



Guide to CAREGIVING



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Introduction

By Amy Goyer, AARP's Family and Caregiving Expert

Some people are thrust into a caregiving role suddenly: Maybe an older family member suffers a severe heart attack or falls and breaks a hip. Overnight, a daughter, son, spouse, sister or friend becomes a caregiver.

For many others, like me, it's a more gradual process.

More than 20 years ago, my mom had a major stroke. At the time, my father was healthy enough to take care of her, with support from my sisters and me. I helped from a distance, doing what I could by telephone and traveling as often as possible from my home in Washington, D.C., to Phoenix, Arizona, where my parents lived. But over the years, my dad also began to decline. After he developed dementia, managing the household — and my mother's medical needs — became more and more difficult for him.

I found myself flying west with increasing frequency, and worrying a lot about my parents when I wasn't there. Eventually, Dad stopped driving, and it was clear we had reached a turning point. I decided to move to Arizona so I could help out on a daily basis. My sisters don't live nearby, and they pitch in as best they can. But as the primary caregiver for both my parents, I've got a lot on my plate.

If you're a caregiver, too, you know what I mean. Whether you're helping take care of a sick friend on an occasional basis or living with a frail parent full time, you no doubt are juggling a lot. And that can be physically, emotionally and financially challenging.

The good news is that, even though you may sometimes feel isolated, you aren't alone: Plenty of other people are in the same situation. No matter what level of assistance you provide — or what stage you're experiencing in your caregiving journey — this e-book is filled with resources, strategies, tips and advice to make the task easier. In the following pages, AARP will help you with the following:

- Build your caregiving team by finding others to help
- Learn to communicate better with family and other helpers
- Determine the best place for your loved one to live
- Get organized to manage legal and financial matters
- Find helpful health information and track medical care
- Deal with end-of-life issues, grief and loss
- Connect with other caregivers and take good care of yourself

As you care for your loved one, remember that we're here. At AARP, one of our mottoes is "Together we are stronger." Find the support you need in this *AARP Guide to Caregiving* and in the [AARP Caregiving Resource Center](https://aarp.org/caregiving) at aarp.org/caregiving.

Chapter 1: Getting Started

Caring for someone you love can be a richly rewarding experience. At the same time, the role comes with enormous responsibilities. The better prepared you are to deal with the situation, the easier the task will be.

Unfortunately, most families wait until there's a crisis to think about caregiving issues. Ideally, you should think in advance about how the effects of aging will impact your loved one so you're not making important decisions at a chaotic and emotional time. The key is recognizing potential caregiving needs — and creating a plan to deal with them. This first chapter will help you with the initial steps:

- Identify what your loved one needs
- Create a caregiving plan
- Set up a team
- Organize the important information you'll need

1. Identify What Your Loved One Needs

Start by having a candid conversation with your family member or friend who may need care. Talk with her about how you can help her and what level of support she would like. Unless she is severely incapacitated, she should continue to make her own decisions and remain a central part of all discussions. Encourage her to articulate her concerns: Typically, people are worried about becoming a burden and losing control of their lives. Have an open conversation about what role your loved one wants you to play.

One way to determine how much help and support a person needs is by doing what social workers call an assessment. That's a comprehensive review of a person's mental, physical, environmental and financial condition. This helps to establish your loved one's ability to remain safely independent and identifies risks and ways to reduce them. You can use AARP's Assessment Checklist in Appendix A to help you through this process.

Families can do assessments on their own but may want to hire an experienced professional to lead them through this process. Some hospitals and clinics have medical/social work teams that look at all aspects of an older person's health and life. The team will counsel you and your loved one about the results and offer practical assistance, such as finding local services and housing options. Individual geriatric care managers, also called case managers, provide similar services. Check with your [local agency on aging](http://eldercare.gov) (find it at eldercare.gov) for information about locating professionals who can help you.

TIP: For gentle ways to begin what can be a difficult conversation with your loved one, see [35 Questions to Ask Your Aging Parents](#) at AARP's Caregiving Resource Center.

2. Create a Caregiving Plan

A thorough assessment should help you make a plan to meet your loved one's needs. What you learn may help you decide that a big change — such as moving to another place — is necessary for a loved one's safety and well-being. Or you may realize that you need to make a few home improvements (install rails in the house, for example, or get an emergency alarm system) that will allow him to remain independent longer.

Whatever the case, once the assessment is complete, involve your loved one in the discussion and decisions about his options and together decide what action you want to take. Remember, always keep your loved one at the center of whatever plan you make. For instance, let him choose the person he would like to handle his finances or accompany him to the doctor. As long as he is able to do so, he should make the decisions.

If it's helpful, make a chart that reflects your plan. Write down your loved one's goals and requirements, what you need to do to meet them, who is responsible for each task, and a timeline for completion. For example, if your parents are considering a move, one sibling can be designated to help research housing options. Another sibling or neighbor could help sort through and prepare their belongings for an eventual move.

3. Set Up a Team

Caregiving is often too big a job for one person, so a key part of any plan is having a team of people who can help you. Consult with all family members, friends and neighbors who might be willing to help. When you involve others in your caregiving team, think about current needs as well as what your loved one might need in the future. When friends or relatives ask, "Is there anything I can do?" having a wide range of specific tasks to be done will help you answer their question — and help you. Is a friend available to do errands? Can a next-door neighbor walk the dog, pick up books from the library or go grocery shopping? Could a cousin who's gone to law school help find a good lawyer (see Chapter 4)? Set up a rotating schedule for their help.

Share a written summary of your plan with everyone on your team. Hold regular meetings — in person, via conference calls, on [Skype](#) — to update the core caregivers.

Use the Internet, too, to communicate with your team. Start a family Facebook page and a blog. Set up a schedule online. It's the easiest way to let your family and friends know what's happening and avoid misunderstandings. For tips on starting a blog, go to www.carepages.com.

Alternatively, use the “[Many Strong](#)” tool at AARP’s [Caregiving Resource Center](#) to coordinate efforts.

TIP: Siblings don’t always agree about what’s best. If you find yourself in this situation, read [When Siblings Disagree About What’s Best for Mom and Dad](#) in AARP’s [Caregiving Resource Center](#).

4. Organize Information

Being organized can make caregiving infinitely more manageable — and one good way to start is to gather key information and important documents into a single place.

First, find the material you need. This may seem like a simple step, but not everyone keeps essential documents in a single place, or even has copies of everything. The papers and documents may be in a file cabinet at home, in a safety deposit box or with an attorney. For a list of what you should look for, see Appendix B.

Then, combine any health information you’ve already gathered about your loved one with a complete health history. See Appendix C for what you’ll need to find out.

Once you have all the important documents, review them, preferably with family or key caregiving team members. Keep them in a safe, accessible place such as a secure file cabinet. The person who is designated as a health care agent should have copies. You should also consider copying the files onto a thumb drive that can be stored at another location.

Chapter 2: Getting Support Systems in Place

You may find that you're overwhelmed with your caregiving responsibilities or are unsure of how much help you and your team will be able to provide. Fortunately, there are many outside resources that you can tap into. A growing number of private and public organizations offer home- and community-based services that you should know about.

In this chapter you will learn about:

- Community support
- Adult day services
- In-home care providers

1. Community Support

Nurses, trained aides and volunteers are often available to help with almost every caregiving need you might have, including household chores, cleaning and round-the-clock care.

Researching the variety of services listed below may take some time, but doing so will be well worth it.

Types of community support

Eldercare Locator

This public service of the U.S. Administration on Aging provides area-specific recommendations, including home care, meal plans, transportation options, and more. Use the [handy search tool at eldercare.gov](https://eldercare.gov).

Companionship services

Local agencies on aging match older adults with a companion, who checks in by phone or in person on a regular basis, supervises the household, and offers a reassuring presence. A companion also gives your loved one someone to talk with, and helps ease your guilt over not being available all the time. To find elder companions, contact your state's [agency on aging](https://eldercare.gov), which you can locate through eldercare.gov.

General housekeeping and upkeep

Homemakers and home-care aides help manage daily tasks such as laundry, cooking, errands and shopping, and can also help with bathing and dressing. Home repair services fix minor

problems and conduct basic maintenance. Both services generally charge by the hour. Your state's [agency on aging](#) or local senior center may be able to direct you.

Meal programs

A meal delivery service can be a lifesaver if your loved one can't prepare food on a daily basis and you can't do it for her. If your loved one lives near a senior center or a facility that arranges group meals, arrange for her to join a lunch or dinner group. Call your local senior center to learn what options are available.

Senior centers

In many communities, senior centers offer older adults the chance to get together with friends in a casual setting, take exercise classes, go on day trips and excursions and, in some locations, enroll in continuing education classes. The centers generally offer meals and, often, health screenings. Check your phone book for a senior center near you or visit the [National Council on Aging website at ncoa.org](#).

Transportation

Most communities offer a variety of services: taxis, hired car services, volunteer drivers, Dial-a-Ride, ride sharing, public transportation, etc. To learn more, read [Transportation Options for Non-Drivers](#) at AARP's [Caregiving Resource Center](#).

Faith communities

Some religious organizations offer many services to older people. If your loved one is already connected to a community, ask about programs for seniors.

Disease-specific organizations

Disease-specific organizations often provide services that can help both patient and caregiver. The [Alzheimer's Association \(alz.org\)](#), for example, offers a 24-hour emergency response service for those suffering from the disease and their families, and an online support community for caregivers.

The [American Cancer Society \(cancer.org\)](#) provides helpful advice on how to be a caregiver to a cancer patient and offers an online community where cancer caregivers can connect and support one another.

2. Adult Day Services

There are a number of community-based daytime programs for older adults who require supervision. An adult day service center provides a chance for an older person to be more active,

socialize and become a part of a network of peers. It also offers you, the caregiver, the chance to go to work or run errands, knowing that your loved one is in a safe environment.

Types of adult day services

Generally, you'll find three kinds of adult day services:

Social adult day services

These provide activities such as arts and crafts, light exercise, discussion groups (such as a book club) and local day trips and outings. This type of adult day care is ideal for the active adult with limited medical needs.

Adult day health services

These usually include all of the services provided through social adult day services, but offer more medical aid — a registered nurse and other medical professionals usually are on staff — as well as occupational, speech and physical therapies. This type of day care usually requires individuals be assessed medically before attending.

Specialized adult day services

Social and health-related services offered in this type of adult day care are tailored to a condition, such as Alzheimer's or other forms of dementia.

Cost of adult day services

The cost of adult day services averages \$60 per day nationally. In some states, Medicaid may pay for some or all of the costs if your loved one meets the eligibility criteria. The U.S. Department of Veterans Affairs may pay for adult day services for former members of the armed forces if the members meet the VA criteria. Many centers receive public funding, which allows them to charge for services on a sliding scale based on ability to pay. Long-term care insurance might also pay, depending on the kind of coverage your loved one has.

How do I find a good adult day service

Recommendations from friends and other people you trust can point you in the right direction. You can also do a little research: A good place to start is the federal government's [Eldercare Locator at eldercare.gov](https://www.eldercare.gov). Also, the [National Adult Day Services Association's website \(nadsa.org\)](https://www.nadsa.org) has a center finder tool on its home page.

Regardless of how you go about finding potential centers, make sure they are reputable and that you and your loved one tour the facility and interview the staff before committing to anything.

You can also check with the [Commission on Accreditation of Rehabilitation Facilities \(carf.org\)](http://carf.org) for further guidance.

3. In-Home Care Providers

Like most people, your loved one probably wants to stay in his home — nine out of 10 older adults do — but may need regular assistance to help him remain comfortable and independent.

Types of home care

The first step to hiring help at home is to figure out exactly what kind of help you need. You can do this on your own, or ask a doctor, geriatric care manager, social worker or hospital discharge planner for advice. You will likely find three types:

Medical professionals

Depending on the care needed, you can arrange for a nurse, physical therapist and even a doctor who can provide skilled care and medical services.

Home health aides

These certified nursing assistants (CNAs) or personal care aides have received formal training and have passed a competency test. They generally work for Medicare-certified home health or hospice agencies that are regulated by state and federal laws and receive reimbursements from Medicare or Medicaid. Typically, a nurse or other medical professional supervises home health aides and the agency that employs them assumes full liability for care. Aides may provide basic health services such as checking a patient's pulse and temperature, administering medications, changing wound dressings and helping with prescribed exercises. Experienced home health aides may assist with medical equipment.

Home care aides

A home care aide, also called a homemaker or a personal care aide, assists with household chores and personal care, though not health or medical care. Home care aides aren't required to have certification, but many are employed by agencies and are supervised by a licensed nurse or social worker. Others are employed directly by an older adult or his family.

Paying for home care

If a doctor orders in-home health care, Medicare may cover part of the cost. A long-term care insurance policy may cover costs when Medicare runs out. Note that Medicare will pay for only part-time or "intermittent" care from a home health aide. This may mean three 90-minute visits a

week during a period when receiving home physical therapy, for example. To learn more about coverage, visit [Medicare.gov](https://www.medicare.gov).

Medicare will not cover homemaker services or personal care services, such as bathing and dressing, provided by a home health aide if that is the *only* care required. Medicaid may pay for some of the services not covered by Medicare. Visit the [Medicaid.gov](https://www.medicicaid.gov) for more information.

Using an agency to find home care

To hire a home care worker, many people find it helpful to use an agency. If you are considering that option, be sure to ask these questions of any agency:

- What credentials do staff members have?
- What training does the agency offer to staff?
- What are the costs?
- What are the coverage options?
- Does this agency offer Medicare or Medicaid payment? (Also see if Medicare or Medicaid covers the type of care that your loved one needs.)
- What emergency procedures are in place?

Also ask for references for the agency and for specific workers within that agency. Beware of any agency that refuses to provide references.

Hiring directly

You could also hire someone on your own. If you decide to do that, here are some tips to consider:

- Ask friends, neighbors, coworkers or other caregivers you know for referrals.
- Post a bulletin board ad at your place of worship, the library or local recreation center, or at a nearby senior center, adult day center or hospital.
- Look into a job placement program at a college that has a social work program.
- Run an ad in the newspaper or on a local website, describing the job and its duties. Include a phone number or email address, but don't give out your name or other personal information.
- Write a detailed job description that you can share with applicants. Include all the tasks you will require, the hours and days of the job and personal preferences for driving and other transportation options. Also jot down questions to ask to get a sense of the applicant's personality.
- Decide how much you're prepared to pay. If you hire someone directly, you need to look into how you will pay taxes and possibly a Social Security contribution. Check with the

Internal Revenue Service for proper tax forms and instructions. See the IRS publications [Hiring Household Employees](#) and [Independent Contractor \(Self-Employed\) or Employee?](#)

- Conduct the initial interview by phone. Ask about work experience, hours of availability, driving experience and special training with any condition your loved one has, such as Alzheimer's disease.

Conducting an interview

- Ask job candidates to bring a résumé or job history as well as names and telephone numbers for at least two references. If possible, make sure your loved one participates in the interview or at least has the opportunity to meet the person you would like to hire.
- Describe your loved one's needs, health concerns, likes and dislikes to the applicant. Outline the duties you expect her to perform. Be friendly but professional. Stick to questions that will help you determine if this person is a good match for the job — and for your loved one.
- Make sure to get the person's name, address, email, telephone number and Social Security number. Don't be afraid to ask for proof of identity, ideally a Social Security card. If not available, ask to see a driver's license or other photo ID. You can also ask if she has ever been in trouble with the law.
- Find out if she has any special training, such as working with clients who have dementia or other conditions, if you don't know this already. Also ask about her work history, including why she left her former job.
- Ask about her expectations of this position and why she is working in the home care field.
- Invite her to ask questions about the job and your expectations. Give honest answers.
- Be clear about salary and benefits, such as vacation and other time off. Head off any misunderstandings by addressing these issues directly.

Checking references

- Always ask for names and contact information for references who can attest to a person's work performance as well as his character. A reference can confirm your feelings about a person or give you important information that you may have missed.
- If the reference is a former employer, ask about the applicant's punctuality and attendance as well as the precise nature of his work. Find out why the applicant left the position and if there were any problems. Take notes on each applicant so you can refer back to them when making your decision.
- Consider paying for a criminal background check. Contact your local law enforcement agency to find out how to do this.
- Consider hiring someone for a one-month trial period before you commit to hiring him permanently. Explain that this would be an opportunity to see if this is a mutually acceptable arrangement.

- Once someone accepts your job offer, put your entire agreement in writing. Include information about the trial period, job duties, salary, pay schedule, time off, start date and termination policy. Keep copies of this job contract signed by both of you.

Try to be at your loved one's house for the first few days to familiarize the new caregiver with the routine. Periodically, you should drop by unannounced to check on how things are going.

Chapter 3: Exploring Housing Options

Most older adults want to stay in their home as they age and chances are your loved one does, too. But is he in a place where he can safely live independently? It's best to investigate these issues while your loved one is still healthy and independent. When you discuss where he wants to live in the years ahead, listen closely to how he feels about his current needs, concerns, worries and hopes for the future.

At the same time, it's smart to arm yourself with information about all the available housing options. In this chapter you will learn about the following:

- Traditional housing options
- Having a loved one move in with you
- Finding an appropriate facility
- New housing alternatives
- The moving process

1. Exploring Traditional Housing Options

If your loved one absolutely wants to remain in her current home, and can do so safely, you should talk to her about improvements or adjustments she can make to help her get around without assistance. Use the [Do You Have a Livable Home?](https://aarp.org/living/older-adults/2017/06/27/do-you-have-a-livable-home/) checklist at aarp.org to find if she has such a home.

You also may need to consider alternatives. The idea of giving up independence may meet resistance, and ultimately, wherever possible, the decision to move is up to her. The good news is that she has plenty of choices.

Living with family

Moving in with relatives, either in their home or in an accessory apartment that's attached to the home or in a separate structure on the same lot, works for some people.

Home sharing

Some adults share a house or apartment. Typically, they will have separate bedrooms (and possibly separate bathrooms) but share a kitchen and other living spaces; they'll also share household chores. Sometimes a homeowner who prefers not to live alone or who needs the income will rent rooms to other people. The homeowner may share the home in exchange for

assistance with cooking, cleaning and other chores. Some faith-based and community groups sponsor large homes shared by several individuals.

Foster care

Sometimes families take in an older person who needs help with daily living. The foster family cooks meals and handles laundry. Ideally, the older adult becomes a surrogate family member and receives emotional support and companionship, as well. [Supplemental Security \(ssa.gov/ssi\)](https://ssa.gov/ssi) may cover the cost of foster care.

Board-and-care homes

Board-and-care homes are an attractive option for folks who need some assistance. The residence provides a room, meals and help with daily activities. In general, these homes are smaller in scale than assisted living residences. They are not always licensed, however, and aren't always monitored by local authorities. In some states, board-and-care homes can provide nursing services, but they are not medical facilities.

Congregate housing/retirement communities

Residents who are mobile and can take care of themselves live in their own apartment units but share some meals in a central dining room and take advantage of housekeeping services. Often, these residences provide a variety of social and recreational activities. Rental fees vary widely, and meals and other services cost extra. There usually is not an entrance fee. Some residences receive public subsidies that help keep rent down, but these places often have long waiting lists and stringent income requirements.

Assisted living residences

These residences provide housing for those who can't live independently but don't need skilled nursing care. The level of assistance varies among residences and may include help with bathing, dressing, meals and housekeeping. Costs vary depending on the services required.

For more details on how assisted living works, read [Assisted Living: Weighing the Options](#), at AARP's [Caregiving Resource Center](#).

Nursing homes

The most widely recognized option, these residences offer skilled nursing care and substantial long-term assistance. They provide meals as well as medical and personal care. Bedrooms and

baths may be private or shared. Medicare may provide short-term coverage following hospitalization. Medicaid may offer coverage to residents who meet medical and financial eligibility requirements.

To understand what it's like to live in a nursing home, read [Living in a Nursing Home](#) at AARP's Caregiving Resource Center.

Continuing Care Retirement Communities

These facilities, which are designed to meet the changing needs of older people, provide a variety of housing options and services on the same campus. A resident might start out living independently in a separate apartment and then move to an assisted-living unit when he needs help with daily activities. Residents can stay in the nursing unit when they need ongoing skilled nursing care. This is one of the more expensive housing options; expect a sizable entrance fee and monthly charges. Entrance fees can range from \$100,000 to \$1 million — an upfront sum to prepay for care as well as to provide the facility money to operate. Monthly charges can range from \$3,000 to \$5,000, but may increase as needs change.

For more information on this option, read [Continuing Care Retirement Communities: What They Are and How They Work](#) at AARP's [Caregiving Resource Center](#).

2. Having a Loved One Move in With You

You may decide that having your loved one live with you is the best option. Though there are certainly challenges to the arrangement, many people have found that living in a multigenerational household can be an enriching experience for everyone involved.

It's a good idea to address potential thorny issues ahead of time, and remember that there will be an adjustment period for all of you. Think about how the move will affect everyone involved, consider and plan for the practical aspects of moving in and making space, and research community services (see Chapter 2) that will help ease the transition.

Family dynamics

No matter how close your family relationships are, adding another person to the household changes the dynamics. Consider these questions:

- How will the move affect your spouse, your children and your siblings?
- How will your loved one's presence impact your family routine, activities and privacy?
- Are there unresolved issues between your spouse and your loved one?

- Will you expect other family members to help out?
- Should part of your loved one's income go toward living expenses?
- Will the move mean you need to adjust your work hours to provide care?
- What will you do when you go on vacation? Take your loved one? Arrange for care?
- Are there issues of smoking, drinking or pets that need to be worked out?

Living space

Having a loved one move in to your home may require some physical rearranging. Some family members may be displaced or inconvenienced by the new setup, so communication with everyone is vital. If you can afford it, consider an addition with a prefab unit attachment or explore converting a garage or side porch into an in-law suite. Some families have even built separate homes next to their home for maximum privacy and independence.

3. Finding an Appropriate Facility

If you are considering a nursing home, assisted living facility or other such placement for a loved one, look for an “ombudsman” who can help you evaluate the quality of the place. Ombudsmen are trained to investigate and resolve complaints about nursing homes and other care facilities but can also help you find a quality home for your loved one. They can also answer questions about nursing home procedures, eligibility and payment as well as help explain resident contracts.

Each state has an office that runs the Long-Term Care Ombudsman Program, often located in the state office on aging. Look in the phone book or use the handy map at the [National Long-Term Care Ombudsman Resource Center](http://ltcombudsman.org) (ltcombudsman.org) to find state-by-state contact information.

You can also go to the federal government's [Eldercare Locator](http://eldercare.gov) at eldercare.gov or call 800-677-1116 and ask for the local ombudsman program that serves your area.

4. New Housing Alternatives

Innovative options for long-term care have been cropping up around the United States and internationally. You may want to explore them:

Eden Alternative

Focused on changing the atmosphere and experience found in long-term care facilities, the [Eden Alternative](http://edenalt.org) (edenalt.org) is a not-for-profit organization with 300 registered homes in the United States, Canada, Europe and Australia. Its mission is to bring life and wellness into institutional-like elder care settings. Often, its facilities are blooming with plants, have pets living onsite and encourage children to visit, which it believes will help ward off the emotional and mental breakdown that can accompany loneliness and helplessness. The goal isn't just to de-institutionalize nursing and long-term care facilities, but also to renovate the culture of each, by incorporating the opinions and ideas of their residents into the management of the facility.

The Green House Project

Much like the Eden Alternative, the Green House Project caters to the life of the older adult rather than only to health needs, focusing on the importance of social relationships among the residents and staff. Six to 10 residents live in a home where they share an open living and dining area, but they all have their own private rooms and bathrooms that can be individually decorated.

Funded by the Robert Wood Johnson Foundation, 50 Green Houses are operating in the United States, another 40 are under construction and more than 100 are in development. To find a Green House near you and learn about those in the planning stages, visit the [Robert Wood Johnson Foundation](http://rwjf.org) at rwjf.org.

Aging in place organizations

Organizations are also beginning to cater to older adults who prefer to stay in their homes rather than move to retirement, assisted or nursing facilities. Here are some model programs that can be replicated in your community.

Beacon Hill Village

Boston's [Beacon Hill Village](http://beaconhillvillage.org) (beaconhillvillage.org) some 400 members age 50 and older who use the village's services, which include everything from dog walking to geriatric care management. Beacon Hill Village operates on a membership basis, with both subsidized and unsubsidized options throughout central Boston available. Members can take advantage of social activities, day trips and exercise classes.

Capitol Hill Village

[Capitol Hill Village](http://capitolhillvillage.org) (capitolhillvillage.org) is a membership organization in the nation's capital developed by a group of local retirees. The organization's main function is to provide a network of services such as in-home health care, gardening and household chores.

Other innovative alternatives

Elite Care: [Elite Care communities](http://elitecare.com) (elitecare.com) are for older adults who rely on daily assistance and want to be part of an active community.

Nikkei Manor: [Nikkei Manor](http://nikkeiconcerns.org) (nikkeiconcerns.org) an assisted living community that focuses on the individual needs of the mainly Japanese Americans who live there.

The NORC (Naturally Occurring Retirement Communities) Aging in Place Initiative: The [NORC](http://norcs.com) initiative (norcs.com) is a program of the Jewish Federations of North America that brings services for older adults into places where they live.

Marion Manor: [Marion Manor](http://marianmanor.com) (marianmanor.com) is a nonprofit skilled nursing and rehab center that offers short- and long-term care. Run by the Carmelite Sisters, the center focuses on the intellectual and spiritual needs of the patient as well as the physical.

5. Managing a Move

Moving out of a home — regardless of where someone is going — can be an incredibly emotional journey. This is especially true for those moving out of the family home after many years and into a smaller place or to a care facility. Many see it as an end rather than a beginning, and that can be difficult. What you, the caregiver, may not expect, though, is your own emotional reaction to the change — even though it's not you who is moving. Be prepared for what to expect, both from your loved one and yourself.

The emotional repercussions

During the flurry of activity leading up to a move — finding a new residence, downsizing, packing — expect your loved one to experience emotional highs and lows. While your loved one may show excitement as you tour potential new residences and shop for necessities for the new space, he will also likely have times of deep sadness while he recalls the fond memories that fill his old residence.

Moving out of the family home is a big change on many levels. First, it's a huge disruption, for a time, to daily routines and a major transition into new surroundings. For an older adult, these disruptions and transitions take much longer to adapt to than for younger people. Second, a move at this stage of life may trigger concerns about loss of independence and what lies ahead. Losing any kind of independence is hard for those of us who have lived an independent life. So it's important to be sensitive to these moments with your loved one. Help them through the process simply by taking the time to listen and be empathetic.

Paring down and packing up

During the downsizing process and subsequent packing phase of the move, memories will be triggered when old keepsakes and treasures are unearthed and heirlooms are passed on to family members. Activities such as paging through a yearbook, reorganizing photos, sorting jewelry and finding old love letters can dredge up old feelings and stories, which should not be rushed through. Allow plenty of time for packing so your loved one has ample opportunity to reminisce and pass on any family history to you.

If the downsizing process ends up being too much to handle, professional organizers and senior move managers can assist in paring down. Visit the [National Association of Senior Move Manager's website at masmm.gov](http://www.masmm.org) to learn more.

Leaving the family home behind

As the move nears, expect emotions to be heightened. With only days left in her home, your loved one may break down at the thought of leaving. While you will most likely be feeling the stress of all that needs to be done, remember to comfort her. Check in with her often to see how she is doing. Talking may be hard for those families who don't communicate emotions easily, but it's necessary. Simply asking, "How are you holding up?" can provide a world of comfort to a parent or loved one leaving the home they've known for some time. It will let them know you're in their corner and understand that this can't be an easy situation for them.

Trivializing your loved one's emotions is one of the worst things to do in this situation. With her entire world in upheaval, making her feel as though she is overreacting can upset her even more. While you may not know exactly what she is going through, try to put yourself in her shoes despite any chaos that may be going on around you.

On moving day it might be best to plan an outing for your loved one — lunch, a trip to the mall, a visit with friends — so she can avoid the trauma of seeing her possessions moved out of her beloved home. This will mean, of course, that managing the move is up to you and any help you

can gather. It may be worth it if it means that your loved one will feel a sense of normalcy during such a tumultuous time.

Moving in

After all the boxes are unloaded and the furniture is in place, expect it to take a while before your loved one feels settled. Arranging his new space similarly to his former home will aid in the transition. A nice gesture to welcome him into his new space would be to stock his fridge with comfort food or bring in his favorite takeout for dinner his first night there. Over time, he should ease back into his old routines and begin to see the advantages of his new home. Just be patient with him as he finds his footing.

For the caregiver

You might be surprised by the emotions you experience when moving your parent or loved one out of the home — especially if you've shared that home with her in the past. Many caregivers get so caught up in what needs to be done for a move that they don't take into account the emotional implications the move will have on them. Expect to be bombarded by fond — or not so fond — memories that deserve attention. Watching your loved one go through her emotional process around the move may also affect you greatly. Indulge in these emotions rather than holding them in. They are important and need to be expressed — whether in private or with your loved one — in order to be the strong support system your loved one will need throughout the move process.

Chapter 4: Dealing With Legal Issues

As you take over caregiving responsibilities, you will likely be helping your loved one with her legal affairs. First, find out if she already has, or wants to make, any kind of legal documents, such as a will or trust. If not, discuss with her what she would like done with her property after her death and if she wants any life-sustaining treatments should she reach a terminal condition. Also find out if she has any preferences about funeral and burial arrangements. Once you have a sense of her preferences, you can help her transfer her wishes into writing. Putting these measures in place will be a big help to you and your loved one during uncertain times. This chapter will help you do the following:

- Find a good lawyer
- Understand legal documents
- Write an ethical will

1. Find a Good Lawyer

If you and your loved one don't have a lawyer who can handle estate planning and elder-law issues, ask friends and relatives for recommendations and line one up. Be sure to shop around. Fees among lawyers vary greatly, so do your research. You may also be able to find free or reduced-cost legal help, which may be available through a legal services agency, [AARP Legal Services Network](http://aarpplsnn.com) (aarpplsnn.com), bar associations or other groups. Ask if the attorney provides a free initial consultation. Ask about his or her experience in the issues you care about. Get references and find out who in the firm will work on the documents. Lastly, ask when they can meet and get a firm estimate on the fees and expenses.

2. Understand Legal Documents

There are a few legal documents that you'll want to know about as you take on the caregiving role.

Wills

A will indicates how people want their property to be allocated after they die. Whether or not they have a will, their estate may need to go through probate, which is the court-supervised process that transfers some types of property from an estate to the will's beneficiaries. It may take six months to several years to complete, depending on the estate's complexity. Many people seek to avoid probate to keep details of the estate private. Several strategies make this possible

including trusts, joint tenancy with right of survivorship and life insurance payable directly to beneficiaries.

For more on wills, visit aarp.org/estateplanning.

Revocable living trusts

Like a will, this written document directs how a person's property will transfer after death. It also lets people choose someone to manage their assets and distribute them after their death. Unlike a will, however, trust property can go promptly to the beneficiaries without going through the probate process. Trusts also differ from wills in that they can take effect during the person's lifetime, when he or she becomes unable to manage the property in the trust. The person creating the trust must also legally transfer the property he or she wants to be managed through the trust. Talk with a lawyer about whether a living trust or a will, or both, are appropriate for the circumstances.

For more on living trusts, read [The Truth About Living Trusts](https://aarp.org/estateplanning) at aarp.org.

Bank account access

Your loved one may want to assign an authorized agent — but not a joint owner — of her bank account to act in an emergency. She may also want to give someone authority to have access to her safe deposit box. Check with the bank for paperwork needed.

Durable power of attorney for finances

This document allows a person to give someone the authority to make financial decisions on his behalf. Without this, the court may need to appoint a spouse, close relative or companion to manage the person's financial affairs as a guardian or conservator if he becomes unable to do so. Typically, a durable power of attorney goes into effect as soon as it is signed, but a date or event in the future can be specified, such as when a doctor certifies that the patient has become unable to make financial decisions.

Get more information at [Understanding Power of Attorney](https://aarp.org/estateplanning) at aarp.org.

Advance directives for health care

This general term describes a variety of documents about health care wishes. Advance directives for health care may also be called a living will, health care directive, health care proxy, health care power of attorney, durable power of attorney for health care decisions or similar names.

- Health care power of attorney (HCPOA): This special kind of durable power of attorney lets people give a loved one the power to be their advocate and make decisions regarding their medical treatment.
- Living will: In this document, more limited than the health care power of attorney, the person states whether he wants life-prolonging treatment should he be diagnosed with a terminal condition and unable to state his preferences.

Many legal experts feel that a person should have both a living will and a health care power of attorney. Adding a statement about life-prolonging treatment helps guide the health care agent in making difficult decisions. Perhaps more important, it improves the likelihood that the doctor will follow the patient's wishes.

Read more at [Advance Directives: Creating a Living Will and Health Care Power of Attorney](#) and download free [advance directive forms](#) at aarp.org/advance_directives.

3. Write an Ethical Will

Unlike a last will and testament, which details how one's possessions will be distributed, an ethical will outlines a person's hopes, dreams and life lessons. It is not a legal document, and it can take the form of a letter written to one's children and grandchildren, or it could be a longer personal history.

The practice of creating ethical wills has existed for centuries. Since ancient times, people have shared stories, wisdom and blessings with future generations in hopes of leaving a personal legacy.

As a caregiver, encourage your loved ones to put their beliefs and advice in writing. That way, you and others can benefit from their wisdom, and you'll always remember what was most important to them.

Where to start

Start the process by writing your own ethical will and sharing the experience with your loved one. Tell her that she might find the experience meaningful and that she might learn more about herself through the writing process.

To craft an ethical will, begin by jotting down notes about your beliefs, life lessons and hopes for the future. You might include details about your family history. You also may want to express gratitude toward family and friends or request forgiveness for past actions.

Record your thoughts and stories for a few weeks or months, and then use your notes to draft a letter or personal history. Then review and revise the document over time.

If you get writer's block, books such as *Ethical Wills: Putting Your Values on Paper*, by Barry K. Baines, M.D., and *Legacy: A Step-by-Step Guide to Writing Personal History*, by Linda Spence, contain writing prompts that you and your loved one may find useful.

For more inspiration, look to books such as *So That Your Values Live On: Ethical Wills and How to Prepare Them*, edited by Jack Riemer and Nathaniel Stampfer, and *The Measure of Our Success: A Letter to My Children and Yours*, by Marian Wright Edelman. You'll also find examples of ethicalwill.com. In addition, some community organizations offer ethical will workshops.

An ethical will is meant to be shared during one's lifetime. Once you or your loved one have completed a final draft, share it with family and friends sooner rather than later. They'll likely cherish it for years to come.

With these documents in place, you and your loved one can be assured that their assets are safely accounted for and their health care wishes will be met.

Chapter 5: Managing End-of-Life Care

Having an advance plan for how your loved ones want to deal with end-of-life issues can make things easier when the time comes. As difficult as it might be, it's crucial to have an open and honest conversation about death and dying.

Getting answers to questions about where your loved ones would prefer to spend their last days, who will take care of them and what they would like to do to achieve a “good death” are vital pieces of the plan. In this chapter, you will read about the following key components to end-of-life care:

- Having the conversation
- Managing symptoms at the end of life
- Palliative care
- Hospice care
- Spiritual concerns of the dying

1. Having the Conversation

Most people have strong preferences and opinions about their final days, and it is imperative that you learn what your loved one views as ideal. If you haven't had a conversation about the end of life, start it by expressing how much you share his desire to stay as independent as possible for as long as possible, and to have his wishes followed after he passes away.

Ask your loved one to consider the following questions:

- Where do I want to die? At home, or in a hospital or medical facility? Surrounded by people who love me, or privately with as little fuss as possible?
- What kind of medical treatment do I want?
- Who do I want to take care of me? Do I have a preference in terms of male or female, or anything else?
- What kind of funeral services do I want? Do I care about an open or closed casket, cremation or donating my body to science?
- Where do I want to be buried? Do I have a burial plot? Do I want to use it or be buried somewhere else?

Then, use your loved one's answers to help him assemble advance directives (see Chapter 4) if he has not already done so — especially a living will and a health care power of attorney —

which will outline your loved one's wishes. Give copies of the directives to the key people involved in his life, with his permission.

2. Managing Symptoms at the End of Life

The approach to the end of life can bring with it a host of symptoms. Talk to your loved one's doctor(s) about these symptoms, with your loved one present, if possible. Inquire about home care services that can help and, if so, if they can be ordered by the doctor. Ask whether home hospice care would be appropriate, if your loved one is willing. You, as the caregiver, do not have to learn how to be a nurse. Reach out to health care professionals and members of your care circle for assistance, guidance and support. The most common symptoms include the following:

Fatigue

Chronic fatigue, the kind that affects most people who are dying, can stem from a number of sources:

- An illness
- Anemia
- Depression
- Poor nutrition
- Deconditioning (becoming out of shape from lack of exercise)
- Side effects from treatments such as chemotherapy and radiation

Persistent exhaustion affects every aspect of a person's life: psychological, physical and emotional. Ask your loved one's doctor to adjust medications or try nondrug interventions such as gentle exercise. Even a walk around the block can help. If untreated, fatigue will overwhelm a patient's quality of life.

Loss of appetite and thirst

As the end approaches, the desire to eat and drink ebbs. Because the body either doesn't need as many nutrients or can't absorb them, it stops asking. Weight loss follows. Bear in mind that it's a natural part of the dying process and the patient isn't suffering. Neither family members nor health providers should force terminally ill patients to eat or drink. If they do ask for food or drink, offer small, frequent meals of high-calorie, high-protein foods, or add nutritional supplements. Keep ice chips handy. They relieve two key symptoms: dehydration and dry mouth.

Before considering more aggressive measures, such as feeding tubes or intravenous lines, confer with the doctor, hospice nurse or primary medical professional about the pros and cons.

Skin breakdown

Anyone confined to a bed for long periods of time will risk bedsores, also known as decubitus ulcers. They usually occur on the arms, legs, feet and back — places where prolonged body weight creates pressure points against the bed. Lack of circulation causes skin to break down at these points. To protect skin and prevent infection, try the following:

- Change your loved one's position every two hours. Ask a medical professional to show you how to do this safely.
- Be sure that your loved one maintains good nutrition as best as possible.
- Talk to your doctor about whether a special bed or mattress can help.

If your loved one develops bedsores, ask a doctor, home care nurse or other medical professional how to care for him. If you cannot cope with changing the dressing, find someone who can.

Cognitive changes

Up to 85 percent of terminally ill patients experience cognitive changes during their final days. The most common include confusion, delirium and agitation. These symptoms arise from any number of causes, including the disease itself, infection, medications, and kidney and liver dysfunction. The reassurance of family and friends can play a vital role in helping someone who suffers cognitive problems. Discuss these cognitive changes with your health care team. Some medications long in use, such as haloperidol, can help with agitation and confusion.

Digestive problems

For those who are terminally ill, digestive issues are a frequent problem. The most common issues are these:

- Constipation: Patients who are bedbound and not eating a regular diet are often affected by constipation. Many medications worsen it, so talk to a doctor or nurse about preventions and solutions.
- Bowel obstructions: A cause of great discomfort, obstructions prevent patients from eliminating stool. An obstruction needs to be diagnosed by a health professional and treated as soon as possible.
- Nausea and vomiting: Nausea affects 60 percent of terminally ill patients, and episodes of vomiting plague another 30 percent. Various medicines complicate nausea and vomiting, so talk to the doctor about changing medications or having an anti-nausea drug prescribed.

Shortness of breath

If shortness of breath occurs, notify your loved one's health team. Certain medications can relax breathing, and home or portable oxygen can help, too. If medical intervention still leaves your loved one feeling short of breath, try the following:

- Keep her sitting up on pillows as much as possible rather than lying flat.
- Open a window or turn on a fan. This can help psychologically.
- Give her a hand or foot massage. Relaxation in general can help calm agitated breathing.

Emotional expectations of the caregiver

Caregivers, as well as care recipients, can expect a whirlwind of emotions during the end-of-life process. Sometimes these emotions can get in the way of the precious time you have left with the one you love. It's important to honor your feelings.

Forced cheer or happiness can be alienating to the person who is ill. Showing sadness is okay at times because it will let your loved one know they are cared for and will be missed.

Talk with family members, the medical team, a social worker or clergy members about how you are feeling. Try resolving lingering issues, and you will discover a sense of closure and peace of mind. Depression and anxiety are common emotions during this time but don't have to be inevitable parts of the end of life, for either the patient or the caregiver.

3. Palliative Care

Palliative care addresses the needs of patients who have chronic or life-threatening illnesses such as heart disease, chronic obstructive pulmonary disease, diabetes and cancer. A medical specialty, palliative care enhances the individual's overall quality of life rather than addressing the symptoms around an illness or the illness in general.

What is palliative care, exactly?

In general, palliative care is an umbrella term that refers to relieving symptoms while not pursuing a cure for the disease. It is a team-oriented approach for people whose illnesses do not respond to curative treatment. Palliative care focuses on the management of the physical, psychological, social and spiritual needs of patients and their families so that they can live life to the fullest each day. While a person can receive palliative care at any stage of illness, it plays its

biggest role at the end of life. With the introduction of a new medical field of expertise devoted solely to palliative care, the term has come to mean much more than pain management.

How does palliative care work?

Palliative care focuses on the whole person during the course of the illness. To do this, it brings together a diverse team of professionals, including these:

- Physicians
- Nurses
- Pharmacists
- Social workers
- Pastoral counselors
- Physical therapists
- Occupational therapists
- Music therapists
- Art therapists
- Specially trained volunteers

This team works with the patient and family members to provide a continuum of care that can begin with the onset of an illness or whenever comfort, support and quality-of-life issues become significant concerns.

Palliative care facts

- Some patients receive palliative care and continue to pursue other life-prolonging programs, including chemotherapy, radiation and surgery.
- General physicians are typically key members of the palliative care team and can coordinate services and participate in care.
- Palliative care is offered in a wide range of locations, including doctors' offices, clinics, long-term care settings and at home. Many medical institutions have begun to develop palliative care programs on site to augment their existing services.
- Medical organizations and professionals recognize palliative care as not only one of the newest disciplines in the health care field, but as a medical specialty. Professionals who specialize in palliative medicine receive special training and certification.
- Several organizations, such as the [American Academy of Hospice and Palliative Medicine](http://aahpm.org), at aahpm.org, provide referrals to physicians who specialize in [palliative](http://palliativecare.org) care, or visit palliativedoctors.org.

TIP: For more information on palliative care, watch AARP's [video, Getting the Facts on Palliative Care](#).

Palliative care vs. hospice care

Hospice care and palliative care are related, but different. Palliative care is the attention to and treatment of symptoms, regardless of the cause. It's a focus of health care that can, and should, be a part of all health care at all times. Hospice care is for people at the end of their lives, who will not recover from their illness. Hospice care is palliative care for the last six months of life. People in hospice care are no longer seeking a cure, or curative treatment. People at the end of life have a choice: to keep trying treatments hoping for an extension of life or a cure, or to focus on quality of life and let nature take its course.

4. Hospice Care

Myths and misconceptions about hospice can cause some to fear it. Find out what hospice is and how it can help you and your loved one during life's final journey.

What is hospice?

Hospice is a holistic approach to caring for people who are terminally ill. It involves a team of trained professionals, available 24 hours a day, who provide medical attention, pain management and emotional and spiritual support tailored to an individual's needs and wishes. It's not a place — it's a concept of care that can be provided anywhere. Along with attending to the patient, hospice teams also provide compassion and support to grieving loved ones during the illness and beyond.

Introduced in England in the 1960s, the hospice philosophy upends old stigmas and treats death as a natural part of life. It does not prolong suffering, nor does it hasten the end. Hospice simply allows nature to take its course, with a sole focus on living life to the fullest in the final days.

Who can receive hospice care?

Anyone, regardless of illness, culture, age, gender or financial status, can receive hospice care. A medical professional must give the individual a prognosis of six months or less to live and the individual must certify that he doesn't wish to pursue treatment. A patient can always leave hospice if he decides to pursue a treatment (and return to hospice after) and certainly can remain in hospice if he exceeds the six-month limit.

How does it work?

The medical professional makes a referral to hospice. Then members of the hospice staff will conduct an assessment of the patient's overall needs as well as establish a care team. Along with the primary caregiver, the hospice team and the patient will outline an appropriate care plan.

From the moment patients enter into hospice care, they may access a wide range of goods and services:

- Physician services
- Regular home visits by registered and licensed practical nurses
- Home health aides to assist in activities of daily living, such as dressing and bathing
- Social work and counseling services
- Medical equipment, such as hospital beds and oxygen
- Medical supplies, such as bandages and catheters
- Pain management and symptom control
- Volunteer support to assist caregivers and family members
- Specialized services, such as nutrition counseling and physical, speech and occupational therapy

Where do I find hospice care?

Hospice comes to the patient. Whether he is in a nursing home, hospice facility, hospital or in his own home, hospice professionals will provide services wherever is most comfortable. This flexibility anchors the hospice mission and lets patients live their lives as they wish during this difficult time. Physicians and other medical professionals will know of hospice programs in the community.

Two other resources for finding hospice care are the [National Hospice and Palliative Care Organization](http://nhpco.org) (nhpco.org) and the [Hospice Foundation of America](http://hospicefoundation.org) (hospicefoundation.org). Both organizations offer databases of hospice programs throughout the United States.

Who pays for hospice care?

Medicare usually pays for hospice care. Medicaid pays in 43 states. Many other types of health plans, including health maintenance organizations (HMOs) and preferred provider organizations (PPOs), cover the costs of hospice care. For patients who do not have insurance and do not qualify for Medicare/Medicaid, many hospice programs will offer free services.

Is all hospice care alike?

Not quite, but there are similarities. Each hospice program has its own characteristics and strengths that set it apart from others. All adhere to the core value of bringing comfort to the terminally ill. It's important to find out all you can about a hospice program you're considering. Some hospices are nonprofits and others are run like businesses. Visit the AARP Caregiving Resource Center for a checklist to help you review programs, [Hospice: What to Ask](#).

Who regulates hospices?

Federal, state and professional organizations evaluate hospice programs. Ongoing surveys ensure that they meet the standards developed by the [National Hospice and Palliative Care Organization](#). The state licenses and Medicare certifies all hospice services.

5. Spiritual Concerns of the Dying

When illness occurs, many people turn inward to understand and deal with the crisis. They ask questions: "Why is this happening to me?" "What is my purpose in life?" "What will happen to me when life ends?" As death approaches, spiritual concerns often become even more important.

Honoring spirituality

To take care of the whole person, all needs must be met: psychological, social, biological and spiritual. Addressing spiritual concerns at the end of life can be as vital to the patient's well-being as medications and comfort. Not only does this provide an opportunity for the individual to grow and find peace, but these issues may influence the behavior and decisions of both the dying person and family members.

Serious illness may cause a person to reflect on what really matters in life and can result in changed priorities. At the end of life, when the physical body becomes more frail, the individual's inner being can become stronger as spirituality is awakened.

Understanding spirituality and religion

Spirituality is the deep inner essence of who we are. Related to our soul, spirituality comes from the unique qualities of each individual. It is based on personal experiences and relationship with God, nature or a higher power. It answers the question, "Why am I here?" Connecting with

spirituality may also involve meditation, relaxation techniques, creating a legacy, enhancing relationships, and turning to a priest, rabbi, minister, chaplain or other religious representative.

Addressing spiritual issues

Because spirituality is based on an individual's inner being, each person addresses it differently. Yet researchers have found some aspects of spiritual fulfillment are universal:

Finding meaning in one's life

"Is my life worthwhile?" This is a common question asked by seriously ill people who are trying to find out whether they have made an impact on the lives of others close to them and society as a whole. Doing a life review — looking at photographs, watching movies or listening to music from particular periods (for instance at [AARP's Internet radio station](http://aarp.org/tv-radio/internet_radio) at aarp.org/tv-radio/internet_radio) allows them to reminisce about events and relationships throughout their lives. It can let them rediscover legacies, meaning and spiritual strengths.

Dying as you wish

Terminally ill people can die meaningfully in a way that is consistent with their own identity. Because death is a personal experience, each person will define his or her own appropriate death differently. As part of this process, a terminally ill person may seek to feel connected to others. This may lead to maintaining and deepening existing relationships, putting affairs in order and taking care of unfinished business.

Having hope beyond the grave

Another spiritual need is transcendence, or a person's awareness and acknowledgement of issues that transcend, or go beyond, earthly concerns. Each person may want assurance that, in some way, life will continue after death occurs. Some people may turn to God for guidance and comfort, while others may focus on the legacy they leave behind.

Chapter 6: Caring for the Caregiver (You!)

Taking care of an older or ill loved one can be enormously rewarding, but also physically and emotionally draining. When asked, caregivers often say the most difficult part of caring for their loved ones is the demand on their time. Figuring out how to take care of yourself while taking care of someone else is crucial. In this chapter, you will read about the following:

- Balancing work and caregiving
- Getting paid for caregiving
- Dealing with stress
- Recognizing burnout — and what to do about it

1. Balancing Work and Caregiving

An estimated 25.5 million Americans face challenges of balancing work responsibilities with caring for a relative aged 50 or older. Not surprisingly, caregivers wind up distracted, emotionally drained and physically exhausted.

Many employers are sympathetic to these demands. Some companies have programs to help caregivers find community services, counseling, respite care, legal and financial assistance and caregiver support groups. Others have begun offering caregiving leave and flexible work arrangements.

Of course, every caregiver's job is different, and even within the same company, different managers may be more or less supportive.

TIP: AARP's [Balancing Caregiving and Work video](#) in AARP's [Caregiving Resource Center](#), may help guide you.

Learn about company policies

Talk to your human resources department or read your employee handbook to ascertain your company's policy regarding caregivers. Find out about any benefits your company may offer, such as an employee assistance program.

Know your rights

Ask your human resources department for information about the [Family and Medical Leave Act](https://www.dol.gov/whd/fmla) (dol.gov/whd/fmla). If appropriate, have your human resources department send a copy to your supervisor as well. Under the FMLA, eligible workers are entitled to 12 weeks per year of unpaid leave for family caregiving, without the loss of job security or health benefits.

Talk to your manager

Be upfront about your role as a caregiver and the demands that it puts on you. It's better that employers hear from you why you're coming in late or seem preoccupied. Spell out the concrete steps you can take to juggle your competing demands. For instance, say, "I just found out my mother needs weekly physical therapy on Wednesday afternoons. While I'm looking for other arrangements, I propose that I work late on Tuesdays." Chances are your company will reward your honesty and sense of responsibility toward both your family and your job.

Ask about flex-time

Even if no formal policies exist, you should ask your boss if he or she would consider an arrangement to help you accommodate your caregiving responsibilities. For instance, you might ask if you could work from home a day or two a week. You could inquire about a part-time job or job-sharing arrangement.

Don't abuse work time

Whenever possible, avoid taking care of caregiving chores when you should be working. If you have to make phone calls or search the Internet for information related to your parent's needs, do it on your lunch break.

Stay organized

Do your best to manage your time efficiently. Use to-do lists and calendar reminders. Set priorities, then tackle the most important items first. Delegate at work and at home.

Seek help

For support, turn to AARP's [online community](https://aarp.org/online-community) (aarp.org/online-community) and the services at AARP's Caregiving Resource Center.

Say thanks

Show your appreciation for colleagues who pitch in and help you out with your job. Agree to take on extra work when the dust settles, and be willing to help someone else who is suddenly thrust into a situation you may know all too well.

2. Getting Paid for Caregiving

Some states have programs that help people pay for the caregiver of their choice, and in certain circumstances that person can be a family member. These programs — called, variously, “consumer-directed,” “participant-directed,” “cash and counseling” or other titles — differ enormously depending on where you live. Most have income and other eligibility requirements that the care recipient must meet, and strict rules often apply as to who can be paid for the caregiving. For information about what’s available in your state, contact your local Medicaid or aging services department or go to the [National Resource Center for Participant-Directed Services](http://bc.edu/schools/gssw/nrcpds) (bc.edu/schools/gssw/nrcpds). Be aware that there are waiting lists for these programs and that states have been cutting back on them because of budgetary pressures.

Veterans’ benefits

A law passed in 2010 provides a monthly stipend to primary caregivers of veterans injured in military conflict after 9/11. Other benefits to caregivers include travel expenses, access to health care insurance, mental health services and respite care for 30 days a year. For more information, call 1-877-222-VETS (1-877-222-8387). Caregivers of veterans of other wars may be eligible for the VA’s Aid and Attendance Pension Benefit. In addition, some state programs are specifically designated for veterans.

Long-term care insurance

If your family member has long-term care insurance, it may cover some home care. Some policies permit family members to be paid, although they may exclude people who live in the same household. Ask your family member’s insurance agent to explain this benefit and its conditions.

Caregiver contracts

If none of these options apply to you, all is not lost, especially if the person you are caring for has some savings or other assets. For example, a parent may be willing to work out a caregiver contract and pay a son or daughter for the care he or she provides. Consult an elder care lawyer

to make sure that the contract meets tax requirements, deals with inheritances and is approved by all other interested parties (siblings, for example). Be mindful of the emotional pitfalls in this arrangement.

Other options

If you are facing financial hardship because of a caregiving situation, here are some other options to consider:

- See whether your family member is eligible for programs that send an outside caregiver into the home so the responsibility doesn't fall only to you. Start with the federal government's [Eldercare Locator](https://eldercare.gov) at eldercare.gov or the National Council on Aging's [BenefitsCheckUp.org](https://www.benefitscheckup.org).
- Look into finding work you can do at home, or find a job that allows you the flexibility you need to be a caregiver.
- Hold a family meeting with siblings and others to discuss ways you can all share the financial burden.

Remember, your financial and emotional health should remain a top priority so you can continue to provide the kind of care your loved one needs.

3. Dealing With Stress

When taking care of others, it's critical that you don't neglect your own mental and physical health. Helping to care for a sick or dying loved one exacts a steep emotional toll. One study found that as many as one in three caregivers rate their stress level as high, and half say they have less time to spend with family and friends. But when you're caring for others, it's critical that you first take care of yourself. By not doing so, you put yourself at risk of exhaustion, health problems and even total burnout.

Put your physical needs first

Eat nutritious meals. Don't give in to stress-driven urges for sweets or overindulge in alcohol. Get enough sleep; if you have trouble sleeping at night, try napping during the day. Schedule regular medical checkups. Find time to exercise even if it means you have to ask someone else to provide care while you work out. If you experience symptoms of depression — extreme sadness, trouble concentrating, apathy, hopelessness, thoughts about death — talk to a medical professional.

TIP: Read [Eat to Stay Young](#) and [Get Back to Sleep: Dr. Oz's Secrets for Catching More ZZs](#) on AARP's website.

Connect with friends

Isolation increases stress. Getting together regularly with friends and relatives can keep negative emotions at bay.

Ask for help

Make a list of things you have to do and try to recruit others to pitch in. Think, again, about even faraway relatives and friends who are not on your core caregiving team who can manage certain tasks.

Take a break

You deserve it. Plus, your ailing loved one might benefit from someone else's company. Think about friends, relatives or volunteers who can take over for you. Or try for a weekend or longer vacation by turning to a home health agency, nursing home, assisted living residence or board-and-care home; these facilities sometimes accept short-term residents. Remember that adult day centers, which usually operate five days a week, provide care in a group setting for older people who need supervision. (See also Chapter 2.)

Make sure to involve your loved one in the planning and get his input when deciding how long you'll be gone and who will fill in when you're away.

Deal with your feelings

Bottling up your emotions takes a toll on your psyche — and even on your physical well-being. Share feelings of frustration with friends and family. Seek support from co-workers who are in a similar situation. Make an appointment with a professional counselor, or join a caregiver support group.

TIP: AARP has a [caregiving support group](#) you can join. Visit aarp.org/online-community.

Find time to relax

Doing something you enjoy, such as reading, walking or listening to music, can recharge your batteries. Some caregivers meditate or use relaxation techniques such as deep breathing or

visualizing a positive place. If you're religious, you might find that prayer can be a powerful tool.

TIP: Read about a [Meditation Technique That Changes the Brain](#) on AARP's website.

Get organized

Simple tools like calendars and to-do lists can help you prioritize your responsibilities. Always tackle the most important tasks first, and don't worry if you can't manage everything.

Just say no

Accept the fact that you simply can't do everything. Resist the urge to take on more activities, projects or financial obligations than you can handle. If someone asks you to do something that will stretch you too thin, you can just say no, or you can explain honestly why you can't — and don't feel guilty.

Stay positive

Do your best to avoid negativity. Hold a family meeting or call an elder care mediator to resolve conflicts with siblings and other relatives. Instead of dwelling on what you can't do, pat yourself on the back for how much you are doing, and focus on the rewards of caring for someone you love.

4. Identifying Burnout — and What to Do About It

You probably know all the details about the health of the person for whom you're caring. You're on top of what medications must be taken and when, and you can even spot minor changes in her mood and attitude. Are you as aware of what's going on with you?

Probably not. When you're caring for a loved one, it's easy to forget about your own needs, putting you at serious risk of burnout. Look for these signs, and take our suggestions to heart.

You feel furious one minute, sad and helpless the next.

Whatever you call it — second-hand stress or the more serious caregiver burnout — the despairing mix of physical and emotional exhaustion strikes many caregivers at one time or another. As you ride the emotional rollercoaster of caregiving, you're easily overwhelmed and

angry. You can't eat or you eat too much. You're exhausted even after a night's sleep. Your brain is foggy and you no longer care about the things that used to bring you joy.

The fix: Your life has changed in profound ways, so it's natural to feel frustrated and to grieve for what you have lost. But untreated anxiety or depression is serious, and you can't take good care of anyone if you don't take of yourself.

Check in with your doctor to rule out any medical conditions that can trigger symptoms of mental health problems. Let your doctor know that you are a caregiver and might need support to be able to continue in this role. Finally, remind yourself that while you are doing everything you can, you will never do everything — and that's OK, too.

You're snapping at everyone.

When you feel helpless and overwhelmed, you're more likely to overreact to the things people do, or don't do. Like a toddler having a tantrum, you need a timeout.

The fix: Don't set the bar so high that you can never meet it. Pick up the phone and call a friend. Studies show that simply giving voice to your frustrations and fears dials down tension and eases the isolation that shadows caregivers.

Mapping out a daily routine that you try to stick to will also give you a greater sense of control. Prioritize your to-do list, whether it's grocery shopping or taking Mom to a doctor's appointment. Don't worry about things lower down on the list that don't get done.

You catch every bug that comes your way.

Stress doesn't just make you anxious and depressed. It takes a toll on your immune system. If you're getting sick more often and staying sick longer than you used to, your body is trying to tell you something. Listen.

TIP: Read [Stress: Why It's Making You Sick](#), at aarp.org, about how anxiety affects your immune system.

The fix: Don't let routine checkups slide because you don't think you have the time. See your primary care doctor and your dentist regularly. Ditto for immunizations, mammograms and other recommended screenings. Eating a nutritious diet and getting at least seven hours of sleep a night boost your body's natural defenses.

TIP: See a guide to [health screenings](#) and [vaccinations](#) you need at aarp.org.

You know you should exercise but you just don't have the time.

No one functions well in crisis mode day after day. Caregiving is a marathon, not a sprint. You need to find a way to dial down the tension.

The fix: Force yourself to get moving. Exercise is the best stress reliever. Not only will you feel better right away, but the surge of endorphins triggered by exercise lifts your mood, clears your head and helps you sleep better at night. A brisk 30-minute walk or jog on the treadmill, even a 10-minute walk around the block, jump-starts your brain, soothes nerves and powers up your immune system.

You can't remember the last time you met a friend for dinner or a movie.

Everyone needs a break from time to time, so why don't you give yourself one? Caregivers — motivated by a mix of love, loyalty and a dash of guilt — rarely do.

The fix: We are not suggesting a two-week Caribbean cruise, though that would be lovely, right? An overnight visit with a college friend, a night at a bed-and-breakfast or even a few hours to write in your journal, sip a cup of hot tea while you read a book or watch reruns of your favorite sitcom can be restorative. One caveat: Taking a break doesn't mean running errands or doing chores. It's "you" time.

You're the go-to caregiver — always.

This may be the hardest job you'll ever have, and it can take time to adjust and come to terms with it. But try going it alone and you'll quickly hit bottom.

The fix: Establish a network of relatives, friends or people in the community you can call on. Schedule a family meeting or video chat about who does what and who pays for it. Let everyone know you will not be available to host holiday meals, organize the book drive or take on any other draining activities that you've normally handled. Keep a to-do list with you and whip it out when others ask if they can help. Your neighbor might be happy to spend a few hours at your house while you go to the gym. A friend can buy groceries when she's at the store.

Meanwhile, join a local or online support group so you can connect with sympathetic ears and glean ideas for coping better. Be aware that a wide range of programs and professionals are available and can help make the job easier for you.

Appendix A: Assessment Checklist

Physical health: You may have to consult your loved one's doctor to get the information you need.

- Diagnosis of any chronic diseases such as diabetes, high blood pressure, arthritis, emphysema or stroke
- Unusual weight loss or gain in a short amount of time
- Incontinence
- Balance problems: How steady is your loved one while walking?
- Persistent fatigue or sleeplessness
- Swollen feet or legs
- Limping
- Vision problems such as cataracts or use of vision aids
- Hearing problems: Does your loved one need a hearing aid? If he has one, is he using it? Is it working properly?
- Dental problems including gum disease, halitosis and ill-fitting dentures
- Complaints of pain

Mental health: Your loved one's primary care doctor can help with this assessment, but a geriatric psychiatrist or neurologist might be more helpful.

- Diagnosis of any psychiatric disorders such as depression, anxiety disorder or psychosis
- Diagnosis of Alzheimer's or other form of dementia
- Recent hospitalizations for any of these problems
- Mood swings, including rage or hostility
- Forgetfulness or wandering off
- Sadness or loneliness
- Decreased interest in reading, writing and communicating
- Difficulty in maintaining friendships
- Decreased interest in life

Medication use:

- List all medicines taken, prescription or over-the-counter, with frequency and dosage.
- List all herbal remedies, supplements, traditional home remedies or vitamins being used.
- Is the person able to take medications as directed and avoid interactions?
- Are there any barriers to proper medicine use, such as forgetfulness, expense, poor understanding of purpose and results of use?

AARP has an easy [Personal Medication Record](#) you can fill in online, print and distribute to caregivers and health care professionals.

Daily routine:

- List special dietary needs and favorite foods.
- Describe ability to dress, bathe, get up from a chair, use the toilet, use the phone, climb stairs, get help in an emergency, shop, prepare meals, do housework and yard work, and drive safely.

Home and community safety:

- At home, are there throw rugs, which can be a tripping hazard? Is there a need for handrails in the bathroom? Does the home have working smoke alarms? For a complete checklist, see the [Home Fit Guide](#) at aarp.org.
- Is the person able to avoid telephone and door-to-door fraud?
- What level of maintenance do the yard and house require? Can the person safely handle those chores?

Support system:

- Know contact information for key family members, friends, neighbors and clergy.
- Does your loved one visit friends and family, and have visitors?
- Is she able to visit a senior or community center?
- List membership in organizations and groups.

Appearance and hygiene: Check for the following:

- Oral care
- Trimmed nails
- Well-showered and well-shaven
- Combed hair
- Clean clothes
- Appropriately dressed for weather and occasion

Finances: Check for the following:

- Insurance coverage
- Long-term care coverage
- Total assets
- Legal documents including trusts, living wills and durable powers of attorney
- Is there an attorney who knows this person?

Personal interests: You should be aware of the following:

- Hobbies
- Reading preferences: Are glasses or larger-print books needed? Would books on tape be enjoyable?
- Favorite TV and radio programs
- Exercise — gardening and walking count!
- Musical instruments played
- Languages spoken, and is there a preferred language?
- Favorite conversation topics
- Travel experience
- Important life events
- Religious/spiritual background
- Accomplishments
- Social activities

Appendix B: Important Documents Checklist

These documents belong in your important papers file:

- Birth certificate
- Marriage certificate
- Death certificate (for deceased spouse)
- Divorce papers
- Military records
- Driver's license/organ donor card
- Passport/citizenship papers
- Will
- Living will
- Durable power of attorney
- Health care power of attorney
- Trust
- Letter of instruction — with funeral arrangements, important contact information such as insurance agent or broker
- Insurance policies (life, disability, long-term care)
- Information about safety deposit boxes (location, number, key, contents)

Appendix C: Health History Checklist

Add the following to the health information you have already gathered (see Appendix A):

1. Basic information:

- Care recipient's full name, birth date, address, phone numbers, and Social Security number
- Information on health insurance company, including member and group identification numbers, as well as address and phone number
- Medicare and Medicaid number, if applicable
- Pharmacy name and telephone number (directions, if applicable)
- Emergency contacts and numbers
- Nearest hospital name with addresses and phone numbers
- Blood type
- Allergies to drugs, foods, insects, etc.
- Whether a living will or health care proxy exists (for more on legal documents, see Chapter 4)
- Height, weight and blood pressure

2. Health care providers' information:

Include specialties, telephone numbers, email and addresses for each provider as well as the conditions they're treating.

- Primary care physician/geriatrician
- Ophthalmologist or optometrist
- Ear, nose and throat specialist
- Dentist
- Podiatrist
- Cardiologist
- Oncologist
- Allergist
- Orthopedist
- Gastroenterologist
- Endocrinologist
- Neurologist
- Urologist
- Psychiatrist
- Psychologist or social worker

- Physical therapist
- Nutritionist or dietitian
- Visiting nurse
- Home-care aide

3. Exams, tests and screenings:

Record dates and results from all exams, including physicals. After each entry, jot down when these exams, tests and screenings are needed again. Consult AARP's [guide to essential screening](https://aarp.org/health/conditions-treatments/health_screenings/) at aarp.org/health/conditions-treatments/health_screenings/. Be sure your loved one is screened for the following conditions:

- Cancer
- Diabetes
- Osteoporosis
- High cholesterol
- High blood pressure
- Obesity
- HIV
- Eye and vision problems
- Hearing problems
- Dental problems

4. Shots:

List dates of shots for flu, pneumonia, tetanus, tuberculosis, allergy and other ailments.

5. Family medical history:

Assemble a family medical history as best you can. Include names of family members who have had cancer, heart disease, dementia, mental health problems, diabetes and other conditions. Write down how old family members were when their conditions were diagnosed. If you can't remember, try to get the information from relatives. Also list the names of family members who have died, including the date and cause of their death.

You can store health records for free at [AARP Health Record](https://aarp.org/healthrecord) at aarp.org/healthrecord.

Appendix D: Questions to Ask When Searching for Housing

Business reputation:

- Is the facility licensed and operating legally?
- Has its license ever been revoked? If so, why?
- Are recent inspection reports available?
- How long has it been in business?
- Are financial records available?
- What about references?

You can find answers to these questions by contacting the state licensing agency (search for the state name plus “licensing” — for example, “Minnesota licensing” — on the Internet), the local agency on aging and the Better Business Bureau.

Quality:

- Do residents look as if they have their needs met?
- Do they seem to be content and interact well with the staff and managers?
- Do staff and residents treat one another with dignity and respect?
- Do staff members take the time to listen and respond to residents’ needs?
- What is the staff-to-resident ratio?
- Are residents’ rights posted?
- What training does the staff receive?
- What do residents and their relatives say about their care?

Safety:

- Does the facility have requisite safety equipment, such as fire extinguishers, smoke detectors and a sprinkler system?
- How’s the sanitation?
- Are doors and locks secure?
- Is someone on duty 24 hours a day, or is there an emergency call service?
- Is a doctor available around the clock?
- Are there obvious hazards?
- Is medical care handled professionally?
- Can those with physical disabilities get around the facility?

Amenities:

- Is the facility attractive and in good shape?
- Does it have the style of living desired, such as a private apartment, private room and private bath?
- Is it comfortable enough, with conveniences such as equipment, electronics, gardens and adequate space for entertaining or hobbies?
- What meals are provided, and are the quality and quantity up to par?
- Does the food suit your parent's taste, nutritional requirements and cultural preferences?
- Are the social interactions and recreational programs appealing?

Location:

- Is it in a safe neighborhood?
- Is it located near shops, doctors' offices, places of worship and social contacts?
- Is it reasonably close to adult children's homes?
- Is public or private transportation easily accessible?

Policies:

- Are there restrictions on behavior such as smoking and drinking alcohol?
- Are pets allowed?
- Are guests, including overnights, welcome?
- Are there formal visiting hours?
- How much flexibility is there for mealtimes?
- In a shared setting, how are responsibilities determined?
- How does management handle rate increases and discharge policies?

You can also download these worksheets from AARP's [Caregiving Resource Center](#) to record information when you visit these specific kinds of places:

- [Assisted living facilities](#)
- [Nursing homes](#)
- [Continuing Care Retirement Communities \(CCRCs\)](#)

Resources

[AARP Advance Directive Forms](http://aarp.org/advancedirectives) (aarp.org/advancedirectives)

Free, downloadable advance directive forms and instructions, by state.

[AARP Care Provider Locator](http://aarp.org/relationships/caregiving/info-02-2012/caregiving-assisted-living-options-tool.html) (aarp.org/relationships/caregiving/info-02-2012/caregiving-assisted-living-options-tool.html)

Use this tool to search for local care provider options.

[AARP Caregiving Bloggers](http://blog.aarp.org/category/caregiving-2/) (blog.aarp.org/category/caregiving-2/)

Offers daily insights and empathy from those who have been where you are.

[AARP Caregiving Online Support Group](http://aarp.org/online-community) (aarp.org/online-community)

You are not alone. If you don't have a face-to-face support group available to you, try this virtual one.

[AARP Caregiving Resource Center](http://aarp.org/caregivers) (aarp.org/caregivers)

Your one-stop shop for information, tools and resources to help you while caring for a loved one.

[AARP Long-Term Care Cost Calculator](http://aarp.org/longtermcarecosts) (aarp.org/longtermcarecosts)

Find and compare the costs of home care, assisted living and other services throughout the United States, by state or metropolitan area.

[Administration on Aging \(AoA\)](http://aoa.gov) (aoa.gov)

The federal agency responsible for advancing the concerns and interests of older people. The website has a variety of tools and information for elders and their caregivers.

[Aging with Dignity](http://agingwithdignity.org) (agingwithdignity.org, 888-5WISHES or 888-594-7437)

Information and instruction on developing a living will and having conversations with family about your care in times of serious illness.

[Alzheimer's Association](http://alz.org) (alz.org, 800-272-3900)

Resources, tools and a 24-hour helpline for people with Alzheimer's disease and their families. Referrals are available to local community programs, services and ongoing support.

Alzheimers.gov

The U.S. government's free information resource about Alzheimer's disease and related dementias.

[American Bar Association Commission on Law and Aging](http://new.abanet.org/aging) (new.abanet.org/aging)

Information on legal issues affecting older adults and referrals to lawyers in your area.

[ARCH Respite Network](http://archrespite.org) (archrespite.org)

Find programs and services in your area that allow caregivers to get a break from caring for a loved one, and see if you qualify for help paying for it.

[Assisted Living Federation of America](http://alfa.org) (alfa.org)

Information and resources on assisted living options and how to find them.

[Benefits QuickLINK](http://benefitscheckup.org) (benefitscheckup.org)

Find out if you or your loved one are eligible for programs that help save money on health care, medication, food, utilities and more.

[Caring Connections](http://caringinfo.org) (caringinfo.org)

This program of the National Hospice and Palliative Care Organization provides free resources, including advance directives, to help people make decisions about end-of-life care and services before a crisis.

[Centers for Medicare & Medicaid Services](http://cms.gov) (cms.gov)

The U.S. government's website for people with Medicare and Medicaid questions.

[Eldercare Locator](http://eldercare.gov) (eldercare.gov, 800-677-1116)

This U.S. Department of Health and Human Services site allows you to search for resources for older people by ZIP code, city or topic.

[Family Caregiver Alliance](http://caregiver.org) (caregiver.org, 800-445-8106)

Tools and resources for family caregivers and a [Family Care Navigator](#) with information on services, by state.

[LeadingAge](http://leadingage.org) (leadingage.org)

Consumer information on not-for-profit long-term care facilities and services and how to [choose a provider](#).

[Many Strong](http://manystrong.com) (manystrong.com)

Help for creating a caregiving community by offering online coordination tools.

[Medicare](http://Medicare.gov) (Medicare.gov, 800-Medicare or 800-633-4227)

Provides information about the parts of Medicare, what's new and how to find Medicare plans, facilities or providers. Helpful consumer information on eligibility and benefits. Online tools help you search and [compare quality measures on nursing homes](#), [hospitals](#), [home health agencies](#), [health and prescription drug plans](#) in your area. The tools also rate performance. The

site also has a [section for caregivers](#).

[n4a](#) (n4a.org)

Membership organization of local Area Agencies on Aging and Title VI programs provides answers to questions about home- and community-based services for seniors and family caregivers.

[National Adult Protective Services Association](#) (apsnetwork.org)

Find public adult protective services agencies in every state and Washington, D.C. Consumers can report abuse online. Immediate dangerous situations should be directed to 911 or local police.

[National Alliance for Caregiving](#) (www.caregiving.org)

Offers research and reviews books, videos, websites and other material to help family caregivers and professionals.

[National Alliance for Hispanic Health](#) (ispanichealth.org, 866-783-2645)

The Hispanic Family Health Helpline and its Su Familia provide free and confidential health information for Hispanic families.

[National Association for Home Care & Hospice](#) (nahc.org)

Consumer information on how to select a home care provider or hospice.

[National Association of Home Builders](#) (nahb.org, 800-368-5242)

This web-based directory provides certified aging-in-place specialists who can identify and/or provide home modifications that make a home accessible, safer and more comfortable.

[National Association of Professional Geriatric Care Managers](#) (caremanager.org)

This association can help you find a private geriatric care manager in your community.

[National Association of Social Workers](#) (socialworkers.org)

The organization maintains a directory of licensed social workers.

[National Clearinghouse for Long-term Care Information](#) (longtermcare.gov)

Information and tools to plan for future long-term care needs.

[National Family Caregivers Association](#) (thefamilycaregiver.org, 800-896-3650)

Information, educational materials and support for family caregivers; includes [familycaregiving101.org](#), a project to educate and assist family caregivers.

[National Hospice and Palliative Care Organization](#) (nhpco.org, 800-658-8898)

Free consumer information on hospice care; puts the public in direct contact with hospice

programs.

[National Long-Term Care Ombudsman Resource Center](http://tcombudsman.org) (tcombudsman.org)

The organization connects you with a local ombudsman, who is a person advocating for quality care for residents of nursing homes and other long-term care facilities, and helping to resolve complaints.

[National Respite Network](http://archrespice.org) (archrespice.org)

Helps people locate respite services.

[NIH Senior Health](http://nihseniorhealth.gov) (nihseniorhealth.gov, 800-222-2225)

U.S. National Institutes of Health fact sheets on a range of health topics can be viewed online or ordered for free.

[SAGECAP](http://sageusa.org) (sageusa.org)

SAGECAP provides counseling, information, support groups and more to gay, lesbian, bisexual and transgender caregivers.

[Social Security Administration](http://ssa.gov) (ssa.gov, 800-772-1213)

Information on eligibility and benefits is available from 7 a.m. to 7 p.m., Monday through Friday.

[State Health Insurance Assistance Program \(SHIP\)](http://shiptalk.org) (shiptalk.org)

Your local SHIP offers one-on-one counseling assistance for people with Medicare and their families. Go to the website or call Medicare at 800-633-4227 to find your state SHIP.

[The National Consumer Voice for Quality Long-term Care](http://theconsumervoice.org) (theconsumervoice.org)

This organization works to improve the lives of people in nursing homes and other long-term care facilities. Find a local ombudsman online.

[U.S. Department of Veterans Affairs](http://va.gov) (va.gov, caregiver.va.gov, 800-827-1000)

Information about eligibility and benefits for veterans and their families, including state and local resources; provides support and services for families caring for veterans; and maintains a VA caregiver support line.

[Village to Village Network](http://vtvnetwork.org/) (vtvnetwork.org/)

This organization helps communities start Villages, which are membership-based groups that respond to the needs of older people within a geographic area. Find Villages across the United States online.

Caregiving Glossary

Activities of daily living (ADLs)

Basic tasks of everyday life that include dressing, bathing, eating, transferring (for example, from bed to chair) and toileting.

Adult day services

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

Adult protective services

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

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

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

Assisted living residences

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

Board-and-care homes

A home for older adults who need some assistance that provides a room, meals and help with daily activities.

Community meal program

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

Congregate housing/retirement communities

A housing option in which adults who can take care of themselves live in their own apartment units but share some meals in a central space.

Conservator

A person appointed by a court to handle someone's affairs when that person cannot handle them

himself. A conservator usually handles only financial affairs.

Continuing care retirement communities

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

Discharge Planner

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

Do not resuscitate (DNR) order

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

Durable power of attorney finances

A legal document that allows a person to give authority to someone else to make financial decisions on her behalf. The designation "durable" means that it will stay in effect if the person becomes unable to manage his or her own financial affairs.

Extra Help

An assistance program for people with Medicare who need help paying their part of the costs of [Medicare Part D prescription drug coverage](#).

Family and Medical Leave Act (FMLA)

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

Foster care

A housing option in which a family takes in an older person who needs help with daily living.

Geriatric care manager

A professional who performs an assessment of a person's mental, physical, environmental and financial conditions to create a care plan to assist in arranging housing, medical, social and other services.

Guardian

A person appointed by the court who is responsible for the care and management of another person who has been determined to be incapable of making decisions for himself.

Health care power of attorney (HCPA, or health care proxy)

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

Health Insurance Portability and Accountability Act (HIPAA)

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

Home-delivered meals

Regular delivery of nutritious meals to homebound people who are unable to prepare food for themselves.

Home health agency (HHA)

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

Home health aide

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

Home sharing

A housing option in which older adults share a house or apartment.

Homemaker services

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

Hospice care

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

Instrumental activities of daily living (IADL)

Basic tasks of everyday life that include managing money, shopping, telephone use, travel in the community, housekeeping, preparing meals and taking medications correctly.

Living will (part of a health care directive)

A legal document that communicates a person's wishes about lifesaving medical treatments, should she be in a terminal condition and not able to communicate her health care wishes.

Long-term care insurance

Insurance that can pay part of the cost of care received in the home, in assisted living residences

or in nursing homes, as well as other designated services, depending on the policy purchased.

Long-term care ombudsman

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

Medicare

The national health insurance program for people age 65 and older, and for some younger persons with disabilities. Medicare covers hospital stays, doctor visits, prescription drugs and other health care-related services.

Medicare savings program

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

Medicaid

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

National Family Caregiver Support Program

A federally funded program available in local communities that provides a range of supports to assist family caregivers who care for their loved ones at home. Services may include caregiver education, training, information, counseling, links to community services and respite.

Nursing home

A nursing facility that provides intermediate care (assistance with personal care and activities of daily living) or skilled care (24-hour medical, nursing and rehabilitation care); often a transition from hospital to home.

Palliative care

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

Personal emergency response system (PERS)

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

Physician orders for life-sustaining treatment (POLST)

A form that states what kind of medical treatment patients want toward the end of their lives.

Printed on bright pink paper and signed by both doctor and patient, it is designed to improve the

quality of life. Available in some states and communities.

Respite care

A break from providing care for a loved one. It can be provided by either family or friends, or through programs such as attending an adult day services center. You can also have a paid home care worker come to the home.

Social Security

A benefit earned by eligible workers that provides guaranteed inflation-adjusted monthly income for life. People with the required number of quarters in Social Security-covered work who are either disabled or age 62 or over, as well as certain family members, are eligible. For more on Social Security, see [AARP Social Security For Dummies](#), available at bookstores nationwide.

Supplemental Security Income (SSI)

A monthly benefit to people who are 65 and older, disabled or blind, and who have limited income and assets.



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