The closest thing to being cared for is to care for someone else.

— Carson McCullers, The Square Root of Wonderful
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INTRODUCTION
Alzheimer’s disease is the most common form of dementia, accounting for up to 80% of all cases.
ALZHEIMER’S DISEASE IS AN EPIDEMIC

More than 15 million Americans are caring for an individual living with Alzheimer’s or another type of dementia.*

As a caregiver, you witness the effects of the insidious disease every day. You handle everything from household chores, such as shopping and cooking, to helping your loved one with bathing, choosing clothing, arranging doctor appointments, transportation, and administering accurate, doctor-prescribed medication. In short, you spend your day trying to help your loved one live with as much dignity as possible.

You also likely manage your loved one’s finances. Research shows declining financial skills are among the first symptoms to appear in the early stages of dementia.

*Alzheimer’s Association 2014 Alzheimer’s Disease Facts and Figures
Sometimes, caregivers assume this job without having adequate experience handling money or dealing with financial issues.

This added responsibility can leave caregivers overwhelmed and wondering where to start. As a result, they might avoid making important financial decisions on behalf of their loved one.

When tackling this responsibility, we suggest you work with a financial advisor who has experience helping clients living with Alzheimer's and other forms of dementia. The information here will help prepare you for the critical conversations you will have with your loved one's advisor.
This guide is a valuable resource because it explains several financial concepts that you should understand. It also outlines several key questions you will have when trying to become a responsible fiduciary for your loved one living with dementia.

Being a caregiver can be overwhelming, and the stress associated with this critical role can make it difficult to take action. This guide was created to offer support and encouragement, and to help you be confident when making decisions about your loved one's finances.
CARING FOR YOUR LOVED ONE: THE THREE STAGES OF DECLINE

In 2013, caregivers provided an estimated 17.7 billion hours of unpaid care valued at more than $220 billion in the United States. That dollar amount is nearly eight times the total revenue of McDonald’s in 2012.
Alzheimer’s is a progressive disease that includes three basic stages: mild, moderate, and severe.

Denial is one serious challenge families often face with Alzheimer’s. Due to the progressive nature of the disease, people with dementia have a limited window in which they will be able to articulate their wishes for future care, living arrangements, finances, and legal matters. For this reason, it’s important for families to discuss their concerns and work through this denial phase in the mild stage of cognitive decline.

People with Alzheimer’s live an average of four to eight years after diagnosis; however, each case is different, and some people may live up to 20 years with the disease. Some people may also experience dementia for several years before receiving an official diagnosis.

Each stage of decline has specific characteristics, and there are several steps you can take to responsibly manage your loved one’s finances.
Characteristics: In mild decline, people with dementia typically have problems managing their bank statements and making bill payments. They may also have trouble remembering names or words and may often misplace things. They might also wander off or get lost. Family and close friends are most likely to recognize a problem. If you suspect a loved one has dementia and the individual has not seen a doctor, you should encourage that person do so as soon as possible. Getting help sooner allows people to receive treatments and participate in drug trials that could help them maintain their independence longer.

During mild decline, you should:

Start the conversation
- Talk with your loved one about financial, legal, and caregiving plans. The earlier planning begins, the more involved your loved one will be in the process.

Engage with others
- Encourage your loved one to talk with family about the dementia and the person’s wishes for care.

Work with professionals
- Ask your loved one to take you to appointments with doctors and meetings with financial advisors.

Obtain legal authority
- Ensure you have legal authority to act on your loved one’s behalf. Your loved one’s documents should accurately reflect the financial power of attorney, medical power of attorney, and successor trustee appointments.
Characteristics: Financial skills deteriorate further during this period. People with dementia may get easily frustrated and be more socially withdrawn. Wandering can also occur in this stage. A caregiver may be needed to shop, cook, and help choose proper clothing. People with dementia may also get frustrated when those around them don’t remember things the same way. In these instances, it’s important to understand that people with dementia have their own sense of reality. Caregivers, friends, and other loved ones should not correct every mistaken memory.

During moderate decline, you should:

Work closely with a trusted financial advisor
• Developing this relationship can help you alleviate some of the burden of managing your loved one’s finances.

Focus on your well-being
• If you need advice or support while caring for your loved one, consider talking with the highly trained staff on the Alzheimer’s Association 24/7 Helpline. Experts are available day or night by calling 800-272-3900.
Characteristics: Memory worsens during severe decline, and people with dementia will have a hard time remembering recent events, including conversations and decisions. Significant mood swings and personality changes might be prevalent, and the individual may need a caregiver to help with eating and using the toilet. In this advanced stage, the person with dementia might be bed-bound and unable to sit without support. It may also appear as though the individual cannot understand words or speech.

During severe decline, you should:

Help your loved one live in a comfortable and respectful manner
  • Financial planning should be complete at this stage.

Seek support from other late-stage caregivers
  • The Alzheimer’s Association offers a Caregiver Support Group page on its website. You may search by ZIP code to find support groups and education services in your area. You may also get support online by joining ALZConnected.
Caregivers provided an average of 21.9 hours of care per week in 2013, or 1,139 hours for the year.
Caring for a loved one with dementia can be overwhelming. As demands grow, caregivers often report feelings of sadness, stress, guilt, anger, isolation, and depression.

The Alzheimer’s Association has prepared a list of 10 signs of caregiver stress. A weary, overwhelmed caregiver is unlikely to provide quality care to a friend or loved one with dementia. Please see your doctor if you experience any of these symptoms on a regular basis:

1. **Denial about the disease and its effect on the person who has been diagnosed.**
   “I know Mom is going to get better.”

2. **Anger at the person with Alzheimer’s, the fact there is no cure, or that people don’t understand what’s happening.**
   “If he asks me that one more time, I’ll scream!”

3. **Social withdrawal from friends and activities that once brought pleasure.**
   “I don’t care about getting together with friends anymore.”

4. **Anxiety about the future.**
   “What happens when he needs more care than I can provide?”
Depression that begins to break your spirit and affects your ability to cope. This can include thoughts of suicide or death.
“I don’t care anymore.”

Exhaustion that makes it nearly impossible to complete necessary daily tasks.
“I’m too tired for this.”

Sleeplessness caused by a never-ending list of concerns.
“What if she wanders out of the house or falls and hurts herself?”

Irritability that leads to moodiness and triggers negative responses and actions.
“Leave me alone!”

Lack of concentration that makes it difficult to perform familiar tasks.
“I was so busy; I forgot we had an appointment.”

Health problems that begin to take a mental and physical toll.
“I can’t remember the last time I felt good.”

*Note: Depression is among the most treatable of mental disorders, according to the American Psychiatric Association. With proper treatment, most people with depression gain some relief from their symptoms.
TIPS TO MANAGE STRESS

Focus on a few vital resources
• Adult day programs, in-home assistance, visiting nurses, and meal delivery are a few services that can help. The Alzheimer’s Association Alzheimer’s and Dementia Caregiver Center is a good place to start.

Get help
• Call the Alzheimer’s Association 24/7 Helpline (800-272-3900). You should also seek support from family, friends, and other caregivers. Tell them what they can do to help.

Become an educated caregiver
• New skills may be needed as the disease progresses. The online Alzheimer’s Association Caregiver Center (alz.org/care) offers training resources that can help you better understand and cope with the behaviors and personality changes that may occur.

Take care of yourself
• Visit your doctor regularly. Watch your diet. Exercise at least 10 minutes each day. Spend at least 30 minutes a week with friends, family, and activities you love. And get plenty of rest.

Are Children Involved?
Dementia affects everyone in the family. It’s important to take time to talk with children and teens about what is happening to their loved one with dementia. Here are a few ways to help:
• Allow them to express their feelings
• Let them know those feelings are normal
• Teach them about dementia and encourage them to ask questions
• Respond honestly to their questions

Visit the Alzheimer’s Association Kids & Teens web page for more information.
CREATING THE FINANCIAL PLAN

Due to the physical and emotional burden of caregiving, Alzheimer’s and other dementia caregivers accrued $9.3 billion in additional health care costs of their own in 2013.
After gaining a better understanding about the three stages of decline — and after taking a moment to remember you must make it a priority to take care of your own physical and mental well-being — you can focus on designing a financial plan for your loved one. We suggest working with a financial advisor to draft and execute the plan.

To help guide you through the process, researchers at the Massachusetts Institute of Technology (MIT) AgeLab developed a five-element framework to discuss financial planning and Alzheimer’s disease.

1. ASSETS
2. INCOME AND INSURANCE
3. INTENTIONS
4. BANKING ADMINISTRATION
5. CARE MANAGEMENT
These five topics cover distinct financial-management issues and caregiving plans. Ideally, you will have these conversations with your loved one and that person’s advisor in the mild decline stage of Alzheimer’s, or even before the diagnosis; however, if the disease has progressed beyond this period, you might need to have these discussions solely with the advisor.

The first two categories, assets and income and insurance, represent your loved one’s revenue sources. The third, intentions, refers to helping loved ones with dementia articulate their plans and wishes. The final two, banking administration and care management, represent how the money will be handled and spent, in terms of planning for day-to-day expenditures and expenses for care. It is important for you and the advisor to understand the source and destination of your loved one’s finances so you can help when the individual may no longer be able to communicate his or her wishes.
The first thing to do when meeting with an advisor is to ensure he or she has a complete view of your loved one’s assets and how they are managed. The advisor should also clearly understand your loved one’s real estate situation, especially with respect to home ownership.

Many older adults incorrectly believe Medicare will cover their long-term care expenses. In reality, Medicare covers care in a skilled nursing facility only for the first 100 days, so people often need Medicaid to cover long-term costs.

There are certain things to consider with Medicaid. For instance, eligibility requirements stipulate that individuals must not have significant assets available that could be used to fund their care. Unless these assets have been transferred or gifted to other parties or family members a full five years before applying for Medicaid, a home and any other assets could be confiscated after your loved one passes to recoup Medicaid or nursing home expenses.

Before making any decisions with respect to Medicaid, it’s practical to have a financial advisor examine your loved one’s unique situation.
Questions you and the advisor should ask your loved one

1. Let’s identify all the assets you have (property, household items, real estate). Whose name are they in? What is their estimated value?
   - This is an opportunity for you and the advisor to complete or update your loved one's existing financial profile to include all identified assets.

2. How is your main residence currently titled? Have you considered transferring or gifting it? Do you want to keep it in the family?
   - Be careful about transferring or gifting property or other assets. Each situation should be handled on its own merits. You might consider working with a financial advisor before making any decisions. In situations where transferring or gifting is warranted, it’s important to remember assets must be transferred five years before applying for Medicaid, or the applicant will be deemed ineligible. The federal government’s Administration for Community Living website can link you to your state area agency on aging. You can also find Medicaid eligibility information for each state on Medicaid.gov.

3. Are you considering selling your house or moving to a facility?
   - More information about housing can be found in the answers to questions within the Intentions section on page 26.
After reviewing assets, the focus should shift to your loved one’s income status and insurance policies. You and the advisor should work with your loved one to identify all existing income sources, including benefits, where more income could be generated — such as disability payments, Social Security, annuities and pensions — and how these payments could be affected by other changes in family circumstances, such as the death of a spouse.

Also, review your loved one’s insurance plans to ensure they fit current and future needs and discuss whether additional policies should be considered to fill coverage gaps. Many insurance policies and benefit programs have time-sensitive requirements. For example, some plans and services (such as COBRA and Social Security Disability Income) are only available to those under 65.
Questions you and the advisor should ask your loved one

1. Have we identified all your main income sources (pensions, Social Security, SSDI or SSI, Medicare, retirement accounts)?
   - Visit the Social Security Administration website for more information about SSDI or SSI.

2. Let’s review your employee benefit package. Does your current health insurance plan cover care for conditions like dementia and Alzheimer’s disease? Can you provide a copy for the advisor to review?

3. Do you have any supplemental insurance plans? Long-term care insurance? Medigap? Any insurance policies with riders?
   - Visit the “What’s Medicare Supplement Insurance (Medigap)?” page on the federal government’s official Medicare site to learn more about Medigap.
It is imperative to understand your loved one’s wishes and how to ensure they are fulfilled. This can involve legal arrangements that people with dementia make with their families. These arrangements include where the client wants to live as the disease progresses, how the person wants care to be managed and delivered, and how the individual wants to ensure his or her finances will be safe. It is difficult for most people to think about disease progression, but talking about this early after diagnosis, in the mild decline stage, can help you and other family members learn your loved one’s wishes and help reduce stress later.

As time passes, your loved one may be less able to make these decisions and articulate what he or she wants. Finally, knowing your loved one’s intentions about care, living arrangements, and desire to protect income for other family members will better prepare you and the advisor to design an effective plan.
Questions you and the advisor should ask your loved one

1. Do you have an elder law attorney? Have you thought about contacting one?
   - Elder law attorneys are experts in several subjects, including powers of attorney, Medicaid, Medicare, retirement benefits, and long-term care financing, among others.
   - The National Academy of Elder Law Attorneys is a good resource to help you and your loved one find a local attorney.
   - Other resources include the American Bar Association and the American Association of Trust, Estate and Elder Law Attorneys (AATEELA).

2. Have you thought about where you want to live as the disease progresses? Have you considered assisted living or a nursing home?
   - Legg Mason Global Asset Management, in collaboration with the Johns Hopkins University School of Nursing and its Center for Innovative Care in Aging, have developed a comprehensive program on housing options in retirement and the associated financial-planning implications. Aging and Its Financial Implications: Planning for Housing includes worksheets to help people evaluate housing in their community. With dementia, it is critical for families to determine whether a facility is appropriately equipped and certified to help those who need that level of care.
• The program discusses the most popular housing options, including (but not limited to):

  1. Aging in place
  2. Continuing care retirement communities (‘CCRCs’)
  3. Assisted living facilities
  4. Skilled nursing facilities

• The program can be found online. It provides answers to four key considerations families should explore with each housing option:

  1. Financial
  2. Family
  3. Lifestyle
  4. Health care

• Other reliable online resources to help you and your loved one search for assisted living or nursing home facilities include A Place for Mom®, Housing for Seniors, and Eldercare Locator.

• One valuable online housing resource not listed in the Legg Mason brochure is the Alzheimer’s Association Community Resource Finder.
Have you arranged for a general power of attorney and a durable power of attorney for your health care? Have you thought about who would be your financial advocate?

- As your loved one’s dementia progresses, he or she will lose the ability to make decisions. It is prudent for your loved one to appoint a power of attorney (POA) to handle his or her financial affairs when he or she can no longer manage these responsibilities. An elder law attorney can help with this. Find a local attorney by visiting the National Academy of Elder Law Attorneys, the American Bar Association, or the American Association of Trust, Estate and Elder Law Attorneys.

- A POA is a fiduciary, meaning the individual is legally bound to place the loved one’s interests ahead of his or her own.

- Great responsibility comes with being a POA. Financial fraud is being labeled “the crime of the 21st century.” The National Center on Elder Abuse says perpetrators are often people in a position of trust, including family members, friends, and caregivers. For this reason, families may choose to use more than one POA.
• Other helpful POA resources include:
  - LegalZoom®
  - Uniform Law Commission (includes Uniform Power of Attorney Act language and which states have adopted it)

There are several types of POA, each having its own unique powers:

• **General Power of Attorney**: The agent can perform almost any act as the principal, such as opening financial accounts and changing beneficiary designations. A General Power of Attorney terminates when the principal becomes incapacitated, dies, or revokes the POA.

• **Durable Power of Attorney**: Designates another person to act on the principal’s behalf and includes a durable clause that maintains the POA after the principal becomes incapacitated.

• **Special or Limited Power of Attorney**: The agent has specific powers always limited to a specific area. An example is a POA that grants the agent ability to make health care decisions only for the principal.

• **Springing Durable Power of Attorney**: In some states, a “springing” power of attorney is available and becomes effective when a specified event occurs, such as when the principal becomes incapacitated.
As your loved one's financial skills erode, he or she will need more help managing day-to-day financial affairs, including tracking expenses and paying bills. Though you may have taken over these responsibilities, you should allow the financial advisor to help ensure your loved one's banking and fiscal responsibilities are being met, both practically (e.g., bills are being paid on time) and legally.

There are several ways you can manage your loved one's affairs. One method is to establish a joint bank account listing you and your loved one, allowing you to assume more responsibility as necessary. Consider talking with the advisor about other options; then speak with your loved one to determine what works best for your situation.
Questions you and the advisor should ask your loved one

1. Have you thought about adding services to your bank account, such as direct deposit, automatic bill pay, late notifications, or overdraft protection?

2. Have you thought about creating a joint bank account with me?
   - Keep in mind, in most states, the money in a joint account automatically goes to the person whose name is on the account upon the death of a joint owner. This could cause an unintended inheritance and friction within the family. Consider talking with an attorney before making a decision.

3. Have you considered using a daily money-management service?
   - The American Association of Daily Money Managers can help you and your loved one find local daily money managers who have signed the organization’s code of ethics. The website also provides consumers with questions to ask before hiring a daily money manager.

4. Have you considered establishing a representative payee for government benefits?
   - The official Social Security website features a representative payee page to help you and your loved one.
Finally, you and your loved one must discuss how to finance and facilitate care, especially when the disease progresses and caregiving demands intensify. You should talk with your loved one about his or her preferences for long-term care (e.g., in-home care, nursing care, assisted living, etc.) and how to pay for it.

If your loved one is determined to stay at home, you can work with the financial advisor to help you understand the costs associated with modifications or renovations, which may be needed to make the home more accessible. The advisor might be able to suggest free or low-cost community care solutions, along with care-management options that you and your loved one can use.

Your loved one may be involved in these decisions in the mild decline stage; however, you may need to work directly with the advisor if the disease has advanced to the point where the person can no longer participate in discussions.
Questions you and the advisor should ask your loved one

1. Do you have a long-term care policy we can review to help determine the extent of coverage as it relates to dementia and Alzheimer’s? Or do you have similar coverage or provisions in a life insurance policy or annuity?
   - The U.S. Department of Health and Human Services’ LongTermCare.gov website provides valuable information. The "Finding Local Services" page lists several government and nongovernment sites designed to connect you and your loved one to a variety of services, including nursing and home health comparisons, assisted-living data, state insurance divisions, and Medicaid offices.

2. Have you considered hiring a geriatric care manager?
   - The National Association of Professional Geriatric Care Managers can help you and your loved one find a care manager by ZIP code or company name; however, the site does not screen or evaluate listed caregivers.

3. Have you considered using a meal service, like Meals on Wheels or a similar program?
   - Meals on Wheels America can help you find a local program.
Nearly seven times as many women as men went from working full-time to working part-time while being a caregiver, and more than twice as many women as men reported giving up work entirely or losing job benefits.
Try not to take negative behavioral changes personally.

2. Remain patient and calm.

3. Explore pain as a trigger for behavioral changes.

4. Don’t argue or try to convince.

5. Accept behaviors as a reality of the disease and work through it.

*Alzheimer’s Association
Caring for someone living with dementia is a noble act of love, but it can be overwhelming. Caregivers often take responsibility for their loved one’s finances, sometimes assuming the duty without having adequate experience. When developing a financial plan for a person with dementia, it’s always prudent to work with a financial advisor who has experience helping this clientele.

You should understand there are three basic stages of cognitive decline and each phase has specific characteristics. You and your loved one’s financial advisor should draft plans as soon as possible so the person with dementia can participate in discussions and disclose his or her wishes for future care, living arrangements, finances, and legal matters.
It’s also important to be aware of caregiver burnout. You cannot provide effective care if you neglect your own physical and mental well-being.

The MIT AgeLab’s five areas of focus provide a comprehensive framework to help you and your loved one’s advisor develop a sound plan designed to help alleviate the family’s financial worries as the disease progresses. The ultimate goal is to help your loved one live in a comfortable and respectful manner.

Nearly 60% of Alzheimer’s and dementia caregivers rate the emotional stress of caregiving as high or very high, and more than one-third report symptoms of depression.
Women are 2.5 times more likely than men to be providing 24-hour care for someone with Alzheimer’s in the late stage of the disease.

*Alzheimer’s Association 2014 Alzheimer’s Disease Facts and Figures*
HELP FOR CHILDREN

- Alzheimer’s Association Kids & Teens page: alz.org/kids

HELP FOR THE CAREGIVER

- Alzheimer’s Association 24/7 Helpline: 800-272-3900
- Alzheimer’s Association Alzheimer’s and Dementia Caregiver Center: www.alz.org/care/overview.asp

HELP FOR ASSETS

- Administration for Community Living: www.aoa.gov/AoA_programs/OAA/How_To_Find/Agencies/find_agencies.aspx
- Medicaid.gov: http://medicaid.gov/Medicaid-CHIP-Program-Information/By-State/By-State.html

HELP FOR INCOME AND INSURANCE

- Social Security Administration: http://www.ssa.gov

HELP FOR INTENTIONS

- National Academy of Elder Law Attorneys: www.naela.org
- American Bar Association: www.americanbar.org/aging
- American Association of Trust, Estate and Elder Law Attorneys (AATEELA): http://aateela.org
- National Center on Elder Abuse: www.ncea.aoa.gov/Stop_Abuse/Partners/Fiduciaries/index.aspx
- Legg Mason’s Aging and its Financial Implications: Planning for Housing: www.leggmason.com/aging
- Alzheimer’s Association Community Resource Finder: alz.org/crf
- A Place for Mom: www.aplaceformom.com
- Housing for Seniors: www.usa.gov/Topics/Seniors/Housing.shtml
- Eldercare Locator: www.eldercare.gov/Eldercare.NET/Public/Index.aspx

HELP FOR BANKING ADMINISTRATION

- American Association of Daily Money Managers: www.aadmm.com/findDMM.php
- Social Security payee page: www.ssa.gov/payee/index.htm

HELP FOR CARE MANAGEMENT

- HHS “Finding Local Services” page: http://longtermcare.gov/the-basics/finding-local-services
- National Association of Professional Geriatric Care Managers: www.caremanager.org
- Meals on Wheels America: http://www.mealsonwheelsamerica.org
This guide would not have been possible without tremendous contributions from the MIT AgeLab, the Alzheimer’s Association, Steven A. Starnes*, MBA, CFP®, and Legg Mason Global Asset Management.

*Steven A. Starnes, MBA, CFP® is a Registered Investment Adviser at Savant Capital Management and is not affiliated with Transamerica.
“I really see this as an opportunity. If my job is to protect clients from various risks in life, this is a significant one. I feel like clients will trust me more and feel better about our relationship if they know that I care.”

— Steven A. Starnes, MBA, CFP®, Savant Capital
The MIT AgeLab (agelab.mit.edu) works with businesses and governments worldwide to develop new approaches, technologies, services, and data to improve the lives of older adults and those who care for them. The AgeLab applies a multidisciplinary and systems approach to invent life tomorrow for people 45 and older—including innovations in transportation, longevity planning, health and well-being, and home services.

The Alzheimer’s Association, formed April 10, 1980, is the world’s leading voluntary health organization in Alzheimer’s care, support, and research. The nonprofit’s mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. The Alzheimer’s Association addresses this global epidemic by providing education and support to the millions who face dementia every day, while advancing critical research toward methods of treatment, prevention, and, ultimately, a cure.
Legg Mason created *Aging and Its Financial Implications: Planning for Housing*, in collaboration with The Center for Innovative Care in Aging at the Johns Hopkins University School of Nursing, to bring the perspective, research, and practical insights to assist people with the challenges of aging. As conversations begin and continue with family members, children, and grandchildren, this can become a “go-to” source of information that informs family decision-making. The objective of the program is to help people plan ahead and maintain control and dignity as they age.

STEVEN A. STARNES, MBA, CFP®

Steven Starnes is a certified financial planner with Savant Capital in McLean, Va. His grandmother was diagnosed with Alzheimer’s in 2004, his first year as a financial advisor. Through this experience, Starnes recognized the value of his services to families affected by the disease, and he has since helped more than 20 clients living with dementia. In 2010, he wrote “Is Your Firm Prepared for Alzheimer’s?” which appeared in the *Journal of Financial Planning*. Two years later, Starnes was named Financial Planner of the Year by the Financial Planning Association of the National Capital Area, and *Washingtonian* magazine recognized him as a Top Financial Advisor.
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