

Section 1

You, the Caregiver



Caregiving at a Glance

By: AARP

A caregiver is anyone who shares responsibility for another person's health, safety, and well being. Many caregivers live with the person for whom they care. Other caregivers live in their own homes. Some people are helped by caregivers who use the phone or the internet because they live so far away. Most people receiving care are spouses, parents, grandparents, or another relative of the caregiver. If you help someone with normal activities and everyday tasks that they can't do for herself or himself, then you are a caregiver.

Many older people, the "young old," do not need caregiving when they are retirement age. As people age, the "old old," their need for help increases. Thirty-nine percent of caregivers cared for someone age 85 or older, while 14 percent provided care for someone age 65 to 69. There were more than a million people in Arizona who were 65 or older in 2016. It's likely that there are more now.

The majority of these unpaid caregivers, 56 percent, were women. Caregivers 55 to 64 were the most likely to provide care, 24 percent, followed by those ages 45 to 54, 21 percent. Those ages 65 and over, 19 percent, were most likely to be providing care to a spouse or partner.

There were about 41.3 million unpaid caregivers in the United States during 2016. The value of services provided by these caregivers has been steadily increasing with an estimated economic value of \$470 billion in 2013. Caregivers providing care for people with Alzheimer's disease or other dementias was \$217.7 billion in 2014.

Almost one-half, 48 percent, of caregivers provided care for 2 years or less. Fourteen percent provided care for 10 years or more.

Forty-five percent of caregivers provided care daily or care several times a week. On caregiving days, 37 percent of caregivers helped with household activities like cooking and cleaning. Personal care, shopping, transportation and helping with medical care were also common activities for caregivers.

Many caregivers work paid jobs along with their caregiving responsibilities. Fifteen percent of these caregivers work full time, and 19.2 percent work part time.

Nearly half of caregivers who provide many hours of help, 46 percent, report high stress. Emotional and financial strain were reported by 38 percent of caregivers.

Did you know?

Caregiving at a Glance

- 41.3 million men and women were caregivers in the U.S. during 2016
- 39 percent of caregivers cared for someone age 85 or older,
- 14 percent of caregivers provided care for someone age 65 to 69
- More than a million people in Arizona were 65 or older in 2016
- 56 percent of caregivers in the U.S. were women
- 24 percent of caregivers were 55 to 64 years of age
- 21 percent of caregivers were 45 to 54 years of age
- 19 percent of caregivers 65 or older were providing care to a spouse or partner
- 45 percent of caregivers provided care daily or care several times a week
- 46 percent of caregivers who provide many hours of care report high stress
- 48 percent of caregivers provided care for 2 years or less
- 14 percent of caregivers provided care for 10 years or more
- Fifteen percent of caregivers work full time
- 19.2 percent of caregivers work part time
- 38 percent of caregivers reported emotional and financial strain
- \$217.7 billion was the estimated economic value of unpaid caregiving for people with Alzheimer's disease or other dementias in 2014
- \$470 billion was the estimated economic value of unpaid caregiving in 2013

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New Study Identifies Challenges for Family Caregivers, Caregiving Solutions Needed

By National Alliance for Caregiving and AARP

The profile of the family caregiver in America is changing as the population ages, according to a new research study from the National Alliance for Caregiving and AARP. While the “typical” family caregiver is a 49-year-old woman who takes care of a relative, caregivers on the whole are becoming as diverse as the American population.

Caregiving in the U.S. 2015 provides surprising insight into today’s family caregivers. The typical higher-hour caregiver (who provides unpaid care for at least 21 hours a week) has been caregiving for an average of 5-1/2 years and expects to continue care for another 5 years. Nearly half of these higher-hour caregivers report high emotional stress (46 percent).

With an average household income of \$45,700, caregivers report not only emotional strain, but financial strain. Higher-hour caregivers report difficulty in finding affordable caregiving services, such as delivered meals, transportation, or in-home health services, in the community for them and their loved ones. Caregivers who live more than an hour away from their care recipient also report higher levels of financial strain (21 percent), perhaps because 4 out of 10 long-distance caregivers report the use of paid help (41 percent).

Also surprising are findings from subpopulations of caregivers. Today, nearly a quarter of America’s caregivers are millennials between the ages of 18 and 34 and are equally likely to be male or female. On the other end of the spectrum, caregivers ages 75 or older are typically the sole support for their loved one, providing care without paid help or help from relatives and friends. Men, a group often stereotyped as failing to take on caregiving responsibilities, currently represent 40 percent of family caregivers and provide an average of 23 hours a week supporting a loved one.

“We’re especially concerned that not enough is being done to support family caregivers in the public or private sector as they age,” explained Gail Gibson Hunt, president and CEO of the National Alliance for Caregiving. “There’s a double-edged sword when we fail to support caregivers, because we put both the caregiver and the care recipient at risk.”

Caregivers of a close relative—like a spouse or a parent—who are likely to provide care for 21 hours or more, indicate that being noted as a family caregiver in the medical records of the care recipient would be helpful in managing their caregiving responsibilities. Other desired supports include respite care, as well as access to resources and tools to assist the caregiver with managing stress and to enable the care recipient to live at home.

“As previous AARP research has shown, we’re facing a caregiving cliff,” said Dr. Susan Reinhard, senior vice president and director, AARP Public Policy Institute; and chief strategist, Center to Champion Nursing in America. “By mid-century, there will be only

three family caregivers available for each person requiring care. That means, to avoid putting them at higher risk as they age, we need to provide support for existing caregivers who are underserved by the current long-term services and support system.”

Caregiving in the U.S. 2015 is a joint report between the National Alliance for Caregiving and AARP. The report was made possible through generous sponsorship from AARP, the Archstone Foundation, Eli Lilly, Home Instead Senior Care, the MetLife Foundation, Pfizer, UnitedHealthcare, and the Family Support Research and Training Center in conjunction with the University of Illinois at Chicago.

Highlights of Today's Caregivers

- 82% care for one person who is likely either living with the caregiver or living within 20 minutes of the caregiver.
- 60% of caregivers are female. The typical caregiver is a 49-year-old female caring for a 69-year-old female relative, most likely her mother.
- 40% of caregivers are male.
- 34% of caregivers have a full-time job, while 25% work part time. Caregivers who work do so for 34.7 hours per week on average.
- Caregivers have been caring for 4 years on average, spending 24.4 hours per week helping with activities like bathing, dressing, housework, and managing finances.
- 32% provide at least 21 hours of care a week, on average providing 62.2 hours of care weekly.
- 38% of caregivers report high emotional stress from the demands of caregiving.

Get the Report

Visit <http://www.caregiving.org/caregiving2015/> or <http://www.aarp.org/caregivingintheus/> to download the report and related materials.

Methodology

The 2015 report is based on quantitative, online interviews conducted in 2014 of 1,248 family caregivers, ages 18 and older, for an individual of any age. Caregivers are defined as those who provide unpaid care to an adult or child. This included a random sample of 1,015 caregivers, with oversampling for African American/black, Hispanic/Latino, and Asian-American/Pacific Islander populations.

About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of 80-plus state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations.

About AARP

AARP is a nonprofit, nonpartisan organization, with a membership of nearly 38 million, that helps people turn their goals and dreams into real possibilities, strengthens communities, and fights for the issues that matter most to families, such as health care, employment and income security, retirement planning, affordable utilities, and protection from financial abuse. We advocate for individuals in the marketplace by selecting products and services of high quality and value to carry the AARP name as well as help our members obtain discounts on a wide range of products, travel, and services. A trusted source for lifestyle tips, news, and educational information, AARP produces AARP The Magazine, the world's largest-circulation magazine; AARP Bulletin; www.aarp.org; AARP TV & Radio; AARP Books; and AARP en Español, a Spanish-language website addressing the interests and needs of Hispanics. AARP does not endorse candidates for public office or make contributions to political campaigns or candidates. The AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older people in need with support from thousands of volunteers, donors, and sponsors. AARP has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands

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Caregiving 101: On Being a Caregiver

By Family Caregiver Alliance

Caregiving often creeps up on you. You start by dropping by your mom's house and doing her laundry, or taking your dad to a doctor's appointment. You find yourself doing the grocery shopping and refilling prescriptions. Gradually, you are doing more and more. At some point, you realize you have made a commitment to take care of someone else.

Sometimes, caregiving is triggered by a major health event, such as a stroke, heart attack, or accident. Maybe you suddenly realize that dad's memory lapses have become dangerous. Life as you know it stops, and all your energy goes to caring for your loved one. Caregiving has become your new career, and you adjust to a new normal.

The Caregiver Role

Caregivers can be spouses, partners, adult children, parents, other relatives (siblings, aunts, nieces/nephews, in-laws, grandchildren), friends, neighbors. Whatever your relationship with the person you're caring for, it's important that you add the title caregiver to the list of things you are. Without identifying yourself as a caregiver, you won't know to search for resources that can help you navigate this new role.

But caregivers play other roles as well. You may be employed full- or part-time. You may be raising children, or be a volunteer, a spouse, have other family commitments. Adding caregiving to that list can easily lead to frustration and exhaustion. You might need to navigate social service systems, call doctors while you're at work, advocate for the care receiver, and take care of their day-to-day needs, while you try to do all of those same things for yourself and your family.

You are rarely trained to do the broad range of tasks you are asked to do as a caregiver. As a result, you may end up, for example, with back strain because you haven't had the benefit of training from a physical therapist on how to correctly transfer someone from bed to chair, or wheelchair to car. Or you find yourself battling with your mother who has Alzheimer's because you have not learned the skills necessary to communicate with someone with a cognitive impairment.

Here are some of the common tasks caregivers do:

- Buy groceries, cook, clean house, do laundry, provide transportation
- Help the care receiver get dressed, take a shower, take medicine
- Transfer someone out of bed/chair, help with physical therapy, perform medical interventions— injections, feeding tubes, wound treatment, breathing treatments
- Arrange medical appointments, drive to the doctor, sit in during appointments, monitor medications
- Talk with doctors, nurses, care managers, and others to understand what needs to be done

- Spend time handling crises and arranging for assistance—especially for someone who cannot be left alone
- Handle finances and other legal matters
- Be a companion
- Be a (usually) unpaid aide, on call 24/7

What are all the things you do? Try making a list, both for your own clarification and for other family members who may not be aware of your efforts.

First Steps for New Caregivers

- It's easy to become overwhelmed as a new caregiver. Here are some steps that can help:
- Identify yourself as a caregiver
- Get a good diagnosis—from a specialist or geriatrician if necessary—of your loved one's health condition
- Learn what specific skills you might need to care for someone with this diagnosis (Caring for someone with Frontotemporal dementia, for example, is different from caring for someone with chronic heart disease)
- Talk about finances and healthcare wishes
- Complete legal paperwork, e.g., Powers of Attorney, Advance Directives
- Bring family and friends together to discuss care
- Keep them up to date on the current situation
- Identify resources, both personal and in the community
- Find support for yourself and your loved one
- Remember, you are not alone

Keys to Caring for Yourself

It's one thing to gear up for a short-term crisis. But it takes different skills to provide care over a longer period of time. You'll be more successful if you learn to take care of yourself, starting immediately. Some things to remember:

- You cannot be perfect
- You have a right to all of your emotions
- Depression is the most common emotion of long-term caregivers
- Set realistic expectations—for yourself and your loved one
- Learn about the disease and what you can expect
- Learn the skills you need to care for the care receiver and which ones you are or are not able to perform
- Learn to say “no” to things you cannot do
- Learn to accept help from others
- Build resilience
- Identify your button-pushers/stressors

- Identify your coping skills
- Remember the big three for successful coping:
 - **Eat right**—good nutrition as opposed to stress-snacking. Limit alcohol and other drugs
 - **Exercise**—it may be hard to find time but it's the best cure for depression and increases your endorphins (“good” coping hormones)
 - **Sleep**—7-8 hours is hard to get, but essential. Admit when you are experiencing burnout and get help

Most importantly, remember that taking care of yourself is as important as taking care of someone else.

The ‘IRS of Caregiving’: Information, Respite, and Support

INFORMATION

The first stages of caregiving are the most challenging. This is when you are least informed about what's needed and expected, and when you feel the most insecure and uncertain.

- In addition to information about the disease/disability your loved one is dealing with, you need to understand his or her medications and medical interventions. What knowledge/skills will you need to be able to care for him or her? Where can you get trained to do the tasks required? How can you learn to successfully:
 - Feed, bathe, groom, or dress someone?
 - Handle toileting or deal with incontinence?
 - Handle a complicated medication schedule?
 - Transfer someone or help them walk?
- How does this disease progress and how will that effect the care receiver's ability to take care of him or herself?
- What are the care needs now and what are they likely to be in the future?
- What are the physical limitations that the care receiver has now or will have?
- What are the cognitive changes you can expect?
 - Are there predictable behavioral changes that go along with them?
 - How do I handle these changes?
 - If you are caring for someone with dementia, for instance, you need to learn the strategies for communication that will make you more successful and increase cooperation.
- What is the financial situation?
 - How much money is available to help with care?
 - Who can access it (is there a Financial Power of Attorney in place)?
 - Are there debts or other constraints on using the money?

- What legal matters should you know about?
 - Is there a Will? A Trust?
 - Has the Medical Power of Attorney been completed (also called Living Will)?
 - Do you have a Release of Information signed and filed with the care receiver's doctor(s)?

You might not be aware of community caregiving resources, but they are there to help you. You can find help in most communities for transportation, home delivered meals, day care programs, home repairs, and more. To learn about them, contact your local Area Agency on Aging (AAA) and find out what's available locally—not only for your loved one, but also for yourself. (In many communities, AAAs can be reached by dialing 211). There may be benefits that you haven't thought about—ask about Title IIIIE funding, part of the Older Americans Act specifically for caregivers. There may be Veterans benefits. Other benefits can be found at Eldercare Locator, or FCA's Family Care Navigator.

SUPPORT

You can't do it alone! And, like respite, getting support for your caregiving situation will help you take better care of yourself. The longer you are a caregiver, the more isolated you can become. How many times can you say, "I can't get together with you" before people stop calling? But this lack of social interaction will lead to poorer health for you. One reason caregivers don't get the help they need is that taking care of yourself feels like just "one more thing you have to do."

But we all need someone to talk to. Special caregiver support groups in your community or online can help to reduce the feeling that you're all alone and help you learn coping skills from others who are in similar situations. Adding stress to an already difficult situation, caregiving can also create family discord, particularly if you feel you're not getting the help and support you need from members of your own family. Resentment can build on all sides. If you are dealing with family conflict, it might help to have a meeting.

Asking for Help

Most of us find it hard to ask for help. About 50% of caregivers get no outside help at all. When someone asks if there's anything they can do to help, most of us usually say, "Oh no, that's OK, we're doing fine." When you're a caregiver, it can be even harder. Whom can you call and what can you ask them to do? Learning to accept help early in your transition to being a caregiver will make it easier down the road.

Little things on a regular basis can mean a lot. Maybe someone would bring an occasional meal or dessert. Having someone help with household chores can be an opportunity to socialize as well as get things done. Maybe someone can just come and sit with your loved one so you can run to the grocery store. Make a list of things that you need help with. Post it on the refrigerator. If someone asks to help, show them the list and let them pick something they'd like to do. That way they're more likely to enjoy the task. If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal prep instead of a ride to an appointment.

Taking Care of YOU

Caregiving has many challenges and also many rewards. But you need to honor your own needs as well as commit to caring for someone else. That's the only way you will be able to sustain your patience and your caring and be successful over time. There are many things to learn and most caregivers are just "making it up" as they go along.

Getting information and training will help you feel confident about the many tasks you perform. Information is available online, at disease-specific websites, at Family Caregiver Alliance, through your medical providers, Area Agencies on Aging, some employee assistance programs, support groups, senior centers, and your community. Start with saying "I am a caregiver and I need help."

For more information, call Family Caregiver Alliance at (800) 445-8106 or visit www.caregiver.org.

*Source: Family Caregiver Alliance, *On Being a Caregiver*, www.caregiver.org. This fact sheet was prepared by Donna Schempp, LCSW, and reviewed by Family Caregiver Alliance.*

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Caregiver Self-Assessment Questionnaire

How are you?

American Medical Association

Physicians dedicated to the health of America

Distributed by:



Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

1. Had trouble keeping my mind on what I was doing Yes No
2. Felt that I couldn't leave my relative alone Yes No
3. Had difficulty making decisions Yes No
4. Felt completely overwhelmed Yes No
5. Felt useful and needed Yes No
6. Felt lonely Yes No
7. Been upset that my relative has changed so much from his/her former self Yes No
8. Felt a loss of privacy and/or personal time Yes No
9. Been edgy or irritable Yes No
10. Had sleep disturbed because of caring for my relative Yes No
11. Had a crying spell(s) Yes No
12. Felt strained between work and family responsibilities Yes No
13. Had back pain Yes No
14. Felt ill (*headaches, stomach problems or common cold*) Yes No

15. Been satisfied with the support my family has given me Yes No

16. Found my relative's living situation to be inconvenient or a barrier to care Yes No

17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____

18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____

Comments:

(Please feel free to comment or provide feedback)

For additional tools for caregiving or aging, visit www.CaregiversLibrary.org

Self-evaluation:

To Determine the Score:

1. Reverse score questions 5 and 15. (For example, a "No" response should be counted as "Yes" and a "Yes" response should be counted as "No")
2. Total the number of "yes" responses.

To Interpret the Score:

Chances are that you are experiencing a high degree of distress:

- If you answered “Yes” to either or both Questions 4 and 11; or
- If your total “Yes” score = 10 or more; or
- If your score on Question 17 is 6 or higher; or
- If your score on Question 18 is 6 or higher.

Next steps:

- Consider seeing a doctor for a check-up for yourself.
- Consider having some relief from caregiving. (Discuss with the doctor or a social worker the resources available in your community.)
- Consider joining a support group

Valuable Resources for Caregivers:

Eldercare Locator:
*(a national directory of
community services)*
1-800- 677-1116
[www.aoa.gov/elderpage/
locator.html](http://www.aoa.gov/elderpage/locator.html)

Family Caregiver Alliance
1-415- 434-3388
www.caregiver.org

Medicaid Hotline
Baltimore, MD
1-800-638-6833

National Alliance for
Caregiving
1-301-718-8444
www.caregiving.org

National Family
Caregivers Association
1-800 896-3650
www.nfcacares.org

National Information
Center for Children and
Youth with Disabilities
1-800-695-0285
www.nichcy.org

Local Resources and Contacts:



For additional tools for caregiving or aging, visit www.CaregiversLibrary.org

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For additional resources, please visit www.CaregiversLibrary.org

Emotional Side of Caregiving

By Family Caregiver Alliance

Whether you become a caregiver gradually or all of sudden due to a crisis, or whether you are a caregiver willingly or by default, many emotions surface when you take on the job of caregiving. Some of these feelings happen right away and some don't surface until you have been caregiving for awhile. Whatever your situation, it is important to remember that you, too, are important. All of your emotions, good and bad, about caregiving are not only allowed, but valid and important.

Many feelings come up when you are caring for someone day in and day out. Many caregivers set out saying, "This won't happen to me. I love my mother, father, husband, wife, sister, brother, friend, etc." But after awhile, the "negative" emotions that we tend to want to bury or pretend we aren't feeling come up. Caregivers are often reluctant to express these negative feelings for fear they will be judged by others (or judge themselves) or don't want to burden others with their problems.

If you don't deal with ALL of your emotions, they can be like a two-year-old who wants your attention: they will keep tugging at you until you stop and acknowledge them. Not paying attention to your feelings can lead to poor sleep, illness, trouble coping, stress eating, substance abuse, etc. When you admit to your feelings, you can then find productive ways to express them and deal with them, so that you and the care receiver can cope better in the future.

This fact sheet will identify some of the common, often hard to admit, feelings that caregivers experience. Once identified, suggestions for how you might better cope with these feelings are offered.

If only we were perfect we would not feel...

Ambivalence

This is the feeling of both wanting to be doing what you are doing and the feeling of not wanting to be doing it. On bad days, one often has the feeling of wishing you didn't have to be there, that this ordeal will be over soon. On good days, caring for someone can be a gift to both you and the care receiver.

Coping: Allow yourself to feel both sets of feelings. Everyone has these feelings sometimes. Neither the bad feelings nor the good ones will last forever.

Anger

How often have you "lost it" while providing care? Or felt like you were on your last nerve? Anger and frustration are a normal part of being around someone who needs help on an ongoing basis and who might not be accepting of help. Caring for someone with dementia, in particular, can be even harder, as the care receiver can be irrational and combative. It's not always possible to be in perfect control of your emotions. Anger "just comes out" sometimes.

Coping: Forgive yourself. Find constructive ways to express yourself, learn to walk away and give yourself a “time out.” Identify supportive people you can talk to who will listen as you vent about the things that happened that day.

Anxiety

Feeling like things are out of control and not knowing how to bring them back into control often produces feelings of anxiousness. Anxiety can emerge as a short fuse, the impulse to run away, not sleeping, heart palpitations, or the urge to cry.

Coping: Pay attention to your anxiety—it is our body’s early warning system that something isn’t right. When you feel anxious: Stop. Breathe. Keep breathing. Pray. Meditate. Make some tea. Anything that will give you a break from what is happening in the moment.

Boredom

It is easy to become bored when you are stuck at home taking care of someone else and not doing things that fulfill your own wants and needs. And by the end of the day, you are often too tired to pursue something of interest to you.

Coping: Respite can help. Getting a break from caregiving and having some time for yourself will not only increase your patience and resilience but will give you a chance to do something that is meaningful to you, whether it is socializing, going for a walk, or reading a good book.

Crankiness, Irritability

When tired and stressed, it is harder to stay in control of the things we say and feel. Feelings can go up and down very rapidly. We can lash out at the littlest thing because we have no reserve.

Coping: If you find yourself feeling cranky and irritable, you probably need a break. You also may need to get some rest, as we are in less control when tired. Often we will turn to alcohol or our favorite junk food to reward ourselves when feeling this way. It’s more beneficial to keep a journal or talk with a friend or professional to let off steam.

Depression/Sadness

As a caregiver, you are at risk for depression. Sometimes this is feeling hopeless or helpless, the inability to sleep, or trouble getting up and facing the day. And sometimes it makes you want to cry.

Coping: Depression is treatable and should be taken seriously. Professional help is available. Talk to your physician if you think you might be depressed, join a caregiver support group, find a counselor who understands caregiving, and ask for help from friends and family. Exercise. Moving your body is a proven way to relieve some of the symptoms of depression.

Disgust

Having to help toilet someone can be too intimate an experience for many caregivers. If the care receiver is incontinent of stool as well as urine, then changing an adult diaper can be nauseating and repulsive. Having to clean the private body parts of someone, like a parent, can be unnerving and uncomfortable. Watching someone eat sloppily or not care for personal appearance, or having to clean up vomit can also cause feelings of disgust.

Coping: The hardest thing about accepting our revulsion to these things is that the care receiver is not in control of these behaviors. But sometimes we think they are doing it on purpose just to get to us. Or we feel guilty because we think we should be accepting but we are not. Finding ways to minimize your need to do personal care tasks including incontinence care is vital to weathering your caregiver journey, which could stretch on for years. Hire an attendant to do routine care or have someone from the family do these things who might cope better. Also, learn tricks to make tasks easier (e.g. during meal times consider, using a spoon that is designed to be spill resistant.)

An occupational therapist can help you find this tool and other tools to make meal time easier and more enjoyable for both of you. It's important to know that when it comes to incontinence, you are not alone. Incontinence is one of the main reasons given for placing someone in a facility. There are resources to aid you in dealing with bathroom problems, such as a webinar entitled *Moving Beyond the Leakages: Practical Strategies to Manage Incontinence*, and a segment from our Caregiver College Video Series on our Video Channel. (Both of these resources are in the Caregiver Education section on our website.)

Embarrassment

Does your care receiver make impolite comments when you are out in public? Does he or she need to use the restroom right away and make a scene as you try to find one? Does he or she refuse to bathe and now have body odor? It is easy for us to feel responsible for the behavior of someone else and feel like it is our fault when these things happen.

Coping: Some people create cards (similar to business cards) which read, "My loved one has dementia and can no longer control their behavior" that they hand out to those around them when they are having trouble, especially in restaurants. Some people just stop leaving the house because this is such a difficult problem to manage, it's easier to stay home. Others have friends, family members, or an attendant accompany them when they go out to offer assistance, when needed.

Fear

What if something happens? Will I be able to cope? Will I feel guilty? Am I responsible for things that go wrong? Caregivers take on a huge amount of responsibility, not only for the day to day care of the care receiver, but also for all the other things that "might" happen while being a caregiver. Scaring ourselves about the "what ifs" can be paralyzing and keep us from enjoying the "what is."

Coping: It is important to have contingency plans. So, it might make sense to have a back up caregiver in mind in case something should happen to you, or to think about how you would handle predictable medical emergencies based on what disabilities your care

receiver has. When you get scared, it is often helpful to talk to someone who knows your situation and can give you perspective and calm your fears.

Frustration

Frustration is part of many other feelings, such as ambivalence, anger, and impatience. Sometimes, as a caregiver, you feel that you can't do anything right or that things just don't go as planned no matter what you do or how hard you try. And if you are tired, you are more likely to get frustrated. Frustration may lead to stress eating, substance abuse, and a higher likelihood of losing your temper.

Coping: Acknowledge how frustrating caregiving can be. Join a support group to learn the tricks other caregivers have learned to make coping easier. Get breaks from caregiving so you have time for YOU and a chance to refresh your energy. Exercise. Sleep.

Grief

Watching the care receiver decline, not being able to do things that used to be easy and natural is sad. We also grieve for the care receiver, the person who used to be and our relationship with that person. We often need to grieve the loss we are experiencing on a daily basis or it will come out as something else.

Coping: Sometimes creating a ritual can be helpful. One caregiver would write on a piece of paper the things her husband could no longer do, then go to the ocean and throw the pieces in the water as a way of letting go. We tend to want to avoid the sadness that comes with grief, but allowing ourselves to feel (it) promotes healing.

Guilt

Guilt is the feeling we have when we do something wrong. Guilt in caring for care receivers comes in many forms. There is guilt over not having done enough to have prevented them from getting sick in the first place. There is guilt over feeling like you want this to end. Or guilt over having been impatient with your care receiver too much. There is guilt over not loving or even liking the care receiver at times. There is guilt over not doing enough for the care receiver or not doing a good enough job as a caregiver. And if the care receiver falls or something else happens, there is guilt about it being your fault that it happened. And sometimes caregivers feel guilty about thinking of their own needs and see themselves as selfish, especially if they should do something like go to a movie or out to lunch with a friend.

Coping: You need permission to forgive yourself. You can't be perfect 24/7. It's impossible to be in perfect control of how you feel at all times. We all carry around a lot of "shoulds," such as "No one will do as good of a job as I do, so I have to be here all the time." Or "If I leave and something happens, I will never forgive myself." Consider changing guilt into regret, "I'm in a difficult situation and I have to make difficult decisions sometimes." "I regret that I am human and get impatient sometimes." "I am doing the best I can even though things go wrong from time to time and I regret that I am not perfect."

Impatience

How difficult is it to get your care receiver up in the morning? How about up, dressed, given breakfast and to their doctor's appointment all before 10 a.m.? And you have other things to accomplish that day. All this and the care receiver is acting unhelpful and moving slowly. Perhaps the care receiver refuses to use his walker even though he has fallen many times and the doctor and physical therapist have emphasized he always needs to use it. It is understandable that you would get impatient at times.

Coping: Forgive yourself. When tired, frustrated, and trying to keep things under control, it's natural to want to speed up and have compliance from the care receiver to keep them safe and healthy. So, first, slow down. Leave a lot of time to accomplish tasks. Leave a LOT of time. Control the environment as much as you can, but know you can't always prevent your father from taking off without his walker. Create a list of the things you are in control of and are not. Understand what you can and cannot control.

Jealousy

Do you sometimes feel jealous of your friends who are able to go out and do things that you can no longer do, because of your caregiving responsibilities? Are you jealous of your siblings who are not doing their share to help? Do you feel jealous of a friend whose parent died quickly and easily while you take care of a parent who has had dementia for many years? Are we jealous of someone who got a big inheritance since we are struggling to pay bills and to be a good caregiver? We often don't admit to this feeling, because we have always been told not to be jealous. But that doesn't mean that we don't, in fact, feel jealous from time to time, of those who have it easier or better than us.

Coping: It's okay to admit to being jealous. Because things are not fair, we often have flashes of resentment and envy at other people's good fortune compared to our own. Jealousy is a problem when we wallow in it and prevent ourselves from enjoying the things we DO have. Focus on what you do have, whatever that may be, and find a place in your heart for gratitude.

Lack of Appreciation

Most of us do not want to be dependent on someone else. Learning to accept help is hard. So, the care receiver is often pushing away our attempts to be helpful and caring. If someone has dementia, this problem is often much worse. And we get our feelings hurt because the care receiver does not thank us or even see how much we are giving up in order to care for them.

Coping: Sometimes we have to give ourselves our own pat on the back. Writing in a journal about the things you do each day might help you to appreciate how much you give and how much you do. Having a support group or a group of friends/family to cheer you on is important, and both comforting and necessary to remain resilient through your caregiving journey.

Loneliness

The longer you are a caregiver, the more isolated you become. With no one to talk to day in and day out except the care receiver, it is easy to lose a sense of yourself. Friends stop calling since we are no longer available and we hesitate to call them because we know “they don’t want to hear about it any more” or “I have nothing to talk about because my life is all about caregiving.”

Coping: Find ways to get out of the house and involved in something other than caregiving. Learn about resources from your local Area Agency on Aging about respite programs or day care programs that will allow you to get a much-needed and well-deserved break. No one can do this job alone. Look at your wider circle of support—faith community, neighbors, friends, distant relatives, etc. to see where you might get some nurturing for you.

Loss

Caregivers experience many losses, some of which have already been mentioned: loss of control, loss of independence, loss of income, loss of your best friend, loss of the future, loss of a sense of yourself. Loss leads to grief and depression.

Coping: Identifying your losses can help you to cope with them. For each of us, the losses will be different. When you know what you are feeling, you will be able to look at the loss and think about what might work for you to help you deal with it.

Resentment

When put in a situation not of our choosing, it's not uncommon to feel negative and resentful. Perhaps you have siblings who are not helping provide care or maybe you are an only child, became the caregiver by default, and feel you have very little desire or support to offer care. Little things easily become big things when we feel unappreciated and unacknowledged. And feeling like you have to do it all, and do it all by yourself, is a guaranteed way to feel resentful.

Coping: Family situations and dynamics can be a real challenge. Having help from family may make your situation easier, but sometimes family tensions make it even harder to get help. The more help and support you accept, the easier it will be to let go of feeling burdened and resentful of those who are not doing their share. If you can't get help from the people you think should be offering it, then you need to broaden your circle of people to include those who can and will help. It is easy to forget about the good things that have happened or are happening when we only focus on the negative.

Tiredness

As a caregiver, how often do you get the full eight hours of sleep they always say you need? Sleep is often postponed while you grab a few minutes of alone time after the care receiver goes to bed. Sleep is often disturbed because the care receiver gets up at night and needs help going to the bathroom or being re-directed back to bed. Sleep is often disturbed because you can't fall asleep or stay asleep because you are worrying about all the stressors that come with being a caregiver.

Coping: Sleep has to be put on the priority list. Lack of sleep leads to obesity, illness, crankiness, impatience, inefficiency in accomplishing tasks, and a state of mental fogginess among other issues. If you are having trouble falling asleep or staying asleep not related to direct caregiving, talk to your physician. If you are having trouble sleeping due to caregiving problems, talk to the care receiver's physician. There are ways to help both of you to get the rest you need.

As a caregiver, you do amazing work caring for others in need. But as a caregiver, you also need to think about yourself. Just pushing through each day will eventually wear you out and cause you to burn out. Emotional issues can weigh you down and impact not only your ability to cope and provide care, but they can also harm your health and well-being. It is important to learn to ask for help and prioritize getting breaks from caregiving, so that you can be the caregiver you want to be.

Source: Family Caregiver Alliance, Emotional Side of Caregiving, www.caregiver.org.

Grief and Loss Introduction

By the Family Caregiver Alliance

We generally think of grief as a reaction to a death. But there is another grief that comes from loss while someone is still living. This grief is often experienced when caring for someone with a chronic illness. Chronic illness, and particularly any illness that impairs a person's cognitive ability, causes caregivers and loved ones to experience grief and loss right now. In this fact sheet, we will discuss the grief related to death and dying, and grief associated with chronic illness. It is natural to grieve the death of a loved one before, during, and after the actual time of their passing. The process of accepting the unacceptable is what grieving is all about.

Chronic Illness and Loss

Over time, with most chronic illnesses, there are changes in a person's abilities. Whether it is someone living with Parkinson's disease who can no longer button a shirt, or someone coping with diabetes who has to follow a special diet, or someone with Alzheimer's disease who can't remember who you are, caregivers have to adjust to the needs of the care receiver. Caregivers may experience many kinds of losses: loss of independence; loss of control; loss of the future as it had been imagined; loss of financial security; loss of the relationship as it once was; loss of freedom, sleep, and family harmony; loss of someone to share chores and other tasks with; or simply the loss of someone to talk things over with. Persons with chronic illnesses also have to adjust to many of the same losses, but also—loss of dignity, mobility, a carefully planned future or retirement, a loss of roles that were played, or the loss of a sense of worth (all depending on what disability is associated with the illness).

It is easy to ignore these losses and just keep doing the things that need to be done. However, these losses lead to grief, and grief can lead to sadness, depression, anger, guilt, sleeplessness, and other physical and emotional problems. It is important to identify our losses, identify our feelings, and let ourselves grieve the changes that have happened in our lives. When we can do this, our feelings will less often erupt as angry outbursts weighed down by guilt, or creep over us as depression and hopelessness; they instead can more easily be expressed as a shared loss of something treasured—which family and friends close to the situation can likely empathize with, leading to deeper communication and stronger relationships with those going through the loss with you.

Writing in a journal can help you to name and express your feelings about these losses. You can combine it with a gratitude journal—things that you are thankful for. Prayer, meditation, relaxation exercises, attending a support group (or simply talking with a friend or counselor), or creating a ritual can help you to let go of the intensity of the feelings so that you can grieve but also heal.

Ambiguous Loss

Ambiguous loss is what we experience when someone is still “there” but also not “there.” This is mainly experienced when someone has a cognitive impairment from dementia, a traumatic brain injury, or a stroke. We also experience ambiguous loss when someone with dementia has “moments of lucidity,” when he/she is clear and makes sense for a short period of time. It is hard not to think that if they can do this every once in a while, they ought to be able to do it all of the time. When they return to their confused state, we often experience anger, frustration, and disappointment—renewed grief.

Anticipatory Grief

When caring for someone over time, we may start to grieve that person long before they die, we grieve the loss of the person’s “former self.” Experiencing loss on a daily basis, as well as anticipating the loss at the end of life, knowing what is coming, can be just as painful as the loss associated with a death. Caregivers may experience guilt or shame for “wishing it were over” or thinking of their loved one as already “gone” (particularly when someone has a cognitive impairment). It is important to recognize these feelings as normal. Ultimately, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. Preparing for the death of a loved one can allow family members to contemplate and clear unresolved issues, make end of life plans for funeral and burial, and experience their pain in stages. Sometimes, when someone has grieved a death over a long period, there is less grief when the person dies; sometimes there is more pain when a person dies.

Grief at Death

Grief is a natural emotion, a universal experience that makes us human. Because it is intense and uncomfortable to feel, we often try to find ways to avoid experiencing the immensity of the emotion—through distraction and busyness. We grieve because we are deprived of a loved one; the sense of loss is profound, the change in roles is confounding, and we may become uncertain of our identity. Often caregivers are in the situation of having to make changes in their circumstances—where to live, financial concerns, relationships—along with fear of not knowing what lies ahead.

Grief lasts a long time. Recent research has shown that intense grieving lasts from three months to a year and many people continue experiencing profound grief for two years or more. Our society expects us to be “doing fine” in about two weeks. It is common to think there is something wrong with us if our grief “lasts too long.” The grieving process depends on our belief system, religion, life experiences, and the type of loss suffered. Many faiths and cultures have rituals for recognizing grief and loss during at least the first year after a death. We also expect other family members to show their grief in the same way we do, even when we can say that everyone grieves differently. There is no right or wrong way to grieve; grief is an individual process. Many people find solace in sharing their grief with family and friends; others find solace by attending grief support groups offered in every community through their local hospice (even if you did not have hospice services). If you are feeling overwhelmed and concerned about your own grief process over time, seek professional help.

When someone dies suddenly, our first response is often denial, then shock, confusion, and pain. Fatal heart attacks and strokes, car accidents, and suicide can leave family members troubled and searching for answers. In these cases, family members may be left with unresolved issues, such as guilt, anger, anxiety, despair, and feelings of emptiness.

Sometimes we have to learn to forgive ourselves and our loved one who died. It can take longer to heal from this loss and it is important to give yourself time to grieve before pushing yourself to “move on.” Getting support from family, clergy, friends, and grief groups can help.

Symptoms of Grief

Grief affects our whole being—physically, socially, emotionally, and spiritually. Each of us will have different symptoms. If you have had a previous loss, you may experience grief this time in a similar or different way, depending on the situation, your relationship with the deceased, and other significant emotional factors in your life at the time. Culture, religion, and social norms influence what we are comfortable showing to others and even what we are comfortable admitting to ourselves.

- **Physical**

- Crying
- Sighing
- Low energy/exhaustion/weakness/fatigue
- Headaches
- Stomach aches, loss of appetite
- Eating too much, particularly comfort foods
- Sleep disturbance—too much or too little, disturbed dreams
- Feelings of heaviness, aches, pains
- Being super busy, pushing yourself to do too much
- Reckless, self-destructive activities such as drinking too much

- **Social**

- Feeling alone
- Wanting to isolate yourself from socializing, finding it hard to pretend to feel OK, being pushed to be social by others
- Feeling detached from others
- Angry that others' lives are going on as usual and yours isn't
- Not wanting to be alone, feeling needy and clingy

- **Emotional**

- Sadness, crying spells
- Anger/frustration/rage
- Confusion/overwhelmed
- Guilt

- Worry/anxiety/panic
- Yearning
- Edginess/irritability
- Memory problems, feeling distracted, preoccupied
- Depression
- Euphoria
- Passive resignation
- Fluctuating emotions
- Sense of lack of control
- Others might see you as “unreasonable” or “overreacting”
- **Spiritual**
 - Questioning your faith/meaning of life/suffering
 - Questioning reason for the death/disease
 - Anger at God
 - Coming closer to faith/God for solace

Stages of Grief

There is no road map for dealing with grief. There are stages that most people go through, but they are not a linear progression from stage 1 to stage 2, etc. We “visit” these stages at different times during the grieving process, depending on what is happening in our lives, for instance, special occasions, like anniversaries and birthdays. And we might go back to a stage years later, such as loneliness and isolation or depression. Although Elizabeth Kübler-Ross defined the five stages below, many clinicians think there are more or different stages.

- **Shock/denial**
 - Trouble accepting the fact of death, diagnosis or new reality, numbness
 - Inability to do usual activities
- **Anger**
 - Anger at yourself, others, professionals (particularly doctors), God, life
 - Feeling helpless and powerless, abandoned
- **Bargaining**
 - Making “deals” with God or friends hoping to change the situation
 - Thinking about “what could have been” or “should have done differently”
- **Depression**
 - Feeling overwhelmed with loss and change, sadness, regret, fear, anxiety
 - Lonely, isolated, self-pity, empty, lost

- **Acceptance**
 - Adjusting to the new reality, starting to move on
 - Sense of hope, healing, and integration

Helping Those Who Are Grieving

We often feel uncomfortable when approaching someone we know who is grieving. It is hard to know what to say or do. Here are some tips:

- Be available. Offer support in an unobtrusive but persistent manner.
- Listen without giving advice.
- Do not offer stories of your own experiences with grief. This can have the effect of dismissing the grieving person's pain.
- Allow the grieving person to use expressions of anger or bitterness, including such expressions against God. This may be normal behavior in an attempt to find meaning in what has happened.
- Realize that no one can replace or undo the loss. To heal, the individual must endure the grief process. Allow him/her to feel the pain.
- Be patient, kind, and understanding without being patronizing. Don't claim to "know" what the other person is feeling.
- Don't force the individual to share feelings if he/she doesn't want to.
- Physical and emotional touch can bring great comfort to the bereaved. Don't hesitate to share a hug or handclasp when appropriate.
- Be there later, when friends and family have all gone back to their routines.
- Remember holidays, birthdays, and anniversaries that have important meaning for the bereaved. Offer support during this time.
- Don't be afraid of reminding the person of the loss; he/she is already thinking about it. Share stories and memories of the deceased.
- Send cards, flowers, deliver a meal, offer to do chores, donate to a cause that is important to the person who died or who is grieving.

Taking Care of YOU

Taking care of yourself in difficult times is hard. Trusting your own process will help you to do what you need to do in order to best take care of yourself. Acknowledging your feelings—good and bad—will help you to cope better with whatever is happening. Read, journal, get support, cocoon, or do whatever is nurturing for you.

Resources

Family Caregiver Alliance National Center on Caregiving (415) 434-3388 | (800) 445-8106
Website: www.caregiver.org Email: info@caregiver.org
FCA CareJourney: www.caregiver.org/carejourney
Family Care Navigator: www.caregiver.org/family-care-navigator

Other Organizations and Links

Center for Loss and Life Transition
www.centerforloss.com

National Hospice and Palliative Care Organization
www.nhpco.org

Hospice Foundation of America
www.hospicefoundation.org

The Fisher Center for Alzheimer's Research Foundation
www.alzinfo.org

Recommended Readings

Beyond Sympathy, What to Say and Do for Someone Suffering an Injury, Illness or Loss, Janice Harris Lord, Pathfinder Publishing, 1992.

Don't Take My Grief Away, Doug Manning, BookBaby, 2013.

A Journey Through Grief: Gentle, Specific Help to Get You Through the Most Difficult Stages of Grieving, Alla Renee Bozarth, Hazeldon Publishing, 2010.

This fact sheet was prepared by Family Caregiver Alliance, revised and updated in 2013, and reviewed by Rabbi Jon Sommer, Professional Grief Caregivers' Network, October 2013. Copyright © 1996, 2013 Family Caregiver Alliance. All rights reserved.

Source: Family Caregiver Alliance, Grief and Loss, www.caregiver.org

Caregiver Depression

By Mayo Clinic Staff

Caregiving can be physically and emotionally stressful. To provide the best care possible, you might put your loved one's needs before your own. In turn, you could develop feelings of sadness, anger and loneliness, as well as guilt. Sometimes, these emotions trigger caregiver depression.

Everyone has a bad day sometimes. However, depression is more than just a bout of the blues. It is a mood disorder that causes a persistent feeling of sadness and loss of interest. During an episode of depression, symptoms occur most of the day, nearly every day and might include:

- Feelings of sadness, tearfulness, emptiness or hopelessness
- Angry outbursts, irritability or frustration, even over small matters
- Loss of interest or pleasure in most or all normal activities, such as sex, hobbies or sports
- Sleep disturbances, including insomnia or sleeping too much
- Tiredness and a lack of energy, so even small tasks take extra effort
- Changes in appetite — often reduced appetite and weight loss, but increased cravings for food and weight gain in some people
- Anxiety, agitation or restlessness
- Slowed thinking, speaking or body movements
- Feelings of worthlessness or guilt, fixating on past failures or blaming yourself for things that aren't your responsibility
- Trouble thinking, concentrating, making decisions and remembering things
- Frequent or recurrent thoughts of death, suicidal thoughts, suicide attempts or suicide
- Unexplained physical problems, such as back pain or headaches

If you're experiencing signs or symptoms of caregiver depression, consult your doctor or a mental health provider. Depression isn't a weakness and you can't simply "snap out" of it. It can also affect the quality of care you're able to provide for your loved one. However, most people who have depression feel better with the help of medication, psychological counseling or other treatment.

You can take steps to prevent caregiver depression. For example:

- Reach out for help. Don't wait until you feel overwhelmed to ask for help caring for a loved one. If possible, get your whole family and close friends involved in planning and providing care. Seek out respite services and a caregiver support group. A support network can keep you from feeling isolated, depleted and depressed.

- Keep up other relationships. Caregiving can take time away from replenishing personal relationships — but showing loved ones and friends you care about them can give you strength and hope.
- Start a journal. Journaling can improve your mood by allowing you to express pain, anger, fear or other emotions.
- Take time for yourself. Participate in activities that allow you to relax and have fun. Go to a movie, watch a ballgame, or attend a birthday party or religious gathering. Regular physical activity and meditation also can help reduce stress. Aim to get plenty of sleep and eat a healthy diet.
- Stay positive. Caregiving allows you to give something back and make a difference in your loved one's life. Caregiving might also have spiritual meaning for you. Focus on these positive aspects of caregiving to help prevent depression.

Remember, if you think you're depressed, seek help. Proper treatment can help you feel your best.

References

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Taking Care of YOU: Self-Care for the Family Caregiver

By Family Caregiver Alliance

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 non-caregivers 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 for themselves

Family caregivers are also at increased risk for depression and excessive use of alcohol, tobacco, and other drugs. 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. Caregivers are more likely to have a chronic illness than are non-caregivers, namely high cholesterol, high

blood pressure, and a tendency to be overweight. 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 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?
- Do you feel you have to prove that you are worthy of the care recipient's affection? Do you do too much as a result?

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.
- Our family always takes care of their own.
- I promised my father I would always take care of my mother.

"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 tends to believe 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 or not 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 that you have too much to do, family disagreements, feelings of inadequacy, or the 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 the following words modified from the original Serenity Prayer (attributed to American theologian Reinhold Niebuhr):

*God 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, or 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.
- Engage in activities that will make you 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 checkup.
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 1 to Step 7 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, or a visit with your loved one. Let the "helper" choose what she would like to do.
- Be prepared for hesitation 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. The physician only sees a moment in time with the patient. Make sure you let him/her know what your concerns are in terms of daily care/health.

- 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 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 rundown. I'd like to make an appointment for myself and my husband next week.” Or “I need a way for my mother to sleep at night as I am now exhausted being up every two hours at night with her.”

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 to which we need to listen. 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.

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, e.g. meditation, prayer, yoga, Tai Chi.
- Attend to your own healthcare needs.
- Get proper rest and nutrition.
- Exercise regularly, even if only for 10 minutes at a time.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities, such as reading a good book, taking a warm bath.
- Seek and accept the support of others.
- Seek supportive counseling when you need it, or talk to a trusted counselor, friend, or pastor.
- Identify and acknowledge your feelings, you have a right to ALL of them.
- Change the negative ways you view situations.
- Set goals.

It's up to you!

Source: Family Caregiver Alliance, Taking Care of YOU--Self-Care for Family Caregivers, www.caregiver.org.

The Resilient Caregiver – Challenges and Opportunities

By: Jan E. Sturges, M.Ed., LPC
Caregiver Consortium



In these historic times of social and economic unrest, most of us do our best to believe that, at the end of the day, our glass will remain half-full and not half-empty. Although we may become discouraged by the stressors of daily life, these challenges make us stronger when we take the opportunity to savor special moments with people who are important to us. We are practicing serendipity – the act of transforming adversity into inspiration.

Caregivers - individuals who have responsibility for the safety and well-being of a dependent person - understand what it's like to live with uncertainty, and be persistent in the face of exhaustion and worry. They become attuned to the power of compassion that emanates from attending to the physical, emotional and spiritual needs of the person in their care. This is serendipity in action - the ability to "get up and dust yourself off" after the daily pitfalls of caregiving gives individuals the strength to move beyond surviving to thriving – for a few minutes, a few days, a few years.

Serendipity is also characteristic of resiliency - the "bounce back-ability" to achieve your personal best *as a result of* difficult times - and the wisdom to respond (not react) to changing circumstances. Resilient people are flexible and creative – they *flow with* change instead of resisting it, and focus on the value of *being* instead of *doing*.

In *Ageless Body, Timeless Mind*, Deepak Chopra, M.D. says that "the wisdom of uncertainty" is a source of growth, understanding and acceptance. We may not always enjoy the process, but the experience of caregiving can create healing and resolution. We learn to adapt when we accept the fact that our spouse, partner, mother, wife, brother, friend may not "get better," and that both caregivers and care receivers may need to make sacrifices to accommodate one another's needs.

So, how do caregivers balance their own needs with those of the person who depends on them? How do they manage day-to-day caregiving responsibilities in addition to the pressures of family, work and other obligations? Here are a few tips from resilient caregivers:

- Give yourself unceasing credit for your efforts. Whether you are providing care for someone out of love or obligation, you are improving the person's safety and well-being.
- Set realistic expectations for yourself. Ask for assistance from family members, friends, health care professionals, and community agencies that serve dependent individuals.

- Seek support from family members, friends, counselors, spiritual advisers or other caregivers with whom you can share your woes, joys, problems and successes.
- Make a commitment to your physical, mental, emotional and spiritual well-being by replenishing your energy with relaxation, recreation and time for yourself.
- Connect with the person in your care by creating a peaceful space to reminisce, share experiences and be comforted.

Author Richard Bach refers to serendipity by saying, "There is no such thing as a problem without a gift for you in its hands." This is the heart of resiliency for caregivers. Our goal is to rise to the challenge without denying the full spectrum of difficulties and delights, and to believe that our caregiving relationship has meaning – both for ourselves and the person receiving care. Whenever we involve ourselves in the life of someone who is vulnerable, we are on hallowed ground.

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Tips for Caregivers

*Edited by: Jan E. Sturges, M.Ed., LPC
Caregiver Consortium*



The caregiver tips and suggestions listed below do not come from just one source. They are pearls of wisdom and practical suggestions that have evolved from the collective experience of family and professional caregivers over time.

The Caregiver Relationship and Well-Being

- Give yourself unceasing credit for what you are contributing to the life of the individual for whom you are providing care. Whether you are a caregiver out of love or obligation, you are undoubtedly adding a dimension of quality and dignity to the person's existence that might not otherwise occur.
- Keep track of your own physical and medical well being; whenever possible, get a minimum of six hours of sleep a night.
- Avoid using drugs and / or alcohol as a remedy, or as a replenishment for fatigue.
- Learn one or two quick and simple relaxation and self-affirmation exercises, and practice them daily. Making this commitment to your own well needs will benefit your care recipient, too. Maybe you can practice a relaxation exercise together.
- Take some time each day, if possible, to write down your thoughts and feelings about caregiving in a journal. List problems and successes as well as short-term and long-term goals. Keep them realistic.
- Develop and maintain regular, planned events that are pleasurable and relaxing. They offer you an opportunity for self-renewal.
- Never feel guilty about taking time for yourself, and enjoy it, even if your loved one is unable to participate.
- Give up unrealistic expectations of yourself, the person for whom you are caring, and others who assist with care. Have the courage to be imperfect.
- Be prepared to reach compromises with your time and effort as well as that of the person who depends on you.
- Spend quality time with your loved one or the person receiving care.
- If your loved one is mentally and emotionally capable, take a risk by sharing some of your thoughts and feelings about what is happening in an honest, but respectful way. Come to some agreement about each other's limitations as well as strengths. Learn to share your fears, and most importantly, learn to share your hopes.

Resources for Caregivers and the Person Receiving Care

- Assess your resources: people, environmental (housing, location, safety/home modification/assistive devices), finances, health care, time, energy and spiritual support.
- Use problem-solving techniques when you are facing a difficult circumstance: define the problem; brainstorm ideas for solving it; prioritize what activities are necessary to address the situation; implement them i.e., take action; evaluate the results.
- Plan ahead by making sure that all financial and legal documents are in place including an estate plan/will and testament or trust, advance directives (Living Will, Health Care and /or Mental Health Care Power of Attorney, Pre-Hospital Medical Directive—Do Not Resuscitate), Durable Financial Power of Attorney, investments and insurance policies.
- If you hire home care workers or respite workers, supervise them enough so that they are accountable without micro-managing them. Treat them as part of the “team” that is giving care—trust encourages people to do a better job.
- Learn to accept help and to respect the fact that others may provide assistance in ways that are different than yours. They may also demonstrate care and concern differently.
- Ask for other family members, friends and professionals to help you. Remember—you, your loved one and the people who assist with caregiving are part of the same team. Be specific and direct in explaining what you want them to do, or what you need.
- Seek out and cultivate at least one professional (mental health professional or spiritual adviser) who understands the impact of your caregiving experience. Maintain regular contact with this person, and evaluate both your challenges and your successes.
- Allow yourself to find the humor in caregiving, and seek ongoing contact with friends and others who are upbeat, and who will listen to you when you need a boost.
- Participate in a caregiver support group. You will discover that you are not alone in this experience, and you will gain invaluable suggestions and ideas from other caregivers.

Quick and Easy Relaxation Techniques for Caregivers

By: Jan Sturges, M.Ed., LPC, Caregiver Consortium



Breathing

One of the best stress reducers and calming techniques available to each of us is something we do 24 hours a day without thinking about it – breathe!

However, the key to breathing as a means of decreasing stress and improving performance is *intentional* breathing. Breathing with purpose allows you to become centered and focused, and allows you to experience the timelessness of the present moment. Intentional breathing improves blood flow, decreases your heart rate and blood pressure, and therefore, increases life-saving circulation of oxygen to all your cells. This, in turn, creates an environment for self-healing. Here are some techniques for proper breathing:

1. Find a relaxing environment, if possible, and sit comfortably with your eyes closed. Make sure all extremities are uncrossed. Sit up straight enough to give your diaphragm room to expand.
2. Pay attention to the rhythm of your natural breathing, and tell yourself to “let go of all thoughts and feelings for now.”
3. Inhale through your nose to the count of four, hold your breath for a moment, and then exhale slowly through pursed lips to the count of four. Breathing should be slow, deep and regular.
4. Repeat this exercise several times until you begin to feel yourself “letting go.” You may feel a slight tingling or warmth in your hands and feet – a sign that there is increased blood flow to your extremities. *It only takes 3 or 4 deep breaths like this to return your body to a state of calm.*

Body Scan (5 minute maximum)

This is a good technique to use whenever you need a quick stress-reducer:

Sit comfortably with your eyes closed. Scan your body starting with your head and continue to scan your body down to your toes to notice if there is any tension. As you do this, breathe slowly and deeply. Keep the pattern regular. Every time you exhale, become even more relaxed. As you pay attention to each muscle group, check to see if there is any tension. If there is, just let it go. For example, check your forehead and eyes. If you feel any tension, release it. Say, “forehead let go,” or “eyes let go.” As you progress through the muscle groups, periodically recheck your breathing to make sure it is slow, deep and regular – relaxing even more with each exhalation. Go through the muscle groups in the sequence listed above.

When you are finished, quickly rescan your body starting with your head, and continue to scan your body down to your feet. Wherever you spot tension, just release it. You will notice that you are more relaxed and serene.

Resources for Body Scan from J.M. Williams, Ph.D.

The Holiday Spirit: From Harried to Heartfelt

*By: Jan Sturges, M.Ed., LPC
Caregiver Consortium*



Holidays at any time of year are about staying connected to the values, people and experiences that enrich us; they acknowledge the importance of our relationships by highlighting the joys of the past and giving us the opportunity to create memorable moments that will nourish us in the future, when we need to be uplifted.

For caregivers, the holidays can be particularly challenging when they are caring for a loved one in declining health. They may have conflicting emotions about how they 'should' feel ('happy' and 'merry'...isn't that what holiday songs suggest?) vs. how they *really* feel (sadness or sorrow) because it is no longer possible for family and friends to enjoy past traditions and celebrations due to illness or dementia. Caregivers often wonder how they can add holiday-related tasks and activities to the long list of caregiving responsibilities they already have, in addition to work and family obligations.

Tips and Treasures for Caregivers

Below are a few caregiver 'Tips and Treasures' for coping with holiday stress. They have been assembled from many different sources.

- Mindfulness – Focus on the intrinsic values of the holidays – stay connected to people and relationships, and participate in one or two meaningful events (not ten or fifteen!) that will nourish you, your family and friends. Instead of cooking a large meal, host a pot-luck party, attend a holiday concert or participate in a faith celebration.
- Compassionate presence - Set aside time to include the elder or dependent person in practical, but meaningful, non stress-producing activities. Even if they are not able to participate or converse at length, your compassionate presence and 'being' vs. 'doing' will create a caring bond.
- Priorities - Set realistic expectations for activities and gift-giving based on your resources – people (family, friends, community resources, and professional health care providers), time, finances and energy.
- Traditions – Decide what past traditions are no longer appropriate, and develop a few new ones. Combine some of the 'old' with the 'new' and create a different set of holiday traditions without comparing them to 'the way it used to be.'
- Affirmations – Be kind, and acknowledge disappointment without judging yourself or others when life gets messy during the holiday rush.

- Self-care:
 - ✓ Eat, drink and be merry, but not too much! Balance sugar and alcohol intake with healthier foods.
 - ✓ Allow yourself a 'time out' every day. Take four deep breaths, walk around the yard, read a few pages of a book or listen to music. (Really, you can *do* this!!)
 - ✓ Arrange for someone to stay with the person in your care while you attend a social event, or complete some of the tasks on your *simplified* 'To Do' list.
 - ✓ Find a supportive listener to help you solve problems that arise, or express your feelings about caregiving during the holidays. Remind yourself that it is normal to have mixed feelings at this time of year.
- Humor – Give the gift of laughter to yourself and others, and relax!

You can also go to the following links online for additional information:

<https://www.caregiver.org/>

<https://www.caregiver.org/caregiving-and-holidays-stress-success>

<http://www.alz.org/care/alzheimers-dementia-holidays.asp>

References:

Family Caregiver Alliance, "Taking Care of YOU: Self-Care for Family Caregivers"
Hope Publications, "How to De-Stress the Holidays"

Caregivers and Exercise—Take Time for Yourself

Taking care of yourself is one of the most important things you can do as a caregiver. Finding some time for regular exercise can be very important to your overall physical and mental well-being.

Physical activity can help you:

- Increase your energy level so you can keep up with your daily caregiving activities.
- Reduce feelings of depression and stress, while improving your mood and overall well-being.
- Maintain and improve your physical strength and fitness.
- Manage and prevent chronic diseases and conditions like diabetes, heart disease, and osteoporosis.
- Improve or maintain some aspects of cognitive function, such as your ability to shift quickly between tasks and plan activities.

Some ways for caregivers to be physically active:

- Take exercise breaks throughout the day. Try three 10-minute "mini-workouts" instead of 30 minutes all at once.
- Make an appointment with yourself to exercise. Set aside specific times and days of the week for physical activity.
- Exercise with a friend and get the added benefit of emotional support.
- Ask for help at home so you can exercise.
- If possible, find ways to be active with the person you're caring for. Both of you can benefit from physical activity!



Quick Tip

Pick an activity you really enjoy to make exercise something you want to do, not have to do.

VISIT

www.nia.nih.gov/Go4Life

- Read more tips for adding physical activity to your day.
- Print useful tools.
- Order a free exercise guide or DVD.
- Share your exercise story.



National Institute on Aging

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The Caregiver's To Do List

*By Laura Michaels, MSW
Pima Council on Aging*



When you are caring for another person, you may find yourself with a long "To Do" list on a regular basis. Lists can be very helpful in keeping you organized and reminding you of tasks to complete. However, although their lists are filled with things to do for other people, caregivers often forget to include some of the most important tasks of all—the ones that will enhance and protect their own physical and emotional well-being. Below are some "to do's" that you may want to place on your list.

- Breathe. You may be breathing enough to keep you alive, but odds are you aren't breathing deeply enough to keep your body energized and your mind clear. Try breathing in through your nose, inflating your belly, then exhaling slowly through your mouth as your belly deflates.
- Drink Water. Even mild dehydration can alter a person's mood, energy level, and ability to think clearly. You have heard it before, and for good reason, drink at least eight, 8-ounce glasses of water a day.
- Nourish Your Body. We all know how we are supposed to eat but it's hard when you are eating on the go, not eating regularly, or just looking for a quick pick me up to boost your mood. It's very important to plan your meals and snacks ahead of time (when you aren't tired or hungry) and keep healthy choices handy so you can keep your blood sugar – and mood – stable.
- Sleep. This one can be tough when there aren't enough hours in the day to get everything done, or the person you care for gets up frequently at night. However, getting those 6 to 8 hours of shut eye is important because sleep deprivation can cause problems such as irritability, difficulty concentrating, poor memory, and impaired driving ability. Try to wind down at night and create a ritual that your mind and body identify with bedtime. A warm shower, writing in a journal, reading, meditating, taking deep breaths—whatever will help you shut down your over-worked mind and relax.
- Move Your Body. Just about any exercise can be of benefit to your physical, emotional, and mental health if you do it on a regular basis. There are many options such as walking, dancing, stretching, lifting hand weights, swimming, taking Martial Arts classes, using exercise DVD's, and others. Just find something that you enjoy and commit to doing it at least three times per week. It can improve your mood, cognitive abilities, energy level, and overall health.

Okay, those are all crucial and life-sustaining suggestions. One of equal importance is to Take a Break. It's important to get time away from the person you are caring for. Even if you don't live with your care recipient, you need time to spend on your own interests without worrying about getting "the call" saying your attention is needed because no one

else can help. Line up a family member, neighbor, friend, paid caregiver, respite stay at a facility, adult daycare—whatever it takes to get some time off.

Additional Suggestions:

- Set Boundaries – Decide what you will and won’t do for your care recipient and what behavior you will and won’t accept from them. Make it as clear to them as you can and stick with what you say. When you behave in new, self-affirming ways instead of repeating old patterns, you may see a difference in the way the other person responds.
- Laugh – As often as you can. We all have “sitcom moments” in our lives when things are just so ridiculously awful they are funny. Read a book from the humor section of a bookstore, watch a funny TV show or DVD, look-up a website filled with jokes and silly pictures – just do something that will make you smile.
- Write in a Journal – Sometimes getting your thoughts down on paper can be cathartic. It can be a safe way to express the feelings churning inside of you. Writing a letter to someone that you never intend to give them can be another way to release some emotions that are troubling you.
- Meditate and /or Visualize – It doesn’t have to be anything fancy to be helpful. Focus on your breath while thinking a word or phrase that makes you feel calm and relaxed. You can also picture a beautiful place and see yourself there. Create a scene so real that you can feel the breeze blowing, smell the flowers, and hear the sounds of the brook – whatever works with your image.
- Give Yourself Some Credit – You are helping another person in a meaningful way – that’s a truly generous gift. It’s true your care recipient may not always be appreciative. They may refuse your advice or take out their frustrations on you. At those times it might help to focus on why you have chosen to be a caregiver and what about it you find rewarding or important. And be compassionate towards yourself. Some days you may be on top of things and get a lot accomplished, and other days you may feel worn out and just want to hide. What’s important to remember is that none of us are perfect and that’s okay. You are still performing a great service to another human being and you deserve applause, not self-recriminations.

Above and beyond all else, take good care of yourself!

Source: Laura Michaels, MSW, Pima Council on Aging; Caregivers To Do List; www.pcua.org.