

Family Caregiver Questions Guide

Find the Help You Need, Ask the Questions That Matter



Family Caregiver Questions Guide

Dear Family Caregiver:

Whether you have been providing care for a loved one for years or have recently stepped into a new caregiving role, you know that finding the right resources and support is vital. Navigating an often-complex system to find options and get the most out of what's available can be overwhelming.

This guide was designed to arm you with important questions to discuss as you explore caregiving resources. Drawing on experienced caregivers who have been in your shoes, you'll find suggested questions to ask and key considerations for various topics, along with AARP tools to help you meet the needs of your loved ones, and yourself too.





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Where Caregivers Go for Resources

Caregiving needs differ for everyone, making it essential to know where to find assistance. The following organizations and agencies may be able to provide resources and local support:

^{*} Many resources included in this guide are not offered by AARP. Any link with an asterisk will redirect you to a third-party site. The privacy policy and terms of use of the third-party site will apply.

211	Central hub for community resource information. Visit 211.org*		
Local Area Agency on Aging (AAA)	Information on programs, senior housing, and benefits counselors. Find Your Local AAA*		
State Division on Aging	Lists programs, mental health lines, and healthcare resources. Explore State Resources *		
Social Services Departments	Public benefits, emergency housing, and assistance programs. www.usa.gov/state-social-services *		
Veterans Affairs	Veteran-specific benefits and services. <u>VA Caregiver Support</u> *		
Developmental Disabilities Offices	Resources for caregivers of individuals with intellectual disabilities. Intellectual/Developmental Disabilities State agencies*		
Hospitals	Social Work/ Case management support and medical / non-medical consultations. Contact your local hospital.		
Community Clinics	Homecare, prescription assistance, and chronic disease management. Search Community Clinics*		
Local Pharmacy	Select durable medical equipment and prescription medication advice.		
Adult Day Care Programs	Additional care resources and professional guidance. National Adult Day Services Association*		
Senior Centers	Recreational programs, transportation, and social worker guidance. <u>Locate a Senior Center</u> *		
Town Services	Localized programs specific to zip codes. Check your local government website.		
Churches	Support groups, food pantries, and volunteer programs.		
Local Libraries	Educational materials such as books and magazines, and community event information.		
Local Non-Profits	Legal support, counseling, and home assistance. <u>Community Resource Finder</u> *		
Disease-Specific Organizations	Find condition-specific education and materials. AARP's <u>Specialized Care Guides</u> offer more information.		
AARP State Guides	Find caregiving assistance and services in your state: www.aarp.org/caregiverresources		



Legal and Financial Basics



Caregivers seeking financial guidance may find tailored support from local non-profit organizations, financial advisors or government programs like Medicaid or Medicare.

- ☐ How do I plan for the cost of assisted living or home care?
 What if we run out of money?
- ☐ Who can help with financial planning and managing other assets?
- ☐ How do I keep track of my loved one's bills and financial statements?
- □ What financial and legal documents are needed to manage my loved one's money?
- ☐ Are there government programs that help cover care costs?
- ☐ Are there tax breaks for seniors?

AARP Financial Go-To Resources

AARP Financial Workbook for Caregivers

Advanced Directives in your State





Medication Management



Caregivers may find assistance from pharmacists at local drug stores for medication management guidance and cost saving options.

- Will all the prescriptions needed be covered under my loved one's insurance?
 Are there generic drug brand options or other cost saving options available?
 Why is this medication prescribed, and how does it help my loved one's condition?
 How can my loved one expect to feel while on this medication?
 Are there potential interactions with other medications, food, or drinks?

 What should we do if a dose is missed or too much is taken?
- $\ \square$ Are there pill boxes or daily pill pouches to help us stay organized?
- ☐ How do I safely dispose of old medicines?
- ☐ Is it possible to get home delivery of medications?
- □ Are there any medications that can be prescribed for a 90-day supply instead of a 30-day supply to reduce the frequency of refills?





Long-Term Care Insurance



Understanding your loved one's long-term care insurance policy (and whether they have coverage) is crucial. Here are key questions to help you assess their coverage, if any.

- ☐ Does my loved one need to sign a form so I can talk to someone about their insurance?
- ☐ What does their insurance policy cover?
- ☐ Does it pay family caregivers who take care of them?
- ☐ Are there any health problems or types of care that the insurance doesn't pay for?
- ☐ How much does my loved one have to pay for the insurance, and can the cost go up?
- □ Does my loved one still have to pay for the insurance while they are receiving the benefits?
- How do we ask the insurance to pay for something, and what do I need to do as the caregiver?

AARP Resources

Understanding Long Term Care





Paid Family Leave Programs



Meet with your manager or human resources representative to discuss the policies and resources available to you.

- ☐ How do I qualify, and how does payment work in my state or through my employer?
- ☐ How do I sign up, and will I keep my job?
- ☐ How much time off can I take? Do I have to take it all at once, or can I take it in parts?

□ Will I still have health insurance and benefits while I'm on leave?If not, how can I get benefits?





Public Benefits



- ☐ What help is available for food, housing, utilities and healthcare?
- ☐ What do we need to qualify? Who can help us apply?
- ☐ Do all of us living in the same household need to qualify, or just one of us?
- ☐ Are there benefits available for Veterans?

Connection to Public Benefits

Call 211 or visit 211.org*





Social Connection and Mental Health



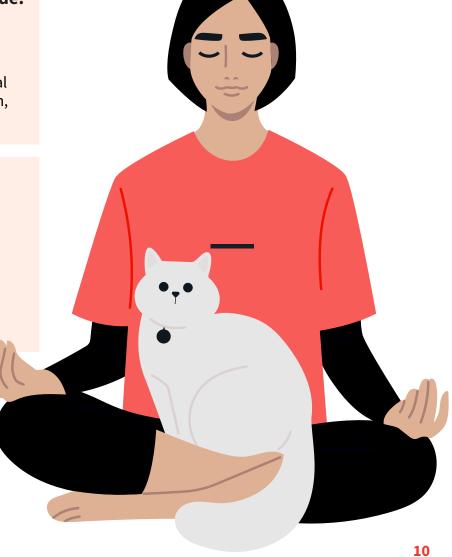
- ☐ What local programs and activities are available?
- ☐ Are there transportation services for seniors?
- ☐ Where can I find support groups for caregivers?
- ☐ Are there faith-based groups for caregivers?
- ☐ Are there respite care services in my community?
- ☐ Are there online caregiving groups I can join?

AARP's Care for the Caregiver guide: aarp.org/careforthecaregiver

Offers practical tools and support to help family caregivers protect their physical, financial, mental, and emotional well-being—because self-care isn't selfish, it's essential.

Join the AARP Family Caregivers Facebook Group: facebook.com/groups/ aarpfamilycaregivers*

Connect with fellow caregivers who understand. Share your feelings, frustrations and victories and join **FREE Facebook live events** and more.





Social Connection and Mental Health



Mental Health

How do I access the 988 Suicide & Crisis Lifeline?

The 988 Suicide & Crisis Lifeline is a free and private phone line that helps people in crisis, operating 24 hours a day. (Dial 9-8-8). For more information visit: 988lifeline.org*

How do I call the VA's Caregiver Support Line?

Call VA's Caregiver Support Line at 1-855-260-3274 for help and support. They can connect you to a local VA Medical center. Visit the VA Caregiver Support Line website for more: www.caregiver.va.gov*

211 Helpline

If you need assistance locating long-term mental health resources, talking through a problem, or exploring mental health treatment options, **dial 211** to speak with a live person who can help.

Finding Mental Health therapists through Health Insurance

- Call Customer Service: Use the number on your insurance card or policy documents.
 Ask for a list of local in- network mental health providers.
- 2. Online Portals: Set up an account on your insurance company's online portal. Use the directory tool to search for providers, filtering by therapy type, location, language and more.
- 3. Psychology Today: Visit Psychology
 Today: www.psychologytoday.com/us/
 therapists* to find therapists, psychiatrists,
 and other mental health professionals.
 Filter by insurance, location, and type of
 support needed (e.g., stress, depression,
 grief). Confirm coverage (if any) with your
 insurance provider.





Home Health Care/Homecare



Home Health Care through Medicare

Home Health Care covered through Medicare includes skilled nursing, physical and occupational therapy, speech-language pathology, rehabilitation, medical equipment, and nursing visits, based on eligibility and medical necessity.

ELIGIBILITY CRITERIA:

1. Homebound:

Unable to leave home without assistance.

2. Certification:

A healthcare provider must determine the need for special therapies or skilled nursing care through in-person evaluations and medical chart reviews.

3. Care Plan:

A doctor must create and review a care plan detailing needed services, frequency, and recovery goals, reviewed every 60 days or as needed.

Out of Pocket/Private Pay (Not Covered by Medicare or Medicaid)

Private-pay services are funded by individuals or families and are not covered by Medicare. Medicaid coverage varies by state; check your state Medicaid office. Home care agencies offer flexible options for private-pay clients.

SERVICES TYPICALLY INCLUDE:

- 24-Hour At-Home Care
- Personal Care: Help with daily activities (bathing, dressing, walking, eating, etc.)
- Household Services: Shopping, cleaning, laundry
- Meal Services
- Companionship

Questions for Home Health Care Agencies

- Is your agency licensed?
 What care services can your staff provide (e.g., personal care, medication management,
 - (e.g., personal care, medication management companionship, respite care, wound care, meal prep)?
- ☐ How often will you check my loved one's health?
- ☐ Can you help with special medical conditions like Dementia, Parkinson's, Diabetes, or Cancer?
- ☐ How many caregivers will take care of my loved one? Will we have the same caregiver every week?
- ☐ Will a social worker or case manager help with my loved one's care?



Home Health Care/Homecare (cont.)



Home Health Care: Financial and Insurance Questions

- ☐ How much do your services cost?
 Is there an hourly rate or a set fee?
- ☐ Do you take Medicare, private insurance, Medicaid, and Veterans benefits?
- ☐ What does my loved one need to qualify for your services?
- ☐ How often will you issue bills for care services? After insurance, how much will be owed?
- ☐ Are there any extra charges that might come up?

Home Health Care: Hours of Coverage

- ☐ Will care be available all day and night, every day?
- ☐ If I have a question for a nurse or doctor, is there a phone number I can call?
- ☐ How quickly does your agency respond to urgent requests like needing a nurse, extra hours, or changing care times?
- ☐ How does your agency decide how many care hours my loved one gets? What if I need more hours of help?
- ☐ Do we have to commit to a minimum number of hours or specific days?
- □ Besides Care Aides, will a Nurse or Doctor visit us at home? Are there Telehealth options? If so, how often?

Home Health Care: Staffing Questions

- ☐ Do you conduct background checks on all care aides and staff?
- ☐ How do you select care aides for a patient?
- ☐ Does the family have an opportunity to interview a potential care aide before they begin?
- ☐ If a care aide calls out sick or is unable to make it to my loved one, how much notice will I have?
 Will someone else be sent in their place?
- ☐ How does communication between a family and a care aide work? Is it through the agency, or does the family have direct contact with the aide assigned?
- ☐ What training and monitoring will care aides receive from your agency?





Assisted Living/Nursing Home



Financial Costs: Rent & Services

- □ Do you take health insurance, waiver programs, Veterans benefits, and long-term care insurance?
- ☐ Can you give me a list of costs, including rent, care levels, room and board, and other services?
- ☐ Is there a meal service program on site?
 Is it included in the rent or basic care?
- ☐ Is pricing à la carte or a flat fee for all services?
- ☐ What happens if my loved one runs out of money? (Consider consulting with a licensed attorney before agreeing to be legally responsible for your loved one's outstanding bills.)

Assisted Living/Nursing Homes Operational Questions

- ☐ Will someone talk to me and my loved one about advanced directives? If we already have them, who needs a copy?
- ☐ Is there an agreement that explains personal care, support services, moving in and out, and standard fees?
- ☐ What are the emergency plans for evacuating residents? Is there a plan for moving residents if needed?
- Are staff trained to spot elder abuse or neglect? Is there a policy to report suspected abuse?



Staff and Services Questions

- ☐ What is the staff-to-resident ratio?
- ☐ Is staff available 24/7 to help with daily activities?
- ☐ Do you do background checks on staff members?
- ☐ Is there a Registered Nurse or Certified Nursing Assistant on staff?
- ☐ Are staff trained to care for people with Dementia and other chronic health conditions?
- □ Do you have Primary Care Doctors and other medical services that come to the facility? How does this work?
- □ Do you provide transportation to stores, community events, and medical appointments if needed?
- ☐ Is there housekeeping to help keep the apartment clean?
- ☐ What types of activities are offered for residents, and how often?

Room/Living space

- ☐ Can residents choose a private or shared room? Can residents decorate their apartments?
- ☐ Is furniture provided for the rooms?

 Can we get a fully furnished room if needed?

 Can residents bring furniture?
- ☐ Are private bathrooms available, and are they wheelchair-accessible?
- □ What appliances are in the room?
 Are there any appliances that are not allowed?
 (e.g., toaster oven, hotplates, etc.)
- ☐ Is there a dining room or other space where resident's families can gather?



Hospitalizations



- ☐ If my loved one doesn't have advanced directives, is there an attorney on staff who can help us fill them out?
 Will they keep these records?
- □ Does my loved one need to sign a consent form so I can talk to the medical team?
- ☐ What health history information should I have ready to share with the medical team? Is there past medical history in the system that I can confirm?
- ☐ Will the medical team communicate with me throughout the hospitalization?
- □ Does the hospital have an up-to-date list of medications for my loved one?



Patient Care Plan for Discharge

ASK THE DOCTOR, NURSE, OR SOCIAL WORKER:

- ☐ Can you give me a list of any follow-up medical appointments I need to make or that have already been made?
- □ Can you confirm that my loved one's pharmacy has received their updated prescriptions from the hospital?
- ☐ Can you tell me about my loved one's care plan and how I can be part of the discharge discussion?
- ☐ Can I share any concerns about my loved one's health history with the medical team to help create the best care plan?

Care plans can include:

- ☐ Changes in medications or treatments
- $\hfill \square$ Follow-up doctor appointments needed
- ☐ In-patient nursing rehab or in-home care (nursing and therapy)
- ☐ Wound care, IV treatments, and other chronic health treatments

Social Workers can help facilitate resource connections for caregivers and their loved ones. Consider asking questions such as:

- What resources are available for caregivers, like emotional support, volunteer services, nurse hotlines, or disease-specific support?
- ☐ If my loved one needs durable medical equipment (such as a walker or wheelchair), does Medicare cover it? If not, are there low-cost options like community lending closets?



Medication Logs



Track prescriptions and dosages.



Prescription Name	Strength	Dosage	Warnings/Instructions







PHARMACY NAME LOCATION DOCTOR PHONE # ADDRESS DOCTOR NAME ADDRESS PHONE #	PHARMACY NAME	PHONE #
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~	Item	Where is it Kept?	Contact Name
	Medicare Original or Medicare Advantage (company name):		
	ID Number:		
	Medicare Prescription Drug Coverage (company name):		
	ID Number: (does not apply to an Advantage plan with drug coverage)		
	Other Health Insurance Policy (Medigap):		
	Company:		
	Premium:		
	Payment schedule:		
	Veterans Health System:		
	ID#:		
	Do Not Resuscitate (DNR) Order:		
	Physician Orders for Life-Sustaining Treatment (MOLST/POLST) form—if available in your state		
	Durable Power of Attorney for Healthcare/Health care Proxy		
	Durable Power of Attorney for Finance/Living Will		



Caregiving Terminology Glossary



Activities of Daily Living (ADLs)

Basic tasks of everyday life that include, but are not limited to, dressing, bathing, eating and toileting.

Adult Day Services

Structured, comprehensive programs, including a variety of health, social and related support services during any part of the day but for less than 24 hours, provided at centers for adults who need some supervision and/or support.

Adult Protective Services

A public agency that investigates reports of abuse and neglect of vulnerable adults, usually working with law enforcement. Immediate dangerous situations should be directed to 911 or the local police.

Area Agency on Aging (AAA) or Aging and Disability Resource Center (ADRC)

An agency designated by the state with the responsibility for planning and coordinating services for older people or for older people and adults with disabilities within a specific geographical area. Both agencies provide information, resources, assistance and links to community services.

Assisted Living Residences

Housing for those who may need help living independently, but do not need skilled nursing care. The level of assistance varies among residences and may include help with bathing, dressing, meals and housekeeping.

Community Meal Program

Balanced, nutritious meals served at community locations for those age 60 and over and their spouses.

Conservator

A person appointed by a court to handle someone's affairs when that person cannot handle them him or herself. A conservator usually handles only financial affairs.

Continuing Care Retirement Communities

Housing that offers a variety of living options and services including independent living, assisted living and skilled care, often all on the same campus, designed to meet a person's changing needs.

Discharge Planner

A professional who assists individuals and their families in developing a plan of care for an individual following a hospital or nursing home stay.

DNR: Do Not Resuscitate Order

An order written by a doctor to fulfill an individual's expressed medical care wishes during a medical emergency.

Durable Power of Attorney for Finances

The durable power of attorney for finances is a legal document that allows you to give authority to another trusted person to make financial decisions on your behalf. The designation "durable" means that it will stay in effect if you become unable to manage your own financial affairs.

Employee Assistance Program (EAP)

An employee benefit program offered by many employers. EAPs are intended to help employees deal with personal issues that affect their job performance, health and well-being. EAPs generally include short-term counseling and referral services for employees and their household members.



Caregiving Terminology Glossary



Family and Medical Leave Act

A federal law that requires some employers to let you take unpaid time off work (up to 12 weeks) for illness, having/adopting a baby, or caring for an ill family member. Your job or equivalent is guaranteed when you return. If you work for a small employer or are a new employee, you may not be eligible for FMLA leave.

Family Caregiver

Anyone who provides unpaid assistance to another person who is ill, has a disability or needs help with daily activities.

Guardian

A person appointed by the court who is responsible for the care and management of another person who has been determined to be no longer capable of making decisions for him/herself.

Health Care Power of Attorney (HCPA Health Care Proxy)

A special kind of durable power of attorney in which you appoint another person to make health care decisions should you become unable to do so.

Health Insurance Portability and Accountability Act (HIPAA)

A federal law that gives you rights over your health information and sets rules and limits on who can look at and ook at and receive it. The law also permits the release of personal health information needed for patient care.

Home Health Agency

An agency often certified by Medicare to provide health-related services in the home such as nursing; occupational, speech, or physical therapy; social work and/or personal care.

Home Health Aide

An individual who helps with bathing, dressing, grooming, assistance with meals, and light housekeeping.

Homemaker Services

A service that provides assistance with general household activities such as meal preparation, cleaning, laundry and shopping.

Hospice Care

Professionally coordinated support services, including pain and symptom management, social services, and emotional and spiritual support for terminally ill people and their families. The care is provided at home and in other settings.

Instrumental Activities of Daily Living (IADL)

More involved tasks of everyday life that include, but are not limited to: managing money, shopping, telephone use, travel in the community, housekeeping, preparing meals and taking medications correctly.

Living Will (Part of a Health Care Directive)

A legal document that communicates a person's wishes about lifesaving medical treatments should he or she have a terminal condition and not be able to communicate their health care wishes.

Long-Term Care Insurance

Insurance that can pay part of the cost of care received in the home, assisted living residences, nursing home, and other designated services depending on the policy purchased.



Caregiving Terminology Glossary



Long-Term Care Ombudsman

A person who investigates and resolves complaints on behalf of residents of nursing homes and other long-term care facilities.

Medicare

A federal health insurance program for people age 65 and over, and for some younger people with disabilities. Medicare covers hospital stays, doctor visits, prescription drugs and other health care related needs. Medicare does not cover long-term care.

Medicare Savings Program

An assistance program for people with Medicare who need help with paying their Medicare expenses, such as premiums and possibly copays and deductibles for Medicare Parts A & B.

Medicaid

The federal/state-funded health and long-term care program for people with limited income and assets. It is administered by the states within federal guidelines, so eligibility and coverage may differ from state to state. For long-term care services, states have additional eligibility rules.

Nursing Home

A nursing facility that provides intermediate care, such as assistance with personal care and activities of daily living and/or skilled care; 24-hour medical, nursing and rehabilitation care; often a transition from hospital to home. The latter may be called a skilled nursing facility.

Palliative Care

Professionally coordinated services that focus on physical, mental, social and spiritual needs of those with life-threatening illness and their families. It seeks to maintain the highest level of comfort.

Personal Emergency Response System (PERS)

A portable electronic device with a call button that a person can use to summon help in an emergency.

Provider

A provider of healthcare is a person or place that helps take care of your health by giving medical advice and treatment.

Respite Care

A temporary break from providing care for a loved one. Respite care can be provided by family and/or friends through services such as attending an adult day services center. You can also have a paid homecare worker come to the home.

Social Security

A benefit earned by eligible workers that provides guaranteed inflation-adjusted monthly income for life. People typically become eligible to receive Social Security at age 62 or if they have a disability. Certain family members may be eligible for benefits as well.

Supplemental Security Income (SSI)

SSI provides a monthly benefit to people who are 65 years of age and older, disabled or blind, and who have limited income and assets.





AARP National, 601 E Street NW, Washington, DC 20049 | www.aarp.org/caregiving
AARP Caregiving Support line: 1-877-333-5885