

Published on *SeniorNavigator* (<https://seniornavigator.org>)

Caregiver Support

Family Caregivers

Despite the changing size and character of American families, families still remain responsible for and connected to each other. Traditionally, family included multiple generations living under one roof with each generation helping the other through life. Until recently, families usually lived in the same community. Though today's families may look different from the families of the past - divorce rates are higher, children are fewer, the distance between family members greater - we still care for each other. A recent National Alliance for Caregiving and AARP report (Caregiving in the U.S. 2020) found that there are now 53 million caregivers providing care in the U.S. More Americans are 1) providing unpaid care has increased over the last 5 years; 2) caring for more than one person; 3) and caring for someone with dementia. Also, these family caregivers report that their own health is fair to poor.

A caregiver is an individual who provides informal support, or unpaid help, to dependent individuals in activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Caregivers also provide emotional and other support. Families, friends, and neighbors usually provide what is considered informal support. This network of individuals plays a critical role in helping individuals remain independent and part of a community. Spouses are usually the primary caregivers, followed by adult children. Daughters and daughters-in-law are more likely to be caregivers than sons. Adult children and adult grandchildren are now often taking care of a parent or grandparent and a child at the same time. Many grandparents are taking on the role of providing parental care for their grandchildren - this all adds to the complexity of caregiving and the diverse roles of the caregiver.

Many people become caregivers gradually as a loved one's health condition deteriorates. Others are thrown into this new role suddenly, feeling tremendous responsibility without knowing what to do. Being a caregiver allows one to feel many different emotions--from unconditional love to feelings of isolation, panic, guilt, and sadness.

Learning About Caregiving

As with anything else, knowledge of what is available in the community can be a powerful tool to help cope with new responsibilities. Knowledge builds self-confidence and can also contribute to preserving dignity in the care recipient. You'll feel better - less stressed and more in control - if you take the time to learn as much as possible about your role as caregiver.

Learning is essential to effective caring. If you are just beginning your journey as a caregiver, it can seem overwhelming. There is so much you don't know and so many different emotions surrounding your experience. Take a few minutes to look over the following list to help you think about what you might need to find out.

Medical Concerns of the Person Receiving Care

As a caregiver, you will interact with many different service providers. Every interaction is an opportunity to learn something new. Your primary health care provider is often the very best resource to help you adjust to the new role of being a caregiver. Even if you're not exactly sure what to ask - ask something! Ask your doctor or nurse where you can learn more about the health condition. Some other questions that your health care professional can help you answer include:

- What do other people in my situation do?
- What questions should I ask?
- What do you think is the most important thing for me to know right now?
- Are there any geriatric specialists locally who can help me be a better caregiver?
- What is the life course of the chronic condition? What are the stages of chronic disease and how will I recognize a new stage?
- What ADLs will be impacted? It's important to learn how to help bathe, toilet, and move someone correctly so that you avoid injury to yourself or your care recipient. Find out if there are classes that can teach you how to perform certain tasks more easily as your care recipient becomes more dependent. For example, sometimes adult day services centers offer transfer classes, that teach caregivers how to transfer, or move, the person in their care from one place to another without hurting themselves or their care recipient (i.e. moving from the chair to the bed, from the toilet to the chair)

- What are the other health issues that your care recipient can expect to face? Are there special dietary considerations that will help improve or prevent the worsening of the specific condition? Are there classes available to help you learn to plan and prepare a special diet?
- How will I know when I can no longer care for my loved one at home?

Living Environment

- Really look at your environment with a new set of eyes. Are there any changes that need to be made in your home for a safer environment? Think: Do I need to add grab bars? Do I need a ramp to gain entrance and exit from my home? Do I need to remove the throw rugs throughout the house? Some changes you may be able to do yourself, other changes may require someone who is skilled in this type of work.
- Are there adaptive devices to help the care recipient perform ADLs independently or with less stress to the caregiver? Would a bath seat allow the care recipient to take a shower by himself? Would a higher toilet seat make going to the bathroom easier? Could a walker basket help move things from room to room safely?
- With a physicians' referral, many agencies will come to your home and help you identify safety risks and solutions to problem areas. Ask your primary health care provider for a referral to a nursing or home health agency for a home safety assessment.
- Do you have an emergency response device for the care recipient if he/she is ever alone? Is your care recipient able to use this device correctly and responsibly?

Social Environment

Waking up each day with a purpose in life and something to look forward to helps us stay happy and functioning. Inactivity can lead to depression and a risk of increased disability. Creating a therapeutic routine will benefit both you and your care recipient. For everyone involved, it's important to think about how you will stay connected to your family, friends, and community. Both caregivers and care recipients can easily become isolated from family and friends. There are formal and informal ways to stay engaged in life beyond caregiving. Adult Day Services, Respite Care, Senior Centers, Lifelong Learning, and Volunteering are options to consider to

keep from becoming isolated.

Caregiver Support

Caregiving is rewarding. Approaching caregiving as a journey of intimacy can deepen your relationship with yourself, your care recipient and those around you. Some of the nice side effects of caregiving are:

- Connecting with others with the same experience,
- Building stronger relations with other family members,
- Demonstrating to yourself and your family that you have strength, courage, and resiliency,
- Finding or giving forgiveness,
- Learning new skills,
- Meeting new people and making new friends, and
- Continuing in a lifelong mutually supportive relationship by being able to give back to a family member or friend.

Caregiving is also exhausting in every way: physically, emotionally, financially. Help is available to you, no matter where you live or how much money you have or don't have. Here are some ways to find the help you need:

Support Groups: Your local [Area Agency on Aging in Virginia](#) can assist you in locating support groups and programs in your community. Often your primary health care provider may suggest that you attend a support group. The local community services board, or mental health agency, may also either run or know about support groups. Other individuals that may have many of the same issues can share thoughts, concerns, and provide new ideas and contacts to others in the group. [Eldercare Locator](#) (1-800-677-1116, Monday - Friday 9:00 a.m.- 8:00 p.m.) is a free, nationwide information and assistance directory that can guide you to the appropriate Area Agency on Aging. Callers should have the address, zip code, and county where the person lives who is in need of assistance. In Virginia, the Statewide Information and Referral System (2-1-1) can help you find services and support in your community.

Family, Neighbors, Friends, Faith Community: These individuals make up the 'informal' network of caregivers. They provide relief for specific tasks, are there for emotional support, and are often just waiting for someone to ask them to help.

When someone offers to say YES! Your first reaction might be to think that you can do it all. In some situations the term for providing care will be for a short while; in other circumstances, it will be for years. It is important for both the caregiver and care recipient to willingly accept help that is offered by the informal network. Make a list of who you can count on for support. Not only will you know who to call when you need help, it will also be a comfort against the isolation you feel.

Children: Involving children in a supporting caregiver role can teach them about family and about compassion. Though children should not be asked to carry inappropriate responsibilities, children of all ages bring concrete skills and abilities that many adults have lost or forgotten. Children know how easy it is to draw pictures of rainbows and beaches. Playing make-believe or making up a new song is second nature to kids. Children who read, or are learning to read, can bring daily joy to an elder confined to the home. Likewise, elders can give children the gift of stories about a long time ago.

Employer: Employers are increasingly offering flexible scheduling to help a caregiver meet responsibilities outside of work. For employees who need to be with the care recipient more than a typical work week allows, there is the Family and Medical Leave Act of 1993. The most widely thought of use of the Family and Medical Leave Act is for maternity or paternity leave. However, it also applies to people caring for spouses, parents, or older children. Under the Act, eligible employees may take up to 12 weeks of unpaid, job-protected leave in a 12 month period for a family medical event. This law does not apply to everyone, click here to learn more about the [Family and Medical Leave Act](#).

Geriatric Care Manager: Sometimes an expert is what is needed most. A Geriatric Care Manager can review the entire caregiving situation and help you assess your needs and prepare for the future. Care Managers are often hired by the caregiver to identify and arrange needed services for the care recipient (i.e. transportation, home care, adult day services, meals). They coordinate the care that is needed to your schedule and needs. Care managers usually charge for services by the hour. [Area Agencies on Aging](#) may also provide care management through their resource coordinators.

Geriatric Assessment: After a health crisis or event, seeing a Geriatrician (a medical doctor certified in geriatrics) for a full assessment could benefit the older adult and the caregiver. A geriatric assessment takes a longer time than a standard

physical and focuses on many different areas of health and well-being. A geriatric assessment considers the individual's history, medications, living situation, and functioning. If you are concerned about multiple risk factors, or significant changes in your loved one's demeanor or abilities, consulting with a geriatrician could be helpful.

Caregiver Notebook: It's a good idea to document everything related to the person in your care and keep all of the information in one notebook that stays with your care recipient. That way, whether respite services come into your home or your care recipient goes to an adult day services program, everything the alternative caregiver needs to know is in one accessible place. The caregiver notebook could include:

- copies of power of attorney,
- copies of advanced medical directives or living will.
- insurance information about Medicare, Medicaid, Medicare supplemental insurance, prescription drug coverage, and long-term care insurance,
- contact information about every healthcare provider
- a schedule of a typical day
- a biography of your care recipient
- emergency contact information and information about yourself and other relatives or friends who could help if you become ill
- dietary information, including allergies
- a list of medications
- a description of any physical limitations of the person in your care
- a description of any risky behaviors such as wandering, locking self in the bathroom,
- if the person in your care suffers from dementia, keep a list of questions that they commonly ask with the correct answers, so that alternative caregivers can answer them in the usual way.
- Simplify schedules, activities, and requirements when feasible.
- Find out if you are eligible to apply for a handicap parking permit.
- Make time for yourself to get physical exercise. This is very important to help maintain your health and a good way to relieve stress and combat depression.
- If appropriate, will your physician recommend physical therapy for the care recipient?
- Do you qualify for Meals on Wheels?

- Can visiting nurses come to your home and provide care, rather than having the care recipient go to the doctor's office.
- As hard as it may be, accept offers of help. Even little things like someone else changing the oil, picking up dry cleaning, or mowing the lawn can allow you to focus on caring or focusing on yourself.
- Find out if there is counseling available for the caregiver or care recipient.
- Thrift stores can be an affordable source for adaptive devices such as walkers, canes, or bath seats. Always keep equipment in good condition.
- The person in your care deserves to be treated with dignity, respect, and kindness. If you are ever unhappy with services that you receive, say something to the administrator. If you ever observe or suspect mistreatment, contact the appropriate ombudsman.

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Last Reviewed

Wednesday, March 20, 2024