



Caring for the Caregiver

Caregiving is hard work...It is important that we listen to caregivers in order to know what their needs are and then address the specific needs they identify.

FORMER FIRST LADY ROSALYNN CARTER, FOUNDER OF THE ROSALYNN CARTER INSTITUTE FOR CAREGIVING

You may be asking:

- *How long can I keep this up? (Ten weeks...ten months...ten years?)*
- *How do I know when my own health is being compromised?*
- *How can I overcome the daily isolation I feel?*
- *What should I do when I feel I can't keep going?*

The information in this section is useful for *all* caregivers—those currently providing care and those who want to plan for providing care in the future. In fact, many current caregivers say that they wish someone had told them to start preparing for eldercare *before* there was a crisis. You are a caregiver if you are a close family member (spouse, domestic partner, child, sibling, or relative), friend, or neighbor, and:

- You manage a variety of tasks, from personal care and managing the checkbook to taking blood pressure and giving medication
- You care for healthy elders or elders who are chronically or acutely ill
- You provide direct service and/or organize and monitor the care others provide
- You provide care in the home, hospital, rehab center, retirement community, nursing home, or other setting
- You provide help intermittently, regularly, and/or on a 24/7 basis
- You live with or near, or far away from the elder you care for

Why Caregivers Need Care

Some people who provide care for an elder do not realize that everything they do is part of caregiving. They may say, “This is just what families do for each other,” or “This is what friends are for.” However true these statements are, they tend to mask the value of the care (for the elder and the community at large) and the significant toll that this work can take.

For many caregivers, the errands, tasks, and daily care they provide are rewarding and based on feelings of love and attachment to the person they are caring for. For most elders, the care they receive enhances their health and well-being and brings comfort, companionship, practical help, and safety. [The Joys of Caregiving](#) outlines some of the benefits caregivers experience.

However, caring for elders can be very stressful, physically and psychologically. Taking on the responsibility for someone else’s affairs, dealing with doctors and insurance companies, finding appropriate and affordable resources, and attending to daily meals, dressing, bathing, or even just providing company can be time-consuming, exhausting, and challenging. Elders may make your job as a caregiver more difficult by being uncooperative, demanding, or bad-tempered. Their frustration, sadness, and fears about being ill, dependent on you for care, or otherwise impaired, may be expressed as anger, irritability, or anxiety.

Caregiving can involve considerable sacrifice on the part of caregivers. Some have to take a leave from work. Some retire early. Others feel constant conflicts between job responsibilities and the demands of caring for family at home. Many baby boomers are now part of the “sandwich” generation—caught between caring for young children and aging parents—and find the demands of both overwhelming.

Caring for an elder can be a very isolating experience, especially for those who have limited help or are the sole caregiver for an elder who cannot be left alone for long periods of time. But you are not alone. There *are* support systems to help you meet the challenges of providing eldercare—short-term or long-term.

Learning Caregiving Skills

Once you learn about your role as a caregiver, you will be better equipped to face the current and future needs of caring for the elder in your life. Two helpful publications are the following:

- **Because We Care** at www.aoa.gov/prof/aoaprogram/caregiver/carefam/taking_care_of_others/wecare/wecare.asp from the U.S. Administration on Aging, introduces families to their new role as caregivers.
- **Eldercare at Home** at www.healthinaging.org/public_education/eldercare/2.xml, published by the American Geriatrics Society, is written for family caregivers and explains how to communicate effectively with doctors and other professionals as part of a caregiving support team, as well as how to care for yourself. (See also the Health Care section.)

New Skills

Caregivers need more than information. You may need to learn new healthcare-related skills. As hospitals and rehab facilities shorten the length of patient stays, families are asked to provide more direct care for elders. Families may be expected to keep wounds clean, give medications, administer CPR, or monitor heart and blood sugar levels, but often they are not given the training they need to provide this care effectively.

These two organizations provide training and courses for caregivers:

- The **American Red Cross** at www.redcross.org/ has courses in first aid that give hands-on training on how to recognize and respond to emergencies, how to perform CPR, and how to use automated external defibrillators (AEDs) to save victims of sudden cardiac arrest. Visit the Web site and enter your Zip Code to find classes near you.
- **Visiting Nurse Association of America** (VNA) at www.vnaa.org/vnaa/gen/html~home.aspx provides in-home training for caregivers about wound care, nutrition, diabetes, asthma, and other topics by registered nurses. To find a VNA near you, visit the Web site and enter your city, state, or Zip Code.

Many organizations related to specific diseases (cancer, diabetes, Alzheimer's, etc.) provide education and training on various aspects of caring for elders with those conditions.

Collecting and Organizing Information

Caregivers need to know how to collect and organize many details about their elder's health care, home care, medications, safety equipment, and so on. These records are vital but difficult to keep track of. "The Caregiver's Organizer" at www.seniorconnection.org/caregiversupport.htm, developed by the Central Massachusetts Family Caregiver Support Program, can be downloaded from its Web site in ten different languages. Click on "Services and Resources Provided," then "The Caregiver's Organizer." See also the Finances and Health Care sections.

Support Groups and Services

The challenges of caring for elders can result in caregivers ignoring their own physical and emotional health. Caregivers often don't recognize the symptoms of stress that they are experiencing. For a simple self-test, see the American Medical Association's **Caregiver Self-assessment Questionnaire**. If you take the test and find you do have a number of symptoms associated with high levels of physical and emotional stress, contact your primary care doctor for an appointment, take the questionnaire with you, and discuss next steps, such as finding a therapist or support group, or taking medication.

You may also want to talk with your clergyperson, a trusted friend, or a close family member. Securing support from other family members, friends, and community groups is essential. It may be hard to ask for and/or accept help, but you cannot do it all alone. Think in terms of concrete actions that can help. Could a friend pick up groceries for you or the elder? Could a neighbor do yard work for you or give you a lift to the doctor's? Could a friend or relative keep the elder company so that you can take a break—go to a movie, the gym, take a walk or a drive, or do some shopping for yourself? Perhaps you could set up a regular visit from a friend (yours or the elder's) so that you don't feel so isolated or overloaded. You may not be able to reciprocate, but don't worry. The people who care about you want to help, and you may be able to return the help at a later time.

You may feel that you are the only one dealing with an elder who is demanding, difficult, or belligerent. You may feel sad that your elder is in need and confused about your new role as caregiver. You may also be dealing with siblings or other family members who criticize you or do not share in caring for the elder. Some caregivers find support groups helpful. They allow caregivers to share their experiences, exchange information, and point each other toward organizations that have been particularly helpful. Some support groups may be linked to stress management or exercise classes.

Support groups also encourage caregivers to care for themselves and help remind you that it is not selfish for caregivers to attend to their own needs. Many support groups are run by professionals, such as social workers, and can help caregivers devise productive strategies for dealing with intra-family conflicts or tensions that may arise around difficult caregiving decisions.

There are many organizations to help you find a support group suited to your needs. Some are organized around a particular city or region, while others are focused on the kind of illness an elder may have. Support groups can be in person or they can be online. There are also some health care providers that provide caregiver support groups. Call your doctor or your health insurance provider to get referrals to groups covered under your health plan.

One of the best ways to find support groups in your area is through the Family Caregiver Support Program in your state. Contact your local Area Agency on Aging (AAA) through the **Eldercare Locator** at www.eldercare.gov/Eldercare/Public/Home.asp, 800-677-1116 toll free.

The National Family Caregiver Support Program (NFCSP)

The NFCSP is administered through the U.S. Administration on Aging (AoA) and its nationwide “aging network” made up of 56 state government agencies and 655 Area Agencies on Aging (AAAs), with more than 25,000 local community programs, such as senior centers and Councils on Aging (COAs).

The program targets two groups: adults who are caring for elders and the disabled, and grandparents who are caring for grandchildren. The information below focuses on eldercare services.

NFCSP primarily serves family caregivers of adults 60 years of age and older, and people of any age with a diagnosis of Alzheimer's. There are no income eligibility requirements for information or services. The overall goal of the program is to enhance the caregiver's ability to keep elders at home and in their communities, in a safe and supportive environment. Each program works to provide support in five key areas:

- 1 **Information** about available services, community resources, and local programs
- 2 **Assessment of needs and access to services** through one-on-one assistance to identify options and gain access to community-based services
- 3 **Training, support, and counseling**, such as caregiver support groups and training classes to assist caregivers in making decisions, solving problems, and managing stress
- 4 **Respite programs** to provide temporary relief through in-home care, or adult day care or emergency respite (see the Caring for the Caregiver section.)
- 5 **Supplemental services**, on a limited basis, for home modifications and repair, transportation, and other things it may be difficult for the caregiver to do

Within these five broad areas, each state program designs its own programs, publications, and resources. The NFCSP has made it a priority to provide caregiver support services and resources that are culturally and linguistically sensitive. AAAs and COAs have developed partnerships with organizations linked to specific ethnic and cultural groups. These partnerships make it possible to get publications translated into languages other than English and/or to have bilingual staff available to answer questions on the phone and link caregivers from diverse communities to the broad array of elder services and resources.

The NFCSP program gives priority to caregivers with the greatest social and economic need, but it is also open to middle-income families. There are no income-related eligibility criteria for adult day care and respite programs, although there are limited slots available in these programs. There are no eligibility criteria for case management services that are provided free for the first six months. Eldercare advisers offer an initial needs assessment free of charge. (Additional services may require a nominal fee.)

Each state has its own version of NFCSP. To see the profile of the Family Caregiver Support program in your state, go to the *National Conference of State Legislatures* Web site at www.ncsl.org. Click on "Bookstore," then "Browse," then "Family Caregiver Support" or call 202-619-0724. For a publication called "Family Caregiver Support: State Facts at a Glance," go to www.aoa.gov/PROF/aoaprogram/caregiver/careprof/resources/fcs.pdf. (Note: This URL links to a large PDF file.) You can also contact your local Area Agency on Aging (AAA) through the **Eldercare Locator** at www.eldercare.gov/Eldercare/Public/Home.asp, 800-677-1116 toll free.

Respite Services

Respite means “time off.” *Every* caregiver needs time off. Respite through substitute care can be provided on a regular basis, such as three days a week, or can be scheduled in advance when needed for vacations or special occasions.

In-home Care

In-home care is provided by a companion who comes to the house. Usually this is done one or two times a week for four hours or less to provide companionship and supervision, but no personal care or household services. In-home care allows caregivers, especially full-time caregivers, to do errands, attend to personal business, socialize, and exercise. It can be arranged through your local AAA or from private service providers. Sometimes volunteers are available through a “Friendly Visitor Program” or local faith-based organizations.

Out-of-home Care

Out-of-home programs offer a secure, friendly environment for elders and provide caregivers with respite. These services can be arranged through your local AAA or COA. There are several types of out-of-home care programs:

- **Social Day Care Groups** provide daytime supervision outside the home, usually with snacks or meals, along with recreational and social activities.
- **Adult Day Care Centers** provide recreational programs and meals for elders who need closer supervision, usually due to dementia or Alzheimer’s.
- **Adult Day Health Care** provides an organized program of health care, supervision, and social activities for elders who have health conditions that need to be monitored.
- **Emergency Relief Respite Programs** are available to caregivers who have a personal or medical emergency, such as a sudden illness or a funeral out-of-town. These programs usually utilize a room in a long-term care facility or rehabilitation center, and the elder is taken care of as if she or he were a resident in that facility.

Paying for respite services can be challenging. There is some funding for low-income caregivers available through Medicaid, and states are increasingly finding additional revenue sources to support moderate-income families. For information on services nationwide, visit the *National Respite Locator Service* at <http://chtop.org/ARCH/ARCH-National-Respite-Locator.html>, a free service that connects caregivers and respite programs in their own community or the community where the elder in their care resides.

Combining Work and Caregiving

Combining a full-time job and eldercare creates special challenges. Check with your employer's Human Resources Department, if available, for information about employee assistance resources. Workplace support programs can assist you with local and long-distance caregiving in the following ways:

- **Information and referral services.** These I&R services can help caregivers with locating home care services, housing options, and long-term care facilities.
- **Flexible work arrangements.** You may be able to leave early or come in late, so that you can give an elder her or his medication, take her or him to doctor's appointments, and so on.
- **Short-term and long-term leaves.** You may be able to take a leave with job protection and continuation of benefits. Employed caregivers may be entitled to 12 weeks of leave to care for an elderly spouse or parent through the Family and Medical Leave Act (FMLA). Although this law only covers 55 percent of the workforce, FMLA provides unpaid leaves that are job-protected and ensure continuation of health benefits for those who are already covered.

For more detailed information on flexible work arrangements and your rights under the FMLA, and to find out if you have additional benefits under state law for family leave, contact the following organizations:

- **The Center for Aging and Work** at Boston College at http://agingandwork.bc.edu/template_index has resources and information on flexible work options that can help employees and employers address the issues created by caring for elders while working.
- **Labor Project for Working Families** at www.working-families.org/, 510-643-7088, is a national, nonprofit advocacy and policy organization providing technical assistance, resources, and education to unions and union members on family issues in the workplace.
- **U.S. Department of Labor, Wage and Hour Division** at www.dol.gov/esa/whd, 866-487-9243 toll free, regulates the FMLA and advises employees on their rights under the law.

More Caregiver Resources

There are many other resources for information, support, and more. The following organizations will help you cope with your role as a caregiver.

National Organizations

- **AARP** at www.aarp.org/learntech/family_care/ has free online seminars for caregivers, such as "Managing Caregiving Details: The Basics" and "Planning for the Care of Aging Parents." Click on "Learning and Technology," then "Family Caregivers." For help with conversations with an elder who is too sick or frail to live independently, check out "Providing the Care."

- **Caring from a Distance** at www.cfad.org is a nonprofit organization geared specifically to the particular challenges faced by caregivers who live far away from the elder. It offers information, support, and helpful links.
- **Children of Aging Parents (CAPS)** at www.caps4caregivers.org, 800-227-7294 toll free, offers caregiver support programs in 13 states for adult children caring for elderly parents.
- **Family Caregiver Alliance** at www.caregiver.org/caregiver/jsp/home.jsp, 800-445-8106 toll free, is a national network that addresses the needs of families and friends providing long-term care at home. The Web site includes information, free publications, and an online caregiver support discussion group.
- **National Alliance for Caregiving** at www.familycaregiving101.org/ provides information for caregivers on how to take care of themselves while providing care. Click on “Family Caregiving 101.”
- **National Family Caregiver Support Program, U.S. Administration on Aging Resource Page** www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp provides links to government, nonprofit, and commercial caregiver Web sites. It also includes information and articles on a variety of topics. Call 202-619-0724 for a caregiver support program near you.
- **National Family Caregivers Association** at www.thefamilycaregiver.org/ provides useful tips and guides for all aspects of family caregiving.
- **Rosalynn Carter Institute for Caregiving** at www.rosalynncarter.org works to establish local, state, and national partnerships committed to building quality long-term care systems and providing greater recognition and support for caregivers. Visit the Web site for publications, workshops, and conferences.
- **Well Spouse Foundation** (also known as the Well Spouse Association) at www.wellspouse.org/index.php?option=com_contxt&Itemid=50, 800-838-0879, is a nonprofit organization providing support and other resources to husbands, wives, and partners of chronically ill or disabled individuals. Click on “About Us,” then “Join a Support Group,” and select your state to find a support group nearby.
- **Women’s Health Information Center** at www.4woman.gov/faq/caregiver.htm, 800-994-9662 toll free, offers useful resources on topics that affect women caregivers. The Web site is part of the U.S. Department of Health and Human Services’ Office of Women’s Health.

Faith-based Organizations

Faith-based organizations have a long tradition of providing assistance to those in need, whether they are members of that faith or not. Faith-based organizations coordinate volunteers to help and visit with the elderly and sponsor meal programs and other direct services at places

of worship. Many faith-based organizations run their own retirement communities and/or nursing homes. The following organizations are just a few examples of the kinds of services provided by faith-based organizations. Check with your clergy or religious affiliation for additional resources.

- **Association of Jewish Family and Children’s Agencies (AJFCA)** at www.ajfca.org/elder.html, 800-634-7346 toll free, links concerned family members of frail elders living in distant cities, with Jewish Family Services Agencies in that community through its Elder Support Network.
- **Catholic Charities**, www.catholiccharitiesusa.org/NetCommunity/Page.aspx?pid=292&srcid=777, 703-549-1390, provides social service programs that may include home visiting programs, adult day health, visiting nurse services, a foster grandparents program, caregiver support programs, and basic needs services (food, fuel, utility, and rental assistance). To find a chapter near you, visit the Web site and enter your state into the search box.
- **Faith in Action** at www.fiavolunteers.org/, 877-324-8411 toll free, provides volunteers who can give caregivers non-medical assistance, such as picking up groceries or running errands, friendly visiting, reading, or helping to pay bills.
- **Lutheran Services in America** at www.lutheranservices.org has more than 300 health and human service organizations that provide care, ranging from health care to disaster response. Visit its Web site and click on “Find Services Near You,” then “Search by Service” (or Location or Organization name), and then “Aging Services,” to find 24 different services to help elders and their caregivers.

Disease-specific Organizations

Sometimes the information caregivers need is specific to a particular disease or condition.

- **Alzheimer’s Association** at www.alz.org/ has extensive information about Alzheimer’s disease, updates on research and treatments, training for caregivers and for people with dementia, and short-term counseling. Contact its 24/7 Helpline at 800-272-3900 for information, referral, and support.
- **American Cancer Society (ACS)** at www.cancer.org/docroot/home/index.asp provides health information, support groups, and other resources for caregivers, including a caregiver discussion board. For your nearest ACS chapter, visit the Web site and click on “Find ACS in your Community,” then enter your Zip Code.
- **American Diabetes Association** at www.diabetes.org/home.jsp provides diabetes research, information, and advocacy. For information about caregiver support groups and other resources in your area, visit the Web site and click on “In Your Area,” then enter your Zip Code, then “Find a Recognized Education Program.”

- The **American Heart Association** at www.americanheart.org/ provides information and resources for consumers, as well as information specifically designed for caregivers at www.americanheart.org. Click on “Diseases and Conditions,” and then on “Caregivers.”
- **The American Stroke Association** at www.strokeassociation.org/presenter.jhtml?identifier=1200037 provides outreach to stroke survivors and their caregivers through a national call center, 888-4-STROKE (888-478-7653) toll free. To reach the support group registry, visit the Web site and click on “Life after Stroke,” then “For Family Caregivers,” then “Getting Support,” then “Support Groups,” then “More.” The locator will help you find the chapter nearest you.
- The **Arthritis Foundation** at www.arthritis.org/, 800-283-7800 toll free, offers resources in English and Spanish, including detailed information about arthritis, drug treatments and pain management, as well as help lines and message boards.
- **Compassionate Care ALS** at www.ccals.org provides educational and legal resources, respite opportunities, instruction and guidance, subsidies for assistance, and conversations with ALS patients and their caregivers, families, and friends.
- **COPD-Support, Inc.** at www.copd-support.com/ provides information on organizations, support groups, and online meeting places for patients with emphysema, chronic bronchitis, and chronic asthma, and their caregivers.
- **The Leukemia and Lymphoma Society** at www.leukemia-lymphoma.org/hm_lls, 800-955-4572 toll free, provides information on the diseases and both online and in-person group support for caregivers. Visit its Web site and click on “Chapter Finder,” then enter your Zip Code.
- The **National Multiple Sclerosis Society** at www.nationalmssociety.org/site/PageServer?pagename=hom_gen_homepage, 800-344-4867 toll free, has a useful Web site that includes publications for caregivers.
- **National Parkinson Foundation** at www.parkinson.org/NETCOMMUNITY/Page.aspx?pid=214&srcid=201 supports related research, patient care, education, training, and outreach. Support groups are listed on its Web site.
- **The Wellness Community** at www.thewellnesscommunity.org/support/, 888-793-WELL (888-793-9355) toll free, provides support for cancer patients and their caregivers, and has online and in-person support groups in Spanish and English.