

# Caregiver Stress and Finding Support

## Overview

Ways to find support and handle the stress of caring for an older family member or someone with an illness or disability.

- Recognizing caregiver stress
- Coping with caregiver stress
- Caregiving and your other responsibilities
- Getting help from your family
- Community resources and respite care
- Planning ahead

If you are a caregiver -- caring for an aging family member or for someone with an illness or a disability -- you could probably use some support yourself. Caregiving is emotionally and physically draining. If you also have a job, children who need your attention, or other responsibilities, it can feel overwhelming at times. Below is information on how to recognize and deal with the stress of caregiving and find support when you need it.

## Recognizing caregiver stress

Caregiving is stressful because you are dealing with so many issues and feelings at once. You are dealing with emotional issues, and medical and financial issues. The stress of trying to handle so much can show up in many ways. The following are some of the most common signs of caregiver stress:

- sleeping and eating problems
- headaches
- susceptibility to illness
- muscle tension
- high blood pressure
- anxiety
- depression
- loneliness
- guilt
- anger
- withdrawal from friends or family
- irritability or impatience

## Coping with caregiver stress

Caring for someone who is ill or disabled is challenging no matter how much energy you have. It can cause you to feel trapped and hopeless. You may feel guilty or "down on yourself" because you can't do more. You may be mourning the loss of the relationship you once had and the hopes you had for a different future together. Here are some ways to cope with these feelings:

- *Recognize the signs of caregiver stress.* Watch for the warning signs of caregiver stress. Pay attention to your physical and mental health.
- *Take steps to reduce feelings of stress.*
  - Ask for help from family members and friends.
  - Exercise regularly.
  - Get enough sleep.
  - Eat a balanced diet.
  - Practice relaxation techniques such as deep breathing or meditation.
- *Make time for yourself every day.* Time for yourself is usually the first thing to go when demands pile up. But if you neglect your own needs, you'll gradually wear yourself down to the point where you won't have the patience and strength you need to be a good caregiver. Arrange to meet someone for lunch or breakfast or for an occasional walk. Making time to take a walk or visit a friend isn't selfish. It doesn't mean that you are neglecting your caregiving responsibilities. Instead, it lets you return to your tasks with new strength. It also gives you the fresh perspective you need to find solutions to the challenges of caregiving.
- *Talk about your feelings.* Talk about what you are going through with people you trust. Find a "phone buddy" for regular check-ins or for those times when you really need to talk. When you keep all your feelings inside, they build up and spill out in destructive ways -- in anger at the person you are caring for, for example.
- *Ask for help.* One of your biggest challenges as a caregiver is learning how to recognize your limits and to ask for help when you need it. You may think it's an admission of failure to say that you need help. Or you may worry about putting a burden on others. The problem is that if you take on more than you can handle, you'll soon burn out. Make a list of people who might be able to help -- friends, family, neighbors, or members of your faith community. Then ask for help with specific tasks and begin to rely on these people for support. Remember that others want to help. But many people hesitate to offer because they don't know what to do. Let friends and family know how they can help.
- *Keep a journal.* If it's hard for you to talk about your feelings, try keeping a journal. This can provide an outlet for some of your emotions and frustrations.
- *Consider talking with a counselor.* Individual or family counseling can help during difficult times.

### **Caregiving and your other responsibilities**

People often try to handle caregiving problems on their own. They may hide these problems when they are at work or meeting other responsibilities. Then

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things begin to spill over and affect their performance. Here are ways to keep that from happening:

- *Let the people you deal with regularly -- at work or in other activities -- know about your caregiving responsibilities.*
- *Explore the possibility of alternative schedules, such as working at home.*
- *Find out if your employer's benefits program or any organization you are affiliated with can help with the costs of care.*
- *Look for a respite care provider who will look after your family member when you cannot be with them.*
- *Look into the possibility of taking time off or leaves of absence from other responsibilities when you are feeling overwhelmed.*
- *Join a support group.* You may get together with others who are caring for a family member. People in the same situation often have practical advice and emotional support to share.

**Getting help from your family**

Caregivers who get help from relatives tend to have lower stress levels than those who don't. Here are some ways to get your family to help:

- *Get everyone together to discuss the situation.* It's often helpful to get family members together, in person or on the phone, to try to come up with a plan as a group. Together you may come up with ideas that wouldn't have occurred to you separately.
- *Be specific.* Talk about specific tasks and how people might help. You might need help picking up prescriptions, driving to the doctor, or bringing dinner on a certain night. If you need a lot of help, you might make up a list of all the things that need to be done and ask people to sign up for tasks they're able to take on -- if not regularly, at least occasionally.
- *Show your appreciation.* Send a note or call to say, "Thanks for taking Mom to lunch. It was great to have a break." When family members feel appreciated, they'll want to help out again.
- *Remember that teenagers in the family can help, too.* They can't assume full-time responsibilities, but they might be able to help with errands and chores.
- *Make your needs clear when family members refuse to cooperate.* Write a letter about your concerns and send it to everyone involved. Or call a family meeting. This will make everyone aware of your feelings and give people a chance to respond. If you aren't comfortable handling a family meeting alone, a social worker affiliated with your family member's health care provider may be able to help.

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### Community resources and respite care

There are a number of resources available in most communities to help with caregiving responsibilities, from support groups to homemaker services to adult day care programs. A good way to find out about them is to call your local agency on aging. Some of these services are expensive, but others may be available at little or no cost. Remember that by getting the help you need, you're making the most of your resources -- physical and emotional -- so that you can continue to care for the person you love.

Here are some resources to look for:

- *Support groups.* Support groups are a way to get together with others who are having similar caregiving experiences and who can provide emotional support, often just by reminding you that you are not alone. Some groups, for instance, focus on families of people with specific conditions, such as Alzheimer's disease. You might not be able to go to regular support group meetings. But if you go to one or two, chances are you'll meet some people on your own. To find a support group, contact associations that specialize in a specific disease or condition, your local senior citizens' center, or try calling the gerontology department of a hospital in your area.
- *Home care services.* Home care services cover a broad range of services, from daily tasks like cleaning or shopping, to personal care like bathing and dressing, to skilled medical assistance like help with medications. A growing number of public and private agencies specialize in finding home care workers. Or you can hire someone on your own. Always check the references of a service provider you are considering letting into the home of an ill or disabled person.
- *Personal emergency response service (PERS).* A PERS is an easy way to call for help in an emergency. Most people use a button, worn on a pendant around the neck or on a bracelet on the wrist, which contains a portable communication unit. This unit is activated when the button is pressed and it sends a signal to a 24-hour monitoring center that will then contact a network of neighbors, friends, and emergency services in the community. Additional services such as medication and appointment reminders may also be available through a PERS.
- *Adult day care.* These programs provide supervised activities for older or disabled adults in the company of other adults. Adult day care gives you a break from caregiving tasks by allowing you to place your family member in a safe and stimulating environment for one to five days a week. Call your local agency on aging or a senior citizens' center to find out if there are adult day care programs near you.
- *Temporary care in a long-term facility.* Many nursing homes now offer short-term respite care in a skilled nursing or specialized facility. There is usually a minimum and maximum length of stay, and there may be other physical or

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medical requirements as well. This kind of care can be especially helpful if your family member has physical or emotional needs that friends or family may not be able to handle in your absence.

**Planning ahead**

Planning ahead can help you anticipate problems that might arise as a caregiver. For example, if you know a particularly busy time is approaching, it helps to prepare for it ahead of time.

- *Take the time to gather vital information about the person you care for.* Pull together key documents, health insurance details, and names and telephone numbers of neighbors, doctors, and pharmacists.
- *Get the legal authority you need to make emergency decisions.* If a loved one's condition is deteriorating, and might get worse, it's a good idea to get legal authorization to handle finances ("power of attorney") and to make medical decisions if the person becomes unable to do so ("health care proxy").
- *Line up extra help and develop backup plans.* Are you going away on a business trip? Is your daughter about to graduate? If you know that a demanding time is approaching, be prepared and line up extra help now.

Caregiving can be draining. It's easy to become so involved in the day-to-day tasks of caring for someone you love that you lose your sense of perspective. Focus on the positive. Recognize that you are doing your best -- even though it may sometimes feel as though you're not doing enough. Don't criticize yourself for being a less-than-perfect caregiver. Try to see past your day-to-day challenges and disappointments to the help and support you are showing by your actions.

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