

Section 1

You, the Caregiver



Are You A Caregiver?

Answer the following questions to identify if you are a caregiver. Do you help someone else with:

- Maintaining normal activities?
- Housekeeping or home maintenance?
- Grocery shopping?
- Transportation?
- Bill-paying or personal finances?
- Staying in touch with friends?
- Preparing or eating meals?
- Medications?
- Dressing or bathing?
- Getting around the house?
- Remembering things?
- Hiring or supervising an in-home care worker?
- Arranging to move to a long term care residence?

If you answered “yes” to any of these questions, you are a caregiver! A caregiver is anyone who shares responsibility for another person’s health, well-being and safety, no matter where they live. The individual needing help can be a relative, friend or neighbor and can be as close as your living room or as far away as a long distance phone call. Whether you help out occasionally with tasks like shopping or doctor’s visits or complex situations for someone needing round the clock care, you are a caregiver.

Why Don’t Caregivers Get Help?

Most caregivers identify themselves as a spouse, daughter, sibling, friend or neighbor of someone who needs help but not as a caregiver. They have a relationship with the person who needs them, so the term “caregiver” seems impersonal. There are also other common reasons why caregivers may not seek help:

- Family and Social Values - People are often taught that taking care of someone is what is expected of children, siblings, etc. and that you shouldn’t get help from “outsiders”.
- Guilt - The caregiver may worry that the person getting help will be upset if someone else takes his/her place so the caregiver can have a break.
- Fear - The term might frighten the caregiver because of the responsibility it implies.
- Cost - Paying for outside help might cause financial hardship.

The demands of caregiving can become difficult and stressful. It can have a negative impact when you, the caregiver, become exhausted, overwhelmed or resentful. Help is available now. Call:

Pima Council on Aging
Primary source for assisting older citizens, including caregivers.
Help Line 790-7262

Source: Caregiver Consortium

Caregiver Self-assessment Questionnaire: How are YOU?

Caregivers are often so concerned with caring for their loved one's needs that they lose sight of their own well-being. Take a moment to answer the following questions.

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.		

Caregiver Self-assessment Questionnaire: Scoring

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».)

Total the number of «yes» responses. 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 is 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 seeing a doctor for a check-up for yourself
- Consider having some relief from caregiving
- Consider joining a support group.

Source: American Medical Association

The Resilient Caregiver – Challenge and Opportunity

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 to 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. It 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 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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The Caregiver's To Do List

By: Laura Michaels, MSW

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.

Keep your body energized and your mind clear.

It’s important to get time away from the person you are caring for.

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 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.

Decide what you will and will not do for your care recipient and what behavior you will and will not accept from them.

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

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 or not 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 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, 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.



Tips for Working Caregivers

If you are a working caregiver, you know what it's like to be a nonstop juggler, trying to have a life while keeping some balance among responsibilities. Your caregiving role may be hard, even overwhelming, but there are steps you can take that may ease the burden.

Symptoms of Stress

Health: Many working caregivers report health problems, depression, lower productivity on the job, and lost time at work. If you are frequently distracted at work, emotionally drained, and physically exhausted, you are not alone. But do not ignore these symptoms. Recognizing them is the first step to finding solutions.

Relationships: You may also find that you have let your social relationships slide. Many working caregivers cut back on community involvement and spend less time with their own families. If this is happening to you, make every effort to rekindle friendships and reconnect with your community—for example, through church or another group. You will be better able to deal with stress if you have a support network.

Steps You Can Take

1. Talk to your employer. Let your manager know your needs related to caregiving. Make it clear that you are committed to your job and want to find ways to remain productive.
2. Resist isolation. Find support in and out of work. Join community caregiver groups for emotional support, and seek out local resources for help. Take advantage of resources, such as Lotsa Helping Hands, to coordinate caregiving tasks within your family and support network.
3. Take care of yourself so that you can take care of others. As often as you can, get enough sleep. Eat sensibly, use alcohol in moderation, and exercise. Take a break when the pressure gets too great, even if it's just a hot bath or a short walk. Walking with a buddy can cover two needs at once—friendship and exercise.

Know Your Rights

Consult with human resources about what you are entitled to under the law. The Family Medical Leave Act (FMLA) requires large employers to provide up to 12 weeks of unpaid time off with job protection when workers must care for a sick or injured parent. Some states have extended this coverage to include small businesses as well.

Take Advantage of Benefits

- Ask about flexible-work options. This could mean a compressed work week or a modified daily schedule based on need. Job-sharing and telecommuting are also caregiver-friendly

options to explore. Many employers offer flexible work options on a case-by-case basis even if there is no formal policy.

- Contact your Employee Assistance Program (EAP) and find out what support services are available, such as counseling on reducing stress and managing your time.
- Many companies offer access to eldercare referral services through an online database or live consultants. Such services reduce the burden of having to do distracting and time-consuming research.
- Respectfully share information with your manager or HR on how employers can support working caregivers.

Build a Support System

- Connect with other caregivers at your place of work. It's likely that some of your fellow workers face the same caregiving challenges.
- Put in a request to human resources to sponsor brown bag lunches or an employee resource group to help with caregiving issues. Or you could organize your own informal group to meet during your lunch hour.
- Thank your coworkers who take on extra assignments or help you with work projects. They are part of your community, too.
- Make sure your manager knows about your accomplishments at work. This will show you are able to deal with multiple priorities.
- Join the caregiving group on the AARP Online Community to share your story, get support, and connect with other caregivers.

Plan for the Future

When it comes to caring for an aging loved one, most families don't have a plan until there is a problem. But as many working caregivers have discovered, the stress of making caregiving arrangements in "crisis mode" can be overwhelming. AARP's Prepare to Care: A Planning Guide for Families is a step-by-step guide for creating a caregiving plan in advance. Even if you have been a caregiver for years, the guide can help you get support and stay organized. Tell your employer about it!

Other articles on the AARP website: www.aarp.org

Source: AARP

“I DON’T HAVE TIME TO TAKE CARE OF MYSELF”

Sound familiar? If so, you may be putting yourself at risk. As an Alzheimer’s caregiver, you devote a significant amount of time and energy to the person with Alzheimer’s disease. You are likely to experience moments of stress, and anxiety that may be severe. Too often, caregivers don’t recognize their own needs, fail to do anything about them, or simply don’t know where to turn for help. For these reasons, the Alzheimer’s caregiver is often called the hidden or second victim, of the disease.

10 SIGNS OF CAREGIVER STRESS

Too much stress can be damaging to both you and the individual that you are caring for. The following stress indicators experienced frequently or simultaneously, can lead to more serious health problems. Learn to recognize signs of stress in yourself. Taking care of yourself will help you be a better caregiver.

1. **Denial** about the disease and effect on the person who’s been diagnosed.
“I know mom is going to get better”
2. **Anger** at the person with the disease or others that no effective treatments or cures currently exists; and that people “don’t understand what’s going on.”
“If he asks me that question one more time, I’ll scream”
3. **Social withdrawal** from friends and activities that once brought pleasure.
“I don’t care about getting together with the neighbors anymore”
4. **Anxiety** about facing another day and what the future may hold.
“What happens when he needs more care than I can provide?”
5. **Depression** begins to break your spirit through apathy and affects your ability to cope.
“I don’t care anymore.”
6. **Exhaustion** makes it nearly impossible to complete necessary daily tasks.
“I’m too tired to do this.”
7. **Sleeplessness** caused by worry over a never-ending list of concerns and anxiety.
“What if she wanders out of the house or falls and hurts herself?”
8. **Irritability** leads to moodiness and triggers negative responses and reactions.
“Leave me alone!”
9. **Lack of concentration**, which makes it difficult to perform familiar tasks.
“I was so busy; I forgot we had an appointment.”
10. **Untreatable** health problems which begin to take their toll, both mentally and physically.
“I can’t remember the last time I felt good.”

10 WAYS TO HELP REDUCE CAREGIVER STRESS

Unfortunately, the ultimate stress reducer- a cure for Alzheimer's disease- has not yet been discovered. But there are programs, services and care techniques that can help. To assist you in providing the best possible care, while maintaining you own health and well being, the Alzheimer's Association suggests the following:

1. **Get a Diagnosis as Early as Possible**

Symptoms of Alzheimer's may appear gradually, and if a person seems physically healthy, it's easy to ignore unusual behavior, or attribute it to something else. Seeing a physician, when warning signs are present (please see, *Is It Alzheimer's? Ten Warning Signs*, available from the Alzheimer's Association), some dementia symptoms are treatable. Once you know what you're dealing with, you'll be able to better manage the present and plan for the future.

2. **Know What Resources are Available**

For your own well-being and that of the person you are caring for, become familiar with Alzheimer's care resources available in your community, Adult day care, in-home assistance, visiting nurses and Meals-on-Wheels are just some of the community services that can help. The Alzheimer's Association Desert Southwest Chapter is a good place to start.

3. **Become and Informed Caregiver**

As Alzheimer's disease progresses, different caregiving skills and capabilities are necessary. Care techniques and suggestions available from the Alzheimer's Association can help you better understand and cope with many of the challenging behaviors and personality changes that may

4. **Get Help**

Trying to do everything by yourself will leave you exhausted. The support of family, friends, and community resources can be an enormous help. If assistance is not offered, ask for it. If you have difficulty asking for assistance, have someone close to you advocate for you. If stress becomes overwhelming, don't be afraid to seek professional help. Alzheimer's Association support group meetings and Helpline are also good source of individualized comfort and reassurance.

5. **Take Care of Yourself**

Family caregivers frequently devote themselves totally to those they care form and in the process, neglect their own needs. Pay attention to yourself. Watch your diet, exercise and get plenty of rest. Use respite services to take time off for shopping, a movie or an uninterrupted visit with a friend. Those close to you, including your loved one with Alzheimer's disease want you to take care of yourself.

6. **Manage Your Level of Stress**

Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, loss of appetite). Note your symptoms. Use relaxation techniques that work for you and consult your primary care physician.

7. **Accept Changes as They Occur**

People with Alzheimer's disease change and so do their needs. They often require care beyond what you can provide at home. A thorough investigation of available care options should make transitions easier. So will assistance from those who care about you and your loved one.

8. **Do Legal and Financial Planning**

Consult an attorney and discuss issues related to durable power of attorney, living wills and trusts, future medical care, housing and other key considerations. Planning now will alleviate

stress later. If possible and appropriate, involve the person with Alzheimer's and other family members in planning

9. Be Realistic

Until a cure is found, the progression of Alzheimer's disease is inevitable. The care you provide does make a difference. Neither you nor the person with Alzheimer's can control most of the circumstances and behaviors that will occur. Give yourself permission to grieve for the losses you experience, but also focus on the positive moments as they occur and enjoy your good memories.

10. Give Yourself Credit, Not Guilt

You're only human. Occasionally, you may lose patience and at times, be unable to provide care the way you'd like. Remember that you're doing the best you can, so give yourself credit. Being a devoted caregiver is not something to feel guilty about. Your loved one needs you and you are there. That's something to be proud of. If your loved one could, they'd thank you.

The Alzheimer's Association® is the only national health and social service organization dedicated to research, and to providing support and assistance to people with Alzheimer's disease, their families and caregivers. Founded in 1980, the association works through a network of more than 80 chapters across the country.

The Alzheimer's Association Desert Southwest Chapter provides programs and services to tens of thousands of families including Helpline – a 24/7 assistance line, MedicAlert®+Safe Return®, Family Care Consultation, Support Groups, Education, Early Stage Programming and Legislative Advocacy. Please, contact us for any more information or assistance, 24 hours a day, seven days a week, at 800.272.3900 or online at www.alz.org/dsw.

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Taking Care of the Caregiver

Learning How to Cope with Caregiver Burnout

When someone is diagnosed with cancer, the patient is not the only one affected. The person responsible for care is also affected. Providing care for a loved one with cancer can be very stressful. When caregivers don't attend to their own needs and allow other pressures to take over, they lose the ability to continue to care for the loved one or friend. This condition may be known as burnout.

Recognize the Signs of Burnout:

- Irritability. You snap at people for small things; you lose patience easily.
- Withdrawal. You don't stay in touch with friends and activities like you used to.
- Fatigue. You are constantly tired and exhausted.
- Insomnia. You have a hard time getting to sleep, staying asleep, or sleep restlessly.
- Apathy. You feel numb and must force yourself to do routine caregiver tasks.
- Appetite Changes. You eat more than you used to, or don't feel like eating anything.
- Increased Substance Use. The only relief you can get is from alcohol, drugs, or smoking.
- Feelings of Guilt. You think you are not doing enough, or you feel resentment for the amount of work you are doing.

What to Do:

In order to care for someone else, you must take care of yourself. Your mental and physical health is just as important as the patient's, so it's important to recognize your limits. Be aware of how much you can do, as well as what you cannot do. You are not super-human. Don't feel guilty when you take time to re-energize yourself.

1. Exercise. Even if you do not have time for a formal workout, incorporate exercise into your daily routine. For example, take a walk around the doctor's office or hospital grounds during the patient's appointment.
2. Eat properly. Many times caregivers are so absorbed in preparing patient meals they neglect their own nutritional needs.
3. Read. For pleasure, or for information, reading can be a wonderful outlet for stress and anxiety.
4. Get a massage. Many people think that they need to spend all their money on medical bills and if they spend money on personal needs, they feel guilty. Getting a massage may not be that expensive. Many major cities have massage schools with low-cost student clinics.
5. Pursue hobbies. Don't lose touch with the things that gave you pleasure before your loved one became ill. Whether it is gardening, music, or art classes, continue to do what brings you joy, even if it is less frequent than before.
6. Practice relaxation techniques. Whether it's progressive muscle relaxation, visualization or deep breathing, anyone can incorporate these skills into their daily lives. Many stress management workshops and books are readily available.

7. Keep a journal or diary. It's helpful to use this as a way to keep track of what you are going through and how you are feeling.
8. Tap into your support network. Don't be afraid to ask for help. Many people want to help but don't know what to offer. Ask friends, relatives, neighbors, co-workers, or people in your church or synagogue to help out with some tasks.
9. Blow off steam. Go to the movies, go to dinner, have fun, play games. It's okay to escape and not focus all your energy on your loved one's illness. They want you to be able to enjoy life.
10. Join a caregiver's support group. Contact your local American Cancer Society to find the nearest group. It's important to connect with people who share similar experiences.

Adapted from the American Cancer Society website www.cancer.org

Article date: 06/11/1998

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

National Institutes of Health

U.S. Department of Health & Human Services

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The 'Art' in the Heart of Caregiving: Quick and Easy Relaxation Techniques

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. You are going to scan your body starting at your head and going down to your toes to see 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 look at 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 at the head and working down to the feet. Wherever you spot tension, just release it.

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

Edited by: Jan Sturges, M.Ed., LPC

The Holiday Spirit – From Harried to Heartfelt

*By: Jan Sturges, M.Ed., LPC
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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 by 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. And, how can caregivers add holiday-related tasks and activities to the long list of caregiving responsibilities they already have, in addition to work and family obligations?

Below are a few caregiver ‘Tips and Treasures’ for coping with holiday stress that have been assembled from many different sources. You can also go to the following websites for additional online information:

www.caregiver.org/caregiver/jsp/home.jsp

www.caregiver.com/articles/holiday/holiday_stress_caregiving.htm

www.alz.org/living_with_alzheimers_holidays.asp

Tips and Treasures for Caregivers

- 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 person who can help you solve problems that arise, or listen to your concerns about caregiving during the holidays.
- Humor – Give the gift of laughter to yourself and others, and relax!

References:

Family Caregiver Alliance, ‘Managing Caregiver Stress’

Hope Publications, ‘How to De-Stress the Holidays’

Caregiver Depression: Prevention Counts

Caregiver depression can take a toll on you and your ability to care for your loved one. Understand the signs of caregiver depression - and know how to prevent it.

Caregiving is often physically and emotionally stressful. In an effort 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. Sometimes, these emotions can trigger caregiver depression.

What are the symptoms of caregiver depression?

Everyone has a bad day sometimes. However, to be diagnosed with depression - also called major depression - you must have five or more of the following symptoms over a two-week period. At least one of the symptoms must be either a depressed mood or a loss of interest or pleasure. Symptoms include:

- Depressed mood most of the day, nearly every day, such as feeling sad, empty or tearful.
- Diminished interest or feeling no pleasure in all - or almost all - activities most of the day, nearly every day.
- Significant weight loss when not dieting, weight gain, or decrease or increase in appetite nearly every day.
- Insomnia or increased desire to sleep nearly every day.
- Either restlessness or slowed behavior that can be observed by others.
- Fatigue or loss of energy nearly every day.
- Feelings of worthlessness, or excessive or inappropriate guilt nearly every day.
- Trouble making decisions, or trouble thinking or concentrating nearly every day.
- Recurrent thoughts of death or suicide, or a suicide attempt.

What can I do if I develop caregiver depression?

If you're experiencing signs or symptoms of caregiver depression, consult your doctor or a mental health provider. Depression isn't something you can simply "snap out of" - and left untreated, depression can lead to various emotional and physical problems. 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.

What can I do to prevent caregiver depression?

You can take active 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 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.
- Remember 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. Physical activity and meditation also can help reduce stress.
- 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.

Source: Reprinted from the MayoClinic.com article "Caregiver depression: prevention counts" (<http://www.mayoclinic.com/health/caregiver-depression/MY01264>)

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Caregiver Grief, Mourning and Guilt

It's normal to feel loss when you care about someone who has Alzheimer's disease. It's also normal to feel guilty, abandoned and angry. It's important to acknowledge these emotions and know that you may start to experience them as soon as you learn of the diagnosis.

Alzheimer's gradually changes the way you relate to the person you know and love. As this happens, you'll mourn him or her and may experience the stages of grieving: denial, anger, guilt, sadness and acceptance. These stages of grief don't happen neatly in order. You'll move in and out of different stages as time goes on. Some common experiences in the grieving process include:

Denial

- Hoping that the person is not ill.
- Expecting the person to get better.
- Convincing yourself that the person hasn't changed.
- Attempting to normalize problematic behaviors.

Anger

- Being frustrated with the person.
- Resenting the demands of caregiving.
- Resenting family members who cannot or will not help provide care.
- Feeling abandoned.

Guilt

- Wondering if you did something to cause the illness.
- Regretting your actions after the diagnosis.
- Feeling bad because you're still able to enjoy life.
- Feeling that you've failed if, for example, you can't care for the person with dementia at home.
- Having negative thoughts about the person or wishing that he or she would go away or even wish he or she would die.
- Regretting things about your relationship before the diagnosis.
- Having unrealistic expectations of yourself, with thoughts such as: "I should have done..." "I must do everything for him or her." "I must visit him or her every day."

Sadness

- Feeling overwhelmed by loss.
- Crying periodically.
- Withdrawing from social activities or needing to connect more frequently with others.
- Withholding your emotions or displaying them more openly than usual

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Respite: The Circle of Care

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

One of the most important “life preservers” for a caregiver is respite care. Temporary relief from caregiving is not only an opportunity to rejuvenate yourself as a caregiver, but a chance to refresh the relationship between you and the person receiving care. Sometimes a little distance does make the heart grow fonder. When you take care of yourself, you are better able to help the person needing your love and support. Caring for self, caring for another - this is the reciprocal circle of care.

According to the National Alliance for Caregiving and AARP, caregiving is being provided for someone who is ill, disabled or aged in almost one in three American households (about 66 million caregivers in 2012). Of those caregivers, 44 million are caring for someone 50 years and older, and 15 million of them are responsible for someone with Alzheimer’s disease or another dementia. Fourteen percent of caregivers also care for a child under age 18, and must juggle competing responsibilities between elder care and childcare. In addition, one in six full or part-time working Americans are caregivers, with the added responsibility of work-related tasks to accomplish.

At least one third of caregivers report an increase in their own health problems as well as feeling depressed and socially isolated. If you don’t take care of yourself properly, you are taking the risk that you won’t be there for your loved ones when they need you the most.

The responsibility of being a caregiver is often all encompassing for people who are caring for a loved one at home, especially if that person is confused or has dementia. When you have a role in the ultimate well-being of another person, your interactions affect both of you at every level - mental, emotional, physical and spiritual regardless of the intensity of care you are providing. Caregiving has a negative impact when the caregiver does not see light at the end of the tunnel and becomes exhausted, overwhelmed and resentful. When you begin to feel this way, it’s time to arrange for respite care services. In fact, the best time to think about respite care is before you get to this point! What’s even better? Arrange for respite care on a regular basis so you can plan ahead, have something to look forward to, and help your loved one adjust to having other people help out.

What is Respite Care?

The dictionary definition of respite is a temporary period of time for rest and relief. From a caregiving point of view, respite care means finding other qualified people to care for the person who depends upon you so that you can take personal time for yourself or focus on other home or work-related tasks. This might mean that you spend a few hours, or even a few days, away from home in order to restore your own sense of well-being. People are higher functioning when they are relaxed. And, the two timeless maxims of stress management are:

- It is physiologically impossible for your body to be under stress and relaxed at the same time. The more you practice “personal respite,” the calmer you will be, and the less impact stress will have on your long-term health.

- You can improve your mental and emotional stamina by returning your body to a brief physiological “state of calm” several times throughout the day. Deep breathing, a short walk, relaxation exercises, journaling, reading, listening to music and other distracting activities will restore the mind/body connection. Recreation means to “re-create.” How creative can you be in the midst of your caregiving experience to give yourself a break?

There are two ways to arrange for respite care by others:

- In-home care, which means that the caregiver arranges for a relative, friend or paid caregiver to come to the house while the caregiver runs errands, goes to medical appointments or participates in pleasurable activities.
- Care for the dependent person at a qualified 24-hours-a-day extended care facility, or adult care home where the person needing care is admitted for a short period of time ranging from a few days to a week or two.

According to the Caregiver Specialists at the Pima Council on Aging, the goals of respite programs of any kind are to:

- Prevent caregiver burnout
- Support the integrity of the family’s lifestyle as much as possible
- Enable the person needing care to live at home for as long as possible

Caregivers that are intentional about scheduling respite care of any type can vastly improve the quality of the caregiving experience.

Why Don’t More Caregivers Use Respite Care?

Many caregivers see themselves as a spouse, son, daughter, sibling, friend or neighbor of someone who needs help, not a “caregiver.” In other words, they see themselves in relationship with the person who needs them. The term “caregiver” may seem too formal. But the necessities of caregiving are more demanding and pervasive, and add an entirely different dimension to the original relationship. The Caregiver Specialists at Pima Council on Aging indicate that there are several reasons caregivers may not seek respite care:

- Personal, family and cultural values that preclude people from getting additional help from non-family members.
- Guilt about “leaving the loved one behind” to do something without them.
- Fear about safety - Will the person or facility providing respite care be qualified, trustworthy and treat the loved one with compassion? This is particularly pertinent if the loved one is confused or immobile.
- Inability to be self-nurturing after taking care of someone else for so long.
- Cost - Caregivers and families with limited funds are often unaware that they may be eligible for respite services at a reduced rate.

Suggestions for Respite Activities

You have finally arranged for respite care. Now what do you do? (It might be hard to remember what you used to do for fun before you were a caregiver.)

- Get some sleep!
- Go for a walk, go to the gym, play your favorite sport.
- Spend time with a friend (one who is supportive and understands your situation).
- Go out for a meal.
- Do some gardening; spend time in nature.
- Start a hobby or rekindle an old one.
- Read a book or magazine.
- Create something artistic - draw, write, play an instrument, sing.
- Attend worship services, and spend time with people who practice the same faith you do.
- Write letters or send emails to friends.
- Follow up with medical appointments.
- Buy something nice for yourself.

Respite Care Produces Positive Results

Respite care can never replace your value as a caregiver. It can only augment, support and strengthen the circle of care and improve the quality of the caregiving relationship. We treat others as we treat ourselves. When you respect yourself enough to be self-nurturing, you will honor and nurture your loved one as well. Here are some of the gains achieved from respite care:

- Stress and resentment reduction
- Improvement in your general health
- Renewed understanding and perspective about caregiving
- Expanded social contact for both you and your loved one
- Opportunity for the person you are helping to give something back to you by accepting help from someone else (if he or she is cognitively able to understand)
- Prolonged capacity over time to care for your loved one

So, protect your loved one by protecting yourself. The best formula for enhancing the caregiver relationship is to schedule respite care on a consistent basis at intervals that are comfortable for you so that the routine becomes comfortable for everyone involved. Remember what the flight attendant says when they talk about the oxygen mask at the beginning of every flight? "If the oxygen mask drops down, make sure you put yours on first before you put it on someone else who needs it." Respite care is like oxygen. Inhale deeply, and relax.

Selected Caregiving Statistics

Compiled by: Julie Bubul, MSW

Caregiving Population

1. More than **65 million people**, 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one. ¹
2. Seven in 10 caregivers are non-Hispanic White (72%), 13% are African-American, and 2% each are Hispanic or Asian-American. Six in ten caregivers are married (58%). Caregivers are predominantly female (66%). They are 48 years of age, on average. One third take care of two or more people (34%). ¹
3. A large majority of caregivers provide care for a relative. More than 37% have children or grandchildren under 18 years old living with them. ¹
4. Caregiving is particularly time-intensive for those who live with their care recipient (39.3 hours/week) and those caring for a child under the age of 18 (29.7 hours/week). ¹

Women and Caregiving

1. Female caregivers spend more time providing care than men do, on average (21.9 vs. 17.4 hours/week). ¹
2. Women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income (SSI). ⁴
3. Stress at home appears to affect younger female employees most, with over 20% of caregiving women ages 18 to 39 reporting they are “almost always” stressed at home. In non-caregiving employees of the same age, only 11% report such a level of stress. ⁷
4. More women than men are caregivers: an estimated 66% of caregivers are female. One-third (34%) take care of two or more people, and the average age of a female caregiver is 48. ¹
5. Other studies have found that 36% of women caregivers handle the most difficult caregiving tasks (i.e., bathing, toileting and dressing) when compared with 24% for their male counterparts, who are more likely to help with finances, arrange care, and other less burdensome tasks. ¹

Caregiving Economic Statistics

1. The value of the services family caregivers provide for “free,” when caring for older adults, is estimated to be **\$450 billion** a year. That is more than total Medicaid spending in 2009, including both federal and state contributions for both health care and Long-Term Services and Supports (\$361 billion).
2. 47% of working caregivers indicate an increase in caregiving expenses has caused them to use up ALL or MOST of their savings. ³
3. The average family caregiver of someone 50 years or older spent \$5,531 per year on out of pocket caregiving expenses in 2007 which was more than 10% of the median income for a family caregiver that year. ⁵

Impact on Family Caregiver’s Health

1. 23% of family caregivers caring for loved ones for 5 years or more report their health is fair/poor. ¹

2. Nearly three quarters (72%) of family caregivers report not going to the doctor as often as they should and 55% say they skip doctor appointments for themselves. 63% of caregivers report having poorer eating habits than non-caregivers and 58% indicate worse exercise habits than before caregiving responsibilities. ²
3. 40% to 70% of family caregivers have clinically significant symptoms of depression with approximately a quarter to half of these caregivers meeting the diagnostic criteria for major depression. ⁶

Caregiving and Work

1. 73% of family caregivers who care for someone over the age of 18 either work or have worked while providing care; 66% have had to make some adjustments to their work life, from reporting late to work to giving up work entirely; and 1 in 5 family caregivers have had to take a leave of absence. ¹
2. **American businesses can lose as much as \$34 billion** each year due to employees' need to care for loved ones 50 years of age and older. ⁷

Caregiving and Health Care

1. Employees providing eldercare were more likely to report fair or poor health, and are more likely to report depression, diabetes, hypertension, or pulmonary disease. ⁷
2. Employees providing eldercare were more likely to report fair or poor health in general. They were significantly more likely to report depression, diabetes, hypertension, or pulmonary disease regardless of age, gender, and work type. ⁷

Caregiver Self-Awareness

1. Over 90% of family caregivers become more proactive about seeking resources and skills they need to assist their care recipient after they have self-identified. ⁸
2. 83% of self-identified family caregivers believe their self-awareness led to increased confidence when talking to healthcare professionals about their loved one's care. ⁸

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