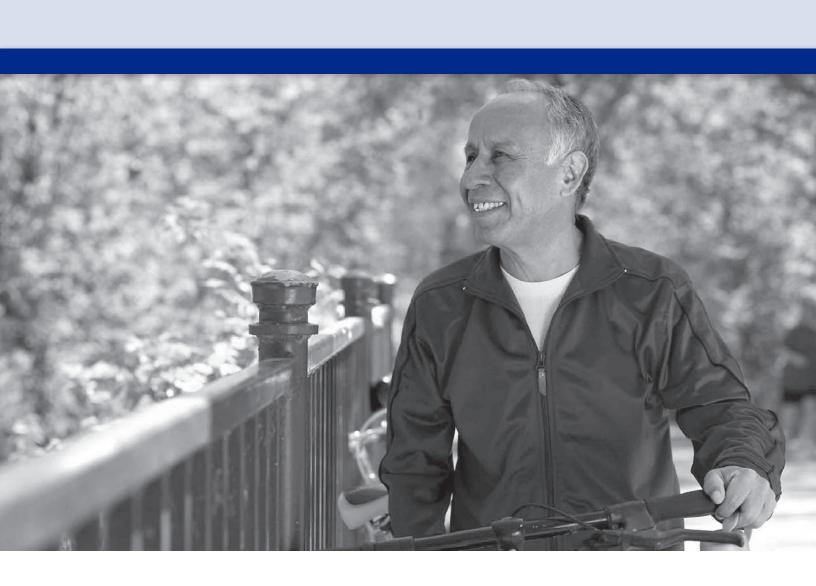
Care for the Caregiver: Managing Stress







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Family members caring for people with Alzheimer's disease face unusual pressures and shoulder an enormous amount of responsibility. What they do can be both physically and emotionally exhausting. As the disease progresses, caregivers are called upon to adapt to constant changes in both the person they're caring for and in the range of skills they need to manage their increasing responsibilities. Contributing to that is the need for ongoing vigilance and around-the-clock monitoring, so it's no wonder that the families of people with Alzheimer's disease suffer high levels of stress.

Severe stress that is sustained over a long period of time can take a major toll on caregivers' well-being. If steps are not taken to periodically relieve these pressures, caregivers face a high risk of burnout and may suffer from a host of physical and emotional problems. Prolonged stress is known to contribute to depression, a weakened immune system, high blood pressure, heart disease, and other negative health outcomes.

The following are ten signs warning you that your caregiving efforts are surpassing your ability to cope well and are causing you excessive stress.

The Warning Signs of Stress

- 1. Denial: maintaining a belief that the care receiver's illness is not serious or that it may not even exist.
- 2. Anxiety: excessive worrying about the future.
- 3. Depression: feeling hopeless or powerless about the situation.
- 4. Irritability: "blowing up" over little things.
- 5. Feeling angry at inappropriate times.
- 6. Having difficulty concentrating.
- 7. Withdrawing from other people and from activities that used to bring enjoyment.
- 8. Sleeping poorly or too much.
- 9. Feeling chronically exhausted.
- 10. Experiencing health problems.

The First Step: Recognizing What You Can and Cannot Change

The news that a loved one has Alzheimer's disease can seem overwhelming at first. However, most caregivers find that the more they learn about the disease and the resources available to them, the better they can cope. A way to control the stress of daily caregiving is to learn to recognize the things that can be changed for the better and to accept the things that cannot. Many experts offer the following advice:

Learn everything you can about Alzheimer's disease so you will know what to expect and won't expend unnecessary time and energy worrying about things you can't change. You can also keep up with the latest research related to future prevention and treatment options.

Accept the inevitable and let go of unrealistic expectations. Sadly, you can't expect your loved one to get better; you are better off making accommodations to cope with the progressive loss of memory and other skills and with his/her need for more help. Don't expect your loved one to relearn information already lost.

Identify sources of help. Once you have learned what to expect from the disease, look for sources of help, such as government services, adult day care, or respite services (assistance with home caregiving) for you. Call upon a support

group, friends, and family to help you control your caregiver stress. Make a list of these resources and keep it in a handy place. Consult the resource list at the end of this pamphlet as a start. Please remember that no one service or plan will be appropriate throughout the entire course of the disease.

Use validation rather than confrontation when your loved one seems out of touch with reality. When someone with Alzheimer's disease experiences fixed false beliefs and confusion about time, don't argue or scold.

Make your home a safe and calming environment for yourself and your loved one by establishing a simple, regular routine and following it daily. Locate sources of special products and advice on how to "Alzheimer's-proof" your home for safety (a list of companies that provide such products can be found at www.ahaf. org).

Establish a predictable routine and follow it daily.

Do legal and financial planning well in advance so these decisions will be made and won't add more stress later, when your loved one is in need of more attention or when a crisis situation occurs. Involve family members in these discussions. Be prepared to manage disagreements, which can heighten stress at crucial times in the Alzheimer's journey.

Accept the fact that your relationship with your loved one will keep changing over time. This means that some longestablished roles you have played will also change. You may have to take charge of things that you're unaccustomed to, such as paying bills, balancing the checkbook, shopping, or cooking. It is important to recognize when your loved one is no longer able to do things he or she used to do. It will be up to you to learn new skills and seek assistance.

Understand that sometimes your attitude is the only thing you can change. Whenever you're feeling overwhelmed, practice reframing the issues in a more positive way. (See the section on Practicing a Positive Attitude.) Learn to forgive everyone—including yourself, your loved one, other family members, friends, and doctors—for making mistakes and for disappointing you.

Trust your instincts. Most of the time, they will lead you in the right direction.

Taking Steps to Reduce Your Stress

There are some tried-and-true techniques that won't completely eliminate your stress but can help you manage and reduce it. These techniques involve both softening the impact of stressors in your life and building up your capacity to cope with them. If you can adopt even two or three of the following suggestions, you may feel less stressed and more in control of your life.

Take time out to meditate or reflect. Spending ten to twenty minutes twice a day to "clear your head" can work wonders when you're feeling overburdened or overwhelmed. Some caregivers learn meditation techniques from classes or books on the subject, while others simply take time out to quietly reflect. Either way, it's important that you slow down and focus on clearing your mind of all the racing thoughts that may be increasing your anxiety. Yoga or tai chi classes are great ways to heal mind and body.

Try to do something you enjoy every day. Nurturing a garden, watching a favorite TV show, reading an article that interests you, or engaging in a favorite hobby can help "center" you and remind you that you still have a life outside of caregiving. Create a sanctuary by turning a room or part of a room into your cozy spot that reminds you to relax and enjoy. You must take some time—even for 10 or 15 minutes—to take care of *yourself*.

Make lists of things that need to be done. Trying to keep all of your care-giving tasks in your head will increase anxiety. Worrying about what you might have forgotten then exacerbates the problem. Calendars and planners can help you prioritize your responsibilities.

Do one thing at a time. Juggling tasks like talking on the phone, opening the mail, and cooking a meal all at the same time only adds to your stress level. Focus on one thing at a time. When one task is completed, move on to the next one.

Set limits on what you can accomplish, and learn to say "no" more often. If you feel exhausted, lower your expectations and re-examine your priorities. You can't do everything. No one can.

Exercise regularly, and take care of your own health. Exercise is one of the best known techniques for reducing stress, revitalizing energy, and maintaining your health. A brisk walk several times each week gives you significant health benefits. Care for your body by continuing to have regular medical check-ups. Take your medicine, and eat healthy meals. Taking care of your body improves your emotional outlook and well-being.

Don't try to cope alone. Maintain friendships and family relationships even if all you have time for is a weekly phone call. Join a support group where you can share experiences, or talk with a counselor. Don't think you can "go it alone" in your caregiving role. Sometimes, talking about your worries can help you sort them out.

Use a computer to connect with friends and the outside world. If you don't have one at home, check out your public library for access to computers and the Internet. If you are unfamiliar with how to use a computer, ask the library staff for assistance.

Keep a journal of your thoughts and feelings. Many caregivers have found that writing their thoughts down gives them an emotional outlet and helps them find clarity in the midst of confusion.

Maintain your sense of humor.

Sometimes there is nothing left to do but laugh, and laughter is great for your mental and physical health. Seek out light-hearted or humorous books and movies. Funny things can happen even on your worst days. Try to appreciate them!

Don't shut out the good moments. Stay open to the moments when you can still enjoy certain things with or without your loved one, such as a walk in the park or playing with grandchildren or pets. A life devoid of pleasure just drains you further and makes you more vulnerable to stress. This is a vicious cycle you can avoid.

Give yourself credit. As a caregiver for someone with Alzheimer's disease, you are probably doing the best you can. It's important that you acknowledge to yourself all the difficult things you do and allow yourself to feel a sense of accomplishment and satisfaction.

Ask yourself, "What am I learning from this?" Chances are that in your care-giving journey, you have changed and developed new skills. You have crossed hurdles you thought you would never overcome.

Applaud yourself for that growth.

Practicing a Positive Attitude

It's clearly difficult to care for someone living with Alzheimer's disease. An important approach to coping and staying on a constructive path to handling your role is to practice keeping a positive attitude. Just as it is vital to exercise your body, it is essential to take steps to create a positive frame of mind.

To develop a more positive attitude in the face of trouble, you practice what you've learned until it becomes more natural.

First, identify your negative thoughts. "I always end up as the caregiver" and "I never get any appreciation" are inherently negative thoughts that can lead to negative emotions.

Instead, replace negative thoughts with positive messages, like "I'm doing the best I can" or "some things are beyond my control" or "sometimes, I just need to do what works now."

The following are examples of negative messages you might tell yourself and some thoughtful, realistic, and positive statements you can use to challenge these negative thoughts.

Negative Self-Talk: No matter how hard I try, I always fail. I just can't make this work.

Thoughtful Challenge: No one could be expected to achieve perfection in my situation. In fact, I've done a lot of things well, including...

Negative Self-Talk: These problems will never end.

Thoughtful Challenge: Nothing stays the same forever, not even Alzheimer's disease. We may be going through a particularly tough time now, but this stage of the disease will inevitably pass.

Negative Self-Talk: No one appreciates me, not even the person I'm caring for.

Thoughtful Challenge: I know I'm doing a good deed, even if no one tells me so. And at least I have my loved one with me, so I can make sure she is receiving the best possible care.

Negative Self-Talk: He is so impossible, no one could manage him.

Thoughtful Challenge: I'm not the first person to deal with a difficult family member with Alzheimer's. There must be ways to learn from others who have gone through this. I'll try to find a good book on the subject and also look for a support group.

Negative Self-Talk: My husband has always paid the bills and taken care of our taxes. I can't do these things, and I'm too old to learn. What am I going to do?

Thoughtful Challenge: Millions of people have learned to take care of their financial affairs after the death or disability of a spouse. If I put my mind to it, I can learn to do it, too. Friends and family can help me.

Notice that this approach does not deny and pretend that everything is the way you want it to be. Instead, it helps you realize that things are not as bad as your most pessimistic thoughts would have you believe.

Remember that there is hardly any situation in life that can't be improved, even if only a little, if we free up our thinking to look for concrete solutions. Even temporary or one-time solutions have value if they help you get through the day.

If you can work toward putting yourself in a calmer, more positive frame of mind, you will be far better equipped to handle the challenges that come your way.

Resources

Alzheimer's Disease Research
A program of the American Health
Assistance Foundation. Provides
information and publications to
Alzheimer's caregivers. The website also
has a wealth of resources, including how to
obtain catalogs of products designed for
Alzheimer's patients.
1-800-437-2423
www.ahaf.org/alzheimers/

Please Note: The following organizations are not affiliated with the American Health Assistance Foundation (AHAF), and AHAF does not endorse any programs or products offered by these organizations. Some of the organizations may charge fees for their services and advice.

Alzheimer's Association CareFinder A private foundation that provides a service to find good care in your community, tackling issues such as planning ahead, care options, and coordinating care 24/7 Helpline:

tel: 1-800-272-3900 TDD: 1-866-403-3073 http://www.alz.org/carefinder

Alzheimer's Disease Education and Referral Center

A service of the National Institute on Aging, part of the US federal government's National Institutes of Health 1-800-438-4380 www.nia.nih.gov/Alzheimers

AARP

A nonprofit membership organization that helps people 50 and older improve the quality of their lives, offering services such as the Caregiving Resource Center and useful and interesting articles 1-888-OUR-AARP (1-888-687-2277) www.aarp.org/caregiving

BenefitsCheckUp

A service of the National Council on Aging (NCOA) that helps people understanding benefits available from federal, state, and local programs (202) 479-1200 www.benefitscheckup.org

Centers for Medicare and Medicaid Services (CMS) Offers a way to compare hospitals, nursing homes, and home care services on its website

1-800-MEDICARE (1-800-633-4227) www.medicare.gov/caregivers

Eldercare Locator A service of the U.S. Administration on Aging 1-800-677-1116 www.eldercare.gov

Joint Commission
Offers Quality Check™, where you can find health care organizations
(630) 792-5000
www.qualitycheck.org

Medicaid

A state-administered program for people with lower incomes. Each state health department sets its own guidelines regarding eligibility and services. www.cms.gov/home/medicaid.asp

Medicare

Federal government health insurance program that pays some health care costs for people age 65 and older 1-800-MEDICARE (1-800-633-4227) www.medicare.gov

National Academy of Elder Law Attorneys, Inc.

Helps people locate an elder law attorney who deals with the many specialized issues involved with legal services for seniors and people with special needs (703) 942-5711 www.naela.org

National Adult Day Services Association Helps locate adult day service in your community 1-877-745-1440 www.nadsa.org

National Association of Professional Geriatric Care Managers
Listings of health and human services specialists who help families caring for older relatives. Geriatric care managers are trained and experienced in any of several fields related to care management, including nursing, gerontology, social work, and psychology. (520) 881-8008 www.caremanager.org

National Center for Assisted Living Serves the needs of the assisted-living community through national advocacy, education, networking, professional development, and quality initiatives. (202) 842-4444 www.ahcancal.org/ncal National Institute on Aging (NIA)
Information Center
NIA, along with the National Library
of Medicine, offers NIHSeniorHealth, a
website specially designed for seniors.
(301) 496-1752
www.nia.nih.gov
www.nihseniorhealth.gov

National Resource Center on Supportive Housing and Home Modifications A university-based nonprofit effort (213) 740-1364 www.homemods.org

National Respite Locator Service Helps caregivers and professionals locate respite services in their communities www.respitelocator.org

Program of All-Inclusive Care for the Elderly (PACE)

Combines Medicare and Medicaid benefits www.cms.hhs.gov/pace
State Health Insurance Assistance Program (SHIP)

A national program offered in each state; identifies local help for people with Medicare

www.shiptalk.org

U.S. Department of Veterans Affairs (VA) Provides veterans with benefits and services 1-800-827-1000 www.va.gov Alzheimer's Disease Research Fact Sheets available online at www.ahaf.org/FactAD

- Healthy Living with Alzheimer's Disease
- Alzheimer's Disease Treatment
- Take Charge of Your Health: Essential Questions to Ask Your Doctor about Alzheimer's Disease
- Alzheimer's Disease Frequently Asked Questions
- Clinical Trial Information for Alzheimer's Disease
- Alzheimer's Prevention: Nutrition & Lifestyle
- Research Questions and Answers









22512 Gateway Center Drive Clarksburg, MD 20871 (301) 948-3244 1-800-437-2423 info@ahaf.org www.ahaf.org/ADRresources

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www.ahaf.org/connect