

4. Australia's carers

Key points

Caring is a major task of families that plays a valuable role in Australian society.

- In 2003 there were around 2.6 million carers who provided assistance to those who needed help because of disability or age-related impairments. About a fifth of these were primary carers; that is, providing the majority of the informal help needed by a person with a disability.
- Most care occurs within families — 42% of primary carers were caring for their partner, 26% for their child (with disability or illness), 23% for their parents, and 9% for other people.
- The contribution of carers is estimated to be valued at around \$30.5 billion per annum.

People's caring responsibilities vary over the course of a lifetime and generally increase with age.

- People aged 35-39 years experience some of the most intense caring responsibilities as they care for children as well as for other people who are frail aged or are living with disability.
- Almost a quarter of all 55-64 year olds are carers.
- Nearly three-quarters (71%) of primary carers are women.

Caring has a substantial impact on carers' lives.

- Primary carers are less likely to be working (or if they are, only part time), have lower incomes and high expenses due to the nature of the caring role, and are more likely to suffer depression.
- Of primary carers, 55% spend 20 or more hours a week actively caring and 37% spend 40 or more hours.
- Caring is often a long-term commitment – over a quarter of carers have provided care for a person with disability or frail aged for between 10 and 24 years. A further quarter of carers have provided care for between five and nine years.

The demand for care is likely to increase in the future as Australia's population ages.

- The proportion of Australians aged 65 years and over is expected to almost double by 2051, to 26 per cent of the population (or more than 7 million people).

Caring is one of the core activities of families, with most Australians likely to undertake caring responsibilities at some time during their lives. The type and extent of care provided tends to vary across a person's life time and is different across family types. Care is provided in both formal and informal settings – formally by people employed in the child care, health, aged care or community services; and informally by relatives or friends. The contribution of carers is of great benefit to those being cared for, as well as to the Australian community more broadly, in both social and economic terms.

Family members manage their caring role alongside many other responsibilities. The reality for many Australians is that a significant amount of their lives is spent shouldering heavy caring responsibilities, sometimes at great personal cost. The impacts of caring on carers and their families cannot be underestimated. Caring can have a significant effect on the financial, emotional and physical wellbeing of carers and their families.

Combined, Australia's low fertility and ageing population have major implications for future caring in Australia. For families themselves, there will be increased pressure to provide further informal care to the frail aged and family members with disability. More broadly, there will be increasing pressure to provide additional aged care and services for frail aged Australians and those with disability.

This chapter discusses the nature of caring in Australian families. It highlights the basic types of care, the motivations to care, and the relationship between carers and people receiving care. It also discusses the impacts

of caring on carers, including on work and finances, time, health, and wellbeing.

Type of care

Caring responsibilities can vary considerably. The types of care likely to be provided by families include care for dependent children by parents, and care for the frail aged or people with disability, whether family or friends. The most common type of care is the care provided by parents for dependent children (29% of adults aged 20 years and over) and care for infirm spouses, or spouses with disability by their partners (8% of adults aged 20 years and over) (AMP.NATSEM, 2006).

Care for children

Caring for one's own children is the most common first experience of caring. While most care is provided by parents for dependent children, other responsibilities mean that, at times, this care is provided informally by other family members or friends, or formally by paid child care workers. The use of child care (separate to that provided by parents) to balance work and family is discussed in more detail in Chapter 7. This chapter focuses on the provision of care for family members with disability or the frail aged, rather than dependent children generally.

Aged care

Throughout the life course, many Australians will at some stage care for frail aged parents and/or partners. In 2006, over 2.7 million people (13.3%) were aged 65 years and over, of which 330,000 people (1.6%) were aged 85 years and over. As Australia's population ages,

the proportion of people aged 65 years and over is projected, by the Australian Bureau of Statistics (ABS), to almost double to 26% of the population in 2051 (or more than 7 million people). The number of Australians aged 85 years and over in 2051 is expected to increase to more than 5% of the population (or over 1.6 million people).

Many older Australians require special care or assistance. Of people aged 60 years and over in 2003 – the latest period for which detailed official statistics are available – 41% reported needing assistance because of disability, or due to their frail age, to help them manage health conditions or cope with everyday activities. People aged 85 years and over reported a much higher need for assistance than those aged 60-69 years (84% compared with 26%). The ageing of Australia's population will increase the number of Australians who require special care and assistance.

People with disability

Caring for people with disability also affects many Australian families. Caring for a family member with disability is not an activity that people necessarily expect or plan for. While caring for people with disability is highly valued by those receiving care, it can be a particularly significant and challenging activity that has impacts for carers and their families. In 2003 one-in-five people in Australia – almost four million – had a reported disability, as defined by the ABS (see box). Of the 3.8 million people living at home with disability, 61% reported needing some form of assistance to help them manage their health conditions or cope with the activities of everyday life.

The ABS defines disability as any limitation, restriction or impairment, which has lasted, or is likely to last for at least six months and restricts everyday activities. Examples range from hearing loss which requires the use of a hearing aid, to difficulty dressing due to arthritis, to advanced dementia requiring constant help and supervision.

Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0).

Carers

The impact of caring responsibilities on families is widespread. In 2003 there were around 2.6 million carers who provided assistance to those who needed help because of disability or old age. About a fifth of these (19%) were primary carers; that is, people who provided the majority of the informal help needed by a person with disability. Most primary carers (78%) cared for a person living in the same household.

Women are more likely than men to be carers. Just over half (54%) of all carers were women. Primary carers are even more likely than other carers to be women (71%), although the difference between the sexes was less pronounced for those primary carers aged 65 years and over (58% female). The 45-54 year old age group contained the largest number of primary carers for both men and women (32,200 and 83,400 respectively) (see Figure 4.1).

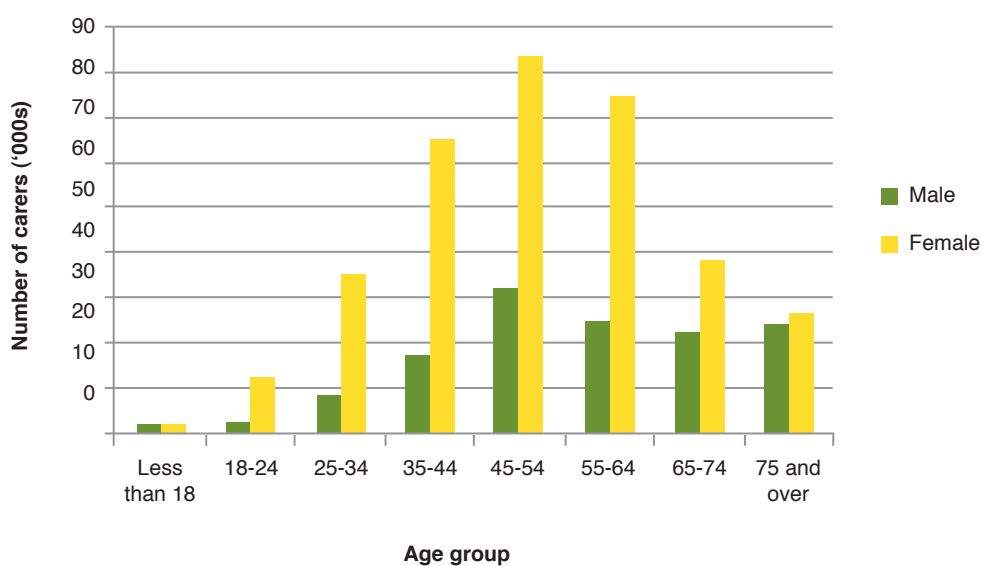
Levels of care

The ABS defines a carer as 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 older persons (i.e. aged 60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months. Assistance to a person in a different household relates to 'everyday types of activities'. Where the person receiving care lives in the same household as the carer, the assistance is for one or more of the following activities: cognition or emotion; communication; health care; housework; meal preparation; mobility; paperwork; property maintenance; self care; and transport.

A primary carer is a person aged 15 years and over who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance is provided for one or more of the core activities (communication, mobility and self care).

Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0).

Figure 4.1 Age profile of primary carers (a)
2003

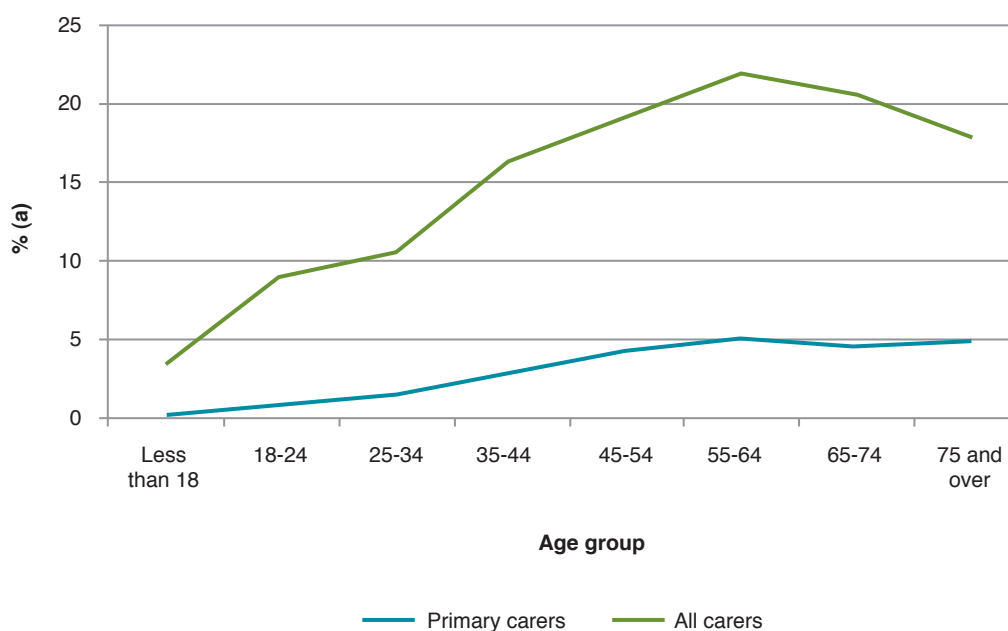


(a) Living in households.

Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0).

Generally, caring responsibilities increase with age. In 2003 the proportion of people living in households that were identified as carers increased from 9% of 18-24 year olds to 22% of 55-64 year olds (see Figure 4.2).

Figure 4.2 Caring responsibilities increase with age 2003



(a) Proportion of persons living in households that are carers.

Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0).

Caring responsibilities vary across a person's life cycle.

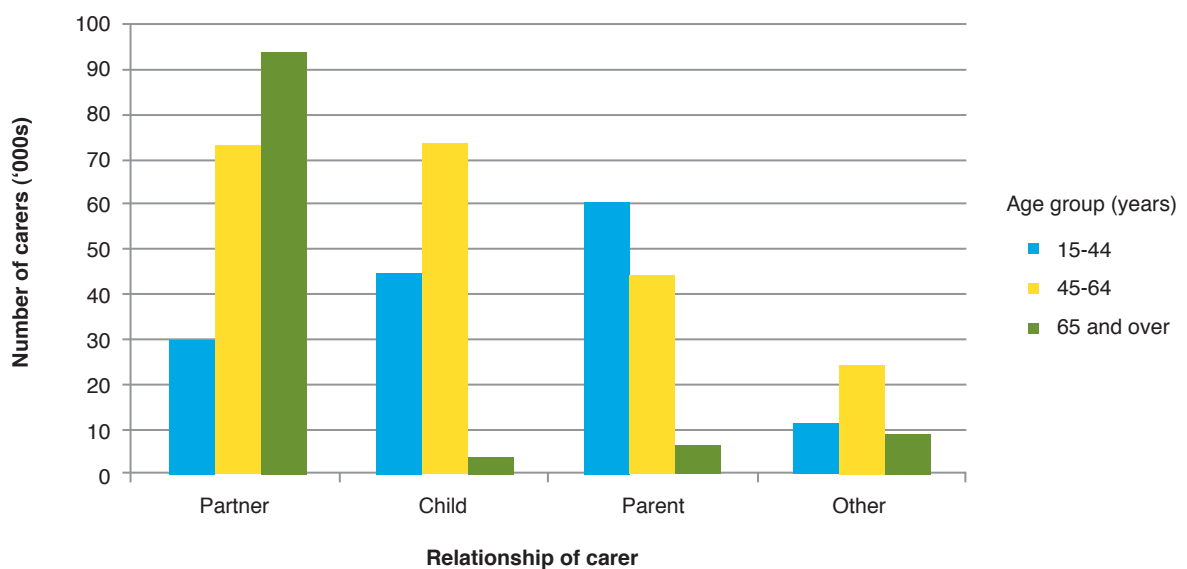
The general pattern of caring usually starts with care for a child as part of parenting responsibilities. However, Carers Australia suggests that in 2003 around 100,000 children aged under 15 years were carers, either caring for their parents or other family members (2008b). Depending on the disability or illness, caring can be time-limited or a life-long responsibility. Generally, people start caring for elderly parents or relatives as they reach their midlife, while many elderly people also provide care for their infirm partners.

Most care for people with disability or the frail aged occurs within families. In 2003, 42% of primary carers were mainly caring for their partner, 26% for their child (with disability or illness as opposed to normal parenting responsibilities), 23% for their parents and 9% mainly caring for other people.

While caring varies over the course of a life time, research shows that there are some ages

where caring is more concentrated than others. Analysis of the results of the 2003 ABS survey data shows that some of the most intense caring responsibilities occur when people are in the age group 35-44 years. There are around 720,000 Australians who have dual responsibilities for caring for younger children and for another person who is disabled or frail aged. Around 40% of these are 33-44 years of age (AMP. NATSEM, 2006).

Figure 4.3 Relationship of primary carer to person receiving care 2003



Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0).

The relationship between a primary carer and the person receiving care is closely associated with age. Figure 4.3 shows that most older carers were spouses or partners

of the person receiving care. For primary carers aged under 65 years, a high proportion were parents or children of the people receiving care.

Indigenous Carers

There is very little information available about the number of Indigenous carers in Australia. However, Carers Australia estimates there are around 43,000 Indigenous carers.

Research by Carers Australia suggests that due to the nature of caring in Indigenous communities, caring for a person with disability, chronic condition, mental illness or who is aged is often a community responsibility. Primary carers are more likely to be women and are less likely to identify themselves as carers because caring is 'just what they do'. An individual carer in an Indigenous community is also likely to be caring for several people across generations.

Source: Carers Australia, *Discussion Paper on Indigenous Carers and Communities*, December 2007.

Motivations for caring

For most carers, their major motivation for caring relates to family. Table 4.1 lists the reasons for taking on caring roles by primary carers. The most common reason given by primary carers for caring for people who are

frail aged or who have disability was due to 'family responsibility'. Other reasons also likely to be connected to being part of a family include 'emotional obligations' and that the carer felt they 'had no other choice'.

Table 4.1 What motivates primary carers?
2003

Reason (a)	Per cent (b)
Family responsibility	58.4
Could provide better care	39.1
Emotional obligation	34.5
No other family or friends available	23.5
Had no other choice	18.4
Alternative care too costly	17.1
No other family or friends willing	15.1
No other care arrangements available	11.9

(a) More than one reason could be reported and components do not add to 100%.

(b) Proportion of persons living in households that are carers.

Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0).

Of all primary carers, just over 39% indicated that the reason they were taking on the role was because they felt they could provide better care for the person needing care. Conversely, there were many carers that indicated they were undertaking caring responsibilities because there was no one else available/willing to provide the care, or because alternative care was too costly.

Impacts of care

The role of carers can be challenging and demanding. Caring for family or friends who have disability or are frail aged can have significant impacts for carers, particularly financially, emotionally and physically. These impacts vary depending on the relationship between carer and the person requiring care, the circumstances of the care arrangement, as well as the availability of support services.

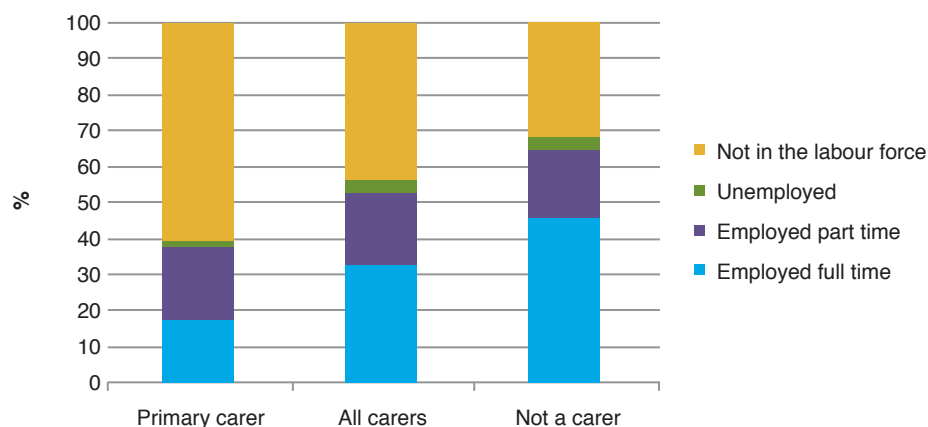
In 2003 around 78% of primary carers lived in the same households with the main recipient of care. For these people, the impact of caring can take a great personal toll.

Employment and income

Caring for someone else can extract a high price financially, by restricting job opportunities and reducing income. Carers of working age are less likely than non-carers to be in the labour force, largely due to the time demands of caring, particularly for those caring for someone who is severely restricted in the activities of daily living.

The 2003 survey conducted by the ABS showed fewer carers are employed compared with those who do not have a caring role – 53% of all carers were employed compared with 64% of non-carers. The difference is much greater for primary carers. In 2003, only 38% of primary carers aged 15 and over were employed (see Figure 4.4). In addition, around a quarter of employed primary carers (23%) had reduced their standard working hours after taking on caring responsibilities; others took time off paid work on a more ad hoc basis (Abhayaratna et al, 2008).

Figure 4.4 Labour force status of carers (a)
2003



(a) Aged 15 and over

Source: ABS Survey of Disability, Ageing and Carers 2003 (4430.0).

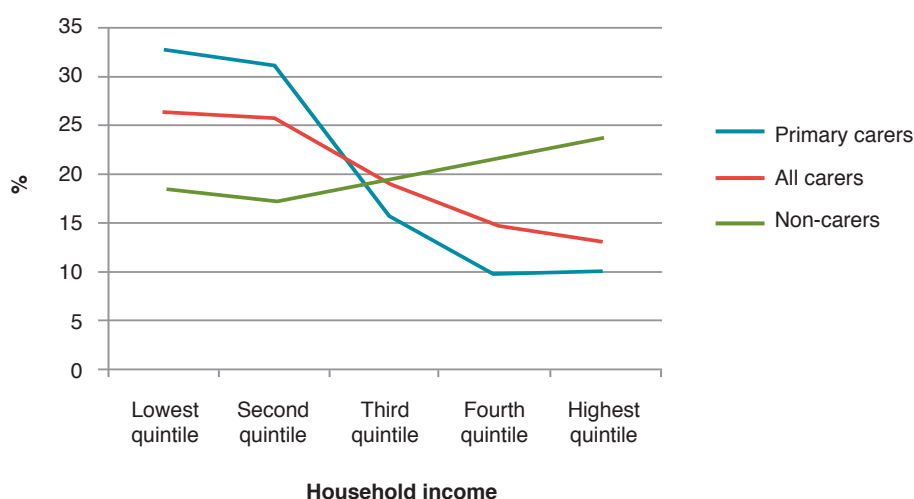
Part-time work is a way in which carers, particularly primary carers, are able to maintain their attachment to the labour force. In 2003, of those primary carers employed, 54% were employed part time, compared with 38% of all carers employed. In contrast, 29% of employed non-carers were employed part time.

Some carers would like to increase their level of labour force participation. Of all primary carers aged 15-64 years who were not in the labour force, 36% reported that they would like paid work while continuing in their caring role; most of these wanted part-time work (80%).

Reflecting their lower levels of employment, on average, carers earn less and have lower living

standards than non-carers. Analysis of the results of the 2003 ABS survey shows a third of primary carers are in households whose equivalised income¹ places them in the poorest one-fifth of households nationally (or in the lowest quintile) (AMP.NATSEM, 2006). Only a tenth of primary carer households have incomes that put them in the highest income quintile (top 20%). While the effect is not as pronounced for all carers, more than a quarter of carer-households have incomes that fall into the lowest quintile, compared with less than a fifth of non-carer households. Conversely, non-carer households are more likely to have incomes nearer the high end of the income distribution (see Figure 4.5).

Figure 4.5 Carers typically live in lower income households (a) 2003



(a) Equivalised gross household income.

Source: AMP.NATSEM *The cost of caring in Australia Today 2002 to 2005*.

¹ 'Equivalised household income' is described in the box **Measures of household income and wealth**, in Chapter 5.

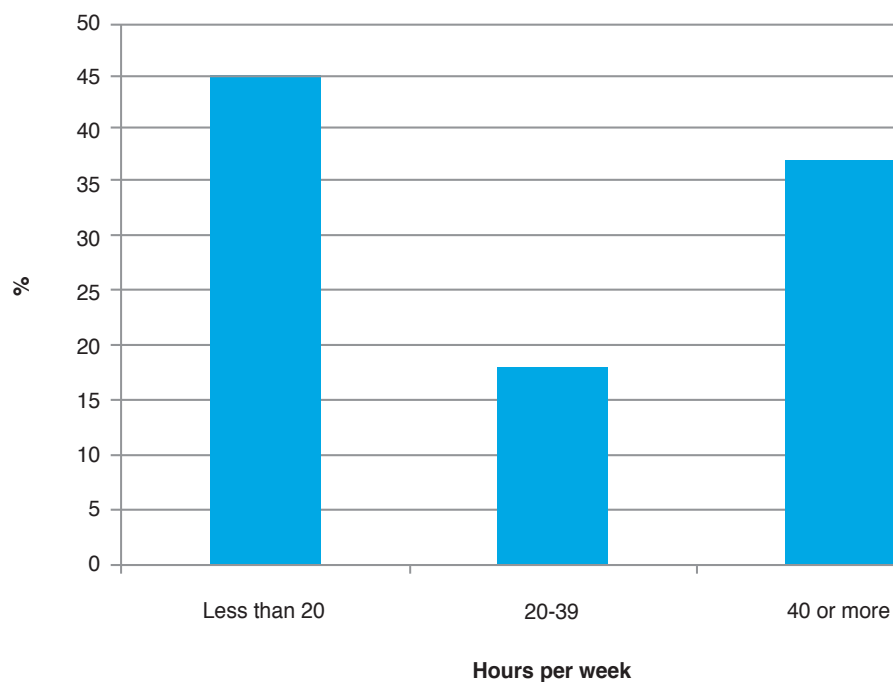
Consistent with their lower level of income, compared to families from the general population, a higher proportion of families with carers suffer from greater financial hardship (Edwards et al, 2008). The costs associated with caring include both direct and indirect financial costs. Direct costs are the additional expenses incurred to meet the special needs of the person being cared for and additional costs that are associated with caring. These include the purchase of special equipment, health services, and respite and other support services. Indirect costs include the earnings that are foregone as carers

either leave work or reduce the hours they work. These costs can be substantial.

Time spent caring

As well as a direct economic impact, caring imposes a substantial burden on carers in terms of time. Caring responsibilities can occur over a number of years and often for many hours a day. These high demands are reflected in the amount of time spent caring, with 55% of primary carers spending 20 or more hours a week actively caring, and 37% spending 40 or more hours (see Figure 4.6).

Figure 4.6 Primary carers' time spent caring (a) 2003



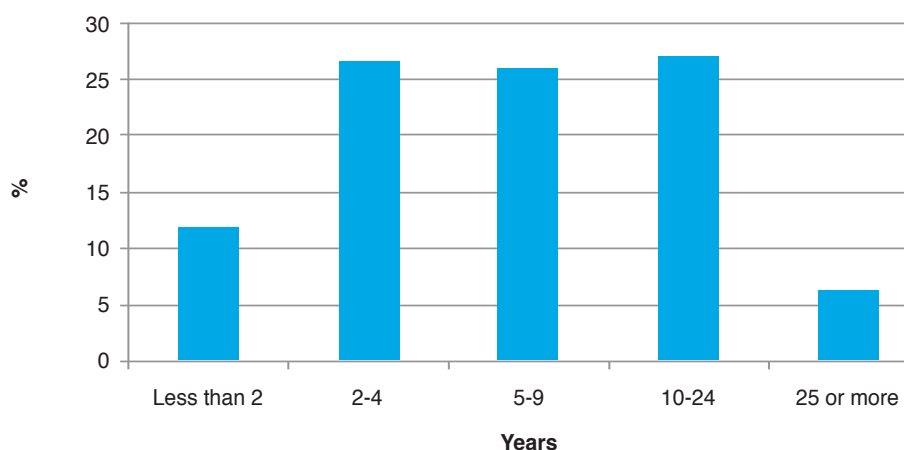
(a) Excludes those carers who did not state time spent caring

Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0).

Primary carers have particularly high demands on their time. Of those providing primary care to someone aged 15 or over, almost 20% felt unable to leave the care recipient alone for even a few hours without difficulty. Some 6% of primary carers felt that the care recipient could not be left alone for even an hour.

For most carers, caring is a long-term commitment. Almost a third of all carers have provided care for a person with disability or frail aged person for ten or more years. A further quarter of carers have provided care for five to nine years (see Figure 4.7).

Figure 4.7 Caring is often a long-term commitment 2003



Source: ABS *Disability, Ageing and Carers, Australia 2003* (4430.0)

Health and wellbeing

In addition to financial and time costs, carers may also experience other impacts due to their caring role. A range of research suggests that the physical, mental and emotional health and wellbeing of most carers is poorer because of their caring responsibilities. This can be exacerbated when caring over long periods of time. A recent survey undertaken by Deakin University found that carers have the lowest wellbeing index score for any large group in Australia, with wellbeing decreasing as

the number of hours spent caring increases (Cummins and Hughes, 2007).

A report by the Australian Institute of Family Studies (AIFS) shows carers and their families experience higher rates of mental health problems than the general public (Edwards et al, 2008). The study found, for example, clinical levels of depression were experienced by 19% of female carers and 13% of male carers, compared with 11% of women and 8% of men

in the general population. Fifty one per cent of female carers and around 31% of male carers also reported that they had been depressed for six months or more since they started caring.

The strain and challenges faced by carers can also impact on the wellbeing of other family members – 27% of partners, 12% of parents and 11% of children of carers had experienced a depressive episode of six months or more since caring began.

The report's findings need to be seen in context. For many carers, their caring responsibilities are motivated by a strong sense of family commitment. At the same time, they highlight the importance of ensuring that carers are effectively supported.

The value of caring to the community

The contribution of carers to the Australian community, in both social and economic terms, is significant. The informal caring undertaken by Australia's 2.6 million carers helps to provide support and maintain independence for those people needing care, and helps to prevent early or inappropriate entry into institutional care.

The annual value of informal care provided in Australia has been estimated to be 1.2 billion hours of care per annum. If replaced by paid providers in a formal context, this would equate to \$30.5 billion per annum (Access Economics, 2005).

Of course, the benefits provided by carers to their families goes beyond the value of their work to the economy. These figures, though, emphasise the importance of the contribution that carers make to their families and to Australian society.

Conclusion

Caring for the frail aged and relatives with disability is a major function of Australian families and plays a valuable role in Australian society. Caring responsibilities vary over the course of a life time and generally increase with age. Caring, however, can be a demanding role at any age, and can have a significant impact on carers' lives whether financially, emotionally or physically.

The ageing of Australia's population will significantly increase demand for caring which will have substantial flow-on impacts both for families and for the provision of government services. Carers within families, most of whom are women, are likely to face increased pressure, as they manage their caring, work and other family commitments. There is likely to be an increasing need for this group to access family-friendly work arrangements and leave provisions to enable them to care for older people or people with disability as well as for children.

At the same time, there is likely to be increased demand by carers for support services, both in terms of respite care and services targeting their own physical and emotional wellbeing. In conjunction with the ageing population, increasing demand for caring services will impact on government policy and program design. How the community and governments respond to these challenges will have a significant impact on the wellbeing of carers and how effectively they can perform their roles.

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