

Finding Your Way

A Guide for Navigating Healthcare and Long-Term Care



The material in this guide has been prepared by VistaLynk and brought to you by Johnson Investment Counsel.



Introduction

Caring for a loved one or parent as they age is part of our human journey. It is a role that can be very rewarding. It can also be a time filled with significant challenges, particularly when a loved one faces illness or disability. Knowing how to *find your way* through a relatively complex and often fragmented care system can be helpful. This guide provides tips and information to better prepare you for what is needed to navigate the health care and long-term care systems with greater understanding and clarity.

Navigating the Healthcare System

As a person ages, routine medical care is vital to help diagnose and treat diseases that could significantly impact their wellbeing. However, for some older adults going to the doctor is challenging. Lack of transportation or limited mobility can make it difficult or impossible to get to an appointment. Someone with cognitive impairment may forget to schedule or keep track of appointments. In some cases, fear or embarrassment may cause a person to avoid going to the doctor altogether.

As a caregiver, you can make it easier for a loved one to navigate the healthcare system. You can provide the necessary physical, emotional, and moral support. Knowing what essential documents and information you should have on hand will also provide comfort. Being organized is one of the keys to successfully navigating the maze of systems and supports for aging loved ones. Having important documents and other relevant medical information gathered and readily accessible empowers you and reassures your loved one.

Collecting Important Information

The first step in getting organized is reviewing your loved one's legal and medical documents to ensure they are up-to-date and in order. If a legal document is needed, your loved one may create, change, and execute these documents if they are mentally competent. If there are concerns about cognitive decline, it is important to consult an elder law attorney early, as legal decision-making capacity may change over time.

Certain documents allow you to manage a loved one's financial and health care needs. These are a Health Care Power of Attorney, a Durable Power of Attorney, and a HIPAA Release Form. An elder law attorney can draft the legal documents. The HIPAA compliant consent forms are available at most doctors' offices.

Along with those documents, other information may be helpful to have readily accessible, such as copies of Medicare and supplemental insurance cards, a list of doctors and specialists with contact information, and an updated list of current medications and dosages. Using digital tools, such as patient portals or shared caregiver apps, can help keep this information organized, accessible, and easy to update as needs change.

Legal and Medical Information Checklist

- ☐ *Durable Power of Attorney (POA)*: Names someone to make decisions and manage finances for an incapacitated person.
- ☐ *Health Care Power of Attorney*: Allows someone to make medical decisions on behalf of an incapacitated person.
- ☐ *HIPAA Release Form*: The Health Insurance Portability and Accountability Act of 1996 (HIPAA) requires protecting sensitive patient health information from being disclosed without the patient's consent or knowledge. All healthcare providers need a HIPAA release form to be on file to discuss health information with anyone other than the patient.
- ☐ Health Insurance information
- ☐ Contact information for doctors and specialists
- ☐ List of current medications and dosages

Medical Appointments

Accompanying a loved one to their doctors' appointments can be reassuring for you and them. Not only can you be there to lend your support, but you can also be there to be another set of ears. Sometimes loved ones have difficulty remembering important details regarding their care or treatment plan. Regularly attending any doctors' visits also helps develop a relationship with your loved one's medical team. It can be beneficial in an emergency or if your loved one's health deteriorates.

Technology and pharmacy-based tools can provide added support and peace of mind. Smart pill dispensers can help ensure medications are taken at the right time, while pharmacy synchronization programs allow all prescriptions to be refilled on the same schedule. Automatic refill and delivery services can also reduce the risk of missed doses and eliminate the need for frequent pharmacy visits.

Telemedicine has emerged as a popular alternative to going in-person to a doctor's office. Virtual office visits are a good alternative for those with limited mobility or difficulty getting transportation to their appointments. Virtual visits can also be less disruptive or disorienting to those with cognitive impairment. Medicare covers certain telehealth services, so be sure to check your loved one's plan.

Medication Management

Medication management can be one of the most significant concerns for caregivers. Many cannot be physically present to ensure a loved one takes medications properly. Taking medications correctly and on time ensures effectiveness and reduces the risk of adverse effects. There are a few ways to make medication management more effective.

Navigating the Long-Term Care System

While routine medical care addresses acute illnesses, long-term care includes the ongoing services that support older adults as they age. These services can range from home meal delivery and transportation to assisted living and nursing care facilities. The services available to help a loved one can vary by location. In some cases, a person must meet specific financial and clinical eligibility criteria for benefits.

It is crucial to plan for long-term care needs before a crisis. Emotions can run high during an emergency, and options may be limited. It is a good idea to start the conversation with a loved one when they can still voice their desires and participate in the planning process. Creating a plan together shifts the burden away from one person making all the decisions. It also avoids having a person feel like they have no control over their own lives. Being aware of a loved one's wishes and desires allows everyone to work toward a common goal.

How to Know When a Loved One Needs Help

Often, changes happen gradually. Paying attention to small shifts can help you intervene earlier. Most people find conversations about future care needs somewhat easier when young and healthy. People do not want to admit when the time has come to ask for help or assistance. So, how do we know when we need to get involved in a loved one's life? How do we know how to intervene in a way that still honors the loved one's need for independence and self-determination? There are several signs that may indicate a loved one needs some help.





Developing a Plan of Care

Assess Everyday Tasks

A care plan is a crucial tool that will help keep you organized. It makes sure everyone in the care circle understands what is needed to support your loved one's well-being. A care plan should encompass all aspects of life, such as home environment, self-care abilities, social-emotional wellbeing, physical health, spiritual practice, medical needs, and finances. Having a plan in place will allow you and the other care partners to adapt more easily as your loved one's situation changes.

To begin, you will need to assess your loved one's ability to carry out the routine, everyday tasks, known as the Activities of Daily Living (ADLs). You can use the Personal Care Plan (*located on page 6*) as a guide. When you go through the items on the list, note areas where your loved one needs help and who might be able to help with those needs.

Assemble Your Team

Once you have identified areas of need, you can locate resources or people to help address them. A team-based approach shifts the burden of care from you alone and allows others to share the responsibility. When it comes to complex issues like finances and legal matters, rely on the expertise of professionals. For medical concerns, be sure to consult your loved one's physician and other medical professionals.

As a primary caregiver, you are handling a great deal of responsibility. Having adequate emotional support is very important for your own health and wellbeing. Be sure to identify people you can talk to about your thoughts and feelings, whether friends, family, or a professional counselor. Having an outlet can help relieve the stress you may feel throughout this process.

Reassess the Plan Periodically and Determine the Need for Adjustments or Modifications

It is important to remember that caring for an aging loved one can be unpredictable and fluid. In some cases, they may need help only for a short, temporary period. In other cases, they may need assistance over a longer duration. You should periodically evaluate the care plan and make any adjustments as needed. *Whenever possible, be sure to include your loved one in the reassessment process.*

Valuable Online Resources

- [Eldercare Locator](#): Connects older adults and their caregivers with trustworthy local support resources.
- [Benefits Checkup®](#): Comprehensive, free online tool that connects older adults with benefits they may qualify for.
- [National Council on Aging](#): Online resource to find benefits, choose a Medicare plan, prevent falls, and plan for a healthy and secure life.
- [Centers for Medicaid and Medicare](#): Find and compare nursing homes, hospitals, and other providers.
- [CareScout](#): Provides a Cost of Care calculator to help estimate the cost of long-term nationwide.

Personal Care Plan

Activities of Daily Living (ADLs)

Bathing
Dressing/Grooming
Going to the bathroom
Getting in/out of bed or chair
Continence
Eating

Area of Concern?

Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐

Solution/Provider

Instrumental Activities of Daily Living (IADLs)

Telephone use
Shopping
Cooking
Housekeeping
Laundry
Transportation
Medication management
Finances
Computer use

Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐

Social Activities

Maintaining current activities/personal interests
Being social - by phone/computer/in-person
Attending church services
Living arrangements

Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐

Physical Condition

Sleeping issues
Hearing loss
Vision loss
Speech problems
Difficulty breathing
Diet & nutrition

Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐

General

Hazards in the home
Mental health or behavioral concerns
Cognitive issues
Driving safety
Weight loss
Loss of balance or strength
Mobility
Abuse/fraud risk

Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐
Yes ☐ No ☐

Notes:

In-Home and Community-Based Services

It may come as no surprise that most people prefer to live at home, or age-in-place, for as long as possible. Several services can help older adults maintain safety and well-being at home. These include a wide range of services such as meal delivery, housekeeping, home repair, transportation, bill paying, and home care assistance. Unfortunately, the availability of these services varies greatly depending on a person's location. Online resources can help you locate the specific services available in your loved one's area.

Home Health Care vs. Home Care

Although the services sound very similar, there are significant differences between *home health care* and *home care* services. Home health care companies are licensed to provide professional medical care, such as nursing care, occupational and physical therapy, and speech therapy. In addition, they can assist with medication management, monitor health, and provide wound care.

Alternately, home care companies are only allowed to provide non-medical services. These non-medical services can include transportation to and from appointments, meal preparation, errands and chores, housekeeping, companionship, bill paying, and other non-clinical care. Home care providers can also assist a person with dressing, bathing, and using the bathroom.

Home Health Care

- Licensed to provide professional medical care
- Patient must meet eligibility criteria
- Help with dressing, bathing, grooming
- Provide physical, occupational, speech therapies
- Medication management
- IV therapy, injections, wound care, pain management
- Medical tests and monitoring
- Visits are a few days per week, depending on doctor's orders
- Covered by Medicare, Medicaid, private insurance
- Length of service depends on eligibility and doctor's orders

Home Care

- Non-medical supportive care
- No eligibility requirement
- Help with dressing, bathing, grooming
- Assistance with everyday tasks, such as meal preparation, errands, cleaning, laundry
- Medication reminders
- Transportation
- Companionship
- Help with toileting and transferring
- Caregiver visits range from a few hours to 24/7
- Paid out-of-pocket, long-term care insurance, or Medicaid
- Length of service depends on need and patient's budget

Below are some additional types of community-based services found in many communities. To find specific services in your area, click the links below.

- [Adult day programs](#)
- [Meals-on-Wheels](#)
- [Senior centers](#)
- [Senior Companion programs](#)
- [Legal assistance](#)

The cost for these services varies depending on the type of care needed. In some cases, individuals pay for these services directly from their own funds or "out-of-pocket." In other cases, Medicare, Medicaid, the Veterans Administration, or a long-term care insurance policy pays some or all the cost of care.

Community-Based Services

Aside from health care and home care, there may be other community-based options to help a loved one remain at home. Some of the services provide opportunities for enrichment and socialization, while others assist with care needs and transportation. Here is a list of services and programs found in many communities.



Residential Options

This decision is often emotional and complex, involving both practical and deeply personal considerations. Research suggests that it is likely that most people will need some type of long-term care at some point in their lives. When a loved one can no longer live independently, the decision on where they should live and what level of care is needed can be daunting. The idea of moving can be a highly emotional time for all involved. Because the cost of residential long-term care is high, some may need to sell their homes to pay for care. Selling real estate and disposing of personal items can take some time. It is a good idea to prepare for this ahead of time.

Continuing Care Retirement Communities (CCRCs)

Continuing care retirement communities (CCRCs) are self-contained campuses that include multiple levels of care. Care may include independent living, assisted living, nursing care, and memory care. CCRCs appeal to many families because the different levels of care are available if needed. Residents also have access to rehabilitation services after a hospitalization.

The fee arrangements for CCRCs vary and sometimes include both a monthly fee and an entrance fee. The monthly payment is based on the size of the unit. In some cases, a portion of the one-time entrance fee is refundable when the resident moves out. There can be year-long or longer waiting lists for available units. You may want to consider putting your name down on the waiting list to ensure having availability when needed.

Independent Living (IL)

In independent living, residents typically reside in separate apartments or stand-alone units. Individuals can come and go as they please with little or no supervision. There are minimal care services provided. However, there may be on-site amenities, such as pools, security, and parking.

Assisted Living (AL)

In assisted living, residents have individual units. Residents receive personal assistance, meals, supervision, activities, and other health-related services. Assisted living is an alternative for people who may need help with dressing, bathing, eating, and toileting but do not require intensive medical or nursing care.

While some assisted living facilities exist as part of a CCRC, some may be stand-alone. Licensing requirements for assisted living facilities vary by state. Residents typically pay a monthly fee and an additional amount for extra services. Costs can vary widely depending on the size of the living areas, services provided, type of help needed, and geographic location.

Skilled Nursing Facilities (SNF)

Skilled nursing facilities are medical care units licensed by each state. These units provide 24-hour care and assistance with personal care, supervision, medication management, medical therapies, and rehabilitation services. Skilled nursing care is for individuals who require round-the-clock medical care.

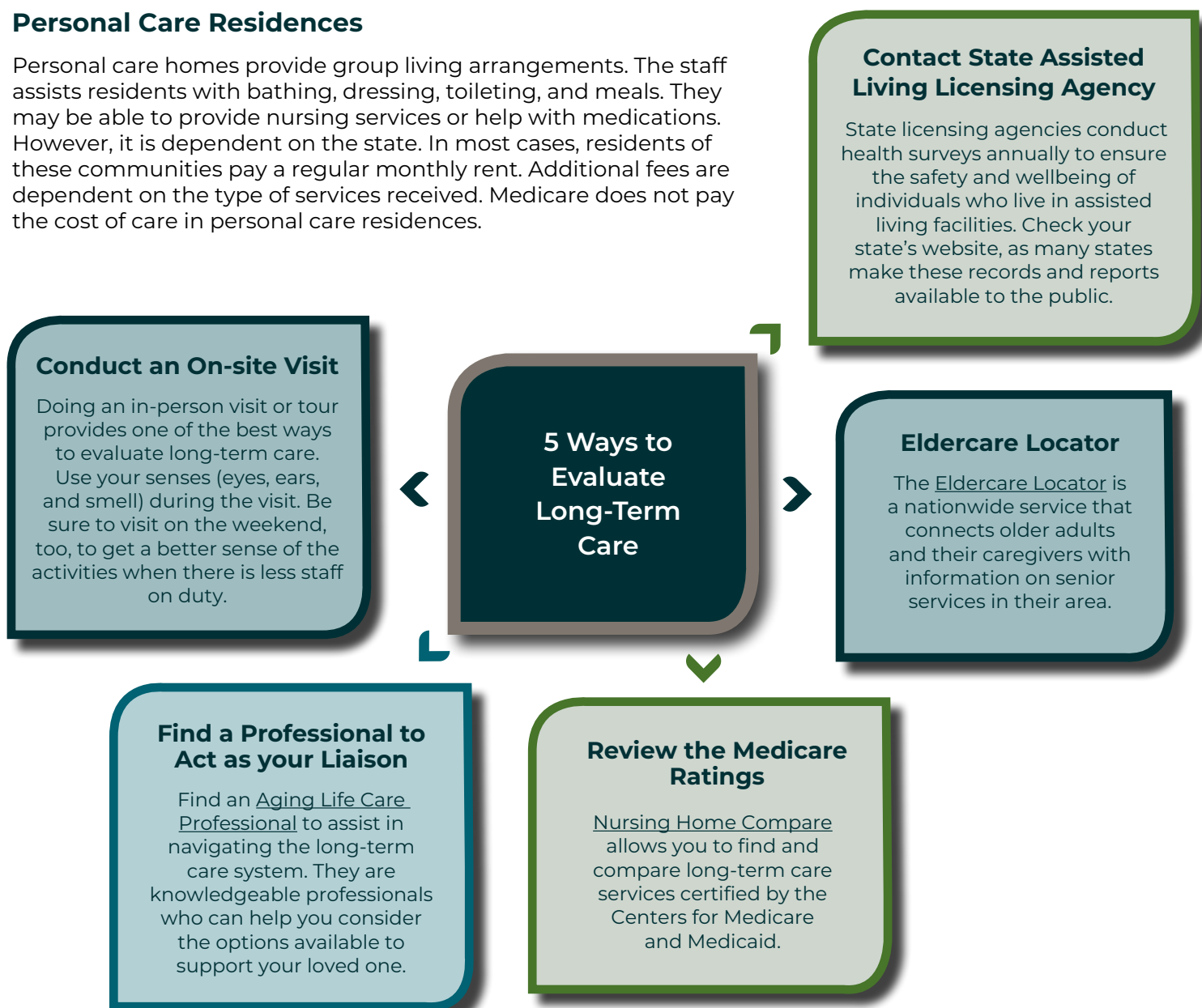
Since skilled nursing care is the most intensive level of care, it is often the most expensive. Paying for nursing home care can come in a variety of forms. Many people who enter nursing homes begin by paying for their care out-of-pocket. If individuals use or spend down all their financial resources during their stay, they may become eligible for Medicaid. Applying for Medicaid is a complicated process. It is wise to consult with an elder law attorney on appropriate Medicaid planning.

Memory Care Units (MCUs)

Memory care units are specialized, secured units designed around the needs of individuals living with dementia or Alzheimer's Disease. These units provide structured activities so that residents can socialize and receive necessary medical services. Memory care units offer private or semi-private rooms. The cost of this level of care can be slightly higher than skilled nursing care.

Personal Care Residences

Personal care homes provide group living arrangements. The staff assists residents with bathing, dressing, toileting, and meals. They may be able to provide nursing services or help with medications. However, it is dependent on the state. In most cases, residents of these communities pay a regular monthly rent. Additional fees are dependent on the type of services received. Medicare does not pay the cost of care in personal care residences.





Other Considerations

Cognitive Decline

You may notice that a loved one is experiencing memory loss or confusion. They may have difficulty remembering names or words, keeping track of appointments, or even how to perform routine tasks. There can be several causes for this, including underlying illness or medication interactions. While some memory loss is not unusual in later life, it can be concerning when it interferes with a loved one's ability to take care of themselves.

If a loved one suffers from significant memory loss, they may need an evaluation to determine the severity of the impairment. A neurologist or other medical professional can perform a formal cognitive assessment. Tests, such as MRIs, may also be done to examine the extent of damage within the brain. Upon official diagnosis, doctors may suggest treatments to slow down the rate of decline. They may also provide general expectations, though progression varies by individual.

Paying for Long-Term Care

The cost of long-term care depends on the type of care and duration needed, the provider used, and where a person lives. Other factors can affect the price. Some providers charge more for services provided in the evenings and on weekends and holidays. In residential settings, it may cost more to receive additional assistance.

Private Pay

Private pay, or out-of-pocket, is when a person pays for long-term care services from their income and savings. Unfortunately, not everyone can pay for care out-of-pocket since the cost of care can be quite expensive, especially over a substantial length of time. The cost of care in a semi-private room in a nursing home costs almost \$100,000 a year, with an average length of stay being 2½ years. In this case, a person would need to have \$250,000 in income and assets to cover the cost of care.

It is important to discuss long-term care financing needs with a financial advisor as early as possible. They can run projections to help determine the ability to pay for long-term care. In addition, they can discuss the benefits of other financial vehicles - such as long-term care insurance, reverse mortgages, and annuities.



Long-term Care Insurance

A long-term care insurance policy can help pay the cost of long-term care, including skilled and unskilled care. The terms of policies can vary widely. Some policies may cover only nursing home care. In contrast, others may include coverage for a whole range of services, such as adult day care, assisted living, medical equipment, and informal home care. In addition to traditional long-term care insurance policies, some whole life insurance policies have riders that allow benefits to be used for long-term care costs. It is important to discuss this option with a financial professional.

Medicaid

Medicaid is a joint federal and state program that helps cover the cost of medical and long-term care for individuals with limited income and financial resources. Eligibility is based on financial and functional criteria that vary by state, and may include coverage for nursing home care and certain home and community-based services. If a person's income or assets exceed eligibility limits, they may need to pay for care out-of-pocket and "spend down" assets to qualify. Many states also enforce a look-back period, typically up to five years, to review asset transfers. Because Medicaid rules are complex and vary by state, consulting an elder law attorney can help ensure appropriate planning.

Veterans' Benefits

The Department of Veterans Affairs (VA) offers several programs to support eligible veterans and their spouses. Some veterans may qualify for pensions or other benefits that can help offset healthcare and long-term care costs. In addition, the Aid and Attendance benefit provides additional financial support to those who require assistance with daily activities such as bathing, dressing, and personal care. Eligibility is based on service history, financial need, and level of care required. You can learn more about VA benefits and eligibility requirements at [VA.gov](https://www.va.gov).

Final Thoughts

There are many aspects to consider when providing support to an aging loved one. At times, the aging landscape can seem overwhelming and difficult to manage. This guide is designed to help you feel more prepared, informed, and confident as you move forward. Taking the first step can make a meaningful difference for you and your loved ones.