

“My father fights me when I’m just trying to help. I get so frustrated some times, I’m afraid I’ll strike back.”

Caring for a sick or disabled elderly family member can be a deeply enriching and personally fulfilling experience. It is a time for sharing memories and offering comfort. For some, it offers a rare opportunity to spend extended time with a loved one.

But the responsibility and challenges of caregiving can be overwhelming. Watching a loved one decline, experience pain or discomfort, or act in unfamiliar ways can be disturbing. Caring for an ill elderly family member can be physically demanding and exhausting; it can leave caregivers feeling overwhelmed, frustrated or fearful. If the relationship between a caregiver and an ill family member was poor to begin with, caregiving can aggravate tensions or cause resentment. Some caregivers feel guilty that they’re not doing enough, while others fear that they will lash out or harm the person for whom they provide care.

Caregivers,

- Do you ever feel like you’ve reached your limit?
- Are you plagued by guilt that you’re not doing everything you should be doing, or that you’re not doing it well enough?
- Are you constantly exhausted, depressed, overeating or drinking too much?
- Do you feel that other family members aren’t doing their share?
- Do you find yourself cutting corners because you’re too tired or overwhelmed to do everything you think you should?
- Have you ever worried that you might lash out at your ill family member?

Although seldom talked about, these feelings aren’t unusual. But they are a warning that it’s time to get help. When ignored, negative feelings can lead to stress, burnout, depression and health problems. They can even lead to abuse or neglect.

Here are some things you can do:

Join a Support Group

Support groups provide caregivers with an opportunity to share experiences, insights and ideas. Just knowing that you’re not alone can bring relief. Developing relationships with other caregivers has actually been shown to reduce stress and relieve fears about lashing out. Many social service agencies and organizations offer groups. For the computer savvy, there are online “virtual” support groups.



Make Use of Social Services

Community services are available to help with just about everything you or your family member needs, from legal assistance to help preparing meals. Unfortunately, finding services can sometimes be frustrating, especially if you or the person you care for has limited financial resources. Publicly financed services and financial assistance may be available to those who qualify. A good place to find out about resources in your community is your local Area Agency on Aging (AAA), which can usually be found in the city or county government section of the telephone directory under “Aging Services” or “Social Services.” You can also get the number from the Eldercare Locator at (800) 677-1116. The following are just a few of the services that are available in most communities:

Respite means relief, and respite care comes in many forms. Agency employees or volunteers may come to your home to give you a break. Some programs will arrange for your family member to come to an adult day center for several hours a day. Still others can accommodate older people in a supervised setting, such as a nursing home, for several days.

Support services can ease caregivers’ load. They include in-home attendants, transportation, home delivered meals and many more.

Assessments can pinpoint what activities your older family member has trouble with and identify ways to help. Getting an unbiased assessment can help ensure that your family member gets everything he needs without paying for unnecessary services. Assessments range from simple checklists to comprehensive examinations performed in hospitals and clinics by teams of medical and social work professionals.

Financial and legal planning can relieve stress by reducing uncertainty about the future, maximizing resources and preventing crises. Services include public benefits counseling, estate planning and assistance with advanced directives — documents with which someone designates another to make health, legal or financial decisions in the event he becomes unable to do so.

Get Healthy!

Exercise, good nutrition, sleep and relaxation can make any stressful situation more manageable. For example, eating at regular intervals helps maintain a steady blood sugar level, which has a calming effect. Common foods like milk, bananas, walnuts and tomatoes contain amino acids that produce serotonin, a chemical that helps the body relax. Other nutrients that can help keep you stay calm and relaxed are the complex carbohydrates found in whole-grain cereals, bread, rice and pasta, and the lecithin contained in dried beans, nuts, soy products and eggs. Exercise can alleviate tension and anxiety, improve your outlook, and strengthen your immune system. It doesn’t have to be grueling — a few minutes of walking, cycling or stretching can really help.

Hire a Helper

If your loved one needs more help than you can provide, consider hiring a helper. Referred to as attendants, home care aides, homemakers, personal care assistants or choreworkers, these employees help with daily chores and activities such as bathing, dressing, preparing food, shopping or going to appointments. You may be eligible for public assistance to pay for a helper. Find out more by contacting your Area Agency on Aging or by checking the phone directory under “Home Care.”



You can also hire helpers on your own. While doing so reduces the cost, it means that you will have to find the person through newspaper want ads, personal contacts or referral services. You will also need to check references, schedule hours and handle payroll tasks. When hiring helpers, always ask applicants for multiple references and check them! If your state licenses home-care workers (ask your local Area Agency on Aging), get the applicant’s license number and confirm it. To find out more about hiring helpers, call your local Area Agency on Aging.

Learn More About Your Family Member’s Illness

Learning about an illness or disability — its symptoms, progression and treatment — can reduce anxiety, relieve uncertainty, help you plan for the future, and alert you to changes. Organizations like the American Cancer Society, the National Parkinson Foundation, and the Alzheimer’s Association are excellent resources.

Learn To Identify Your “Stress Triggers”

Caregivers commonly find certain aspects of caregiving or certain behaviors of those they care for particularly stressful. Learning to identify your personal triggers is the first step in getting back in control. The next steps are learning how to respond to difficult behaviors more effectively and getting help.

Learn to Respond Appropriately to Difficult Behaviors

Some behaviors, particularly those associated with dementia, are disturbing and can cause embarrassment, frustration, exhaustion, stress and anger. These behaviors are often a part of the disease process or a response to frustration, pain or the inability to communicate. Carefully observing your family member’s behavior and discussing it with professionals or other caregivers may help you figure out what’s wrong and how to correct it. Although you will need to explore what works best for you and your impaired relative, the following suggestions and strategies have been found to be helpful:

Aggressive behavior that doesn't pose a physical threat can often be diffused by remaining calm, ignoring the behavior, showing affection and trying to help the person regain a sense of control. Because aggressive behavior often occurs during personal care activities such as bathing, it helps to remember that you can always postpone the task until a later time when the patient is calmer. Avoid arguments. Confrontation or challenges make matters worse. At times, it may be necessary to isolate the older person or call for help to ensure your own safety or the safety of the patient and others.



Anger and agitation may result from medical causes or the adverse side effects of medications. Check with your family member's physician if the anger or agitation becomes severe.

Lack of empathy. People who suffer from dementias may lose the ability to think abstractly, which can result in difficulty seeing things through someone else's eyes. The result can be thoughtless or hurtful remarks or unreasonable, demanding requests. It may help to remind him how he affects others.

RESOURCES

Alzheimer's Association

The largest national voluntary health organization committed to finding a cure for Alzheimer's disease and helping those affected by it. State and local chapters provide services to people with the disease, their families and caregivers, and health care professionals. The Alzheimer Association's website contains a section for caregivers, which includes resource directories, instructions in behavior management, and information about the disease and its treatment.

919 North Michigan Avenue,
Suite 1100
Chicago, Illinois 60611-1676
(800) 272-3900
<http://www.alz.org>

Family Caregiver Alliance

A national information center and pioneer in the development of caregiver services. FCA's website provides a wealth of information and online services for caregivers.

690 Market Street, Suite 600
San Francisco, CA 94104
Telephone: (415) 434-3388
Website: www.caregiver.org
Email: info@caregiver.org

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AARP

The nation's leading organization for people over the age of 50. The organization has produced a variety of publications on caregiving, many of which are available on its website. These include A Caregiver Guide to Information and Resources (Document # D16697):

601 E Street, N.W.
Washington, DC 20049
(202) 434-AARP
<http://www.aarp.org/confacts/caregive/planning.html>

Additional Websites

There are now hundreds of Internet sites with information on caregiving. Some are operated by non-profit organizations, while others are operated by businesses such as homecare agencies. Two good starting points for finding online resources are listed below:

National Aging Information Resource Center Resources for Caregivers

<http://www.aoa.gov/NAIC/Notes/caregiverresource.html>

Operated by the Administration on Aging of the U.S. Department of Health and Human Services, this site includes information on government-sponsored resources, national caregiver organizations, articles, and links to other sites.

Caregiver Resources

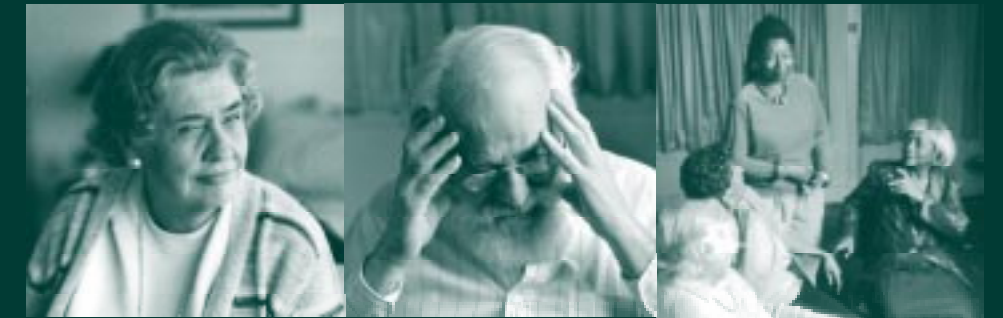
Washington University-St. Louis
<http://www.biostat.wustl.edu/ALZHEIMER/submit/caregive.html>

This site describes (and links to) more than 100 other sites for caregivers.

Recommended Reading

- ★ **Stephanie Hoffman and Constance Platt.** *Comforting the Confused: Strategies for Coping With Alzheimer's Disease.* New York: Springer, 1981.
- ★ **Mary Kaplan and Stephanie B. Hoffman** (eds.) *Behaviors in Dementia: Best Practices for Successful Management.* Baltimore: Health Professionals Press, 1998
- ★ **Wendy Lustbader.** *Counting on Kindness: The Dilemma of Dependency.* Old Tappan, NJ: Free Press, a Division of Simon & Shuster, 1994
- ★ **Nancy Mace and Peter Rabins.** *The 36-Hour Day.* Baltimore: John Hopkins University Press, 1999 (revised).
- ★ **Northeastern Ohio Universities College of Medicine.** *A Guide for Individuals Who Care for Persons with Dementia: Preventing Stress from Becoming Harmful.* Rootstown, OH: Northeastern Ohio Universities College of Medicine, 1998
- ★ **Anne Robinson, Beth Spencer and Laurie White.** *Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses.* Ypsilanti, MI: Geriatric Center of Michigan, Eastern Michigan University, Alzheimer's Education Program, 1991. ■

Preventing Stress from Becoming Harmful:



A Guide for Caregivers