



AARP Family Caregiving Guide

A Guide for Caring
for Older Adults



AARP FAMILY CAREGIVER RESOURCE GUIDE

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YOUR CAREGIVING JOURNEY

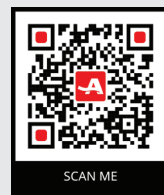
Caring for a family member or close friend is one of the most important roles you'll ever play. Everyone's caregiving journey is unique. You may be checking in, providing transportation, shopping, making meals or doing housework. Perhaps you're helping with personal care, performing medical/nursing tasks or coordinating care. You may be caring for one person or multiple people. Regardless of where your role falls on the spectrum of caregiving, we want to make it easier.

Whether preparing for future caregiving or currently taking care of a loved one, this guide is a practical tool to help you get organized, determine needs and resources, create your caregiving plan and find support.

You can go through the guide from start to finish, or skip to the section that concerns you the most right now. When your loved ones' situations change, review the pertinent section of the guide, reassess and adjust the plan accordingly.

GUIDE RESOURCES

Access more in-depth resources related to every section of this guide at aarp.org/careresources or scan this QR code with your smartphone camera.



ASSESS AND ADDRESS YOUR LOVED ONES' NEEDS

Here are some things to consider as you evaluate your loved ones' resources, abilities and needs.

FIND HELP WITH THE ASSESSMENT

An objective professional can help you assess the situation. Your loved ones' doctors can help you understand their health conditions. A social worker, physical therapist, occupational therapist or care/case manager can help gauge their personal care needs and safety factors. A neurologist, geriatric psychiatrist or dementia clinic can help evaluate cognitive abilities, including memory and judgment. A financial adviser can help assess finances. A lawyer can help create necessary legal documents.

START THE CONVERSATION

Talk with loved ones about their situation and their wishes for now and in the future. It's best to do this long before caregiving is needed. It's also vitally important that they feel a sense of control over their own lives. So listen to them, get their input and help them make decisions. It will make adjusting to change easier.

DETERMINE NEEDS AND RESOURCES

Caregiving constantly evolves. You may be able to understand and address some of these issues quickly; others may take more effort. Prioritize the critical issues first.

1. Finances: Assess their current financial situation and determine if they have enough budget to meet their care needs. Consider:

- **Income** via employment, retirement and benefits; include contributions from family members.
- **Savings and investments**, such as savings accounts, stocks,



bonds and investment accounts. Determine if income from these can contribute to their care.

- **Debt**, including mortgage, other loans and credit cards.
- **Expenses**, like housing, utilities, transportation, insurance, personal care, health care, medications, medical equipment and supplies, entertainment, food and discretionary spending.

Evaluate their ability to manage their financial matters.

If they are unable to do so, decide if you can help or take over financial tasks and responsibilities, or recruit another family member to do so (this can be a good role for a long-distance caregiver). You can also use a bill-pay service or a money management professional.

2. Legal: It's crucial to get legal affairs in order while our loved ones are able to make decisions for themselves.

- **Advance directives** spell out individuals' wishes and designate who will make medical decisions for them if they are unable to do so. These documents typically consist of a power of attorney for health care and a living will and may also include Do Not Resuscitate (DNR) orders, Physician Orders for Life-Sustaining Treatments (POLST) and Medical Orders for Life-Sustaining Treatment (MOLST).
- **Powers of attorney for property and finances** allow a designated person to manage these matters if the owner is unable to do so.
- **Estate planning documents**—a will or living trust—detail how a person's assets will be managed and distributed upon death.

3. Abilities: A functional assessment can help determine individuals' care needs by evaluating their abilities and skills for everyday living.





- **Activities of daily living (ADLs)** such as bathing, dressing, grooming, mouth care, toileting, transferring to a bed or chair, walking, climbing stairs and eating.
- **Instrumental activities of daily living (IADLs)** such as safety procedures and dealing with emergencies, shopping, preparing meals, managing medications, communicating (including use of a phone), doing house and yard work, doing laundry, caring for pets, driving or using public transportation and managing finances.
- **Healthy habits**, like getting quality sleep, wearing clean clothes, maintaining strength and balance, exercising regularly, eating nutritious meals and adhering to a special diet.
- **Cognitive functions**, such as attention, judgment, memory, problem-solving, communication and use of computers, telephones or other technology.
- **Safety**, at home and in the community, including physical safety and safety from fraud and scams.

You may be increasing support gradually over time as they need more assistance. Always keep an eye out for changing abilities.

4. Health: Gather information about your loved ones' physical and mental health. They can sign forms permitting practitioners to discuss health issues with you if you do not have health care power of attorney.

- **Discuss physical and mental health conditions** with doctors and other health care providers. If you see cognitive changes, get an evaluation from a qualified professional specializing in dementia, such as a neurologist or dementia clinic.

- **Put together a medical history**, with a simple list of health conditions, surgeries (and dates), chronic health conditions, allergies and family medical history.
- **Create a medication list**; include prescription drugs, vitamins and supplements. Update the list as medications change, keeping copies of the old lists to create a medication history. Note drug allergies, reactions, interactions, and effective medications.
- **Make a list of health care practitioners**, including phone numbers, specialties, locations and appointments.
- **Organize health insurance information**, including Medicare, Medicaid, supplemental insurance, private insurance or employer-based insurance.
- **Ensure health information is accessible** whenever and however you need it; keep digital copies on your phone or computer, taking care to keep personal information safe and protected.

5. Socialization and Support System: Spending time with family and friends or in community events is critical for both physical and mental health.

- **Evaluate the risk of isolation** by determining whether your loved ones have adequate virtual, telephonic or in-person socialization opportunities.
- **Ensure connections** with family, friends, neighbors and service providers who can offer support and keep you informed, especially if you are a long-distance caregiver.



6. Housing/Living Situation: Where your loved ones live will help determine the type of care they need.

- **Evaluate the current residence**, whether it's their home, your home, an assisted living facility, a group

home, a skilled nursing facility (nursing home) or elsewhere. If your loved ones are living in a private home, be sure to assess safety and make any needed modifications.



- **Determine whether a change in housing** is needed and research local options, including available services, type of care provided, costs, quality of life and socialization opportunities in each setting.

7. Transportation: Determine if your loved ones have adequate, safe transportation.

- **If they are still driving**, ride along and observe their capabilities. Share your observations with them, and discuss the benefits of taking a driving course to refresh their skills.
- **If you think they should stop driving**, prepare for a compassionate conversation about hanging up the keys. Give specific examples of your concerns and address how they will get where they need to go, when they need to get there.
- **Transportation options** may include family and friends, public transportation and transportation services for older adults provided by the city, county or facility where they live.

8. Services: Investigate which organizations and government agencies can help provide low-cost, sliding-fee-scale or free services for your loved ones.

- **Home- and community-based services** may include information and referral, congregate meals (often at a senior center), meal delivery, personal care, home health, transportation, personal emergency response systems, home modification and repairs, adult day care, legal and financial assistance, help applying for public benefits, case management, respite care and caregiver support. Contact your local area agency on aging or tribal organization for more information.

- **Veterans Affairs (VA)** provides a variety of supports, depending on a veteran's specific eligibility, including VA Aid and Attendance benefits (funds to help pay for care), VA health care (may provide medications, home health care, medical care, medical equipment and supplies, grants for home modifications, adult day care services, personal care, therapies, light housekeeping and other services) and caregiver support.
- **Facilities** where your loved ones live, whether independent living for older adults, assisted living or nursing homes, may provide medication management, personal care and medical care.
- **Care or case managers** can help you find, coordinate and monitor care, apply for benefits and be there in an emergency. These are especially helpful for long-distance caregivers.



9. Technology: Determine how technology can help.

- **Communication and socialization** can be enhanced with smartphones, video chat and smart speakers.
- **Safety** can be improved with a personal emergency response system (PERS) or medical alert system. These may include wearable devices or wall-mounted radar devices that detect falls and call for help. Motion sensor lights and alarms, floor mat and bed/chair alarms and digital locks can help prevent falls and help prevent the person from getting lost.
- **Finances** can be managed with apps and websites, even from a distance.

- **Telehealth** (virtual phone and video chat appointments) makes for faster and easier contact with health care providers and fewer in-person trips.
- **Mobile health** is a way to access care—doctor or nurse visits, labs, X-rays, ultrasounds and physical/speech/occupational therapy—from the comfort of home.
- **Health care monitoring devices** can be used at home to communicate information to doctors, including pacemaker checks and blood pressure or blood sugar tracking.

10. End-of-Life Care: It's important to have conversations with loved ones about their wishes and the options for compassionate care. In addition to ensuring the appropriate legal documents are in place, research the various local care options and costs.

- **Palliative care** is specialized medical care for people of any age who have serious illnesses regardless of the prognosis. Patients may receive comfort care and curative treatments.
- **Hospice care** is also focused on providing comfort. It is for people nearing the end of their lives who meet certain criteria, who are not getting curative treatments and who are not expected to recover from their illness. People can go off and back on hospice if treatment is desired at any time.
- **Making funeral arrangements** may be your final act of caregiving. Determine your loved ones' preferences and find out if they have prepaid funeral services or body donation plans already in place. If not, discuss planning ahead so their wishes can be more easily carried out.



CREATE AND UPDATE YOUR CAREGIVING PLAN

INCLUDE KEY COMPONENTS

After you assess your loved ones' current situation, create or adjust your caregiving plan in line with their wishes. Your plan is a simple framework that you will adjust as their abilities and resources change. Include these key components:

- How your loved ones will be supported to remain as independent as possible for as long as possible with optimal quality of life and adequate socialization.
- How their care will be coordinated, including who will care for them and when.
- How their finances will be handled.
- Who will make legal decisions for them if they are unable.
- How they will be kept safe.
- How their health conditions will be managed.
- Where they will live.
- How their transportation will be handled.
- How agencies, organizations and professionals can provide support.
- How they will be cared for at the end of their life and how their assets and personal belongings will be handled after death.

BUILD YOUR CAREGIVING TEAM

Once you have developed the caregiving plan, determine:

- Which caregiving needs are already met?
- Which needs and roles can you fulfill?
- Where are there gaps and who can fill them?

Generally, family members will not be able to meet all the needs. We encourage you to think more broadly about your team. Imagine your caregiving plan as a big puzzle, with many different people and organizations bringing puzzle pieces that come together to form support for your loved ones and for you, including:

- **Family, neighbors, friends and volunteers** from local organizations, universities, or your loved ones' faith community.
- **The services, supports, organizations** and agencies you researched in your assessment.
- **Paid professionals**, such as caregivers, home health aides and others who help care for your loved ones' personal care and daily needs.
- **People who help and support you** so you can fulfill your caregiving role.

As you create and manage your team, be sure to:

- **Communicate the caregiving plan**, including your loved ones' goals and wishes.
- **Create clear roles** and responsibilities.
- **Discuss how the team will communicate** and be managed.
- **Show appreciation** and support for your team members.



***A note for long-distance caregivers:** It is especially important for you to have team members who are located where your loved ones live and who can be your “eyes and ears” on the ground, reporting to you about how they are doing and any changes or problems that arise.*

CARE FOR THE CAREGIVER

Caregiving can be very rewarding and also very draining. While your loved ones are the center of their caregiving plans, you are equally important; there wouldn't be care for them without you. That's why making a conscious effort to care for yourself while caring for others isn't selfish or optional—it's practical.

- **Take care of your mental health** because you may experience a roller coaster of emotions ranging from joy, satisfaction and triumph to guilt, stress, anxiety, depression, grief and burnout.
 - > **Consider counseling or therapy**, which can help with the emotional and mental strain of caregiving. Check your health insurance to find out what your coverage and costs are and try to find a counselor who understands family caregiving.
 - > **Connect with other family caregivers** via local in-person facilitated caregiver support groups, virtual groups that meet online with video chat, or social media groups that can be accessed at any time.
 - > **Arrange for respite care** for loved ones so you can get breaks from caregiving, creating time for self-care and rest, going to appointments, seeing friends or simply doing nothing.



- **Maintain your identity** because it's easy to feel like you've lost yourself in caregiving. You will likely need to make sacrifices but try to adapt and keep up with friends, hobbies, other relationships and home life on some level.
- **Keep working if you can**, so you don't have a financial crisis in the future. Take advantage of employer supports which may include flexible work options; employee assistance programs (EAPs) that assist with counseling, services, referrals, legal matters and more; employee resource groups or support groups for caregivers; caregiving leave; and human resources counseling about your employee benefits. If you need to take an extended time off work, explore your eligibility for family and medical leave via the Family and Medical Leave Act (FMLA), a state-mandated policy or an employer policy.
- **Protect your own financial security** now and in the future. Financial advisers can help you monitor your finances and ensure you don't take on too many caregiving costs or assume debt.





GRIEF AND LIFE AFTER CAREGIVING

You may experience grief while loved ones are still living, including anticipatory grief as you face an impending loss, or ambiguous loss when a loved one has changed drastically due to a health condition like dementia.

After caregiving, the loss of someone you've cared for can be complicated; your day-to-day life will be very different. Everyone's experience with grief is unique and there is no one "right" way to grieve. Consider these options to help you as you create a new life after caregiving.

- **Seek emotional and mental health support** to help process sadness, pain and grief.
 - > **Find a grief counselor**, especially if, over time, you are unable to cope with everyday life.
 - > **Connect with others** in grief support groups available through hospice organizations, faith communities and online websites.
 - > **Get support from family and friends.** Be clear with them about what you need—whether it's a listening ear, time alone, or a distraction from your grief.

- **Honor your loved ones and celebrate their lives** by writing a tribute, dedicating a scholarship, planting a tree, volunteering for their favorite cause or helping other caregivers.
- **Ask for help with difficult tasks.** An attorney can settle the estate; financial advisers can help with money issues. There are companies that specialize in sorting belongings and emptying homes. If there are no pressing deadlines, take your time.
- **Set new goals** for yourself and focus on enjoyable activities that provide motivation or a mental break from grief.

Take comfort in knowing that you did your best for your loved ones and honor their memory by moving forward and living your life to the fullest.

GLOSSARY



SCAN ME

Visit AARP's online *Caregiver Glossary: Definitions of the Most Confusing Acronyms and Terms* at aarp.org/caregivingglossary

or scan this QR Code with your smartphone camera.

GUIDE RESOURCES



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