



# The Caregiver's Handbook

A guide to getting started, finding support,  
and taking care of yourself





“There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

Rosalynn Carter

# Table of Contents

Introduction.....	2
Chapter 1: Getting Started.....	5
Chapter 2: Finding the Care You Need at Home.....	11
Chapter 3: Choosing a Long-Term Care Facility.....	20
Chapter 4: Covering the Costs of Caregiving.....	27
Chapter 5: Coordinating Medical Care.....	33
Chapter 6: Planning Ahead.....	40
Chapter 7: Caring for Yourself as a Caregiver.....	47
Summary.....	52
For More Information.....	53
Worksheets.....	55

# Introduction

**T**his guide is for anyone who provides care for family members or friends who need help with daily living. It focuses on the needs of older adults who require care because of a serious health condition or disability, but it could also apply to other situations in which caregiving is needed. Included are tips to help you as a caregiver and ways to get support, as well as guidance on how to take care of yourself. The worksheets at the end of this guide provide questions to help coordinate care and checklists to keep track of your caregiving responsibilities and needs. Additionally, each chapter includes caregiving resources that can provide further information and support.



another setting, such as an adult day care center, residential facility, or long-term care facility.

Some people use the term **care partner** rather than caregiver to show that caregiving is a two-way street involving both the caregiver and the person needing care. However, a partnership may not be possible if a loved one needs significant help or cannot care for themselves. In this guide, we use the term caregiver, but the information also applies to care partners.

You may also see the term **care team**, which refers to all the people who are providing care to a person. The team may include family, friends, volunteers, health care providers, formal caregivers, and others.

## What is a caregiver?

A **caregiver** is someone who helps another person with everyday activities, medicines, appointments, or other tasks. An **informal caregiver** is usually a family member, friend, or neighbor. These people are generally not paid for their help. This guide is meant for informal caregivers.

A **formal caregiver** (for example, a nurse or health aide) is paid for their services. They may provide care in a person's home or in

Caregiving can take many forms. The kinds of activities that a caregiver may assist with include:

- Household tasks, such as shopping, laundry, and cleaning
- Personal care, such as dressing, bathing, grooming, using the toilet, and brushing teeth
- Getting in and out of beds and chairs or walking
- Taking and keeping track of medicine
- Medical care, for example, keeping wounds clean or giving shots
- Preparing food, feeding, and monitoring dietary restrictions
- Transportation, such as car rides to appointments
- Health care, including talking to doctors, making medical decisions, researching care services, and coordinating doctor visits
- Money and finances, such as handling bills and budgets
- Legal matters, including managing official documents such as wills and insurance policies

## Caregiving By the Numbers

About **1 in 4** Americans are caregivers.



Most caregivers also have other jobs and responsibilities yet spend an average of **24 hours** each week caring for a loved one.



**1 in 6** adults who are not currently caregivers expect to provide care in the future to a friend or family member.



## Grandfamilies and Kinship Families



Most of the information in this guide is designed for people who are taking care of older relatives and friends. However, many grandparents and older adults are caregivers for grandchildren and other young relatives. These child care arrangements are often called grandfamilies (in the case of grandparents and grandchildren) or, more generally, kinship families.

These resources can provide information and support for grandfamilies and kinship families:

### **The Child Welfare Information Gateway**

This service of the Administration for Children and Families offers information, resources, and tools for kinship caregivers, including grandparents.

**800-394-3366**

**[info@childwelfare.gov](mailto:info@childwelfare.gov) | [www.childwelfare.gov/topics/outofhome/kinship](http://www.childwelfare.gov/topics/outofhome/kinship)**

### **The National Family Caregiver Support Program**

This program from the Administration for Community Living provides information and assistance via state governments to family caregivers, including older relatives (not parents) age 55 and providing care to children under the age of 18.

**202-401-4634**

**<https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>**

Additional resources for caregivers are listed at the end of this guide.



# Chapter 1:

## Getting Started



Alicia was worried about her Uncle James. He lived alone and took care of the house by himself. He sounded fine when she spoke with him on the phone, but she wasn't sure how he was really doing. The last time she stopped by for a visit, she noticed dishes piled up in the sink and clothes scattered on the floor in his bedroom. Because he was usually very neat and tidy, Alicia was concerned that he might need more support and wondered how she could help.

After exploring resources through a local senior center, Alicia planned another visit to look for trouble spots and, with permission, to talk with one of her uncle's neighbors. Once she knew more about the situation, she was able to have an open conversation with her uncle about what types of support would be most useful. Although she didn't live nearby, she was able to coordinate an aide to come by regularly to help her uncle manage his home.

**I**f you have never been a caregiver before, it may feel daunting at first. There might be tasks to organize, new medical terms to learn, and schedules to coordinate. If you live far away, you may need to find new ways to stay in touch. This chapter will help you figure out where to start as a caregiver and how to coordinate with family and friends to share responsibilities.

---

**“Caregiving can be overwhelming, especially at the beginning. Try to tackle one task at a time.”**

### How can I tell whether a family member or friend needs help?

It is not always clear whether someone needs help. Sometimes a person will recognize that they need help and request it, or an emergency or sudden illness will make it clear that assistance is needed. But there are often other signs that indicate someone may need extra support.

A phone call, email, or text message is not always the best way to tell whether an older adult needs help handling daily activities.

The person might not want to worry you, or they might not want to admit that they're often too tired or sick to cook a meal or clean up.

When you spend time at the person's home, you might notice possible trouble spots. Some examples include:

- Is the person taking their medications and going to their medical appointments?
- Can the person prepare meals on a stove safely?
- Are they bathing regularly and wearing appropriate clothing for the weather?
- Is the home relatively clean and free of clutter?

Make sure that any potentially dangerous situations are addressed as soon as possible.

In addition to safety issues and the overall condition of the home, the person's mood and general health could indicate a need for help. Sometimes depression in older people is confused with normal aging. A depressed older person might brighten up for a phone call or short visit, but it's harder to hide serious mood problems during an extended visit. Other signs relate to the person's general health. These include whether they have gained or lost significant weight, have poor hygiene, seem confused, have fallen, seem lonely or isolated, or have trouble

walking. Seek help right away if the person says they feel hopeless or have no reason to live, if they've lost interest in things they previously enjoyed, or if you're worried they may harm themselves.

With the older adult's permission, it can be helpful to check in with others who see them regularly — such as neighbors, friends, doctors, or relatives — and ask these people to call you if they have any concerns.

## I'm new to caregiving. Where do I start?

Caregiving can be overwhelming, especially at the beginning. Try to tackle one task at a time. Here are some ways to get started:

**Find out as much as you can about the person's medical situation.** Learn about the person's health and any treatments they are receiving. Knowing the details of their situation can help you understand what is going on, anticipate how an illness might change or worsen over time, and manage the person's health care. It can also make talking with the person's doctors easier and reduce the likelihood of a medical crisis.

The older person may be hesitant to share their health information. They may not

## When To Get Emergency Help

If you or someone you know is struggling with thoughts of suicide, a mental health or substance abuse crisis, or any other kind of emotional distress, immediate help is available. Call or text the 24-hour 988 Suicide & Crisis Lifeline at **988** or call **800-273-TALK (800-273-8255)**.





---

**“Caregiver training is available from many sources, including hospitals, state and local governments, and nonprofit organizations.”**

---

want to worry you, or they may not want others to know how serious their health issues have become. Approach these conversations sensitively and explain why you’re asking questions about their health. If the person isn’t comfortable talking about it themselves, they may be willing for you to talk with their health care provider instead. By law, you will need written permission to receive medical information about the person unless they are with you in person and able to give consent. The health care provider’s office can explain the process and provide the necessary forms.

**Determine where to get help.** Consider asking family members and friends to share caregiving tasks. If someone you know and trust is also a caregiver, ask them for tips and recommendations for resources near you. You can also look for resources online or in your community, such as local and state offices on aging, social service agencies, or nearby senior centers.

The Eldercare Locator can help you find resources in your area, including in-home help, transportation, and modifications to make a person’s home safer and easier to get around. It can also provide information about paying for care. You can contact the Eldercare Locator at <https://eldercare.acl.gov> or by calling **800-677-1116**.

**Get training if needed.** Many people don’t have caregiving experience when they are first needed. Caregiver training

is available from many sources, including hospitals, state and local governments, and nonprofit organizations. Training courses are often free or low-cost, and some can be completed online. Medicare and Medicaid, which are government insurance programs, will sometimes pay for caregiver training.

## How can I share caregiving responsibilities with others?

Caring for an older person often requires teamwork with family, friends, or formal caregivers. While a person who lives nearby might take on most of the everyday responsibilities, people who live farther away can also play an important role in coordinating care.

These steps can help you decide how best to share caregiving tasks:

**Define the caregiving responsibilities.** You could start by setting up a meeting or conference call with the person and everyone who will be involved in their care. This conversation will be most productive when there is not an emergency. A calm discussion about what kind of care is wanted and needed now, and what might be needed in the future, can prevent a lot of confusion and misunderstanding later.

**Decide who will be responsible for which tasks.** When several people are involved in caregiving, many find that the best first step is to name a primary caregiver. This is the person who takes on most of the everyday caregiving responsibilities. Even if a primary caregiver is not needed immediately, identifying someone now will allow that person to step in right away if there is a crisis.

Ideally, each person providing care will be able to take on the tasks best suited to

their skills and interests. When thinking about everyone's strengths, consider what each person is particularly good at and how those skills might help in the current situation:

- Who is best at finding information and keeping people up to date on changing conditions?
- Who is most comfortable using email, text messages, and other forms of technology?
- Who do people call when they need emotional support and someone to talk to?
- Who is most confident about speaking with medical staff and conveying information to others?
- Who lives close enough to assist with day-to-day tasks, such as grocery shopping, cooking, and cleaning?
- Who likes coordinating larger tasks, such as helping to organize a move?
- Who is good with numbers? Could they take charge of tasks such as paying bills, keeping track of bank statements, and reviewing insurance policies and reimbursement reports?

- Other than the primary caregiver, who can step in to help occasionally? For example, can someone else stay with the person needing care so the primary caregiver can take a short break or go on vacation?

**Be honest about your limits.** No one can be expected to do everything. Be gentle with yourself and realistic about how much you can do and what you are willing to do. For example, you might ask yourself:

- How will my decision to take on caregiving responsibilities affect my work and home life?
- If I don't live nearby, how often, both mentally and financially, can I afford to travel?
- Am I emotionally prepared to take on what may feel like a reversal of roles between me and the older person — such as taking care of my parent instead of my parent taking care of me? Can I continue to respect their independence?
- Can I be calm and assertive when communicating with the older person and any other caregivers? Could I seek advice or training to get better at this?

## Stay in the Know With a Caregiving Notebook

To keep everyone involved in caregiving informed, it may be useful to compile a notebook with details about the person's medical care, social services, contact numbers, financial information, and other pertinent details. This list can be created and updated electronically or in a paper notebook that's kept in a central location. There are also smartphone apps that enable you to divide up caregiving duties, keep an appointment calendar, and share updates with others. Whichever format you choose, make sure everyone has access to the caregiving notebook and that it is reviewed regularly and updated as needed.



**Update the plan for sharing tasks as circumstances change.** Over time, caregiving responsibilities may need to be revised. There can be changes in the needs of the person receiving care and in family members' availability. Check in with the person receiving care and the other caregivers regularly to make sure the current arrangement is still working for everyone.

*Worksheet: Coordinating Caregiving Responsibilities*, on page 55 of this guide, can help you have a productive conversation about identifying and sharing caregiving tasks.

## Who is a long-distance caregiver and how can that person help?

Many people live far away from their family or friends who need help. If you don't live nearby, you can still provide support and assistance as a long-distance caregiver.

From a distance, you may be able to:

- Assist with finances, money management, insurance claims, or paying bills
- Arrange for care management or in-home care by hiring formal caregivers such as home health aides
- Order medical equipment, medicines, and other supplies the person needs
- Research long-term care options, such as an assisted living facility or nursing home
- Serve as an information coordinator by researching information about relevant health conditions and medicines, navigating changing needs, and overseeing insurance benefits

- Keep family and friends informed and updated
- Plan occasional in-person visits to see how things are going and to help the primary caregiver, the person who takes on most of the everyday caregiving responsibilities

Make the most out of your visits with your loved one. Talk to the person ahead of time and find out what they would like to do during your visit. Also check with the primary caregiver, if appropriate, to learn what they need. You may be able to handle some of their caregiving responsibilities while you are in town. These conversations can help you set clear-cut and realistic goals for the visit. Decide on your top priorities — that may mean reserving other tasks for a future visit.

Because there's a lot to do during a short visit, it's easy to overlook simply spending time with the person and doing things together. Try to make time for activities unrelated to being a caregiver, such as watching a movie, playing a game, enjoying music, or taking a drive. Finding time to enjoy something simple and relaxing together is good for everyone.

Several organizations offer information and tips for long-distance caregivers. Check out the websites of AARP ([www.aarp.org](http://www.aarp.org)), the Caregiver Action Network ([www.caregiveraction.org](http://www.caregiveraction.org)), or the Family Caregiver Alliance ([www.caregiver.org](http://www.caregiver.org)) and search "long-distance." The Eldercare Locator can also provide resources for long-distance caregivers, including a guide called "Caring Across the Miles." Visit the Eldercare Locator online at <https://eldercare.acl.gov> or call **800-677-1116**.

## Staying in Touch



When you don't live close by, it may take more effort to find out what's going on and stay up to date with an older person's needs. Here are some strategies and technologies that long-distance caregivers can use to stay connected:

- Create a list of important phone numbers and email addresses. Keep it in a shared document or spreadsheet online and update it regularly.
- Set up a shared calendar online or in a smartphone app to coordinate with other caregivers.
- With permission, attend the person's telehealth visits. Telehealth visits are remote appointments with health care providers often done with video conferencing. Learn more about telehealth on page 35 of this guide.
- Participate remotely in conference calls or video meetings with the assisted living facility team or nursing home staff.
- Help the older person learn about the features of their mobile or smart phone, such as texting and video calls.
- If the older person is comfortable using a computer or tablet, set up an email account for them and teach them how to stay safe online. (See "Beware of Scams!" on page 14 of this guide.)



# Chapter 2:

## Finding the Care You Need at Home



Marlon's 80-year-old mother moved in with him about a year ago so he could care for her. He loves her and is happy to help, but lately she needs more assistance around the house. Sometimes Marlon feels exhausted and overwhelmed, and he feels guilty that she is alone while he's at work. A friend suggests that Marlon consider having a professional come in to help.

Marlon isn't sure where to start, so he searches online for services in their area. He finds a professional service that can help his mother with meals, housekeeping, and personal care. After reading reviews and checking references, he hires an aide from the service to be with his mother for a few hours each morning. Marlon's mom is now getting the help she needs, and Marlon doesn't worry as much when he's at work.

**L**ong-term care services help people live as independently and safely as possible when they can no longer perform everyday activities on their own. This care is provided in different places by different caregivers, depending on a person's needs. In many cases, long-term care is provided at home by informal caregivers, such as family members, friends, and neighbors. It can also be supplemented by formal caregivers, including in-home and community services. This chapter offers

suggestions and resources for long-term care to support an older adult who wishes to continue living in their home.

### How do I know if an older adult can continue living at home safely?

Many people want the same things as they get older: to stay in their own homes, to maintain independence for as long as possible, and to turn to family and friends

for help when needed. But many older adults and their families have concerns about safety, getting around, or other daily activities. Living at home as a person ages requires careful consideration and planning.

To get started, you can think about the kinds of help an older person needs now and might want in the future. Maybe the person lives alone and is struggling with daily tasks that they could previously do on their own. Maybe they will soon need more support because their neighbor who helped with grocery shopping and yardwork is moving out of the area. Or maybe their partner recently passed away, so there is no longer another person to share the household responsibilities. The best way to know what someone needs is to ask them directly. However, if the person can't acknowledge their need for help or is unwilling to ask for it, you may need to be more proactive.

Another step is to consider any illnesses, such as diabetes or emphysema, that the older person might have. Find out about how the illness could make it hard for them to get around or take care of themselves in the future. The person's health care provider may be a good place to start. (Chapter 5 of this guide, which begins on page 33, has tips for talking with an older person's doctor.)

Additional factors to consider include:

- Can the older person take care of themselves independently?
- Does the person have family, close friends, and other support?
- Is the home set up to meet the needs of an aging person? Do you have any concerns about their safety? See *Worksheet: Home Safety Checklist*, on page 59 of this guide, for tips on making an older person's home safer.

Talk with the older adult and any other caregivers about what support would be needed for the older person to stay in their home. Be realistic and plan to revisit the decision as the person's care needs change over time.

## How can I make an older person's home safer and more accessible?

There are a variety of ways to make an older adult's surroundings safer and easier to manage. Go through the house room by room to identify potential problems and safety issues. First correct any immediate dangers, such as loose stair railings and poor lighting, and then work on other ways to ensure the person will be as safe as possible at home.

*Worksheet: Home Safety Checklist*, on page 59 of this guide, provides room-by-room suggestions to help you identify and remove hazards around the house.

Are you worried that making changes might be expensive? You may be able to get help paying for repairs and safety updates to an older adult's home. Check with your state housing finance agency, social services department, community development groups, or the federal government for financial aid programs and discounts. You can also contact the Eldercare Locator for help finding resources at <https://eldercare.acl.gov> or by calling **800-677-1116**.

## What services are available for older adults living at home?

Family members and friends may be able to help with some personal and

household tasks. But you might want to hire professionals to assist with others. There are many types of services available to help meet a person's long-term care needs when living at home. These include:

**Personal care.** The most common type of long-term care is personal care. An older adult can get help with everyday activities, also called “activities of daily living,” including bathing, dressing, grooming, using the toilet, eating, and moving around — for example, getting out of bed and into a chair. To provide support for personal care, a relative, friend, or trained aide could help for a short time each day.

**Household chores.** Does the older adult need help with chores, such as housecleaning, yard work, grocery shopping, or laundry? Some grocery and drug stores will take orders over the phone or online and deliver the items to a person's home, and someone you know may have a housekeeper or gardener to recommend. Laundry and dry-cleaning services that pick up and deliver clothes are another option.

**Meals.** Maybe you're worried that the person isn't eating nutritious meals or is eating alone too often. You might suggest they share cooking duties with a friend or have a potluck dinner with a group of neighbors. Find out if their religious community or a local senior center serves meals. Is it hard for the person to get out? Plan to bring them a healthy meal a few times a week, ask a neighbor or friend to help out, or consider a meal delivery program.

**Money management.** If the older adult needs help with tasks such as paying bills and filling out health insurance forms, you or a trusted relative could lend a hand.

Trained volunteers, financial counselors, and other professionals can also help. Just make sure you get a referral from a trustworthy source, such as your local Area Agency on Aging. If the older adult uses a computer, you could help them pay their bills online through the websites of service providers or their bank. Some regular bills, such as utilities and rent or mortgage payments, can be paid automatically from a person's bank account each month.

Ask the person to consider providing someone they trust with legal permission to discuss their financial matters with others. One way to do this is through a power of attorney, which allows a trusted relative or friend to make financial decisions on their behalf. That person could help deal with creditors, pay bills from the older person's bank account, or find out about Social Security or Medicare benefits. For more information, visit the Consumer Financial Protection Bureau online at [www.consumerfinance.gov](http://www.consumerfinance.gov) or call **855-411-2372**.

**Health care.** In some areas, professionals can provide health care services in a person's home — the modern-day equivalent of a house call. In-home services are available to help older people with many aspects of health care, including giving medications, caring for wounds, helping with medical equipment, and providing physical therapy. If the person just left the hospital and still needs nursing care at home for a short time, the hospital can help make arrangements for a home health aide. In-home health services can also help manage long-lasting (chronic) conditions such as diabetes, for example, by testing a person's blood sugar or giving insulin through a pump.

## Beware of Scams!



Older adults are often the target of scams. Scammers are savvy and convincing, and their scams are designed to catch people off guard. Don't be ashamed if you think you or someone you're caring for has been a victim of a scam — it can happen to anyone.

Common scams aimed at older adults include:

- **Government impersonator scams**, such as someone posing as a Medicare representative asking for account information
- **Fake prize, sweepstakes, and lottery scams**, in which you are asked to pay money or provide account information to claim winnings
- **Computer tech support scams**, in which a scammer tells you that your computer has a problem and wants you to pay for support services to fix it
- **The grandparent scam**, in which a caller pretends to be a grandchild or other relative in distress

There are steps you can take to help protect yourself and your loved ones from scams. Remind your family and friends that they should not give out sensitive personal information over the phone or in response to an email, social media post, or text message. Sensitive information includes Social Security, bank account, and credit card numbers; PINs; and passwords. Always check incoming bills, including utility bills and credit card statements, for charges that were not authorized.

One reason that scammers target older adults is that they are less likely to report suspected fraud. If you think that an older adult in your life has been the target of a scam, contact the National Elder Fraud Hotline at **833-372-8311**.

Does the older adult forget to take their medicines? You can set an alert on a smartphone or smart home speaker to remind someone when it is time for their next dose. Special pill boxes enable you to organize pills daily for an entire week.

**Transportation.** If the person has trouble walking, a cane or walker could help them get around more easily. If they need more assistance, think about getting an electric scooter or chair. If the person can no longer drive, neighbors or volunteers may be able

to help take them to the doctor's office or run errands, such as grocery shopping. There may also be free or low-cost public transportation, ride-sharing services, and taxis available in your area.

**Safety.** If an older person lives alone, you might be concerned they will become sick, fall, or get lost when there's no one around to help. Services such as an emergency medical alert system, fall monitor, or GPS tracking device can help lower these risks. These technologies alert emergency



personnel when a person goes outside a specified area or needs urgent medical assistance. However, these devices must be set up correctly and worn by the older adult to be useful, and they can't replace regular check-ins by family, friends, and other caregivers.

## Who provides care services for older adults living at home?

There are many services that can help you care for an older adult at home. Trained professionals deliver different types of care, depending on the person's specific needs and preferences. The most common services include:

**Home health care services.** These are typically part-time medical services ordered by a physician for a specific condition. They may include in-home nursing care to help a person recover from surgery, an accident, or an illness. Home health care may also include physical, occupational, or speech therapy. The provider may come for a few hours each day or stay 24/7.

What to know about costs:

- Home health services charge by the hour.
- Medicare has limited coverage of home health service costs. The services must be short-term and provided by agencies certified by Medicare. Medicaid also provides coverage for home health service costs, but these benefits vary by state.
- Most private health insurance plans do not cover these costs.
- You must pay all costs not covered by Medicare, Medicaid, or insurance.

To find a home health care service, ask your doctor or other health care professional about good options in your area. A tool for finding Medicare-certified home health agencies is available online at [www.medicare.gov/care-compare](http://www.medicare.gov/care-compare).

**Geriatric care managers.** A geriatric care manager, also called an aging life care expert, is usually a licensed nurse or social worker who specializes in geriatrics (health care for older adults). This provider is a sort of "professional relative" who can help you identify needs and find ways to meet them —

## Finding Resources for Home Care

Looking for someone to help an older adult at home? The Eldercare Locator can help you learn which services are offered in your area. Visit <https://eldercare.acl.gov> or call **800-677-1116** to find Area Agencies on Aging and other resources in your community.

Medicare ([www.medicare.gov](http://www.medicare.gov)) and Medicaid ([www.medicaid.gov](http://www.medicaid.gov)) may cover the cost of some home-based services. Find out whether you are eligible and which benefits are available. Contact the Center for Medicare and Medicaid Services at **877-267-2323**.



both for you and the person receiving care. They can work with you both to make a care plan and find services in your community. Geriatric care managers can be especially helpful when a caregiver lives far away. They can also:

- Discuss difficult topics and complex issues
- Make home visits and suggest services
- Address emotional concerns and provide support
- Make short- and long-term plans
- Evaluate in-home care needs
- Coordinate medical services
- Refer to other care specialists
- Evaluate potential living arrangements
- Provide stress relief to caregivers

What to know about costs:

- The cost of an initial evaluation varies and may be expensive.
- Geriatric care managers charge by the hour.
- Medicare and Medicaid do not pay for this service.
- Most private health insurance plans don't cover these costs. Long-term care insurance may pay for some of the costs: Check the plan to see if it includes coverage.
- Most people must pay for some or all of this service themselves.

There are several ways to locate a geriatric care manager. Your doctor or other health care provider may be able to provide a recommendation. Or contact the Aging Life Care Association at [www.aginglifecare.org](http://www.aginglifecare.org) or **520-881-8008**. The Eldercare Locator can also help you find resources; visit <https://eldercare.acl.gov> or call **800-677-1116**. Additionally, you can contact a support group for diseases related to aging. These groups may be able to

## Home Health Care Services: Do Your Research!

Get as much information as you can about a service before you sign an agreement. It's always a good idea to get a referral from a friend or trusted resource, and to check references before hiring a particular person or company. Ask home health care providers for references from people who have used their services. If possible, check for any complaints filed against a company.

Medicare offers a tool to find and compare home health care providers in your state: Visit [www.medicare.gov/care-compare](http://www.medicare.gov/care-compare). You can also check with state and local agencies that regulate health services or contact the Better Business Bureau ([www.bbb.org](http://www.bbb.org)) in your area.

See *Worksheet: Questions To Ask Before Hiring a Care Provider*, on page 61 of this guide, for considerations when choosing a home care service.

recommend geriatric care managers who have assisted others in your area.

**Meal services.** Meal services deliver healthy, nutritious meals to a person's home on a daily or weekly basis. Many of these services offer options for special diets and

can handle dietary restrictions. However, the delivery staff do not assist with making meals at home or feeding the person.

What to know about costs:

- In some cases, a person must qualify for the service based on certain guidelines. These can include age, mobility, and economic need.
- Medicare does not generally cover meal delivery services, although under certain circumstances, it will provide this benefit for a short time. Medicaid may pay for some meal delivery services if the person is eligible.
- Some meal delivery services do not require payment. Others charge a fee or accept donations.

To find a meal delivery service in your area, contact Meals on Wheels America at [www.mealsonwheelsamerica.org](http://www.mealsonwheelsamerica.org) or **888-998-6325**. Some local governments provide low-or no-cost meals to older adults. Call or check their websites for details. Your health care provider or local senior center may also be able to recommend a service. Additionally, there are many subscription services that deliver ready-to-eat meals and meal kits. These can be arranged online and generally involve a regular weekly or monthly charge. For more resources in your community, visit the Eldercare Locator at <https://eldercare.acl.gov> or call **800-677-1116**.

**Adult day care services.** Adult day care services can provide a much-needed break for caregivers at home. These programs provide a safe environment for older adults with trained staff in a nearby facility. An adult day care center may offer social activities, exercise, meals, personal care, and basic health care services. Some will provide transportation — the facility may

pick up the person, take them to day care, and then return the person home.

What to know about costs:

- Adult day care tends to be less expensive than in-home or nursing home care. Charges can be hourly or by the day.
- Medicare will not pay for adult day care, but Medicaid and other government programs may provide coverage.
- Most private health insurance plans don't cover the costs of adult day care. Some long-term care insurance plans pay a portion of the costs.
- You must pay all costs not covered by a government program or insurance.

To find an adult day care center in your area, contact the National Adult Day Services Association at [www.nadsa.org](http://www.nadsa.org) or **877-745-1440**. For resources in your community, visit the Eldercare Locator at <https://eldercare.acl.gov> or call **800-677-1116**.

**Respite care.** Respite services provide short-term care for an older adult at home, in a health care facility, or at an adult day care center. The care may last anywhere from a few hours to several weeks at a time. These services provide regular caregivers with a break to rest, travel, or spend time with other family and friends.

What to know about costs:

- Respite services charge by the hour or by the number of days or weeks that services are provided.
- For a person receiving hospice care, Medicare will cover most of the cost for up to five consecutive days of respite care in a hospital or skilled nursing facility. Medicaid also may provide payment assistance.

- Most private health insurance plans do not cover these costs. Some long-term care insurance plans may help pay for respite care.
- You must pay all costs not covered by insurance or government programs.

To search for respite care programs in your area, visit the ARCH National Respite Locator at <https://archrespite.org/respitelocator> or call **703-256-2084**. For more resources in your community, visit the Eldercare Locator at <https://eldercare.acl.gov> or call **800-677-1116**.

**Counseling from a mental health professional.** Counselors can help older adults and caregivers deal with stress they may be feeling. They can help you understand your feelings, such as anger, sadness, or feeling out of control and overwhelmed. Counselors can also help develop plans for unexpected or sudden events.

Professionals who provide mental health counseling include psychologists, therapists, and social workers, among others. Counseling can occur in-person at an office, at a person's home, or in a community setting. Virtual counseling sessions, which take place remotely on a computer or smartphone, are becoming more common.

What to know about costs:

- Professional mental health counselors charge by the hour. Rates vary widely.
- Medicare or Medicaid may cover some of the costs.
- Some private health insurance companies will cover some of the costs.
- You must pay all costs not covered by Medicare, Medicaid, or private health insurance.

Check with your health insurance provider to find out which counselors and services are in your plan's network. Then ask your doctor, local family service agency, or community mental health agency for referrals to counselors who participate with your insurance plan.

**Friendly visitor and senior companion services.** Some organizations have volunteers who regularly pay short visits (less than two hours) to older adults. The volunteer can provide support, assistance, and companionship.

What to know about costs:

- Volunteer services are available at no cost. You can also get this type of service from home health agencies for a fee.
- Medicare, Medicaid, and private health insurance generally do not cover these services. Some long-term care insurance plans help pay for companion visits.

The Eldercare Locator can help you find senior companion services in your community. Visit <https://eldercare.acl.gov> or call **800-677-1116**. Nearby senior centers and your state or local government can also help connect you with volunteers near where you live.

**Transportation services.** When you aren't available to take an older adult to the doctor's office or grocery store, transportation services can help. They drive people to and from medical appointments, shopping centers, and other places in the community.

Various state and local agencies, nonprofit organizations, and companies offer transportation services for older adults. Some senior housing complexes and community groups also offer rides. Many

public transit agencies have discounted fares and other services for older adults and people with disabilities. Many communities also have taxis, ride-sharing services, and other transportation resources available. If needed, you can request a vehicle that will accommodate a wheelchair, walker, or electric scooter.

What to know about costs:

- Some services are free. These include programs from state and local governments and some nonprofit organizations.
- Other services, such as taxis, car services, and ride-sharing companies, charge a fee for transportation. Some offer discounts for older adults.
- For people who do not have access to a ride, Medicaid provides transportation for emergency medical care and for doctor's appointments. Medicare provides transportation via ambulance for health care emergencies and limited nonemergencies (such as a ride to a dialysis facility).

Learn more about transportation services available in your area from the Eldercare Locator. Visit <https://eldercare.acl.gov> or call **800-677-1116**.

**Emergency medical alert systems.** These systems respond to medical and other emergencies via an electronic monitor that a person wears. The monitor alerts emergency personnel when a person becomes lost, falls, or needs urgent medical assistance. This type of service is especially useful for people who live alone or who have a high risk of falling. However, these devices won't be useful in every kind of emergency.

The user wears a necklace or bracelet with a button to call for emergency help. Some sensors can detect automatically when a person falls or travels away from their home unexpectedly, and the system will alert caregivers or emergency personnel. Make sure the devices are set up and worn correctly, and that batteries are charged or replaced as recommended.

What to know about costs:

- Emergency medical alert systems typically charge a fee to get started, followed by a monthly service fee. The costs vary based on the company, available features, and coverage area.
- Medicare will not pay for emergency medical alert systems, but Medicaid and other programs may provide coverage.
- Some private health care insurance plans cover emergency medical alert systems. Some long-term care insurance plans also pay a portion of the costs.
- You must pay all costs not covered by private health insurance or government programs.

The Eldercare Locator can help you find a service that's right for you. Visit <https://eldercare.acl.gov> or call **800-677-1116**.



# Chapter 3:

## Choosing a Long-Term Care Facility



June lived in Phoenix with her children, while her father, Zhuang, lived alone in Los Angeles. She visited him several times each year. When she noticed that her dad was starting to have problems managing on his own, they sat down together to talk about their options. June's job and family needed her in Phoenix, while Zhuang's friends, doctors, and religious community were all in Los Angeles. June brought up the possibility of moving him to an assisted living facility close to his current home. There, Zhuang

could get help when he needed it but still have the freedom to see his friends and go to the grocery store and to church.

June interviewed several facilities, and she and her dad toured one that seemed like a good fit. Zhuang said he could see himself living there. Within a month, they signed a contract. After Zhuang moved into assisted living, it took some time to adjust. He missed his old neighborhood and his former home. But he found that the facility had a weekly movie night, which he enjoyed, and computers he could use to email June and his grandchildren. Assisted living seemed like a good choice, and June was glad that he was getting the care he needed.

**S**ometimes an older person can no longer live safely or comfortably in their own home. They may be able to move in with family or friends. Some people, however, need more help than a family member or friend can provide. They might move to a residential (live-in) facility, such

as a board and care home, an assisted living facility, a nursing home, or a continuing care retirement community.

---

**“The goal is to come up with a plan that works for everyone, especially the older person.”**

## How can I help an older adult decide if it's time to move from their home?

The decision about whether and when an older adult should move from their home is often difficult and emotional. Everyone will have their own reasons for wanting (or not wanting) to take such a step. One person may decide a move is right because they can't or don't want to manage the home any longer. For another person, the need for regular, hands-on care motivates a change.

Making a decision that is best for the older person and their caregivers can be difficult. Try to learn as much as you can about the available housing options. These may include:

- Moving to a smaller home, such as from a single-family home to a condominium or apartment
- Moving in with a family member or friend
- Moving to a residential facility, such as an assisted living facility or a nursing home

The choices for where to live might be limited by factors such as illness, ability to perform activities of daily living (for example, eating, bathing, dressing, and using the toilet), and personal preferences. Money is often part of this decision as well. In some cases, a move frees up cash so that the older adult can afford a more suitable situation. For others, the desire to move to a safer location is hampered by a lack of funds to cover the cost of the new home.

Some families and caregivers find that a meeting or conference call is a good way to talk through the pros and cons of each option. The goal is to come up with a plan that works for everyone, especially the older person.

To a long-distance caregiver, a move may provide a solution to the problem of not being close enough to help regularly. For some caregivers, moving an older person who needs help to their own home or community is an option. Others decide to have a family member move back to the older person's local area to become the primary caregiver. *Worksheet: Questions To Consider Before Moving an Older Adult Into Your Home*, on page 63 of this guide, lists some questions to think about when considering this kind of move.

Keep in mind that leaving a home, community, and familiar medical team can be disruptive and difficult, especially if the older person is not enthusiastic about the change. You might first want to explore what services are available in the person's community to assist them in their home, including home health care, housekeeping, personal care, and transportation services. If a move becomes necessary, look for resources to help the person handle the transition. These may include counseling and support, guidance from health care professionals, and suggestions from your local senior center or Area Agency on Aging.

## What types of long-term care facilities are available?

Some facilities offer only housing and housekeeping, but many also provide personal care, social and recreational activities, meals, and medical services. Some facilities offer special programs for people with Alzheimer's disease and other types of dementia. Information about how to find and choose a facility is available on page 23.

The most common types of long-term residential facilities are:

**Board and care homes.** These small private facilities, also called residential care facilities or group homes, usually have 20 or fewer residents. Rooms may be private or shared. Residents receive personal care and meals, and staff are available around the clock. Nursing and medical care usually are not provided at the home.

In most cases, you must pay the costs of living at a board and care home. Medicare does not cover these costs. Medicaid may provide partial coverage, depending on the state and whether the person is eligible. If the older person has long-term care insurance, check their plan to see if it includes coverage for this type of facility.

**Assisted Living.** Assisted living is for people who need help with daily care, but not as much help as a nursing home provides. Assisted living facilities range in size from as few as 25 residents to 100 or more. Typically, a few levels of care are offered, and residents pay more if they need extra services or special care.

Assisted living residents usually live in their own apartments or rooms and share common areas. They have access to many services, including up to three meals a day; assistance with personal care; help with medications, housekeeping, and laundry; 24-hour supervision, security, and on-site staff; and social and recreational activities. Some assisted living facilities are part of a larger organization that also offers other levels of care. For example, continuing care retirement communities may also offer independent living and skilled nursing care. Exact arrangements vary by facility and by state.

Most people pay the full costs of assisted living themselves. This option tends to be more expensive than living independently but less expensive than a nursing home. Medicare does not pay for assisted living. Medicaid may provide coverage for some aspects of assisted living depending on the state and whether the person is eligible. This care option is partially covered by some long-term care insurance policies.

**Nursing homes.** Nursing homes, also called skilled nursing facilities, provide a wide range of health and personal care services. Their services focus more on medical care than most assisted living facilities or board and care homes. Services offered in a nursing home typically include nursing care, 24-hour supervision, three meals a day, and assistance with everyday activities. Rehabilitation services, such as physical, occupational, and speech therapy, are also available.

In many cases, people must pay for nursing home care themselves. Medicare generally doesn't cover long-term stays in a nursing home, but it may pay for some related costs, such as doctor services and medical supplies. Medicaid may also cover some of the costs of nursing homes for people who are eligible based on income and personal resources. If the older person has long-term care insurance, the policy may include some coverage for nursing home care. Check with the insurance company for details.

You can find and compare Medicare-certified nursing homes in your state at [www.medicare.gov/care-compare](http://www.medicare.gov/care-compare).



## Resources for Choosing a Long-Term Care Facility



There are many sources of information about long-term care facilities. Visit [LongTermCare.gov](https://www.longtermcare.gov) to learn more about long-term care options and find local services. You can also call your local Area Agency on Aging or department of human services from your state or local government. Search the Eldercare Locator at <https://eldercare.acl.gov> or call **800-677-1116** to find contacts in your area.

Medicare offers a tool to find and compare nursing homes and other health care facilities in your state: Visit [www.medicare.gov/care-compare](https://www.medicare.gov/care-compare).

To check the quality of nursing homes and other health care facilities, visit the Joint Commission at [www.qualitycheck.org](https://www.qualitycheck.org).

**Continuing care retirement communities (CCRCs).** These facilities, also called life care communities, offer different levels of service in one location. Many of them offer independent housing (in houses or apartments), assisted living, and skilled nursing care all on one campus. Health care services and recreation programs are also provided.

In a CCRC, where you live depends on the level of service you need. People who can no longer live independently move to the assisted living facility or sometimes receive home care in their independent living unit. If necessary, they can enter the CCRC's nursing home.

Most CCRCs charge a one-time entrance fee, which may be relatively expensive, and a monthly fee after that. People must pay most of these costs themselves. Medicare, Medicaid, and long-term care insurance may cover some services, depending on the level of care provided.

## How can I find the right long-term care facility for my loved one?

Choosing a nursing home or assisted living facility is a big decision. It can be hard to know where to start. Follow these steps to find the right place:

### **Consider which services the person needs.**

How much support does the person need now, or might they need in the future? For example, do they need assistance with everyday activities, physical therapy, nursing care, hospice care, or a special unit for people with memory problems or dementia? To best understand their needs, it may be helpful to get permission to speak with the person's health care provider.

### **Also consider what the person wants.**

What features are important to the older adult, for example, meals, social and recreational activities, or a religious

connection? Do they want a place close to family and friends so they can easily visit?

**Talk to friends, family, and others in your area.** Talk with friends and relatives who have had family members in long-term care facilities. Were they happy with the care they received? Social workers, religious groups, and support groups in your community may also be able to suggest the best quality places. Check with health care providers about which facilities they feel provide good care.

**Call different facilities.** Once you've made a list of possibilities, get in touch with each facility on your list. Ask questions about how many people live there and what it costs. Mention any special needs or preferences. Find out whether there is immediate availability or a waiting list.

**Visit the facility.** Before deciding, it's a good idea to visit several facilities in person. Make plans to meet with the director, nursing director, or other key staff members. Visit [www.medicare.gov](http://www.medicare.gov) and search for "Nursing Home Checklist" to download a form to fill out when visiting. For example, look for:

- Medicare and Medicaid certification
- State licensing
- Accessibility for people with disabilities
- Residents who look appropriately dressed and well cared for
- Warm and respectful interaction between staff and residents
- A clean, fresh-smelling, comfortable, and well-maintained facility

Don't be afraid to ask questions during your visit. Ask about anything that is important or concerning. Here are a few ideas for questions to ask the staff:

- How many care providers are there per resident? What kind of training do they have? How many of them are trained to provide medical care if needed?
- How long have the director and heads of nursing, food, and social services departments worked at the facility? How often do key staff members turn over?
- Is there a doctor who checks on residents on a regular basis? How often?
- What activities are planned for residents during the week and on weekends? Can you attend activities yourself to see what they're like?
- Is there a safe place for the older adult to go outside?
- How will the person get to medical appointments?
- If you need it, does the facility have a special unit for people with Alzheimer's or another form of dementia? If so, what kinds of services does it provide?
- Is there information on state regulations for how care is provided? For example, what happens when there is an infectious disease outbreak requiring quarantine? How do they ensure residents still get the physical activity and social interaction they need if they have to stay in their rooms for a long time?

**Visit the facility again.** Make a second visit without calling ahead. Try another day of the week or time of day so you will meet other staff members and have an opportunity to attend different activities. Stop by at mealtime. If there is a dining room, is it attractive and clean? Does the food look appetizing, and can you sample it?

**Find out about costs of care.** Each facility is different, so get detailed information about costs and which services are included. Find out if Medicare, Medicaid, or

## Making the Transition to a Long-Term Care Facility



Moving an older adult to an assisted living facility, group home, or nursing home can be stressful and is a big change for both the person and their caregivers. It may take some time for everyone to adjust. Here are some suggestions that can help:

- Get to know the staff before the person moves into a facility. Talk with them about ways to make the transition go smoothly.
- Be an advocate for the needs and preferences of the older adult.
- Be supportive and listen to any concerns, but don't argue with the older adult about why they need to be there.
- Share your feelings with a social worker or mental health professional. Feelings about moving an older adult into a new place may range from loss and guilt to a sense of relief. Get the support you need to help you and the older adult adjust.

Once the person has moved to their new home, check in regularly to see how they are doing. Look for signs that the person may need more attention or may not be getting the care they need. Build a relationship with staff so that you work together as partners.

long-term care insurance will pay for any of the costs. The facility may have a financial office that can help you determine what assistance is available.

**Carefully read your contract.** Once you select a facility, carefully read the contract. Make sure all the agreements are clear and ask questions about anything you don't understand. Read over the contract again before signing it.

### What should I do if I suspect an older adult is being mistreated?

Mistreatment can happen anywhere: at home, a family member's house, an assisted living facility, or a nursing home. Abuse can happen

to any older adult, but it most often affects those who depend on others for help with activities of everyday life, such as bathing and dressing themselves. Older adults without family or friends nearby and people with disabilities, memory problems, or dementia may be more vulnerable to abuse.

Long-term care facilities must take steps to prevent (and report) abuse. Nursing homes and hospitals are subject to strict state licensing requirements and federal regulations. Still, neglect and abuse can occur. Physical abuse by another resident or someone who doesn't work at the facility is also possible.

It can be hard to assess the quality of an older adult's caregivers. Perhaps you, a friend,

or a neighbor can stop by unannounced to see how things are going. Stay in touch with the older adult by phone and take note of any comments or mood changes that might indicate neglect or mistreatment.

## What are some signs of abuse?

Abuse of older adults can be physical, emotional, sexual, or psychological. Mistreatment can also take the form of neglect, abandonment, or financial exploitation. An older person might be a victim of abuse if they:

- Become withdrawn or act agitated or violent
- Display signs of trauma such as rocking back and forth

- Have unexplained pressure marks, bruises, burns, cuts, or scars
- Develop preventable conditions such as bedsores (open sores that can develop when a person stays in one position for a long time, such as being confined to a bed)
- Have hazardous, unsafe, or unclean living conditions
- Look messy, with unwashed hair or dirty clothes
- Lack personal health care items such as glasses, a walker, dentures, or hearing aid
- Have sudden and unexpected financial losses or unpaid bills despite adequate financial resources

Watch for a pattern that might indicate a problem and seek help if you are concerned.

## Where To Get Help



If you suspect an older person is being abused, report what you see to an authority. Many older adults are too ashamed to report mistreatment. Or they're afraid if they make a report, it will get back to the abuser and make the situation worse. Therefore, family and friends must step in to resolve any problems.

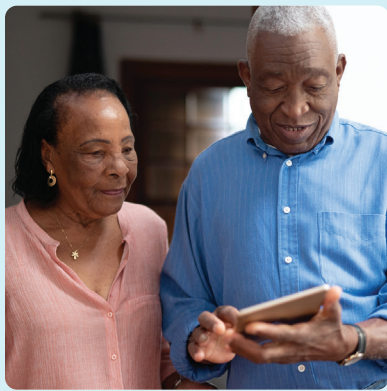
Some types of mistreatment may be criminal. You do not personally need to prove that abuse is occurring; professionals will investigate. These resources can help:

- **Adult Protective Services programs** help protect vulnerable adults from abuse, neglect, and exploitation. Phone numbers for these programs in each state are available at [www.napsa-now.org/aps-program-list](http://www.napsa-now.org/aps-program-list) or by calling **202-370-6292**.
- **The National Center on Elder Abuse** provides guidance on how to report abuse, where to get help, and state laws that deal with abuse and neglect. Visit <https://ncea.acl.gov> or call **855-500-3537** for more information.
- **Long-term care ombudsmen** advocate for the needs of people who live in assisted living facilities, board and care homes, and nursing homes. They are trained to help resolve problems. To find a long-term care ombudsman in your state, visit [https://theconsumervoice.org/get\\_help](https://theconsumervoice.org/get_help) or call **202-332-2275**.

**If you think someone is in urgent danger, call 911.**

# Chapter 4:

## Covering the Costs of Caregiving



Jim and Sally retired a few years ago. They recently decided they wanted to move into a continuing care retirement community closer to their kids. They had resources, including retirement income, money from selling their home, and long-term care insurance policies. But they weren't sure which resources they should use to pay the costs of moving into their new apartment. They called their financial professional, who discussed the pros and cons of tapping into their different funding sources, including how it might affect their taxes. They also wanted to make sure there would still be money to leave their adult children as an inheritance. After talking through the options, Jim and Sally felt more confident about coming up with a plan for their next steps.

**M**any caregivers and older adults worry about the costs of long-term care. These expenses can use up a significant part of monthly income, even for people who thought they had saved enough. How people pay for long-term care depends on their financial situation and the kinds of services they use.

Some people believe that their current health or disability insurance will pay for their long-term care needs, but most of these insurance policies include limited, if any, long-term care benefits. In most cases,

people must find other means of paying for long-term care. They may rely on a variety of payment sources, including personal funds, federal and state government programs, and private financing options. Read on to find out more about each of these options.

### How can personal funds be used to cover out-of-pocket expenses?

Many older adults pay for part or all of long-term care with their own money. They may

use personal savings, a pension or other retirement fund, income from investments, or proceeds from the sale of a home.

Much home-based care is paid for by using personal “out of pocket” funds. Initially, family and friends often provide personal care and other services, such as transportation, for free. But as a person’s needs increase, paid services may be needed.

Many older adults also pay out of pocket for adult day care programs, meals, and other community-based services that help them remain in their homes. In some cases, these services are provided for free or at low cost by local governments and nonprofit groups.

Professional care in assisted living facilities and continuing care retirement communities is almost always paid for out of pocket. In some states, Medicaid may cover some costs for people who are eligible.

## What government programs are available to help pay for long-term care?

Older adults may be eligible for some government health care benefits. Caregivers can help by learning more about possible sources of financial help and assisting older adults in applying for aid as appropriate.

Several federal and state programs provide help with health care-related costs. Over time, the benefits and eligibility requirements of these programs can change, and some benefits differ from state to state. Check with the individual programs directly for the most recent information.

**Medicare.** This federal government health insurance program helps pay some medical costs for people age 65 and older, and for people under 65 with certain disabilities and serious health conditions. Covered services include hospital stays, doctor visits, some home health care, hospice care, and preventive services such as vaccinations. The program does not cover assisted living or long-term care. The parts of Medicare include Part A (Hospital Insurance), Part B (Medical Insurance), and Part D (Drug Coverage). Medicare also offers another way to get your Part A and Part B coverage through Medicare Advantage Plans.

Call Medicare at **800-633-4227** or visit [www.medicare.gov](http://www.medicare.gov) for more information about its programs and coverage options.

**Medicaid.** Some older adults qualify for Medicaid, a combined federal and state program for low-income people. This program covers the costs of medical care and some types of long-term care for people who have limited income and meet other eligibility requirements. Who is eligible and which services are covered vary from state to state.

To learn more, contact your state Medicaid agency or visit [www.medicaid.gov](http://www.medicaid.gov).

**Program of All-Inclusive Care for the Elderly (PACE).** Some states offer PACE, the Program of All-Inclusive Care for the Elderly. It is a combined Medicare and Medicaid program that provides services to people who otherwise would need care in a nursing home. PACE enables most people who qualify to continue living at home instead of moving to a long-term care facility. The program helps cover the costs of medical care, social services, and long-term care

for frail older adults. Participants receive coordinated care from a team of health care professionals.

You will need to find out if the person who needs care qualifies for PACE and if there's a PACE program near you. PACE is available only in certain states and in specific locations within those states. There may be a monthly charge.

To find out more, contact Medicare at **800-633-4227** or visit [www.medicare.gov](http://www.medicare.gov). You can also search for local programs by state or ZIP code through the National PACE Association at [www.npaonline.org/pace-you](http://www.npaonline.org/pace-you).

**State Health Insurance Assistance Program (SHIP).** This national program has offices in each state. It provides one-on-one counseling and assistance with Medicare, Medicaid, and related programs to individuals and caregivers. SHIP can help navigate eligibility, coverage, appeals, and out-of-pocket costs, and answer questions about your family's unique situation and needs.

To find contact information for SHIP in your state, visit [www.shiphelp.org](http://www.shiphelp.org) or call **877-839-2675**.

**U.S. Department of Veterans Affairs (VA).** The VA provides coverage for long-term care at a facility or at home for some veterans. If your family member or relative is eligible for veterans' health care benefits, check with the VA or get in touch with the VA medical center nearest you. There could be a waiting list for VA nursing homes.

Visit [www.va.gov/geriatrics](http://www.va.gov/geriatrics) or call **877-222-8387** for information about long-term care and other services for older veterans.

**Social Security Disability Income (SSDI).** Social Security is a program that provides financial benefits to retired people and to those with disabilities. SSDI is a type of Social Security for people with a medical condition that meets the Social Security Administration's definition of "disability."

For a person to qualify for SSDI, they must be able to show that:

- They worked in jobs covered by Social Security
- They are unable to work
- The condition will last at least a year or is expected to result in death

Social Security has "compassionate allowances" to help people with early-onset Alzheimer's, some other forms of dementia, and certain other serious medical conditions get disability benefits more quickly.

For details about SSDI eligibility, benefits, and the application process, visit the Social Security Administration at [www.ssa.gov](http://www.ssa.gov) or call **800-772-1213**.

## What are private financing options for long-term care?

In addition to personal funds and government programs, there are several private payment options, including long-term care insurance, reverse mortgages, certain life insurance policies, annuities, and trusts. Which option is best depends on many factors, including the person's age, health status, and financial situation.

**Long-Term Care Insurance:** This type of insurance covers services and support for people needing long-term care, including help with the activities of daily living. Policies cover a wide range of benefits in a

variety of settings, including the person's home, an assisted living facility, or a nursing home. The exact coverage depends on the type of policy and the services it includes. Make sure you understand what your policy does and does not cover, and how long benefits last.

Many companies sell long-term care insurance. Costs and benefits vary, so it's a good idea to shop around and compare policies. The cost of a policy is based on the type and amount of services, how old the person is when they buy the policy, and any optional benefits. Some employers are starting to offer group long-term care insurance programs as a benefit. It may be easier to qualify for long-term care insurance through an employer-sponsored program, and group rates may be cheaper than the cost of an individual policy.

Buying long-term care insurance can be a good choice for younger, relatively healthy people at low risk of needing long-term care in the next 25 years. Costs go up for people who are older, have health problems, or want more benefits. Someone who is in poor health or already receiving end-of-life care services may not qualify for long-term care insurance.

For more information about long-term care insurance, visit your state's insurance administration or [LongTermCare.gov](http://LongTermCare.gov).

**Reverse Mortgages.** A reverse mortgage is a special type of home loan that lets a homeowner convert part of the ownership value in their home into cash without having to sell the home. Unlike a traditional home loan, no repayment is required until the borrower sells the home, no longer uses it as a main residence, or dies.

## Finding Government Benefits

Do you wonder which benefit programs would be most helpful for you or a family member? Do you have questions about eligibility? Do you need to learn how to sign up?

**Benefits.gov** is the federal government's official benefits website. It offers numerous state and local resources for health care and financial assistance. The Benefit Finder questionnaire can help you find specific benefits and learn where to apply for them.

You can also check out the National Council on Aging's free service called BenefitsCheckUp ([www.benefitscheckup.org](http://www.benefitscheckup.org)) to find federal and state benefit programs for older adults.

There are no income or medical requirements to get a reverse mortgage, but this option is only available to those age 62 or older. The loan amount is tax-free and can be used for any expense, including long-term care. However, if the person has an existing mortgage or other debt against their home, they must use the funds to pay off those debts first.

If you are thinking about a reverse mortgage, talk to an expert. A reverse mortgage can be complicated, and other borrowing options may be available. These might include a



home equity loan or refinancing an existing mortgage to lower the monthly payments. Like a reverse mortgage, these options can free up cash for covering long-term care expenses. Additional information about reverse mortgages and other borrowing options is available from the Consumer Financial Protection Bureau. Visit [www.consumerfinance.gov](http://www.consumerfinance.gov) or call **855-411-2372**.

**Life Insurance Policies.** Some life insurance policies can help pay for long-term care. Companies are starting to offer a combination product that includes both life insurance and long-term care insurance.

Policies with an “accelerated death benefit” provide tax-free cash advances while a person is still alive. The cash advance is subtracted from any proceeds that beneficiaries receive after the person dies. A person can get an accelerated death benefit if they live permanently in a nursing home, need long-term care for an extended time, are terminally ill, or have a life-threatening diagnosis. Check the life insurance policy to see exactly what it covers and when the older person can access the benefits.

Selling a life insurance policy for its current value can be another way to raise cash. This option, known as a “life settlement,” is usually available only to women age 74 and older and men age 70 and older. The proceeds are taxable and can be used for any reason, including paying for long-term care.

A similar arrangement, called a “viatical settlement,” allows a terminally ill person to sell their life insurance policy to an insurance company for a percentage of the death benefit on the policy. This

option is typically used by people who are expected to live two years or less. A viatical settlement provides immediate cash and is tax-free, but they can be difficult to obtain. Companies decline more than half of people who apply.

Keep in mind that if a person chooses to take life insurance benefits early or to sell their policy, there will be little or no money left from the policy to pass on to heirs. For more information about using life insurance to pay for long-term care, visit your state’s insurance administration or [LongTermCare.gov](http://LongTermCare.gov).

**Annuities.** An annuity is a contract with an insurance company that can help pay for long-term care services. In exchange for a lump sum contribution or series of contributions, the insurance company will provide regular payments over a specified period. For example, the annuity can provide monthly income to cover long-term care costs. These payments, however, may not be enough to cover all of a person’s expenses.

Annuities can have complicated effects on a person’s taxes, so speak with a tax professional before buying one. For more details about annuities, visit [LongTermCare.gov](http://LongTermCare.gov).

**Trusts.** A trust is a legal arrangement that allows a person to transfer assets (such as cash, property, or insurance benefits) to another person, called the trustee. The trustee then manages the assets for that person’s benefit. A trust can provide flexible control of assets for an older adult or a person with a disability.

To find out more about the types of trusts that can be used to fund long-term care, visit [LongTermCare.gov](http://LongTermCare.gov).

## Can I get paid to take care of a family member?

Family caregivers make a lot of sacrifices to care for older, sick, or disabled relatives. Some even quit their jobs to care for the person full-time. There are many costs involved in caregiving, for example, covering travel expenses, paying bills, and buying household essentials. These costs can add up to create a significant financial burden for caregivers.

Many states offer some form of pay for family caregivers. But the laws, eligibility, and funding for this support vary by state. The most common source of assistance is Medicaid, which offers several state-based programs to people who are eligible based on income or disability. These programs include home and community-based services, adult foster care, and Medicaid personal care services. Contact your state Medicaid agency to learn more.

Veterans and people living with certain diseases may also be eligible for financial assistance through federal and state agencies or private organizations. Information is available from the Eldercare Locator at <https://eldercare.acl.gov> or by calling **800-677-1116**.

Long-term care insurance usually provides coverage for care at home. However, policies differ regarding who can deliver that care. In some cases, only a professional service will be paid for long-term care. In other cases, the policy will pay for a family member to provide care. Contact your long-term care insurer to find out the details of your policy.

## Finding a Financial Professional

Navigating the details of paying for long-term care can be challenging. Some options can have implications for a person's taxes and any inheritance they want to leave to their heirs. It may be useful to speak with a financial professional when you're considering how to proceed. Helpful professionals may include:

- Accountants
- Financial planners
- Investment advisors
- Tax preparers
- Attorneys

Check out [Investor.gov](https://www.investor.gov) for more information about finding, choosing, and working with a financial professional.



# Chapter 5:

## Coordinating Medical Care



Jesse's grandfather was diagnosed with dementia last year. When he could no longer manage his own health care, Jesse stepped in to help. After his diagnosis, Jesse's grandfather started seeing several new health care providers and was given many new medications. There was a lot to keep track of. Jesse made sure he took his medications every day and scheduled his doctor's appointments. But she was having trouble keeping up with the whirlwind of new information, prescriptions, and specialists.

Jesse shared her concerns with a friend who worked as a nurse. Her friend recommended smartphone apps that could help her keep her grandfather's medications straight and set reminders to take them. Jesse also found out how to access his electronic health records online and make telehealth appointments with some of his doctors. Using these tools, Jesse felt that she had a better handle on managing her grandfather's care.

If you are a caregiver for an older adult, you may be juggling many different aspects of their care. You might need to go with them to doctor's appointments, look up information about an illness online, or help manage their medications. This chapter provides suggestions and resources that can help.

---

**“Working with health care professionals can be an important part of being a caregiver.”**

### How can I talk with an older adult's health care providers?

Many older adults find it helpful to bring a family member or friend with them to the doctor's office. And working with health care professionals can be an important part of being a caregiver.

First, you will need to make sure that the person's health care providers have permission to speak with you. There are federal and state laws that protect a person's

private medical information. If the person would like their health care providers to share information with you, here's what you can do:

- If you go with the person to an appointment, they can tell the doctor verbally that they agree to have you there. The person can also tell the health care provider that it's okay to share information with you later.
- If you want to access a person's medical records or speak with a provider when the person isn't there, you will need to get legal permission.
- Most doctor's offices and hospitals have a consent form (sometimes called a HIPAA release or a HIPAA waiver) to specify who can have access to a person's private medical information. Ask the older person to provide your name and contact information on this form at each provider's office.
- In some cases, it might make sense to get a medical power of attorney. This will enable you to access information and make health care decisions on the person's behalf. Make sure all the person's health care providers have a copy of the legal document.

## How can I be most helpful during a doctor's visit?

If you go with the person to see their doctor, here are a few tips that will help you be an ally and an advocate:

**Be prepared.** Gather important information beforehand and take it with you to the appointment.

- Take the person's insurance cards, names and phone numbers of other doctors they see, and their medical records if the doctor doesn't already have them. You may want to ask the doctor to send you all the forms the person will need to complete for their visit.
- Bring a list with the names, dosage, and schedule of all medicines, vitamins, herbal remedies, over-the-counter drugs, and dietary supplements the older adult is taking. Don't forget to include those prescribed by other doctors. To keep track, you can use the *Worksheet: Managing Medications and Supplements* on page 65 of this guide.
- Make sure the person remembers to take their eyeglasses or contact lenses

## Share Any Signs of Depression

If you are worried the person might be depressed, you might want to discuss this with the doctor before the appointment. Depression is not a normal part of aging. Emotions such as sadness, grief, and temporary "blue" moods are normal, but continuing depression that interferes with daily living is not okay.

Even some health professionals seem to think depression is a normal response to the illnesses and other problems that can happen as we grow older. Make sure the doctor is taking action in response to your concerns.



to the doctor's visit. If they have a hearing aid, make sure that it is working well and they're wearing it. Tell the person to let the doctor and staff know if they have a hard time seeing or hearing.

- If the doctor doesn't speak the person's language, ask the office staff to provide an interpreter. Call the doctor's office ahead of time because they may need to plan for an interpreter from the same area or country to be available. Ensuring that the older adult can easily understand and talk with the interpreter is important for getting good care.

**Ask questions and take notes.** This will help both you and the older person

remember what the doctor said, and you can share the information with other caregivers later.

- Before the appointment, ask the older adult and any other caregivers if they have any questions or concerns that they would like to bring up.
- Bring the list of questions, starting with the most important ones, and take notes on what the doctor recommends.

**Be respectful.** Remember that you're there to support the older person and help them get the most out of their appointment.

- Ask the older adult in advance how you can be most helpful during the visit.

## What Is Telehealth?

Telehealth is a service that uses video calling and other technologies to help you see your doctor or other health care provider from home instead of at a doctor's office or medical facility. Telehealth may be particularly helpful for people who have limited mobility or live in a rural area. Talking with your doctor online or through a smartphone, computer, or other electronic device can be easier, faster, and less expensive than making a trip to an office.

Telehealth can also support family caregivers who are taking care of older adults either close by or from afar. If you need to ask the doctor a question, you can do so online rather than waiting for an in-person appointment.

As a caregiver, you can help an older person prepare for a telehealth appointment by:

- Finding a quiet space with good lighting
- Testing the camera and microphone on your device in advance
- Making sure your device is fully charged and ready
- Using a stable internet connection

Medicare, Medicaid, and some private insurers are beginning to cover telehealth services. However, coverage can vary by your location and insurance plan. Check with your insurance company or your health care provider's billing department for the latest information about coverage for telehealth services.



- When the doctor asks a question, let the older adult answer unless you have been asked to do so.
- It's easy to get into a two-way conversation between you and the doctor — try not to do this. Always include the person you care for when you talk with the doctor.
- Respect the person's privacy and leave the room when requested. The person may want a chance to ask questions or discuss sensitive topics privately with their doctor.

## Finding Trustworthy Health Information Online



As you may have discovered, not all health information on the internet is of equal quality. So how do you find websites that are accurate and reliable? Use the following questions to evaluate the health information you find online:

- **Who runs the website?** In general, you'll find good health information on websites run by a federal agency, medical school, hospital, or large professional or nonprofit organization. If the site is from another source, is it written by a health care professional, or does it reference one of these trustworthy sources for its health information?
- **What's the purpose of the site?** Is the mission or goal of the website sponsor clear? Is it aimed at selling a product or service?
- **Who authored the information?** Is it clear who wrote the health information? Is there a way to contact the sponsor of the website?
- **Is the information up to date?** Pages should include dates when health information was written, reviewed, or updated.
- **Is your privacy protected?** Look for a privacy policy section to see how your personal information will be used.
- **Does it sound too good to be true?** Does the website offer overly simple or unrealistic solutions to challenging health problems? Are quick, miracle cures promised? Use common sense and good judgment.

When you find a website that seems to be trustworthy, don't stop there. Check if other websites have similar health information. Discuss the information you find with a health care provider before you rely on it. You may have found good information, but only your provider can tell you whether it's good for you or the older adult in your life.

To get started, you can access reliable health information from government websites such as the National Institutes of Health (NIH) ([www.nih.gov](http://www.nih.gov)) and [MedlinePlus.gov](http://MedlinePlus.gov). A doctor, nurse, or other health care provider can also point you toward accurate, trustworthy resources online.

**Find resources and follow up.** There are many ways you can be helpful after the appointment.

- If you live out of town, talk to the doctor about how you can keep up to date on the older adult's health. With the person's permission, it might be helpful to get access to their electronic health records.
- Ask the doctor for written materials to take home and see if they can recommend helpful community resources.
- Larger medical practices, hospitals, and nursing homes often have a social worker on staff who may have valuable suggestions about online or community resources.
- The National Institute on Aging (NIA) provides printable worksheets to track medications, organize questions and concerns, collect family and medical history, and record information when talking with the doctor. Search "Talking With Your Doctor Worksheets" online at [www.nia.nih.gov/health/twyd-worksheets](http://www.nia.nih.gov/health/twyd-worksheets).

## How can I help manage the person's medications safely?

Medicines can help us live longer, stay healthy, and treat many diseases and conditions. But taking them the wrong way or mixing certain prescription drugs, over-the-counter (OTC) medicines, and dietary supplements can be dangerous. The use of multiple drugs or more drugs than are medically necessary — called polypharmacy — is a growing concern for older adults. Some combinations of medicines and supplements make it more likely that a person will become confused or dizzy, fall and get hurt, or develop other health issues. Also, complicated regimens involving multiple drugs make it more likely

that a person will miss doses or take the medicines incorrectly.

As a caregiver, you can help an older person keep track of their medicines and supplements and use them safely. *Worksheet: Managing Medications and Supplements*, on page 65 of this guide, offers a place to record the name, dose, and frequency of every prescription drug, OTC medicine, and supplement the person is taking. You can also note any concerns that you have. Keep this list handy for yourself and other caregivers, and share it with all of the person's health care providers.

Here are some additional tips for managing a person's medications:

### Stay Organized

- **Create a file.** Save all the written information that comes with the person's medicines and keep it somewhere you and other caregivers can easily refer to it.
- **Give medicine on time.** Use meals or bedtime as reminders to give the person their medicine. Or use charts, smartphone apps, or weekly pill boxes. You can also set timers and write reminders to give the medication.

### Focus On Safety

- **Keep medicines out of reach of young children.** Make sure you don't give the person medicines in front of young children, as they might try to copy you. Also, if the older adult's medicines are kept in bottles without child safety caps, be extra careful about where you store them.
- **Turn on a light.** Don't give medicine in the dark. Otherwise, you might make a mistake.

- **Don't share.** Do not give the person medicines prescribed for someone else or give their prescription medicines to another person.
- **Check expiration dates on bottles.** If a medicine is past its expiration date, you may be able to dispose of it at a pharmacy. You can also check with the person's doctor about how to safely discard it.

### Follow instructions

- **Read all medicine labels.** Make sure to give the older adult's medicines the right way. For example, don't use a combined cough and cold syrup if the person only has a runny nose with no cough.
- **Use the right amount.** Don't give the person a larger dose of a medicine, thinking it will help them more. Doing so can be very dangerous, even deadly. And don't skip or give half doses of a prescription drug to save money.
- **Check before stopping.** Give prescription medicine until it's finished or until the person's doctor says it's all right to stop. Note that some medicines are supposed to be taken only "as needed."
- **Take special care with prescription pain medicines.** Pain medications can be helpful when used under a doctor's care, but misusing certain types of prescription drugs increases the risk of dependence and addiction. Never take more of these medicines than the doctor prescribes. Learn more about using medicines safely from the NIH National Institute on Drug Abuse at <https://nida.nih.gov>.

### Watch for side effects

- **Write down any side effects so you can report them to the doctor accurately.** Unwanted or unexpected symptoms or feelings that occur when a person takes medicine are called side effects. Call the

doctor right away if the older adult has any problems with their medicines.

- **Call 911 if the person has life-threatening side effects from a medication.** Rarely, drugs can cause serious side effects, such as severe bleeding or damage to the liver or kidneys. If you see any concerning changes, contact emergency services right away.

### Talk with health care providers

- **Report problems.** Call the person's doctor if you have any trouble with their prescription or OTC medicine, or if you are worried that it might be doing more harm than good. There may be another medication the person can take.
- **Tell the person's doctor about alcohol, tobacco, and drug use.** These substances can affect how well the person's medicines work or lead to side effects when combined with certain medicines. Be honest with the doctor about how much the person uses.
- **Talk with the person's health care providers before starting a new medicine.** Make note of any special instructions for how to give the medicine. Find out whether the person will need to change or stop taking any of their other prescriptions or OTC drugs while using this new medicine.
- **Get help from a pharmacist.** Try to have all of the person's prescriptions filled at the same pharmacy to reduce the risk of taking medicines that will interact with each other. If you're not able to use just one pharmacy, share your list of the person's medicines at each pharmacy when you drop off their prescription. Remember that pharmacists can answer questions about over-the-counter medications, vitamins, and supplements as well as prescriptions.



## Saving Money on Medicines



Medicines can be costly. Even with private health insurance or Medicare, people may have to pay part of the costs for prescription medications themselves. If you are caring for an older adult with limited resources, help may be available.

First, tell the person's doctor if you're worried about paying for medications. They may have suggestions or resources to share. Here are some other ideas that could help:

- When available, consider switching to a generic drug or a less expensive brand-name medicine. The doctor may be able to suggest an alternative that would work just as well.
- Shop around to find the best prices from neighborhood or legitimate online pharmacies. In some cases, ordering medications through a mail-order pharmacy costs less than using a retail pharmacy.
- Pharmaceutical assistance programs can help with drug costs. Discount programs and other savings are offered by some retail pharmacies, drug companies, and nonprofit organizations. Visit [www.medicare.gov](http://www.medicare.gov) and search for "Pharmaceutical Assistance Programs" or call **800-633-4227** to find programs that can help pay for specific drugs.
- Some states also have drug assistance programs. Contact your State Health Insurance Assistance Program (SHIP) for more information. To find the SHIP in your state, visit [www.shiphelp.org](http://www.shiphelp.org) or call **877-839-2675**.
- People with financial hardship who receive Medicare drug benefits may qualify for Medicare's Extra Help program to help cover their costs. To apply, visit [ssa.gov](http://ssa.gov) or call **800-772-1213**.

Be careful if you're thinking about buying prescription medications online to save money. Medicines from a fake online pharmacy can be ineffective, unsafe, or even dangerous. It's important to order from a website that's safe: Many are not, and it can be hard to determine which ones are reliable. Make sure that an online pharmacy requires a valid prescription, is licensed in your state, and has a pharmacist available to answer questions.

For more tips, visit [FDA.gov](http://FDA.gov) (search "BeSafeRx") or call **888-463-6332**.

# Chapter 6:

# Planning Ahead



Nadia wanted to help her parents make plans for their future medical care, but she wasn't sure how to start the conversation with them. What care would they want if they couldn't make decisions for themselves? Who would make those decisions? Did they have a living will?

One weekend, Nadia sat down with her parents. She said, "Mom and Dad, I remember how hard it was for Tia Rosa's family when she got so sick. The doctors asked them whether she would have wanted more treatment, but no one was sure of her wishes. I don't want that to happen to us." It was an emotional conversation, but it helped Nadia understand what her parents would want if they were in a similar situation. Nadia was relieved that they had opened the door to planning for her parents' future care.

If you are caring for an older adult, one way you can support them is to help get their health, legal, and financial affairs in order. (And yours too, while you're at it!) You want to plan for the future as well as you can, preferably with their help while they can still make decisions. Work together to make sure their legal and financial paperwork is complete and reflects their wishes. You can also discuss what future health care they would want, including palliative care and hospice care, should they need it. For more information about advance care planning, visit <https://order.nia.nih.gov>

to order or download more materials on this topic.

## How can I talk with an older adult about their wishes for future medical care?

For most of us, it's hard to start a conversation about the kind of care a person would want if they became seriously ill or unable to make decisions on their own. The possibility of someone becoming ill or dying can be uncomfortable to talk about. It

can be especially difficult when the person is a parent or someone else close to you. Yet it's important to be prepared, especially in case of unexpected illness or a medical emergency. For some families, these honest conversations can also bring people closer together.

Ideally, you'll want to have this conversation face-to-face with the older adult. For most people, this subject is too sensitive for a text, email, or phone call. But different approaches will work best for different families. Once you can sit down with the older adult, here are a few ways you might start the conversation:

- Ask directly whether they have considered what kind of medical care they would want if they could no longer make decisions for themselves.
- Mention that you've been thinking about plans and wishes for your own future care.
- Bring up a friend's or neighbor's recent illness and how their family helped with future planning.
- Ask if the person has talked with their doctor already about their preferences.
- Discuss a recent TV show, newspaper article, or movie on the subject. Have a conversation about who would like to have the family's antique dishes, for example, if you're looking for a less direct way to start.

When talking about plans for future medical care, assure the older adult that as long as they are able, they will be the one to make decisions. But by discussing their wishes now, you can make decisions in line with what they would want if it ever becomes necessary. Discussing these matters early may also help avoid some of the conflicts that can occur when

family members disagree over treatment decisions. Making their wishes known increases the chances that an older adult will receive the care they want.

Talking about an older adult's wishes for future medical care will probably take more than one conversation. Once you've started the discussion, it usually gets easier. If you need help navigating this kind of talk, the person's doctor, a mental health professional, a religious leader, or a close friend may be able to offer suggestions and support. You can also contact the Conversation Project at <https://theconversationproject.org> or by calling **866-787-0831** for a free guide to starting the conversation.

## What is an advance directive and how can I help an older person set one up?

Planning for future medical care is often done through an advance directive, a formal document that includes written instructions and preferences for a person's future care. An advance directive goes into effect if the person can't communicate their own wishes. The goal is to ensure that the family and doctors understand the person's values, goals, and preferences, and could make decisions that reflect what they would want.

There are typically three main types of advance directives that can be used separately or in combination to indicate a person's wishes for their care:

**A durable power of attorney for health care** identifies someone — called a health care proxy or health care agent — to make decisions for a person if they are unable

to communicate their wishes themselves. The health care proxy can decide on care based on the person's values and what they believe the person would want.

**A living will** indicates which common medical treatments or care a person would want if they had a life-threatening illness, which treatments they would want to avoid, and under which conditions each of their choices applies.

**Physician orders for life-sustaining treatment (POLST) or medical orders for life sustaining treatment (MOLST)** provide guidance about a person's medical care preferences that health care professionals can act on immediately in an emergency. These may also be called portable medical orders or Physician Orders for Scope of Treatment (POST). Typically, these orders are created when a person is near the end of life or is critically ill and knows the specific decisions that might need to be made on their behalf.

Most people ask a close friend or family member to be their health care proxy. You can be a health care proxy even if you live far away. The role can be challenging: You may have to discuss sensitive topics, make difficult decisions, and advocate on the person's behalf. If someone asks you to be their health care proxy, you can decide whether the role is right for you. There may be reasons that you choose not to be one. It's okay to say "no" if you are not comfortable with the responsibility.

Advance directives can be established for little or no cost. Many states have their own forms that you can access and complete for free. Here are some ways you can find free advance directive forms for your state:

- Reach out to the Eldercare Locator. You can call the Eldercare Locator at **800-677-1116** or visit <https://eldercare.acl.gov>.
- Contact your state's department of aging or state attorney general's office.
- Download your state's form online from one of these national organizations: AARP ([www.aarp.org](http://www.aarp.org)), American Bar Association ([www.americanbar.org](http://www.americanbar.org)), or National Hospice and Palliative Care Organization ([www.nhpco.org](http://www.nhpco.org)).
- If you are a veteran, contact your local Veterans Affairs (VA) office. The VA offers an advance directive specifically for veterans. Visit [www.va.gov/geriatrics](http://www.va.gov/geriatrics) or call **877-222-8387** for information about future care planning and other services for older veterans.

To make the plan official, most states require an advance directive to be witnessed. This means there are people who watch everyone sign the form. Some states require the signatures to be notarized. A notary is a person licensed by the state to witness signatures. You might find a notary at your bank, post office, shipping store, local library, or insurance agent's office. Make sure you follow the requirements for your state to finalize advance directive documents.

Share the completed advance directive with family members, other caregivers, and health care providers. Keep a copy at home as well. And remember, a person can change their wishes at any time. As a caregiver, you can remind the older person to review and update their advance planning documents as needed, and at least once a year.

## How can I help an older person get their important papers in order?

One way you can help an older adult is to collect, organize, and maintain their important paperwork. Keeping a person's information in order and up to date is a big part of effective caregiving.

Getting these materials together can be a lot of work at first. But once you have everything, many other caregiving tasks will be easier. Maintaining current information about an older person's health and medical care, as well as finances, home ownership, and other legal issues, lets you get a handle on what's going on. And you'll be thankful to have everything in one place to respond quickly if there's a crisis. *Worksheet: Important Documents and Paperwork*, on page 67 of this guide, provides a checklist of records, documents, and other information to gather and store.

Then follow these steps to get it all together:

1. **Talk to the older adult about the kinds of records they have and where they are.** Some of this information may already be together in a desk drawer or filing cabinet or on a computer, and that can be a good place to start.
2. **Determine what paperwork or information is missing.** You may need to contact the person's financial advisor, bank, lawyer, or insurance company to get copies of important documents.
3. **Put everything in one place.** You can set up a file, put everything in a desk or dresser drawer, or list the information and location of papers in a notebook. If their papers are in a bank safe deposit

box, keep copies in a file at home and make sure you know the location of the safe deposit box key.

4. **Get rid of papers that are no longer needed.** You may come across old receipts, bank statements, and other papers. Many of these documents can now be accessed online, so you don't necessarily need to keep the paper versions. Check with your tax preparer or other financial professional if you aren't sure how long you need to keep important documents.
5. **Have the person give permission for their doctor, bank, or lawyer to talk with you.** There may be questions about their medical care, a bill, or a health insurance claim. Without their consent, you may not be able to get that information. The person can give their okay in advance to Medicare, a credit card company, their bank, or their doctor. Find out whether they can agree verbally or if they need to sign and return a form.
6. **Save login information for online records.** Write down usernames, passwords, PINs, and other information needed to access online accounts and records. Keep the information in a safe place. Passwords can also be saved in a password management app.
7. **Check to see if there's anything new to add.** Put new documents in the file as soon as they arrive and update login information for online records as needed. Review everything at least once a year.

One visit may not be enough time for you to get all the paperwork organized. If there's a lot to find and update, don't try to do it all at once. Instead, focus on gathering the essentials first — you can fill in the blanks as you go along.

## Finding Legal Help



If an older adult is considering a legal arrangement such as a power of attorney, a joint bank account, a trust, or an advance directive, they may want to talk with a lawyer first. A lawyer may not be required to set up these arrangements, but they can provide guidance and advice if you need it.

You can find a directory of lawyers on the internet or at your public library, or you can contact your local bar association for the names of lawyers in your area. Be sure to ask about the lawyer's fees before you make an appointment. Your local bar association or state legal aid office can help you find out what free or low-cost options your state has to offer. Visit [www.usa.gov/legal-aid](http://www.usa.gov/legal-aid) for additional resources.

## How can I help an older adult plan for the end of life?

When thinking about the end of life, there are many issues to consider and decisions to make. The end of life will look different depending on a person's preferences, needs, and choices. Some people may want to be at home when they die, while others may prefer to seek treatment in a hospital or facility until the very end. Palliative care, which can be used along with other medical treatments throughout the course of an illness, or hospice care, which is available in the final months of life, may also be options. These types of care focus on a person's comfort and quality of life and support for the family and caregivers.

One of the best things you can do as a caregiver is to discuss end-of-life care with the older person in advance. Make sure their wishes are known to any other caregivers, family, or friends who might make decisions on their behalf. Also encourage the older person to discuss

their end-of-life preferences with their doctor. The doctor can explain which health decisions the older adult may need to make in the future and the treatment options available. Discussing advance care planning decisions with a doctor is covered by Medicare during an annual wellness visit and at other times as needed. Private health insurance may also cover these discussions.

To make their wishes clear, the person may need to state their preferences in a living will and have doctor's orders (special forms that the person completes with their doctor). Doctor's orders in a person's medical chart make it much more likely that their wishes will be carried out, even in emergency situations. Here are examples of doctor's orders:

**Do not resuscitate (DNR) order** tells health care staff not to try to return the heart to a normal rhythm or attempt other life-support procedures in case the heart or breathing stops.

**Do not intubate (DNI) order** lets medical staff in a hospital or nursing facility know that you do not want to be put on a ventilator to breathe for you.

**Do not hospitalize (DNH) order** indicates to long-term care providers, such as nursing home staff, that you prefer not to be sent to a hospital for treatment at the end of life.

**Physician orders for life-sustaining treatment (POLST) or medical orders for life sustaining treatment (MOLST)**, described on page 42, provide guidance about your medical care preferences that health care professionals can act on immediately in an emergency.

As you are considering advanced care planning with an older person, other end-of-life decisions that may come up include:

**Organ and tissue donation.** In some cases, healthy organs and tissues from someone who has died can be transplanted into living people who need them. People of any age can be organ donors. Some states will add a person's organ donation status to their driver's license, or they can carry a donor card in their wallet. Encourage the older person to state their wishes about organ donation in their advance care directive. Sign up to become an organ donor by visiting [www.organdonor.gov](http://www.organdonor.gov) or by visiting your state motor vehicle office.

**Brain donation.** Donating a brain contributes to scientific research, helping scientists discover new treatments and preventions for disease. Registering as a brain donor is a separate process from becoming an organ and tissue donor. People who are interested in brain donation should consider enrolling in a research study or brain donation program. Visit *Brain Donation:*

*A Gift for Future Generations* at [www.nia.nih.gov/braindonation](http://www.nia.nih.gov/braindonation) or the Brain Donor Project at [braindonorproject.org](http://braindonorproject.org) to learn more about brain donation.

Having a care plan in place at the end of life is important to ensure that the person's wishes are respected as much as possible. A care plan summarizes a person's health conditions, medications, health care providers, emergency contacts, and end-of-life care wishes, such as advance directives and doctor's orders. A care plan may also include the person's wishes for what happens after they die, such as organ donation and funeral or memorial service arrangements.

## What are palliative care and hospice care?

There are many factors to consider when choosing care at the end of life, including the older person's desire to pursue life-extending treatments, how long they have left to live, and the preferred setting for care. Palliative care or hospice care may provide the support and treatment the older person would want. Talk to the person about their wishes during advance care planning. Learning about the available options can help you be prepared.

**Palliative care** is medical care that focuses on relieving the symptoms of serious illnesses, such as cancer, dementia, or heart failure. Patients work with a medical care team and continue to receive all other appropriate treatments for their illness. Palliative care can be helpful at any stage of a serious illness, from the time of diagnosis to the end of life. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

Palliative care can be provided in hospitals, nursing homes, outpatient palliative care clinics and certain other specialized clinics, or at home. Most private health insurance plans cover palliative care services, at least in part. Medicare and Medicaid also typically cover most of these services. Veterans may be eligible for palliative care through the Department of Veterans Affairs. If you have concerns about paying for palliative care, a social worker, a geriatric care manager, or the financial office at your hospital or clinic may be able to help you.

**Hospice care** focuses on the care, comfort, and quality of life of a person approaching the end of life. At some point, it may not be possible to cure a serious illness, or a patient may choose not to undergo further treatments intended to prolong life. Hospice care is available when a doctor believes the person has limited time to live if the illness runs its natural course, typically six months

or less. Like palliative care, hospice provides comfort care as well as support for the family. But in hospice care, attempts to cure the person's illness are stopped.

Hospice care can be offered at home or in a facility such as a nursing home, hospital, or a dedicated hospice center. Many hospice care services are covered by Medicare, Medicaid, and private health insurance. In most cases, the person or their representative will need to sign a statement choosing hospice care instead of other covered treatments for their illness.

For more information about palliative care, hospice care, and end-of-life decisions, visit [www.nia.nih.gov](http://www.nia.nih.gov) or call the NIA Information Center at **800-222-2225**. You can also contact the National Hospice and Palliative Care Organization at [www.caringinfo.org](http://www.caringinfo.org) or **800-658-8898**.





# Chapter 7:

## Caring for Yourself as a Caregiver



Caring for teenagers and two sets of older parents felt like a full-time job to Lee and Andy — and that was on top of their full-time careers. They loved their family but felt a little overwhelmed by all the sports practices, doctor’s appointments, and trips to the grocery store. Taking care of themselves was the last thing on their minds. But when they realized that they hadn’t had a day off in more than a year, they knew that they needed to take a break. Lee and Andy found people to help them so they could go away for a long weekend. When they returned, they set up regular assistance with volunteers who could visit their parents weekly, a carpool for sports games, and a grocery delivery service. Creating some breathing room in their schedules helped them be better caregivers to the people who needed them.

**C**aregiving is not easy — not for the caregiver and not for the person receiving care. It comes with sacrifices and adjustments for everyone. Taking care of an older adult can be demanding, difficult, and stressful. Often, family caregivers must juggle work and family life to make time for these new responsibilities.

Caring for an older adult can also be rewarding. Many people find that caregiving

provides a sense of fulfillment and that they like feeling useful and needed. Caregivers who reach out to others for support often make new friends and deepen their existing relationships. Some caregivers learn more about themselves and find more meaning in life through the experience.

Despite these benefits, the emotional and physical stress of caregiving can take its toll. The ongoing demands of taking care of someone else can strain even the most

resilient person. Too much stress, especially over a long time, can harm your health and relationships. That's why it's so important for you to take care of yourself. This chapter will give you some ideas for ways to look out for your own well-being so you can be there for others.

## As a caregiver, how do I know if I need help?

Caregivers do a lot for others. Because there is so much on their plate, many caregivers don't spend time taking care of themselves. For example, they are less likely than others to get preventive health services, like annual check-ups, and to practice regular self-care. As a result, they tend to have a higher risk of physical and mental health issues, sleep problems, and chronic conditions such as high blood pressure. They are even at an increased risk of premature death.

It's not always obvious when a person needs help. It may seem like certain problems are unavoidable or a normal part of caregiving. But there are ways to make things better. Watch out for these signs of caregiver stress:

- Feeling exhausted, overwhelmed, or anxious
- Becoming easily angered or impatient
- Feeling lonely or disconnected from others
- Having trouble sleeping or not getting enough sleep
- Feeling sad or hopeless, or losing interest in activities you used to enjoy
- Having frequent headaches, pain, or other physical problems
- Not having enough time to exercise or prepare healthy food for yourself
- Skipping showers or other personal care tasks such as brushing your teeth

- Misusing alcohol or drugs, including prescription medications

Identify your own sources of stress. Ask yourself, "What part of this is hardest for me?" It might initially feel like it's all too difficult, but you may be able to pinpoint certain tasks that are causing you the most stress. Don't wait until you are completely overwhelmed: Learn what your own warning signs are and think about changes you could make.

Long-distance caregiving brings its own kinds of stress. Sometimes, long-distance caregivers feel guilty about not being closer, not doing enough, or not having enough time with the person. They may even feel jealous of those who live closer and can do more. Many long-distance caregivers also worry about taking time off from work, being away from family, and paying for travel. Even though they're far away and might not have the same stressors as a primary caregiver, long-distance caregivers should be aware of when they may need help, too.

## How can I ask others to help?

When people have asked you if they can lend a hand, have you told them, "Thanks, but I'm fine"? Accepting help from others isn't always easy. You may worry about being a burden, or you may feel uncomfortable admitting that you can't do it all yourself. But many caregivers later say they did too much on their own, and they wished they had asked for more support from family and friends.

Understand that many people want to help, and it makes them feel good to contribute. But if you hesitate to ask others for assistance, here are some ideas:

- Ask for small things at first, if that makes it easier for you. Many large jobs can be broken down into simpler tasks.
- If you aren't comfortable asking face-to-face, send a text or email with your request.
- Consider a person's skills and interests when thinking about how they could help.
- Be prepared with a list of things that need to be done, and let the other person choose what they'd like to do. *Worksheet: Coordinating Caregiving*, on page 55 of this guide, provides a list of caregiving activities that you could divide up with others.
- If someone offers to help, practice saying, "Thanks for asking. Here's what you can do."
- Be honest about what you need and what you don't need. Not every offer is going to be helpful.
- Be prepared for some people to say "no," and don't take it personally.

## What else can I do if I'm feeling overwhelmed?

If you're feeling overwhelmed by caregiving, tending to your own needs may be the last thing on your mind. But taking time for yourself can actually make you a better caregiver. If you can find small ways to lower your stress and boost your mood, you'll have more strength and stamina to take care of someone else.

This list provides some activities you can try. If you only have a few minutes every day, start with one or two. You don't have to do everything all at once, especially if the thought of self-care just makes you feel more exhausted.

**Be active.** Even short periods of exercise can be beneficial. Find something active that you enjoy. That might be walking, dancing, gardening, or playing with a pet.

**Eat well.** Work on having a well-balanced diet that includes a variety of healthy foods. Drink plenty of water every day.

**Prioritize sleep.** Aim to get 7 to 9 hours of sleep each night. Develop a relaxing bedtime routine to make it easier to fall asleep. Try to go to asleep and get up at the same time each day.

**Reduce stress.** Experiment with relaxation techniques like meditation, tai chi, or yoga. Download a smartphone app with guided meditations or relaxing music. Many of these apps are free.

**Make time to relax.** Carve out time each week to do something you enjoy that has nothing to do with caregiving. It can be as simple as watching a favorite TV show, reading a magazine, or working on a hobby.

**Keep up with your own health.** Make that doctor's appointment you've been putting off. Tell your doctor that you're a caregiver: They may be able to suggest resources online or in your community.

**Reach out for support.** Talk to a trusted family member or friend, or seek counseling from a mental health professional. Join an online or in-person support group for caregivers. These are people who will know what you're going through and may have suggestions or advice.

**Take a break if you need it.** Ask another family member or friend to step in, hire an aide to come for a few hours a week, or sign up the older person for an adult day care program.

**Be kind to yourself.** You don't have to pretend to be cheerful all the time. Feelings of sadness, frustration, and guilt are normal and understandable. Express your feelings by writing in a journal or talking with a friend.

Remember that you are doing the best you can and that you are not alone. Many caregivers have trouble tending to their own health and well-being. But give yourself credit for everything you're doing. Your caregiving makes a big difference in someone else's life.

## If I'm not the primary caregiver, how can I support that person?

In many cases, one person takes on most of the everyday responsibilities of caring for an older person. It tends to be a spouse or the child or sibling who lives closest. If you are not the primary caregiver, you can still play an important role in supporting that person. Be sure to acknowledge how important the primary caregiver is in the older person's life. Also, discuss the physical and emotional effects caregiving can have on people. Although caregiving can be satisfying, it also can be very hard work.

You can lighten the primary caregiver's load by providing emotional support, taking on specific tasks, and giving occasional respite care. Ask them what you can do that would be most helpful. Staying in contact by phone or email might also take some pressure off the primary caregiver. Just listening may not sound like much, but it can mean a lot.

A primary caregiver — especially a spouse — may be hesitant to ask for a break. Here are some ways you could help them get the rest they need:

- Offer to stay with the older person for one afternoon a week, for example, so the primary caregiver can have some personal time.
- Arrange for regular respite care in the form of a volunteer, an in-home aide, or an adult day care program.
- If you live far away, travel to stay with the older person for a few days so the primary caregiver can take a vacation or just have some time off.

In time, the older person may have to move to assisted living or a nursing home. If that happens, the primary caregiver will need your support. You can work together to select a facility and coordinate the move. The primary caregiver may need extra support while adjusting to the person's absence and to living alone at home. More information about transitioning to a long-term care facility can be found in Chapter 3 of this guide on page 20.

---

**“Many caregivers have trouble tending to their own health and well-being. But give yourself credit for everything you're doing. Your caregiving makes a big difference in someone else's life.”**

---

## Caregiver Support Resources



These organizations provide free support, guidance, and assistance to caregivers.

- **The ARCH National Respite Network and Resource Center** (<https://archrespite.org/respitelocator> or **703-256-2084**) provides options for respite care and can suggest services in your community. Their Respite Locator enables you to search for local respite resources, including state-sponsored programs, adult day care centers, and services for veterans.
- **The Eldercare Locator** ([eldercare.acl.gov](http://eldercare.acl.gov) or **800-677-1116**) connects older adults and their caregivers with state and local agencies on aging, as well as community-based organizations.
- **The Family Caregiver Alliance** ([www.caregiver.org/connecting-caregivers](http://www.caregiver.org/connecting-caregivers) or **800-445-8106**) offers in-person, online, and email-based support groups for people providing care for adults with serious health conditions.
- **The Caregiver Action Network (CAN)** ([www.caregiveraction.org](http://www.caregiveraction.org) or **202-454-3970**) has an online forum for caregivers to connect with one another. The CAN Story Project offers family caregivers a platform to both share their stories and to read about other families' caregiving experiences.
- **AARP** ([www.aarp.org/caregiving/life-balance](http://www.aarp.org/caregiving/life-balance) or **877-333-5885**) offers articles for caregivers on self-care, dealing with stress, work-life balance, and finding support.

Here are more places for caregivers to access help and support:

- **Your doctor.** Tell your doctor that you are a caregiver. They can give you advice about taking care of your physical and mental health. Health care professionals may also know about support groups, respite care, and other resources offered in your community.
- **A counselor or other mental health professional.** If you are feeling anxious, frustrated, or depressed, help is available. Ask your doctor for referrals to counselors, and check with your health insurance provider to find out about your plan's coverage.
- **Your local senior center, state office on aging or social services office, or local Area Agency on Aging.** These organizations will be familiar with resources available in your community and may have tips for accessing them.
- **Your faith community.** Larger congregations may host support groups for caregivers. You can also ask for guidance from your pastor, rabbi, or other religious leader.

# Summary



Caregiving can be challenging and time-consuming, but it can also be very rewarding and meaningful. We hope this guide helps you and the older adult you are caring for.

Here are some main points to remember:

- Learn as much as you can about the older adult's health issues and care needs and desires so you can cope with challenges and manage their care more effectively.
- Identify people who can help with caregiving — for example, family members, friends, or neighbors — and define caregiving roles and responsibilities.
- Make sure the person's home is safe, accessible, and meets their needs. Get help, such as an in-home aide or a meal delivery service, if needed.
- If the older person can no longer live at home, explore options for long-term care. These might include assisted living, a nursing home, or a continuing care retirement community.
- Establish good communication with health care providers to help ensure the best care for the older adult.
- Find out about resources from government programs, insurance, and other sources to help cover the costs of caregiving.
- Talk with the older adult about their wishes for future medical care and help them set up advance directives.
- Organize important information so you know where it is when you need it.
- Ask for help. No one can be expected to do everything by themselves. Talk with others who are involved in caregiving to get their suggestions and support.

As the older person's needs change, so will your role as a caregiver. You can refer back to this guide for ideas and resources to help you along the way. We hope that it will help you stay organized, have productive conversations, and take good care of yourself and your loved ones.

# For More Information

## **National Institute on Aging (NIA) Information Center**

800-222-2225 (English and Spanish)

[niaic@nia.nih.gov](mailto:niaic@nia.nih.gov)

[www.nia.nih.gov/health](http://www.nia.nih.gov/health)

The NIA Information Center offers information and publications on health and aging for families, caregivers, and health professionals.

---

## **Eldercare Locator**

800-677-1116

[eldercarelocator@USAgings.org](mailto:eldercarelocator@USAgings.org)

<https://eldercare.acl.gov>

The Eldercare Locator is a nationwide service from the U.S. Administration on Aging and U.S. Administration for Community Living that connects older Americans and their caregivers with trustworthy local support resources.

---

## **LongTermCare.gov**

800-677-1116

<https://acl.gov/ltc>

LongTermCare.gov is a resource from the U.S. Administration on Aging and U.S. Administration for Community Living. It provides basic information about long-term care, costs and insurance coverage, and help finding local services.

---

## **Medicare.gov**

800-633-4227

[www.medicare.gov](http://www.medicare.gov)

Medicare is health insurance for people 65 or older and those with certain disabilities and serious illnesses. Its Care Compare tool ([www.medicare.gov/care-compare](http://www.medicare.gov/care-compare)) can help you find Medicare-certified providers and services in your area.

---

## **Medicaid.gov**

877-267-2323

[www.medicaid.gov](http://www.medicaid.gov)

Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant people, elderly adults, and people with disabilities. Its website provides information about eligibility, benefits, and how to find your state program.

---

## **Social Security Administration**

800-772-1213

[www.ssa.gov](http://www.ssa.gov)

The Social Security Administration website provides information about retirement and disability benefits, ways to sign up, benefit statements, and account access.

---

## **AARP**

888-687-2277

[www.aarp.org/home-family/caregiving](http://www.aarp.org/home-family/caregiving)

AARP offers health and lifestyle information for people age 50 and older, as well as articles, guides, and interactive resources for people providing care to older adults. You can search the AARP website for printable advance directive forms for your state.

---

## **ARCH National Respite Network and Resource Center**

703-256-2084

[www.archrespite.org](http://www.archrespite.org)

The ARCH National Respite Network and Resource Center provides information and resources related to respite care. It also has a National Respite Locator feature (<https://archrespite.org/respitelocator>) to help you find respite services and programs in your area.

---

## **Caregiver Action Network**

202-454-3970

[info@caregiveraction.org](mailto:info@caregiveraction.org)

[www.caregiveraction.org](http://www.caregiveraction.org)

The Caregiver Action Network provides support, information, and resources to family caregivers.

## **Family Caregiver Alliance**

800-445-8106

[info@caregiver.org](mailto:info@caregiver.org)

[www.caregiver.org](http://www.caregiver.org)

The Family Caregiver Alliance provides information, resources, and support to family caregivers of adults with physical and cognitive impairments, such as Parkinson's disease, stroke, Alzheimer's disease, and other types of dementia. They also provide a searchable list of caregiver services by state.

---

## **Meals on Wheels America**

888-998-6325

[info@mealsonwheelsamerica.org](mailto:info@mealsonwheelsamerica.org)

[www.mealsonwheelsamerica.org](http://www.mealsonwheelsamerica.org)

Meals on Wheels America supports local programs across the United States that provide nutritious meals, friendly visits, and safety checks to older adults. You can search the website for meal programs in your community.

---

## **National Adult Day Services Association**

877-745-1440

[info@nadsa.org](mailto:info@nadsa.org)

[www.nadsa.org](http://www.nadsa.org)

The National Adult Day Services Association provides information about adult day services and a search feature to locate a center near you.



# Worksheet: Coordinating Caregiving Responsibilities



Caregiving comes with many responsibilities, from helping with housework to driving an older person to doctor’s appointments. It can be helpful to divide up the caregiving duties among family and friends. You can use this checklist to help you coordinate. It is arranged by type of task, such as “health and medical care.” Add other activities as needed and note who is taking care of each one in the “Caregiver” column.

Type of task	Related activities	Caregiver
<b>Household needs</b>	Do laundry and other housework	
	Prepare meals, with awareness of any special diets or dietary restrictions	
	Shop for food and other necessities	
	Assist with home maintenance, such as making repairs and doing yardwork	
	Provide transportation, such as car rides to appointments	
<b>Self-care, supervision, and mobility</b>	Assist with personal care, such as bathing, dressing, eating, and using the toilet	
	Help with getting in and out of beds and chairs	
	Getting around inside or outside the home	

Type of task	Related activities	Caregiver
<b>Emotional and social support</b>	Provide companionship and someone to talk to	
	Encourage the person to participate in hobbies and other leisure activities	
	Help the person manage their feelings	
	Troubleshoot problems that come up	
	Provide respite care to a primary caregiver	
<b>Health and medical care</b>	Encourage a healthy lifestyle and self-care	
	Keep track of medicines and make sure they are taken at the right time	
	Manage other medical care at home, such as wound care or giving shots	
	Respond to acute needs and emergencies	
<b>Coordinating care</b>	Find out information and keep other caregivers up to date on changing conditions	
	Manage a shared notebook and calendar to coordinate care among family members and friends	
	Communicate with doctors, nurses, pharmacists, and other health care providers	

Type of task	Related activities	Caregiver
<b>Coordinating care (continued)</b>	Locate, arrange, and supervise nurses, social workers, home care aides, and other service providers	
	Coordinate medical appointments	
	Participate in treatment decisions	
	Order and pick up prescription medicines	
<b>Financial and legal</b>	Handle financial matters, such as paying bills and managing budgets	
	Manage legal matters, including official records such as wills and insurance policies	
	Participate in advanced care planning	
<b>Other tasks</b>		



# Worksheet: Home Safety Checklist



The following room-by-room checklist can alert you to potential hazards in an older person's home. Use it to identify any changes or repairs needed to help keep them safe. Keep in mind that it may not be necessary to make all of the suggested changes. It is important, however, to reevaluate home safety every so often as the person's behavior and needs change.

Throughout the home	
<input type="checkbox"/>	Are any repairs needed?
<input type="checkbox"/>	Is the house well lit, inside and out, particularly at the top and bottom of stairs? Do any lightbulbs need to be replaced?
<input type="checkbox"/>	Are emergency phone numbers (ambulance, Poison Control, doctors, hospital, etc.) and the person's home address near all telephones?
<input type="checkbox"/>	Is there clutter, which can cause disorientation and confusion and increase the risk of falling?
<input type="checkbox"/>	Is mail, recycling, or trash piling up? Do there need to be more trash and recycling containers around the house?
<input type="checkbox"/>	Is each bottle of prescription medicine clearly labeled with the person's name, name of the drug, drug strength, dosage frequency, and expiration date?
<input type="checkbox"/>	If there are guns in the home, are they locked up and unloaded, with ammunition stored separately?
Floors	
<input type="checkbox"/>	Are there any tripping hazards at exterior entrances or inside the house (throw rugs, for example)?
<input type="checkbox"/>	Are there non-slip strips or mats on tile and wood floors or surfaces that may get wet? Are carpets fixed firmly to the floor?
<input type="checkbox"/>	Are all walking areas free of furniture and extension and electrical cords?
<input type="checkbox"/>	Have smoke and carbon monoxide alarms been installed near the kitchen and in all bedrooms? Have the batteries been checked recently?
Stairs	
<input type="checkbox"/>	Are the stairs manageable, or is a ramp or gate needed?
<input type="checkbox"/>	Could handrails be installed on both sides of the staircase?

Is there at least one stairway handrail that extends beyond the first and last steps on each flight of stairs?

Are any outdoor steps sturdy and textured to prevent falls in wet or icy weather? Mark the edges of steps with bright or reflective tape.

### Bathrooms

Are there grab bars near toilets and in the tub or shower?

Have nonskid adhesive strips, decals, or mats been placed in the tub and shower? If the bathroom is uncarpeted, consider placing these strips next to the tub, toilet, and sink as well.

Have a plastic shower stool and a hand-held shower head been installed to make bathing easier?

Is the water heater set at 120° F to avoid scalding tap water?

Is there a night light to make overnight trips to the bathroom safer?

### Kitchen

Are there safety knobs and an automatic shut-off switch on the stove?

Is there enough food in the fridge? Is any of it spoiled? Are there staple foods (such as cereal, sugar, canned soup) in the cabinets?

Has a drain trap been installed in the kitchen sink to catch anything that may otherwise become lost or clog the plumbing?

### Outdoors

Are there secure locks on all outside doors and windows?

If a walker or wheelchair is needed, can the entrances to the house be modified — perhaps by putting in a ramp to the front door?

Is there a small bench or table by the entry door to hold bags and packages while unlocking the door?

Is outside lighting adequate? Light sensors that turn on lights automatically as you approach the house may be useful.

Have bushes and foliage been pruned away from walkways and doorways?

If there is a swimming pool, is it safe? Restrict access to a swimming pool by fencing it with a locked gate, covering it, and closely supervising it when in use.

Have you addressed any uneven surfaces or walkways, hoses, and other objects that may cause a person to trip?

# Worksheet: Questions To Ask Before Hiring a Care Provider



Before signing an agreement for home health care or geriatric care management, get as much information as you can about the services, fees, terms, and restrictions. You can use this worksheet to help you collect information about each service you're considering.

**Name of service provider:** \_\_\_\_\_

**Contact person:** \_\_\_\_\_ **Date:** \_\_\_\_\_

<b>1</b>	<b>Is your service licensed and accredited by the state or local government and/or a professional association?</b>	
<b>2</b>	<b>How long have you been providing care management services?</b>	
<b>3</b>	<b>What are your fees? Will you provide information on fees in writing prior to starting services?</b>	
<b>4</b>	<b>What is included and not included in your services?</b>	
<b>5</b>	<b>How many days per week and hours per day will a care provider come to my home?</b>	
<b>6</b>	<b>Is there a minimum number of hours required?</b>	

7	Will it be the same provider each time?	
8	How do you check the background and experience of your care providers? Can you provide references?	
9	How do you train your care providers?	
10	Are you available for emergencies around the clock? What types of emergency care can you provide?	
11	How will you communicate information to me?	
12	Who do I contact if there is a problem?	
13	If I wish to discontinue services, how much notice do you require?	
14	Other questions to ask:	

**Notes**



## Worksheet: Questions To Consider Before Moving an Older Adult Into Your Home



In some cases, it makes sense for an older parent, relative, or friend to move into your home so you can take care of them. If you're considering whether that's the right arrangement for you, here are some questions to think about:

Is there space in your home? Is the home safe and accessible for an older person?

How does the older person feel about moving into your home? How do you and others in the household feel about it? Do you get along well?

Is someone around to help the older person during the day? Is transportation available?

What is the older adult able to do for themselves? What do they need help with?

What personal care are you willing and able to provide – for example, moving the person from a chair to a bed or toilet, giving medications, changing incontinence pads, or bathing?

Are there other family members, friends, or neighbors nearby who can help care for the older person?

What services for older adults are available in your community? Can you afford to hire professional services to assist with caregiving?

What kind of specialized medical care is available nearby? Will the person have to switch doctors or other health care providers?

What other living options are available? Have you considered all the alternatives?



# Worksheet: Managing Medications and Supplements



The person you're caring for may be taking multiple prescription drugs, as well as over-the-counter medicines and dietary supplements. It can be confusing to keep track of everything! This form can help. Because medication regimens may change over time, consider making copies of this form to use in the future. Or you can download additional copies from NIA's website at [www.nia.nih.gov/health/twyd-worksheets](http://www.nia.nih.gov/health/twyd-worksheets). Try to bring a current list of medications and supplements to every doctor appointment.

Name of medication or supplement	What it's for	Date started	When and how often it's taken	Dose	Color/shape	Prescribing doctor	Concerns

Name of medication or supplement	What it's for	Date started	When and how often it's taken	Dose	Color/ shape	Prescribing doctor	Concerns

# Worksheet: Important Documents and Paperwork



It can be helpful to store an older person's official records and legal documents together in one place so you can access them quickly when you need them. Keep these materials somewhere safe and easy to find, like a fireproof lock box. This checklist can help you figure out what information to assemble.

## Personal Records

- Personal information**, such as their Social Security number, date and place of birth, and education and military records.
- Identity documents** including Social Security card, passport, name change documentation, and a copy of their driver's license or other ID card.
- Vital records** such as birth and death certificates, and certificates of marriage, divorce, citizenship, or adoption.
- Contact information** for children, neighbors, other close family and friends, lawyers, financial advisors, and religious contacts.
- Legal documents** including advance directives, powers of attorney, trusts, and the most up-to-date will with the person's original signature.
- Health information**, such as a list of diagnoses and medications, and contact information for health care providers.
- Usernames and passwords** for online banking, bill paying, and other critical services.

## Financial Records

- Banking information**, including the name of their bank(s) and account numbers for checking, saving, money market, and other accounts. Location of safe deposit box and key.
- Assets and income**, such as pensions from their employer, Social Security, IRAs, 401(k)s, and other investment income. Include the name and contact information for any financial professionals.

**Debts and other liabilities** including loans, lines of credit, and mortgages.

**Credit and debit card** companies, authorized users, account numbers, and balances.

**Insurance information** such as Medicare, Medicaid, private health insurance, long-term care insurance, and life insurance. Include policy numbers and the name and contact information of insurance agents.

**Homeowner information** including property taxes, homeowner's insurance policies, warranties or service plans, and the original deed of trust for the home.

**Car paperwork**, including car title and registration, details of any car loans, and auto insurance policies.

**Recent income tax returns** and related documentation.





National Institute  
on Aging

NIH Publication No. 23-AG-5496

February 2023