



Guidelines for Caregivers¹

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Are you a caregiver of a frail family member who needs some kind of assistance with his or her daily activities? Sometimes caregivers:

- Feel overwhelmed by the demands of caregiving;
- Find it difficult to spend time with and enjoy friends and family;
- Have little time left for hobbies, exercise, or other activities; or
- Feel irritable, sad, or lonely at times.

If this sounds familiar, you may be experiencing caregiver burden or stress. This publication provides guidelines for managing stress, maintaining health, and getting the help that is needed to better enjoy all parts of your life.

Caregiver Burden and Stress

Caregivers who are faced with the many demands of providing care often experience caregiver burden. This term refers to the feeling that caregiving has had a negative impact on the



caregiver's emotional or physical health and financial status. For example, some caregivers find that the demands of caregiving lower their time and energy for personal interests and friendships. Caregivers may also leave their jobs to care for a family member. They may be worried about meeting household expenses due to the cost of medical care. These life changes may last as long as the caregiver's assistance is needed.

In contrast to burden, stress refers to feelings of being pressured, fatigued, and depressed. Stress is the short-term, emotional response to caregiving situations. For example, a caregiver may experience stress when they must cancel an outing with friends if

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their mentally impaired elder is particularly confused or upset that day. Burden, however, refers to the long-term impact of this situation on the caregiver's life. The burdened caregiver might think, "Caring for Sam means I just don't have a social life any more."

Despite the difficulties of providing care, there are steps the caregiver can take to reduce stress and to cope with burden. These steps include managing stress, maintaining health, and reaching out. . These steps will help you, the caregiver, reduce the demands of caregiving so that you can enjoy other aspects of your life.

Managing Stress

Accept Your Feelings

Caregiving is a difficult job. In many ways it can be rewarding. Caregivers feel a deep sense of caring, love and pride. They may also feel angry at the many demands on their time. They grieve that the older person is not the same anymore. They feel burdened by financial pressures. Caregivers may feel unappreciated for all of the many things they do.

These feelings are normal. Feelings of anger, frustration, or helplessness do not mean that you, as a caregiver, love your relative less. Recognizing and accepting all these feelings is a necessary step in resolving problems, reducing stress, and preventing physical and emotional problems.

Be Aware of Stress

Caregivers sometimes expect too much of themselves and are constantly worried about neglecting others. They may not recognize feelings of stress or burden in themselves, and, in the long run, harm their own physical and emotional health.

The first step toward managing stress is to be aware of it. Try monitoring your stress with the stress symptoms checklist.

Stress Symptoms

- headaches



Figure 2.

- fatigue
- insomnia
- weight change
- digestive upsets
- increased use of alcohol, drugs, tobacco
- neck and shoulders tighten
- anxiety
- mood swings
- crying spells
- irritability
- depression
- forgetfulness

- poor concentration
- low productivity
- negative attitude
- confusion
- lethargy
- boredom
- feelings of isolation
- hypertension

Whenever you start to notice stress symptoms, you may want to practice relaxation exercises. Get into a comfortable position -- place your feet flat on the floor, relax your shoulders, and loosen your face muscles. Take a few deep breaths -- in, out, in, out. Or, go on a mental vacation. Get into a comfortable position, close your eyes, and imagine yourself somewhere you find soothing, such as overlooking the beach at sunset.

Think and Act Positive

Those who keep a positive outlook on life are better able to manage stress than those who see the world in negative ways. Positive thinkers "reframe" difficult situations, changing them from bad to good. Positive thinkers tend to look at things in the long run and that helps to put the situation in perspective.

Caregivers seem to feel less stress when they face problems head on, take charge of situations, and look for solutions. In addition, caregivers who feel high levels of affection for the care receiver experience less stress. Caregivers may be able to keep a positive outlook by remembering the love and caring they feel for the impaired elder and the benefits of caregiving.

Exercise in Positive Thinking

Start by relaxing and thinking in positive ways. Think positively about yourself: "I really did a great job of caring for my wife today," or, "I took a walk to get some exercise and relax." Think positively about even small victories with your older family member: "She seems to feel a little better today and ate well this morning."

Remember how you feel about your relationship with the impaired elder: "I love him so much and I do this to show I care." Recognize the good things about other important parts of your life, such as other family members or personal interests. For example: "My son Jim did well on his algebra test. We are proud of him." And, "I enjoyed watching that video with my family last night."

Maintaining Health

One of the most important things caregivers can do is to take care of themselves. Caregivers who maintain their health are less burdened. Proper personal care also helps caregivers prevent their own health problems, which can interfere with caregiving and lead to institutionalization of the impaired elder. Good health practices enable the caregiver to meet the demands of caregiving and other things they have to do. Following are guidelines for maintaining health.

Eat Nutritious Foods

Food is fuel for your body. Eating poorly or skipping meals reduces energy and puts you at risk for health problems. Learn to prepare and eat simple, nutritious meals.

Get Exercise and Rest

Physical activity reduces stress and improves health. Bicycling, walking, or swimming are good outlets and in the long run prevent various health problems. Rest is essential for caregivers. Sound sleep refreshes and enables caregivers to function well during the day.



Figure 3.

Guidelines for Caregivers

Plan Leisure Time

Leisure time helps you to feel better and cope with the demands of caregiving, working, and rearing a family. It is very important to take time to do something you enjoy. If you are a woman, you may tend to give up your free time and opportunities for recreation and socialization. If you are a man, you may be more likely to set aside time for your own interests. It is important for both men and women to guard against isolation and depression. Set aside personal time and spend time with others.

Avoid Destructive Behaviors

Some people handle stress in ways that are harmful to them and to their loved ones. Instead of expressing their feelings, they use food, drugs, or alcohol to hide their difficulties. While you build your healthy lifestyle, also take care to avoid destructive behaviors. Use alcohol in moderation, if at all. Use medications carefully and only as prescribed. Don't overeat. If you try to make a major lifestyle change, you do not have to go it alone. Friends, counselors, family members, clergy, and caregiver support groups can help.

Reaching Out

Get Support from Family and Friends

Our culture emphasizes independence, so it is not easy to ask for help. The truth is that caregivers who get help and support from family and friends tend to feel less stress and may be better able to cope with caregiving. Caregivers who are supported by others have a feeling of being loved. They also get practical help with caregiving, housework or errands. As a result, caregivers are better able to solve problems and to prevent difficult situations from getting worse. Their own health is better.

Sometimes family members and friends are willing to help but don't know how to ask. They may look to you, the caregiver, for guidance. You might make a specific suggestion, such as "Could you visit with mother for an hour or so while I go to the store?" Let people know how much their help means to you.



Figure 4.

On the other hand, at times family members may be critical of your caregiving. Although you might want to get angry or withdraw, try to listen to their point of view. Then, talk about your ideas and feelings. Try to express your feelings in an honest but non-hostile way. Schedule family meetings from time to time to help other family members understand the situation and to involve them in sharing the care.

Although we tend to think of support as coming from family or friends, caregivers who feel a sense of spiritual support also feel less stress. Cultivate your spiritual beliefs in whatever ways are meaningful to you -- praying or meditating, attending worship services, or taking walks in the woods or watching the sun set.

Get the Help You Need

Community resources are available that can help you provide care for your loved one and to replenish your own vitality. It is sometimes difficult to turn to community organizations for help. But it is not at all

unusual for caregivers to ask for help with providing care.

Join a Support Group

Most people benefit from sharing their feelings with someone who is supportive and listens without judging. Support groups can help caregivers to feel less isolated and to build strong bonds of mutual help and friendship. These support groups often provide useful information that helps improve caregiving skills.

Use Community Resources

Many caregivers report that they do not use community resources because there is no need. However, professionals who work with caregiving families say that caregivers tend not to see themselves as needing help until they reach a crisis or can no longer cope. They advise caregivers to look ahead and get help before there is a crisis. A range of community resources are available to help older persons and their families. Although services vary between communities, some of the commonly available types of assistance are listed below. For more information about what is found in your community, contact your Area Agency on Aging. In Florida, the number to call is 1-800-262-2243. Your local library may also offer resources, books and references on aging, caregiving and information about nursing homes.

Guide to Community Resources

In-home medical alert (Lifeline). A wearable electronic device that sends a signal to a central dispatcher if the older person falls or needs help.

Homemaker and chore services. Help with household tasks and minor home repairs to keep a person living independently.

Home health care. Nursing and personal hygiene assistance such as bathing, toileting, and feeding.

Nutrition services. Hot meals delivered to home-bound elders and congregate meals provided in senior centers or other community settings.

Transportation services. Vans or buses to and from congregate meals programs, doctor appointments, shopping, banking, and rehabilitation sessions.

Companions or friendly visitors. Friendship, support, companionship, or supervision to older adults for a few hours.

Telephone reassurance. Regular friendly telephone contact for home-bound or ill or disabled persons.

Respite care. Support services for family members providing in-home care for an ill or recovering relative. Respite care frees the caregiver for other tasks, such as meal preparation or shopping, or for leisure time and social activities. Respite care may be located from a number of sources, including other friends or family members; volunteers or paid companions; or professional service providers in adult day care programs, nursing homes, and hospitals.

Adult day care. Supervised care provided for frail older people who need health care and social stimulation. Programs vary, but may include health and medical monitoring, meals, and recreational activities. Adult day care enables some caregivers to continue their employment and care for their relative at the same time, or to have some time away for other activities.

Care planning and management. Professional help in choosing the best care arrangements and in following up on progress.

References

Administration on Aging. (2000). Elder Action: Action Ideas For Older Persons and Their Families. Retrieved July 16, 2003 from <http://www.aoa.dhhs.gov/aoa/eldractn.caregive.html>.

Allen, K. R., Blieszner, & Roberto, K. A. (2000). Families in the middle and later years: A review and

critique of research in the 1990s. *Journal of Marriage and the Family*, 62, 911-926.

American Association of Retired Persons. (n.d.) Balancing Work and Caregiving. Retrieved July 16, 2003, from <http://www.aarp.org/confacts/caregive/balance.html>

Begany, T. (1996). Caring for the caregiver. *Patient Care*. 30, 108-132.

Bensing, K.M.. (2002). Helping Hands: caregiving resources. *Library Journal*. 127, 65-68.

Braus, P. (1998). When the Helpers Need a Hand. *American Demographics*. 20, 66-72.

Chio, A. Gauthier, A., Calvo, A., Ghiglione, P., & Mutani, R. (2005). Caregiver burden and patients perception of being a burden in ALS. *Neurology*, 64, 1780-1782.

Hooyman, N., Gonyea, J., & Montgomery, R. (1985). The impact of in-home services termination on family caregivers. *The Gerontologist*, 25, 141-145.

Mastlish, R. (no date). Help for the working caregiver. Washington, DC: American Council on Life Insurance.

Montgomery, R. (in press). Gender differences in patterns of child-parent caregiving relationships. In J. Dwyer & R. Coward, *Gender, families, and elder care*. Newbury Park, CA: Sage Publications.

National Council on the Aging (1988). Taking care of yourself while you take care of others. Washington, DC: The National Council on the Aging.

National Council on the Aging (1988). Respite: You deserve a break. Washington, DC: The National Council on the Aging.

Osterkamp, L. (1988). Family caregivers: America's primary long-term care resource. *Aging*, 358, 3-6.

Parent Care. (1989). National survey of caregivers finds low use of helping services. *Parent Care*, 4.

Parent Care (1985). When is caregiving more stressful? *Parent Care*, 1.

Pinquart, M. & Sorensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology: Psychological Sciences*, 58B, 112-128.

Schmall, V.L. & Stiehl, R.E. (1987). *Coping with caregiving: How to manage stress when caring for elderly relatives (PNW 315)*. Corvallis: Oregon State University.

Stoller, E. P. (1992). Gender differences in the experiences of caregiving spouses. In J. Dwyer & R. T. Coward (Eds.), *Gender, families, and elder care* (pp. 49-64) Newbury Park, CA: Sage Publications.