

Information for People Who Provide Care for Elders

Caregiver

FACT SHEET

Bulletin #4206

Support for Caregivers

As a caregiver, you may be providing care out of love or out of a sense of obligation. More often than not, you feel both love and obligation. You may be providing support alone or coordinating the work with others. You may find caregiving tasks satisfying and rewarding, and you may find them very frustrating.

Caregivers who are faced with the many demands of providing care often experience caregiver burden. This term refers to the impact of many emotional, physical and financial responsibilities of caregiving on the normal activities of life.

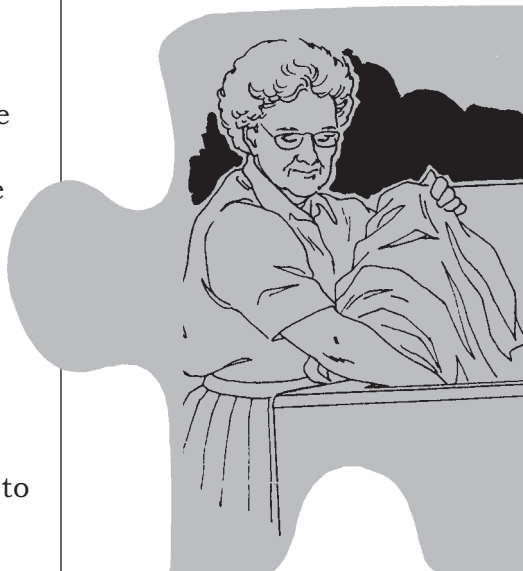
Burden has to do with the life changes that have come about when you take on the caregiving role. It may endure as long as your help is needed. Because the demands of caregiving can continue indefinitely, it is difficult to find solutions to caregiver burden. However, there are things the caregiver can do to cope with the situation.

Get Support from Family and Friends

Our culture emphasizes independence, so it is not always easy to ask for help. The truth is that caregivers who get help and support from family and friends tend to feel less stress and may be better able to cope with the burdens of caregiving.

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Caregivers who are supported by others have a feeling of



being loved and cared for. They also gain practical help with caregiving tasks, housework or errands. As a result of this support, caregivers are better able to solve problems and to prevent difficult situations from getting worse.

Join a Support Group

Most people benefit from sharing their feelings with someone who is supportive and listens without judging. Support groups can help caregivers feel less isolated and build strong bonds of mutual help and friendship. They can often provide useful information that helps improve caregiving skills.

Seek Out Respite Care

Respite care provides a structured opportunity for a caregiver to be relieved of his or her caregiving duties for a period of time. This may be for three or four hours a week, or maybe even longer. Respite care is provided in two ways:

1. A person comes into the home of the person needing care while the caregiver is away.
2. The older person is taken to another location, where he/she is cared for.

Respite programs are sponsored by hospitals, in-home service organizations, day care centers, nursing homes, religious organizations, senior centers, area agencies, area social agencies or area agencies on aging. The level of care can vary from custodial to short-term medical care.

Maintain Good Health

One of the most important things a caregiver can do is to take care of herself or himself. Caregivers who maintain their health are less burdened than those who have poor health. Good health practices enable the caregiver to meet the demands of caregiving while working, rearing a family and pursuing interests and hobbies. Follow these guidelines to maintain your health:

- **Eat nutritious foods:** Food is fuel for your body. Eating poorly or skipping meals reduces energy and puts you at risk for health problems. Learn to prepare and eat simple nutritious meals.

- **Get exercise and rest:** Physical activity reduces stress and improves health. Bicycling, walking or swimming are good outlets and, in the long run, prevent serious health problems. Sound sleep refreshes and enables caregivers to function well during the day.

- **Plan leisure time:** It is important to take time for yourself and do something you enjoy. If you are a woman, you may tend to give up your fun

time and opportunities for recreation and socialization. If you are a man, you may be more likely to set aside time for your own interests. It is important for both men and women to guard against isolation and depression. Set aside personal time and spend time with others.

The truth is that caregivers who get help and support from family and friends tend to feel less stress and may be better able to cope with the burdens of caregiving.

- **Avoid destructive behaviors:** Use alcohol in moderation, if at all, use medications carefully and only as prescribed, and don't overeat. Avoid expressing feelings with food, drugs or alcohol.

Accepting Your Feelings

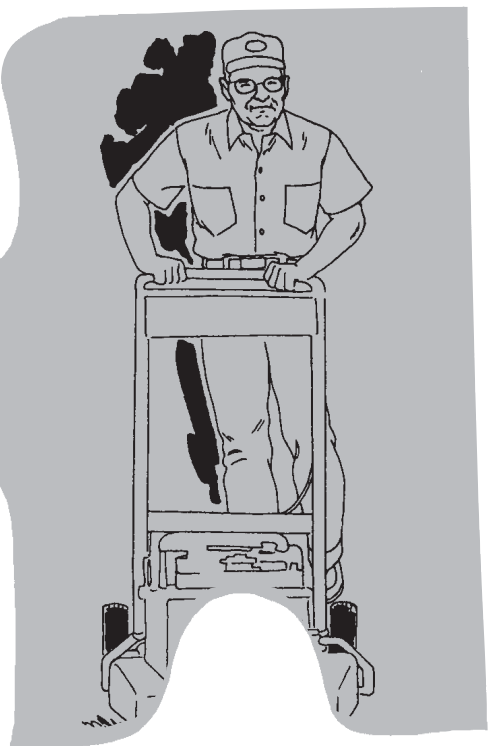
Caregiving is a difficult and sometimes unrewarding job. Although caregivers often feel a sense of satisfaction about being "good" caregivers, they also experience a range of feelings that may be confusing and upsetting. Caregivers feel a deep sense of caring and love. They also feel anger at the many demands on their time.

They grieve that the person is not the same anymore. They feel burdened by financial pressures. They feel unappreciated for all the many things they do.

These feelings are normal. Feelings of anger, frustration or helplessness do not mean that you, as a caregiver, love your relative less. Recognizing and accepting all these feelings are necessary steps in resolving problems, reducing stress and preventing physical and emotional problems.

Beware of Stress

Caregivers sometimes expect too much of themselves and are constantly worried about neglecting others. They may not recognize feelings of stress as burden in themselves, and in the long run, harm their own physical and emotional



health.

Stress Symptoms

The first step toward managing stress is to be aware of it. Try monitoring your stress. Do you have any of these symptoms? If so, you may want to talk with a health care provider.

- headaches
- digestive upsets
- depression
- fatigue
- anxiety
- boredom
- insomnia
- crying spells
- confusion
- weight change
- irritability
- mood swings
- lethargy
- forgetfulness
- poor concentration
- low productivity
- negative attitude
- tight neck and shoulder muscles
- increased use of alcohol, drugs, tobacco

Think and Act Positive

People who keep a positive outlook on life are better able to manage stress than those that see the world in negative ways. Positive thinkers “reframe” difficult situations, changing them from bad to good. They see problems as challenges to be mastered. Also, positive thinkers tend to look at things in the long run, which helps put the situation in perspective. Caregivers seem to feel less stress when they face problems head on, take charge of situations and look for solutions. This helps them feel that they have

mastered the problem.

Exercise Positive Thinking

Start by relaxing and thinking in positive ways. Think positively about yourself: “I really did a great job of caring for Mom today,” or “I took a walk to get some exercise and relax.” Think positively about even small victories with your family member. Recognize the good things about other important parts of your life, such as other family members or personal interests.

Feelings of anger, frustration or helplessness do not mean that you, as a caregiver, love your relative less.

Establish Your Limits

You have the right to set limits on what you will do. It’s all right to say no. Providing care at the expense of your mental and physical health or relationships with other family members does not benefit anyone. Communicate your limits to your family and to your ill relative.

Getting help is a sign of personal strength, not weakness, and will enable you to be a more effective caregiver.

Seek Professional Guidance

You should consider seeking professional guidance under the following circumstances:

- You find yourself using alcohol or drugs to forget your problems, relieve stress, fall asleep or get yourself going in the morning.
- You become depressed.
- You don’t understand your family member’s behavior or don’t know how to deal with specific care tasks.
- You find yourself feeling resentment or losing emotional control, or neglecting, humiliating or becoming physically rough with a family member.
- You are being physically or emotionally abused by your impaired family member.
- Your family cannot resolve problems or reach agreement on care decisions.
- You feel a conflict between caregiving and other responsibilities.

A professional can often help you gain objectivity and a clearer perspective of the situation. Don’t be afraid to seek help, and don’t wait until you are overwhelmed by a crisis. Getting help is a sign of personal strength, not weakness, and will enable you to be a more effective caregiver.

As a caregiver, you will sometimes wish you had done things differently. You are only human. If you make a mistake, admit it, learn from it and then go on.

Too often, caregivers focus on what they have not done well. Remind yourself of the many things you have done well. It will make you feel better about yourself. Ask yourself:

“What are my personal strengths?”

“How have I made a difference for my family member?”

“What things have I done that I feel good about?”

You are doing many things well. Don't fail to give yourself the credit you are due.

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Remember the **Caregiver Bill of Rights** I have the right to:

- **Take care of myself.** This is not an act of selfishness; it will allow me to take better care of my relative.
- **Get angry, depressed and express other difficult feelings occasionally.** These are normal feelings.
- **Take pride in what I am accomplishing and applaud the courage it takes to meet the needs of my relative.**
- **Seek help from others even though my relative may object.** I recognize the limits of my own endurance and strength.
- **Reject attempts by my relative to manipulate me through guilt, anger or depression.**
- **Protect my individuality and my right to make a life for myself that will help me after my relative no longer needs my help.**
- **Maintain parts of my own life that do not include the person I care for, just as if he/she were healthy.** I have the right to do some things just for myself.
- **Receive consideration, affection, forgiveness and acceptance for what I do from my loved one for as long as I offer these qualities in return.**

Why not read this list every day? It may remind you to put your “job” into a perspective with a wider view.

Excerpted with permission from Jo Horne, Caregiving: Helping an Aging Loved One (Washington, DC: AARP, 1985).