supply of carers at 5-year intervals from the base year of 1998 through to 2013. Results of the 1998 ABS Survey of Disability, Ageing and Carers were used to describe the characteristics of carers on which these future projections are based. Projected changes in population age and sex distribution and labour force status, as calculated by the Department of Treasury, and changes in living arrangement, as calculated by the ABS, were used to calculate projections based on a set of assumptions about trends in informal care. The four scenarios are:

- existing patterns of caring continue, taking into account the changing trends in demographic structure, labour force participation and living arrangement
- an across-the board 20% decrease by 2013 in the willingness of people to provide ongoing care
- a 20% decrease by 2013 in the proportion of women who have (historically) reduced their hours of paid work, or resigned from a paid position, in order to take on a caring role
- a 20% increase by 2013 in the proportion of older spouses and partners who take on a caring role.

Contrary to the concerns and expectations of some commentators, the results of these projections indicate that a substantial reduction in the willingness of women to substitute time spent in unpaid caring for paid employment is unlikely to have a marked impact on the availability of carers over the next decade. While female workforce participation is projected

to rise over the next decade, particularly for women aged 55 years and over, it is unlikely that all of those women continuing or returning to work will not provide care in some capacity. Other research has suggested that women are more likely than men to arrange their working hours to fit in with family caring responsibilities (Fine 1994). Thus, the proposed scenario could be considered an extreme position. The result of projecting the availability of primary carers to 2013 based on this scenario is the same as if there were no change in carer rates over the projection period (both scenarios yield a 'care ratio' of 0.40).

The unique characteristics of the period 1998 to 2013, in terms of demographic change, contribute to this result. This period will see large population increases in age groups that are the traditional source of primary carers. In 1998, women aged between 35 and 64 years accounted for 65% of all female primary carers (ABS 1999a: Table 28). Baby-boomers who survive the projection period will age from between 37 and 51 years in 1998 to between 52 and 66 years respectively in 2013. The women's career preference scenario projection, relative to the situation in 1998, reflects the fact that throughout the projection period the effect of ageing baby-boomers on the primary carer pool will probably mask any decreased propensity to care among employed women.

Nevertheless, these results emphasise the point that a large proportion of female carers is actually in the labour force, highlighting the need to specifically consider employed carers in the ongoing development of carer support programs. Employed women accounted for 34% (102,400) of all primary carers in 1998 and working-age women made up a high proportion of carers of older people. The ability of many women to balance work and family caring responsibilities and to continue to do so into the future will no doubt depend upon the availability of other family and community supports. As the 1999 National Survey of Carer Health and Wellbeing reports, respite care and other services are seen by carers as an integral part of their lives and essential to their ability to continue in their role as carers (CAA 2000). Furthermore, the scenario examines the effect of a reduction in the proportion of women who are prepared to sacrifice employment to provide care, based on a pool of female carers whose motivations and aspirations may be very different to another pool of same-aged potential carers at a future point in time.

The projections also indicate that an increase in the number of older co-resident spouse or partner carers is likely to be the source of a relatively small number of additional carers over the next decade. A scenario which posits a 20% increase in the proportion of co-resident spouse or partner carers over the projection period is likely to differ little from the 1998 situation of 43 primary carers per 100 persons with a severe or profound restriction. This is perhaps an optimistic scenario. It assumes that surviving partners will remain married rather than become divorced or separated, and that, in addition to physical wellbeing, these partners will have the necessary skills and emotional capacity to undertake a caring role. These assumptions may not always find support in reality. For example, Sammut (1996) describes some of the difficulties faced by carers of those with dementia who can sometimes exhibit disturbing and physically exhausting symptoms.

While projections for the career preference and converging life expectancies scenario do not point to any dramatic shift in the level of informal care, measured as the number of primary carers, a 20% decline in the proportion of carers across all age and sex categories and across all labour force and living arrangement categories would have serious consequences. This latter scenario projects a decline from 43 primary carers per 100 persons with a severe or profound restriction in 1998 to only 32 primary carers per 100 persons in 2013. Even compared to the baseline scenario result for 2013 of 40 primary carers per 100 persons with a severe or profound restriction, this represents a marked decline in informal care. It would

necessitate looser informal care networks together with formal sources of assistance caring for people who most likely need constant supervision and guidance with core daily activities.

The plausibility of a broad decline in carer availability is difficult to assess, not least because of the multitude of variables relevant in determining carer supply, many of which are not well understood. This report has only investigated the impact of some of these factors and even then only in the artificial environment of holding all other factors constant at 1998 levels, including the provision of cared accommodation. Developing a detailed predictive model to fully address the question of the future supply of carers would require a level of detail in the data, together with time series data, which is not currently available. The absence of time series data from which a trend could be determined also adds to the difficulty of projecting future carer supply. It is not surprising that, until now, there has been no published research into the likely future number of carers in Australia.

4.10 Discussion

Given the constraints imposed by existing national data collections, the most robust methodology in addressing questions about future supply is to construct a set of scenarios which describe a clear set of assumptions and a corresponding range of possible future outcomes. The analysis presented in this chapter follows such an approach, applying trend data for the key variables of population change, labour force participation, and shifts in living arrangement over time. The most common assumption in the absence of actual analysis has been that the future will see a shortage of carers owing to the increasing labour force participation of women. Reality is likely to be much more complex, as many factors come into play in the decision to care.

The projections examined in this report are based on data for primary carers: that is, individuals providing the most assistance to persons with a disability. Many people with a disability receive help from more than one person, usually other family members (Miller & McFall 1991). This group of additional carers is not included in the projections. Thus, scenarios that project a decline in primary carers do not allow for the possibility that these carers will be replaced by carers in other circumstances beyond those identified in the model. A survey of carers by Braithwaite (1990) found that 25% of primary carers took on the role because there was no one else to do so, and 28% of carers said that other potential carers had refused. According to the 1998 Survey of Disability, Ageing and Carers (ABS 1999a), 30% of carers of parents felt that there were no other family or friends available and 19% felt that no one else was willing to take on the role of primary carer. In contrast, Miller and McFall (1991) have observed that additional informal assistance varies in intensity and size (in terms of the number of additional carers) as a function of, among other things, the need of the recipient, with greater care needs finding more support from an additional carer network. The contribution of additional carers and the implications of this for future care burden are difficult to assess and beyond the scope of this report.

Carer accessibility, in terms of geographic location, is a further consideration in the interpretation of the scenario projections presented here. An implicit assumption in the scenario projections is that additional primary carers arising from population growth and ageing will be available in a practical sense. However, the phenomenon of geographic ageing and the tendency of many people to retire to coastal locations will play a part in future patterns of informal care.

While these limitations are important to note, they do not detract from the strength of the conclusions. The scenario projections offer an empirical base for some likely future trends. An overall reduction in people's motivation to provide care, as opposed to the projected increase in female labour force participation, emerges as the main potential threat to the future availability of informal care. Reports from primary carers on the subject of motivation confirm that sense of responsibility and obligation that comes from interpersonal relationship is a prime motivating factor for the majority of carers. Any shift in the balance of care that results from the changing availability of the group identified as primary carers will have implications for the demands placed on formal services and secondary carers.

Jones and Cullis (2003) argue that 'perceptions of the intrinsic value of altruism rely on signals that intrinsic value is acknowledged'. To rely primarily on intrinsic motivation as a driver for the provision of informal care is unlikely to fully realise the capacity of families to care for their own. Family, community and government support for primary carers provides a vital positive signal to continuing and potential carers. Chapter 5 examines formal service use with informal care and describes some important national carer support programs.

5 Informal care and formal services

5.1 Introduction

Formal services provided under the auspices of the Commonwealth–State/Territory Disability Agreement (CSTDA) and programs such as Home and Community Care (HACC), Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), Veterans' Home Care, and Day Therapy Centres complement the assistance provided by primary and other carers and support people with limited access to informal care. Among all people with a severe or profound restriction in 1998, 46% said they received assistance only from carers, 3% said they were assisted only by formal services, and 48% said they received assistance from carers and formal services (Table 5.1). Formal aged-care and disability services have evolved to offer packages of assistance that are designed to meet the needs of people living in the community. Carers provide direct care and act as advocates in organising and facilitating contact with health and welfare services.

Table 5.1: Type of assistance received by people with a severe or profound restriction living in households, 1998

Type of assistance	Age (years) of person with a severe or profound restriction							
	0–24		25–64		65+		All ages	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Percent
Informal only	72.8	37.4	257.1	58.3	110.1	33.8	440.0	45.7
Informal and formal	107.1	55.0	160.2	36.3	198.7	61.0	466.0	48.5
Formal only	*8.0	*4.1	*7.4	*1.7	11.5	3.5	26.9	2.8
Not applicable or none specified	*6.8	*3.5	16.5	3.7	*5.3	*1.6	28.7	3.0
Total	194.7	100.0	441.3	100.0	325.6	100.0	961.6	100.0

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

Differences in the mix of informal care and formal service use are apparent across the age groups. Age groups in Table 5.1 were constructed to produce reliable estimates whilst still discerning age-related patterns. A breakdown of the middle age group into those aged 25–44 and 45–64 years revealed similar patterns of sources of assistance, so these age groups were combined. Around one-third of people with a severe or profound restriction aged under 25 years and 65 years or over in 1998 relied solely on assistance from carers. The majority of people in these age groups reported having received assistance from both formal services and carers (55% and 61% respectively). The pattern is reversed in people aged between 25 and 64 years, 58% of whom received assistance only from carers (Table 5.1). Total reliance on formal services appears to have been higher in the younger and older age groups in the household population, although some age-specific estimates are subject to moderately high sampling error.

Of interest, then, is whether different patterns of uptake of formal services according to the presence or absence of a primary carer are seen in program data at the national level. Analysis of this question is complicated because carer availability is itself associated with level of need and age. Therefore, some measure of client dependency or, alternatively, client

population screening, is required. It is also important to recognise that utilisation statistics can reflect supply constraints.

Utilisation data for the HACC program and CSTDA that were available for this publication are not amenable for analysis of patterns of formal service use with informal care. The current HACC national data collection does not contain client dependency information. Prior to September 2004, data on services delivered under the CSTDA data do not contain carer items. The 2002 Day Therapy Centre census specified carer and dependency data items for collection. However, the data returned contained as many records with missing as with valid values for the carer items.

Ongoing data development is leading to improvements in the national collections so that, in future, it should be possible to make comparisons of formal service use between the with- and without-carer client groups in the wider population of care recipients. Data on 2002–03 activity under the CSTDA becomes available in late-2004 will for the first time include items related to the presence of a carer who provides support to the service user. These items include existence of carer, whether the carer lives in the same household, the relationship between the carer and the service user, and the carer's age group. The redeveloped collection will give new information on carers in Australia, in particular the relationship between formal services and informal care. Likewise, the HACC Data Reform Working Group is developing a framework for client dependency data in the HACC national minimum data set. Inclusion of standard dependency data items will facilitate analysis of service utilisation by carer availability among HACC clients. However, the timeframe for the supply of nationally consistent sets of HACC client dependency data by the states and territories is not yet clear.

This chapter examines data collected in the 2002 CACP census (AIHW 2004a), which is arguably the most reliable national program data available for the purpose at hand. CACPs target older people in the community with complex care needs. Approximately 93% of package recipients are aged 65 years or over. Lack of comprehensive data for HACC and CSTDA clients, as discussed above precludes a more complete coverage of patterns of formal service use with informal care.

5.2 Patterns of service use by carer availability among CACP recipients

A census of 25,439 CACP clients conducted in September and October 2002 enumerated clients by service type and carer status. Dependency is expressed in terms of need for assistance and diagnosis of dementia. These data are amenable to a descriptive comparison of service utilisation in the with-carer and without-carer client groups. The following comparison is inclusive of 23,286 clients aged 65 years or over (72% female) with valid data for age and carer status. Of these, 13,297 (57%) clients had an unpaid carer and 9,989 (43%) clients did not have a carer.

Women comprised just over 70% of both with-carer and without-carer groups. Similar proportions of men and women said they had a carer (57% of female clients and 59% of male clients). The median age of the two groups was similar – 83 years for clients with carers and 82 years for clients without carers. There was a higher proportion of clients aged 85 years or over in the with-carer group (39% versus 27% of clients without a carer). This group also recorded a higher rate of diagnosed dementia (25% versus 12%) (AIHW analysis of 2002 CACP census data).

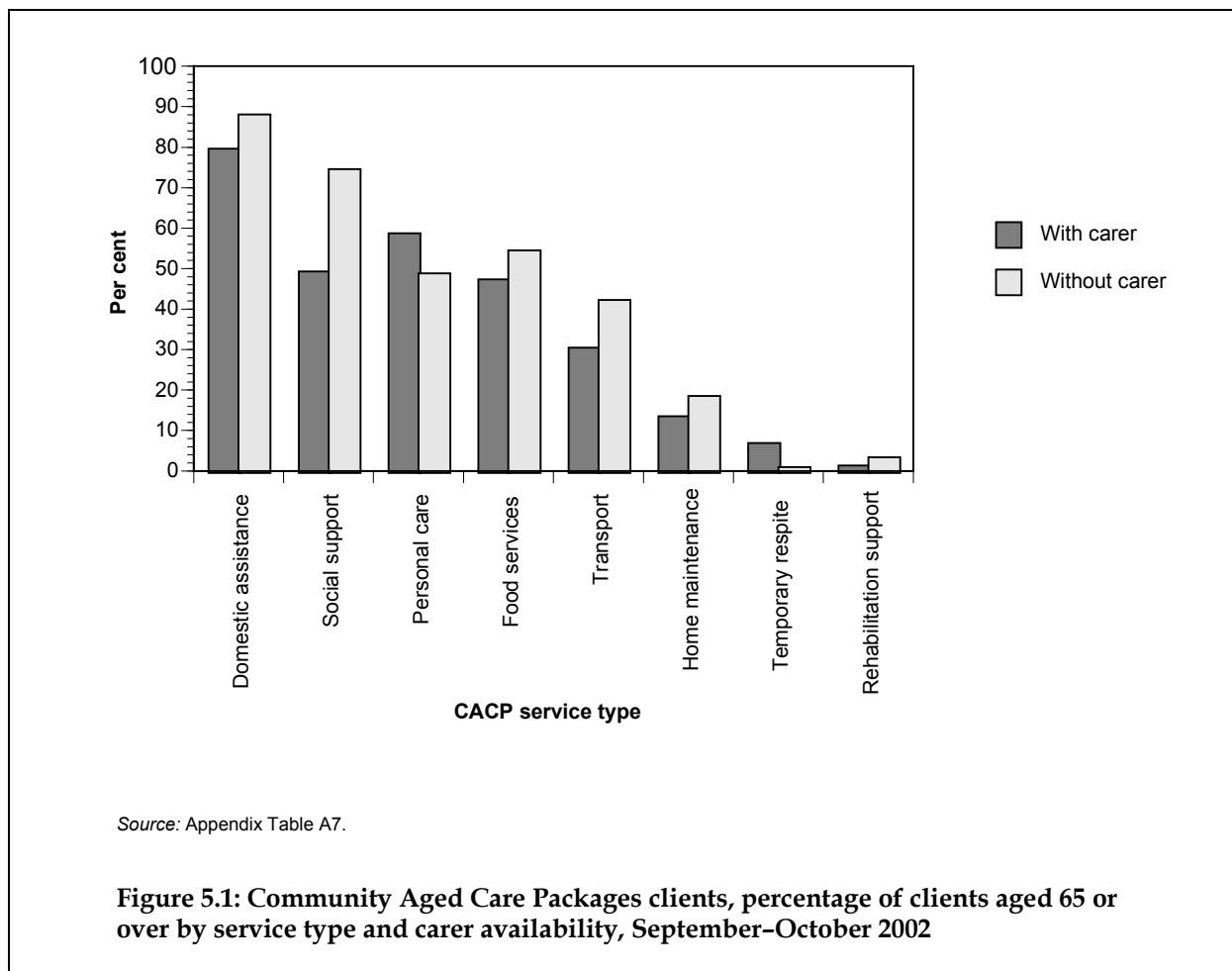
The types of assistance provided under the CACP program can be classified into case management and 10 categories of direct assistance. Figure 5.1 shows the percentage of clients in the with-carer and without-carer groups who used each type of direct assistance during the census period. Delivered meals and food preparation services are combined under the heading 'Food services'. Linen services are not shown because of the low number of clients recorded against this service type. The majority of clients with a carer (80%) and those without a carer (88%) used domestic assistance services during the census period. This type of assistance was used more by more clients in each group than any other service type. Higher proportions of clients without a carer were recorded against each service type apart from personal care and temporary respite care⁹.

A higher proportion of clients with a carer used personal care services (59% versus 49% of those without a carer), suggesting that clients with a carer may be a more dependent group (and is possibly associated with the higher rate of diagnosed dementia among clients with a carer). This margin is consistent across the age groups 65–74, 75–84 and 85 years or over (Table A7). It is not immediately obvious that a person who receives formal assistance for personal care is more likely to have a primary carer. Firstly, most older primary carers are spouses of their care recipients so that the caring role is inseparable from marriage and cohabitation, neither of which is necessarily correlated with level of need for personal care at older ages. Secondly the capacity for a person with high personal care needs to remain at home depends on the total amount of personal assistance that is available from both formal and informal sources. The degree to which use of personal care services by clients with a primary carer represents primarily substitution or supplementation of informal care cannot be ascertained from the data.

The greatest difference between the groups was associated with the use of social support services (75% of clients without a carer versus 49% of those with a carer). Age stratification reveals that the difference between the two groups with respect to the proportion using social support services is only apparent at ages 75 years and over (Table A7). Among clients aged 75 to 84 years, 75% of those without a carer used social support services compared to 50% of clients with a carer. The corresponding proportions of clients aged 85 years or over are 82% and 46%.

Approximately half of the clients in each group used food services, with slightly higher utilisation among clients without a carer (54% versus 47%). The proportion of clients who used food services appears to increase with age: 46% of clients aged 65–74 years without a carer and 39% of those with a carer used food services, with the respective proportions rising to 62% and 53% of clients aged 85 years or over (Table A7). Similarly, proportionately more clients without a carer used transport services. However, the proportion of clients who used transport services does not tend to increase with increasing age: 43% of clients aged 65–74 years without a carer versus 34% of those with a carer use transport services, falling to 41% and 28% respectively of clients aged 85 years or over (Table A7).

⁹ Although the CACP Census guidelines stipulated that temporary respite care is by definition a service for package recipients with a primary carer, CACP recipients who used temporary respite may have been recorded as being without carer because the carer was unavailable during the census period.



In summary, apart from personal care and respite services, a higher proportion of clients without a carer used each CACP service type than clients with a primary carer. The most striking difference between the with- and without-carer groups is seen in the use of social support and transport services. Lincoln Gerontology Centre has noted that Aged Care Assessment Team clients living alone at home are more likely to be recommended for low-level than high-level care and suggest that many such recommendations are based on the psychosocial needs of these clients (LGC 2002:55).

These results underscore the important contribution of carers to the social and physical wellbeing of their care recipients. They also demonstrate that older people with a severe level of restriction in daily activities call on formal services for personal and domestic assistance, even when they have a primary carer. This at least partly reflects the fact that primary carers of older persons are likely to be an older co-resident spouse or partner, or an ex-household family member with other family responsibilities.

A report on the 2002 census of EACH clients – EACH clients have been assessed as needing the equivalent of high-level residential care – noted that ‘many EACH package recipients are able to remain at home only because a carer provides regular assistance with physical tasks’ (AIHW 2004b). At the time of the census, EACH was a pilot program of around 290 care packages. Approximately 90% of EACH clients at the time had a primary carer and almost one in three of all clients had a diagnosis of dementia. Dementia in an EACH care recipient was associated with more extensive needs. However, the association between dementia and

use of EACH services was found to vary according to the availability of a primary carer, as evident in the CACP census data. For example, among EACH care recipients with a carer, the average number of hours of assistance was similar for those with and without dementia (17.3 and 17.7 hours respectively). Yet for care recipients without a carer, those with dementia received more care on average (26.0 hours) than those without dementia (18.6 hours) (AIHW 2004b).

Improved CSTDA and HACC data collections will help to determine whether these patterns of service utilisation hold for the wider household population with severe or profound restriction.

5.3 Carer support programs

Formal services available to people through the HACC program, Veterans' Home Care, CACP, EACH, the CSTDA and other government aged care and disability programs help to reduce the load on carers. Services that directly assist carers, such as respite care, counselling, and care planning and coordination services are also offered through these programs. Growth in the community care sector has seen an expansion of programs that specifically offer assistance to carers in the form of respite care, counselling and education, and information services (Box 5.1) and financial support (Box 5.2). State and Territory health and disability programs complement Australian Government initiatives that recognise and support carers. The support and acknowledgment of carers of frail elderly people is one of the key principles of a proposed national framework for the care of older Australians (AHMAC 2003).

Respite care was a key component of the Staying at Home measures announced in the 1998-99 federal Budget and continues to be an important area of service provision. The 1998 ABS survey revealed that just on 36% (160,000) of primary carers did not have a fall-back carer and a further 8% (36,300) did not know if a fall-back carer was available (AIHW 2000: Table 16.7). However, an estimated 87% of primary carers (388,900 people) at that time had never made use of respite care services and 11% indicated that they needed respite but had not received it (AIHW 2000:145). It is anticipated that more carers are now able to make greater use of formal respite care through developments in the National Respite for Carers Program.

Box 5.1: Australian Government carer support programs

Commonwealth Carelink Centres

A network of Commonwealth Carelink Centres was established in 2001 to provide an information service to help put older Australians, people with a disability, and their carers in touch with a range of community, aged care and disability services. Carers can access the network by telephoning Freecall™ 1800 052 222 or by visiting one of over 60 shopfronts throughout Australia, by visiting one of over 90 access points in 54 regions, or through the Commonwealth Carelink website, www.commcarelink.health.gov.au.

National Respite for Carers Program

The aim of the National Respite for Carers Program is to contribute to the support and maintenance of caring relationships between carers and their dependent family members or friends by facilitating access to information, respite care and other support appropriate to their individual needs and circumstances, and those of the persons for whom they care.

The National Respite for Carers Program is an Australian Government-only funded program. It was established as a 1996–97 Budget initiative and built on the existing Commonwealth Respite for Carers Program. Funding for the National Respite for Carers Program has increased more than five-fold from \$19 million in 1996–97 to an estimated total of \$104.9 million in 2004–05 (figures supplied by the Department of Health and Ageing).

The National Respite for Carers Program consists of the following components:

- ***Commonwealth Carer Respite Centres***

There is a national network of 61 Commonwealth Carer Respite Centres (89 outlets in all) to assist carers obtain short-term or emergency respite. These Centres have a pool of funds that can be used to purchase or subsidise respite care. Centres encourage services to develop more flexible approaches to respite care as well as linking carers to appropriate respite care services, including residential respite. They are reached through a regionally diverted Freecall number, 1800 059 059.

- ***Commonwealth Carer Resource Centres***

These Centres provide information, support and advice to carers on a range of issues. They are auspiced by Carers Associations in each state and territory and by Carers Australia for the national Commonwealth Carer Resource Centre. They are located in each capital city and are reached through a state-wide Freecall number, 1800 242 636.

- ***Respite services***

There are 432 community-based respite services providing respite in a variety of settings, including in-home, day centre, host family, residential overnight cottage-style accommodation and in aged care homes.

- ***National Carer Counselling Program***

Carers Australia is being funded to manage this 2002 Budget initiative and implement the program through Commonwealth Carer Resource Centres. The aim is to address issues specific to carers such as carer stress, grief and loss, coping skills and transition issues. Counselling is provided on a sessional basis by qualified counsellors.

- ***National Dementia Projects***

The National Respite for Carers Program provides funding to the National Dementia Behaviour Advisory Service, the Carer Education and Workplace Training Project, and the Early Stage Dementia and Respite Project.

The National Dementia Behaviour Advisory Service provides a telephone advisory service, 1300 366 448, staffed by clinicians for carers and respite workers concerned about the behaviours of people with psychological and behavioural symptoms of dementia. The Carer Education and Workplace Training

(continued)

Box 5.1 (continued): Australian Government carer support programs

Project provides coordinated national accredited training for carers and respite workers caring for people with dementia and challenging behaviours. The Early Stage Dementia and Respite Project provides a nationally coordinated support and respite service for people in the early stages of dementia and their carers delivered through Alzheimer's Associations.

- **Carer Information and Support Program**

This program provides carers with information and practical advice about services that can help them in their caring role. Commonwealth Carer Resource Centres in each State and Territory and a national Commonwealth Carer Resource Centre receive funding through the Carer Information and Support Program to distribute carer information products.

Residential respite care

Residential respite provides short-term care in aged care homes for people who are in temporary need of residential care. Some \$81 million was provided in 2002–03 to subsidise the cost of using about one million bed days for respite stays in aged care homes (see AIHW 2004c for additional statistics on residential respite care provision in 2002–03). Residential respite may be used on a planned or emergency basis to help with carer stress, illness, breaks away from homes or the unavailability of the carer for any reason.

As at 31 December 2002, Carer Payment provided income support to 71,210 carers (Centrelink unpublished data). Fewer older carers than carers aged less than 65 years receive Carer Payment because the payment compensates carers for lost earnings while providing full-time care (Table 5.2). Of the 74,229 persons who received assistance from a carer supported by Carer Payment or Carer Allowance, 72% were aged 45 years or over, and 37% were aged 65 years or over (Table 5.4).

Box 5.2 Financial support for carers

Carer Payment

Carer Payment (Adult and Child) is an income-support benefit payable to people who, because of their caring responsibilities, are unable to engage in a substantial level of paid work but are not eligible for other income support payments such as the Age Pension. It is set at the same rate as the Age Pension, and is subject to the same income and asset tests. Because Carer Payment is for people who are unable to work because of their caring responsibilities, the vast majority of people receiving the Payment are aged between 25 and 64 years (see tables 5.2 and 5.4 for the distribution of Carer Payment in 2001–02).

Carer Allowance

Carer Allowance (Adult and Child) is currently payable to co-resident carers who provide full-time care on a daily basis for up to two people who need substantial amounts of care because of a disability, severe medical condition or age-related frailty. As of 1 September 2004, eligibility for Carer Allowance extends to carers who are not co-resident if they provide a minimum of 20 hours per week of personal care assistance to a person who is in need of personal care.

Carer Allowance can be paid to carers in receipt of a government pension or benefit, including Carer Payment. It is not income- or asset-tested, but eligibility is determined according to an assessment of the care recipient's care needs. The level of Carer Allowance, adjusted on 1 January each year, is designed to help meet additional costs involved in caring for a person with a disability (see tables 5.3 and 5.4 for the distribution of Carer Allowance in 2001–02).

Table 5.2: Carer Payment: carers by age and sex, 31 December 2002

Age	Males	Females	Persons	Males	Females	Persons
	Number			Per cent		
Carer looking after person(s) aged under 65						
<24	823	1,316	2,139	1.8	2.9	4.6
25–34	1,825	2,927	4,752	4.0	6.3	10.3
35–44	3,445	6,167	9,612	7.5	13.4	20.8
45–54	4,659	9,890	14,549	10.1	21.5	31.6
55–64	6,922	7,496	14,418	15.0	16.3	31.3
<65	17,674	27,796	45,470	38.3	60.3	98.6
65–74	297	267	564	0.6	0.6	1.2
75+	11	58	69	0.0	0.1	0.1
65+	308	325	633	0.7	0.7	1.4
Total	17,982	28,121	46,103	39.0	61.0	100.0
Carer looking after person(s) aged 65 and over						
<24	196	305	501	0.7	1.2	1.9
25–34	611	879	1,490	2.3	3.3	5.7
35–44	1,836	2,763	4,599	7.0	10.5	17.5
45–54	2,862	6,338	9,200	10.9	24.1	34.9
55–64	2,662	6,752	9,414	10.1	25.6	35.7
<65	8,167	17,037	25,204	31.0	64.7	95.7
65–74	369	568	937	1.4	2.2	3.6
75+	81	111	192	0.3	0.4	0.7
65+	450	679	1,129	1.7	2.6	4.3
Total	8,617	17,716	26,333	32.7	67.3	100.0

Source: Centrelink unpublished data.

Table 5.3: Carer Allowance: carers by age and sex, 31 December 2002

Age	Males	Females	Persons	Males	Females	Persons
	Number			Per cent		
Carer looking after person(s) aged under 65						
<24	903	3,493	4,396	0.4	1.7	2.1
25–34	2,871	38,252	41,123	1.4	18.5	19.9
35–44	6,511	74,554	81,065	3.2	36.1	39.2
45–54	6,982	37,758	44,740	3.4	18.3	21.7
55–64	8,900	16,984	25,884	4.3	8.2	12.5
<65	<i>26,167</i>	<i>171,041</i>	<i>197,208</i>	<i>12.7</i>	<i>82.8</i>	<i>95.5</i>
65–74	3,562	3,733	7,295	1.7	1.8	3.5
75–84	466	1,299	1,765	0.2	0.6	0.9
85+	47	233	280	0.0	0.1	0.1
65+	<i>4,075</i>	<i>5,265</i>	<i>9,340</i>	<i>2.0</i>	<i>2.5</i>	<i>4.5</i>
Total	30,242	176,306	206,548	14.6	85.4	100.0
Carer looking after person(s) aged 65 and over						
<24	194	308	502	0.2	0.3	0.5
25–34	631	1,086	1,717	0.7	1.2	1.9
35–44	1,998	4,018	6,016	2.2	4.4	6.6
45–54	3,497	9,381	12,878	3.8	10.2	14.0
55–64	3,653	15,382	19,035	4.0	16.8	20.7
<65	<i>9,973</i>	<i>30,175</i>	<i>40,148</i>	<i>10.9</i>	<i>32.9</i>	<i>43.7</i>
65–74	8,104	18,297	26,401	8.8	19.9	28.8
75–84	9,612	12,525	22,137	10.5	13.6	24.1
85+	1,836	1,264	3,100	2.0	1.4	3.4
65+	<i>19,552</i>	<i>32,086</i>	<i>51,638</i>	<i>21.3</i>	<i>35.0</i>	<i>56.3</i>
Total	29,525	62,261	91,786	32.2	67.8	100.0

Source: Centrelink unpublished data.

Table 5.4: Care recipients of carers receiving Carer Payment and/or Carer Allowance, by age and sex of care recipient, 31 December 2002

Age	Carer Payment				Carer Allowance			
	Males	Females	Persons		Males	Females	Persons	
	Per cent care recipients			Number	Per cent care recipients			Number
0–14	1.3	0.9	2.2	1,639	27.2	14.0	41.3	132,938
15–24	4.3	3.2	7.5	5,567	5.9	3.4	9.3	29,989
25–34	3.9	3.9	7.8	5,787	1.5	1.3	2.8	9,126
35–44	5.0	5.3	10.3	7,647	1.9	1.7	3.7	11,869
45–54	7.4	7.7	15.2	11,251	3.0	2.4	5.4	17,392
55–64	11.2	8.9	20.1	14,890	5.2	3.4	8.6	27,871
65–74	4.8	5.7	10.5	7,795	5.3	4.4	9.6	30,997
75–84	4.3	11.4	15.7	11,622	6.6	6.3	13.0	41,789
85+	2.6	8.2	10.8	8,031	2.3	4.0	6.3	20,284
Total	44.7	55.3	100.0		59.0	41.0	100.0	
Total Number	33,194	41,035		74,229	190,101	132,154		322,255

Source: Centrelink unpublished data.

Aged Care Assessment Team guidelines have long required formal aged care assessment to consider the needs of carers when making recommendations. Carers are an official target group for HACC services and recent developments in the CSTDA national data collection also indicate that the key role of carers is well recognised in the delivery of assessment and care services throughout Australia.

Care coordination and case management, often viewed as primarily a service to care recipients, carries direct benefits for carers, particularly carers of people with impaired decision-making capability. Primary carers have been likened to ‘bridges’, connecting their care recipients to health and community care networks (Edelbrock et al 2003; Schneider et al. 2003; Jette et al. 1995). Case management, such as that available through CACPs, EACH and HACC Community Options (or ‘Linkages’ in Victoria), can relieve carers from the time-consuming detail of investigating alternative services, assessment procedures, eligibility criteria and fees, and liaison with service providers to establish and manage services at home. As an example of the value of case management to carers as well as care recipients, this particular feature of formal services is highly valued by carers who are participating in pilot dementia-care programs funded through the Australian Government Aged Care Innovative Pool.¹⁰

The 2003 Review of Community Care has focused attention on the complexity of the community care system due to multiple assessment points, multiple funding programs and a vast array of services, each with its own set of rules and procedures (DoHA 2004). Case management is a necessary rather than optional form of support for the ‘bridging’ role of primary carers, especially while the Review of Community Care remains a work in progress.

¹⁰ The AIHW is conducting a national evaluation of Aged Care Innovative Pool dementia pilot programs.

5.4 Discussion

This chapter has examined the role of formal services in supplementing and substituting for informal care, albeit with a relatively narrow focus of older care-recipients. Population ageing will lead to higher uptake of formal services to complement the assistance given by carers and offer more specialised assistance that many carers are not equipped to provide. Tailored packages enable people without a primary carer to remain in the community, which might be otherwise impossible. Data on CACP recipients in 2002 reveal that clients with a primary carer include a higher proportion of very old people (85 years or over) and a higher rate of diagnosed dementia than clients without a primary carer. It is intuitively appealing to observe that a highly dependent person stands a better chance of remaining at home if there is a primary carer.

It does not necessarily follow that having a primary carer reduces a person's need for all types of formal assistance. The relationship between use of formal services and carer availability is inextricably linked with the care recipient's level of disability. Naturally, individual preferences and habits of a lifetime feature in the equation.

This chapter has cited several studies of older populations which suggest that, for a given level of disability, a care recipient with a primary carer is likely to be less reliant on formal assistance of a non-professional nature than a person without a primary carer but is likely to use professional services at a higher rate. Theories of substitution and supplementation are supported by this model in which carers and formal service providers work together to provide an appropriate level of care.

Jette et al. (1995) undertook a six-year cohort study to characterise patterns of substitution and supplementation between formal and informal care in the United States. The study led to a proposal that the degree of supplementation or substitution between informal care and formal services depends on an underlying care continuum. The continuum starts with mainly informal care, progresses to mixed informal and formal care and, in some cases, finishes with full formal (institutional) care. Consistent with this model, cross-sectional data show varying degrees of mixed modes of assistance corresponding to individuals at different points on the care continuum. Supplementation is likely to occur when special needs arise that cannot be adequately met by a primary carer (e.g. wound dressing and medication review). Further along the continuum formal care increasingly substitutes for the care given by a primary carer (e.g. high-level personal care and residential respite care).

Cross-sectional service utilisation profiles of the with-carer and without-carer groups in the 2002 CACP Census are similar, which likely reflects efficient targeting in the Aged Care Assessment Program. High proportions of both groups used most types of assistance associated with daily activities during the census week. Lower proportions of clients using home maintenance services and rehabilitation support reflect the fact that these needs arise more sporadically and would ideally be measured over a longer timeframe. The picture that emerges is that older people with severe restrictions require assistance with domestic duties and 50% or more will seek formal assistance in the areas of personal care, social support, and food services. At least one-third of such people require transport assistance. These observations hold irrespective of carer availability, although a slightly higher proportion of CACP clients without a carer used most services concerned with the instrumental activities of daily living (meal preparation, transport, domestic duties etc.). Similar service utilisation profiles possibly reflect the homogeneity of this client population, and the fact that most carers of older people are themselves an older person or an ex-household family member. Older CACP clients without a primary carer appear more likely than clients with a carer to

use social support services. Social support services are aimed at increasing social contact for clients, thus the observed difference possibly relates to the high likelihood that CACP clients without a carer live alone.

Demand for personal care services, including home nursing, will increase in line with increasing numbers of people with a severe or profound restriction living in the community. Unless the data examined here more strongly reflect patterns of supply than demand, they suggest that demand for formal assistance with domestic work is likely to be ongoing and consistently high, irrespective of trends in informal care. Previously it has been found that demand for formal assistance in the instrumental activities of daily living, e.g. meal preparation and domestic duties, among community-dwelling older people with severe disability appears to be higher among certain population groups (Mawby et al. 1996). These include the 'old old', those aged 80 or over, people with higher levels of non-core activity restriction, and people with severe disability who live alone. Mawby and colleagues also reported that use of personal care services is highly correlated with restriction in the core activities of daily living, age and recent hospitalisation.

Observations in relation to CACP clients may not generalise to younger people with a disability or indeed to the wider disability population – including frail, older people – serviced by HACC. Ongoing data developments hold a promise of more broad-based analysis of the interaction between informal care and use of formal services.

Tennstedt, Crawford & McKinlay (1993) in the United States have observed that, controlling for disability, higher levels of unpaid informal assistance are associated with lower use of non-professional community services such as domestic assistance, shopping, transport and home maintenance. The Sydney Older Persons Study provides evidence of the relationship between the availability of informal care and use of formal services in an Australian community (Edelbrock et al. 2003). This latter study investigated the availability of informal network support and use of formal services among 537 community-dwelling older people in inner metropolitan Sydney. The results of a regression analysis on these data indicate that among individuals of equal disease and disability, those without access to unpaid informal assistance made greater use of formal services for help with the instrumental activities of daily living, e.g. meals, transport, domestic help and home maintenance, shopping, laundry and day care, while care recipients with a primary carer accessed professional services (e.g. nursing and medical care, allied health therapy) at a higher rate. The researchers concluded that carers act as a 'bridge' to medical and other professional services, in terms of identifying need, managing referral processes, and facilitating timely contact between care recipient and professionals. At the same time, carers are seen to reduce the care recipient's reliance on formal services for domestic assistance and community access.

The ABS projects that many more 'old old' people, and very old women in particular, will be living alone in the years ahead. Effective community care in this demographic climate implies increasing demand for formal assistance, to compensate for a lack of informal care when a primary carer is not available and to supplement informal care provided by older primary carers, ex-household primary carers, and secondary carers. Chapter 1 showed that, in 1998, over one-third of primary carers with an older care recipient did not live with the care recipient. Thus, as the Australian population ages, formal services will need to respond to the different needs of two distinct groups of primary carers: older, co-resident spouse carers and working carers. A broader range of data than was available for this report is needed to explore trends in the use of formal services by people of all ages with co-resident and non-co-resident carers.

6 Conclusion

Both in Australia and overseas, there has been considerable attention to the role of informal care in the future sustainability of community care systems (examples of recent work in Australia include AIHW 2003 and NATSEM 2004). Yet uncertainty remains because of the myriad of psychosocial factors which influence whether, and under what circumstances, an individual will accept primary responsibility for the welfare of a family member or friend with a severe level of disability. Many such factors cannot be reliably quantified in mathematical and statistical models; the results of most analytical exercises need to be qualified by our limited understanding of substitution and supplementation between informal care and formal services. This report aims to characterise informal care in Australia to enable the reader to form an impression of which factors might play the greater role in shaping informal care over the next decade. Such an appreciation provides a basis for assessing the validity of alternative projection models for informing public policy.

The effects of population ageing, changing patterns of family formation, and work and family balance, particularly as perceived and experienced by women, the traditional primary carers, are central to the international commentary on informal care. A number of overseas studies have been reviewed and are discussed here by way of providing a context for the findings of this report.

Some observers of change in the United States have proposed that the ageing of the population will bring with it a larger proportion of the population with health and personal care needs and that this is occurring at the same time as the traditional supply of paid and unpaid caregivers is shrinking (NHPF 2002). While these trends are evident in the Australian context, researchers have pointed to characteristics of the Australian situation that may support the continuing availability of carers. Although fertility rates are currently declining, the decline in the number of children per family will not occur until the baby boomers replace their parents at the top of the population pyramid. In Australia, the post-Second World War 'baby boom' was notably later and longer than in many other developed countries, thus delaying this decline in family size.

Rowland (1991) has suggested that the post-war marriage boom resulted in an increase in potential family support. Over time, however, marriage rates have declined while divorce rates have increased (ABS 1999b) and these factors may offset this additional family support. Litwin (1997) contends that informal support structures are becoming more fragile and cautions against the 'back-to-the family' policy of long-term care provision. Others have also questioned whether past patterns of informal care can withstand the stresses of contemporary life and the changing nature of 'family' (see for example the discussion in RIS 1998).

While the number of people remaining single is increasing, Howe and Schofield (1996) argue that this is mainly in the generation who are the children of the baby-boomers. Among the oldest generation, improving life expectancies for men reduces the proportion of people at these ages who are widowed. Indeed, Rowland proposes that caring outcomes as affected by marriage should be examined using cohort analysis.

Shaw and Haskey (1999) and Shaw (2000) have proposed that a rise in the proportion of older women with partners will occur in the United Kingdom in the future because the proportions of women ever marrying are higher for cohorts currently aged 40–65 years than for older cohorts and because improved male life expectancies will result in fewer widows.

Australian projections to 2006 derived by McDonald (in AIHW 1997) indicate an increase in the number of older people living as couples in households. McDonald (1997) points out that, while married couples may be surviving longer together, it is possible that both will require care at the same time. Although there is no evidence that disability-free life expectancy is increasing in Australia, disability-free life expectancy is increasing in line with average life expectancy (Mathers 1996). This would suggest that couples surviving longer together have more years in which they are able to provide assistance to each other.

Concern has been expressed about the impact that increased female labour force participation will have on carer availability (e.g. Schofield & Bloch 1998). Chappell (1990) has argued that there is little evidence that this increased workforce participation has resulted in reduced care for older people in the United States, an argument supported by the research of Aytac and Waite (1995). Howe and Schofield (1996) maintain that changes in labour force participation patterns will not be so large as to threaten the availability of carers in the future, and that increased flexibility of work arrangements will allow carers to work and continue their caring role. Since the time of Howe and Schofield's paper, however, older women's labour force participation has risen beyond projected participation rates. Between 1988 and 2001 Australian female labour force participation rates rose from 33% to 49% for women aged 55–59 years, while that for women aged 60–64 years increased from 16% to 25% (AIHW 2002). Howe and Schofield further argue that family changes will not impact negatively on the supply of carers, as future cohorts of women will, on the whole, have completed child-rearing responsibilities before they may need to care for their ageing parents. Millward (1999) contests that there is evidence of many carers having dual caring responsibilities or other responsibilities in addition to caring.

This report contributes to the debate, firstly by describing the main players and context of informal care in Australia and, secondly, by attempting to quantify the relative impact of certain factors on informal care over the next decade. There is a strong focus on primary carers – those people who provide the most ongoing assistance with the core activities of daily living to a person with a disability. The ABS collects detailed data on primary carers and the work they perform in its 5-yearly Survey of Disability, Ageing and Carers. Although primary carers numbered 450,900 out of an estimated 2.3 million carers at the time of the 1998 survey, these numbers do not translate proportionately in terms of nature, duration and intensity of the care that is provided. The vast majority of primary carers provide assistance to one or more individuals with a severe or profound restriction in self-care, mobility or communication.

Relative to approximately one million persons with a severe or profound restriction in 1998, the number of primary carers does not imply that over half a million people did not receive informal care in 1998. Around 20% of primary carers provide ongoing assistance to more than one person and many people receive assistance from their care networks without identifying a primary carer.

Chapter 1 summarised the results of the most recent ABS survey, which revealed that caring for a person with a severe or profound restriction was a predominantly female occupation in 1998. Women comprised 70% of primary carers, according to the survey definition. Primary carers of young people were mostly mothers, those caring for middle-aged people were mostly partners or spouses, and primary carers of people aged 65 or over were a mix of adult offspring and spouses or partners. However, at ages 75 years and over a primary carer in 1998 was just as likely to be male as female (Figure 1.1). In 1998, 64% of male primary carers were spouses or partners of their care recipient, whereas female primary carers were more evenly represented among spouses or partners (34%), parents (27%) and children (26%) of

care recipients (Table 1.3). Overall, spouses and partners accounted for 43% of primary carers in 1998. Most primary carers (79%) lived with their care recipient, while carers of older people (65 years or over) were less likely to be co-resident (62%) (Table 1.1). Most ex-household carers of older people are daughters and daughters-in-law with other family responsibilities. Changes to women's predisposition to care and trends in the formation of spouse and partner relationships are likely to have a profound impact on the level of informal care.

Chapter 2 described the nature of caring work in terms of intensity, duration and the disabling conditions that care recipients report as causing the most problems. Over 50% of primary carers in 1998 reported spending 20 or more hours per week in the caring role and over one-third reported spending 40 or more hours per week on caring activities (Table 2.4). Over 60% of primary carers aged 15 or over usually assisted their main care recipient with self-care (dressing, bathing, feeding, using the toilet and managing incontinence) and 74% reported that they usually assisted with mobility (lifting, transferring, and moving around in and outside the home). These results underscore the important contribution of primary carers to the welfare of older Australians and people with a disability.

Chapter 3 examined the changing context of community living with a focus on dimensions that might influence future levels of informal care. Primary carers in 1998 most often cited family obligation and duty to care as motivating factors for accepting their caring role.

Chapter 4 described four scenarios of informal care to 2013. A 'baseline propensity to care' scenario assumes that population projections with respect to age, sex, labour force participation category and living arrangement drive changes in the number of primary carers over the next decade. In this scenario, the proportion of people in each age group by sex, labour force participation category and living arrangement who are primary carers is held at the 1998 level. Three other three scenarios separately assess the impact of some commonly held assumptions: that in the future, relatively fewer women will reduce paid employment to take on a caring role; that higher average life expectancy could mean a higher proportion of supportive co-resident relationships at older ages; that there will be an overall decreased propensity to care as a result of high rates of relationship breakdown bringing an altered community sense of duty to care. More specifically, the chapter examines the relative impact on future numbers of primary carers of:

- (a) projected demographic changes (focusing on changes in the age and sex structure of the population and patterns of living arrangement) and projected trends in labour force participation throughout the projection period which combine to drive change in the size of the primary carer pool in the absence of any underlying change in propensity to care among population groups by age, sex, living arrangement and labour force participation category. This is the 'baseline propensity to care' scenario, which applies 1998 carer rates;
- (b) a decrease, arbitrarily set at 20%, in the proportion of women aged 25–59 years who are willing to reduce paid employment to take on a primary carer role (this proportion was 7% in 1998) that might result from higher labour force participation among older working-aged women;
- (c) an increase, arbitrarily set at 20%, in spouse or partner carers aged 60 years or over that might result from converging male and female life expectancies; and
- (d) an arbitrary 20% decline in the proportion of primary carers by age and sex.

The objective was not to forecast the number of primary carers to 2013, but to isolate the impact of changes that have been hypothesised in the informal care literature and assess them relative to each other. Compared to the situation in 1998 and considering just these

scenarios, it appears that only an across-the-board decreased propensity to care will have a marked impact on the ratio of primary carers to the 'at risk' population over the next decade. In the social context of informal care in the 21st century, such a scenario is not entirely unrealistic. Overall decline in the propensity to care could occur through a complex interplay of altered patterns in interpersonal relationships, family formation, living arrangements, labour force participation and life expectancy affecting multiple generations.

There is a sense that higher rates of relationship breakdown could prove a significant factor in the future of informal care. While these trends signal lower caring potential, this report does not intend to imply that the reduction will equate to a 20% decline in age- and sex-specific proportions of primary carers. A figure of 20% was used consistently to compare the same magnitude of effect on the trajectories listed above, and the sensitivity of the outcome of each scenario was verified using alternative rates of 10% and 30%.

Chapter 5 presented an overview of patterns of substitution and supplementation of formal and informal care among CACP recipients in 2002. Package recipients with a primary carer were more likely to have a diagnosis of dementia as recipients without a carer, highlighting the important role of primary carers in helping vulnerable older people to remain in the community. Package recipients with a carer were about as likely as recipients without a carer to receive help with personal care and domestic activities from formal services. Marked differences in service utilisation between the with- and without-carer groups of package recipients are evident only in the areas of social support and transport. These data highlight the importance of formal community services in supplementing the work of family carers and in providing a substitute to those people who have limited access to care from family and friends. Further investment in data development is required to more fully explore the relationship between formal and informal care across all age and disability groups.

Chapter 5 also described the key national carer support programs that are intended to help sustain carers in their caring role: financial support, respite care, and programs for the delivery of carer information and education services. Delivered effectively, these programs decrease the costs to carers, increase the benefits of the caring experience and in so doing, help to maintain the balance of care.

Primary carers are just one, albeit significant, component of informal care in Australia. Many care recipients receive assistance from members of a care network without identifying a primary carer as such. This at least partly explains the 'gap' between the number of primary carers and the number of people with severe or profound restriction in core daily activities who were living in households in 1998. Approximately 11% of primary carers in 1998 were a friend or relative, other than immediate family, of their care recipient; however, it cannot be assumed that people from these groups will step in to compensate for any future reduction in care provision by the immediate family. More distant relatives, friends and neighbours are not generally involved in providing support of the type and intensity given by a spouse or offspring carer (RIS 1998). Further, if the dependency levels of individuals living in the community without a primary carer were to increase substantially over time, then a care ratio of the 1998 proportion could represent an entirely different scenario from the baseline presented in this report. While the difference in the projected number of people in need of assistance and the projected number of primary carers does not necessarily define unmet need for informal care, any widening of that gap or any change in the dependency levels of people who do not have access to a primary carer should be closely monitored.

In applying analytical methods to the question of the future of informal care, one should recognise that the level of informal care provision represented by primary carers in 1998 is a quantitative measure of society's response to prevailing needs at a point in time. Disability-

related need in the community reflects not only the total population of people with severe or profound restrictions, but also the provision of care accommodation and the preferred living arrangements of those in need of assistance. To suppose that a proportionate response based on 1998 primary carer numbers would prevail throughout a period in which there will be a dramatic increase in the older population is highly questionable. In this respect, a scenario based on 1998 carer rates by age, sex, labour force category and living arrangement category is no more likely than any of the other scenarios considered here. It is used only as a baseline against which to compare the effect of the other scenarios, relative to each other.

Assuming that 1998 age- and sex-specific disability rates prevail, the number of people aged 10 years or over with severe and profound core activity restriction will rise to just over 1.4 million by 2013 (Table 3.1). Older people, 65 years and over, will account for approximately 67% of projected growth between 2003 and 2013 in the population with a severe and profound restriction and a further 30% growth in this population will occur in the 45–64 years age group (Table 3.1). Significantly, the number of people aged 85 years or over with a severe or profound activity restriction is projected to grow by over 50% (96,400 people) between 2003 and 2013.

In 1998, approximately 29% of people aged 65 years or over with a severe or profound restriction lived in some form of cared accommodation excluding hospitals (ABS 1999a: Table 8). Critical factors that are likely to determine whether growth in the number of primary carers keeps pace with growth in the population at risk of needing assistance include:

- how the household population with a severe or profound restriction grows in proportion to the total number of people with this level of disability i.e. the level of provision of permanent cared accommodation and the preferred living arrangements of people in this population group; and
- the willingness and capacity of people to care for very old and highly impaired family members.

The discussion in Chapter 3 on motivation to provide care highlights the critical factor of sense of duty to care that comes from family belonging and interpersonal relationship. On the surface, there is reason to be optimistic that future numbers of primary carers and carers in general will represent a proportionate response to increasing numbers of people with severe disabilities living in the community. Close attention should be paid to meeting the needs of primary carers, especially the projected growing number of older carers and carers with multiple caring roles.

As the population ages steady growth in the number of primary carers who do not live with their care recipient can be expected because of growth in the number of older people in need of assistance for whom traditionally, there has been a higher proportion of ex-household carers. Crucial issues for these carers, who are more likely than co-resident carers to be female, younger and have other family responsibilities, include their ability to combine paid employment with the caring role, extra costs that are associated with caring, and the impact of competing demands on their psychological and emotional wellbeing. The ability to continue to provide adequate care for a son or daughter with a disability, or an ageing partner, will be a source of anxiety for a growing number of older, mainly co-resident, carers. Awareness of, and confidence in, the system of assessment, referral and service delivery is critical if care recipients and their carers are to receive timely and appropriate support, particularly as care recipient needs, hence carer support needs, are rarely static. Effective ongoing communication of this type of information to people who may have become isolated

for any number of reasons including disability, age, cultural background, social or financial disadvantage, or the circumstances that can be associated with full-time provision of care, presents a major challenge.

Recalling that the achievement of policy objectives in aged and community care depend on 'the extent to which the relationship between the carer and the person cared for can be sustained without unacceptable costs to either' (DHFS 1996), the challenge over the next ten years will be to implement a framework for community care that facilitates early intervention for carers and care recipients who are in need of formal support and to continue to develop support mechanisms that are responsive to the needs of individuals.

Appendix: tables

Table A1: Data for Figure 1.1: carers by carer status in 1998 and estimated resident population in 2002 ('000)

Sex/age	Primary carers	Non-primary carers	All carers	1998 survey population	Estimated resident population 2002
Males					
0–14	1.2	51.9	53.1	2,000.6	2,041.8
15–24	5.0	122.9	127.9	1,378.0	1,385.3
25–34	6.5	109.1	115.6	1,429.5	1,430.4
35–44	22.9	138.7	161.5	1,435.4	1,481.9
45–54	34.9	157.7	192.5	1,238.1	1,332.5
55–64	26.9	130.7	157.6	808.6	976.8
65–74	17.6	114.6	132.2	614.4	646.5
75+	18.5	62.7	81.2	377.3	458.5
<i>All ages</i>	<i>133.5</i>	<i>888.4</i>	<i>1,021.9</i>	<i>9,282.0</i>	<i>9,753.8</i>
Females					
0–14	1.5	50.5	52.0	1,905.0	1,940.2
15–24	8.6	122.7	131.3	1,303.8	1,336.9
25–34	41.0	151.7	192.7	1,440.0	1,447.9
35–44	74.0	189.3	263.3	1,450.0	1,501.4
45–54	79.8	192.0	271.8	1,206.3	1,342.5
55–64	52.2	156.0	208.2	795.7	955.0
65–74	44.0	88.4	132.4	674.8	686.5
75+	16.2	37.8	54.0	602.0	698.5
<i>All ages</i>	<i>317.3</i>	<i>988.4</i>	<i>1,305.8</i>	<i>9,377.6</i>	<i>9,909.0</i>
Persons					
0–14	2.8	102.4	105.1	3,905.6	3,982.0
15–24	13.6	245.7	259.2	2,681.8	2,722.3
25–34	47.5	260.8	308.3	2,869.5	2,878.4
35–44	96.9	328.0	424.9	2,885.5	2,983.3
45–54	114.6	349.7	464.4	2,444.4	2,675.1
55–64	79.1	286.7	365.8	1,604.3	1,931.7
65–74	61.7	203.0	264.6	1,289.2	1,333.0
75+	34.7	100.5	135.2	979.4	1,157.0
All ages	450.9	1,876.8	2,327.7	18,659.7	19,662.8

Source: 1998 ABS Survey of Disability Ageing and Carers Confidentialised Unit Record File; ABS preliminary population estimates for 30 June 2002 (Series Q).

Table A2: Data for Figure 2.1: labour force status of carers and non-carers aged 25–54 years, 1998^(a)

Sex/employment status	Primary carer		Other carer		Not a carer		Total	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
Males								
Employed FT	29.9	46.6	285.5	70.4	2,905.9	80.1	3,221.3	78.7
Employed PT	*7.1	11.0	37.2	9.2	259.9	7.2	304.1	7.4
Unemployed	*8.4	13.1	37.0	9.1	198.6	5.5	244.0	6.0
Not in LF	18.8	29.4	45.8	11.3	261.8	7.2	326.5	8.0
<i>Total</i>	<i>64.2</i>	<i>100.0</i>	<i>405.5</i>	<i>100.0</i>	<i>3,626.3</i>	<i>100.0</i>	<i>4,096.0</i>	<i>100.0</i>
Females								
Employed FT	34.6	17.8	180.6	33.9	1,299.8	38.7	1,515.1	37.0
Employed PT	61.6	31.6	162.0	30.4	1,043.9	31.0	1,267.5	31.0
Unemployed	*8.8	4.5	24.5	4.6	152.5	4.5	185.8	4.5
Not in LF	89.8	46.1	165.8	31.1	866.4	25.8	1,122.1	27.4
<i>Total</i>	<i>194.8</i>	<i>100.0</i>	<i>533.0</i>	<i>100.0</i>	<i>3,362.6</i>	<i>100.0</i>	<i>4,090.5</i>	<i>100.0</i>
Persons								
Employed FT	64.5	24.9	466.1	49.7	4,205.7	60.2	4,736.4	57.9
Employed PT	68.7	26.5	199.2	21.2	1,303.8	18.7	1,571.6	19.2
Unemployed	17.2	6.6	61.5	6.6	351.1	5.0	429.8	5.3
Not in LF	108.7	42.0	211.7	22.6	1,128.3	16.1	1,448.6	17.7
Total	259.0	100.0	938.5	100.0	6,988.9	100.0	8,186.5	100.0

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

Table A3: Data for Figure 2.2: labour force status of carers by hours of caring per week, and non-carers aged 25–54 years, 1998

Sex/hours of caring	Employed FT		Employed PT		Unemployed		Not in the labour force		Total	
	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent	'000	Per cent
Males										
Primary carers										
Less than 20 hours	23.7	67.9	**3.2	**9.2	*4.3	*12.3	*3.7	*10.6	34.9	100.0
20–39 hours	**2.8	**38.9	—	—	**1.1	**15.3	**3.3	**45.8	*7.2	100.0
40+ hours	**2.9	**14.7	*3.9	*19.8	**2.2	**11.2	10.7	54.3	19.7	100.0
Not stated	**0.5	**0.2	—	—	**0.8	**0.3	**1.2	**0.5	**2.5	100.0
<i>Total</i>	29.9	46.6	*7.1	*11.0	*8.4	*13.1	18.8	29.4	64.2	100.0
Other carers	285.5	70.4	37.2	9.2	37.0	9.1	45.8	11.3	405.5	100.0
Non-carers	2,905.9	80.1	259.9	7.2	198.6	5.5	261.8	7.2	3,626.3	100.0
<i>Total</i>	3,221.3	78.7	304.1	7.4	244.0	6.0	326.5	8.0	4,096.0	100.0
Females										
Primary carers										
Less than 20 hours	25.9	27.5	36.6	38.8	*4.5	*4.8	27.2	28.9	94.2	100.0
20–39 hours	*4.4	*13.8	*7.9	*24.8	**2.6	**8.2	16.9	5.3	31.8	100.0
40+ hours	*3.8	*6.5	13.8	23.5	**1.6	**2.7	39.6	67.3	58.8	100.0
Not stated	**0.5	**0.1	**3.2	**32.3	—	—	*6.2	*62.6	9.9	100.0
<i>Total</i>	34.6	17.8	61.6	31.6	*8.8	*4.5	89.8	46.1	194.8	100.0
Other carers	180.6	33.9	162.0	30.4	24.5	4.6	165.8	31.1	533.0	100.0
Non-carers	1,299.8	38.7	1,043.9	31.0	152.5	4.5	866.4	25.8	3,362.6	100.0
<i>Total</i>	1,515.1	37.0	1,267.5	31.0	185.8	4.5	1,122.1	27.4	4,090.5	100.0
Persons										
Primary carers										
Less than 20 hours	49.6	38.4	39.8	30.8	*8.8	*6.8	30.9	23.9	129.1	100.0
20–39 hours	*7.2	*18.5	*7.9	*0.3	*3.7	*9.5	20.1	51.5	39.0	100.0
40+ hours	*6.7	*8.5	17.7	22.5	*3.8	*4.8	50.3	64.1	78.5	100.0
Not stated	**1.0	**8.1	**3.2	**25.8	**0.8	**6.4	*7.4	*59.7	12.4	100.0
<i>Total</i>	64.5	24.9	68.7	26.5	17.2	6.6	108.7	42.0	259.0	100.0
Other carers	466.1	49.7	199.2	21.2	61.5	6.6	211.7	22.6	938.5	100.0
Non-carers	4,205.7	60.2	1,303.8	18.7	351.1	5.0	1,128.3	16.1	6,988.9	100.0
Total	4,736.4	57.9	1,571.6	19.2	429.8	5.3	1,448.6	17.7	8,186.5	100.0

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

Table A4: Estimated and projected number of people with a severe or profound restriction 10 years and over, by age and sex, 1998, 2003, 2008 and 2013

Age/sex	1998	2003	2008	2013
Males				
10–24	62,200	64,600	66,200	66,500
25–34	35,500	36,400	36,500	37,600
35–44	43,900	45,200	46,000	46,900
45–54	67,600	74,000	79,900	82,300
55–59	39,200	50,400	56,900	61,200
60–64	30,600	35,600	46,300	52,300
65–69	26,100	26,700	31,400	41,000
70–74	33,500	34,900	36,200	43,000
75–79	37,100	43,800	46,600	49,100
80–84	26,800	34,600	41,000	44,500
85+	38,500	51,000	67,500	85,000
<i>Total</i>	<i>441,000</i>	<i>497,200</i>	<i>554,500</i>	<i>609,300</i>
Females				
10–24	37,900	39,200	39,900	39,900
25–34	35,000	35,500	34,900	35,500
35–44	57,800	59,300	60,400	61,100
45–54	80,900	90,400	98,100	100,800
55–59	34,300	44,200	51,200	55,800
60–64	34,700	39,600	51,300	59,400
65–69	31,300	31,800	36,500	47,400
70–74	49,300	49,100	50,200	57,800
75–79	66,300	73,900	74,300	76,700
80–84	63,800	76,200	85,400	87,200
85+	106,800	132,700	164,100	195,100
<i>Total</i>	<i>598,100</i>	<i>671,800</i>	<i>746,300</i>	<i>816,700</i>

(continued)

Table A4 (continued): Estimated and projected number of people with a severe or profound restriction 10 years and over, by age and sex, 1998, 2003, 2008 and 2013

Age/sex	1998	2003	2008	2013
Persons				
10–24	100,100	103,900	106,200	106,400
25–34	70,500	71,900	71,400	73,100
35–44	101,700	104,500	106,400	108,000
45–54	148,500	164,300	178,000	183,100
55–59	73,400	94,700	108,100	117,000
60–64	65,300	75,200	97,600	111,800
65–69	57,500	58,500	67,900	88,300
70–74	82,700	84,000	86,400	100,800
75–79	103,500	117,600	120,900	125,800
80–84	90,600	110,800	126,400	131,700
85+	145,300	183,700	231,600	280,100
Total	1,039,100	1,169,000	1,300,700	1,426,100

Source: Jenkins et al. (2003: Table A1).

Table A5: Primary carers aged 10 years and over, by age and sex, 1998

Age	Females	Males	Persons
Number			
10–24	10,100	6,200	16,300
25–34	41,000	6,500	47,500
35–44	74,000	22,900	96,900
45–54	79,800	34,900	114,600
55–59	28,200	14,500	42,700
60–64	24,000	12,400	36,400
65–69	22,000	8,800	30,900
70–74	22,000	8,800	30,800
75–79	11,600	12,100	23,700
80–84	*3,300	*5,100	*8,500
85+	**1,200	**1,300	**2,500
Total	317,300	133,500	450,900
Per cent			
10–24	3.2	4.7	3.6
25–34	12.9	4.9	10.5
35–44	23.3	17.1	21.5
45–54	25.1	26.1	25.4
55–59	8.9	10.8	9.5
60–64	7.6	9.3	8.1
65–69	6.9	6.6	6.8
70–74	6.9	6.6	6.8
75–79	3.7	9.1	5.3
80–84	*1.1	*3.8	*1.9
85+	**0.4	**1.0	**0.6
Total	100.0	100.0	100.0

Source: Jenkins et al. (2003: Table A2).

Table A6: Primary carers by sex, relationship to care recipient and whether they live with the care recipient, 1998

Sex/relationship to care recipient	Lives with care recipient	Does not live with care recipient	Total
Males			
Spouse or partner	85,000	**400	85,400
Parent	10,400	**600	11,100
Child	15,200	12,600	27,800
Other relative or friend	*5,200	*4,000	*9,200
<i>Total</i>	<i>115,900</i>	<i>17,600</i>	<i>133,500</i>
Females			
Spouse or partner	107,700	**500	108,200
Parent	82,100	*3,300	85,400
Child	36,100	46,900	82,900
Other relative or friend	14,600	26,200	40,800
<i>Total</i>	<i>240,500</i>	<i>76,800</i>	<i>317,300</i>
Persons			
Spouse or partner	192,700	**900	193,600
Parent	92,600	*3,900	96,500
Child	51,300	59,400	110,700
Other relative or friend	19,800	30,200	50,000
Total	356,400	94,400	450,900

Source: Jenkins et al. (2003: Table A3).

Table A7: Community Aged Care Packages clients by service type and carer availability, census week 2002

Age group	CACP service type								Total ^(a)
	Domestic assistance	Personal care	Social support	Food services	Transport	Home maintenance	Temporary respite	Rehabilitation support	
Number (clients)									
65–74									
With carer	1,548	1,089	1,144	795	694	309	220	39	2,023
No carer	1,592	792	1,061	847	788	363	28	29	1,835
<i>Total</i>	<i>3,140</i>	<i>1,881</i>	<i>2,205</i>	<i>1,642</i>	<i>1,482</i>	<i>672</i>	<i>248</i>	<i>68</i>	<i>3,858</i>
75–84									
With carer	4,725	3,357	2,944	2,674	1,877	804	402	88	5,925
No carer	3,941	2,070	3,367	2,306	1,941	827	47	79	4,472
<i>Total</i>	<i>8,666</i>	<i>5,427</i>	<i>6,311</i>	<i>4,980</i>	<i>3,818</i>	<i>1,631</i>	<i>449</i>	<i>167</i>	<i>10,397</i>
85+									
With carer	4,321	3,362	2,465	2,826	1,485	693	299	54	5,349
No carer	3,266	2,013	3,018	2,291	1,490	666	26	163	3,682
<i>Total</i>	<i>7,587</i>	<i>5,375</i>	<i>5,483</i>	<i>5,117</i>	<i>2,975</i>	<i>1,359</i>	<i>325</i>	<i>217</i>	<i>9,031</i>
Total	19,393	12,683	13,999	11,739	8,275	3,662	1,022	452	23,286
Per cent (clients)									
65–74									
With carer	76.5	53.8	56.5	39.3	34.3	15.3	10.9	1.9	100.0
No carer	86.8	43.2	57.8	46.2	42.9	19.8	1.5	1.6	100.0
<i>Total</i>	<i>81.4</i>	<i>48.8</i>	<i>57.2</i>	<i>42.6</i>	<i>38.4</i>	<i>17.4</i>	<i>6.4</i>	<i>1.8</i>	<i>100.0</i>
75–84									
With carer	79.7	56.7	49.7	45.1	31.7	13.6	6.8	1.5	100.0
No carer	88.1	46.3	75.3	51.6	43.4	18.5	1.1	1.8	100.0
<i>Total</i>	<i>83.4</i>	<i>52.2</i>	<i>60.7</i>	<i>47.9</i>	<i>36.7</i>	<i>15.7</i>	<i>4.3</i>	<i>1.6</i>	<i>100.0</i>
85+									
With carer	80.8	62.9	46.1	52.8	27.8	13.0	5.6	1.0	100.0
No carer	88.7	54.7	82.0	62.2	40.5	18.1	0.7	4.4	100.0
<i>Total</i>	<i>84.0</i>	<i>59.5</i>	<i>60.7</i>	<i>56.7</i>	<i>32.9</i>	<i>15.0</i>	<i>3.6</i>	<i>2.4</i>	<i>100.0</i>
Total	83.3	54.5	60.1	50.4	35.5	15.7	4.4	1.9	100.0

(a) Total clients by age and carer availability. Clients may use more than one service type.

Source: Community Aged Care Packages census September–October, 2002.

Glossary

Cared accommodation – includes general hospitals, psychiatric hospitals, aged care homes, retirement villages and other ‘homes’.

Care recipient – a person receiving assistance from a primary carer.

Carer – used to refer to primary carers, as defined by the ABS. These are people, of any age, who provide the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance must be ongoing, for at least six months and must be provided for one or more of the core activities (self-care, mobility or communication) (ABS 1999a:71).

Core activity restriction – a definition used in the ABS Survey of Disability, Ageing and Carers to mean a restricted capacity for self-care, mobility and/or communication.

Dynamic microsimulation – uses a population of individuals who are representative of the population by the characteristics used for the projection. The projection proceeds by asking a yes/no question in respect to each individual, as that individual ages by one year. The chance that the answer is ‘yes’ is generated by random numbers based on transition probabilities. Interdependencies are then taken into account. A microsimulation run twice will produce two different results because it is a stochastic process (McDonald 2001).

Macrosimulation – a matrix of probabilities is specified that determines the chance that an individual in a category at an age will be in a different category at the next age. This matrix of transition probabilities is applied to a vector of possible states using an increment/decrement life table. The solution is obtained through matrix inversion (McDonald 2001).

Projection – is not a forecast, but simply illustrates future changes which would occur if the stated assumptions were to apply over the projection period.

Propensity method – an assumed proportional distribution of characteristics is applied to population projections by age and sex (McDonald 2001).

Severe or profound restriction – used to refer to people with a severe or profound core activity restriction, as defined by the ABS (see Box 2.1). These are people who sometimes or always require assistance from another person with the core activities of self-care, mobility or communication.

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