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The National Women's Health Information Center

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Frequently Asked Questions about Caregiver Stress

What is caregiving?

Caregiving means caring for others, whether friends or relatives, who have health problems or disabilities and need help. Caregivers provide many kinds of help to care receivers, from grocery shopping to helping with daily tasks such as bathing, dressing, and eating. Most people who need help from caregivers are elderly.

- About one fourth of American families are caring for an older family member, an adult child with disabilities, or a friend.
- According to recent surveys, more than 7 million persons are informal caregivers to older adults. Caregivers include spouses, adult children, and other relatives and friends. Other surveys found that almost 26 million family caregivers provide care to adults (aged 18+) with a disability or chronic illness, and 5 million informal caregivers provide care for older adults aged 50+ with dementia.
- Studies show that more than half of caregivers are women. Care receivers are about half women and half men.
- The average amount of time that caregivers spend on caregiving is about 20 hours per week. Even more time is required when the care receiver has multiple disabilities.
- Caring for a person with disabilities can be physically demanding, especially for older caregivers, who make up half of all caregivers.
- One third of all caregivers describe their own health as fair to poor.
- Caregivers often worry that they will not outlive the person for whom they are caring.
- Caregivers often suffer from depression. Caregivers are also more likely to become physically ill.

What is caregiver stress?

Caregiver stress is a daily fact of life for many caregivers. Caregiving often takes a great deal of time, effort, and work. Many caregivers struggle to balance caregiving with other responsibilities including full-time jobs and caring for children. Constant stress can lead to “burnout” and health problems for the caregiver. Caregivers may feel guilty, frustrated, and angry from time to time.

Caregivers often need help caring for an elderly or disabled care receiver. Sometimes other family members or friends and neighbors are able to help, but many caregivers do most or all of the caregiving for a loved one alone. Research has shown that caregivers often are at increased risk for depression and illness. This is especially true if they do not receive enough support from family, friends, and the community.

Caring for a person with *Alzheimer's disease* (AD) or other kinds of *dementia* at home can be overwhelming. The caregiver must cope with declining abilities and difficult behaviors. Basic activities of daily living often become hard to manage for both the care receiver and the caregiver. As the disease worsens, the care receiver usually needs 24-hour care.

What can caregivers do to prevent stress and burnout?

Caregivers can call upon others for support and assistance. Other family members, friends, and neighbors may be able to help in different ways. It may not be easy to ask for help, and you may need to make very specific requests. But getting help from others will benefit you and the person you are caring for.

Respite care can be a good way to get a break (respite) from constant caregiving. If other caregivers aren't available to fill in for the main caregiver, respite care services may be available in the community.

As a caregiver, you can take steps to take care of your own health:

- Eat a healthy diet rich in fruits, vegetables and whole grains and low in saturated fat. Ask your health care provider about taking a multivitamin as well.
- Try to get enough sleep and rest.
- Find time for some exercise most days of the week. Regular exercise can help reduce stress and improve your health in many ways.
- See your health care provider for a checkup. Talk to your provider about symptoms of depression or illness that you may be having. Get counseling if needed.
- Stay in touch with friends. Social activities can help keep you feeling connected and help with stress. Faith-based groups can offer support and help to caregivers.
- Find a support group for other caregivers in your situation (such as caring for a person with dementia). Many support groups are available online through the Internet.

What is the National Family Caregiver Support Program (NFCSP)?

The National Family Caregiver Support Program (NFCSP) is a federally-funded program through the Older Americans Act. It helps states provide services to help family caregivers. These services include:

- Information to caregivers about available services
- Help to caregivers in gaining access to services
- Individual counseling, organization of support groups, and caregiver training

- Respite care
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

How can I find out about caregiving resources in my community?

There are resources with staff who can help you figure out whether and what kinds of assistance you and your care receiver may need.

The local Area Agency on Aging (AAA) is one of the first resources you should contact when help is needed caring for an older person. Almost every state has one or more AAAs, which serve local communities, older residents, and their families. In a few states, the State Unit or Office on Aging serves as the AAA. Local AAAs are generally listed in the city or county government sections of the telephone directory under “Aging” or “Social Services.”

You can also call the National Eldercare Locator, a toll-free service funded by the Administration on Aging (AoA), at 800-677-1116. The Eldercare Locator can help you find your local or state AAA. Eldercare Locator operators are available Monday through Friday, 9:00 a.m. to 8:00 p.m., Eastern Time. When contacting the Locator, callers should have the address, zip code, and county of residence for the person needing assistance. The Eldercare Locator is also available online at www.eldercare.gov.

If your family member has a limited income, he or she may be eligible for AAA services including homemaker home health aide services, transportation, home-delivered meals, chore and home repair as well as legal assistance. These government-funded services are often targeted to those most in need. While there are no income criteria for many services, sometimes you may have more service options if you can pay for private help.

AAAs can direct you to other sources of help for older persons with limited incomes such as subsidized housing, food stamps, Supplemental Security Income, and Medicaid.

Supportive services for the person needing care can include both in-home and community-based services, such as:

- Transportation
- Meals
- Personal and in-home care services
- Home health care
- Cleaning and yard work services
- Home modification
- Senior centers
- Respite services including adult day care.

If you are an employee covered under the federal Family and Medical Leave Act, if you meet the eligibility requirements, you are entitled to take up to 12 weeks of unpaid leave during any one-year to care for certain relatives.

What kind of paid help is available for home health care? Is there government support for this?

People with low incomes may be eligible for AAA services including homemaker home health aide services and other services. Check with your local or state AAA or the Eldercare Locator service (see resources below). Government-funded services are often targeted to those most in need. While there are no income criteria for many services, sometimes you may have more service options if you can pay for private help.

If you decide to hire a home care worker, you will need to decide how much help your older relative needs. Will several hours a day be enough, does he or she need help all day until the family returns home, or does your relative live alone and need round the clock care? You also need to decide what type of home care worker your relative needs. Home care personnel include:

- A Housekeeper or Chore Worker is supervised by the person hiring them and performs basic household tasks and light cleaning.
- A Homemaker or Personal Care Worker is supervised by an agency or you and provides personal care, meal planning and household management and medication reminders.
- A Companion or Live-In is supervised by an agency or you and provides personal care, light housework, exercise, companionship, and medication reminders.
- A Home Health Aide, Certified Nurse Assistant, or Nurses Aide is supervised by an agency's registered nurse. Services include personal care; help with transfers, walking, and exercise; household services that are essential to health care; and assistance with medicines.

Nonprofit and for profit home care agencies recruit, train, and pay the worker. You pay the agency.

Home health care agencies focus on the medical aspects of care and provide trained health care personnel, such as nurses and physical therapists. Medicare may pay for their services.

Who is eligible for Medicare home health care services?

To get Medicare home health care, a person must meet all of these four conditions:

- A doctor must decide that the person needs medical care in the home and make a plan for care at home.
- The person must need at least one of the following: intermittent (and not full time) skilled nursing care, or physical therapy, or speech language pathology services; or continue to need occupational therapy.
- The person must be homebound. This means that he or she is normally unable to leave home. Being homebound means that leaving home is a major effort. When the person leaves home, it must be infrequent, for a short time, or to get medical care, or to attend religious services.

- The home health agency caring for the person must be approved by the Medicare program.

For more information about Medicare, call 800-MEDICARE or visit the Medicare Web site (www.medicare.gov).

Will Medicaid help pay for home health care?

Medicaid is a joint federal and state program that helps with medical costs for some people with low incomes and limited resources. To qualify for Medicaid, you must have a low income and few savings or other assets. Medicaid coverage differs from state to state. In all states, Medicaid pays for basic home health care and medical equipment. Medicaid may pay for homemaker, personal care, and other services that are not paid for by Medicare.

For more information about what Medicaid covers for home health care in your state, call your state medical assistance office. If you need the telephone number for your state, call 800-MEDICARE.

For more information...

For more information, call the National Women's Health Information Center at (800) 994-9662 or contact the following organizations.

Administration on Aging

Phone Number(s): (202) 619-0724

Internet Address: <http://www.aoa.dhhs.gov>

Family Caregiver Alliance

Phone Number(s): (415) 434 3388

Internet Address: <http://www.caregiver.org/index.html>

Alzheimer's Association

Phone Number(s): (800) 272-3900

Internet Address: <http://www.alz.org>

National Family Caregivers Association

Phone Number(s): (800) 896-3650

Internet Address: <http://www.nfcacares.org>

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