

Fact Sheet

Taking Care of YOU: Self-Care for Family Caregivers

First, Care for Yourself

On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When *your* needs are taken care of, the person you care for will benefit, too.

Effects of Caregiving on Health and Well Being

We hear this often: “My husband is the person with Alzheimer’s, but now I’m the one in the hospital!” Such a situation is all too common. Researchers know a lot about the effects of caregiving on health and well being. For example, if you are a caregiving spouse between the ages of 66 and 96 and are experiencing mental or emotional strain, you have a risk of dying that is 63 percent higher than that of people your age who are not caregivers.¹ The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age place you at risk for significant health problems as well as an earlier death.

Older caregivers are not the only ones who put their health and well being at risk. If you are a baby boomer who has assumed a caregiver role for your parents while simultaneously juggling work and raising adolescent children, you face an increased risk for depression, chronic illness and a possible decline in quality of life.

But despite these risks, family caregivers of any age are less likely than noncaregivers to practice preventive healthcare and self-care behavior. Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They report:

- sleep deprivation
- poor eating habits
- failure to exercise
- failure to stay in bed when ill
- postponement of or failure to make medical appointments.

Family caregivers are also at increased risk for excessive use of alcohol, tobacco and other drugs and for depression. Caregiving can be an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are enormously stressful. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed.

Taking Responsibility for Your Own Care

You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal that you can do to take responsibility for your personal well being and to get your own needs met.

Identifying Personal Barriers

Many times, attitudes and beliefs form personal barriers that stand in the way of caring for yourself. Not taking care of yourself may be a lifelong pattern, with taking care of others an easier option. However, as a family caregiver you must ask yourself, “What good will I be to the person I care for if I become ill? If I die?” Breaking old patterns and overcoming obstacles is not an easy proposition, but it can be done—regardless of your age or situation. The first task in removing personal barriers to self-care is to identify what is in your way. For example,

- Do you feel you have to prove that you are worthy of the care recipient’s affection?
- Do you think you are being selfish if you put your needs first?
- Is it frightening to think of your own needs? What is the fear about?
- Do you have trouble asking for what you need? Do you feel inadequate if you ask for help? Why?

Sometimes caregivers have misconceptions that increase their stress and get in the way of good self-care. Here are some of the most commonly expressed:

- I am responsible for my parent’s health.
- If I don’t do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.

“I never do anything right,” or “There’s no way I could find the time to exercise” are examples of negative “self-talk,” another possible barrier that can cause unnecessary anxiety. Instead, try positive statements: “I’m good at giving John a bath.” “I can exercise for 15 minutes a day.” Remember, your mind believes what you tell it.

Because we base our behavior on our thoughts and beliefs, attitudes and misconceptions like those noted above can cause caregivers to continually attempt to do what cannot be done, to control what cannot be controlled. The result is feelings of continued failure and frustration and, often, an inclination to ignore your own needs. Ask yourself what might be getting in your way and keeping you from taking care of yourself.

Moving Forward

Once you’ve started to identify any personal barriers to good self-care, you can begin to change your behavior, moving forward one small step at a time. Following are some effective tools for self-care that can start you on your way.

Tool #1: Reducing Personal Stress

How we perceive and respond to an event is a significant factor in how we adjust and cope with it. The stress you feel is not only the result of your caregiving situation but also the result of your perception of it—whether you see the glass as half-full or half-empty. It is important to remember that you are not alone in your experiences.

Your level of stress is influenced by many factors, including the following:

- Whether your caregiving is voluntary. If you feel you had no choice in taking on the responsibilities, the chances are greater that you will experience strain, distress, and resentment.
- Your relationship with the care recipient. Sometimes people care for another with the hope of healing a relationship. If healing does not occur, you may feel regret and discouragement.
- Your coping abilities. How you coped with stress in the past predicts how you will cope now. Identify your current coping strengths so that you can build on them.
- Your caregiving situation. Some caregiving situations are more stressful than others. For example, caring for a person with dementia is often more stressful than caring for someone with a physical limitation.
- Whether support is available.

Steps to Managing Stress

1. *Recognize warning signs early.* These might include irritability, sleep problems, and forgetfulness. Know your own warning signs, and act to make changes. Don’t wait until you are overwhelmed.
2. *Identify sources of stress.* Ask yourself, “What is causing stress for me?” Sources of stress might be too much to do, family disagreements, feelings of inadequacy, inability to say no.

3. *Identify what you can and cannot change.* Remember, we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration. Ask yourself, “What do I have some control over? What can I change?” Even a small change can make a big difference. The challenge we face as caregivers is well expressed in words from the Serenity Prayer:

*...Grant me the serenity to
Accept the things I cannot change,
Courage to change the things I can,
And the wisdom to know the difference.*

4. *Take action.* Taking some action to reduce stress gives us back a sense of control. Stress reducers can be simple activities like walking and other forms of exercise, gardening, meditation, having coffee with a friend. Identify some stress reducers that work for you.

Tool #2: Setting Goals

Setting goals or deciding what you would like to accomplish in the next three to six months is an important tool for taking care of yourself. Here are some sample goals you might set:

- Take a break from caregiving.
- Get help with caregiving tasks like bathing and preparing meals.
- Feel more healthy.

Goals are generally too big to work on all at once. We are more likely to reach a goal if we break it down into smaller action steps. Once you’ve set a goal, ask yourself, “What steps do I take to reach my goal?” Make an action plan by deciding which step you will take first, and when. Then get started!

Example: Goal and Action Steps

Goal: Feel more healthy.

Possible action steps:

1. Make an appointment for a physical check-up.
2. Take a half-hour break once during the week.
3. Walk three times a week for 10 minutes.

Tool #3: Seeking Solutions

Seeking solutions to difficult situations is, of course, one of the most important tools in caregiving. Once you’ve identified a problem, taking action to solve it can change the situation and also change your attitude to a more positive one, giving you more confidence in your abilities.

Steps for Seeking Solutions

1. *Identify the problem.* Look at the situation with an open mind. The real problem might not be what first comes to mind. For example, you think that the problem is simply that you are tired all the time, when the more basic difficulty is your belief that “no one can care for John like I can.” The problem? Thinking that you have to do everything yourself.
2. *List possible solutions.* One idea is to try a different perspective: “Even though someone else provides help to John in a different way than I do, it can be just as good.” Ask a friend to help. Call Family Caregiver Alliance or the Eldercare Locator (see Resources List) and ask about agencies in your area that could help provide care.
3. *Select one solution from the list.* Then try it!
4. *Evaluate the results.* Ask yourself how well your choice worked.
5. *Try a second solution.* If your first idea didn’t work, select another. But don’t give up on the first; sometimes an idea just needs fine tuning.
6. *Use other resources.* Ask friends, family members and professionals for suggestions.
7. *If nothing seems to help, accept that the problem may not be solvable now.* You can revisit it at another time.

Note: All too often, we jump from step one to step seven and then feel defeated and stuck. Concentrate on keeping an open mind while listing and experimenting with possible solutions.

Tool #4: Communicating Constructively

Being able to communicate constructively is one of a caregiver’s most important tools. When you

communicate in ways that are clear, assertive and constructive, you will be heard and get the help and support you need. The box below shows basic guidelines for good communication.

Communication Guidelines

- *Use “I” messages rather than “you” messages.* Saying “I feel angry” rather than “You made me angry” enables you to express your feelings without blaming others or causing them to become defensive.
- *Respect the rights and feelings of others.* Do not say something that will violate another person’s rights or intentionally hurt the person’s feelings. Recognize that the other person has the right to express feelings.
- *Be clear and specific.* Speak directly to the person. Don’t hint or hope the person will guess what you need. Other people are not mind readers. When you speak directly about what you need or feel, you are taking the risk that the other person might disagree or say no to your request, but that action also shows respect for the other person’s opinion. When both parties speak directly, the chances of reaching understanding are greater.
- *Be a good listener.* Listening is the most important aspect of communication.

Tool #5: Asking for and Accepting Help

When people have asked if they can be of help to you, how often have you replied, “Thank you, but I’m fine.” Many caregivers don’t know how to marshal the goodwill of others and are reluctant to ask for help. You may not wish to “burden” others or admit that you can’t handle everything yourself.

Be prepared with a mental list of ways that others could help you. For example, someone could take the person you care for on a 15-minute walk a couple of times a week. Your neighbor could pick up a few things for you at the grocery store. A relative could fill out some insurance papers. When you break down the jobs into very simple tasks, it is easier for people to help. And they do want to help. It is up to you to tell them how.

Help can come from community resources, family, friends and professionals. Ask them. Don’t wait until you are overwhelmed and exhausted or your health

fails. Reaching out for help when you need it is a sign of personal strength.

Tips on How to Ask

- *Consider the person’s special abilities and interests.* If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal preparation.
- *Resist asking the same person repeatedly.* Do you keep asking the same person because she has trouble saying no?
- *Pick the best time to make a request.* Timing is important. A person who is tired and stressed might not be available to help out. Wait for a better time.
- *Prepare a list of things that need doing.* The list might include errands, yard work, a visit with your loved one. Let the “helper” choose what she would like to do.
- *Be prepared for hesitance or refusal.* It can be upsetting for the caregiver when a person is unable or unwilling to help. But in the long run, it would do more harm to the relationship if the person helps only because he doesn’t want to upset you. To the person who seems hesitant, simply say, “Why don’t you think about it.” Try not to take it personally when a request is turned down. The person is turning down the task, not you. Try not to let a refusal prevent you from asking for help again. The person who refused today may be happy to help at another time.
- *Avoid weakening your request.* “It’s only a thought, but would you consider staying with Grandma while I went to church?” This request sounds like it’s not very important to you. Use “I” statements to make specific requests: “I would like to go to church on Sunday. Would you stay with Grandma from 9 a.m. until noon?”

Tool #6: Talking to the Physician

In addition to taking on the household chores, shopping, transportation, and personal care, 37 percent of caregivers also administer medications, injections, and medical treatment to the person for whom they care. Some 77 percent of those caregivers report the need to ask for advice about the medications and medical treatments. The person they usually turn to is their physician.

But while caregivers will discuss their loved one's care with the physician, caregivers seldom talk about their own health, which is equally important. Building a partnership with a physician that addresses the health needs of the care recipient *and* the caregiver is crucial. The responsibility of this partnership ideally is shared between you the caregiver, the physician, and other healthcare staff. However, it will often fall to you to be assertive, using good communication skills, to ensure that everyone's needs are met—including your own.

Tips on Communicating with Your Physician

- *Prepare questions ahead of time.* Make a list of your most important concerns and problems. Issues you might want to discuss with the physician are changes in symptoms, medications or general health of the care recipient, your own comfort in your caregiving situation, or specific help you need to provide care.
- *Enlist the help of the nurse.* Many caregiving questions relate more to nursing than to medicine. In particular, the nurse can answer questions about various tests and examinations, preparing for surgical procedures, providing personal care, and managing medications at home.
- *Make sure your appointment meets your needs.* For example, the first appointment in the morning or after lunch and the last appointment in the day are the best times to reduce your waiting time or accommodate numerous questions. When you schedule your appointment, be sure you convey clearly the reasons for your visit so that enough time is allowed.
- *Call ahead.* Before the appointment, check to see if the doctor is on schedule. Remind the receptionist of special needs when you arrive at the office.
- *Take someone with you.* A companion can ask questions you feel uncomfortable asking and can help you remember what the physician and nurse said.
- *Use assertive communication and "I" messages.* Enlist the medical care team as partners in care. Present what you need, what your concerns are, and how the doctor and/or nurse can help. Use specific, clear "I" statements like the following: "I need to

know more about the diagnosis; I will feel better prepared for the future if I know what's in store for me." Or "I am feeling run-down. I'd like to make an appointment for myself and my husband next week."

Tool #7: Starting to Exercise

You may be reluctant to start exercising, even though you've heard it's one of the healthiest things you can do. Perhaps you think that physical exercise might harm you or that it is only for people who are young and able to do things like jogging. Fortunately, research suggests that you can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities like walking and gardening. Even household chores can improve your health. The key is to increase your physical activity by exercising and using your own muscle power.

Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time for exercise is a problem, incorporate it into your daily activity. Perhaps the care recipient can walk or do stretching exercise with you. If necessary, do frequent short exercises instead of those that require large blocks of time. Find activities you enjoy.

Walking, one of the best and easiest exercises, is a great way to get started. Besides its physical benefits, walking helps to reduce psychological tension. Walking 20 minutes a day, three times a week, is very beneficial. If you can't get away for that long, try to walk for as long as you can on however many days you can. Work walking into your life. Walk around the mall, to the store or a nearby park. Walk around the block with a friend.

Tool #8: Learning from Our Emotions

It is a strength to recognize when your emotions are controlling you (instead of you controlling your emotions). Our emotions are messages we need to listen to. They exist for a reason. However negative or painful, our feelings are useful tools for understanding what is happening to us.

Even feelings such as guilt, anger and resentment contain important messages. Learn from them, then take appropriate action.

For example, when you cannot enjoy activities you previously enjoyed, and your emotional pain overshadows all pleasure, it is time to seek treatment for depression—especially if you are having thoughts of suicide. Speaking with your physician is the first step. (Please refer to the Fact Sheet on Caregiving and Depression, listed below.)

Caregiving often involves a range of emotions. Some feelings are more comfortable than others. When you find that your emotions are intense, they might mean the following:

- That you need to make a change in your caregiving situation.
- That you are grieving a loss.
- That you are experiencing increased stress.
- That you need to be assertive and ask for what you need.

Summing Up

Remember, it is not selfish to focus on your own needs and desires when you are a caregiver—it's an important part of the job. You are responsible for your own self-care. Focus on the following self-care practices:

- Learn and use stress-reduction techniques.
- Attend to your own healthcare needs.
- Get proper rest and nutrition.
- Exercise regularly.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities.
- Seek and accept the support of others.
- Seek supportive counseling when you need it, or talk to a trusted counselor or friend.
- Identify and acknowledge your feelings.
- Change the negative ways you view situations.
- Set goals.

It's up to you!

Credits

¹ Shultz, Richard and Beach, Scott (1999). *Caregiving as A Risk for Mortality: The Caregiver Health Effects Study*. JAMA, December 15, 1999 – Vol. 282, No.23

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The Caregiver Helpbook, written by Vicki Schmall, Ph.D., Marilyn Cleland, R.N. and Marilynn Sturdevant, RN, MSW, LCSW, (2000) is highly recommended reading for caregivers. The book can be ordered directly from Legacy Health Systems, (503) 413-8018. caregiver@lhs.org or www.legacyhealth.org

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Websites

Administration on Aging

This site offers links to hundreds of resources on age related issues.

www.aoa.gov

Dr. Koop's Community Resource Center

This site is a project of Empower Health, a company led by former U.S. Surgeon General Dr. C. Everett Koop and others dedicated to improving quality of life.

www.drkoop.com

Healthfinder

A searchable list of dozens of health-related sources for information.

www.healthfinder.gov

Mayo Clinics Health Oasis

A wealth of information about health matters provided by the Mayo Clinic based in Rochester, Minnesota.

www.mayoclinic.com

National Library of Medicine's MEDLINE

Free access to Medline, a database of none million abstracts from four thousand journals containing peer-reviewed studies on every aspect of health care.

www.ncbi.nlm.nih.gov/PubMed/

Recommended Reading

Heath, A. (1993). *Long Distance Caregiving: A Survival Guide for Far Away Caregiving*. Impact Publishers.

Lustbader, W. (1992). *Counting on Kindness: The Dilemmas of Dependency*. New York. The Free Press.

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Resources

Family Caregiver Alliance

National Center on Caregiving

180 Montgomery Street, Suite 1100

San Francisco, CA 94104

(415) 434-3388

(800) 445-8106

Web Site: www.caregiver.org

E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating disorders that strike adults.

Family Caregiver Alliance Fact Sheet on Caregiving and Depression

www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=393

Family Caregiver Alliance Fact Sheet on Dementia, Caregiving and Controlling Frustration

www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=891

Alzheimer's Association

225 North Michigan Ave. Suite 1700

Chicago, IL. 60601-7633

(312) 335-8700

(800) 272- 3900

www.alz.org

The Alzheimer's Association provides education and support for people diagnosed with the condition, their families and caregivers. Chapters across the country provide local support.

Eldercare Locator

(800) 677-1116

www.eldercare.gov

The Eldercare Locator helps older adults and their caregivers find local services including health insurance counseling, free and low-cost legal services and contact information for local Area Agencies on Aging.

National Association of Professional Geriatric Care Managers

A nonprofit organization of professionals who assist families in caring for older adults and disabled persons on a fee-for-service basis.

(520) 881-8008

www.caremanager.org

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