

Prepare to Care

Why Plan? Preparing for Potential Care Needs in Late Life

Former First Lady, Rosalyn Carter once said, “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 care.” Caregiving affects us all, yet there are few existing programs preparing individuals to serve as caregivers for older adults or to be care receivers in old age. This lack of preparation can lead to increased caregiving distress and burden.

Preparation and planning can strengthen families and help individuals age with purpose and dignity. Planning ahead for the possibility of needing long-term care is imperative because the vast majority of people over age 65 will require some type of long-term care assistance in regards to physical care, social resources, finances and housing. In general, people do not proactively plan for long-term care needs. Instead of obtaining information and making concrete decisions, they are forced to act in times of crisis and under increased stress and often emotional turmoil.

The goal of this publication is to highlight the importance of caregiving preparation, to motivate families to be ready to address potential care needs in later life, and to reinforce the factors that affect the likelihood of people making plans for their own aging and end-of-life care. Just because you research options and talk about them and have a plan for care needs in late life, does not mean you will ever have to use it. The key however, is to have plans *if* and *when* you need them. It is much easier to plan when you are not in crisis than when you are.



The following terms and definitions are important to know when developing plans for yourself or for your relatives:

- ***Activities of Daily Living (ADLs)***. ADLs is a term used to refer to people's ability to take care of themselves in terms of ambulating (walking), transferring (getting up from a chair), dressing, eating, drinking, taking care of personal hygiene and taking medication. The degree to which people can do these daily self-care activities influences a person's need for caregiving.
- ***Instrumental Activities of Daily Living (IADLs)***. IADLs are secondary level activities that are not necessarily performed every day, but are nonetheless important for living independently. Examples of IADLs include driving, doing housework, preparing meals, shopping, managing personal finances, managing medication, and using the telephone.
- ***Caregiver***. A caregiver or carer is a paid (formal caregiver) or unpaid (informal caregiver) person who helps another who is ill, impaired or unable to safely complete activities of daily living. Caregiving includes both physical and emotional support. Family caregiving (care provided by one family member to another) is the most common type of unpaid caregiving.
- ***Durable Power of Attorney for Finances***. A durable power of attorney for finances allows for a person to legally name another trusted person to be in charge of acting on their behalf regarding legal and financial matters in instances where the person can no longer make his/her own decisions.
- ***Durable Power of Attorney for Health Care***. A durable power of attorney for health care allows for a person to legally name another trusted person to be in charge and act on their behalf regarding medical decisions when the person themselves can no longer do so.
- ***Long-distance Caregiving***. Long-distance caregiving describes a situation in which a caregiver and care recipient are separated by distance, usually exceeding 50 miles or at least one hour travel time.
- ***Long-term care (LTC)***. LTC encompasses a wide range of assistance, supportive and housing services provided to individuals with chronic illness or disability unable to function safely and/or independently on a daily basis. LTC takes place in a range of settings from in-home companion and adult day care social support services to 24 hour skilled nursing care depending on the care recipient's needs, abilities, preferences, financial means and availability of informal and/or formal caregiving support.
- ***Planning***. Planning is defined as the degree to which people think ahead to the future and set goals as opposed to focusing on the here and now or just one day at a time. For older adults and their family members, planning for later life should include the consideration and possible need of long-term or later life care or providing care to an aging relative. At a minimum, caregiver preparation should include planning for physical care, social resources, finances, and housing. This is because health problems, frailty and dependency are often unavoidable aspects of advanced age and often associated with age-related diseases and disorders, including end-of-life issues and care.

Why Don't People Plan?

If you have yet to plan for long-term care needs for yourself or a family member, you are not alone. The tendency for Americans not to plan is often due to our cultural values and attitudes toward aging and issues and negative stereotypes related to long-term care. Thoughts and fears of being ill and/or frail and dependent on others, while inevitable for many, can be frightening. People respond to this by avoiding and ignoring thoughts of decline in later life—waiting for a crisis to occur and then being forced to make decisions.

People also lack caregiving preparation due to assumptions made about friends and family and care wishes. For example, it is not uncommon to assume that family automatically knows a loved one's preferences for later life care. It is also not unusual for a person to assume or trust that their family members will “just know” to make the “right” decisions when it comes to caregiving. As a result, wishes, values and preferences go undiscussed and all family members—caregivers and care recipients alike, can become stressed and/or overwhelmed, even disappointed or let down.

Lastly, certain barriers make it harder for some people to plan for late life. For example, research indicates that adults with higher socioeconomic status and more contact with adult children are likely to have concrete plans in place to help in situations where care assistance is needed. This is probably because they have more options from which to choose, such as the number of family members available as potential caregivers and/or access to formal services. In comparison, less knowledge about health and aging services is associated with a lack of caregiver planning. Sometimes, rather than making individual arrangements for long-term care, people will rely on a network, including health care professionals, clergy and adult children to make plans, but this may not reflect certain preferences or values.

As people live longer in the coming decades, increasing numbers of older adults will be living with chronic, life-threatening diseases and will require ongoing care. Failing to think about and plan for future needs is often associated with premature institutionalization of older adults and increased caregiver burden. According to AARP, starting the conversation and putting a caregiving plan together before a crisis helps families move more quickly and effectively should the need arise for caregiving develop.

Why Should People Plan for Potential Care Needs?

The benefits of planning for later life are well documented. They help keep families on the same page, they help family's focus on the best interest of their loved one and they help everyone respect the wishes, preferences and values of a loved one in addition to roles that people will be expected to fill. Additional benefits to both family caregivers and care recipients include:

- **Increase Options:** Without the pressure of time or a health crisis, individuals can research and compare options, plan for financial means and get names on waiting lists or make down payments on housing or services, if applicable. Increased options can relieve anxiety and help families wrap their minds around or accept what the future may hold in terms of care, safety, health, well-being and life quality.
- **More Control:** Discussing and planning for caregiving needs and wishes in advance helps give a care recipient a voice to help ensure his/her needs are met if he/she becomes too incapacitated or impaired to make decisions. In return, knowing a plan helps the caregiver prepare for, understand and feel as comfortable as possible with their loved one's wishes. With a plan, families can work together as a team, each with their unique role, to carry it out.
- **Decrease Stress:** There is a peace of mind and sense of security that comes with knowing family and health care providers recognize a loved one's care wishes, preferences and values. Family members, while they may not totally agree with a loved one's wishes, can feel comforted for knowing their loved one's preferences and they can use that information to help focus on what is best for that person.
- **Receive Preferred Care:** Communicating plans and preferences to family and friends, even doing so in writing, increases the likelihood that the preferred care will be received. In addition, there is more likely to be an increase in satisfaction regarding the care arrangement if preferences are recognized, documented and honestly carried out.

Matters to Think about when Planning for Late Life Care

Because health problems, frailty and dependency are often unavoidable aspects of advanced age and common age-related diseases and disorders, preparation for later life, at a minimum, should include planning for physical care, social resources, finances and housing:

- **Physical Care:** Planning for physical care involves seeking preventative care, being well informed about health and wellness, making good lifestyle choices and getting regular health exams and screenings—for both the caregivers and

receivers. It also entails discussions about what type of care will be necessary and what is preferred and affordable to carry out activities and instrumental activities of daily living when a loved one can no longer do so for him/herself. Even caregivers will need to evaluate what type of physical care they can/cannot do, especially related to medical care, hygiene and transferring.

- **Social Resources:** Preparing for the social side of care may involve creative ways to create or maintain meaningful social relationships. This might include moving closer to family if possible and/or feasible, joining clubs or organizations, volunteering, or staying connected through social media and technology. It is important for caregivers to stay plugged in and to feel supported. It is also important for loved ones to stay meaningfully connected and to feel a sense of purpose despite disease and/or disability.

- **Finances:** Financial planning should include a review of current insurance coverage and investigating other resources to help cover long-term care expenses, such as

long-term care insurance and reverse mortgages. It should also include family members asking themselves how much they are willing/able to financially help an aging family member,



including parents, especially as many middle age caregivers have to think about their children that they are likely supporting and their own retirement just around the corner. Because so many families wait for an emergency before talking about a long-term care plan, it is a good idea to set up an emergency care fund—both as a potential care recipient to pay hospital bills, transfer and prescription fees and for a caregiver due to last minute travel and accommodations plans. Lastly, it is important that families complete and file the proper legal paperwork necessary for family members make financial (durable power of attorney for finances) and medical (durable power of attorney for health care) decisions based on a loved one's behalf if/when

he/she is no longer of capacity to make those decisions for him/herself. The paperwork for these roles should also be accessible, especially in cases of emergency.

- **Housing:** Housing adjustments and transitions should be included in planning for late life, especially since most older adults prefer, when able, to stay in their own home and be cared for in a home/community setting. Environmental changes might involve home modifications, downsizing to a smaller home requiring less maintenance or moving close to family or a support network. Planning for housing might also include gathering information on housing options such as assisted living facilities or nursing homes. It is important to talk about and understand housing options and communicate concerns and preferences.

Preparation and planning can strengthen families. The reality is that most people over age 65 will require some type of long-term care assistance. Remember that simply researching options and talking about or having a plan for care needs in late life does not mean you will ever have to use it. But it is important to have plans in place for *if* and *when* they are needed. Planning involves making preferences and wishes known, gathering and obtaining information, deciding on preferences, communicating with family members, and making decisions. Attached are two worksheets from AARP (Goals and Needs and Financial Checklist), to help get you started.

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GOALS & NEEDS CHECKLIST

With time constraints, we often find ourselves focusing solely on the needs or tasks that need to be addressed for our parents. It is equally important to begin the conversation about what is most important to your loved ones as they grow older and what strengths do they bring to bear.

Goals

- To remain healthy and active
- To stay/move near family
- To remain in my own home for as long as possible
- To stay active with religious or community groups
- To maintain hobbies
- To be around people
- To move to a residence with support services
- Other

Strengths

- Great negotiator
- Adequate savings
- Low-maintenance single story home
- Large network of friends
- Close relations with family
- Other

Needs

First determine if there is an immediate need under each area. If there is not a pressing issue, the team (with your parent) might prioritize the tasks to be addressed and develop a timeline.

GENERAL NEEDS ASSESSMENT
 (One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Home Maintenance and Living Situation	<input type="checkbox"/> Pay rent/mortgage <input type="checkbox"/> Home repairs <input type="checkbox"/> Ongoing maintenance <input type="checkbox"/> Safety concerns <input type="checkbox"/> Grocery shopping & meal preparation <input type="checkbox"/> Lawn care <input type="checkbox"/> Pet care <input type="checkbox"/> Housekeeping <input type="checkbox"/> Research alternative living arrangements <input type="checkbox"/> Other: _____	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Financial Affairs	<input type="checkbox"/> Paying bills <input type="checkbox"/> Keeping track of financial records <input type="checkbox"/> Managing assets <input type="checkbox"/> Applying and supervising public benefits programs	<hr/> <hr/> <hr/> <hr/>
Transportation Needs	<input type="checkbox"/> Driving decisions <input type="checkbox"/> Coordinating rides <input type="checkbox"/> Locating transportation services	<hr/> <hr/> <hr/> <hr/>
Personal Care	<input type="checkbox"/> Organization of family and professional care providers <input type="checkbox"/> Help with daily grooming and dressing <input type="checkbox"/> Rides to hair stylist <input type="checkbox"/> Clothes shopping	<hr/> <hr/> <hr/> <hr/>

GENERAL NEEDS ASSESSMENT (One for each individual who will need care)

Area of Need	Types of Possible Tasks	Point Person
Health Care	<input type="checkbox"/> Determine medical or emotional problems <input type="checkbox"/> Make, accompany, drive or make alternate logistic arrangements for doctor's appointments <input type="checkbox"/> Submit medical insurance and bills <input type="checkbox"/> Explain medical decisions <input type="checkbox"/> Medication management (fill prescriptions, fill pill boxes, give reminders, and dispense medications) <input type="checkbox"/> Perform medical tasks (wound care, injections, and catheter)	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Communications	<input type="checkbox"/> Keeping family caregiving team informed <input type="checkbox"/> Coordinating team visits <input type="checkbox"/> Daily check in	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Socialization	<input type="checkbox"/> Sending greeting and thank you notes <input type="checkbox"/> Arranging for visitors <input type="checkbox"/> Arranging outings	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
Adaptive Devices	<input type="checkbox"/> Ordering, maintaining, and paying for adaptive devices (e.g., wheelchair, walker, etc.) <input type="checkbox"/> Training on how to use devices <input type="checkbox"/> Other: _____	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

FINANCIAL CHECKLIST

X	Item	Where is it kept? Contact Name
	Bank Records (checking/savings accounts) Pin number clues — online banking and accounts with passwords and clues	
	Trusts	
	Will	
	Durable Power of Attorney for Finances	
	Any rental agreements or business contracts	
	Complete list of assets & debts	
	List of routine household bills	
	Federal & State Tax Returns (past 3-5 years): Tax Preparer:	
	Records of any personal loans made to others:	
	Financial Planner or Broker:	
	Life Insurance Policy or Policies:	
	Disability Insurance (long- and short-term):	
	Long-Term Care Insurance:	
	Safe Deposit Box(es):	Location(s): Number(s): Keys: