

# CAREGIVER STRESS

CARING FOR YOUR PARENTS: EDUCATION FOR THE FAMILY CAREGIVER®



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When it comes to defining the extent of the volume of caregivers, former first lady Rosalyn Carter said it best: **“There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.”**

Caregiving can be a very rewarding and bonding experience – but it can be very stressful. According to a recent study conducted by Home Instead Senior Care network, 31% of family caregivers admit they'd like more help, and 25% actually resent other family members who don't help out more. The stress gets worse if the caregiver has other important and pressing responsibilities, such as a job, children to care for, a busy social life, or some distance to travel to care for their elderly relative.

Caregiving can be particularly hard for a spouse, especially when the care recipient requires around-the-clock assistance. It can even become dangerous if the spousal caregiver has his or her own health issues to deal with, because those problems can be made worse by the stress of caregiving and the lack of attention to the caregiver's own needs.

You can't ignore the needs of the person you are caring for, but there are a number of ways to make sure you remain as stress-free and healthy as possible during the process. In this workshop, we'll discuss the extent of the caregiver stress problem and give you some signs to look for that show you might be suffering from stress yourself. We'll also look specifically at the challenges of dealing with patients who have Alzheimer's or other dementia. Then, we'll give you some tips and ideas about how you can ease your stress level and protect your health.

## THE CAREGIVER STRESS PROBLEM

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### Did you know...?

In the United States, one quarter of adults are presently caring for an aging parent, relative or spouse. In most cases, the caregiver is the spouse or the eldest daughter or grown child who lives the closest to the senior loved one needing care.

### Did you know...?

The typical family caregiver is a 46-year-old woman caring for her widowed mother who does not live with her. She is married and employed. Approximately 60% of caregivers are women.

Source: *The National Alliance for Caregiving*

According to the U.S. Department of Health and Human Services, more than 50 million people provide care for a chronically ill, disabled or aging family member or friend during any given year. Thirty percent of caregivers are themselves aged 65 or over; another 15% are between the ages of 45 to 54. While there is no reliable estimate of the number of family caregivers, at least 7 million Americans are caring for a parent at any given time.

The need for caregivers will increase as the boomer population ages. People over the age of 65 are expected to increase at a 2.3% rate, but the number of family members available to care for them will increase by less than 1%. That is expected to result in added stress on the family caregiver who might not have others to help with caregiving duties.

Already, millions of working adults are juggling the competing demands of caring for a chronically ill or disabled parent, raising a family, and managing a career. The negative effects include time lost from work, lower productivity, quitting a job to give care, lost career opportunities, lower future earnings, and stress-related illnesses.

### According to recent studies:

- Caregivers comprise about 13% of the workforce. Nearly 20% of family caregivers are providing 40 hours of care a week or more. As a result, some 10% have to go from full-time to part-time jobs because of their caregiving responsibilities.  
*Source: Home Instead Senior Care*
- During the year 2000, the typical working family caregiver lost \$109 per day in wages and health benefits due to the need to provide full time care. Eventually, some 12% of caregivers quit their jobs to provide care full-time.  
*Source: The American Council of Life Insurers*
- American businesses lose as much as \$34 billion each year due to employees' needs to care for senior loved ones. Both male and female children of aging parents make changes at work in order to accommodate caregiving responsibilities, such as modifying work schedules, coming in late or leaving early, or altering work-related travel.  
*Source: The MetLife Mature Market Institute*

### There are a number of employee programs that can provide support for family caregivers:

- Some employers offer "**cafeteria style**" **employee benefits** which allow employees to select supplemental dependent care coverage to reimburse costs for in-home care or adult day care. Benefits might also cover therapeutic counseling for the employee to help cope with the stresses of family caregiving.
- **Human Resource or employee assistance program (EAP) staff** can provide information on helpful Internet sites, local information and referral services or resource centers. Some larger businesses organize in-house caregiver support groups or coordinate with local community groups or hospitals so that employees can attend an outside support group.
- **Alternative work schedules** such as flexible work hours, family illness days, and leave time may be available. Check with your manager to see if you can modify your own work schedule to accommodate your caregiving needs.
- If you work for a company that has 50 or more employees, it must comply with the **Family and Medical Leave Act (FMLA)**, which allows for up to 12 weeks of unpaid leave to care for a seriously ill parent, spouse or child, while protecting job security. Some smaller firms also use the FMLA guidelines to provide support for individual employees.

It's important that you take the time to learn what is offered by your employer. Doing so could alleviate some of your stress.

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## SIGNS OF STRESS

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The first step in dealing with caregiver stress is to recognize the signs. Then, you can find ways to deal with it and enlist support or medical help when needed.

### Common signs that stress may be affecting your physical health include:

- Disturbed Sleep
- Back, shoulder or neck pain
- Headaches
- Stomach and digestive problems
- Weight gain or loss
- Loss of hair
- Fatigue
- High blood pressure, irregular heart beat, palpitations
- Chest pain
- Perspiration
- Skin disorders such as hives, eczema, psoriasis, tics, or itching
- Periodontal disease, jaw pain
- Reproductive problems or infertility
- Weakened immune system suppression
- Sexual dysfunction or lack of libido

### Emotional signs of caregiver stress include:

- Anxiety
- Depression
- Moodiness or mood swings
- Butterflies in your stomach
- Increased irritability
- Memory problems
- Feeling out of control
- Increased substance abuse
- Phobias
- Being more argumentative
- Feeling isolated
- Job dissatisfaction

Many people know how difficult it is to be a family caregiver, so your friends, family and coworkers may not say anything to you about a change in your attitude or demeanor. However, if you're wondering about yourself, consider asking a close friend or family member if they've noticed a difference in you. Their feedback may be just what you need to help put your finger on your symptoms and start getting help.

**If you are experiencing any of these signs, especially if you're noticing more than two or three, consider talking with a healthcare professional who can help you evaluate your situation.**

Getting support will help reduce stress, as well as reduce the associated physical and emotional risks of ongoing stress. A study by Elissa Epel from the University of California found that family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as ten years off a caregiver's life.

It is not selfish to focus on your own needs and desires when you are a family caregiver. In fact, it is vital that you take initiative with your own physical and emotional care. If you neglect yourself it could make you less useful to the person for whom you are caring and it could negatively impact you for years to come.

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## CAREGIVER DEPRESSION

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A study from the American Journal of Public Health says that family caregivers who provide care 36 or more hours a week are more likely than non-caregivers to experience symptoms of depression or anxiety. For a spouse, the rate is six times higher and for those caring for an aging parent the rate is twice as high. And, in general, women caregivers experience depression at a higher rate than men.

Certainly family caregiving does not cause depression, nor will everyone who provides care experience the negative feelings that go along with depression. However caregivers often sacrifice their own needs and the emotional and physical experiences involved with providing care can strain even the most capable person. The resulting feelings of anger, anxiety, sadness, isolation, and exhaustion can take a heavy toll.

Unfortunately, feelings of depression are often seen as a sign of weakness rather than a sign that something is out of balance. Comments such as “snap out of it” or “it’s all in your head” are not helpful. Ignoring or denying your feelings will not make them go away either.

**People experience depression in different ways. The following symptoms, if experienced for more than two consecutive weeks, may indicate depression:**

- A change in eating habits
- A change in sleep patterns
- Feeling tired all the time
- A loss of interest in people or activities
- Becoming easily agitated or angered
- Feeling that nothing you do is good enough
- Thoughts of death or suicide
- Ongoing physical symptoms that do not respond to treatment

### Did you know...?

Elderly spousal caregiver with a history of chronic illness themselves who are experiencing family caregiving related stress have a 63% higher mortality rate than their non-caregiving peers.

*Source: American Medical Association*

Early attention to symptoms of depression may help to prevent the development of a more serious depression over time. The National Institute of Mental Health offers the following recommendations:

1. **Set realistic goals** in light of the depression and assume a reasonable amount of responsibility.
2. **Break large tasks into small ones**, set some priorities, and do what you can as you can.
3. **Try to be with other people** and to confide in someone; it is usually better than being alone and secretive.
4. **Participate in activities** that may make you feel better, such as mild exercise, going to a movie or ballgame, or attending a religious, social or community event.
5. **Expect your mood to improve gradually**, not immediately. Feeling better takes time.
6. **Postpone important decisions** until the depression has lifted. Before deciding to make a significant transition – change jobs, get married or divorced – discuss it with others who know you well and have a more objective view of your situation.

People rarely “snap out of” a depression, but they can feel a little better day by day. The most frequent treatment for depressive symptoms that have progressed beyond the mild stage is antidepressant medication in conjunction with ongoing talk therapy. A mental health professional can assess your condition and arrive at the treatment most appropriate for you.

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## DEALING WITH ALZHEIMER’S PATIENTS

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Many family caregivers care for a parent or spouse who is suffering from some form of dementia. The frequency of dementia increases with age from less than 2% for 65-69 year-olds, to 5% for 75-79 year-olds, and to more than 20% for 85-89 year-olds.

Caring for someone with dementia often requires a great deal of time and patience. According to Dr. Janice-Kiecolt Glaser and Dr. Ronald Glaser, the stress of family caregiving for persons with dementia has been shown to impact a person’s immune system for up to three years after their family caregiving ends thus increasing their chances of developing a chronic illness themselves.

### What is dementia?

- The term dementia describes a group of symptoms that are caused by changes in brain function. These changes have serious consequences on memory, personality and behavior.
- Those with dementia tend to repeat questions, become disoriented in familiar places, neglect personal hygiene or nutrition, or get confused about people or time.
- Dementia can be caused by many things, some of which are reversible such as vitamin deficiencies and poor nutrition, reactions to medications, or problems with the thyroid. However, some forms of dementia are irreversible, such as that caused by mini-strokes or Alzheimer's.

**Alzheimer's disease** occurs when the nerve cells deteriorate in the brain due to a build up of plaques and tangles, which actually results in the death of a large number of brain cells. Doctors are not sure why this occurs, but research is underway to determine causes and cures.

Caring for someone with Alzheimer's can be physically and emotionally demanding. Often, a senior with this disease can become abusive, verbally and physically abusive, which further compounds the incredible stress for the family caregiver.

Richard Schulz, Ph.D., caregiver stress expert at the University of Pittsburgh, warns that family caregivers of senior relatives or spouses with Alzheimer's disease and other forms of dementia are at great risk of suffering from depression, anxiety, frustration, stress and anger. Research shows that caregivers of a family member with dementia face particularly stressful demands because of the length of period of care, the behavioral and cognitive problems associated with dementia, and the extreme impairment of patients with end-stage dementia.

### Did you know...?

According to the Alzheimer's Association, 4.5 million Americans are presently living with Alzheimer's disease.



To better understand and care for a relative suffering from Alzheimer's disease or other forms of dementia, follow these nine guidelines:

- 1. Understand the disease.** Read about the disease and its affects so you are prepared as it progresses. With your understanding also comes additional patience, as you realize that the person is not doing this on purpose or to make you angry. It is a medical condition.
- 2. Enter their world.** Instead of trying to correct a person with Alzheimer's disease, ask them simple questions about their statements, even if they seem strange or are about a person who is no longer living. This will make you and your relative less frustrated.
- 3. Strike a balance.** Encourage as much independence as possible. Help the person by prompting or cueing them to do things for themselves when possible, but realize you'll need to step in if their safety or well-being will be compromised in any way.
- 4. Get support.** Enlist the help of family and friends to spend some time with your senior loved one to give you respite. You can also join a local support group for people who care for those Alzheimer's disease or other dementia.
- 5. Tap into resources.** Find professionals in your area to assist with practical, yet emotional, tasks such as making senior care decisions, elder law issues such as Power of Attorney, asset management or creating a will.
- 6. Get assistance.** Investigate enlisting the help of a professional caregiving service for the everyday tasks, such as shopping and cleaning, so you can spend more quality time with your loved one and appreciate them.
- 7. Create a positive environment.** Distractions, such as street noise, a loud television or radio, can lead to agitation or anxiety.

- 8. **Use effective communication.** When speaking with someone with Alzheimer's disease or other dementia, be aware of your rate of speech, pitch and tone. Try to modify it so they can best understand you.
- 9. **Use positive body language.** Greet the individual with relaxed facial expressions and shoulders. If you are tense the person with Alzheimer's disease may pick up on it.

Certainly caring for a senior loved one Alzheimer's disease or other dementia is challenging. However there are a number of helpful Internet sites that offer information and resources, including:

<b>The Alzheimer's Association</b>	<a href="http://www.alz.org">www.alz.org</a>
<b>Leeza's Place</b>	<a href="http://www.leezasplace.org">www.leezasplace.org</a>

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## HOW TO DE-STRESS

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Most caregivers struggle to balance caregiving for an aging parent or relative with other major responsibilities, including jobs and caring for young children. This often means that they have little time to care for themselves, which can result in poor health and high levels of stress.

However, if you don't take care of yourself, you will never be able to continue taking care of your loved one. This means eating right, getting adequate rest, building exercise into your schedule, and keeping up with your own medical appointments, as described below:

**Did you know...?**  
According to a national survey conducted by the Home Instead Senior Care network, 72 % of adults who are currently providing care for an aging loved one do it without *any* outside help.





<b>Exercise</b>	Do something you like to do like walking, dancing, biking, running, or swimming, for a minimum of 20 minutes at least three times per week. Consider learning a stress-management exercise such as yoga or tai-chi, which teach inner balance and relaxation.
<b>Meditate</b>	Sit still and breathe deeply with your mind as "quiet" as possible whenever things feel like they are moving too quickly or you are feeling overwhelmed by your responsibilities as a family caregiver. Many times you will feel like you don't even have a minute to yourself, but it's important to walk away and to take that minute.
<b>Ask for help</b>	<p>To avoid burnout and stress, enlist the help of others family members and friends, or consider hiring a professional caregiver for assistance. Don't feel bad or guilty for reaching out.</p> <p>Asking for help is sometimes difficult, but there are four sure-fire ways to enlist support.</p> <ol style="list-style-type: none"> <li>1. <b>Give each person a responsibility</b> to help spread out the tasks. Even if your sibling lives 1,000 miles away, make it his or her responsibility to call your elderly parent once a week to check in or to visit for one or two weeks each year to allow you to take your own family vacation.</li> <li>2. <b>Divide up the tasks.</b> Have a specific family member handle the medical aspects of your relative's care such as talking with doctors and medications, while another is responsible for groceries and meals. By dividing up the tasks, each person becomes more involved with the details of these tasks and can keep each other abreast of changes and problems.</li> <li>3. <b>Converse with other family members</b> about your elderly relative. If you don't express your concerns, such as their debilitating health or amount of time you are spending caring for them, you can't expect your other family members to know what you are thinking and feeling.</li> <li>4. <b>Don't be a control freak.</b> If you want to control every aspect of the care, other family members may be less apt to step in, thinking you have it all under control. They'll be less able to understand your stress level if they believe you are creating it yourself.</li> </ol>
<b>Take a break</b>	Make arrangements to provide any necessary fill-in family, friends, volunteers or professional caregivers. Take single days or even a week's vacation. Just make sure you line up your support system so you can be confident that your loved one is safe and happy. And when you're away, stay away. Talk about different things, read that book you haven't been able to get to – there is no excuse not to.
<b>Eat well</b>	Eat plenty of fresh fruits, vegetables, proteins – including nuts and beans – and whole grains. Indulging in caffeine, fast food and sugar as quick "pick-me-ups" also produce a quick "let-down."
<b>Take care of your health</b>	Just like you make sure your loved one gets to the doctor regularly, make sure you get your annual check-up. Being a family caregiver provides many excuses for skipping your necessary check-ups, but don't do it.
<b>Indulge</b>	Treat yourself to a foot massage, manicure, nice dinner out or a concert to take yourself away from the situation and to reward yourself for the wonderful care you are providing to your aging relative. You shouldn't feel guilty about wanting to feel good.
<b>Find support</b>	Look for a local caregiver support group that will help you understand that what you are feeling and experiencing is normal for someone in your position. This is a place to get practical advice from people who are in your situation and bounce off those feelings of stress since everyone is likely to be in the same situation and can empathize.

As mentioned above, one of the most important things you can do for yourself is to take a break. Consider arranging for **respite care** – short-term, temporary care provided to someone who needs assistance so that a family caregiver can take a break from the daily routine and challenges of caregiving. Respite services may involve overnight care for an extended period of time, or just a few hours per day. Respite is often referred to as the gift of time.

While respite care may require some financial outlay, it must be weighed as an option to support the mental stability and health of the family caregiver. Even using just a couple of hours of service such as errands and shopping can lessen the burden of caregiving considerably.

**Agencies that provide information and respite services are:**

- hospice care,
- home health agencies,
- in-home senior care agencies,
- social services,
- private nursing companies,
- senior centers,
- churches, or
- The National Family Caregivers Association.

Remember to maintain your sense of humor, know that it is alright to say “no” to another responsibility, and never feel guilty about needing to take time for yourself. Your health and well-being is of the utmost importance.

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**TAKING ACTION**

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Caring for a family member or friend is challenge, but there are things you can do to de-stress. Identify any signs of stress or depression and then enlist help from other family members and friends, professional caregivers, and healthcare professionals. Taking care of yourself will allow you to be there for your senior loved one.

**Think about your next steps, and how you can create your own action plan:**

1. The things I will do to lessen my stress or depression related to caregiving are:
2. Resources I need to search, talk to, or meet with to learn more about Alzheimer’s or other dementia are:
3. I will focus on taking better care of myself by:

**Action plan:**

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