



PATIENT EDUCATION

*Information for Caregivers:
Taking Care of Yourself*

learning **EDUCATION** EXCELLENCE
HEALTHY CARING INTERACTION
LIVING

BARBARA WOODWARD LIPS
PATIENT EDUCATION CENTER

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Introduction

Caregivers play a special role in the lives of people who are chronically or terminally ill, developmentally delayed or otherwise impaired. More and more, family members and friends are providing essential care that allows loved ones to enjoy a higher quality of life than they would on their own. There are more than 22 million unpaid caregivers in the United States, and that number is growing every day.

Caregivers may give significant time and energy to helping their loved ones. Caregiving may include activities that range from emotional support and companionship to activities of daily living, such as personal hygiene and health care needs. And caregivers often take on other tasks, including managing finances, scheduling health care related appointments, helping children with educational needs, and doing daily chores, such as grocery shopping, cooking, laundry, and home maintenance.

If you offer ongoing assistance to someone who is ill or otherwise impaired, you are considered a caregiver. As a caregiver, you may provide direct physical care for a loved one, or you may offer support in other ways.

As a caregiver you know that your support brings personal rewards because it is an expression of the love you feel for someone close to you. However, caregiving can be physically and psychologically exhausting. At some point, it is not uncommon for caregivers to feel resentful, guilty or isolated. Caregivers also may have physical symptoms that signal they are under increased stress, such as irritability, fatigue, headaches, muscle aches, and depression.

To avoid being overwhelmed by the responsibilities of caregiving, it is important to balance the demands in your life. One of the biggest challenges caregivers face is balancing caregiving tasks with other responsibilities. Often, caregivers are so focused on caring for others that they forget one of the most important things they can do as caregivers — taking care of themselves.

Caregiving may be one of the greatest gifts you can give your loved one. Knowing how to take care of yourself and cope with the stress involved may increase your and your loved one's feelings of well-being. This information is meant to help you recognize, understand and manage the challenges you face as a caregiver. Different strategies to help you take care of yourself (self-care) are discussed. If you have questions about this information or about the issues you face as a caregiver, talk to a member of your health care team or the health care team of your loved one.

Addressing the Challenges and Stressors of Caregiving

Caregivers face challenges and stressors that can change from day to day. Common sources of stress may include:

- Additional demands and responsibilities you have taken on
- Adjustments you have made that have affected your lifestyle, social life and future plans
- Routine and unexpected frustrations in your daily life as a caretaker, which often are beyond your control
- The sense of personal loss or grief related to the circumstances that led you to become a caregiver

Addressing the challenges and stressors of caregiving is an important part of a caregiver's job. It is not selfish to focus on your own needs and desires. In fact, it is essential to take care of yourself so that you have the emotional and physical energy to care for others.

As a caregiver, it is important to:

- Recognize the warning signs of stress
- Identify the sources of stress
- Acknowledge what you can and cannot change
- Manage stress

Common signs of stress

Often, people who care for others do not recognize the stresses involved in caregiving until they have one or more of the most common symptoms that signal too much stress:

- Overwhelming feelings of anger, frustration or anxiety regarding a loved one's needs or the daily caregiver routine
- Frequent headaches, backaches or colds
- Insomnia
- Increased use of alcohol, over-the-counter or prescription drugs or other substances
- Feelings of grief, hopelessness or depression
- Diminished sense of humor
- Loss of interest in your usual activities, such as church, community or social groups
- Periods of crying or other emotional outbursts
- Loss of interest in recreational activities
- Lack of attention to your own physical health (over- or under-eating, avoiding exercise, allowing yourself to become physically run-down, etc.)

List warning signs of stress you have had:

While caregivers commonly have some or even all of these stress-related warning signs, people may feel ashamed and alone when such symptoms strike.

Identifying your sources of stress

Caregiving is important work, and the challenges and stressors you face can impact your health and your ability to do that work. As a caregiver, you most likely have experienced stress and one or more of the common symptoms of too much stress.

Identifying the warning signs (irritability, fatigue) of too much stress can help you recognize and deal with the causes of those signs. Then, you can make changes before you become overwhelmed.

Try this exercise to identify what causes stress for you.

First, ask yourself, "What is causing stress for me?" Common causes of stress may include:

- Having too much to do
- Uncertainty in what the future holds
- Family disagreements
- Feelings of inadequacy
- Reluctance or inability to say no

List the things that cause you the most stress as a caregiver:

Once you have identified sources of stress in your life, you can sort the stressors into groups and decide on the appropriate action. For example, if you have too much to do and too little time, you can manage by asking for help. Learning to recognize, anticipate and offset your stressors is the foundation of good stress management.

Managing stress

You can manage or reduce your stress level by changing the things you can control. Follow the steps below and use the worksheet to identify your stressors and develop a plan for change.

1. Think about the changes you are most motivated to make or that seem most doable (things that you can control).
2. Write down the stressors you are ready to address (see the example, "Help I need").
3. Set a goal regarding the stressor you have identified (see the example, "Help I need").
4. Identify realistic things you can do to work toward your goal. For example, if you decide to set a goal to exercise regularly, make specific commitments that will help you work toward your goal (see the example, "Help I need").

Sample action plan entry – use the blank boxes to make your own action plan to identify and reduce stressors in your life

Stressor	Goal	Action Plan (Steps you will take to achieve your goal)
<p>I spend all of my physical energy caring for my spouse.</p> <p>This makes me feel angry and a little depressed because I used to walk with my neighbor in the mornings, but now it seems I never have the time</p>	<p>Make time to exercise regularly</p>	<ol style="list-style-type: none"> 1. I will walk when my spouse is napping or ask someone to care for him/her three times a week if necessary. 2. I'll give my neighbor a call to invite him/her to walk with me for 15 minutes three mornings a week. 3. If the weather's poor, we can walk in the mall before it opens.

Avoiding Caregiver Burnout

Taking care of others without nurturing yourself can lead to physical, emotional, psychological and spiritual distress or exhaustion. This is commonly called caregiver burnout. However, by addressing stressors and using relaxation skills and strategies such as positive thinking and self-talk, you can improve your caregiving skills while taking care of yourself.

Relaxation skills

Relaxation means eliminating tension from your body and mind. When you feel anxious or stressed, the normal response is arousal — your body prepares to fight a threat or flee. Repeated, unnecessary arousal may harm your health. To help protect your health, learn how to relax.

As you learn the skill of relaxing, you become more aware of when your muscles are tense. Those times may occur during your daily activities or during stressful situations. The goal of relaxing is to reduce the effects of stress on your health.

After practicing relaxation techniques, many people gain benefits such as the following:

- Fewer symptoms of illness (such as headaches, nausea, diarrhea and pain)
- Fewer emotional responses (such as anger, crying and frustration)
- More energy
- Improved concentration
- Better able to handle problems
- More efficiency in daily activities
- More relaxed

Types of relaxation therapy include:

- Relaxed breathing is also called diaphragmatic breathing and is a technique that can help you breathe more efficiently, even in stressful situations.
- Progressive muscle relaxation is used to reduce muscle tension by tensing and relaxing certain muscles.
- Autogenic relaxation is a process during which you use your mind to relax your muscles. You repeat words or suggestions to relax, reducing your tension.
- Imagery is a technique in which you form mental images of places or situations you find relaxing. Choose an image that works well for you and try to use as many senses as you can (smells, sights, sounds, textures).
- Tai Chi, self-hypnosis, yoga and meditation are other activities that help to develop relaxation skills.

Talk to your health care provider about relaxation skills and where you can learn them.

Positive thinking and self-talk

Some caregivers find it difficult to acknowledge — or are unable to recognize — the strain associated with caregiving. The many responsibilities required of a caregiver can take their toll on one's self-esteem and can cause negative thinking.

Do you criticize yourself or think negative thoughts about yourself or your situation? If you do so regularly, you may be setting yourself up for increased feelings of anxiety or depression that can prevent you from nurturing yourself. This can diminish your capacity to care for your loved one.

Avoid self-criticism and negative thinking by acknowledging the important work you do and giving yourself credit for it. If you engage in negative thinking regularly, try these strategies:

- Replace negative thoughts with positive self-talk. When you find yourself thinking critically about yourself or your situation, replace those thoughts with positive ones. Tell yourself that you are an important part of your loved one's health care team.
- Avoid self-critical statements. Focus on your strengths and identify the things you are doing well.
- Talk to a friend, family member, counselor or clergy member. Positive feedback and support can help you avoid negative thinking.

Make a list of your strengths as a caregiver:

Depression: When to seek help

It is not unusual for caregivers to feel depressed occasionally. After a short time, most people begin to feel better. But if those sad, lonely, irritable, tired feelings don't go away, you may be experiencing depression.

The following are common symptoms of depression:

- Persistent sadness
- Irritability
- Overwhelming feelings of anxiety
- Loss of interest or pleasure in life
- Neglect of personal responsibilities or personal care
- Changes in eating habits
- Changes in sleeping patterns
- Fatigue and loss of energy
- Extreme mood changes
- Feeling helpless, hopeless or worthless
- Physical symptoms (for example, headaches or chronic pain) that don't get better
- Increased alcohol or drug use
- Thoughts of death or suicide

Talk to your health care provider if you have any of the above symptoms for a prolonged time. If you find yourself thinking about suicide or making a suicide plan, immediately seek medical help.

Self-care strategies

Taking care of yourself should be a priority, but many caregivers find it difficult to take time for even the essentials of self-care. For example, you may find it difficult to take time to prepare and eat balanced meals, get adequate sleep, and take an occasional break from daily caregiver duties. However, it is critical for you to make self-care a priority.

In addition to monitoring your stress levels and addressing stressors, make a commitment to focus on your own physical and mental health. Plan to incorporate healthy self-care strategies into your daily routine. Prioritize tasks — decide what must be done now and what can be done later.

From the list below, identify at least four things you can do right now to be good to yourself — remember, you want to be able to care for your loved one, so you need to make self-care a priority.

- Eat at least one healthy, balanced meal every day.
- Get enough sleep.
- Ask for help and accept help when it is offered. Prepare a list of things that need doing — this might include shopping, a visit with your loved one, errands, etc. — and let your “helpers” choose tasks that are right for them (Use the check list, “Help I Need” to identify specific tasks that you could use help with). Many caregivers may be reluctant to ask for help. However, family and friends often find it rewarding to help loved ones — it’s a way to show they care.
- Schedule regular breaks from daily duties. Even short outings, quiet time at home, a visit with a friend, etc., can help to revive your spirit.
- Schedule respite care for your loved one, if necessary, to give yourself a break.
- Monitor your own health. See your health care provider if you are experiencing any signs of poor health. Make and keep regularly scheduled health and dental appointments.
- Exercise regularly. Even a 10-minute walk can help lift your mood, get you into a more positive environment and refocus your thoughts, even temporarily, away from negative or self-critical thinking patterns. Talk to your health care provider about an exercise program that’s right for you.
- Get support from other caregivers. Seek out a caregiver support group in your area. Ask your health care provider about support groups or other resources.
- Seek supportive counseling, or talk to a trusted counselor or friend if you are feeling overwhelmed.

Help I need:

- Someone to stay with my loved one so that I can have a break from caregiving
 - The shopping done
 - The house cleaned
 - A shoulder to cry on
-

Help with paying the bills

Help with car repairs

A weekend away

- Yard work done (mow lawn, shovel snow)
 - Pick up prescriptions or other health care items
 - Other help I need:
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Taking care of yourself will enhance your ability to care for your loved one. Focusing on your own needs and desires when you are a caregiver is an important part of the job!

Resources

While many caregivers feel they need to shoulder all of the work of caring for their loved ones, this is an impossible task. Feelings of guilt are common as caregivers realize that they need to ask for help or even entrust their loved ones' care to others. However, your goal is to offer your loved one the best possible care, and this is only possible if you ask for help and make use of available resources.

There are a number of resources available to caregivers, including medical social workers, support groups, home health services, home delivered meals, respite care, and churches. Your county social service agency or county nurse can help you identify caregiver resources in your area.

Ask your health care provider about resources that are available in your community.

Support groups

A support group is made up of individuals who share a common interest or are troubled by the same problem. The goal of a support group is to help individuals adjust to their situations and develop problem-solving skills.

To find a support group that fits your needs, consider the following:

- Discuss your needs with your health care provider.
- Contact the social services department at your local clinic or hospital, or ask your health care provider for a referral to this department.
- Contact your county public health services.
- Check your local newspaper for a listing of support groups, resources and community events.
- Look in the telephone book or on the Internet for:
 - Social services organizations or support dgroups.
 - Alcoholics Anonymous, Narcotics Anonymous, Center for Independent Living, Parents Anonymous, etc.
- Call your state Council on Disability.
- Contact a state or national organization dedicated to the condition of your loved one. Your local library should have listings of these organizations.
- Ask your chaplain or clergy person. Many religious organizations hold regular support group meetings that may meet the needs of caregivers.

Additional resources

- Your local YWCA or YMCA may have exercise programs or group activities designed to meet your needs.
- The Salvation Army and local churches may provide fellowship and spiritual guidance.
- Senior citizen organizations offer a wide range of recreational and social activities as well as health counseling and education.
- Mental health organizations frequently offer programs that provide emotional support for patients and their families.
- If your loved one has a specific disease-related disability, contact the specific organization (such as the Alzheimer's Association or the MS Society).
- Community education offers both recreational and educational courses.
- Home health services can provide skilled nursing care as well as assistance with tasks like bathing or dressing. Ask your health care provider if such resources are available in your area.
- Home-delivered meals, in-home respite care or extended out-of-home respite care may be available in your area. Ask your health care provider if such resources are available in your area.

Your health care provider may recommend other resources.

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If Caregiving Becomes Too Much

A time may come when you can no longer care for your loved one. If the demands of your situation become impossible for you to meet or if your own health is compromised, immediately contact your health care provider, community nurse or social worker. They will be able to help you and give you advice about your options for continuing home care, as well as options for nursing home or respite care.

Conclusion

Caring for yourself is one of the most important things you can do as a caregiver. When your needs are taken care of, the person you are caring for will benefit too. Setting self-care goals is an important part of caregiving:

- Take a break from caregiving to refresh your mind and restore your health.
- Schedule time for activities you enjoy.
- Make time (even as short a time as 15 minutes) to relax, meditate, go for a walk, talk to a friend, pursue a favorite hobby, read a book, work out, garden, knit, do needlepoint.
- Practice positive self-talk; give yourself credit for your work.
- Practice relaxation techniques.
- Reward yourself.
- Look for resources available in your community. Ask your health care provider about respite care or other services, classes or group meetings in your area.
- Make a commitment to exercise regularly. Remember, exercise doesn't have to be strenuous to be effective. Walking, for example, is considered by most experts to be one of the best forms of exercise.

Recognizing your needs, identifying and addressing stressors, dealing with symptoms that you are under too much stress (such as fatigue, irritability, and feelings of depression), and reaching out to family and friends or a caregiver support group are all ways that you can care for yourself so that you can better care for your loved one.

Notes

Notes

BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal Mayo Clinic patient of more than 40 years and a self-made business leader who significantly expanded her family's activities in oil, gas and ranching. Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.

This material is for your education and information only. This content does not replace medical advice, diagnosis or treatment. New medical research may change this information. If you have questions about a medical condition, always talk with your health care provider.



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