

Sharing & Caring: How to Share the Work of Family Caregiving

By Jessica Farthing

Without the right approach, sharing family caregiving responsibilities can be almost as stressful as going it alone. Here are some strategies for getting along with a co-caregiver.

My sister and I shared caregiving responsibilities for my mother, and I know from experience that while those of us with a caregiving team are fortunate to have the help and support, sharing caregiving duties can be a stressful experience. Studies show that there is a higher risk of negative psychological effects for caregivers, especially those who care for older adults with advanced dementia.

While there is a clear benefit to splitting the overwhelming duties that come with the responsibilities of care, issues can erupt between even the most cohesive team. How do you maximize the benefit and reduce the conflict? Through my own journey and in speaking with experts, I know there are a few clear strategies that can help make sharing tasks easier.

Jill Costello, a certified dementia counselor and the program coordinator for the Edel Caregiver Institute in Savannah, Georgia, helps families navigate the many issues that come with caregiving.

“The most stress comes from guilt for the caregiver,” Costello told *Being Patient*. “They wonder if they’re doing enough, or doing things the right way, like they promised.”

When someone is diagnosed with dementia, Costello feels it’s a group issue. “When someone in the family gets dementia, the whole family gets dementia,” she said. “Then, they have to decide how they are going to deal with it.”

Here are a few guidelines for those beginning with caregiving—and hoping to share the responsibilities with others.

1. Plan—Together

From the beginning, Costello said, it helps to set up a meeting for everyone involved with your loved one.

Before the meeting, identify different jobs that need to be done. Then, during the discussion, assign duties and roles to all helpers.

In divvying up these roles, everyone should build on their strengths: Is one person especially good with finances or dealing with insurance issues? Is there a great cook in the group? Is someone located closer, who can be there quickly if sudden help is needed? Find someone who meets that last criterion and appoint them the person who will be in charge in the event of an emergency.

Keep in mind, geography doesn’t limit caregiving ability. While long-distance caregiving team members may not be present for the physical day-to-day, they are well positioned to help with online tasks, from research on medication or available resources to financial paperwork and insurance issues. Establishing a role for those who don’t live close by is an important step to engage them and to allow them to feel useful and involved.

2. Don’t Try to Do It All

“Allow yourself to feel whatever comes up, because it’s a frustrating and sad process, and we’re not superheroes. I

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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.



Caregiver Support Staff

Virginia Vazquez

Caregiver Support Specialist
vvazquez@seniorresourceswmi.org
231.733.3531

Paula Kolberg

Caregiver Support Specialist
pkolberg@seniorresourceswmi.org
231.683.4760

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kport@seniorresourceswmi.org.

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think we have an expectation that we're supposed to be happy all the time and caring for our loved ones while caring for ourselves, and you can't do it all—so just recognize when you need help—and when it comes along, take it.”

While caregivers might feel that no one can look after the person with Alzheimer's or other forms of dementia as well as they can, there is more than one benefit to allowing others into the situation. A new person might view the situation with fresh eyes, with a different perspective and new ideas for solutions.

The person receiving the care also gets advantages. “Your loved one might also benefit from a break from you,” cautioning that those who aren't involved in the day-to-day should be careful of not overwhelming the person they're helping to care for.

“People living with dementia can rise to the occasion and then crash. We must teach the whole family to rally not only around the person living with dementia or Alzheimer's, but also the caregiver.”

3. Be Your Own Advocate

Communication is important in a situation where everyone is sharing work. For example, sometimes a primary caregiver might simply need a few days to recharge. But caregivers are no strangers to guilt, and if the request for a little break is seen as a complaint to the other members of the network, it can open the floodgates for guilt and resentment. In my experience, and in Costello's, this can be avoided with the right kind of open communication.

Costello suggested focusing on your own feelings. “Don't make things sound accusatory. Use a sense of gratefulness, and say that you need a break,” she advised. “Be willing to compromise. Tell the others you'll make it up to them at another time.”

Caregivers can fear angering other members of the care team, but being assured and direct in seeking help gets better with practice. A good way to self-monitor requests is to pretend that the roles are reversed. How would you feel if a caregiver was asking the same things of you?

It works to understand that the person you're asking has feelings and stressors also. Try framing your request with a statement that shows this. It might be, “I know you are really busy with your travel schedule, but if you can block off a few days, I need to spend time with my husband.”

Even with a team, caregiving can be isolating. That's why communication with the team is key.

“But when you're living day-to-day with people suffering from this disease, you can kind of start to feel like all these emotions—this roller coaster that you're on—are strictly your own feelings. I think that's where the loneliness comes in.” ❖

How to provide emotional support to someone with depression

Be there to listen without judgment. Talking about mental illness can be uncomfortable, so it's important that you create a safe space for someone who is depressed to open.

Try expressing your love, care, and support. Acknowledge that depression is awful and feels terrible. Support them by recommending treatment, including offers to seek out a good and appropriate therapist, and even to go with them to a first appointment.

If you have concerns, ask them if they feel like harming themselves. This is very important. Often times, a person with depression will suffer in silence, but friends and family need to be mindful of behavior changes and make sure not to ignore them.

If they answer yes to harming themselves, ask them if they have a plan. If they don't, remove any threats for their access and escort them to an emergency room.

How to provide physical support to someone living with depression

Offer to help with daily tasks. Take them to a therapy appointment, help them get things done they feel too overwhelmed to do like grocery shopping, help them with self-care or home care if they are unable or just not doing it, show up and take them to dinner or to meet other friends or family who can support too.

Make sure they stay connected. It's common for someone with depression to isolate, but as a caregiver, it's crucial to make sure they stay engaged with other people. Help them to leave the house and be with others by making arrangements and showing up to get them—in other words, don't take no for an answer.

Get moving. Physical activity is a great way to improve mood. A depressed person does not have the motivation and the energy to get up and be active; it can also be severe when they don't want to leave home. However, you can suggest making plans for different activities together—things like taking a brisk walk in a park, swimming, yoga, dancing, and gardening. Pretty much anything that involves movement, activity, and stimulation is beneficial.

Tips for caregivers to avoid burnout

As the saying goes, it's important to buckle your own seatbelt first—so it's important for caregivers to take care of themselves, too. Here are a few ways to do that.

Take breaks. Enlist others to help you, and treat yourself well in terms of sleep, eating, and avoiding alcohol or drugs.

Make sure you have your own outlet. Being a caregiver for someone with depression can take a toll mentally and physically. Have someone you can talk to about how you are feeling and doing.



Engage in physical activity. Movement can change the way you feel. “Try to exercise three to four times a week to destress and boost your mood.”

Manage your time effectively. Making sure to find balance in your life is crucial. When life is not balanced and you have neglected yourself, you may become quite anxious and overwhelmed. Plan your week, allowing time for your needs, responsibilities, and wants. As a caregiver, sometimes one may feel they are not a priority. But, on the contrary, the caregiver needs to be well to provide care.

Take some time to enjoy simple pleasures . It's essential to decompress from the stress of caregiving, simple things like reading a book, sitting quietly, meditation, and listening to music.

Get enough sleep. If you aren't rested, it's like trying to drive a car on an empty tank. Sleep is vital for your emotional wellness and daily functioning. ❖



August's Website

www.aarp.org/aarp/caregivers

Quotes

Love yourself, you are worthy.
Anonymous

Begin and end each day with a grateful heart.
Anonymous

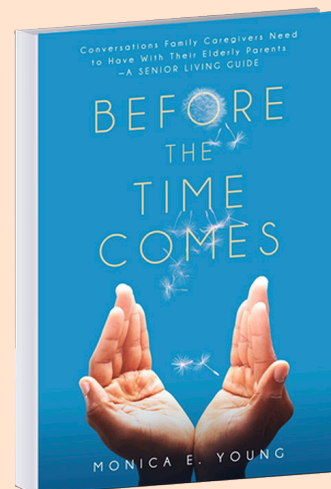
You make a living by what you get,
you make a life by what you give.
W. Churchill

This Month's Book

Before the Time Comes

by Monica E. Young

Most important for any caregiver is a guide to all the things to consider as you take over your parent's life. If you begin by talking and sharing with the whole family, you can then complete the worksheets presented in *Before the Time Comes* and use this concrete information as your tool to help with successful aging.



Strategies to Support Nutrition

Your loved one has a low appetite. They only eat small amounts of food. Food may not taste good to your loved one. Their senses of smell and taste can diminish with age. Medication can also cause food to taste bad. Serve small portions frequently throughout the day instead of serving three large meals. Keep in mind that if your loved one is less active, then they won't need to eat as much as they used to. Use additional seasoning to make foods more appealing. Try out different foods. The food your loved one likes may change from day to day.

Your loved one's digestive system does not absorb nutrients as well. This is common with aging. Provide nutritional supplements, such as smoothies or prepared beverages.

Your loved one is less sensitive or more sensitive to the temperature of their food. Ensure that food is a proper temperature when served. Consider testing the food before serving it to your loved one.

Your loved one experiences constipation. This may be due to digestive problems or medications. Prepare fiber rich foods like fruit, dark vegetables, beans, whole wheat bread, brown rice, and oatmeal. Look for cereals with 5g or more of fiber.

Your loved one experiences fatigue or tiredness that makes it hard for them to finish a meal. Try to serve food ready to eat. For example, put butter on bread before serving. If your loved one has trouble sitting up, try using pillows to improve their posture.

Your loved one has problems with their vision. Ensure that the eating environment is attractive and well lit. Arrange food around the plate

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Five Stages of Parkinson's Disease

By Kristeen Cherney

The stages of Parkinson's disease can help give a person and their doctor an idea of how the disorder may progress. The disease is characterized by certain hallmark symptoms (resting tremor, stiffness, and slowness of movement), but no two cases of the disease are alike.

A person may experience only mild symptoms that don't interrupt their daily activities in the early stages of Parkinson's disease. Over time, people with Parkinson's disease may develop severe mobility challenges that make it difficult to stand or walk.

While there's no telling what any individual's Parkinson's disease stages timeline will look like, understanding what to expect over the course of the disease can help you and a caregiver plan ahead.

Parkinson's disease is a neurological movement disorder that's progressive, meaning symptoms worsen over time. According to the Parkinson's Foundation, most people move through the stages of Parkinson's disease gradually (and if symptoms happen to get worse quickly, over days or weeks, it might be a sign that something else is going on).

There's no lab test that can tell a person which stage their disease is in. Instead, it's based on how severe a person's movement symptoms are, and how much the disease impacts their ability to go about daily life.

While the stages of Parkinson's disease can look a little different for everyone, here's a typical pattern of the disease, per the Parkinson's Foundation:

Stage 1

In the early stages of Parkinson's disease, a person may have mild motor symptoms, like a tremor, but can still go about their daily life, whether they're working, running errands, or enjoying hobbies, without incident. Movement symptoms usually occur only on one side of the body. Stage 1 Parkinson's disease may include changes in a person's facial expressions, posture, or walking, as well.

Stage 2

Symptoms become more noticeable in stage 2 Parkinson's disease. Movement difficulties and muscle stiffness tend to affect both sides of the body and chores may become more time-consuming. The person at this stage of Parkinson's might also have trouble walking or maintaining good posture.

Stage 3

Stage 3 is considered mid-stage Parkinson's disease. It's when a person often begins to have a loss of balance and a higher risk of falling.

Everyday activities like cooking, cleaning, dressing, and eating can be more challenging, but most people with stage 3 Parkinson's disease are still fully independent.

Stage 4

In stage 4 Parkinson's disease, a person starts to experience more severe and debilitating symptoms. They may need to use a walker or another form of

assistance to get around. You may need full-time help to live in your home as you progress through mid-to-late-stage Parkinson's.

Stage 5

This is the most advanced stage of the disease and symptoms can be intense. A person with late-stage Parkinson's disease usually has leg stiffness that prevents them from standing or walking. They may need to use a wheelchair or be unable to leave their bed and require 24/7 nursing care while living with stage 5 Parkinson's disease. Hallucinations and delusions also become more likely at this stage.

Doctors may refer to these stages of Parkinson's as the Hoehn and Yahr scale: stages 1 and 2 are considered early-stage; stages 2 and 3 are considered mid-stage; and stages 4 and 5 are considered late-stage.



What are the non-motor symptoms of Parkinson's?

Parkinson's disease stages are defined by the severity of a patient's motor symptoms and how much those symptoms impact one's ability to function every day. But there are non-motor symptoms that are more likely to develop later in the disease, too, and a doctor may take those into consideration when assessing someone with the disorder.

For example, people with late-stage Parkinson's disease might have difficulty chewing, eating, speaking, or swallowing ("dysphagia"), which is considered both a motor and non-motor symptom. Dysphagia in particular can lead to serious health problems like malnutrition, dehydration, and aspiration.

In the final stages of Parkinson's disease, a person might develop cognitive changes, including slowness of memory or thinking, trouble planning and accomplishing tasks, and difficulty concentrating. (According to the Parkinson's Foundation, approximately 50% of people with Parkinson's will experience some form of

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and tell them where each item is. For example, say "the fish is at 2 o'clock, the potatoes are at 6 o'clock."

Your loved one has problems with their teeth or gums that make it difficult to eat. Food may need to be cut into small pieces. Serve soft foods that are easy to chew. Ensure that your loved one has regular appointments with their dentist or dentist. Mouth discomfort could be from poorly fitting dentures or a treatable problem.

Your loved one has difficulty using a fork and knife due to weakness in their hands or a tremor. You can purchase utensils with larger handles that are easier to grip. You can also purchase plates that have high sides.

Your loved one has experienced a change in mental status or cognition. Some people who have cognitive impairments do well when provided with soft finger foods such as chopped hard-boiled eggs; sandwiches cut into small pieces or small pieces of soft fruits such as strawberries or bananas.

Your loved one has difficulty swallowing. The medical term for this is dysphagia. If your loved one has dysphagia, you should consult your healthcare provider for tips on how to prepare meals.

As a caregiver, you may have many responsibilities. Supporting the nutrition of your loved one is just one of them. You may find it helpful to make individual portions in advance and keep them in the freezer. Check to see if there are any meal delivery programs for older adults available in your area. You can also consider purchasing pre-cut foods, frozen dinners, and pureed foods to reduce the time required to prepare food. ❖

Detective Caregiver

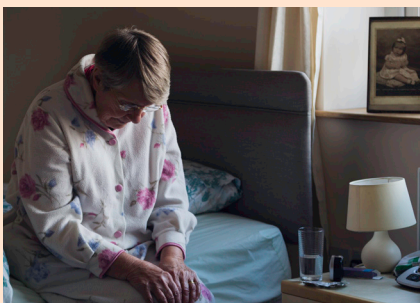
by Gary Barg

Now that a summer is upon us where we feel at ease about traveling once again (except, of course, when standing at the gas pump), it is time to put on our deerstalker hat and reflectively puff on an empty Calabash pipe ala Sherlock Holmes and in his shadow become a loving (but slightly nose) caregiver detective. If you are traveling to visit your loved ones who may need care, your trip affords an ideal time to assess any changes in their health and well-being.

As any good detective knows, the first step is to follow the clues.

Clue One - Your loved one's home:

- What condition is it in? Is it a clean, clutter free and safe environment?
- The kitchen is where you can find a lot of telling clues. Look for signs of spoiled food, or an excess of junk/convenience foods compared to the last visit. This may be a sign they have stopped cooking.
- Is the bathroom safe, with grab bars (if necessary) and slip proof mats? Are cords dangling dangerously near running water?



Clue Two - Your loved one's behavior:

- How do they handle their medication regimen? Are they using expired medications?

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cognitive impairment, and that can lead to full-blown dementia for some.) Or they might notice changes in their bone health or vision.

But there's no telling for sure if or when these symptoms will occur in any individual because Parkinson's disease symptoms vary from person to person.

How fast does Parkinson's disease progress?

People tend to move through the Parkinson's disease stages slowly, usually over the course of years. Research has shown that the disease tends to progress less rapidly in people who are diagnosed at a younger age (say, their mid-50s) than those diagnosed later in life.

What's more, Parkinson's disease may begin decades before a patient even notices a single motor symptom.

"We know that Parkinson's disease actually starts many, many years before you see that tremor or that shuffling."

That early stage of Parkinson's disease is called the "pre-motor" stage. It happens before a person has been diagnosed, and may include symptoms like loss of smell, REM sleep behavior disorder (where a person acts out their dreams), and constipation.

But the reality is that, as with Parkinson's disease symptoms, Parkinson's disease progression will vary from person to person. "Some people have had Parkinson's for two years and they're not doing so well, and then some people have Parkinson's for 20 years and they're doing great and living their lives."

Fortunately, treatments can help a person manage symptoms and live a more functional life throughout many stages of Parkinson's disease. ❖

Hot Weather Health Tips

For most people a long hot spell is just uncomfortable. Heat waves can be more serious for elderly people. Older adults perspire less than younger people. Without perspiration body temperatures rise quickly, posing a threat to the older person's comfort and health. Chronic diseases—diabetes, high blood pressure or overweight—interfere with the body's normal cooling processes. Certain medications like diuretics ("water pills"), tranquilizers, heart or blood pressure drugs reduce the amount of perspiration—the body's natural coolant—produces.

If you are caring for an older relative, it is important to know how to keep your older relative as cool and comfortable as possible during a hot spell.

Heat Stress

Older people usually feel better once the weather cools down. Check in with your parent daily during the heat spell. Encourage her to avoid heat-related discomforts by:

- Keeping a pitcher of water in the refrigerator and drinking a small glass regularly throughout the day.
- Avoiding drinking alcoholic beverages or caffeine. They cause the body to lose water.

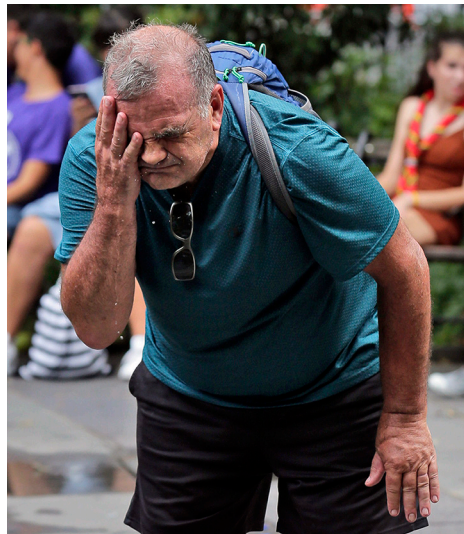
- Eating small light meals or snacks that require little or no preparation. Salads, fruits, cheese and crackers, cereal, Jell-O, or Popsicles are good choices.
- Relaxing in a cool bath or shower.
- Taking a siesta during the hottest part of the day.
- Wearing loose-fitting, light-weight clothing.
- Applying sun blocks with a protection factor of 15 (SPF 15) or greater if your parent goes outdoors.
- Turning on the fan or air conditioner. Some older people don't use air conditioning to avoid a big electric bill. Encourage them to use a fan—especially in the bedroom and the room where they spend the most time during the day.

If your relative doesn't have air conditioning, spend a day together in the air-conditioned comfort of a mall or library or take in a movie.

Heat Stroke

Heat stroke occurs when the body becomes so overheated that it can no longer produce enough sweat to control its temperature. Symptoms include:

- Extremely high body temperature (104 degrees or higher).
- Mental confusion.
- Flushed, dry skin,
- Faintness, delirium, or coma.
- Dizziness, nausea, headache.



Heat stroke is a life-threatening emergency that must be treated immediately. Call an ambulance for assistance or drive the older adult to the nearest emergency room.

Heat Exhaustion

Heat exhaustion symptoms issue a warning that the body is overheating. They include:

- Weakness, nausea, faintness.
- Loss of coordination.
- Rapid pulse.
- Cool, moist skin.

People with these symptoms should rest in a cool place; drink water or fruit juice and cool down with a sponge bath. Do not use salt replacements without the advice of a doctor.

Staying Healthy in Hot Weather

Very hot weather can be unpleasant and even dangerous for older people – especially if they suffer from chronic illnesses or are very old. A daily phone call or quick visit once or twice a day from family, friends or neighbors will ensure the older person's health, safety, and comfort and give him or her confidence that help is available when it's needed most. ❖

- Is your loved one acting withdrawn, or making excuses not to participate?
- Are there noticeable changes to hearing, sight, or speech?
- What is their balance like? Are stairs becoming an issue?
- Observe memory capabilities. A good way to check this is to see if a loved one is remembering to pay bills or keep appointments.
- What are your loved one's grooming habits like?

Once your detective is done and you have a clear picture of your loved one's living situation, it is time to assess if you need to take further next steps in providing additional care for them.

- What services (appointments, shopping, banking, etc.) do they need access to on a regular basis?
- Is your loved one still able to drive? Don't just take their word for it.
- What socialization opportunities exist in the community to help prevent isolation and depression?
- Is another family member or close friend living nearby and able to help?
- What local help is available?

Before making any big changes, it's essential to talk (respectfully) with your loved one about what they see as their greatest needs. Discuss solutions, and then bring some options forward that may work for all involved.

While a well-deserved vacation hopefully includes some much needed rest and relaxation, it's also a great time for a long-distance caregiver to take the extra time to observe a loved one's living situation and address any new needs. ❖

YOUR IMPACT

on others is bigger than you think. Someone still giggles when they think of that funny thing you said. Someone still smiles when they think of the compliment you gave them. Someone silently admires you. The advice you give has made a difference for people. The support and love you've offered others has made someone's day. Your input and opinions have made someone think twice. You're not insignificant and forgotten. Your existence makes a positive difference, whether you see it or not.

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