

Carers in Australia

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

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**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.