

Managing Stress: **Care for the Caregiver**



Alzheimer's Disease Research

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Care for the Caregiver

The nonprofit BrightFocus Foundation is an international leader in supporting innovative research to find cures for Alzheimer’s disease, macular degeneration, and glaucoma. Guided by scientific review panels of world-class researchers, we invest in promising and rigorous science to end diseases of mind and sight. Through free publications such as this one, we share research findings and helpful tips with those impacted by these diseases, including families and caregivers.

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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 your loved one'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 cannot 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 cannot 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 for assistance with home caregiving. Make a list of these resources and keep it in a handy place.

Consult the resources at the end of this brochure 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 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/adresources).



Do legal and financial planning as soon as practical. 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 are unaccustomed to doing, such as paying bills, balancing the checkbook, shopping, or cooking. It is important to recognize when the person you are caring 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 are 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.



Photo credit: Stephen Bowler

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 are 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 is 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 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. There are many good indoor choices, too, like 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.

Connect online with friends and the outside world. If you don’t have a computer 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 yourself for 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 is 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:

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:

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:

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 overwhelmed 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

This brochure is produced by **Alzheimer’s Disease Research (ADR)**, a BrightFocus Foundation program, which funds promising research investigating ways to slow, treat, or prevent Alzheimer’s disease. ADR serves as a resource for the latest news about research, prevention, healthy choices, treatment and caregiving including resources like this one. www.brightfocus.org/alzheimers
1-855-345-6237

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 BrightFocus, and BrightFocus does not endorse any programs or products offered by them. Some of the organizations may charge fees for their services and advice.

ARCH National Respite Network. Assists families to locate respite and crisis care services in the community, and provides a consumer guide for family caregivers, *The ABCs of Respite*.

<http://archrespite.org/respitelocator>
(206) 632-5208

Alzheimer's Disease Education and Referral Center (ADEAR). Provides current Alzheimer's disease information and resources from the National Institute on Aging. Offers information for people with Alzheimer's disease, their families, and professionals, including information on clinical trials.
www.nia.nih.gov/alzheimers
1-800-438-4380

Caregiver Resource Center. Provides information on caregiving, planning for long-term care services, and employee assistance.
www.caregiverresourcecenter.com
(203) 861-9833

CarePathways. Created and maintained by nurses to provide access to healthcare information, products, and services. www.carepathways.com
1-877-521-9987

Family Caregiver Alliance, National Center on Caregiving. Information, education, services, research, and advocacy for those caring for people with chronic, disabling health conditions. www.caregiver.org
1-800-445-8106

Federal Government Programs may offer support. They include:

- **Center for Medicare and Medicaid Services (CMS)** provides the latest information and resources on government-sponsored health programs, such as:

Medicare, which is a federal program that provides some coverage for people who meet certain qualifications. Alzheimer's disease is not listed as a specific condition covered, but many aspects of treatment may be covered

Medicaid programs, which are run by individual states.

- **Social Security Administration (SSA)**, which may also provide certain benefits to qualified individuals.
- **Veterans Benefit Programs**, those who served in the armed services may qualify for certain Veterans Administration program benefits.

To find out what services are covered by Medicare, Medicaid, Social Security, or Veterans programs, visit www.brightfocus.org/alzheimers/financial-aid or call: **CMS** at 1-800-633-4227, **SSA** at 1-800-772-1213, or **Veterans Benefits** at 1-800-827-1000.

Latino Alzheimer's & Memory Disorders Alliance. Empowers Hispanic and Latino caregivers and families of those living with Alzheimer's disease and memory disorders by providing education, skill building training, and support programs. Also provides training programs to healthcare providers who work with the Hispanic and Latino communities.
www.latinoalzheimersalliance.org
(708) 395-5472

LeadingAge. Provides a searchable database of aging services, including assisted living, nursing care, and home meal delivery.
www.leadingage.org
(202) 783-2242

Meals on Wheels Association of America. Provides information on local meal delivery and group meal locations for seniors.
www.mealsonwheelsamerica.org
1-888-998-6325

National Adult Day Services Association. Use the website database to find adult day services in your area.

www.nadsa.org
1-877-745-1440

National Caregivers Library. An extensive online library for caregivers with articles, forms, checklists, and links to topic-specific external resources.

www.caregiverslibrary.org
(804) 327-1111

National Center for Assisted Living. Represents long-term care providers; contains information for consumers on assisted living.

www.ncal.org
(202) 842-4444

National Long-Term Care Ombudsman

Resource Center. Click "Locate an Ombudsman" to find a professional to serve as an advocate as you deal with decisions concerning long-term care for your loved one.

www.ltcombudsman.org
(202) 332-2275

Pro Health. Offers search capability for finding support groups for caregivers of Alzheimer's disease.

www.prohealth.com/supportgroups 1-800-366-6056

Transportation Safety Administration (TSA)

Cares. Assists travelers with medical conditions, such as Alzheimer's disease, as they prepare for travel prior to getting to the airport. Provides answers to questions about screening policies, procedures, and what to expect at the security checkpoint.

www.tsa.gov/travel/special-procedures 1-855-787-2227

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, supporting innovative research around the world and promoting better health through our three programs:

Alzheimer's Disease Research
Macular Degeneration Research
National Glaucoma Research

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