



## 8.3 Informal carers

Informal carers provide care to others who need help or support due to disability, health conditions or ageing, outside the formal care sector (where paid care is provided by trained professionals). Often, informal carers are people close to the person in need, such as family and friends. Informal care covers a wide range of activities, such as personal care, transport assistance and medical care. It may be provided alongside formal care, or shared with other informal carers. Informal carers play an important role in assisting people who need help in their daily lives, with an estimated 1.9 billion hours of unpaid care provided in 2015 (Deloitte Access Economics 2015).

This article focuses on carers of people with disability, health conditions, or frailty due to old age, and not on the large number of Australians who provide informal care for children (Box 8.3.1).

### Box 8.3.1 Informal carers of children

Other people beside parents or guardians may care for children on an informal basis. Grandparents are the most common informal carers for children aged 12 and under (ABS 2015). Other informal carers may be (step) brothers or sisters, other relatives (including a parent living elsewhere) or other (unrelated) people such as friends, neighbours, nannies or babysitters.

In 2014, 1 in 5 (22%) children aged 12 and under usually received care from a grandparent; grandparents provided an average of 10 hours of care per week—almost all (98%) of their care was unpaid (ABS 2015).

For more information on formal and informal child care in Australia see Chapter 2.1 'Children in child care and preschool programs'.

Being an informal carer can be rewarding, but challenging. Informal carers may experience social isolation, physical and emotional strain and restricted education and employment opportunities. Recent research has shown that carers who provided a high level of care and were employed in the workforce were most likely to be adversely affected (Kenny et al. 2014).

## How many informal carers are there in Australia?

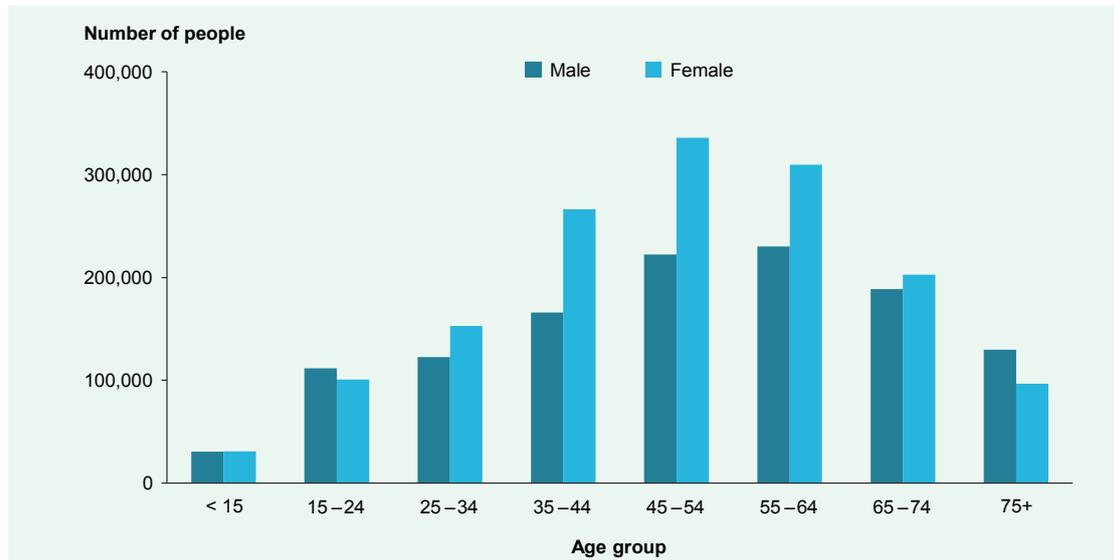
In 2015, 1 in 9 Australians (2.7 million people) were informal carers according to the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC). The SDAC collects information about people who provide informal care in Australia—their health, wellbeing and participation in the community and workforce. In particular, information is collected about primary carers (the main caregivers): people aged 15 and over who live in the same household as the person with disability and provide them with the most help. In 2015, there were an estimated 856,100 primary carers in Australia, representing 3.7% of the population.





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In 2015, more than half of informal carers were female (56%). There were significantly more female carers than male carers aged 35–64 (Figure 8.3.1). One in 10 (10%) carers were aged under 25, and more than 2 in 10 (23%) were aged 65 and over.



Source: ABS 2016.

Figure 8.3.1: Number of carers, by age group and sex, 2015

Between 2009 and 2015, the number and proportion of carers in Australia has remained steady, with an estimated 2.6 million carers in 2009 and 2.7 million in 2015, representing 12% of the population in both years. Over the same period, the number of primary carers increased from 771,400 (3.6%) to 856,100 (3.7%), although the proportion of primary carers in the population remained similar. Primary carers now make up 32% of all carers, compared with 29% in 2009.

The 2015 SDAC found that:

Almost all (96%) primary carers care for a family member.

Two-thirds (67%) of primary carers stated 'family responsibility' as their reason for taking on a caring role.

2 in 5 (38%) primary carers reported having disability, with 1 in 5 (21%) experiencing severe or profound core activity limitation.

One-third (33%) of primary carers spend 40 hours or more each week caring for their main recipient of care.

One-third (33%) of primary carers have spent 10 or more years caring for their main recipient of care.





## What challenges do carers face?

The time and costs associated with providing care to another person can be challenging for carers, particularly for the primary carer. The caring role may create increased financial stress, limit the carer's access to education and employment, or restrict their participation in social and community life. Table 8.3.1 shows differences in income, employment and education between primary carers, other (non-primary) carers and non-carers.

**Table 8.3.1: Income, employment and education levels for primary carers, other (non-primary) carers and non-carers, 2015**

Measure	Primary carers	Other (non-primary) carers	Non-carers
Median gross personal weekly income <sup>(a)</sup> (\$)	520	813	900
Government pension or allowance as main source of income <sup>(a)</sup> (%)	42.7	18.0	11.3
Unemployment rate <sup>(b)</sup> (%)	7.3	6.4	5.4
Workforce participation rate <sup>(b)</sup> (%)	43.3	63.9	69.2
Educational attainment of Year 12 or higher <sup>(b)</sup> (%)	63.2	69.0	71.3

(a) People aged 15–64 years.

(b) People aged 15 and over.

Source: ABS 2016.

In 2015, in the 3 months before the survey, most (94%) primary carers had participated in a social or community activity away from home, such as visiting friends or relatives or taking part in sport or physical recreation. Three-quarters (76%) of primary carers took part in such activities without the person they cared for. Primary carers who spent, on average, 40 hours or more caring per week were less likely to participate in social and community activities outside the home without the person they cared for (65%), compared with primary carers who spent fewer than 20 hours on average providing care (86%).

## Young carers

Young carers are people aged under 25 who provide informal care for another person, often a parent or family member. According to the 2015 SDAC, there were an estimated 272,200 young carers in Australia, including 59,100 aged under 15 (ABS 2016). This equated to around 1 in 12 (8.3%) people aged under 25 in Australia being carers. About 20,700 carers aged 15–24 were primary carers, and the majority (61%) of these were caring for a parent.





Aspects of the caring role can be enjoyable and rewarding. But an intensive caring role may affect the ability of young carers to participate in life—such as in education, employment and social activities—to the same extent as other young people. Analysis of the SDAC indicates that primary carers aged 20–24 were less likely to have completed Year 12 or equivalent (32%) than both non-primary carers (72%) and non-carers (80%) of the same age (ABS 2016). Primary carers aged 15–24 were also less likely to be employed (43%) than non-primary carers (56%) and non-carers (60%). However, most (97%) young primary carers (aged 15–24) had participated in a social or community activity away from home without the recipient of care in the last 3 months.

## Older carers

Older carers are people aged 65 and over who provide informal care for another person, often their spouse or partner, their child, or their own parent. There were an estimated 618,000 older carers in Australia in 2015, representing close to 1 in 5 people (18%) aged 65 and over (ABS 2016). More than one-third of older carers were primary carers (234,100 people). The majority cared for their partner (76%), with a smaller proportion caring for their child (9.1%) or parent (8.1%).

As well as the challenges faced by all carers, older carers may experience increased stress and anxiety over the decline of their own health, or the future care of their care recipient when they are no longer able to provide care (Bellamy et al. 2014). Close to 1 in 5 (19%) older carers reported often feeling worried or depressed due to their caring role, while more than 2 in 5 (44%) reported that their main recipient of care did not have a fall-back informal carer. Many older carers are long-term carers, with 2 in 5 (41%) having been a primary carer for their current recipient of care for 10 years or more. Long-term care may amplify the social, emotional, physical and economic challenges faced by carers (Carers Australia 2010). However, it is important to note that caring can also provide many positive benefits for both the carer and recipient of care, with 40% of older carers reporting that their caring role contributed to a closer relationship with the person they cared for.

## Carers of people with autism

People with autism spectrum disorder and their carers are a growing population, in Australia and around the world (WHO 2016). Analysis of the SDAC indicates that, in 2015, an estimated 164,000 people had autism spectrum disorders in Australia (ABS 2016). This number has more than doubled since 2009, when 64,400 people were identified as having autism (ABS 2014). This increase has been mirrored by an increase in the number of people who provide care to someone with autism who is living in their household, from 35,000 primary carers in 2009 to 79,900 primary carers in 2015.

In 2015, there were 69,700 primary carers whose main recipient of care reported autism as their main condition (that is, the condition that causes the most difficulty in daily life). Close to two-thirds (65%) of these carers were women aged 35–54. Compared with primary carers for people with other conditions, primary carers of people with autism were more likely to work part time, care for 60 hours or more per week, and to have reported needing further support in their caring role (Table 8.3.2). Primary carers of people with autism were as likely to be employed full time as other primary carers. These findings, particularly those relating to employment, may be partly related to the age profile of primary carers of people with autism.





**Table 8.3.2: Primary carers of people with autism as their main condition compared with primary carers of people with other main conditions, 2015**

Measure	Primary carers of people with autism as main condition (%)	Primary carers of people with other main conditions (%)
 Employed working full time	16.4	15.1
 Employed working part time	38.6	19.0
 Provides care for 60 hours or more per week	46.8	31.5
 Has suffered financially because of their caring role, through a decrease in their income or an increase in expenses	80.6	52.3
 Has lost touch (or is losing touch) with existing friends	37.3	23.6
 Has experienced a change in their physical or emotional wellbeing because of their caring role	56.4	38.5
 Needs further support to assist in their caring role	58.1	36.4

Source: AIHW analysis of ABS 2015 Survey of Disability, Ageing and Carers (TableBuilder).

## What support is available for carers?

A variety of government-funded services and financial support programs are available to assist carers with their caring responsibilities.

### Support services

Non-financial support services for carers include counselling, information and advice, and respite care (short-term alternative care arrangements to provide a break for both the carer and the person being cared for). In 2015, 14% of carers reported they had used respite care for their main recipient of care. Female carers were more likely to have used respite care than male carers.





Under the National Disability Agreement, respite services are also available to people with disability, their families and carers. In 2015–16, more than 38,200 people with disability were provided with respite services under this Agreement (excludes data from the Australian Capital Territory Government, which did not collect data in 2015–16; see the AIHW report *Disability support services: services provided under the National Disability Agreement 2015–16* for more information). Most of this group (91%) reported having a primary carer.

The Young Carers Respite and Information Services Program also supports young people with a substantial caring role to complete their secondary education or vocational equivalent (DSS 2016d). The program helps carers who need support due to the demands of their caring role by way of respite care, education support services and information, referral and advice. Respite and education support services are delivered by the national network of 54 Commonwealth Respite and Carelink Centres; information, referral and advice are delivered by Carers Australia and state and territory carers' associations. Respite services will move to the National Disability Insurance Scheme (NDIS) as the scheme rolls out, to be accessed through the care recipient's plan. For more information on the NDIS, see Chapter 8.1 'People with disability'.

Several local and national organisations provide counselling and information services for carers. In 2015–16, Carers Australia, the national peak body representing carers, provided counselling for more than 8,000 carers, and helped more than 60,000 people with information and advice (Carers Australia 2016).

## Financial support

Carers may receive financial payments, depending on their caring arrangements and the needs of the person they care for (DSS 2016b). In 2015–16, close to 605,800 people received the Carer Allowance. This is a supplementary payment for carers who provide a certain level of daily care and attention to a person with disability or a severe medical condition (excluding carers whose care recipient qualified for a Health Care Card only) (DSS 2016a). This represents more than two-thirds (71%) of the estimated number of primary carers in 2015 (from SDAC). The number of people receiving the Carer Allowance has increased in recent years, up from around 590,200 recipients in 2013–14 and almost 601,400 recipients in 2014–15 (DSS 2016a). In June 2016, 70% of Carer Allowance recipients were aged 45 and over (DSS 2016c). Carers aged under 25 accounted for 2.0% of recipients.

In 2015–16, financial support was also provided, through the Carer Payment, to almost 260,600 carers who were unable to support themselves through substantial paid employment because of their caring responsibilities (DSS 2016a). As well, there were about 629,000 recipients of the Carer Supplement and around 154,400 recipients of the Child Disability Assistance Payment. (Both these payments depend on recipients receiving specific qualifying payments, such as the Carer Allowance.) Carers may also be eligible for other forms of financial assistance, such as support for education, housing or access to Health Care Cards.





## What is missing from the picture?

At present, it is difficult to gain a consolidated picture of the experiences of carers in Australia. While some self-reported information is available from the Survey of Disability, Ageing and Carers, detailed data about the use of support services is limited. Carers may receive support through a number of government and non-government programs across a wide variety of areas, including the disability, aged care and health systems. In addition to specific programs targeted at carers, carers are also affected by the support provided to the person they care for. There is a lack of comprehensive data on the support services used by carers (such as counselling and information services), including interactions with mainstream and specialised services, pathways through these services, and the outcomes of these interactions (including how the type and level of support provided to care recipients impacts carers' lives). This is particularly an issue for groups such as young carers, who face unique challenges because of their age. Data linkage, such as between carer payments and health or education datasets, could enable a better understanding of the experiences of carers in Australia, their interactions with services, and their associated outcomes, providing a clearer evidence base for policy decisions.

The introduction of the NDIS presents an opportunity to collect better data on informal carers of people with disability. From 1 July 2013, people with disability who met eligibility requirements started the transition to the NDIS to receive formal assistance with everyday life (see Chapter 8.1 'People with disability'). Carers of NDIS participants may be involved in planning and implementing a person's care plan. The NDIS reports some information on families and carers of participants, including baseline outcome indicators covering financial support, workforce participation, social participation and health (NDIA 2017). However, detailed information on the carers of NDIS participants, such as their relationship to the participant and the extent of their caring responsibilities (for example, the number of hours spent caring per week, the type of caring activities undertaken) is not currently available. Such information would also be limited to carers of NDIS participants, meaning a gap will remain around those who care for people who are not eligible for the NDIS, such as older Australians.

## Where do I go for more information?

For more information on informal carers, see [www.aihw.gov.au/informal-care-ageing](http://www.aihw.gov.au/informal-care-ageing). Information on carers of people with disability who access disability support services under the National Disability Agreement is available in the bulletin [Disability support services: services provided under the National Disability Agreement 2015–16](#), which is available for free download from the AIHW website. Information on carers from the most recent ABS Survey of Disability, Ageing and Carers is available from [Disability, ageing and carers, Australia: Summary of findings, 2015](#).

The [Carer Gateway](#) is a national website and phone service launched in December 2015. It provides information and advice to carers, and can connect carers with suitable services in their local area.





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