



Caregivers and Caring for Persons in Need

Caregiving is helping a person accomplish the activities of daily living. The person is unable to accomplish these activities independently and the help provided enables him or her to maintain dignity and well-being. Caregiving can range from straightforward tasks such as providing a meal or doing someone's laundry, to 24 hour care and supervision that can include assuming full responsibility for an person's personal, medical and financial matters. The tasks or roles the caregiver takes on depend on the needs and abilities of the person receiving care. These include:

- Physical, emotional and cognitive (thinking, judgment, memory) status
- Ability to get around independently
- Mobility level
- Specific needs for help with activities of daily living
- Supervision to ensure safety and security needs (e.g. need for help down stairs, need for help in taking medication)

Who needs caregiving?

Many types of people at different stages of life might need a caregiver. Some examples are:

- a child with a developmental delay in the school system whose assistant accompanies her through the school day
- a widowed and retired 65-year-old man whose teenage granddaughter visits him every noon hour through the week to "have lunch with him, to keep him company and make sure he eats his noon meal"
- a 78-year-old woman following recovery from a stroke visited in hospital every day by her daughter and husband who are helping her to make plans for her return home
- an 86-year-old man whose wife has just learned he has a "dementia", confirming her impression that his memory and judgement were "getting worse".

Who are caregivers?

An "informal" or "family" caregiver is one who is an unpaid family member. When there are several family members who directly provide care, a primary caregiver is usually identified. The primary caregiver is the one who provides the majority of the help and often has the closest relationship with the person needing care. The primary caregiver is often also the person with the enduring Power of Attorney and who has legal authority to make decisions on behalf of the person if he or she is

not competent to do so. A single caregiver might provide care to several different older relatives as well as to their own dependent children.

There are natural caregivers, obliged caregivers, and there are reluctant caregivers; sometimes a single caregiver can think he is both on any given day. The natural caregivers tend to be female and are "always ready with a helping hand." Obligated caregivers are those who are asked to help because of their relationship to the person needing care or because the relative has no one else to help.

The reluctant caregiver may or may not feel obliged to provide help, but there are limits to the tasks she wants or is able to take on.

The risks and rewards of caregiving

The rewards of caregiving can be felt even by the most reluctant caregiver over time. Caregiving builds self-esteem (for a job well done) and one's sense of self-worth (knowing one has made a positive difference in someone's life); it increases confidence and is empowering.

There are risks to caregiving, however, that can affect the physical and emotional health of the caregiver. Some caregivers, particularly the "naturals", can easily overdo it. People feel useful and good about themselves when providing care and they can receive a lot of respect and positive regard from others for their caregiving role. The formal caregiver's job satisfaction depends on these two factors.

Both formal and informal caregivers, however, can burn out, from demands that are too great or difficult, last too long, and/or might be more than the caregiver can cope with. Signs of burnout include physical and emotional exhaustion, decreased satisfaction in the "job", and a sense of detachment from the person to whom care is being provided. Caregivers who always put themselves in the caregiver role are particularly at risk for burnout. Beliefs such as "I should be able to help everyone"; "I would be selfish if I thought myself first", "I am inadequate if I have to ask for help." or "Only I can provide the right care because I know my mother/husband best" might signal a need for the caregiver to think about whether she is at risk.



How well a caregiver thinks she is coping, how well she is actually coping, and the change in what she has to cope with, affect how burdened she feels by her role and her risk for burnout. For example, a wife who feels able to cope with her husband and his early-stage dementia and is in fact coping well, might not feel or cope so well as his dementia worsens, she develops her own age-related health problems, and their only adult child, who had been some help and support, left town for a new job in another city.

The stress of caring for a person with a dementia puts the caregiver at higher risk for health and emotional problems than she might be otherwise. She may be feeling impatient and angry with his constant and repetitive questioning and his “stubborn” unreasonableness – feelings about which she then feels guilty. She may not be sleeping well because of her own health problems and be feeling frustrated that constant supervision of her husband leaves her with little time to attend to her own mental or physical health and enjoyment.

If she feels unable to cope, she will also feel anxious and self-critical which in turn can contribute to problems in eating, sleeping and general self-care.

Why the caregiving needs to care for him or herself

About one-third of the population over 18 is involved in caregiving at some level.

At least 40 % of caregivers are male.

Caregiving lasts for an average of 8 years and can “last” for up to 18 years. Some of these years overlap with child-rearing responsibilities for adults in the “sandwich” generation.

In the US, the “free” caregiving services are estimated to be worth twice the amount spent on paid home care and nursing home services.

There is a 63% higher mortality rate among older caregivers of spouses, who have a chronic illness themselves and who experience caregiving-related stress.

A family caregiver’s immune system is negatively affected for up to 3 years after caregiving ends, increasing chances of their developing a chronic illness.

Spouses, who provide more than 36 hours of caregiving, have rates of depression and anxiety that are 6 times higher than in non-caregivers. In adult children caregivers, the rate is twice as high as it is in non-caregivers.

How psychologists can help

Psychologists are trained to assess how a person is coping with stress and whether the stressor or problems in coping have led to mental health problems or disorders (e.g. depression, anxiety). Psychologists can also help caregivers by:

- providing psychoeducation about chronic or debilitating illness and its effects on physical and mental well-being
- training caregivers to cope better and to better manage challenging behaviours of their care receivers
- providing individual supportive therapy and/or psychotherapy for the caregiver who might have developed a mental health problem
- facilitating support groups or consulting to peer-led groups