



## FEATURE ARTICLE

### 2.4 Informal carers

Many Australians need assistance with activities in their lives, whether this is due to disability, medical conditions, mental illness or because they are frail aged. Formal assistance, provided by organisations that are funded to provide these services, plays an important part in care. However, people needing such assistance want to be cared for by family and friends where possible, and indeed, most of this kind of care is provided by people close to the person in need (Productivity Commission 2011a:xliv).

The role of informal carers (people such as family or friends who provide unpaid care) cannot be underestimated: in fact, the Productivity Commission (2011b: 312) indicated that the contribution of informal carers is so great that no insurance scheme would be likely to fully fund its replacement.

As well as providing vital support, informal carers themselves have particular needs for assistance; meeting these needs is the focus of government policy and programs designed specifically to assist informal carers. However, the pressures on informal carers remain significant, along with the rewards that come from providing care.

#### Carer-specific policy

Australian government policy recognises the role played by informal carers: the *Carer Recognition Act 2010* aims to increase recognition and awareness of the role carers play in providing care and support to people with a need for assistance. The National Carer Strategy, delivered in 2011, has shaped the Australian Government's response to the needs of informal carers in recent years.

In addition to the National Carer Strategy and the Carer Recognition Act, carers are recognised in a range of other contexts including employment, community care, youth, national health and mental health reforms, disability standards and services, aged care reform and action on dementia—see a detailed description in *Australia's welfare 2013* (AIHW 2013:323–324). Since that time, the *Fair Work Act 2009* has been amended (in the *Fair Work Amendment Act 2013*) to give employees who are informal carers (among others) the right to request changes to working arrangements to better fit in with their caring responsibilities.

#### What is informal care?

Informal carers provide help, support or supervision to family members, friends or neighbours with a range of physical, mental and end-of-life health conditions, and disability. Informal carers are defined as those who provide care within the context of a pre-existing relationship, with demands that go beyond that which would normally be expected of the relationship. Informal carers are not paid for the care they provide, although some carers receive government benefits (see 'What assistance do informal carers receive' below). This is quite distinct from the care provided by formal care providers, parents of young children, and volunteers (see Chapter 2 'Volunteering').

Informal care can be diverse, ranging from personal care (such as showering and support with eating), in-home supervision, transport and help with shopping, through to the use of medical devices, therapeutic interventions and wound management. An informal carer may augment the support provided by formal care providers, share care with a network of informal carers, or be the sole carer. The person responsible for the majority of informal caring is known as the primary carer.



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There are many advantages for the individual receiving assistance from an informal carer. These include the potential for avoiding or delaying entry into formal residential care or hospital settings; greater inclusion in the community; and better quality of life—including physical and mental health—that comes from remaining in the community. For the carer, there can be negative as well as positive effects of caring. For example, it can reduce ability to engage in work, affect mood and stress and cause disruption to sleep patterns (House of Representatives 2009:44–47; Yeandle et al. 2007; ABS 2014a). On the other hand it can draw the carer closer to the recipient of care, bring family closer together, and provide feelings of satisfaction (ABS 2014a; Cass et al. 2009).

Changing demographics and current health trends are increasing the demand for informal carers. These include the ageing of the population, increased longevity, and the increasing incidence of dementia and mental health conditions. At the same time, the supply of carers is diminishing. Reasons include: the changing roles of women, who were traditionally carers, but now are typically re-entering the workforce after childbearing; pressure on carers to remain in the workforce later into life, thereby reducing the time available for caring; and complex family structures. The end result has been that fewer people are willing and able to provide informal care (AIHW 2013; PC 2011a).

### What do we know about informal carers?

In 2012, 2.7 million Australians were informal carers (12% of the population), and of these, around 770,000 were primary carers (ABS 2014a).

Overall, 13% of Australian women (1.5 million) were carers in 2012, and 5% (540,000) were primary carers, compared with 11% and 2% of men (1.2 million and 230,000) respectively. Within each age group, slightly different patterns emerge which reflect the age of the care recipient and the nature of the relationship (Figure 2.4.1) (ABS 2014a). For example, higher proportions of men aged 65 and over have tended to be carers than women, even though there were slightly more female carers in this age group. This is because women have a greater life expectancy, thus outliving and therefore less likely to be caring for a spouse/male partner, men tend to be older than their spouses/female partners, and older men are therefore more likely to be living with a spouse needing care than older women (ABS 2008).

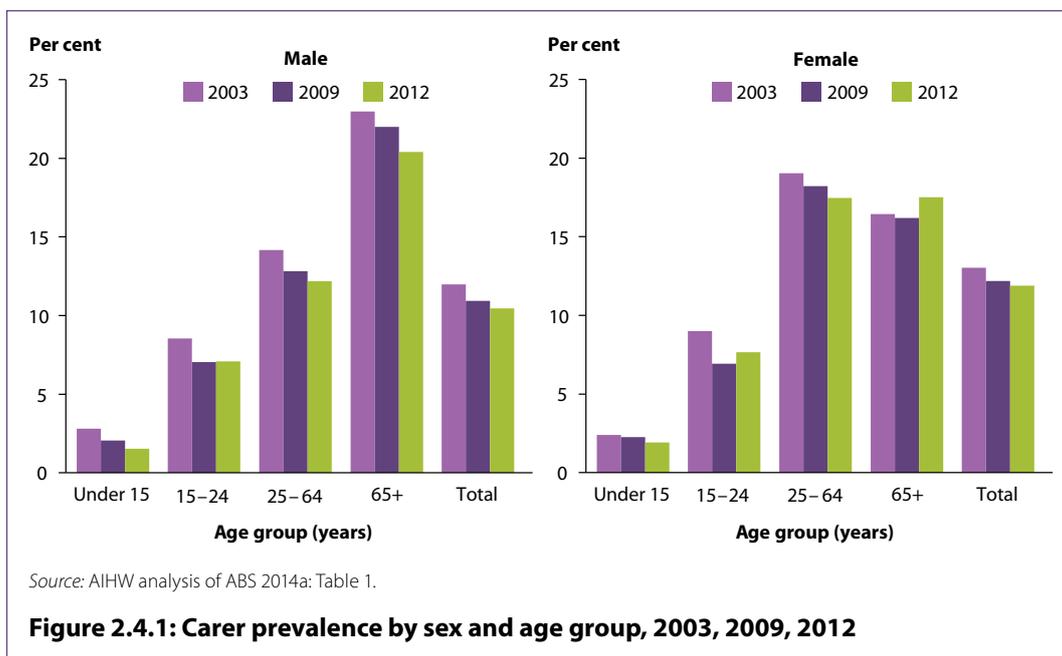
Between 2003 and 2012, the proportion of older men providing care declined, while that of older women increased. This was partly due to demographic factors—there was a greater increase in the total number of older men (36%) than the number of older male carers (21%), and a faster growth of older female carers (37%) than in the total number of older women (28%) (ABS 2014a). Between 1998 and 2012, the gender gap in life expectancy narrowed due to greater gains in life expectancy for males than females (AIHW 2014a).

In 2012, carers living with their recipient of care (co-resident carers) comprised 71% of all carers. Among co-resident carers aged 65 and over, 86% of males and 76% of females were caring for a partner (ABS 2014a).

Between 2003 and 2012, the proportion of carers in the population declined slightly, from 13% to 12%, with male carers dropping from 12% to 11% and female carers dropping from 14% to 13% (ABS 2014a). While this may reflect in part changes in disability prevalence, there is also the possibility that the availability of carers has begun declining, as predicted for some years.



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As mentioned earlier, there are many advantages to caring for people who need assistance. In 2012, among primary carers who lived with other family members, 13% stated that their caring role brought the family closer together. Of those with a spouse or partner, 31% stated they were closer to their spouse or partner due to their caring role. Similarly, 43% of primary carers felt closer to their recipient of care due to caring for them, and 28% gained a feeling of satisfaction from caring for their recipient of care (ABS 2014a).

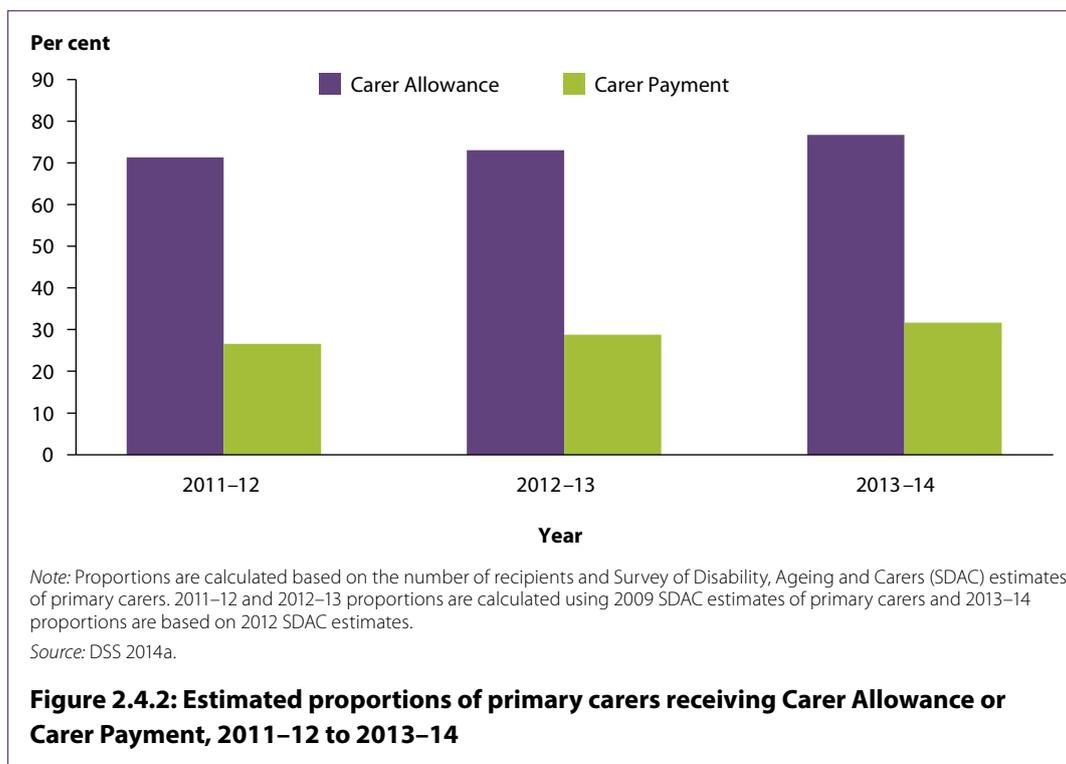
However, for many primary carers, there were negative effects as well. For instance, 61% in this group reported that their sleep was frequently or occasionally interrupted; 10% had been diagnosed with a stress-related illness; and 11% frequently felt angry or resentful due to their caring role (ABS 2014a).

### What assistance do informal carers receive?

A range of services and support groups are funded by governments to provide carers with respite, counselling, information and education. The Australian Government provides financial support, in the form of the Carer Allowance for those in a primary carer role, and the Carer Payment for primary carers who are unable to maintain employment due to caring responsibilities. As Figure 2.4.2 demonstrates, the majority of primary carers receive payments or allowances, and the proportion has increased slightly in each of the last two years. The Carer Payment is means-tested, including a requirement that the carer's employment capacity is affected by their caring responsibilities; the higher proportions receiving Carer Allowance reflect the fact it is not means-tested (DSS 2015a, 2015b).



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In 2013-14, under the National Respite for Carers Program (NRCP), 67,600 carers received information, support or emergency respite through Commonwealth Respite and Carelink Centres, 32,500 received planned respite and 6,600 received counselling services. This comprised 106,800 instances of support for carers through the NRCP. The numbers of instances of support declined from 110,400 in 2012-13 and 109,200 in 2011-12 (DSS 2014b).

Respite is also provided by temporary admission to a residential aged care facility. In 2013-14, there were 63,600 admissions providing 1.5 million respite days (DSS 2014b).

From 1 July 2015, the Commonwealth Home and Community Care Program, NRCP, Day Therapy Centres Program, and Assistance with Care and Housing for the Aged Program, were combined under a single streamlined Commonwealth Home Support Programme (DSS 2014c). Some of the services under these programs provide respite to carers, including both domestic assistance and personal care.

Carers of people with dementia can also access support for behaviour management through the Dementia Behaviour Management Advisory Service. Under this program, services are funded by the Australian Government to provide assistance to people caring for someone with dementia who has behavioural and psychological symptoms adversely affecting their care (DBMAS 2014).



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### Young informal carers

In recent years, the specific needs of young informal carers have received greater attention, in recognition that they may require additional support because of reduced opportunities to access education and employment, or to participate in social and community activities. A reduced opportunity to participate in education and employment, and an increase in expenses, means that informal carers may also experience financial hardship (ABS 2013; Cass et al. 2009, 2011).

In 2012, there were an estimated 306,000 carers aged under 25 (11% of all carers), including 74,800 aged under 15 (3%). Around 4% of all Australian young people under 25, and 7% of young people aged 15–24, were carers. An estimated 23,200 young people aged 15–24 were primary carers in 2012, and these carers were most often children of care recipients (ABS 2014a).

In 2012, 56% of carers under 15 and 53% of carers aged 15–24 were in the lowest two-fifths of households by income, compared with 44% of non-carers under 15, and 34% of non-carers aged 15–24 (ABS 2014a).

Early intervention in the form of support aimed at young carers and the person requiring care is fundamental to preventing inappropriate caring responsibilities for young people (Purcal et al. 2012). Early support in these cases may reduce the level to which young carers are at risk of social, economic and educational exclusion.

At 30 June 2014, 10,200 people under 25 years were receiving the Carer Payment, and 13,500 were receiving the Carer Allowance (DSS 2014a).

Further, government and non-government organisations provide information, respite services, counselling, educational support and recreational activities for young carers. In particular, the Young Carers Respite and Information Services Program funded 39 organisations, in 2013–14, to support over 4,200 young carers in 54 locations across Australia. These young people were assisted with respite services, as they were at risk of not completing their secondary education (DSS 2014a: 75). Of those receiving respite services, 9% were Indigenous young people and 12% were young people from culturally and linguistically diverse backgrounds (DSS 2014a).

### Informal carers of working age

Most informal carers in Australia are of working age (25–64 years). People in this category experience the same benefits and burdens as most other informal carers. However, they are more likely to experience the difficulties involved in needing or wanting to work, or to remain in education or training, while providing care to others.

In 2012 there were 1.8 million informal carers of working age (25–64)—two thirds (67%) of all informal carers. However, less than one-third of these (31%) were primary carers. As with all carers, primary carers in this age group were predominantly female (74%). The likelihood of being a primary carer increases with age: nearly 1 in 4 (24%) of all primary carers in this age group were aged 55–64, and 21% were aged 45–54. More than 1 in 7 (15%) of all people aged 25–34 were informal carers, and 1 in 20 (5%) were primary carers (ABS 2013: Table 33).



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### Work and income

For this age group, as with others, being a primary carer was associated with reduced participation in the labour force, increased unemployment and reduced earnings. Just over one-half (53%) of primary carers aged 25–64 were in the labour force, compared with 80% of people in this age group who were not carers; and unemployment was 9.3% compared with 5.1% for non-carers (ABS 2014a).

The effect on the working lives of working primary carers in this age group is also considerable. In 2012:

- 39% of primary carers in this age group stated that their weekly hours of work had changed as a result of their caring role
- 12% stated they had had to leave work for at least 3 months as a result of their caring role
- 37% indicated that their caring role had resulted in needing to take time off work at least once a week
- 29% indicated their income had decreased and 31% that they had extra expenses
- nearly two-thirds (65%) indicated they had difficulty meeting everyday living costs because of their caring role (ABS 2014b).

Nearly one-third (31%) of people in this age group who were not carers lived in households in the top one-fifth of household income, compared with one-sixth (16%) of primary carers. Primary carers were twice as likely to live in the bottom two-fifths of households by income (43%), compared with non-carers (22%) (ABS 2014a). Associated with this, primary carers in this age group were much more likely to receive their main income from pensions and allowances (47%) compared with people who were not carers (12%) (ABS 2014b).

At 30 June 2014, 199,200 people aged 25–64 were receiving the Carer Payment and 414,700 were receiving the Carer Allowance (DSS 2014a).

### Older informal carers

In 2012, there were an estimated 579,700 older carers aged 65 and over, or 22% of all informal carers. As with carers in younger age groups, most were women, but only by a small margin in this age group (51% to 49%). Men in this age group were more likely to be carers than men in younger age groups—20% of all men aged 65 and over were carers, compared with 12% of men aged 25–64 and 7% of men aged 15–64 (ABS 2013). As married and otherwise partnered men grow older, their wives and partners are more likely than in other age groups to become frail and need care in the home.

As with female primary carers, men were also more likely to be primary carers in this age group than in younger age groups (5.7% for men 65 and over, compared with 2.4% of men aged 25–64 and 0.6% of males aged 15–24). Older men who were primary carers were more likely to be caring for their partner (87% of male 65 and over primary carers) than younger male primary carers (15–24: 19%; 25–64: 61%) (ABS 2014a).

As primary carers age, they may experience the same changing circumstances (such as frailty) as non-carers, and such changes may directly affect the lives of other family members or others who need their care. As would be expected, older primary carers were more likely to have a disability themselves than younger primary carers—11.7% of primary carers aged 65 and over had a severe or profound core activity limitation, compared with only 7.2% of younger primary carers (ABS 2014a).



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On the other hand, circumstances are better in some ways for older primary carers. ABS (2014b) found that:

- they were more likely to be able to care for others without assistance than younger primary carers (86% not needing assistance for primary carers aged 65 and over compared with 72% for primary carers aged under 65) (ABS 2014a)
- their income was more likely to be unaffected by their caring role (59% not affected, compared with 38%) (ABS 2014b)
- their friendships were less likely to be affected (53% unaffected, compared with 42%) (ABS 2014b)
- they were more likely to feel satisfied due to their caring role (37% compared with 25%) (ABS 2014b).

### What is missing from the picture?

Data on disability support services funded under the National Disability Agreement are collected by the AIHW for the Disability Services National Minimum Dataset (DS NMDS), including information on informal carers of service users (AIHW 2014b). However, the data are not of sufficient quality to present in this article for the most recently published year. The main deficiency is in completeness of information on carers of people receiving employment services.

The National Disability Insurance Scheme (NDIS) does not currently report any information on informal carers caring for NDIS recipients (National Disability Insurance Agency 2014: 60).

### Where do I go for more information?

Most of the information on informal carers presented in this article is drawn from the ABS Survey of Disability, Ageing and Carers. A much wider breadth of information on carers is available from this survey, both from published reports and unpublished data that can be used for tailored analyses. For more information, see [www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0](http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0).

Information on informal carers collected from the DS NMDS is included in the *Report on government services* (SCRGSP 2015: Volume F). While the quality of information on informal carers has been very low for 2011–12, 2012–13 and 2013–14 (the latest year), in 2010–11 the DS NMDS showed that 41% of users of disability services had an informal carer, and 34% of users had a primary carer, that is an informal carer who provides assistance with core activities.

The Census of Population and Housing collects information on people who provide unpaid assistance to a person with a disability, long term illness or problems related to old age. This information can be cross-classified by other information, including age, sex, whether the carer has a need for assistance themselves, and special needs groups such as Aboriginal and Torres Strait Islander Australians and culturally and linguistically diverse people.

The Household, Income and Labour Dynamics in Australia (HILDA) Survey has included questions on whether respondents provide ongoing help with self-care, mobility or communication to someone who is elderly or who has a disability (since Wave 5). Some of the information derived from these questions has been presented by the Melbourne Institute of Applied Economic and Social Research (2014) in a chapter entitled 'The characteristics and wellbeing of carers'.



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