



Informal carers

Extracted from Australia's welfare 2009

Chapter 5, pages 188–120

In 2003, an estimated 1.1 million people living in households had a severe or profound limitation in one of the core activities of communication, mobility or self-care, and needed help with at least one specified activity. Of these, 61% received help from a formal service provider, but 95% received help from an informal carer. It has been estimated that the value of services provided by all informal carers exceeded \$27 billion in 2005–06.

Informal carers (here called simply 'carers') commonly help with a range of tasks including self-care, health care, mobility, transport, housework and property maintenance. But carers also play a significant role in supervising and providing a sense of security for people who need assistance with day-to-day activities (including communication and social interactions), supporting the social inclusion of people with disability and the aged, coordinating and managing their care recipients' formal care services, and advocating on their behalf.

Carers are mostly female and mostly live with the person for whom they care. They may provide care for short or long periods of time, and for more than one person concurrently (including the care of children without disability). And despite the important help they provide to another person, not all carers identify themselves as a 'carer'.

For some people with disability, the help provided by carers means that they do not need further support from formal services, although, for most, informal care is supplemented by the use of formal services.

Formal services are those services provided by government or non-government agencies that mostly rely on paid staff and are usually subject to regulation. Formal services may be funded by governments, purchased privately, or a mix of both. By contrast, informal care is largely provided on an unpaid basis, although carers may receive financial assistance from the Australian Government. Carers might also have private arrangements for some payment or payment-in-kind from the person for whom they care, for example, a grandchild living with an elderly grandparent might receive free board in return for household help and meal preparation.

A primary carer is 'a person who provides the most informal assistance ... to a person with one or more disabilities'. Over 90% of primary carers are close family members of the person for whom they care: 41% are spouses or partners, 26% are sons or daughters and 23% are parents.

For many carers the experience of looking after a relative or friend can be positive and rewarding. In 2003, one-third of all carers (34%) reported that the caring experience had brought them closer to the person for whom they cared, and 42% reported that their relationship was unaffected. Carers were more likely to report that their relationship had become closer when they did not live with the person for whom they cared (45%, compared with 31% of carers who lived with the person for whom they cared).



But many carers do not find the caring role satisfying, and many experience lower health and wellbeing than non-carers, as well as social and financial disadvantage. In terms of overall satisfaction with their caring role, only 26% of primary carers reported that they felt satisfied as a result of their caring role.

Notwithstanding the potential rewards of caring and the availability of programs and benefits that support carers, there are costs involved in being a carer. The economic costs incurred by carers include direct costs and opportunity costs. Direct costs are those additional costs incurred by the carer that arise directly from their role as a carer. This includes the cost of specialised equipment or aids, home and vehicle modifications to accommodate the person with care needs, medicines or medical therapies, and increased household utility and transport costs.

In considering the economic costs of caring, however, the more significant costs for most carers are the opportunity costs: lost income associated with reduced working hours or withdrawal from the workforce, and missed opportunities for career advancement or further education.

Questions for discussion

1. Carers help with a range of tasks including self-care, health care, mobility, transport, housework and property maintenance. Give two examples for each of these tasks.
2. Carers play a significant role in supervising and providing a sense of security for people who need assistance with day-to-day activities (including communication and social interactions), supporting the social inclusion of people with disability and the aged, coordinating and managing their care recipients' formal care services, and advocating on their behalf. Pick two of these roles and describe what they might involve.
3. The two types of financial costs borne by carers are direct costs and opportunity costs.
 - (a) Explain in your own words what these terms mean.
 - (b) What are some specific examples of direct costs and opportunity costs?
 - (c) If government increased funding to carers, which of the two types of cost would be most reduced?
4. Discuss the following topics:
 - (a) A tertiary student puts their study on hold to care for a grandparent during the last 5 years of their grandparent's life. Discuss a day in the lives of the two people.
 - (a) Devise a funding scheme for carers. Decisions to be made (and then justified!) include the weekly amount to be paid, whether the payment should be made in cash or through vouchers (for example for free taxi travel), who is eligible to receive the money and how long the payment will continue for.