

Care for the Caregiver: It's Not Selfish...It's Practical

By Amy Goyer

Five tips to make self-care easier when caring for others.

Caregiving for family or friends can be stressful, time-consuming, challenging, and sometimes overwhelming. Before we know it, we are exhausted and our own lives suffer with mental and physical health issues, relationship conflicts, and financial problems. The prolonged stress can lead to burnout, and burnout hurts both the caregiver and the care recipient. We can't care well for others when we are so depleted. We become cranky, short-tempered, unobservant, have difficulty juggling it all, and some caregivers become ill and can't care for loved ones anymore.

Many caregivers say they feel guilty if they do things for themselves while caregiving. It's important to remember that caring for ourselves while caring for others isn't selfish. Reasonable self-care isn't wrong, it's an important part of caring for others. Just as musicians take care of their instruments – which are the tools of their trade and needed to do their jobs – we must take care of ourselves so we can care for others. It's just practical.

I've been a caregiver my entire adult life, so I get it. We just keep going and going because people need us, and we put ourselves at the bottom of the list over and over. And aren't they more vulnerable than we are? Sometimes they really are – we all experience caregiving crises when we must drop everything and focus on those we care for. But the truth is, caregiving is more like a marathon than a sprint, so we must pace ourselves. Family caregivers are also very vulnerable. We just don't realize it until it's too late.

It can be hard to figure out how to fit self-care into our busy schedules. So here are 5 tips to help you take care of your loved ones' most valuable resource...you.

1. **Schedule it.** It's as simple as this: if it's on the calendar, we are much more likely to do it. Schedule check-ups, lab tests, and medical procedures ahead of time. You can start by scheduling a time to call doctors, counselors, therapists, and other healthcare practitioners to set up several appointments at once. When you leave an appointment, be sure to schedule the next one. (Be sure to let your health care practitioners know that you are a caregiver.) Schedule time for exercise classes and other physical activity – even if it's a simple walk around the block or just three minutes to meditate, stretch or do jumping jacks. Schedule time to rest. Schedule caregiver support groups. Schedule fun and relaxation time too!



2. **Accept Help.** Caregiving is, at minimum, a part-time job, and for some, it's a full-time job (with overtime). No one can, or should be expected to, do it all on top of their own lives. You may feel like you must do it all because no other family members will help. But we must build our caregiving teams beyond family. Neighbors, friends, organizations/services, and others are team members too.

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Mission

To provide a comprehensive and coordinated system of services designed to promote the independence and dignity of older persons and their families in Muskegon, Oceana, and Ottawa – a mission compelling us to target older persons in greatest need but to advocate for all.



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Go Green or Stop Receiving Newsletter

If you would like your copy of the *Caregiver Link* emailed or would like to discontinue receiving our newsletter, simply send your request to:

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Mom's hair stylist and manicurist were important members of our caregiving team (I don't know what I'd have done without their help!). Veterans Affairs was also a crucial part of our team, as were our mobile doctors. A geriatric care manager or patient advocate can help too. People who help you are also part of the team. My neighbor who mowed my grass, a "concierge" or personal assistant who helped me stay organized, a handyman, and others were crucial so I could do the things that only I could do for my parents. The next time someone asks if they can help, say "yes"! And tell them specifically what would help you the most.

3. Stay Connected. Caregiving can be very isolating. Our world gets a bit smaller as we focus on our loved ones and other top priorities like our jobs or raising children. Socialization and fun become minimized as we let go of hobbies, gatherings with friends, and other activities. Even if it's once a month or every two months, schedule time with friends, a class, or another outing so you have them to look forward to. No one understands quite like another current or former family caregiver, so consider joining an in-person or online caregiver support group. Therapy, counseling, or life coaching may be helpful too.

4. Fill Up and Take Breaks: I've learned that I can't run on empty any easier than my car can – and I'm not as efficient when I'm running on low reserves of mental or physical energy. You fill your car's gas tank on a regular basis, get tune-ups, and do routine maintenance. Do the same for yourself! Think about what 'fills you up' – regular, quick things like getting a cup of coffee, texting a friend, or sharing a hug; and premium things every now and then like dinner out, seeing a movie, or taking a class. For you, routine maintenance includes getting good quantity/quality sleep, going to doctor appointments, and laughing on a regular basis. Time away from caregiving is our 'tune-up' and respite care may be helpful for that. Remember that doing things to fill yourself up will help you support your loved ones better.



5. Adjust Your Attitude. Some family caregivers come through the experience better than others, and generally, I find that their attitude is what makes the biggest difference, not the circumstances of their caregiving situation. For example, try to get out of a victim mentality and instead focus on what you choose to do – you choose to be there for your loved ones (even though you don't choose the specifics of the situation) and there are many people who have no one who chose to care for them. If you feel like a failure because you are not a perfect caregiver, focus on the fact that there is no perfect caregiver, and you are doing the best you can; that's all that anyone can ask for. I realized that success for caregivers isn't perfection, it's resilience – getting back up when we get knocked down and continuing the journey with our loved ones. Being there for them as best we can – *that* is success! ❖

What is Hospice?

Source: American Hospice Foundation

Hospice includes medical care with an emphasis on pain management and symptom relief. Hospice teams of professionals and volunteers also address the emotional, social, and spiritual needs of the patient and the whole family. Overseeing all patient care is the hospice medical director who may also serve as the attending physician. Alternatively, the patient's own physician may continue in this role, in coordination with the hospice team and its plan of care.

Medical Care

Pain management is of particular concern for a patient with a life-threatening illness. Hospice staff are the experts in state-of-the-art pain treatments, helping patients feel comfortable with pain management alternatives. If administering pain medication requires a new skill, family members can count on the hospice staff for training and guidance.

Most medical treatments needed to make a terminally ill patient physically comfortable can be provided at home. Recent technological advances allow for a wide variety of equipment to be installed in the home, thus reducing the need for hospitalization, except in the most complicated cases. In rare cases when symptoms cannot be controlled at home, inpatient facilities are available.

Emotional and Spiritual Support

The fear of death is often due to the fear of pain and abandonment. Hospice staff includes bereavement and spiritual counselors who help patients and families come to terms with dying. They assist patients in finishing important tasks, saying their final goodbyes, healing broken family relationships, distributing precious objects, and completing a spiritual journey.

Unfinished business can make dying harder and grieving more difficult for those left behind. Hospice staff recognizes that a person who comes to terms with dying has a less stressful death, and that the family benefits from a less complicated grieving process. A source of relief and comfort for many hospice patients is the knowledge that the family will receive ongoing bereavement support.

Practical Considerations

The day-to-day chores of life can become overwhelming for family caregivers. Hospice staff can teach them to care for the dying person at home — administer medications, operate equipment, and coordinate services. Volunteers are integral members of the hospice staff, providing companionship and assistance in household chores.

Financial Concerns

Financial worries can be a major burden for a patient facing a terminal illness. Most hospice patients are Medicare participants with ready access to a hospice benefit that minimizes out-of-pocket expenses in the last months of life. The Medicare hospice benefit covers prescribed medications, visits by medical and nursing professionals, home health aides, short-term inpatient care, and bereavement support for the family after the patient has died. The Medicare

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May's Website

www.aarp.org/aarp/caregivers

Quotes

"A mother understands what a child doesn't say."

Jewish Proverb

"There's no way to be a perfect mother, but a million ways to be a good one."

– Jill Churchill

"A mother is the one who fills your heart in the first place."

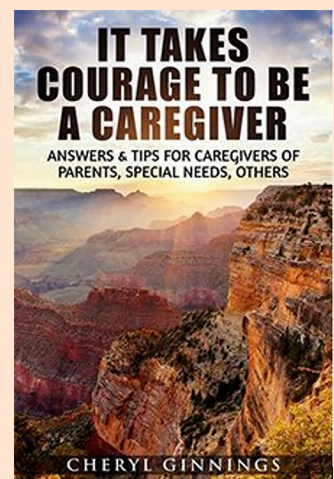
– Amy Tan

This Month's Book

It Takes Courage to be a Caregiver

by Cheryl Ginnings

Be the voice for those who have no voice!" Cheryl is a Caregiver from her early years watching as one grandparent, her parents, and her son had cerebral palsy.



Exercise: Good Medicine for the Brain

by Leilani Doty, PhD

Regular physical exercise is important for brain health. Being active is important whether a person has normal memory and thinking abilities or has a memory disorder.

Improvements have been measured in older men and women with normal memory who live independently in the community and are physically active, even if they start becoming active later in life. Research using a simple test of memory and thinking functions on people with early-stage Alzheimer's disease has shown that inactive people have a significant decrease in their scores when their scores are compared to those of more active people. A careful review of 10 research studies found evidence that exercise improves walking and slows the decline in personal care activities of daily living such as eating, bathing, dressing, etc., of people who have Alzheimer's disease and live in residential care facilities.

Exercise That Helps the Brain

A routine that involves 30 to 40 minutes at a time of physical exercise for 5 days a week improves memory, attention, language skills, and other thinking functions. Some research found improvements in older people who exercised as little as 2 or 3 times a week.

Any one or a mix of the following types of exercise seem to be the most helpful:

- **Walking** - such as moderate walking that works up a light sweat.
- **Bicycling** – 2- or 3-wheel bicycle or on a stationary or exercise bike

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What is Hospice?, continued from page 3

hospice benefit also eliminates the burden of paperwork, as families are not required to submit claims or pay bills. For patients without hospice insurance, financial accommodations are made based on ability to pay.

Hospice: The Challenge to American Health Care Consumers

Hospice is easily confused with less attractive alternatives, and, as a concept, it suffers from a powerful denial syndrome in our society. Hospice must be better understood if it is to reach all those who need it. When all Americans know what hospice is, they will not only make it an explicit part of their long-term plans, but their fear of death will be abated. Increased visibility of hospice, locally and nationally, will result in more people becoming pro-active advocates for themselves and their families.

How is the American Hospice Foundation addressing the challenge?

The American Hospice Foundation's mission is to spread the hospice message in local communities and across the country. This is the message of hope that a dignified death at home is an option for all Americans and that grief support is readily available for all adults and children. To fulfill its mission, the Foundation conducts public education campaigns and fosters research that benefits hospice consumers.



To educate the public about hospice, the American Hospice Foundation works with strategic messengers such as employee assistance professionals, teachers, school psychologists, and pastoral counselors. These professionals are in the position of teaching or counseling others about grief, death, and dying issues. Since it is still difficult to discuss death in our society, we often begin our efforts with messages related to grief. When hospice organizations provide this informal. ❖

COMMON MYTHS OF HOSPICE

Source: American Association of Hospice

Myth #1: Hospice is a place. Hospice care takes place wherever the need exists – usually the patient's home. About 70 percent of hospice care takes place where the patient lives.

Myth #2: Hospice is only for people with cancer. More than one-half of hospice patients nation-wide have diagnoses other than cancer. In urban areas, hospices serve many HIV/AIDS patients. Increasingly, hospices are also serving families coping with the end-stages of chronic diseases, like emphysema, Alzheimer's, cardiovascular, and neuromuscular diseases.

Myth #3: Hospice is only for old people. Although the majority of hospice patients are older, hospices serve patients of all ages. Many hospices offer clinical staff with expertise in pediatric hospice care. Almost 20% of hospice patients are under 65 years of age.

Myth #4: Hospice is only for dying people. As a family-centered concept of care, hospice focuses as much on the grieving family as on the dying patient. Most hospices make their grief services available to the community at large, serving schools, churches, and the workplace.

Myth #5: Hospice can only help when family members are available to provide care. Recognizing that terminally ill people may live alone, or with family members unable to provide care, many hospices coordinate community resources to make home care possible. Or they help to find an alternative location where the patient can safely receive care.

Myth #6: Hospice is for people who don't need a high level of care. Hospice is serious medicine. Most hospices are Medicare-certified, requiring that they employ experienced medical and nursing personnel with skills in symptom control. Hospices offer state-of-the-art palliative care, using advanced technologies to prevent or alleviate distressing symptoms.

Myth #7: Hospice is only for people who can accept death. While those affected by terminal illness struggle to come to terms with death, hospices gently help them find their way at their own speed. Many hospices welcome inquiries from families who are unsure about their needs and preferences. Hospice staff are readily available to discuss all options and to facilitate family decisions.

Myth # 8: Hospice care is expensive. Most people who use hospice are over 65 and are entitled to the Medicare Hospice Benefit. This benefit covers virtually all hospice services and requires little, if any, out-of-pocket costs. This means that there are no financial burdens incurred by the family, in sharp contrast to the huge financial expenses at the end of life which may be incurred when hospice is not used.

Myth # 9: Hospice is not covered by managed care. While managed care organizations (MCOs) are not required to include hospice coverage, Medicare beneficiaries can use their Medicare hospice benefit anytime, anywhere they choose. They are not locked into the end-of-life services offered or not offered by the MCOs. On the other hand, those under 65 are confined to the MCO's services, but most provide at least some coverage for hospice.

Myth # 10: Hospice is for when there is no hope. When death is in sight, there are two options: submit without hope or live life as fully as ever until the end. The gift of hospice is its capacity to help families see how much can be shared at the end of life through personal and spiritual connections often left behind. It is no wonder that many family members can look back upon their hospice experience with gratitude, and with the knowledge that everything possible was done towards a peaceful death. ❖



Exercise, continued from page 4



- **Jogging**
- **Resistance training to improve muscle strength** - using push-pull exercise machines in a gym; wide rubber stretch-bands (sometimes called resistance bands, they range from easy-highly stretchable to a firm-heavy-duty stretchable.); or lifting small free weights.

Healthy Changes in the Brain

One research project measured the hippocampus, the brain area responsible for storing short-term memories. Measurements of the hippocampus took place at the beginning and again at the end of the study. In the older people who were in the walking-group, there was a 2% increase in their hippocampus while the comparison group which only did stretching and toning exercises had a 1.5% decrease in that area of the brain.

Researchers have concluded that routine physical exercise makes a significant difference in brain health, brain function, as well as general health such as improving muscle and bone strength, reducing (high) blood pressure, strengthening the heart, increasing the effectiveness of insulin, helping the GI tract, and especially reducing caregiver stress. And it is never too late to start being active and gaining benefit from physical exercise! A healthier caregiver can manage much better the ongoing challenges of decline in a loved one who has progressive dementia. ❖

Tips for Older Adults to Drive Safely

Source: National Institute on Aging

Maybe you already know that driving at night or in rainy weather is a problem for you. Some older drivers also have problems with certain routes or driving on busy highways, for example. Consider these tips to help you make safe choices about driving:

- Talk to your doctor. If you have any concerns about your health and driving, see your doctor. Don't risk hurting yourself or others.
- Be physically active. This will help you keep and even improve your strength and flexibility, which may help your driving abilities.
- Consider your car. If possible, drive a car with automatic transmission, power steering, power brakes, and large mirrors. Newer cars come equipped with backup cameras, which can make parking and backing up easier, as well as other sensors that can alert a driver to a nearby object or vehicle before an accident occurs.
- Take care of your eyes and ears. Always wear your glasses or contact lenses if you need them to see clearly. If you use hearing aids, be sure to wear them while driving.
- Avoid driving at certain times of day. Cut back on or stop driving at night if you have trouble seeing in the dark. Try to avoid driving during sunrise and sunset, when the sun can be directly in your line of vision.
- Check in with yourself. Don't drive if you feel lightheaded or drowsy. Be sure to check any warnings on your medications. Try to avoid driving when you are stressed or tired.

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My Mother Doesn't Listen to Me! The New Role of Eldercare Mediation

by Doris Haas, RN, CCM, CMC, QDCS

As a geriatric care manager, I am considered an expert in issues relating to the elderly. However, where my mother is concerned, I am just a daughter who cares. She often takes the advice of friends and even strangers over mine.

So now she has become the caregiver for her boyfriend, a man diagnosed with Alzheimer's disease. Though I have been watching him decline, and discussing the disease process with her, she still does not want to believe that he can no longer take care of himself. Recently at the doctor's office, he was told that he could no longer drive, and needs someone to visually see him take his medications. He has sent away the aides that were hired and needs to move to an assisted living residence.

My mother does not live with him, nor does she want to take on that kind of responsibility. She cannot make this man move when he thinks it is unnecessary. She has been communicating with his son who lives out of state and he has not come down to help. He has been comfortable having my mother look after his father and does not want to accept that she can no longer do this.

I see that there is a place for an eldercare mediator. There is a breakdown of communication between my mother and his son, and caregiver responsibilities need to be clarified. Since neither one of them will listen to me, another professional needs to be called in to help. I know other geriatric care managers that are also certified mediators.

What Is Mediation?

Mediation is a process in which people meet in a private confidential setting to work out a solution to their problem with the help of a neutral person (a mediator). The mediator is not a judge, does not decide who is right or wrong, and does not force the parties to accept any agreement or terms to an agreement. Instead, the mediator listens to the parties explain their concerns and helps them develop and agree upon a workable, mutually acceptable solution.



Eldercare mediation deals with any conflicts involving seniors and their families. Sometimes children argue about their parents' care. Sometimes seniors argue with their children. When the conflict begins to deteriorate relationships, a mediator should be called in.

Why Try Mediation?

Mediation is private and confidential. Participants can express themselves in a safe situation where the other participants listen. Mediators keep the focus on the issues so that families can move beyond underlying problems. Exploration of different options and creative problem solving is encouraged. They become empowered and design their own agreements. Older persons participate if able, which gives them maximum control over basic life decisions. This approach is non-adversarial.

What Kinds of Issues Can Be Mediated?

- Medical/Healthcare decisions
- Financial decisions
- Living arrangements
- Communication issues – sharing of information
- Family relationships
- Decision-making authority
- Respite care and support for caregivers
- Personal, household care and maintenance
- Safety/risk-taking/autonomy – should autonomy be limited?
- Needs of other family members
- Less restrictive alternatives to guardianship

How Successful Is Mediation?

In a recent study, 8 out of 10 cases were successfully resolved; 8.5 out of 10 mediated cases were followed through by the parties. The success rate is so high because the solutions are designed by the parties themselves. Even if an agreement is not reached, the parties will walk away with clarified issues and a better understanding of each other's viewpoints.

Why Do Geriatric Care Managers (with mediation training) Make the Best Eldercare Mediators?

Unlike lawyers, who have specialized knowledge of elder law and legal issues, geriatric care managers have specialized knowledge of elder care. We know what successful aging is, understand the healthcare system, know the local resources for seniors, understand housing options, insurance, and the different types of home health services. We can talk about end of life decisions and discuss palliative versus aggressive care. The utmost important goal is to provide the highest quality of life for our elders and can offer different options to achieve this.

Professional geriatric care managers are generally nurses and social workers with extensive experience working with seniors. We can evaluate and assist families in determining what course of action will provide the best care for their loved one. ❖

Tips, continued from page 6



- Don't crowd. Leave ample space between your car and the car in front of you and start braking early when you need to stop.
- Plan your timing. Avoid heavy traffic areas or rush-hour driving when you can.
- Plan your route. Drive on streets you know and find a way to go that requires few or no left turns. Choose a route that avoids highways or other high-speed roadways. If you must drive on a fast-moving highway, drive in the right-hand lane, where traffic moves more slowly.
- When in doubt, don't go out. Bad weather, such as rain, ice, or snow, can make it hard for anyone to drive. Try to wait until the weather is better, or use buses, taxis, ridesharing services, or other alternatives.
- Wear seat belts. Always wear your seat belt and make sure your passengers wear theirs, too.
- Limit distractions. Eating, adjusting the radio, or chatting can all be distracting. If you use your cellphone while driving (for navigation, for example), use it hands-free and use voice activation when possible. Never type on your phone while driving.
- Use window defrosters. These will help keep windows and windshields clear. ❖



Happy Mother's day

Wishing you time,
just to dream, just to relax,
just to enjoy!

Sunday, May 14 MOTHER'S DAY

Source: *Town & Country*

Did you know?

More phone calls are made on Mother's Day than any other day of the year.

Mother's Day is the third highest selling holiday for flowers and plants.

One of the earliest Mother's Day celebrations was in Ancient Greece

Normally, Mother's Day is the busiest day of the year for restaurants.

The history of American Mother's Day starts with peacemaker Ann Jarvis. Ann's daughter continued her legacy by creating the official holiday.

Woodrow Wilson signed Mother's Day into law in 1914.

The most popular gift for Mother's Day is the greeting card.

Mother's Day is celebrated all over the world.

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