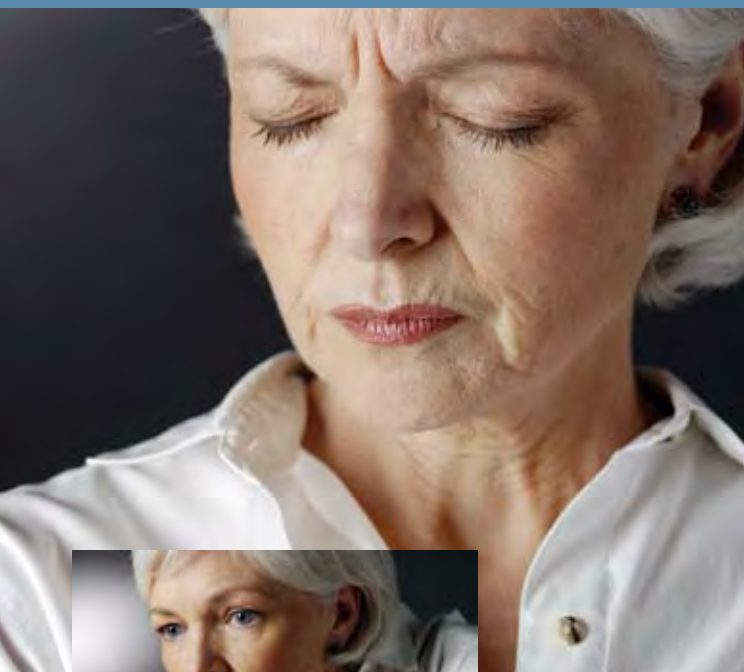


Care for the Caregiver:
MANAGING STRESS



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The caregivers of Alzheimer’s patients face unusual pressures and shoulder an enormous amount of responsibility. The job they do is both physically and emotionally exhausting. As the disease progresses, caregivers are called upon to adapt to constant change in both the patient and in the range of skills they need to care for them. Add to that the need for endless vigilance and 24-hour-a-day care, and it’s no wonder that the caregivers of Alzheimer’s patients suffer a high level of stress.

Severe stress that is sustained over a long period of time can take a major toll on both mental and physical well-being. If special steps are not taken to periodically relieve the pressures of caregiving, caregivers face a high risk of burnout and of suffering 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 many other serious conditions.

The following are ten warning signs for caregivers that stress is taking an inordinate toll on their lives.

The Warning Signs of Stress

- **Denial**, or a sense that what is happening in one's life simply can't be faced.
- **Anxiety** and excessive worrying about the future.
- **Depression**, feeling hopeless or powerless about the situation.
- **Irritability**, “blowing up” over little things.
- Feeling **angry** at inappropriate times.
- Difficulty **concentrating**.
- **Withdrawal** from other people and activities that used to bring enjoyment.
- Trouble **sleeping** or sleeping too much.
- Feeling chronically **exhausted**.
- **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, but most caregivers find that the more they learn about the disease and the resources that are available to them, the better they can cope. In order to get a handle on the stress of daily caregiving, it is important 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 the patient's illness so that you know what to expect and don't waste your time and energy trying to change that which is inevitable. For example, don't expect your loved one to recover functions that he or she has lost.

Accept the inevitable. You can't expect the patient to recover; you are far better off making arrangements and accommodations to deal with the patient's progressive loss of memory and other skills.

Once you have learned what to expect from the disease, start **identifying sources of help**, such as government services, respite services for you, a support group and friends and loved ones you can call upon to help. Make a list of these resources and keep it in a handy place.

Use validation rather than confrontation when your loved one seems out of touch with reality. An Alzheimer's patient will almost certainly experience delusions and time-displacement. This is an unavoidable part of the disease. Don't argue or scold when this happens—simply connect with the person by entering their world. Validate what they have said by agreeing with them, then gently redirect their attention to something else.

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).

Let go of unrealistic expectations of yourself and the patient. You can't expect yourself to do everything, or to do it perfectly, any more than you can expect the patient to get better.

Do legal and financial planning early so that these decisions will be in place and won't add more stress to your job later, when the patient is in need of more attention.

Accept the fact that your relationship with the patient will keep changing over time. This means that some long-established roles that you have played will also change. You may

have to take charge of things that you're unaccustomed to, such as paying bills and balancing the checkbook or doing the shopping and cooking for yourself and your spouse. It is important to recognize when your loved one is no longer able to do things he used to do, and it is incumbent on you to learn a new skill or seek assistance from someone else.

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).

Taking Steps to Reduce Your Stress

There are some tried-and-true techniques that, while they won't totally eliminate your stress, they can help manage and reduce it. These involve both reducing 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, the less stressed and more in control you will feel.

Take time out to meditate or reflect. Ten to twenty minutes twice a day to “clear your head” can work wonders when you're feeling overburdened. 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 making you even more anxious than your caregiving duties.

Try to do something you enjoy every day, even if it's only for a few minutes. 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.

Do one thing at a time. Trying to juggle 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, and when one task is completed, move on to the next one.

Make lists of things that need to be done rather than trying to keep it all in your head and then worrying about what you might have forgotten.

Exercise regularly. Exercise is one of the best-known techniques for reducing stress, revitalizing energy and maintaining your health. A brisk walk several times a week is all it takes to get the enormous health benefits of exercise.

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 in which you can share experiences or

talk with a counselor if needed. It is unrealistic to think that you can “go it alone” in your caregiving role, and sometimes just talking about your worries can help you sort them out.

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—you might as well 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. Some caregivers are so preoccupied with the pain and stress of their life situation that they become unable to enjoy life's simple pleasures. A life devoid of pleasure just drains you further and makes you more vulnerable to stress.

Give yourself credit. As stated at the beginning of this booklet, you have one of the hardest jobs on earth. It's important that you are able to acknowledge to yourself all that 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 caregiving journey, you have changed, grown, developed new skills and crossed hurdles you thought you would never overcome. Recognizing the ways you have grown can offset some of the painful feelings you have about your loved one’s illness.

Try to **reframe the issues** to see things in a more positive light. For example, instead of brooding about how difficult it is to take care of a parent as if she were your child, remind yourself that she once took care of you, and now you have the opportunity to repay her. This leads us to the next section, where you can learn how to translate your negative self-talk into a more positive mental attitude.

Practicing a Positive Attitude

Being in a very difficult long-term situation like that of an Alzheimer’s caregiver is fertile ground for feelings of hopelessness and failure. After all, no matter how hard you try, you can’t make your loved one get well, and the person will eventually pass away. As painful as this is, you need to recognize that it doesn’t mean you have failed. In fact, if you have done your best to care for your loved one while he is alive, you will have succeeded.

Some people are born with a naturally sunny disposition, but most of us have to work at it, especially when faced with major life difficulties. To develop a more positive attitude in the face of trouble, we must first learn how to frame our thoughts in a positive way, and then we must practice what we have learned. Over time, the process becomes more natural, even if we have to frequently remind ourselves to re-evaluate our pessimistic thoughts.

Having a positive attitude does not entail denying reality and replacing it with false emotions that you do not feel. It means that we acknowledge reality while challenging our most catastrophic, irrational thoughts with thoughts that focus on the real, but more positive, aspects of our situation. A positive attitude usually involves replacing snap judgments and vague generalizations such as “always” (“I always end up as the caregiver”) and “never” (“I never get any appreciation”) with concrete, specific facts.

The following are examples of negative messages we give ourselves, and some thoughtful, realistic and positive statements we can use to challenge them.

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*

such a trying situation. In fact, I've done a lot of things right, 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 that I do so much for."*

Thoughtful Challenge: *"I know that I'm doing a good thing, even if no one tells me so. And at least I have my loved one with me, where I can make sure she is cared for."*

Negative Self-Talk: *"My loved one is so impossible, no one could manage him."*

Thoughtful Challenge: *"I'm not the first person to deal with a difficult Alzheimer's patient—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 I can join."*

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."*

Notice that the pattern here is not to pretend that everything is the way you want it to be, only that it is not as bad as your most pessimistic thoughts. 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. After all, tomorrow is a new 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 Education and Referral Center

1-800-438-4380

www.alzheimers.org

Alzheimer's Disease Research

(helpful publications for Alzheimer's disease patients and their caregivers)

1-800-437-2423

www.ahaf.org

Benefits Check Up

(to find out what benefits you may qualify for)

www.benefitscheckup.org

Eldercare Locator

(to find local services available to you)

1-800-677-1116

www.eldercare.gov

National Academy of Elder Law Attorneys, Inc.

(520) 881-4005

www.naela.org

National Resource Center on Supportive Housing & Home Modifications

(213) 740-1364

www.homemods.org



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