Managing Stress: Care for the Caregiver

Alzheimer’s Disease Research
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More than 5 million Americans now have Alzheimer’s disease. This brochure is directed to all the people who care for them, whether family members or friends or community caregivers. Through this and other resources in our Alzheimer’s Disease Research program, BrightFocus Foundation wants to educate and inform caregivers in order to help you remain strong and confident in the face of this difficult disease.

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Caring for people with Alzheimer’s disease brings unusual pressures and an enormous amount of responsibility. The role of caregivers is both physically and emotionally exhausting. As the disease progresses, you may be called upon to adapt to changes in the person you are caring for and develop new skills to shoulder an increasing amount of responsibility.

As time goes on, there is the need for ongoing vigilance and around-the-clock monitoring. It’s no wonder that caregivers 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 one’s well-being. If steps are not taken to periodically relieve pressures, caregivers face a high risk of burnout and may suffer from both 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 Warning Signs of Stress

If your caregiving efforts are surpassing your ability to cope well and are causing you excessive stress, you may experience:

- **Denial**: maintaining a belief that the care receiver’s illness is not serious or that it may not even exist.
- **Anxiety**: excessive worrying about the future.
- **Depression**: feeling hopeless or powerless about the situation.
- **Irritability**: “blowing up” over little things.
- **Anger**: feeling angry at inappropriate times.
- **Poor concentration**: having difficulty focusing.
- **Withdrawal**: feeling alienated from other people and from activities that used to bring enjoyment.
- **Sleep problems**: sleeping poorly or too much.
- **Exhaustion**: feeling chronically tired.
- **Illness**: experiencing health problems.
The First Step: Recognize What You Can and Cannot Change

The news that someone in your life 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. To get more information, visit www.brightfocus.org/alzheimers

**Accept the inevitable, live in the moment, and let go of unrealistic expectations.** Unfortunately, you can’t expect someone who has Alzheimer’s disease to “get better,” and this can be especially hard if you are caring for him or her. However, day-to-day life can improve with good care and coping skills. By reconciling yourself to his or her progressive loss of memory and growing need for help, you will be able to concentrate on finding ways to cope. Don’t expect a person with Alzheimer’s disease 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 local, state, and federal government services; adult day care; and respite services—assistance with home caregiving—for yourself. Make a list of these resources and keep it in a handy place.

Consult the resources at the end of this pamphlet as a start. (No one service or plan will be appropriate throughout the entire course of the disease.)

Find and join a support group, and don’t be afraid to ask for help from your family and friends. (See “Don’t try to cope alone,” page 6.)

**Use validation** rather than confrontation when the person you are caring for seems out of touch with reality. When someone with Alzheimer’s disease experiences fixations on false beliefs and confusion, don’t argue or scold.

**Create a safe and calming environment** for yourself and your loved one (or the person you care for) by establishing a simple, regular routine and following it daily. Locate sources of special products and advice on how to “Alzheimer’s-proof” the home for safety. (A list of companies that provide such products can be found at www.brightfocus.org/homesafety.)

**Do legal and financial planning** as soon as practical, or encourage the family you provide care for to do it. That way, these decisions will be made and won’t add more stress later, when the person with Alzheimer’s may need more attention or when a crisis situation occurs. If your other family members are involved, bring them into 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 will keep changing over time. For family members, this means that some long-established roles you have played will also change. You may have to take charge of things that you’re unaccustomed to doing, such as paying bills, balancing the checkbook, shopping, or cooking. It is important to recognize when your loved one, or the patient you care for, is no longer able to do things he or she used to do. It will be up to you to learn new skills or 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 “Practice a Positive Attitude,” page 6.) Learn to forgive everyone—including yourself, the person you care for, 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.

Take 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 10 to 20 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, tapes, DVDs, or books on the subject, while others simply take time out to quietly reflect. Whichever way you choose, it’s important that you slow down and focus on clearing your mind of all the racing thoughts that may be increasing your anxiety.

Exercising is another good way to heal mind and body. It’s 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. There are many good indoor choices, too, from walking in place to yoga or tai chi. Your library may offer exercise DVDs. Invite a friend over to join you.

Care for yourself by having regular medical check-ups. Take medications as directed, and eat healthy meals. Taking care of your body improves your emotional outlook and well-being.

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 make 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 caregiving tasks in your head will leave you worrying about what you might have forgotten. Calendars and planners can also help you prioritize and keep track of 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 reexamine your priorities. You can’t do everything. No one can.

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 times when you can still enjoy certain things with or without the person you care for, 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 doing the best you can. Be sure to acknowledge to yourself all the difficult things you do and let yourself feel a sense of accomplishment and satisfaction.

Ask yourself, “What am I learning from this?” Chances are that in your caregiving journey, you have changed and developed new skills. You have crossed hurdles you thought you would never overcome. Applaud yourself for that growth.

Practice a Positive Attitude

It’s undeniably difficult to care for someone living with Alzheimer’s disease. A crucial element of coping with and managing 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. And just as you build muscle by repetition, to develop a positive attitude in the
face of trouble, you practice until a positive attitude becomes a natural emotional state.

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

When you notice such thoughts occurring, replace them with positive messages, such as “I’m doing the best I can” or “some things are beyond my control” or “sometimes, I just need to do what works now.”

These “replacement” thoughts disrupt the habitual negative thoughts that can sap your energy and make you feel sad, angry, and hopeless.

The following are examples of negative messages your mind might suggest, 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 will pass.

**NEGATIVE SELF-TALK:** He is so impossible, no one could manage him.

**THOUGHTFUL CHALLENGE:** I’m not the first person to deal with these difficult behaviors of Alzheimer’s patients. 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:** No one appreciates me, not even the person I’m caring for.

**THOUGHTFUL CHALLENGE:** I know I’m doing the right thing, even if no one tells me so. It’s up to me to make sure the person in my charge is receiving the best possible care.

**NEGATIVE SELF-TALK:** My spouse (or the person I’m caring for) has always been in charge of paying bills, doing the taxes, and making decisions. 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 or partner. If I put my mind to it, I can learn to do it, too. Friends and family can help me.
This approach, of “challenging” your negative thoughts, does not deny them or 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. You will also become a better caregiver and gain more confidence and satisfaction in that role.

Resources

Alzheimer’s Disease Research
In this BrightFocus Foundation program, information and publications are available on Alzheimer’s disease.
1-855-345-6237
www.brightfocus.org/alzheimers

Resources include:
• Understanding Alzheimer’s Disease: It’s Not Just Forgetfulness
• Staying Safe: Wandering and the Alzheimer’s Patient
• Alzheimer’s Disease Research Review newsletter
• Safety and the Older Driver
• Fact sheets on treatments, healthy living, frequently asked questions, and more

Please note: the following organizations are not affiliated with the BrightFocus Foundation, and BrightFocus does not endorse any programs or products offered by them. Some of the organizations may charge fees for their services and advice.

Agingcare.com. Online community providing support to family caregivers for elderly individuals with Alzheimer’s disease and other special needs.
239-594-3222
www.agingcare.com

Alzheimer’s Association. Nonprofit foundation that assists with local care options. Alzheimer’s and Dementia Caregiver Center:
24/7 helpline: 1-800-272-3900
TTY: 1-866-403-3073
www.alz.org

Alzheimer’s Disease Education and Referral Center (ADEAR). Information and services offered by the National Institute on Aging, part of the National Institutes of Health.
1-800-438-4380
www.nia.nih.gov/alzheimers

Alzheimers.net. Forum and blog for Alzheimer’s caregivers.
1-888-704-7779
www.alzheimers.net

The Alzheimer’s Store. Products for people with Alzheimer’s disease and for those caring for them.
1-800-752-3238
www.alzstore.com
American Association of Retired Persons (AARP). Nonprofit membership organization serving people 50 and older. Offerings include the Caregiving Resource Center.
1-888-687-2277
www.aarp.org

Medicaid. State-administered health insurance and other benefits, including assisted living, for people with low incomes. Each state health department sets its own guidelines regarding eligibility and services.
www.medicaid.gov

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

Medicare. Federal health insurance for people age 65 and older.
1-800-633-4227
TTY: 1-877-486-2048
www.medicare.gov

Centers for Medicare and Medicaid Services (CMS). Federal agency with information on hospitals, nursing homes, and home care services.
www.cms.gov

National Academy of Elder Law Attorneys, Inc. Database of elder law attorneys who specialize in legal issues for seniors and people with special needs.
703-942-5711
www.naela.org

Eldercare Locator. Directory of services for older adults and their families from the federal Administration on Aging.
1-800-677-1116
www.eldercare.gov

National Adult Day Services Association. Listing of adult day services in local communities.
1-877-745-1440
www.nadsa.org

Fall Prevention Center of Excellence. Resources on preventing falls and making the home safe.
www.stopfalls.org

National Association of Professional Geriatric Care Managers. Aging specialists offering professional services and advice on caring for older adults.
520-881-8008
www.caremanager.org

The Joint Commission. Directory of accredited healthcare organizations.
630-792-5800
www.qualitycheck.org

National Center for Assisted Living. Organization that represents assisted living communities and their staff.
202-842-4444
www.ncal.org
National Institute on Aging (NIA) Information Center. Offers NIHSeniorHealth, a website specially designed for seniors.  
1-800-222-2225  
TTY: 1-800-222-4225  
www.nia.nih.gov  
www.nihseniorhealth.gov

National Resource Center on Supportive Housing and Home Modification. University-based nonprofit offers an extensive library that includes home modification resources (stair lifts, auto flushers, grab bars, etc.).  
213-740-1364  
www.homemods.org

National Respite Locator Service. Information and assistance locating respite care services in local communities.  
919-490-5577 x 223  
www.archrespite.org/respitelocator

Program of All-Inclusive Care for the Elderly (PACE). Federal-state initiative that combines Medicare and Medicaid benefits to pay for long-term care needs of Alzheimer’s patients. Only available in some states; eligibility requirements vary.  
1-800-633-4227  
www.pace4you.org

State Health Insurance Assistance Program (SHIP). National program to help Medicare recipients identify local health services and assistance.  
www.shiptalk.org

U.S. Department of Veterans Affairs (VA). Health care services and benefits for U.S. military veterans.  
1-800-827-1000  
www.va.gov

For more information, visit our website www.brightfocus.org/ADRresources

Para información en español, visite www.brightfocus.org/espanol
BrightFocus is at the forefront of brain and eye health, advancing catalytic research around the world and promoting better health through our three programs:

Alzheimer’s Disease Research
Macular Degeneration Research
National Glaucoma Research