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Caregiver Stress

Q: What is a caregiver?

A: A caregiver is anyone who provides help to another person in need. Usually, the person receiving care has a condition such as dementia, cancer, or brain injury and needs help with basic daily tasks. Caregivers help with many things such as:

- grocery shopping
- house cleaning
- cooking
- shopping
- paying bills
- giving medicine
- bathing
- using the toilet
- dressing
- eating

People who are not paid to provide care are known as informal caregivers or family caregivers. The most common type of informal caregiving relationship is an adult child caring for an elderly parent. Other types of caregiving relationships include:

- adults caring for other relatives, such as grandparents, siblings, aunts, and uncles
- spouses caring for elderly husbands or wives
- middle-aged parents caring for severely disabled adult children

- adults caring for friends and neighbors
- children caring for a disabled parent or elderly grandparent

Q: Who are our nation's caregivers?

A: Most Americans will be informal caregivers at some point during their lives. During any given year, there are more than 44 million Americans (21% of the adult population) who provide unpaid care to an elderly or disabled person 18 years or older. Altogether, informal caregivers provide 80 percent of the long-term care in the United States.

- Sixty-one percent of caregivers are women.
- Most caregivers are middle-aged.
- Thirteen percent of caregivers are aged 65 years and older.
- Fifty-nine percent of informal caregivers have jobs in addition to caring for another person. Because of time spent caregiving, more than half of employed women caregivers have made changes at work, such as going in late, leaving early, or working fewer hours.

Q: What is caregiver stress?

A: Caregiver stress is the emotional and physical strain of caregiving. It can take many forms. For instance, you may feel:

- frustrated and angry taking care of someone with dementia who often wanders away or becomes easily upset
- guilty because you think that you should be able to provide better care, despite all the other things that you have to do



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- lonely because all the time you spend caregiving has hurt your social life
- exhausted when you go to bed at night

Caregiver stress appears to affect women more than men. About 75 percent of caregivers who report feeling very strained emotionally, physically, or financially are women.

Although caregiving can be challenging, it is important to note that it can also have its rewards. It can give you a feeling of giving back to a loved one. It can also make you feel needed and can lead to a stronger relationship with the person receiving care. About half of caregivers report that:

- they appreciate life more as a result of their caregiving experience
- caregiving has made them feel good about themselves

Q: Can caregiver stress affect my health?

A: Although most caregivers are in good health, it is not uncommon for caregivers to have serious health problems. Research shows that caregivers:

- are more likely to have symptoms of depression or anxiety
- are more likely to have a long-term medical problem, such as heart disease, cancer, diabetes, or arthritis
- have higher levels of stress hormones
- spend more days sick with an infectious disease
- have a weaker immune response to the influenza, or flu, vaccine

- have slower wound healing
- have higher levels of obesity
- may be at higher risk for mental decline, including problems with memory and paying attention

One research study found that elderly people who felt stressed while taking care of their disabled spouses were 63 percent more likely to die within 4 years than caregivers who were not feeling stressed.

Part of the reason that caregivers often have health problems is that they are less likely to take good care of themselves. For instance, women caregivers, compared with women who are not caregivers, are less likely to:

- get needed medical care
- fill a prescription because of the cost
- get a mammogram

Also, caregivers report that, compared with the time before they became caregivers, they are less likely to:

- get enough sleep
- cook healthy meals
- get enough physical activity

Q: How can I tell if caregiving is putting too much stress on me?

A: Caregiving may be putting too much stress on you if you have any of the following symptoms:

- feeling overwhelmed
- sleeping too much or too little
- gaining or losing a lot of weight
- feeling tired most of the time
- loss of interest in activities you used to enjoy



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- becoming easily irritated or angered
- feeling constantly worried
- often feeling sad
- frequent headaches, bodily pain, or other physical problems
- abuse of alcohol or drugs, including prescription drugs

Talk to a counselor, psychologist, or other mental health professional right away if your stress leads you to physically or emotionally harm the person you are caring for.

Q: What can I do to prevent or relieve stress?

A: To begin with, never dismiss your feelings as “just stress.” Caregiver stress can lead to serious health problems and you should take steps to reduce it as much as you can.

Research shows that people who take an active, problem-solving approach to caregiving issues are less likely to feel stressed than those who react by worrying or feeling helpless. For instance, someone with dementia may ask the same question over and over again, such as, “Where is Mary?” A positive way of dealing with this would be to say, “Mary is not here right now,” and then distract the person. You could say, “Let’s start getting lunch ready,” or involve the person in simple tasks, such as folding laundry.

Some hospitals offer classes that can teach you how to care for someone with the disease that your loved one is facing. To find these classes, ask your doctor, contact an organization that focuses on this disease, or call your local Area Agency on Aging (see

below). Other good sources of caregiving information include:

- doctors and nurses
- library books
- web sites of disease-specific organizations

Here are some more tips for reducing stress:

- Find out about caregiving resources in your community (see below).
- Ask for and accept help. Be prepared with a mental list of ways that others can help you, and let the helper choose what she would like to do. For instance, one person might be happy to take the person you care for on a walk a couple times a week. Someone else might be glad to pick up some groceries for you.
- If you need financial help taking care of a relative, don’t be afraid to ask family members to contribute their fair share.
- Say “no” to requests that are draining, such as hosting holiday meals.
- Don’t feel guilty that you are not a “perfect” caregiver. Just as there is no “perfect parent,” there is no such thing as a “perfect caregiver.” You’re doing the best you can.
- Identify what you can and cannot change. You may not be able to change someone else’s behavior, but you can change the way that you react to it.
- Set realistic goals. Break large tasks into smaller steps that you can do one at a time.
- Prioritize, make lists, and establish a daily routine.



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- Stay in touch with family and friends.
- Join a support group for caregivers in your situation, such as caring for someone with dementia. Besides being a great way to make new friends, you can also pick up some caregiving tips from others who are facing the same problems you are.
- Make time each week to do something that you want to do, such as go to a movie.
- Try to find time to be physically active on most days of the week, eat a healthy diet, and get enough sleep.
- See your doctor for a checkup. Tell her that you are a caregiver and tell her about any symptoms of depression or sickness you may be having.
- Try to keep your sense of humor.

If you work outside the home and are feeling overwhelmed, consider taking a break from your job. Employees covered under the federal Family and Medical Leave Act may be able to take up to 12 weeks of unpaid leave per year to care for relatives. Ask your human resources office about options for unpaid leave.

Q: What caregiving services can I find in my community?

A: Caregiving services include:

- transportation
- meal delivery
- home health care services (such as nursing or physical therapy)
- non-medical home care services (such as housekeeping, cooking, or companionship)

- home modification (changes to the home that make it easier for your loved one to perform basic daily tasks, such as bathing, using the toilet, and moving around)
- legal and financial counseling

Q: What can I do if I need a break?

A: Taking some time off from caregiving can reduce stress. “Respite care” provides substitute caregiving to give the regular caregiver a much-needed break. Below are the various types of respite services that are available:

- In-home respite. In this type of service, someone comes to your home to provide care. The type of care can range from simple companionship to nursing services.
- Adult day-care centers. Many adult day-care centers are located in churches or community centers. Some day-care centers provide care for both elderly adults and young children. During the day, the two groups meet for several hours to share in activities such as reading stories. This type of contact seems to benefit both young and old.
- Short-term nursing homes. If your loved one needs occasional nursing care and you must leave town for a couple weeks, some nursing homes will care for your loved one while you are gone.
- Day hospitals. Some hospitals provide medical care to patients during the day and then at night, the patient returns home.



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Q: What devices can I buy that will help me provide care?

A: There are devices that you can buy that can help you make sure that your loved one is safe. Below are some examples:

- Emergency response systems involve a button on a necklace, bracelet, or belt that your loved one wears. If she has an emergency and you are not home, she presses the button to alert a monitoring center. The center then alerts medical personnel and you. These systems are intended for people who can press the button and do not have dementia.
- An intercom system allows you to hear your loved one from another area of your home.
- A Webcam is a video camera that allows you to see your loved one from another area of your home.
- Mobility monitors use a small transmitter to help keep track of people with dementia. When your loved one wearing a transmitter strapped to her ankle or wrist passes out of a set range, the transmitter alerts you that your loved one is wandering away.

Also, researchers are developing technologies to allow doctors and nurses to examine and treat patients from locations different than the patient's. This new field is called telemedicine. It uses a communication system, like the Internet or two-way television, to collect medical information and provide instructions to the caregiver and patient. Telemedicine will be most useful in rural areas where few doctors are available. Some states already have limited telemedicine programs in operation.

Q: How do I find out about caregiving services in my community?

A: Contact your local Area Agency on Aging (AAA) to learn about caregiving services where you live. AAAs are usually listed in the city or county government sections of the telephone directory under "Aging" or "Health and Human Services." The National Eldercare Locator, a service of the U.S. Administration on Aging, can also help you find your local AAA.

You might also want to consult with an eldercare specialist, a professional who specializes in aging-related issues. An eldercare specialist assists older adults and their family members by assessing their needs and identifying the best services and devices available to meet those needs. To find an eldercare specialist in your area, ask your doctor or local AAA.

Q: How will I pay for home health care and other caregiving services?

A: Medicare, Medicaid, and private insurance companies will cover some of the costs of home health care. Other costs you will have to pay for yourself.

The costs of home care depends on what services you use. Non-medical workers like housekeepers are much less expensive than nurses or physical therapists. Also, some home care agencies are less expensive than others.

To find out if you are eligible for Medicare home health care services, read the free publication Medicare and Home Health Care (Publication No. CMS-10969), available at <http://www.medicare.gov/Publications/Pubs/pdf/10969.pdf>. You can also call your



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Regional Home Health Intermediary. To find the phone number, go to the Contacts Database of the Centers for Medicare & Medicaid Services at: <http://www.cms.hhs.gov/apps/contacts>. You can also call 1-800-MEDICARE (1-800-633-4227).

To qualify for Medicaid, you must have a low income and few other assets. To find out if you qualify for Medicaid, call your State Medical Assistance Office. To find the phone number, go to the Contacts Database of the Centers for Medicare & Medicaid Services at: <http://www.cms.hhs.gov/apps/contacts>. You can also call 1-800-MEDICARE (1-800-633-4227).

Besides Medicare and Medicaid, there is another federal program, called the National Family Caregiver Support Program, that helps states provide services for family caregivers. To be eligible for the program, a caregiver must:

- care for an adult aged 60 years and older, or
- care for a person of any age with Alzheimer's disease or a related disorder

- be a grandparent or relative 55 years of age or older who is the primary caregiver of a child under the age of 18, or
- be a grandparent or relative 55 years of age or older providing care to an adult, aged 18 to 59 years, with a disability

Each state offers different amounts and types of services. These include:

- information about available services
- help accessing support services
- individual counseling and organization of support groups
- caregiver training
- respite care
- supplemental services, supplies, and equipment, such as home modifications, emergency response systems, nutritional supplements, incontinence supplies, etc.

To access services under the National Family Caregiver Support Program, contact your local Area Agency on Aging. ■



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For more information

For more information on caregiver stress, call womenshealth.gov at 1-800-994-9662 or contact the following organizations:

Administration on Aging

Phone number: (800) 677-1116

Internet address: <http://www.aoa.gov>,

<http://www.eldercare.gov>

National Alliance for Caregiving

Internet address:

<http://www.caregiving.org>

Centers for Medicare and Medicaid Services

Phone number: (800) 633-4227

Internet address: <http://www.cms.hhs.gov>

National Family Caregivers Association

Phone number: (800) 896-3650

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

Family Caregiver Alliance

Phone number: (800) 445-8106

Internet address: <http://www.caregiver.org>

The National Respite Locator Service

Phone number: (919) 490-5577

Internet address:

<http://www.respitelocator.org>

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