

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

—Rosalyn Carter



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The Senior Care Journey

A guide to understanding your options



Welcome to caregiving

Getting started

You're concerned. Your mom is not as perky as she used to be—she's forgetful. To be honest, she's more than forgetful. You're beginning to realize that she might not be able to live alone. You're afraid to bring it up. You don't want to hurt her feelings, but you don't want her to fall, forget to take her meds or spend all day by herself. You have to work and you can't always be there for her when she needs you. What's best for your mom—and for you? Should you hire a caregiver, investigate home health agencies or look into assisted living communities? You're not even sure what options you have.

Being a caregiver isn't always easy. It isn't even easy to define. Being a caregiver doesn't mean you give up all the other things you are—spouse, mother, sister, friend or employee. A caregiver is a person who cares for someone who can no longer manage without assistance. That person may be elderly, may be rehabilitating from an accident or surgery, or may have a chronic illness.

Caregiving covers a wide spectrum of needs. It may include physical care, moral support and household management. You may be a care advocate and help to coordinate care by hiring professional caregivers, or by helping someone find and relocate to senior housing. You may be caring for a relative: a parent, spouse, child, grandparent or sibling. You may help out with a neighbor or a dear friend. You may live nearby or in the same city—or across the country or even out of the country. Most of us will have seasons of caregiving that will flow in and out of our lives, so it's important to figure out how to do this and in ways that benefit everyone involved—including yourself.

Whether it's your mom or dad needing a helping hand, your sister recovering from breast cancer, your spouse showing signs of early-onset dementia or your grandmother who recently broke her hip, you realize that you're now a caregiver. You have a million questions. There's so much you don't know—everything from medication interactions to safety issues to what the heck's a CNA? Where do you start?

No matter where you are on your caregiving journey, know this: it's constantly changing.

Just as you feel like you've got a decent routine, doctors you connect with, or medications that seem to work, something goes haywire and you're back to scrambling and trying to figure out how to juggle the next challenge. It can be frustrating, and it can feel as if you can never do enough or be enough. One thing that does help is to have a plan. This guide is meant to be a roadmap, to help you navigate your caregiving journey. You'll become familiar with the various types of care that can support and assist you and your loved one, learn what best suits your needs, and know the right questions to ask.



So take a deep breath and keep reading.

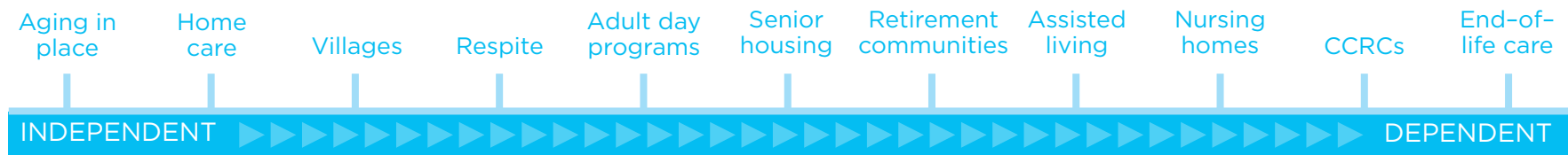
Learn what to expect past your current caregiving stage—so you'll be ready when the next inevitable monkey wrench comes hurtling your way. Be willing to see what does and doesn't work for you and your loved one, laugh at your mistakes, reach out to others for support and encouragement and learn to embrace the moment, right where you are now.

Look at the Continuum of Care graph below.

Do you see about where you and your loved one might fit? Is your loved one still relatively independent or is it time to consider assisted living?

The Continuum is not a ladder, nor is it a universal predictor.

You might skip over several "rungs." It's a guide to help you know where you are, what options and assistance you have now and what might be up ahead.



Continuum of care



About aging in place

What you need to know about aging at home

You're afraid your mom is not eating enough. She slipped in the shower last week and got a nasty bruise. Dad is recovering from a hip replacement and he seems depressed since your mom died. Your grandmother is fighting breast cancer and needs someone to drive her to chemo. You go over to help out as much as you can but you can't quit your job, and you still have kids at home and their college expenses to think about.

A 2011 AARP survey* found that nearly 90% of all Americans over the age of 65 state they'd like to stay in their own homes as they age. Aging in place allows people to stay in their own homes and communities. In order to stay at home, many older adults need added assistance, and their homes may need some safety and comfort modifications.

In fact, some contractors and construction companies have begun to specialize in aging-in-place renovations.

But the ability to continue to live at home is about more than just support bars in the bathroom and remote-controlled appliances. Consider the questions on the following page.

*<http://assets.aarp.org/rgcenter/ppi/liv-com/aging-in-place-2011-full.pdf>

Are your parents able to live at home?

10 key topics

1. HOME CONDITIONS:

- Is their home safe?
- Have the repairs been kept up?
- Do the heating and air conditioning work properly?
- Are the floors even, and is there adequate lighting?
- Are there any leaks, cracks or other major structural issues?

2. COGNITIVE FUNCTIONING:

- Can your parents continue to make sound decisions?
- Are they able to discern if someone who calls on the phone or comes to the house is trying to scam them?
- Do they remember basic safety practices when walking to their car, doing their banking, hiring home repair people or listening to a telemarketer on the phone?

3. HOME LAYOUT:

- Do they have to navigate stairs inside or outside the home?
- Is that a problem, or do you foresee it being a problem in the future?
- Are their bedrooms on a floor other than the main floor of the house?

4. DRIVING:

- Do your parents still drive, or is there reliable and convenient transportation available to them?
- How much longer do you see them being able to drive themselves?
- Do you have a plan if the time comes to put away the keys?
- Have you talked about it with them?

5. MEALS/HOUSEKEEPING:

- Do your parents still cook or have ways to get nutritious meals?
- Do your parents need help with cleaning, daily activities, shopping or cooking?
- Is there a clutter issue that could become a safety hazard?

6. FALL HAZARDS:

- Are your parents at a high risk for falls?
- Do they tend to get dizzy, shuffle, walk with a cane or use a wheelchair?

7. BATHING:

- Do they take showers or baths without trouble, and can they manage the hot water settings?
- Have they had any falls in the bathroom?

8. EMERGENCY COMMUNICATION:

- Can your parents call for help?
- Do they use a monitoring system of some kind?
- Do they use cell phones or computers?
- Can you stay in touch with them throughout the day?
- Do they have neighbors who can check on them?

9. DEMENTIA CONCERNS:

- Are there memory issues?
- Do they remember to take their medications?
- Do you see problems with anxiety or paranoia?
- Do they wander, become confused or make excuses?
- Does normal aging forgetfulness seem to be increasing over the last few weeks or months?

10. EVACUATION PLAN:

- What's the plan if there's a natural disaster such as a fire, flood or ice storm?
- Do they have a way to evacuate?
- Can you or someone else get to them quickly?

It's possible for older loved ones to still enjoy living at home, even if they need a little extra help with daily activities or household chores. Many aging adults surround themselves with unpaid care and support given by family members, friends, neighbors and other volunteers. Others find that hired caregivers, scheduled to assist several times a week, or even to live-in, is best for their situation.

Do you assist an aging adult who wants to stay in their own home? Start by making sure their home is safe, and that they're safe at home, in their community, and in their daily interactions with others. As an adult child, you want the peace of mind to know that your parent isn't going to fall, get burned, have a car accident, forget to take their medications or become a victim of a scam or violence.

It may be a fine balance between your need to ensure your parent's safety and their need for independence. There may be times, however, when you need to make tough decisions to intervene on your loved one's behalf before something unfortunate and preventable occurs.

Ten warning signs

Signs that your parents need some outside help in their home.

1. One or both of your parents are losing weight. There are half-opened cans on the counter, refrigerated items left out overnight or old take out food containers sitting around for days or weeks.
2. There are bugs, garbage or clutter throughout the house.
3. You notice frequent bruises. They're falling and not telling you. The stories they're telling you aren't making sense—you can tell they're hiding something.
4. There are new dents in the garage or on the car. Or, maybe they won't let you see their insurance policy documents, or you find traffic and parking tickets.
5. They mention they got confused or lost while driving or just walking someplace. They blame others for accidents: "They turned right in front of me, I didn't see him."
6. You notice they're wearing the same clothes over and over again or are suddenly mismatched when they were always impeccably dressed. They smell of body odor or urine.
7. The house seems dark all the time. All they seem to do is sleep in their recliner or favorite chair. They're drinking alcohol or taking sleeping or pain pills—a lot. They don't talk about visiting their friends. They've stopped attending religious services or participating in volunteer activities.
8. Their outbursts are louder and more frequent. They're paranoid about someone stealing from them or trying to hurt them. They may even accuse family members or people they've known for years.
9. They've made some rash decisions lately that worry you—giving a lot of money to a televangelist or charity, buying useless items on television, hoarding or exhibiting obsessive behavior.
10. They are forgetting their normal routine, doctor appointments or medication. They're forgetting how to get home or where a room in the house is located. They avoid answering you, blame others for their confusion and make a dozen excuses.



How can my parents remain in their home safely?

What are the options?

After assessing your parents' health, their maneuverability and their living situation, you've come to the decision that something—either something major or, at the moment, minor—has to be done. But what, exactly? There's no one-size-fits-all solution to the question of senior living arrangements. Fortunately, there are plenty of options. Here are a few to discuss with your parents:

- Your parents stay in their own home, but you help them modify it for safety and ease. That may include moving their bedroom downstairs or installing a stairlift, modifying their bathroom or kitchen, etc. If you're doing some remodeling, go ahead and widen doorways to at least 36-inches for wheelchair and walker access.
- Your parents stay at home but you augment it with daily care including: part-time home-care professionals, a live-in family member or friend, or a paid live-in care person. You or another family member may cover nights or weekends.
- Your parent or parents move in with you or another family member. You may alternate weeks or months if your parents can be moved without too much upset or difficulty.
- You investigate various living arrangements including moving to a smaller, more manageable home, condo or apartment, or living closer to family members. Other options include senior housing, continuing care retirement communities, assisted living or group homes. Depending on their health needs, a nursing home or memory care program might be most appropriate.

Tips for success

- ✓ Agree together on the importance of continuously assessing their situation. This includes how their home is being kept up, ensuring they are taking their medication properly, assessing their driving skills, etc. You may even want to begin to scout other forms of transportation for when the time comes to put away the car keys.
- ✓ Establish ways you can check on them throughout the day and night. Discuss with them the advantages of using a web/nanny cam, as well as a monitoring system for falls and other emergencies. Also consider daily check-in calls or visits from neighbors or other people who will stop by to say hello.
- ✓ Investigate Meals on Wheels or other elder agencies that make house calls. And you can stop by often to see for yourself that they're eating, taking their meds and functioning well.
- ✓ Keep a list of "helpers" nearby—neighbors, your siblings and other extended family members, church or synagogue friends, volunteers, community outreach and elder care agencies—all of whom can be pressed into service for an emergency or just an important errand.



About home care

The essentials

Home care is about helping seniors maintain their independence while ensuring they are well cared for and safe. Oftentimes, this involves some type of assistance in the home. There are lots of reasons to consider in-home support, and it doesn't make you a bad child, grandchild or friend. Home care can range from volunteers to paid care, from neighbors and friends to professional CNAs (certified nursing assistants). You have lots of choices and finding the right fit for you and your loved one is worth the time and effort you'll need to invest.

What are the different types of home care?

Let's review your options. Here are the main sources of home care, with full details on each. Read through the descriptions, because while you may start with one type of care, you may find yourself needing other options eventually.

- [Volunteers: family, friends, church or synagogue, community and hospice programs that offer assistance](#)
- [Skilled care \(Medicare-certified\)](#)
- [Non-medical care](#)
- [Technology to help monitor care](#)

Volunteer care

Extended family, neighbors and volunteers—how do I manage so many people in my already hectic life?

Some caregivers may not prefer enlisting neighbors, extended family, friends and volunteer help. Still, they go this route because their elder mother, father or grandparent is more accepting of this natural setting. Your senior loved one may already be friends with a neighbor or prefer the company of relatives or community acquaintances. This familiar situation might be the ideal way to ease your loved one into the idea of caregiving in a way that's not threatening or demeaning. It doesn't feel like "babysitting," and the volunteer and your loved one already have things in common to talk about.

And, in the early stages of a senior's dependent years, having a friend stop by for a few hours each day may be a more comfortable, less emotionally-charged option for the primary caregiver, as well. The important thing is to do your part to manage and ease the way for volunteers.

Tips for creating an amazing team of caregiving volunteers:

- ✓ **Stay organized:** Use your smart phone, a daily planner, email reminders or your computer calendar. It's a lot to coordinate, so try to lay out at least one to three months of activities and scheduling at a time.
- ✓ **Streamline care:** Find a champion for each care need (picking up medications, grocery shopping, preparing meals, cleaning, hands-on care, etc.). How much help can each person provide and with what consistency?
- ✓ **Be ready for Plan B:** Ask for volunteers to help in a pinch, so you have a backup for that important doctor appointment or physical therapy session.
- ✓ **Show your gratitude:** Treat them to lunch the next time they take your loved one to an appointment. Offer heartfelt compliments for all they do.
- ✓ **Accept change and plan ahead:** As care needs increase, you'll have to consider other options of care.
- ✓ **Enjoy this season:** As tough as caregiving can be, see the good in each day. Create a community around both of you. Notice small moments of connection. One day you'll look back—what will you remember?

Skilled/Medicare-certified home care

Visiting nurses can be just what the doctor ordered.

Skilled care, also known as visiting nurses, offer a range of services including wound care, pain management, infusion therapy, rehabilitation therapies and medication management.

If you or your relative is disabled or chronically ill, skilled care can be a big help. Visiting nurses can be especially helpful if your loved one has cancer, cardiac issues, immune disorders or some diabetic complications. Visiting nurses assist by coming to you or your relative's home, monitoring vitals and assisting with pain medication management, medical appliances and wound care. Other skilled care, such as physical therapists, can help a hip or knee replacement patient regain the ability to function comfortably after surgery.

Visiting nurse care is usually covered by Medicare or Medicaid and can offer skilled or unskilled care. Here's a quick summary:

Who benefits from Medicare-certified home care? People with:

Cancer • Heart disease • Immune disorders • Certain surgeries • COPD • Other chronic illnesses

What type of care might be provided?

- Post-operative care
- Wound care
- Symptom management
- Physical therapy and rehabilitation care
- Certified chemotherapy nurses can offer in-home consultation and care
- Home infusion therapy
- Pain management
- Monitoring vital signs, disease management
- Hospice and end-of-life care

How much do visiting nurses cost?

Most people hire visiting nurses based on their doctor's recommendation and hire from an agency or health care organization. Medicare-certified home care is most often provided to individuals who are considered homebound and have short-term skilled needs post-hospitalization. A physician's order is required for care to be covered by Medicare. [If you are paying out of pocket, expect \\$25-75 per hour, depending on the market and the level of care required.](#)

Tips for hiring a visiting nurse:

- Ask for a visiting nurse who specializes in your loved one's condition—cancer, heart disease, immune disorders, etc.
- Ask what background checks the agency does.
- Ask if you can request the same visiting nurse each time, or if you will be assigned different nurses each visit.

Non-medical home care

Includes CNAs, companion care, and personal care attendants

Non-medical care offers assistance to family caregivers and to those in need of care, providing services that include personal care, respite care and companionship. Duties include feeding, dressing and bathing, medication reminders, walking/ transportation assistance, errands and social support.

A companion caregiver is solely focused on tending to the needs of the elderly person, but does not have a medical background nor are they trained to perform personal care duties. These employees typically perform household work for the individual, such as preparing meals, cleaning and doing their laundry.

When hiring privately “companions” are not just a type of caregiver, but also a formal employment category by the IRS. By the IRS definition companions are focused on providing company to an adult or senior by chatting, playing games, taking walks or driving them to appointments. They can also help with light housekeeping and other duties. The IRS allows companions to assist with personal care like bathing, dressing and feeding as long as it doesn’t comprise of more than 20% of their total duties.

“Companions” is a formal employment category by the IRS. Companions are focused on providing fellowship and company for the person by watching TV and playing games with them, taking walks or driving them to appointments provided that it doesn’t comprise of more than 20% of these duties. They can also help with light housekeeping and other chores. They are not trained to provide personal care or assist with basic care needs (known as ADLs or activities of daily living).

Skills	Companion Care	Certified Nursing Assistant (CNA)/ Personal care
Companionship (reading, games, talking)	✓	✓
Errands and shopping	✓	✓
Medication reminders and observations	✓	✓
Cooking	✓	✓
Cleaning and other household chores	✓	✓
Laundry	✓	✓
Bathing and dressing		✓
Feeding		✓
Assistance with walking and moving		✓
CPR certified		✓
Incontinence care		

A CNA or certified nursing assistant is additionally trained to assist with some personal or hands-on care needs. He or she has completed a training program and received a certificate valid within the state. When a CNA works for a home care agency, he or she is generally supervised by a registered nurse. CNAs also work contractually and can be individually hired. Not all states require paid caregivers providing personal care to be certified.

How much does non-skilled (companion/personal care) assistance typically cost?

The hourly fee can range from \$15-\$25 if hired through an agency, depending on your location. In addition, agencies may charge cost differentials for care on weekends or holidays. If you want to hire a certified nursing assistant or certified nursing aide, they will typically charge a bit more per hour.

How do I find a reliable companion, in-home caregiver or CNA?

- Local, individual caregivers can be found online through us at www.care.com. You can also find home care agency options on the site.
- Word of mouth is an excellent way to find help. Perhaps you receive a recommendation from another family member or neighbor. Don't be afraid to ask others who have faced a similar care need. Also, consider finding recommendations through a caregiver's workshop or support group where others have hired care and know of an aide they particularly like.
- Contacting agencies and organizations (such as your local area agency on aging) that cater to local seniors, memory-impaired seniors or disabled individuals and ask for a list of companies they recommend. You can contact these agencies yourself.

How do I know if hiring an individual home health aide or companion caregiver is right for my loved one?

- You have obtained a background check of the individual and called references. Care.com provides access to free preliminary checks to all premium members on our site. For your family's safety we do suggest that you purchase a more in-depth background check as well.
- You are willing to hire, supervise and coordinate care on your own, rather than through an agency.
- You are comfortable opening your home or your loved one's home to an individual.
- You or someone else can check on the care aide and care recipient often.

What to ask when hiring a companion, in-home caregiver or certified nursing assistant:

It's important to be very specific about what you expect from a paid caregiver. Are you looking for someone who can assist with bathing, dressing or other activities of daily living? Or maybe just someone to be there for your loved one and help them around the house from time to time. Either way, be honest about what the caregiver might encounter.

Write a specific job description based on the help that is needed. Do you want someone who is:

- Trained to handle incontinence?
- Strong enough to transfer the care recipient from bed to chair and back again? You may want to include the care recipient's weight.
- Experienced with dementia/Alzheimer's or other specific diseases?

- Licensed and trained to provide hands-on or personal care? Let them know they will be asked for documentation.
- Willing to prepare meals and do laundry and light housekeeping?
- In possession of a valid driver's license and good driving record (if transportation is needed)?
- Able to help the care recipient in and out of a car?
- Willing to run errands in their own car? Do they have insurance coverage?

Go with an agency or hire independently?

There are real benefits and drawbacks to both going with an agency or hiring independently, so the best thing to do is consider the pros and cons on the next page to determine which option is right for you. Hiring an individual home care worker through Care.com can lower costs by 10-30%. Care.com also has profiles of agencies throughout the country. Costs for care vary from state to state and rural versus urban areas, but generally agencies cost more because they provide more. Agencies provide supervision for their care providers, conduct background checks on their providers and will coordinate care for you. Additionally, agencies often have a minimum requirement of 4 hours per shift, and some agencies will charge a nurse assessment fee to open a case. Typically, 24-hour, live-in care is more affordable, but it all depends on the level and intensity of care needed.

On the next page are some things to consider when deciding which route to take.



Home care agency & independent hire pros and cons

Things to consider when deciding which route to take.

Home care agency pros and cons

PROS

There are national, regional and local agencies, so there is generally good coverage

Background checks are done for you

The agency and its workers are licensed and typically bonded

The agency handles Internal Revenue Service and Social Security tax reporting

Caregivers are supervised

Coordinating caregivers is the responsibility of the agency, so backup care is handled for you

CONS

They usually cost more

You may have multiple caregivers (this could also be a positive if the care recipient is very social)

There may be a minimum hourly requirement per shift

There may be rate differentials for care during weekends and holidays

Independent hire pros and cons

PROS

You may be able to negotiate a better rate dealing directly with the worker

You have more control over exactly who will be providing care, as you are the employer

The worker might be more flexible in negotiating their schedule directly with you

A flexible worker might be willing to sign on for live-in or for weekend care, as well

CONS

You or your loved one are the employer and that means dealing with taxes, social security. Fortunately our HomePay service can take the challenge out of this. You will be responsible for back-up care if the worker is ill or needs time off, and issues or challenges that arise around work quality or expectations

If the caregiver is not licensed or bonded, you may have a safety or property issue arise and not have a course of action

Even if the worker signs a contract, they may be unreliable or quit without notice leaving you without any recourse

If you decide to hire on your own

Steps for hiring a caregiver

1. Get qualified applicants from Care.com's national database of care providers and take advantage of background check options that we make easily available

- Post a detailed job description and a summary of your loved one's condition, including any emotional/mental/cognitive issues and special needs.
- View profiles for the caregivers who apply for your job.
- Request preliminary checks for your top candidates.
- Conduct phone screens for the top 10 or so caregivers who fit your desired profile.
- For the top 5 who pass the phone screen stage, arrange to meet them for an in-person interview in a public place.
- Arrange for the individuals you like the most to meet for another interview with your loved one.
- Go ahead and let the candidates know that you will call former employers and references before you come together for the interview.

2. Conduct in-person interviews (see following page for our interview tips)

During the interview process, involve your loved one as much as possible. Their input is important, but don't bombard them with too many questions—try to make the meeting feel natural. After you introduce the candidate and your loved one, allow them to interact without your interference. Offer light snacks, something to do or enjoy (puzzle, crafts, sitting outside, etc.) and see if they can strike up a natural conversation. Observe how the candidate assists your loved one when sitting up, putting on a jacket or taking a sip of tea. See if your loved one is talking, looks them in the eye and feels valued.

3. Gather documentation and run in-depth background checks

If the person is a good fit, ask them to send you a photocopy of their driver's license, car registration, insurance card and any documentation around care certifications they have for your files. As has been mentioned, let the candidate know that you will contact former employers for references. . If the person is a strong fit, purchase an in-depth background check, which are more comprehensive than preliminary checks, to learn more about the candidate's history.

4. Write a contract

Once you select a candidate, get it in writing. The job contract is based on the job description and should include:

- Wages: when and how payment will be made
- Hours of work
- Information needed for a service like HomePay to properly pay employees.
- Job description
- Unacceptable behavior (such as smoking, abusive language, tardiness, etc.)
- Termination (how much notice, reasons for termination without notice, etc.)
- Vacation policy (paid versus unpaid)
- Dated signatures of employee and employer

Click [here](#) for Care.com's sample adult and senior care contract.

If you decide to hire on your own

Steps for hiring a caregiver: Tips

Do I need to pay for a background check?

Yes, if someone is caring for your family member and is left alone, then take this precaution. Premium Members can run free, unlimited preliminary checks on Care.com caregivers. You can also purchase additional background checks that will give you a more comprehensive look into the caregiver's background. We encourage you to run these more in-depth checks on your top candidate before hiring. If you elect to hire someone completely independently, you can run a background check for about \$150 on your own.

Seniors can fall victim to being abused, neglected and having their finances ransacked by individuals who know they're vulnerable. Unscrupulous people bank on you being too busy and too trusting to keep a close eye on what's really going on. Check with your local police department, legal aid service or attorney for referrals to reputable investigators or search online for "background checks" plus your "city/area."

Ask any home care agency, non-profit or care community what type of background checks they do. Hiring practices vary widely. You want to know if they run criminal background checks as well as driving background checks. A person with a string of DUIs and a suspended license isn't who you want driving your mom around on her weekly errands. Many places allow minor offenses, so don't let that surprise you— but you need to know who has access to your loved one and his or her belongings.

Don't forget the paperwork!

- Hiring an individual caregiver makes you or your loved one an employer, which means you'll be responsible for withholding your employee's share of Social Security and Medicare, federal income tax, and (in most cases) applicable state taxes, and remitting these taxes to the IRS and your state tax agencies, along with your employer share of Social Security and Medicare and the unemployment taxes.
- Consider outsourcing these responsibilities through a cost-effective solution like Care.com HomePay. As a HomePay client, all payroll and tax compliance work will be managed under one umbrella by our household employment tax experts.
- In many states, when you hire a caregiver to work in your home, you must purchase a workers' compensation insurance policy. This covers your caregiver's medical expenses and lost wages in the event she/he is sick or injured on the job. It also protects you because workers that accept benefits generally forfeit their right to sue their employer - regardless of fault. Whether it's required in your state or not, a workers' compensation policy is a good piece of mind purchase. The easiest way to obtain a policy is to call your homeowners insurance agent as many times they can bundle a policy with your existing coverage. Learn more from Care.com about the importance of workers' compensation

Interview Tips:

- Are you willing to submit to a background check? *Note: If you use Care.com to find candidates, you can request unlimited preliminary checks with Premium Membership. You can also purchase more comprehensive background checks*
- Do you have a driver's license and clean driving record? (Request a copy of the driver's license.) Do you have reliable transportation and insurance? How far from here do you live?
- What are your responsibilities outside of work? Do you have to account for the schedules or needs of others in your workday, or are you flexible?
- Will you be working other jobs that might be affected if I'm delayed getting home? Would you be available for respite care, or to stay over for a long weekend?
- Do you smoke? (Many people say they don't smoke but they do—offer an outside smoking area and insist it be used.)
- What caregiving certification training do you have, if any? Do you have any CPR or first-aid training? (Request a copy of the certification.) If I pay for it, would you be willing to add to your skills?
- Here is a list of expected caregiving related duties—is there anything on the list that poses a problem or concern? Are you comfortable with

If you decide to hire on your own

Steps for hiring a caregiver: Tips (con't.)

pets? Are you comfortable with my (parent/spouse) having guests or other family members stopping by?

- Are you able to work the hours needed? When are you available to start working? Would you agree to a 30-day trial period? Would you be willing to commit to a (fill in a time frame/6 months, a year is common) long term?
- Have you ever cared for someone with (conditions relatable to your loved one's care: memory problems, elderly, wheelchair bound, etc.) before? If so, please elaborate.
- Are you willing to sign a contract stating you will not accept money or gifts from my (parent/grandparent/spouse, etc.) without clearing it with me?
- Are you willing to sign that you will not have guests come into our home unless I have given prior approval?
- Will you be comfortable driving my mother's car if need be, or using your own car to run errands if we request it?
- What are your expectations for for paid time off?

Create scenarios:

Ask the prospective caregiver how he or she would handle various care issues that might arise and are similar to your situation.

- How would you handle it if my mother wakes up grumpy and doesn't want to get dressed or eat her breakfast—but she has a doctor's appointment later that morning?
- If my father is running a fever and is acting lethargic and you think there's blood in his urine, what would you do? If I'm out of town and can't be reached, what would you do then?
- My aunt falls, seems confused, doesn't recognize you and won't let you help her. She's combative, what do you do?

Once you have hired someone and have all of the documentation and paperwork squared away, it helps to have a plan for the first week to ensure a smooth transition.

The first week of care: Off to a good start

- Be available. If you don't live near your loved one, it's ideal to make plans to be there the first few days. Plan one day for them to observe you and take notes (at least for a couple of hours) and then another day where you're the observer, taking notes, answering questions and making suggestions.
- Create a notebook and include a typical schedule, important numbers, contacts, etc.
- Don't expect your ways to be followed to the letter, but pick one or two very important items that you do want done "your way," and follow through until you get the results you want. Be clear, be consistent.

- Allow the caregiver to find new ways to tackle certain problems—and acknowledge his or her input.
- Don't be surprised if your loved one rebels and doesn't like this person right away—give it time.
- Don't be surprised if it turns out they like the new caregiver better than you do!
- Resist the urge to move too fast emotionally and make your new employee an extended family member—trust should be natural and takes time.
- Stop by at odd times. Not practical? Check on them often by phone, email or visits.
- Ask what the most challenging part of the week was—and brainstorm together for solutions.
- Expect this to take a bit of time—try to not to nitpick—and allow the caregiver to give care and attention in his or her own unique style.



Home & personal safety

What you need to know to keep your loved ones safe

So, the collective decision is to have your parents live independently as long as possible, and you have now lined up the care they need to assist them in doing so.

The next steps are to make sure your loved one, the house and your loved one's personal belongings are as safe as possible.

Ten home dangers

every caregiver should know

- Poor lighting.** Inside or out, this creates a fall hazard, cooking or fire hazard and could even make your elderly relatives easy targets for criminals. Many seniors suffer from eye conditions. Make sure walkways, halls and stairs are well lit. Consider motion sensors by entry ways, hallways and even bathrooms.
- Clutter.** Many seniors don't like walking with bulky items in their arms, so they tend to let things pile up on the stairs, by the door or on the counters too near (or even on) the stove. Be aware of clutter on shelves and in upper cabinets that can fall and cause injury.
- Throw rugs.** Be aware of too much furniture in a room and other "floor" items. Try to get rid of all extension cords or cables strung across walk areas. Many seniors tend to shuffle due to arthritis, Parkinson's or other movement disorders. Tripping on a rug or snagging a foot on a table or chair sticking out in the traffic path can cause a serious fall.
- Bath and water hazards.** Turn the water heater down to a safe 120-degrees. Burns from scalding water are too common and can be particularly dangerous for those with diabetes who have diminished feeling in their extremities. Place non-skid mats in front of the sink and tub to absorb excess water and prevent falls. Tubs can be dangerous, even with a non-skid surface. Add a shower chair. It's easier for a senior to sit and hold a handheld showerhead. If you're updating their home, consider a tub/shower combo that has a step and molded seat, or a sit-in shower that has specially-designed drains and no step at all. Install grab bars next to the toilet and around the tub—go for the screw-in type. Exchange faucet knobs in the kitchen and bath for levers since loss of strength can make it difficult to adjust the temperature.
- Cooking and fire hazards.** Hang out and watch your mom or dad cook. Notice how steady their hands are, how they handle knives, if they can open cans properly, if their food is stored properly or how long they leave food out on the counter. Watch where they place a towel or oven mitt—are they aware of burners? You won't know what you're dealing with until you pay attention and decide if they simply need items to make jobs easier or if they're downright unsafe. Get rid of candles and cover up or dismantle fireplaces if you think they can't manage them. Space heaters—get rid of them if at all possible, or secure them. Central heating avoids the dangers of a piece of clothing getting too close to a heating element, a heating unit or cord tripping hazard, or just forgetting to turn it off. Radiators should have well-constructed, heat-safe covers to avoid burns.
- Home Temperature.** Look out for a house that's not cold enough or warm enough. Your parents might not realize they're overheated, or they might be trying to save on electricity costs. Either way, make sure your loved one is not in danger of heat exhaustion or hypothermia—both real concerns. Stop by at odd times to make sure they're not scrimping and placing themselves in danger.
- Car safety.** Where do your elderly relatives park their car—in the driveway or garage? Make sure there is ample room for the car as well as for getting into and out of the car. This might mean getting rid of some stuff in the garage. Do they use their emergency break and can they manage it? Does their bumper have dents? Have you checked the glove compartment for tickets and to see that their insurance and registration are up-to-date? Have they hit the garage door? Do they have the strength to open the garage door manually if they needed to?
- Outdoor safety.** Do your parents have a way to open the front door to talk to someone and still be safe? (Is there a speaker or security/glass door that can stay locked?). Do they still have sliding glass back doors? If so, these can be a safety hazard (break-in), as well as a tripping hazard. Consider changing them out for French doors with lever handles and deadbolts. Are the outdoor steps cracked or too large for them to comfortably climb, or have they pulled away from the house? Are there vines or other debris in the yard they could trip over? Are there overhanging branches, a leaky roof or other housing repair issues?
- Communication concerns.** How will your parents connect with you and others? Can they operate cordless telephones? Do you need to purchase a simpler phone with fewer features? Do they forget where they put the phone? Can you place neon stickers on the phone or devise some other way to find phones in the dark or when they're misplaced? Can they use a cell phone and keep it charged? Have you considered a monitoring system that can reach them by speaker phone? Would a personal emergency response system be helpful?
- Emergency situations.** Floods, fires, hurricanes, tornadoes, ice storms, lightning strikes and heat waves—all of these natural disasters can wreak havoc with trying to reach your elder parent to make sure they're safe and can manage. Know where your parent's nearest safety shelter is located. Know someone who lives with them or very nearby who can get to them quickly. Have their meds and pertinent documents ready at all times. Talk about how to handle an emergency and create mock scenarios you can walk through for practice.



Consider yourself a care-coordinator

You can't do it all alone. Don't even try. It's not good for your health, your relationships, and honestly, this is a journey that should be shared—not only the challenges, but the lessons learned and love experienced along the way.

Nine ways to protect your loved one

In addition to making adjustments to the home to provide a safe environment, there are many steps you can take to protect your parents' personal documents and valuables.

1. Put your legal documents in a safe.
2. Consider a dead-bolt lock on the home office door, or put the safe in a place that is not commonly trafficked.
3. Put your loved ones' documents, jewelry and other valuable items in the safe, or in a safety-deposit box.
4. Don't mention when you'll be out of town—online or in person.
5. Consider that other people may be visiting your house—the caregiver's spouse, community members or friends. Ask that all visitors' names, phone numbers and other contact information be placed on a sheet along with the days they visited.
6. Don't leave laptops, smart phones and other devices that may hold important information lying around the house.
7. Consider that your mail may be perused.
8. If you can, section off the house so the caregiver only has access to "care rooms," such as the kitchen, bathroom, bedroom, living room, etc.
9. Check your accounts, jewelry and personal records often.

Want to move Mom or Dad in with you?

Consider these questions first

After evaluating After evaluating in-home care options, you may come to the conclusion that your elderly relative or relatives can no longer live alone in their own home. Should they move to your house?


How do you know if you and your family can handle full-time caregiving?

The prospect of increasingly dependent elderly relatives moving in generally brings on visceral emotions. Some adults immediately assume that they can handle caring for their parents or grandparents in their elder years, and quickly make plans to expand their households. Others have the opposite reaction, based on financial, emotional or logistical concerns.

Both reactions should be given further consideration. Before making a decision—which will affect you, your elderly relative and your immediate family—consider these issues:

- Do you need to modify your home for your parent to move in? Is your home senior safe? Will another family member have to give up his or her space? If so, have you talked to him or her about it?
 - How will you handle privacy issues, and time for your marriage and children? Are you single—how will you see friends or date?
 - Have you talked to your spouse/partner? How much care are you expecting them to do and what are they not comfortable doing (bathing, toileting, etc.)?
 - Will your parent be left alone all day? If so, are they safe? Is there a way to break up their day, such as have visitors? Can they volunteer or go to an adult day program?
 - Will they need care 24/7? How will you cover the night time? Can they get up to go to the bathroom safely? Do they tend to wander or have memory problems?
 - If you have children, how will you juggle their activities, care needs and everyday life? How will you handle jealousies or personality differences?
- Who else is impacted by bringing your parent into your home? Have you talked with them and asked for their input and encouraged them to voice their concerns? What will be expected of them? How will you handle the emotional side of your parents' illnesses?
 - Do you have back-up people to help you with care and provide respite? Do you have siblings, extended family or neighbors who can pinch hit or champion certain areas if you get overwhelmed or simply need a break?
 - How will caregiving impact your finances? If you're consolidating two households, can you find ways to cut corners? Will you also be taking over their finances? What insurance or assistance payments do or can they receive? If you have to supplement care out of pocket, will you be able to afford it—or will your parent?
 - How much time can you take off work to care for your parent? If or when your parent needs full-time care, will you cut back your hours, take a leave of absence or have to quit your job?

If you are able to address the questions and concerns above, you are in good shape to bring Mom and Dad into your home. However, if any of these questions bring up serious concerns, you may want to pause and consider other options such as assisted living or CCRCs.



“An inconvenience
is an adventure
wrongly considered.”

-G. K. Chesterton

Villages and intentional communities

What they are and how they work

Intentional communities and “villages” typically are, or are affiliated with, non-profit organizations and have much in common with a buying co-op.

These loosely defined communities are planned to help the aging populations stay in their own neighborhoods and create a network of connections that allow them to lead safe, healthy productive lives in their own homes.

You get to live right where you are, and become part of an association and community that organizes and delivers programs, amenities and discounted services.

How villages and intentional communities work

The basics

Participants pay a membership fee and have a variety of services available, such as social and educational programs, household care (cleaning, grocery shopping, errands and meals), personal and companion care assistance, and nursing care if needed.

These communities are located all across the world, including many in the U.S., such as Beacon Hill Village in Boston, Massachusetts and Avenidas Village in Palo Alto, California. People can even start one of their own if they live in or near a naturally aging community; there may already be many of the potential members, interests, access and resources needed.

Is a village or intentional community right for your situation?

This is a wonderful concept that allows high-functioning, community-minded seniors to remain in their homes and social circles, while receiving access to the services and supports that enable them to continue to live independently.

If your loved one can answer “yes” to the following questions, villages might be a good option to consider:

- Do you live in a naturally aging area?
- Are there intentional communities/villages already nearby?
- Would you enjoy knowing your neighbors?
- Do you want to volunteer, contribute, teach and be an active member of a community?
- Do you like feeling as if you're a part of something bigger than you—and feeling connected?
- Do you like the notion of easily accessible services and amenities such as grocery delivery, snow plowing, etc., that you would have to find on your own if you weren't living in a village?
- Would you like access to educational seminars, films, exercise programs, trips and social events held in nearby religious or cultural institutions, restaurants and community centers?

How much do villages/intentional communities cost?

Individual membership costs range from \$500-\$1,000 per year, varying by location and amenities provided.

You can also purchase a household membership. Some are even subsidized by community donations and grants for those with lower incomes. Many villages reach out to those with varying income ranges and encourage diversity. Do take note that if you need 24/7 nursing assistance or in-home skilled care—this is sometimes available at a discount with a vetted agency. Or you can find the care you need through Care.com, as noted in the Home Care section of this guide.

Most villages have a small hired staff and volunteers to help run daily operations. Every community has a slightly different focus because the services and activities are membership driven. There is usually a board so amenities and services can be voted on by that group. Control and direction are decided by an elected governing body. You can visit the Village to Village Network (vtvnetwork.clubexpress.com) and learn more about different villages.



About respite care

**Repeat this mantra ten times a day:
Taking breaks makes me a better,
happier, healthier caregiver.**

**Intellectually, we all know it's true, but
we put it aside. We worry our loved one
will miss us or that they won't be taken
care of "quite the same," tell ourselves
it's too much trouble or that we won't
be able to find good care...but we must
consider the facts.**

Respite care can literally help your mental and physical health.

The Caregiver Action Network states that 40-70% of family caregivers have clinically significant symptoms of depression and approximately 25-50% of these caregivers meet the diagnostic criteria for major depression.

Other studies show a correlation between caregiver stress and obesity, insomnia, diabetes, heart disease and immunological deficiencies. So, there is a physical impact of caregiving that shouldn't be ignored, and respite helps caregivers avert the negative toll it can take on their health.

What's the hardest part about respite care? Believing you deserve it, and that it will actually make you a better caregiver. Well, that and taking the first step. As a caregiver, you're used to rallying the troops. You know how to get things done, so now it's time to utilize those amazing planning skills for your own benefit.



Respite care

A little break goes a long way.

Respite care may include breaks of:

- a few hours
- overnight
- a few days a week
- a long weekend
- several weeks

Respite care can be offered by:

Low cost options

- Extended family members
- Friends/recommended friends of friends
- Neighbors
- Non-profit organizations such as church members/volunteers
- Community volunteers/disease-specific volunteers
- County or state programs or private adult day programs
- A caregiving/respice co-op that you find or start

Private pay options

- Care (day stays or overnight stays) offered by non-medical home care agencies or found individually
- Residential care facilities that offer overnight/weekend/extended stay

Give yourself daily respite. Don't wait until you can take a whole week off to give yourself a break. Try a three-minute mini-break. (That can seem monumental at first, but like weight training, you get stronger and it gets easier with each attempt.)

Helpful daily “Respite Minute” hints

Everyday tips to stay focused and feeling great

- Start your day by saying thank you. Keep a gratitude journal and jot down three things each day. Notice the small things—a cardinal playing in your bird bath or the opening of the first crocus in spring.
- Keep that door shut! If your loved one can safely be alone at a point during the day, take some time to physically be by yourself.
- Turn your bedroom into a sanctuary. Don't let boxes, papers and other clutter bugs migrate back to your room. Paint one wall a color you love and begin to nurture yourself.
- Dress before you leave your room. Shoes and all. Being dressed means you take what you do seriously and you're ready to meet the day.
- Consider purchasing a small coffee maker for your bedroom or bathroom. Have that first cup o' joe or hot tea undisturbed.
- Get off the emotional rollercoaster. Have your arsenal of distractions (headphones, a friend on speed-dial, humor and mini-breaks) ready.
- Plan your first three-minute break. If your morning is spent in caregiving chores, then set the timer for a short walk or playing ball with the dog.
- Call or email a friend, go onto a caregiver's forum or branch out to dog breed boards, knitting or photography sites. Not everything has to be about caregiving!
- Close your eyes mid-day. You need to call Medicare. You need to load the dishwasher. You need to phone in that prescription. You need to...put your feet up. A ten-minute nap can make you sharper, stronger and add years to your life.
- Reward yourself. After a particularly exhausting task plan a hot tea and cookie break. Don't wait on someone else to pat you on the back.

Give a little encouragement

How to inspire family members and other volunteers to participate in respite:

- Facebook and other social media tools are an easy way to stay in touch. Update them about the highs and lows of your day. Include the humorous and touching day-to-day moments.
- Text. Stay in touch with your grandchildren, nieces, nephews and those younger than you—create a sense of family every way you can.
- Start a blog about your care journey. Keep it short, use humor and, yes, be honest—even about the tough times.
- Skype or use a speakerphone to update family and friends about health matters, but also for holidays when you can't get together.
- Handwrite or email for your loved one. Let them dictate their message through you.
- Invite family and friends over—yours and your loved ones. They might offer a few hours of respite—but more than that—their friendship is invaluable for both of you.
- Ask for help. Post it on Facebook, send out an email or ask at your church or synagogue. Ask for a three-hour break so you can go to the dentist or have lunch with a friend—start small. Show your vulnerability. People want to give, but you need to be specific.

Why join a caregiving support group?

Finding respite in your own community

The best reason to join a caregiving support group? So you will realize you're not alone. There are people right in your own community (or your online community) facing many of the same battles you face. You're free to gripe, ask questions, get on a crying jag, rant and be really, really honest.

Some people like to join an online care group forum. They like the anonymity and the freedom to jump online at two in the morning. Sometimes it really helps to talk to someone across the country—or even across the ocean—who is going through the same exact thing with their mom that you are. Plus, you don't even have to get out of your slippers. But don't forget the value of meeting folks in your own community—you can network both online and in your own backyard.

If those aren't good enough reasons, another important aspect of care groups is that you will find resources you never knew you had. There is no one central clearing house for all caregiving information that's tailored just for you. But what you find and share together are tried and tested ideas. For instance, you can learn about community resources, what's free, what's low cost and what's worth the money or time. You can also learn who's around to help and how you can get in touch with them.

One more reason to join a care group—you can actually help someone else. There are always newcomers to the caregiving experience. They're lost, in shock and grieving, and completely befuddled at how to do all this. Your encouragement and suggestions can literally change their lives. It shows you how everything you have been through is valuable.

Another perk—many caregiving support groups offer programs for your loved ones. Some offer volunteers to come to your home, others offer activities in an adjoining room or another location. As much as you need to be with other caregivers, your loved one also needs to be with people his or her age who are dealing with similar health, living arrangement and family issues (remember, you're not the only one who needs to blow off a little steam). Even though they might balk at going the first time, don't be surprised if they enjoy the stimulation of hanging out with and getting to know new people their own age.

Questions about respite care

What you should ask providers

Questions to ask respite care program and agencies:

- How are your caregivers screened? (Background checks? References?) Are your volunteers screened?
- What is the ratio of caregivers to care receiver?
- What kind of training is required for the caregivers? Is additional training offered, and if so, what kinds?
- Do you match caregivers' training and/or experiences with the family's needs or care receiver's condition?
- Who supervises the care aides? Are there nurses, or other care professionals on staff or on call?
- How is medication handled?
- Are caregivers trained to deal with behavioral issues?
- What activities/events do you provide?
- What safety precautions do you take to prevent falls? If this is a dementia care/Alzheimer's program, what additional safety measures are in place regarding wandering?
- How are emergencies handled? Who do the caregivers call?
- How many hours or days of service can I utilize?
- Are transportation, meals and snacks included?
- What costs are there?

How much does respite care cost?

Costs vary. Some states and organizations underwrite respite care, so be sure to ask. Don't give up—many organizations work with caregivers and their families to find funds for respite care. And don't think that higher cost equals better care. Check out each community, talk to the director and spend some time there observing the interactions of the staff and care recipients. Be sure to visit during the time your loved one would be there—staffing can vary greatly from day to night to weekend care.

How can I pay for or find funds for respite care?

- **Nonprofit organizations:** The United Way, the Alzheimer's Association, Parkinson's Foundation, Multiple Sclerosis Organization and other disability-specific organizations offer respite care/retreats/funding. Go to their websites and search for respite care or respite care funding, and be sure to check with your state or local chapter. You can also go to the ARCH National Respite Network (www.archrespite.org) for information about respite services and resources.
- **State agencies:** Many states offer funding for respite care. Check with your Area Agency on Aging and other aging organizations to see if you're eligible. They may also offer funding or payment, or be able to tell you what respite care organizations they work with

- **Insurance:** Generally, medical insurance doesn't cover respite care unless licensed medical professionals are involved. Long term care insurance may cover respite care—but there are usually limits of respite time and cost, so check your policy.
- **Supplemental Security Income:** Those with disability coverage may be eligible for home health care benefits. Call or go to your local Social Security office to find out if your loved one is eligible.
- **Medicaid:** Medicaid doesn't cover respite care, but some states use waivers that can apply to federal funds that help to cover (or offset) costs of respite care. Check with your state's Administration on Aging website.
- **Veterans benefits:** The Department of Veterans Affairs offers in-patient respite care for up to 30 days a year for qualified veterans. Another benefit for war-time vets is that they can ask for home care services, including respite care, for their spouses. Check with the VA website for your state's specific coverage and eligibility requirements.
- **Foundation grants:** Private foundations offer respite grants. Check into these grants online or check with your employer to see if there's funding available. The Robert Wood Johnson Foundation and the Brookdale Foundation are two organizations that offer respite grants.



About adult day programs

A cost-effective option

Adult day programs are designed for older adults and can be a cost-effective alternative to home care. Adult day programs offer a coordinated program of professional care in settings that can range from home-like environments that provide care for 8-20 elders at a time, to larger centers that service a greater number of seniors. Working caregivers rely on adult day programs so their parent, grandparent or spouse isn't left alone all day.

Adult day programs generally operate during normal business hours, Monday through Friday; however, some are open as early as 7 a.m. to as late as 8 p.m. Some programs even offer services on weekends. A nurse or other health services are on-call, as well as a number of caregivers to assist as needed.

Adult day programs exist all around the country, and are invaluable. They assist our aging population by offering daily care so that family members can either work, or take respite. They also allow our loved ones to gather, meet friends and enjoy daily activities. Some adult day programs also provide transportation, usually at an additional cost.

There are three types of adult day programs:

1. Those designed to meet social needs.
2. Those to meet medical needs.
3. Those that are disease-specific, such as Alzheimer's and dementia.

These programs offer a variety of services such as meals, activities and educational programs, and minimal medical support, such as medication monitoring and vital signs checks. Adult day health programs meet the medical needs of its participants and offer more medical services and have a nurse and CNAs on staff. They can even provide certain therapies, such as oxygen and insulin injections. Alzheimer's and dementia programs offer stimuli and activities to enhance care regimens and are designed to prevent wandering and monitor other safety aspects.

Adult day programs

The basics

How much do adult day programs cost?

Some adult day programs are subsidized by the state or by private funds, typically dependent on the senior's income level. [The average cost can vary greatly based on geographic location and level of care needs.](#) Some long-term care insurance also covers adult day programs. Medicare part B (or their health insurance) may also cover at least part of the skilled services and therapies your loved one might need at an adult day program. Be sure to ask what charges you will be responsible for and if you're charged a daily, weekly or monthly rate. Most adult day programs allow you to come half days, one day a week or the whole five days, but fees will of course vary.

How are adult day programs regulated?

Adult day programs are regulated at the state level and provide care for those with a wide range of family incomes. Many offer free or low-cost transportation to and from the program, and most programs are within your community..

Tips for selecting an adult day program:

- ✓ Tour the adult day program, hang out for a few hours with your loved one and let them get acquainted with the staff and other participants.
- ✓ Talk to the staff and administrators. Ask them what they like about working here.
- ✓ What is the staff-to-client ratio?
- ✓ Ask about additional programs: What art, health, educational and entertainment types of activities take place throughout the week?
- ✓ What types of background checks do they do for staff and volunteers?
- ✓ Eat a meal and see if you enjoy it—and if your loved one will.
- ✓ Take note of bathroom breaks and unlocked or unmonitored doors.
- ✓ Note medication times and who dispenses medicine, if they're noted and how closely they're checked.
- ✓ How do they handle natural disasters and how you can get in touch with them in case of an emergency—do they have cell phones or other ways to contact them quickly? Where would they go if they needed to evacuate?
- ✓ Ask how they handle medication complications and emergencies.
- ✓ Notice if there are upcoming events on the board, happy photographs of the participants, if they are spoken to by name and if the staff spends time with the participants.
- ✓ Do the participants just sit around and watch TV all day?
- ✓ Is the program cheerful or cluttered? Clinical or homey?
- ✓ Did your loved one find someone to talk with and relate to while you were visiting?
- ✓ Is there a garden or outside gathering area?



About senior housing

A broad spectrum of accommodations

The term “senior housing” covers an incredibly broad spectrum of accommodations, ranging from upscale, active-retiree suburban golf course communities to condo complexes to high-rise apartment buildings.

Also known as independent living, congregate living or retirement homes, dedicated senior housing developments have one common thread: they are designed and marketed to meet the needs and interests of relatively healthy men and women over the age of 55. Generally, the housing units are limited in size with senior-friendly open layouts, handicap-accessible features and low-maintenance outdoor areas. Groundskeeping and housekeeping services

may be included in monthly fees, and most communities offer onsite dining facilities, laundry facilities, transportation, fitness centers and clubhouses. Independent senior communities do not include any type of medical care or help with personal tasks like bathing and dressing, although such services may be easily arranged for an additional cost. Some senior housing units are owner-occupied, while most are rented or leased from a for-profit or non-profit organization.



What are the different types of senior housing?

While investigating senior housing, you'll find two things: a lot of buzzwords related to carefree retirement and pictures of seniors having a grand time. A retirement community may be indistinguishable from a nice suburban subdivision, while an independent living community—with units more like hotel-suite accommodations—may have the word “retirement” in its name or brochures. To make matters more confusing, both may offer similar activities and non-medical services.

That said, you can divide non-medical, non-assisted-living senior housing into these general categories:

Retirement communities, also known as 55-plus lifestyle communities

These neighborhoods can include single-family homes, patio homes, condominiums or apartments that are purchased outright by the occupants (similar to an ordinary community with deed restrictions), owned as part of a cooperative, leased from a management company or rented. Most come with a selection of lifestyle amenities such as community pools, tennis courts or golf courses. However, any medical, personal or senior-care services would be contracted separately. These communities are a growing segment of the housing market and will be addressed in more detail separately.

The fees include home rental, utilities, grounds maintenance and any service options. Medical care may be available on site, but generally is not included in fees.

Senior high-rise apartments and apartment complexes

These facilities have the advantage of being secure, well-staffed and centrally-located. Apartment rents are inclusive of all utilities, maintenance costs and use of common areas. They're generally more affordable than some other senior housing options, and many qualify for Housing and Urban Development (HUD) subsidies, allowing residents to pay a certain portion of their income on rent. Senior apartments usually have social directors and enrichment programs, and many offer transportation to doctors' offices, supermarkets and houses of worship. While most independent living and retirement communities welcome residents 55 and over, senior apartments often require residents (or one member of a couple) to be at least 62.

Independent living communities

Independent living communities usually provide a senior-safe environment with some communal activities and service options—such as meals, housekeeping and transportation. Individual units can range from freestanding homes to efficiency apartments. Units are contracted from a non-profit or for-profit corporation, and usually require a significant upfront payment plus a monthly fee.

Senior housing

The basics

Who should consider senior housing?

Senior housing is designed for able-bodied singles or couples above a designated age who:

- Wish to be relieved of the burden of home maintenance
- Want to enjoy the company of others at the same life stage
- Want to take advantage of the amenities offered at a particular facility or a particular geographic location
- Want a more convenient home to age in place
- Do not have primary responsibility for young children or grandchildren
- Do not have pets above the specified weight or number for a particular community
- Do not mind moving from their existing home
- Can afford the type of senior housing that suits their tastes

The fine print

In the United States, senior housing is made possible by an exemption in the Fair Housing Act, which states that housing developments cannot discriminate based on age, race, nationality, sex, disabilities or family status. However, the exemption says the standards around age and family status don't apply to senior housing. So, most senior housing venues restrict the number of permanent residents under the age of 55, and restrict the length of time underage visitors can hang around.

That makes perfect sense if you think of the problems inherent with pre-school children shrieking and running through the halls of a senior apartment building. Things get a little fuzzier when nine-year-old twins Suzie and Steve want to spend the summer with able-bodied Grandma and Grandpa at their resort-like retirement community in Florida.

Senior housing communities also can restrict the number and size of pets allowed, which is fine if you have a calico cat and the apartment of your dreams accepts one pet under 25 pounds. But if your dog is a 14-year-old beloved lab that you've had since he was a puppy, that might be a whole different scenario.

Finally, some able-bodied seniors choose to live in their homes, or in non-senior environments, specifically because they do not wish to live apart from an age-diverse community. So, when considering senior housing, it's important to consider what you're getting, but also, what you may be giving up. Fortunately, able-bodied and mentally-sharp seniors can make their own decisions about such a move.

Senior housing

Costs

What does senior housing cost?

Senior housing costs can be very cut-and-dry, or incredibly complex. The most important thing to remember is that senior housing does not include medical assistance. Medicare and insurance companies will not foot the bill for day-to-day living expenses.

If you purchase a home or condominium in a retirement community or independent living community, then you're faced with the same financial obligations you'd have with any other deed-restricted development. There's the cost of the house itself. If you sell your previous, spacious home before moving to a modest-sized home in a senior community, then the actual cost of the house may be covered. But all the amenities of a retirement or senior community come at a price. Be prepared for mandatory monthly fees of \$1,000 to \$2,000. If your previous home was in a luxury development with a swim club or golf club, and you were paying for lawn maintenance and other services, then you may find the monthly fees comparable. If you were living in a small town with low taxes, a community pool and the next-door-neighbor mowed your lawn, the fees could come as a shock.

Senior apartments can be HUD-subsidized or not. Any HUD-subsidized apartment will cost around 30% of a senior's monthly income, and there's generally a long waiting list for units. Non-subsidized apartments range in price from \$600 a month to as much as \$6,000, depending on market rates, apartment size and the amenities offered.

Independent living cottages or condos that are part of a comprehensive, continuing care campus usually are priced on a two-tier structure. The "A" structure means residents buy into the complex, paying an entry fee ranging from \$60,000 to \$400,000, with a monthly fee of \$1,000 to \$4,000 after that. In exchange for that financial investment, residents get a cottage or condo to call home, along with all the amenities and services offered by the community. They also get a guaranteed ticket into an assisted living unit or a nursing home unit when they need it, at no increase in monthly fee.

In other words, moving into one of these developments while you're independent and mobile is the equivalent of buying an insurance policy. You pay while you don't need expensive services, and then you benefit when you do. Of course, some residents don't live long enough to use nursing home care, or even many years of assisted living. That's how these facilities manage to subsidize those who need nursing home care for many years. There's also a "B" payment structure that requires a lower initial investment and may or may not guarantee a berth in assisted living or nursing home care when the time comes. In the event that nursing home care is available, the "B" plan resident must pay out of pocket.

Senior housing

Tips for selecting senior housing

There's no huge mystery to selecting housing for able-bodied seniors. The most important things to review are whether your loved one is ready to move, and whether he or she feels at home in the new environment. Can your loved one imagine living there happily until the day when he or she can no longer live independently?

Beyond that, there are a few things to consider:

- ✓ Do the current residents speak well of the development or apartment complex?
- ✓ Do lawns and common areas appear well-tended? Are the home exteriors well-maintained?
- ✓ Does management answer your questions clearly?
- ✓ Are all deed restrictions, services and obligations stated in writing?
- ✓ Is the corporation (profit or non-profit) that operates the facility financially sound?
- ✓ Do the amenities fit your interests?
- ✓ Can you "opt out" of certain club amenities? (There's no point in paying for the maintenance of a designer golf course if your idea of a good time is reading a book by the pool.)
- ✓ Is the complex or development near people and places you wish to visit?
- ✓ Are there medical facilities nearby? Does the development offer transportation?
- ✓ Does the complex or development feel safe?
- ✓ Do local crime statistics show a safe community, or one riddled with complaints?
- ✓ Can you afford to rent or buy the unit or home you want? Can you afford the monthly fee?
- ✓ Should your circumstances or needs change, can you extricate yourself from the lease agreement?
- ✓ If units are owner-occupied, how quickly do the resale units turn over? Do owners or owners' heirs compete with a never-ending supply of new construction in the development?
- ✓ If you're buying in to a continuing care community, are you willing to bet your savings or your existing home equity that you'll be happy there for the foreseeable future? If your feelings change, how much money will you lose?
- ✓ After assessing all of the options for independent living, you may still be confused about whether it is best for your loved one. In this situation it is helpful to consult with an expert before making this important decision. Talk to your medical provider, a geriatric social worker or a geriatric care manager (napgcm.org). If, however, you feel strongly that independent living is simply no longer safe, you may want to consider the option of assisted living, discussed on page 36.

About retirement communities

The basics

Retirement communities represent the entry level tier of senior housing. Take a drive through or past a retirement community and you'll likely be amazed at the lack of distinguishing features. Retirement communities look like any other apartment building, condo complex or suburban development in North America. The one difference is the age of the residents. Retirement communities are exempt from fair housing laws that prevent discrimination based on age or family status. As long as at least 80% of residents are over 55 years of age, a housing complex can be declared a retirement community and refuse permanent residency to young adults and families with young children.

The advantages of an “all seniors all the time” community is the camaraderie of neighbors at the same life stage, community activities and amenities geared toward the active retiree, and the removal of the distractions and issues that come with child-centered communities. In addition, retirement communities create a demographic critical mass that attracts senior-targeted service providers. So, near the entrance to a retirement community, you’ll likely find doctors, clinics, prepared food take-outs, cleaning services, car services, specialty travel agents, physical therapists, senior centers and other senior-targeted businesses. Retirement communities also make it easier to organize cooperative services, like food deliveries, cleaning, home nurse visits and carools that make it easier for retirees to stay in their own homes longer.

Retirement communities are designed for seniors who can live on their own, however, many retirement communities have on-site or nearby assisted living communities or nursing homes.

The disadvantages of a retirement community include the lack of diversity. Some active seniors find a community filled with people of all ages to be more stimulating and fulfilling. They'd rather not be in an artificially protected environment as long as they still have the ability to care for themselves. Also, moving to a retirement community means moving away from homes and neighborhoods that may still hold an emotional pull. Finally, if you live in a retirement community, you will not be able to invite your daughter and her two kids to move in with you. Most retirement communities have strict limits on the amount of time underage houseguests can visit.

If you decide a retirement community sounds like a good option, look into buying your home or condo as early in your senior years as possible. A pair of healthy 62-year-olds will be able to enjoy the golf, tennis, enrichment classes, clubs and parties offered by a community for much longer than two 78-year-olds who already need help getting around.



“ Life’s challenges are not supposed to paralyze you; they’re supposed to help you discover who you are.”

- Bernice Johnson Reagon

About assisted living

Assisted living communities offer small living spaces (duplexes, condos, apartments or studios for couples or individuals) and a variety of support services while still allowing residents the independence they value.

You can live in your own living area but also receive help with ADLs (activities of daily living) such as bathing, grooming, dressing, and other forms of personal care. Some (depending on the state where the home is located) can also assist you with medications, but don’t usually offer more extensive levels of medical care, unless they’re a part of a CCRC (continuing care retirement community). Assisted living is state regulated.

Is assisted living right for my Mom or Dad?

If you are worried all the time about the below issues, assisted living is a good option to consider:

- Do your parents need help with everyday living activities such as dressing, cooking, toileting, house cleaning, medication management or errands? Have you tried to piece together in-home care but find there are too many gaps?
- Do you worry about them falling? Setting the house on fire? Getting locked out of the house if they go to the mailbox?
- Are your parents having a difficult time keeping up with their house and yard, even with significant assistance?
- Have your parents stopped driving—or do they need to? Are you struggling to find a way to meet their transportation needs?
- Are your parents isolated? Do you worry about them being depressed? Do they go days without seeing anyone?
- Do you feel it is virtually impossible for you, your siblings and others to meet all their needs?



How much do assisted living communities cost?

With the exception of some long-term care insurance policies, most assisted living care is paid for privately, by the individual. A few states allow Medicaid funds and waivers to help defray the cost of assisted living. Check www.Medicaid.gov for more information.

The average cost for assisted living communities run by for-profit and non-profit organizations can range from \$2,000 to \$10,000 per month, with significant variation depending on location, amenities, and type of services included.

Veterans and other special segments of the population may qualify for care homes designed especially for them. Check www.va.gov and www.Veteranaid.org to see if you qualify.

Other cost considerations:

- Don't be fooled by all the bells and whistles or think a more expensive place provides better care. Nothing replaces a facility with heart, a staff that really cares and works together and one that encourages your loved one to socialize with others.
- Understand how the billing works. Does the assisted living facility bill a flat fee, or are there additional services and costs that will be added each month? Will you be informed of these charges before you get the "big bill"? If they have access to your credit card you should ensure you are able to approve the bill before they charge your card.
- How often do the rates increase—and what happens if your parent needs more care? How often have the rates increased in the past and is there a pattern?

[Ask these questions going in, find out how the billing works and check the billing often.](#)

Assisted living

How to choose a great assisted living community

- Ask friends or neighbors in the area for advice on facilities that they would recommend.
- The local Area Agency on Aging should be able to provide you with listings of communities in the area where your parent lives or wishes to relocate. Make sure you do your homework and spend time gathering as much information as you possibly can on each prospective community.
- Call to make an appointment to visit those that are at the top of your list.
- Consider going the day (or hours) before the appointment to see what “everyday life” is like.
- Does the staff welcome you and answer your questions?
- Are the buildings clean and well lit? Are the grounds appealing? Would your parent like the gardens and sitting areas? Would he or she prefer a golf course nearby?
- Would your parent feel welcome and safe here?
- Does the staff actually talk to the residents coming in and out?
- Do the residents seem to know one another?
- Find a gathering of residents, and see if they are willing to strike up a conversation. You could even buy them a piece of pie and ask them what they think of the place.
- Are people doing things? Chatting, playing cards, attending an exercise class?
- Are there activities on the board? Do you see people coming and going?
- Are there comfortable gathering places? A library? Chapel or synagogue? Activity rooms?
- Eat a meal here—is there a healthy menu? Would your loved one like the choices? Does the staff serve you in a timely and friendly manner?
- Is there a nurse on staff? What hospitals are they affiliated with?
- What would happen if your mother or father got sick and had to be hospitalized? What’s the procedure? How long until he or she could come back to the fold? Could you hire a health aide, CNA, or visiting nurse to assist your parents?
- Find out whether the community can accommodate seniors in wheelchairs or scooters. Some do not allow such means of mobility in dining halls, believing it detracts from an atmosphere of “active” senior living, or due to safety reasons.
- Determine what types of problems would indicate that the assisted living community could no longer care for your parent, such as aggressive behavior, wandering, cognitive impairment or incontinence.

Once the collective decision has been made for your loved one to move, take the time to consider the emotional impact this move will likely have on him or her. Advanced planning is always a good idea so you can help make the transition as smooth as possible.

How to help your aging family member adjust to a big move

A survey by the Mental Health Association of America states that moving is one of the top five stressors. This stress is even bigger if you're an aging adult who isn't sure you want or need to move. Even if the house no longer meets needs, change can make seniors feel vulnerable, isolated and unsure.

Tips to helping smooth a move:

1. Help your parents come to the conclusion that it's time to move and help them decide where to move. Your role is to help them figure out what's best for them. Offer choices. Be honest about your concerns. Let them waffle a bit (it's part of the process). Expect them to talk to other people and get other opinions.
2. Some seniors may not want to rush into selling their home and car. If this is practical, let them get settled in their new digs before letting go of their old life.
3. Be involved, but be sensitive. This is their journey, not yours. Some people want help moving, packing, sorting and decorating their new place, others would not enjoy that type of attention.
4. Senior moving companies can be a great resource and can provide tactical assistance to prepare for and execute a move.
5. Ask them when you can visit. Get a feel for whether they'd like weekly visits at the same day and time (something they can look forward to), or if they'd enjoy you stopping by whenever it's convenient for you.
6. Find new ways to stay in touch. Smart phones, laptops, emails, texts, care packages, books or audio books to share, Facebook, online photo sites...be inventive!
7. Don't be surprised if the first weeks are a bit tough—or a romantic high. Don't let this upset you, or think either extreme will last. Give it time. Some people love change and meet everyone in the first week and sign up for every outing and class available. Others like to nest first and dip one toe at a time into the social pool. Resist trying to push them. Let them find their own way.
8. Practice active listening. No one likes being in the "interrogation spotlight." Hang out and allow your conversation to be a natural give and take. Some people open up when they're walking or washing dishes, others are more honest on the phone when they don't have to be in the room with you—or they may want to talk to someone else about what bothers them.
9. Do something together. Let them show you the new grounds, fold clothes, or help them hang their pictures. Listen while you work.
10. Even if your loved one tends to gripe, don't dismiss legitimate concerns, such as depression, abuse or neglect. Stop by at odd hours when the night or weekend staff is there. Find a quiet place out of the way where you can blend into the wallpaper and simply observe. See if medications are delivered on time. See if the staff gets annoyed. See if calls or requests are handled promptly.
11. Be consistent. It's easy to become complacent, to visit less, to feel they're taken care of and don't really need you. However, be aware of the potential for elder abuse and neglect in communities. You may not be their primary caregiver anymore, but you're always their care advocate and your simple presence can go a long way.

If they're feeling lost and unsure, resist the urge to try to fix it. They may simply want you to be their sounding board. If you have a thought or suggestion, see if you can lead the conversation in a way that they feel they've come up with this great idea themselves.



About nursing homes

When is the right time to consider this option?

Nursing homes, also referred to as extended care communities or nursing and rehabilitation centers, are for people who have medical conditions that require 24/7 care.

They offer various kinds of medical care including dispensing of medications, wound care, different therapies, rehabilitation from surgeries and pain management.

Many doctors visit nursing homes instead of having the patient transported to them. A licensed nurse is on duty at all times, and CNAs (certified nursing assistants) and health aides assist, as well. In addition to medical care, they also offer dining,

personal care services, activities such as entertainment and holiday festivities, and opportunities for social gathering and physical and mental stimulation. Nursing homes are generally in every community and are often connected to or near a local hospital.

Nursing homes

Costs, payment and qualifying

How much do nursing homes cost?

Nursing home fees range between \$4000 and \$8000 or more per month depending on level of care needed, location, and other determining factors.

Costs for long-term care in a nursing home can be covered by Medicaid (for those who meet income eligibility and care criteria for nursing home care), long-term care insurance, Veterans benefits (specifically for honorably discharged veterans in Soldier's homes or Veteran facilities) and private pay funds.

How do you pay for a nursing home?

Medicare generally does not cover long-term stays in nursing homes. Medicare does cover some skilled and rehabilitative care under the skilled Medicare benefit. Medicare may pay for a nursing home post-hospitalization for rehabilitation purposes for up to 100 days. Most people pay for a nursing home beyond their skilled benefit (over 100 days) with:

- Medicaid (for individuals who are considered indigent under the state/federal guidelines).
- Long-term care insurance.
- Veterans benefits (for individuals who meet the criteria for honorably discharged veterans and are using a VA facility).
- Private or self-pay.

How do you qualify for nursing home care?

Nursing homes are often recommended by your loved one's physician. Many nursing homes have their own staff of doctors, so patient care will then transfer over to the home staff. For Medicaid-eligible care recipients, there is an assessment that qualifies your loved one for nursing home placement based on impairments with activities of daily living.

Nursing home

Choose the right nursing home

Use your five senses

SEE:

Do you see real care going on? Is it well lit inside and out? Are residents ignored when they call or ask for help? Is the staff friendly and helpful? Is there a community calendar? Are the nurses or care stations organized? How are medications and cleaning supplies stored? Is there a garden or outdoor area? Can you find a chapel or place for contemplation? Do the other residents look clean, shaved and content?

HEAR:

Do you hear conversations? Do people sound happy and engaged? Is the staff interacting with the residents? Are calls answered in a timely manner? Do you hear moans that go unanswered? Are music, movies or entertainment available?

SMELL:

Do you smell urine? Body odor? Old food? Do you see the cleaning staff? What about on weekends? Are the sheets changed after they're soiled? Are accidents or spills cleaned up quickly? Is the restroom clean, including under the seat?

TASTE:

Visit the dining room or ask to see the kitchen or food. Are the meals tasty and do they get picked up soon after eating, or do trays sit around for hours? Will your loved one have access to snacks and water and other drinks?

TOUCH:

Are surfaces cleaned regularly to prevent MRSA (a type of highly infectious staph infection common in health care settings)? Are baseboards, handrails and doorknobs wiped throughout the day? Are the residents touched, hugged, laughed with and handled gently and respectfully during dressing and bathing times? Is their privacy respected by both staff and other residents? Do people simply wander about?

Can you create and encourage a care community?

Will you be encouraged to stop by any time of the day or night? Can you find ways to support the staff? Can you treat them to a pizza party on a holiday or bagels one morning? The more you show you care, not only about your loved one but also about their care community, the better care your loved one will receive. Get to know who comes and goes out of your loved one's room at all times, including the maintenance staff.

What if I am not pleased with the quality of care or my loved one doesn't like it there? How do we find a new nursing home?

Don't ever stop being a vigilant care advocate—the staff or level of care can change months, or even years, from now. Follow your gut and listen to your loved one. Check often. Communicate with the staff, including the director of nursing and facility administrator, when needed. If your concerns go unheeded, contact your long-term care ombudsman, through the state agency that oversees elder affairs.

Ombudsmen offer a way for residents and their loved ones to voice their complaints and have their concerns addressed so that residents can live with dignity and respect. You do have choices. You don't have to keep your loved one in a place that feels unsafe or just simply doesn't work, for any number of reasons. Always have a backup plan and check other nursing homes in the area to see if they have a wait list or accept emergency/quick placements.



About continuing care retirement communities

As your needs change

Continuing care retirement communities are just what their name says they are: communities that offer various levels of housing and care, so the community changes with you as your needs change.

They typically offer individual homes or apartments, assisted living and a nursing home all in one place. And residents can “move” within the community as needs change.

Continuing care retirement communities

The basics

Levels of care you can expect in a continuing care retirement community:

- Independent living (also known as residential living) for those who aren't ready for assistance.
- Assisted living (sometimes called extended living) that offers assistance with daily living activities that might include personal care, home care, dining options and transportation.
- Nursing home and rehabilitation care (short- and long-term) for those who need medical attention and round-the-clock care.
- Memory care for those with Alzheimer's or other forms of dementia, and other brain disorders.

Who can benefit from continuing care retirement communities?

CCRCs are for any senior—single, married or partnered, widowed, those in great health or those experiencing health challenges. It's most helpful if residents move into the community when they're at the house/condo/apartment stage and can enjoy the freedom, peace of mind and variety of amenities that will enhance their retirement years. That also means that as their needs shift to the CCRC's other living and care levels, those transitions will be easier because the resident already is a part of the community and feels established.

CCRCs are also helpful for those with spouses or partners who have different care needs than their own. One spouse can stay in a house or condo and yet be easily able to see their spouse or partner who needs a higher level of care. Often, spouses and friends can dine together, attend events and even continue to enjoy mutual friends, even if their care needs differ. For those who are single, widowed or don't have adult children or other family members, CCRCs offer not only continuing care benefits but also the social connections we need and that are sometimes harder to make as we age.

Upon entering a CCRC residents sign a contract. There are several different kinds of contracts or levels of care one can select. CCRC contracts include extensive, modified and fee-for-service clauses. You get to choose how much care you think you'll want and need. You'll get your choice of housing options, care services, and amenities. Be sure to consider not only where you or your loved ones are today in terms of health needs, but what the situation might be five or ten years down the road. Ask if residents can change their level of care and make sure there's a cancellation clause that gives you a breakdown of fees and refunds available.

Continuing care retirement communities

Costs and tips

How much do continuing care retirement communities cost?

There's usually a considerable entry fee, as well as monthly fees. Fees range widely depending on the amenities offered. CCRC entry costs may range from \$40,000-\$400,000, with additional monthly fees that range from \$600 to \$4,000, depending on care.

Questions for seniors when choosing a CCRC:

- Do I want to live near my current location?
- Am I free to visit family and friends on weekends and take other trips? Are they free to visit or even stay with me? Are young children welcome to visit?
- Will I continue to meet friends, have the same doctors and attend the same religious services if I stay nearby?
- Do I want to move to another city or state so I can be closer to other family members or be able to enjoy nicer weather?
- What types of living/care arrangements are available where I want to live?
- How much personal space do I really want or need?
- Do I want a kitchen and, if so, how big? Is there a place for dining/meals when I don't want to cook?
- Do I want property/grass/a patio or ground floor living?
- Are there cleaning services available?
- Would I prefer a view and enjoy an elevator?
- Are the grounds and buildings well kept? What amenities appeal to me such as tennis courts, golf courses, walking trails or a workout room?
- What transportation do they offer if I choose to stop driving?
- What's their transportation schedule for shopping and excursions?
- What are the average age/gender/religious affiliations/education/life experience and other interests of the residents? What connections might I have with other residents?
- What happens when I need other types of care? Will I need to change doctors or does the community have their own in-house medical staff for emergencies?
- How do they run background checks on their staff? What level of offense is acceptable?
- How do I handle issues I might have with the staff?



“No matter how they make you feel, you should always watch elders carefully. They were you and you will be them. You carry the seeds of your old age in you at this very moment, and they hear the echoes of their childhood each time they see you.”

- Kent Nerburn,
Letters to My Son

About end-of-life care

Hospice

Hospice care is for people who are facing the end-of-life or have a life-limiting diagnosis.

Hospice organizations can be for-profit or non-profit and are located throughout the world. Hospice can come to you or your loved one's home and provide for care needs. Many also have hospice care centers for those who need more skilled nursing care, or for those who do not have family members or friends to care for them during this time. Additionally, many organizations provide hospice care in local nursing homes.

Hospice also offers palliative medical care, or pain management and addresses the emotional and spiritual aspects of facing end-of-life with compassion and dignity. Hospice also supports the family and loved ones by educating and informing them about the dying process providing them with grief and bereavement counseling, and enabling you to spend quality time with your loved one.

End-of-life care

Cost and benefits

How much does hospice cost?

Hospice cost is covered under Medicare Part A (hospital insurance), Medicaid, long-term care insurance and other types of private insurance. You (if you have Durable Power of Attorney that allows you to make medical decisions on their behalf) or your loved one will sign a statement choosing hospice care instead of routine care. Medicare will still continue to cover any health problems that are not related to your loved one's terminal illness.

Benefits of hospice:

- Hospice will cover the cost of your loved one's medications.
- Hospice also covers medical supplies such as a hospital bed, walker, incontinence supplies and other supplies that may be needed.
- Your loved one will be given a hospice team of a nurse, a social worker, a chaplain, a CNA and home health aides. You and your loved one will have 24-hour access to support.
- Hospice can allow your loved one to come home to say goodbye.
- If being home isn't comfortable, hospice allows for a natural setting whether at another home, a nursing home or in a hospice care center.
- Hospice offers a variety of supplemental services such as chaplains, spiritual advisors, music or pet therapy, last wishes fulfilled, meditation gardens, support groups and other end-of-life quality opportunities to ease and comfort the patient and their loved ones.

*****Note:** Hospice only covers pain management and comfort measures. It does not cover treatment to cure an illness. Family members will receive information and assistance as well as grief and bereavement counseling. An individual can only utilize one hospice organization at a time. The cost of room and board at a nursing home or hospice care center is not covered and must be paid for out of pocket, by your long-term care insurance, or by Medicaid if the individual is eligible.

Hospice

Types of questions to ask

Are there different types of hospices— or just one?

Hospice isn't just one organization. There are many, and you may have several types of hospices to choose from, depending on the size of your city or community. While hospices are required to have a multi-disciplinary team consisting of physicians, nurses, social workers, aides, spiritual care givers and bereavement counselors, they are not created equal. Be sure to investigate and find a hospice that meets your care needs and expectations.

Questions to ask before deciding on a particular hospice:

- Is this hospice for-profit, non-profit or government-operated? Who owns this hospice? Is it a corporation? Can I check with the Better Business Bureau or get some other rating?
- How many hospice patients do they care for throughout the community?
- What's the staff-to-patient ratio per day and per shift?
- Whom do I talk with if I have a concern?
- How many licensed nurses do they have on staff in a 24/7/weekend time period? What other staff members do they have?
- Do they have a full-time social worker? Therapist? Chaplains of varying faiths?
- What services are available? What happens if my loved one needs dental care, skin care or some other treatment not related to their terminal illness? Are these things covered? Are there any additional costs I should know about?
- How are patients and family members/caregivers informed of patient care or changes? What services will family members/caregivers be responsible for providing?
- What resources are available for in-home hospice care?
- How long can my loved one stay at a hospice care center? Is there any additional cost?
- How often will hospice caregivers and staff come to my home and how long do they stay?
- Can I take respite overnight, or for several nights? If so, how does that work?
- Is there a contract I have to sign? Do I receive paperwork listing what I can expect regarding my loved one's care?
- How is pain managed and will I need to monitor this?
- What happens at the end? Will I be left alone with my loved one or can I expect support?
- If my loved one passes away while I am at home alone, who do I call?
- What benefits might I receive in the days, weeks and months after my loved one passes? Will hospice continue to offer support to me and other family members?

The rewards of caregiving—a personal epilogue

By Jody Gastfriend, LICSW/ VP of Senior Care Services, Care.com

“Where is Dad?” I remember asking, after my family and I had spent a good part of the day in synagogue during one of the Jewish high holidays. My brother checked the men’s room and I walked around asking family friends if they had seen my father.

It was a beautiful fall day, and my father loved to take walks along the old railroad track behind the synagogue that had recently been converted to a bike trail. And then he emerged from the woods which marked the perimeter of the winding, scenic bicycle path. My father, in his suit and tie who a few hours earlier looked so dapper, now appeared slightly disheveled, agitated and confused.

“Dad, where have you been? We’ve been looking all over for you!” I exclaimed. In an angry tone, he answered, “I went to pick up my dry cleaning!”

That was 15 years ago and it marked the beginning of our family’s journey as caregivers. As a social worker with more than 20 years’ experience in the eldercare field and as an adult child of a father with progressive dementia, I know the challenges, burdens and uncertainties that caregivers face every day. I understand the difficulties of juggling my own family and work responsibilities with the demands of caring for a parent who cannot care

for himself. I have heard hundreds of stories of people like myself, who find themselves in a role that they did not anticipate or prepare for. At times isolated, uncertain, sad and hopeful, family caregivers move forward with compassion and strength and are the centerpiece of our nation’s system of long-term care.

Over the years, my family has struggled with many difficult decisions regarding my father’s care, faced numerous obstacles within the health care system and tried to balance my father’s needs with my mother’s ability to care for him safely at home. Four years ago, we made the difficult decision to place my father in a nursing home. Making effective decisions about the care of a loved one often takes more time than anticipated and requires an understanding of the long-term care system that many caregivers lack. Care.com’s Senior Care Guide is meant to be a valuable resource, providing important information about types of care, costs, resources and the complex and ever-changing landscape faced by caregivers throughout their journey.

While a tactical approach to caregiving is essential in providing the knowledge and tools to make informed decisions, caregiving is so much more than checklists and roadmaps. It is an opportunity to redefine our relationships with our parents and loved ones, learn from them as they endure

chronic illnesses and the infirmities of old age and embrace the precious time to just be together. Our family is fortunate in many ways. My mother, who visits my father every day in the nursing home, finds ways to remain engaged with my dad through story-telling, humor, reminiscing and compassion. Despite the toll that dementia takes, my father has taught me many things as he has bravely retained his personhood. Through his kindness, loving nature and remarkable ability to live in the moment, my father has demonstrated that quality of life can persevere despite a devastating illness and that loving bonds can, in fact, be strengthened as the caregiving torch is passed from one generation to the next.

As you approach your own unique caregiving journey, I hope you can find the support and guidance you need to deal with the emotional, physical and logistical challenges ahead. And while there will certainly be hurdles, may you also cherish the small rewards: a sweet smile of appreciation, a warm embrace and the unspoken recognition that your efforts as a caregiver will enrich and sustain the lives of those you love.