

Planning for Changing Needs

Multiple choice quiz:

Which people are caregivers?

1. The neighbor who stops by on Saturdays to see if an older friend needs something from the grocery store.
2. A man who drives his mother-in-law to her regular visits to the doctor and gives her \$25 each month to help with her bills.
3. A woman in New York who calls her much older sister in Ohio every Sunday and helps her deal with financial matters like filling out insurance forms.
4. A daughter who moves in to care for her mother, who is recovering from a hip fracture.

Answer: All of the above. A caregiver is anyone who provides unpaid assistance to another adult who is ill, disabled, or needs some help. The caregiver may live in the same house, live nearby, or provide help from another town or state. The care involved may range from rather modest tasks, like those described in numbers one and three above, to heavy-duty, round-the-clock assistance with many tasks, like the one described in example four. Of course, there are many variations in between.

Caregiving for family members is very common. A recent study by the National Alliance for Caregiving and AARP found that there are over 33 million caregivers in the United States caring for someone 50+. Why do caregivers take on this responsibility? Probably the most common reasons are love and a desire to help someone stay in familiar surroundings. Cost may also be a factor, since paid care, when available, can be expensive. Some caregivers feel a sense of duty or worry that no one else will provide good enough care.

Issues Caregivers May Face

Caregivers are a diverse group who vary in age, length of time they have been providing care, culture, financial situation, and the abilities they bring to the task. While each person's experience is unique — and a high percentage of caregivers feel positive about the experience — the following are common issues that many caregivers face:

- **Less time for personal and family life. Caregiving takes time.** As a result, caregivers have less time to spend with other family members and less leisure time for themselves. More than half report that their responsibilities have caused them to give up vacations, hobbies, or other activities.

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A common situation is the daughter caring for older parents who also has children at home who need her time and attention.

- **Need to balance job and caregiving responsibilities.** Caregiving tasks such as taking your father to the doctor, or talking to a social worker about community services, usually must be done during work hours. As with child care, arrangements you make with paid helpers or other family members don't always work out, and your time and energy for the job may suffer. Caregivers often modify their work schedules, including taking leaves of absence.
- **Financial impact.** The products and services associated with providing caregiving quickly add up financially. Some needs are covered by public or private insurance policies, but many caregivers report that coverage is inadequate. For many caregivers, out-of-pocket expenses can be a large expense.
- **Physical and mental health considerations.** Caregiving can be physically and emotionally stressful, especially for those providing intense levels of care for long periods of time. Although most caregivers don't report having serious health problems, some say they commonly feel frustrated, exhausted, angry, or sad.

Planning Before a Crisis Occurs

Most people are not prepared to be caregivers. Many parents are capable of taking care of their own needs and don't need or want their adult children to make decisions for them. But as parents grow

older, chances are they will eventually need some help. Trying to figure out what a parent needs and how to meet those needs is very difficult. Finding help with services in the community is complex, and people are often under time constraints, for example, if a parent is going to be discharged from the hospital on short notice.

The following are some steps that new caregivers can take to address their own and their parents' needs.

Meeting Needs

- **Determine housing options and preferences.**
Questions to ask: Are you able to do things around the house? Have you thought about living somewhere else? Options to consider: Staying in current home with some changes or help, assisted living, retirement communities, shared housing, nursing homes.
- **Learn medical history.**
Questions to ask: Do you have any medical conditions or health problems I should know about? Who are your doctors? What medications do you take? If your parents are unclear about the details, you may want to ask if you can go with them on their next visit to the doctor.
- **Make a list of people in their personal support system and get contact information for each.**
Questions to ask: Emergency contacts, close relatives, close friends, neighbors, friends from their place of worship, housing managers or apartment front-desk staff, clergy, local pharmacy.

- **Create a financial profile.** Financial information may be difficult to obtain from your parents, but it is critical to have an objective picture about money.

Key elements: A list of income sources such as Social Security and pensions, monthly and yearly income and expenses, bank accounts and investments, and statement of net worth.

- **Review legal needs.**

Questions to ask: What relevant legal documents do you already have or want to have (for example, wills, advance directives such as living wills and health care proxy forms, trusts, and powers of attorney)? Where do you keep important documents (for example, birth certificate, deed to home, and insurance policies)? Is your will up to date?

- **Get important account numbers in case you need them in an emergency.**

Key numbers: Social Security, bank or other financial accounts, credit cards, health insurance, driver's license, life insurance.

- **Gather information about services that can help for current or future needs.**

Services to consider: Home care, adult day care services, home-delivered meals, help with everyday activities, and more.

Addressing Your Needs

- **Take care of your own health.**

Key steps: Eat properly, get regular exercise, and set aside some time each week to do something you enjoy.

- **Speak up when you need support or assistance.**

Key step: Ask for help from family and friends before you get to the breaking point. Knowing when to get help is an important skill that helps caregivers keep going.

- **Find out about services that help caregivers and the older person.**

Services to consider: Care/case management from a social service agency to help link your parents to services and benefits, adult day services, respite care that provides a break for the caregiver, and caregiver support groups both in your community and on the Internet.

- **Seek help or training to improve your caregiving or coping skills.**

Where to look: Hospitals, volunteer organizations like the Alzheimer's Association, and community service agencies are good places to look for appropriate training programs.

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