

# The Senior Helpers Aging Advantage Series<sup>SM</sup>



## GUIDE 4: NAVIGATING THE CARE AND CAREGIVING JOURNEY



  
Senior Care, Only Better.

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# Developing a Plan is a Powerful First Step

Research indicates that few individuals are ready for the challenges, complexities, and unpredictability of managing the care for themselves or a parent or loved one. Understanding the various stages of care empowers people to make informed decisions on how to offer better support that enhances the quality of life for an aging loved one.

## How to Be Informed

- 1 Decide what matters most to you or the care recipient and understand both immediate and potential needs.
- 2 Understand the care options you can access.
- 3 Understand the providers and the services they can provide.
- 4 Have a clear definition of what excellence means.

## How to Be Prepared

- 1 Determine what is important to you or the care recipient and their Circle of Care. Note the differences which will then need to be reconciled.



Emotionally



Legally



Geographically



Medically



Financially



Spiritually

- 2 Proactively decide how you or the care recipient want to navigate the continuum of care from independent living to end-of-life care.
  - » What are your/their needs and preferences (likes and dislikes)?
  - » How do you want to make decisions? Who should make decisions on your/their behalf? What are the relative priorities?
  - » Play out "What if?" scenarios.

## Understanding How Care Needs Evolve



**No urgent needs:** These individuals want to stay in their current home but are not experiencing immediate health or mobility issues. They may see an opportunity and/or have a desire to be proactive and plan for their future needs.

**Progressive condition-based needs:** These individuals suffer from chronic or progressive conditions that will require special modifications for staying at home. They are usually aware of their needs but meeting them is not necessarily urgent. Many have chronic conditions such as arthritis, macular degeneration, diabetes, Parkinson's, Alzheimer's/ Dementia, depression, and lung/heart disease that challenge them and impact their ADLs and IADLs. Keep in mind changes merely due to aging.

**Traumatic-event needs:** These individuals experience an abrupt or immediate change, such as due to a medical event, fall, surgery, or the death of a spouse/partner, that demands adjustments in the living environment.



# Four Factors to Guide Care Decisions

There are various stages of care from independent living to end-of-life care. It's helpful to have a holistic approach to addressing the progressive nature of needs and how they change throughout the aging journey.



## Factor 1



### What type of care do I need?

#### What are my needs and wants?

- » Do my needs present life choices for me or those I depend on?
- » Do I need professional care, or will my family or others in my Circle of Care support my needs?
- » What types of professionals provide care? How do they differ, and what are the key factors for each type?

## Factor 3



### What do my options cost?

- » What is my time horizon? What's important to consider in the short, medium, and long-term?
- » What is included?
- » What is my budget?
- » Does my insurance pay for this?
- » How do I protect assets for my spouse or heirs?

## Factor 2



### Where do I live?

#### What are the tradeoffs?

- » What are my options for aging in place?
- » What are the different living options, locations, services, and care?
- » What options are appropriate for me? Do I pick based on my current needs or what I anticipate them to be in the short-term or long-term future?
- » There are two of us and we are at different acuity (capability) levels. What then?

## Factor 4



### What resources are available?

- » What people and professionals are available to help?
- » Are there public programs?
- » Does it vary by town and state?

# Signs that Assistance May Be Needed

Physical Health	YES	NO
Trouble with activities of daily living (ADLs) such as bathing, dressing, toileting, grooming, or eating?	<input type="checkbox"/>	<input type="checkbox"/>
Chronic health conditions (such as diabetes, Parkinson's, Alzheimer's/Dementia, depression, and lung/heart disease) that require ongoing management?	<input type="checkbox"/>	<input type="checkbox"/>
Frequent or unexplained weight loss?	<input type="checkbox"/>	<input type="checkbox"/>
Sensory problems (loss of hearing, sight, smell, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>
Gait challenges, difficulty walking, or recent accidents/falls?	<input type="checkbox"/>	<input type="checkbox"/>
Other physical limitations (temporary or permanent)	<input type="checkbox"/>	<input type="checkbox"/>
<b>Cognitive Health</b>		
Noticeable changes in memory, attention, thinking, or problem-solving abilities?	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty following conversations or understanding instructions?	<input type="checkbox"/>	<input type="checkbox"/>
Struggling to make conversation and can't find the right words?	<input type="checkbox"/>	<input type="checkbox"/>
Confusion or disorientation, especially in familiar settings, such as getting lost going to the grocery store or other frequented places?	<input type="checkbox"/>	<input type="checkbox"/>
Forgetfulness, such as misplacing items or forgetting appointments?	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting to take or mixing up medications?	<input type="checkbox"/>	<input type="checkbox"/>
Financial problems, not paying bills on time, or not being able to account for spending when this was not previously an issue?	<input type="checkbox"/>	<input type="checkbox"/>
Losing awareness of potentially dangerous activities like leaving the stove on or touching a hot item?	<input type="checkbox"/>	<input type="checkbox"/>
<b>Emotional Well-being &amp; Social Support</b>		
Significant personality changes (moody, irritable, angry) or signs of anxiety or social withdrawal?	<input type="checkbox"/>	<input type="checkbox"/>
Feelings of loneliness or isolation?	<input type="checkbox"/>	<input type="checkbox"/>
A recent loss or significant life change?	<input type="checkbox"/>	<input type="checkbox"/>
Lack of social interaction or engagement	<input type="checkbox"/>	<input type="checkbox"/>
A support system to help meet emotional and social needs?	<input type="checkbox"/>	<input type="checkbox"/>
Ability to maintain relationships with friends and family members?	<input type="checkbox"/>	<input type="checkbox"/>
Ability to participate in social activities or hobbies once enjoyed?	<input type="checkbox"/>	<input type="checkbox"/>
<b>Safety and Home Environment</b>		
Any accidents or incidents that indicate potential safety concerns in their home?	<input type="checkbox"/>	<input type="checkbox"/>
Is home cluttered or disorganized, making it difficult to navigate safely?	<input type="checkbox"/>	<input type="checkbox"/>
Any tripping hazards or obstacles that could increase the risk of falls?	<input type="checkbox"/>	<input type="checkbox"/>
Stairs that are hard to navigate?	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty managing household tasks such as cooking, shopping, managing finances, doing housework, or laundry?	<input type="checkbox"/>	<input type="checkbox"/>
Any trouble getting in or out of the tub and/or shower?	<input type="checkbox"/>	<input type="checkbox"/>

# Understanding the Types of Care, Services, and the Respective Financial Considerations

*Note: Accurate cost information is limited and inconsistent. It is often outdated as the data lags between 2-4 years. Sources: Leading Age MA, Massachusetts Assisted Living Association (Mass-ALA), and National Council on Aging.*

Home Care Services: Personalized 1:1 care at home (wherever home is): home health aides, companions, and homemakers.		
Benefits	Tradeoffs	Financial Considerations
<p><b>Personalized care:</b> Offers personalized care tailored to the specific needs of each individual. Caregivers can provide assistance with activities of daily living, medication management, meal preparation, and other tasks based on the senior's requirements.</p> <p><b>Familiar environment:</b> Aging in place and/or returning home to recover after a medical event, allows seniors to stay in a familiar and comfortable environment. Being in their own home can contribute to a sense of security, promote independence, and maintain a connection to their community.</p> <p><b>One-on-one attention:</b> This individualized care allows for a more focused and personalized approach to meet the senior's needs and preferences.</p> <p><b>Cost-effective/flexibility:</b> In some cases, in-home senior care services can be more cost-effective compared to other senior care options. Seniors can choose the level of care (scope and frequency) they require, which can help manage costs.</p> <p><b>An agency minimizes legal risk and continuity:</b> Hiring an agency ensures proper following of state and federal labor laws and provides liability protection. An agency with a broad staff also provides a roster of caregivers to support both proper fit (compatibility choices) and function (skills). Additionally, in the event of a caregiver callout, this roster enables continuity of care.</p> <p><b>Control:</b> Individual maintains control of what, when, where and how their needs are met.</p>	<p><b>Limited socialization:</b> While home care in an individual's home provides personal attention, it may not offer the same level of socialization and community engagement as living in a seniors housing community. Seniors may need to try to maintain social connections outside of their home. Additionally, effort is needed to create a "life engagement plan" to support a quality-of-life engagement.</p> <p><b>Potential caregiver turnover:</b> Caregiver turnover can lead to a lack of continuity in care, which may be challenging for seniors who prefer consistency and building a rapport with their caregivers.</p> <p><b>Limited resources:</b> Seniors with complex medical needs may require additional resources that may not be readily available in a home setting.</p> <p><b>Home modifications may be necessary:</b> Depending on the senior's mobility and accessibility needs, home modifications may be required to ensure a safe and comfortable living environment. These modifications can add to the overall cost of in-home care.</p>	<p>Fees are charged on an hourly or daily rate. Federal and state labor law dictate what is applicable.</p>

**Independent Living:** Offers a maintenance-free lifestyle in a supportive community. Residents live in apartments ranging from studios to 1,2,3 bedroom and enjoy meals with peers in a restaurant-style dining room. Most independent living communities provide light housekeeping, and residents can enjoy the social activities offered daily.

Benefits	Tradeoffs	Financial Considerations
<p><b>Maintenance-free living:</b> Independent living communities often provide maintenance and housekeeping services and often meal plans, relieving seniors of the burden of home maintenance and allowing them to focus on their interests and hobbies.</p> <p><b>Socialization and activities:</b> Independent living communities offer a variety of social activities, events, and amenities that promote socialization and a sense of community. Seniors have the opportunity to make new friends, participate in group activities, and engage in recreational pursuits.</p> <p><b>Safety and security:</b> Many independent living communities have security measures in place to ensure the safety of their residents. This can include gated entrances, surveillance systems, and response protocols 24/7 to respond to emergencies.</p> <p><b>Access to amenities:</b> Senior apartments and retirement communities often provide access to amenities such as fitness centers, swimming pools, libraries, and common areas for socializing. These amenities contribute to a fulfilling and enjoyable lifestyle.</p>	<p><b>Cost:</b> Independent living communities can be costly, with monthly fees and potential upfront costs (community fees or buy-in fees). The cost varies depending on the location, amenities, and services provided. Seniors should carefully consider their financial situation before committing to independent living.</p> <p><b>Lack of personalized care:</b> Independent living communities do not provide medical or personal care. While some communities may offer third party provided services such as medication management or help with daily tasks, seniors with significant care needs may need to consider other options.</p> <p><b>Limited control over the living environment:</b> Seniors living in independent living communities may have limited control over their living environment compared to owning or renting a private residence. There may be restrictions on modifications or changes to the unit.</p> <p><b>Potential isolation:</b> While independent living communities promote socialization, there is still a risk of isolation for seniors who are less inclined to participate in community activities. It's important for seniors to actively engage in the community to avoid feelings of loneliness.</p>	<p>Monthly flat fee with basic services. Add-ons may be available.</p>

**Assisted Living Residence (ALR):** Combines apartment-like living with a variety of support services including meals, assistance with personal care, housekeeping, laundry, social and recreational programs, oversight of residents' self-administration of medication, 24-hour security, and on-site staff to respond to emergencies. Some assisted living residences offer special services for residents who have Alzheimer's Disease or other related dementias.

Benefits	Tradeoffs	Financial Considerations
<p><b>Independence:</b> Assisted living allows seniors to maintain a level of independence while receiving the necessary support within provided levels of care.</p> <p><b>Social engagement:</b> Residents have opportunities for socialization and activities with peers.</p> <p><b>Assistance with ADLs:</b> Trained staff can assist with tasks like bathing, dressing, and medication management.</p> <p><b>Amenities and services:</b> Assisted living residences offer amenities like dining options, housekeeping, transportation, and recreational activities.</p> <p><b>Memory support neighborhoods:</b> Many assisted living residences are a stand-alone or have a special care unit (memory support neighborhood) which provides specialization for those with cognitive impairment. These amenities include a locked unit, higher ratio of staff to resident, and appropriately defined activity programs.</p>	<p><b>Limited medical care:</b> Assisted living facilities are not equipped to provide medical care or nursing services. Services are typically limited to medication management.</p> <p><b>Cost:</b> Assisted living can be expensive, and rarely are services covered by insurance outside of long-term care insurance or workers compensation if situation is the result of a work-related accident.</p> <p><b>Care limitations:</b> Facilities have limitations on the level of care (scope and type) they can provide, and residents may need to transition to a higher level of care if their needs increase; or supplement with private services such as home care.</p>	<p>Most assisted living residences are paid for privately, while some accept payment for eligible residents through state, federal, VA or other programs. Some long-term care insurance policies also pay for assisted living.</p>

**Memory Care Communities:** Specialize in providing care for individuals with Alzheimer's disease, dementia, or other memory-related conditions.

Benefits	Tradeoffs	Financial Considerations
<p><b>Specialized care:</b> Memory care facilities have staff trained in managing the unique needs and challenges of individuals with memory loss.</p> <p><b>Safety measures:</b> Facilities are designed to provide a secure and safe environment, reducing the risk of wandering or accidents. Often referred to as a secure dementia unit.</p> <p><b>Memory-stimulating activities:</b> Memory care programs offer activities and therapies designed to engage individuals with memory loss and promote cognitive function.</p> <p><b>Support for families:</b> Memory care facilities often provide support groups and resources for families and caregivers.</p>	<p><b>Cost:</b> Memory care can be more expensive than other types of senior care due to the specialized services and security measures.</p> <p><b>Limited independence:</b> Individuals with advanced memory loss may have limited independence and require more assistance with daily activities.</p> <p><b>Transition challenges:</b> Moving to a memory care facility can be emotionally challenging for both the individual and their family.</p>	<p>Incremental cost above and beyond Assisted Living.</p>

**Skilled Nursing and Rehabilitation Facilities (SNFs):** Commonly referred to as nursing homes, long-term care or rehab facilities, these offer 24-hour nursing care, in addition to providing personal care, recreational activities, physical and occupational therapy, and all meals. Many facilities provide short-term rehabilitation services for individuals recuperating from a hospitalization in addition to longer-term care for individuals. Some nursing facilities have special units for residents with dementia or Alzheimer's disease.

Benefits	Tradeoffs	Financial Considerations
<p><b>Medical care:</b> Nursing homes have registered nurses and medical professionals available around the clock.</p> <p><b>Rehabilitation services:</b> SNFs offer physical, occupational, and speech therapy for individuals recovering from surgery or illness.</p> <p><b>Specialized care:</b> Nursing homes can provide specialized care for conditions like wound management, respiratory care, and chronic illnesses.</p> <p><b>Safety and security:</b> Facilities have security measures in place to ensure the safety of residents.</p>	<p><b>Loss of independence:</b> Nursing homes may have more structured routines and less individual freedom.</p> <p><b>Limited privacy:</b> Residents often share rooms and common areas, which can limit privacy.</p> <p><b>Cost:</b> Nursing home care can be expensive, and not all costs may be covered by insurance.</p> <p><b>Institutional environment:</b> Some individuals may find the institutional setting less homelike or less conducive to personal preferences.</p>	<p>Costs depend on if private pay, Medicaid or other insurance agreements.</p> <p>Some residents or their families pay for nursing facility care out of their own private funds or with private long-term care insurance. Others, who have limited finances or who "spend-down" their finances on their care become eligible for Medicaid. Medicare covers some nursing facility care for shorter-term stays following a hospitalization.</p>

**Continuing Care Retirement Communities (CCRCs):** These are different from other types of senior housing because they provide various levels of housing, personal care services, and health care services – all usually in one location. CCRCs offer a supportive environment where elders can live amongst their peers and receive services that will allow them to age in place.

Benefits	Tradeoffs	Financial Considerations
<p><b>Convenience:</b> CCRCs provide a convenient and all-inclusive living arrangement, with various levels of care available on one campus. This eliminates the need for seniors to move to a different facility as their care needs change. Instead, they can move within the campus through their continuum of care.</p> <p><b>Continuum of care:</b> CCRCs offer a continuum of care, from independent living to assisted living and skilled nursing care. Seniors can transition seamlessly between different levels of care without having to leave the community.</p> <p><b>Socialization and activities:</b> CCRCs often provide a wide range of social activities, events, and amenities that promote an active and engaging lifestyle. Residents can socialize, make new friends, and participate in various recreational activities.</p> <p><b>On-site healthcare services:</b> Many CCRCs have on-site healthcare services, including medical clinics, rehabilitation centers, and access to healthcare professionals. This ensures that seniors have easy access to healthcare services when needed.</p>	<p><b>Cost:</b> CCRCs can be expensive, with entrance fees (buy-in) and monthly fees (rent, food, housekeeping, activities). The cost varies depending on the location, amenities, and level of care provided.</p> <p><b>Long-term commitment:</b> Joining a CCRC often requires signing a long-term contract, which may be binding for several years. This can limit the flexibility of seniors to move to other locations or communities if desired.</p> <p><b>Waiting lists:</b> Some CCRCs have waiting lists for entry, which means seniors may have to wait for availability. This can be a drawback for those who require immediate care or wish to move into a CCRC quickly.</p> <p><b>Loss of independence:</b> Moving to a CCRC may involve relinquishing some degree of independence, as the community may have rules and regulations that residents must abide by. Seniors who value complete independence may find this restrictive. These are the most common types of contracts:</p> <p><b>Type A (extensive) agreement:</b> Includes housing, residential services, amenities, and unlimited, specific health-related services with little or no substantial increase in monthly payments, except to cover normal operating costs and inflation adjustments.</p> <p><b>Type B (modified) agreement:</b> Includes housing, residential services and amenities and a specific amount of health care with no substantial increase in monthly payments, except to cover normal operating costs and inflation adjustments. After the specified amount of health care is used, persons served pay either a discounted rate or the full per diem rates for required health care services.</p> <p><b>Type C (fee-for-service) agreement:</b> Includes housing, residential services and amenities for the fees stated in the resident agreement. Access to health care services is guaranteed, but it may require full fee-for-service rates.</p>	<p>In CCRCs, the variety and intensity of health care provided varies greatly by CCRC. Some offer pre-paid insurance as a part of their regular fees; others require residents to purchase insurance on their own. Most CCRCs require a one-time entrance fee and then monthly payments thereafter. These fees vary by community, depending on the type of housing and services they offer. At some CCRCs, residents pay the same monthly fee whether they are in an independent living unit or the nursing facility, while at others, different rates apply to Independent Living, Assisted Living and Skilled Nursing Care. Fees vary for services, so it is important to ask questions to be sure to understand the differences between basic and extra fees and how they may increase in the future.</p>