

PROTECTING WEALTH FOR AN AGING AMERICA

A CAREGIVER'S FIELD GUIDE TO FINANCIAL
STRATEGIES FOR THOSE LIVING WITH DEMENTIA



Developed in collaboration with

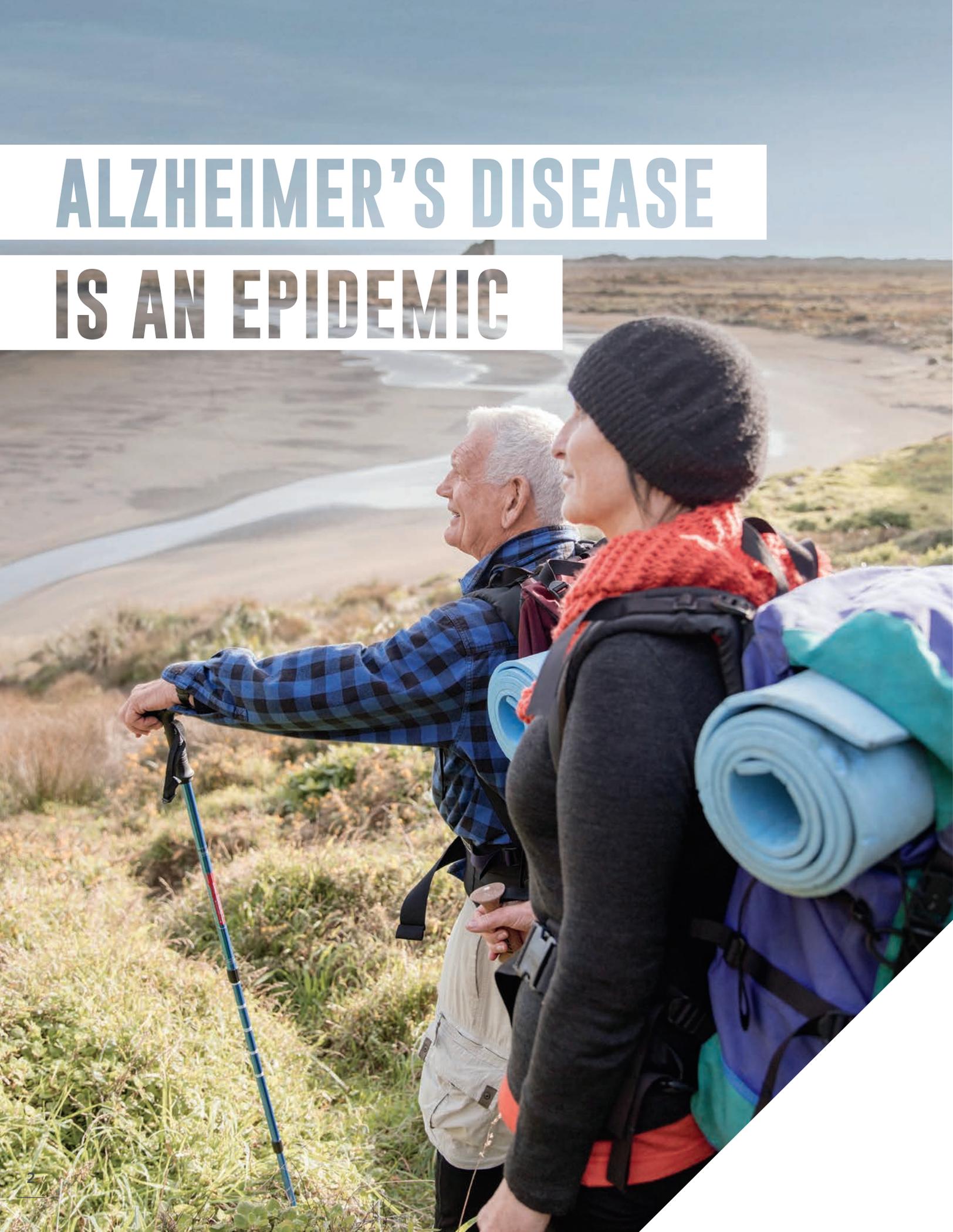
MIT AGELAB



TRANSAMERICA®

ALZHEIMER'S DISEASE

IS AN EPIDEMIC



MORE THAN 15 MILLION AMERICANS PROVIDE UNPAID CARE FOR PEOPLE LIVING WITH ALZHEIMER'S OR OTHER DEMENTIAS.¹

There is an inextricable link between health and wealth. A dementia diagnosis, in particular, can have a huge impact on not only the patient's finances, but also those of their caregiver. When a loved one needs your care, the first instinct is to jump in and immediately do anything you can to help. Some caregivers sacrifice more than their time. They may also risk their financial future. This can happen when caregivers feel compelled to cut back hours at work, quit a job altogether, or dip into retirement savings to help offset some of the care recipient's dementia-related costs.

According to the Alzheimer's Association's® *2016 Alzheimer's Disease Facts and Figures*, caregivers spend an average of \$5,155² out of their own pockets each year to help someone living with Alzheimer's or another dementia. On average, Medicare beneficiaries age 65 and older with Alzheimer's or other dementias paid \$10,315¹ out-of-pocket annually for health care and long-term care services not covered by other sources.

Simply put, the financial ramifications of Alzheimer's, the most common cause of dementia, can be devastating for their loved one as the disease progresses.

This guide can help answer questions about funding care and explains how to strategize financially for dementia.

Alzheimer's disease is the most common form of dementia and accounts for an estimated 60% to 80% of cases.¹

¹2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association, 2017

²2016 Alzheimer's Disease Facts and Figures, Alzheimer's Association, 2016

CARING FOR YOUR LOVED ONE

As a caregiver, you witness the effects of dementia every day. You may handle everything from household chores, such as shopping and cooking, to helping your loved one get dressed.

You may also manage the individual's finances. Research shows declining financial skills are among the first symptoms to appear in the early stages of dementia, and sometimes caregivers assume this job without having adequate experience dealing with financial issues. As a result, many caregivers can be left wondering where to start. When tackling this responsibility, we suggest you work with a financial professional who has experience working with clients living with Alzheimer's and other dementias.

over

\$230 billion

Value of 18.2 billion hours of unpaid care given by caregivers of people with Alzheimer's and other dementias in 2016.



THREE STAGES OF COGNITIVE DECLINE

And actions to take.

It's important to understand Alzheimer's is a progressive disease that includes three basic stages: mild, moderate, and severe. Each phase has specific characteristics, and there are several steps you can take to responsibly manage your loved one's finances at every stage.



STAGE 1: MILD DECLINE

In mild decline, people typically have trouble managing their bank statements and paying bills. They may also misplace things, struggle to remember names or words, or confuse dates and places. For some, the mild stage may last several years. 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.

THINGS TO CONSIDER:

START THE CONVERSATION

Talk with your loved one about preferences and values regarding financial, legal, and caregiving strategies. The earlier this begins, the more involved your loved one will be in the process.

ENGAGE WITH OTHERS

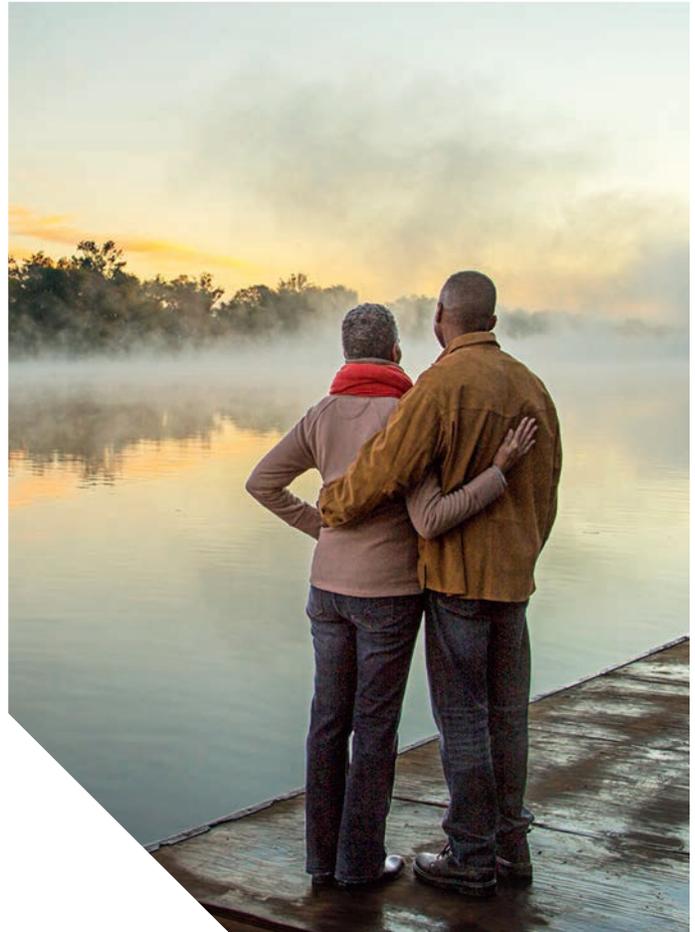
Encourage your loved one to talk with family about his or her wishes for care.

WORK WITH PROFESSIONALS

Ask your loved one if you can accompany him or her to appointments with doctors and meetings with financial professionals to help listen.

OBTAIN LEGAL AUTHORITY

If your loved one grants you legal authority through a properly executed power of attorney (POA) for finances, the documentation should clearly state which powers are being given and whether the power of attorney remains in effect during incapacity. If there is no power of attorney or if the power of attorney is not durable, you may need to go to court to seek guardianship. Without power of attorney, you are simply a “helper” and cannot act or give instruction on your loved one’s behalf. See page 10 for more information about powers of attorney.



UNDERSTAND YOUR CLIENT’S “LEGAL CAPACITY”

Your loved one may need to demonstrate legal capacity—the ability to appreciate the nature and consequences of one’s actions—to make decisions and complete legal documents. Even though your loved one will show signs of dementia in this mild stage, he or she may still be able to understand information, make informed decisions, and communicate those decisions to others.

Research shows declining financial skills are often among the first symptoms to appear in the mild stage of Alzheimer’s.

STAGE 2: MODERATE DECLINE

Financial skills may further deteriorate during this period, and your loved one will probably not be able to adequately manage daily finances. The person may get easily frustrated and be more socially withdrawn. Wandering can also occur. A caregiver may be needed to shop, cook, and help the individual get dressed. People with dementia may get upset when those around them don't remember things the same way, and it's important to understand they have their own sense of reality. Caregivers, friends, and other loved ones should not correct mistaken memories.

THINGS TO CONSIDER:

WORK CLOSELY WITH A TRUSTED PROFESSIONAL

Developing this relationship can help alleviate some of the burden of managing your loved one's finances. Because the person's legal capacity can be in question, all financial strategies should be complete.

FOCUS ON YOUR WELL-BEING

If you need advice or support while caring for your loved one, consider talking with the staff at the Alzheimer's Association 24/7 Helpline. Experts are available day or night by calling 800-272-3900. The Association's website, alz.org, also contains a wide array of information and resources.

STAGE 3: SEVERE DECLINE

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 may be prevalent, and the individual may need a caregiver to help with eating and using the toilet. In this advanced stage, the person may be bed-bound and unable to sit without support. It may also appear as though the individual cannot understand words or speech. The Association's website, alz.org, also contains a wide array of information and resources.

THINGS TO CONSIDER:

HELP YOUR LOVED ONE LIVE IN A COMFORTABLE AND DIGNIFIED MANNER

In this stage, your loved one's legal capacity is almost certainly lost. Working with a professional will help maintain financial peace of mind so you and other family members can focus on being there for your loved one.

SEEK SUPPORT FROM OTHER LATE-STAGE CAREGIVERS

The Alzheimer's Association offers information about caregiver support groups on its website, alz.org/care. You may search by ZIP code to find support groups and education services in your area. You may also get online support by joining ALZConnected (alzconnected.org).



POWERS OF ATTORNEY

A power of attorney is a written document that allows a person, known as the principal, to grant permission to another to act as an agent in legal and financial matters in the event the principal becomes incapacitated.

The scope of power can cover all the principal's legal matters or can be limited to authorization over a single bank account. These powers can only be granted when the principal has legal capacity. A POA is a fiduciary, meaning the individual is legally bound to place the principal's interests ahead of his or her own. Unfortunately, some abuse this power and commit fraud. The National Center on Elder Abuse (NCEA) says perpetrators are often people in a position of trust, including family members, friends, and caregivers. For this reason, families should be careful to select a trustworthy person to serve as an agent.

THERE ARE SEVERAL POWERS OF ATTORNEY, AND EACH HAS ITS OWN UNIQUE PURPOSE

GENERAL POWER OF ATTORNEY

The agent can perform almost any act as the principal such as opening financial accounts and managing personal finances. A general power of attorney terminates when the principal becomes incapacitated, dies, or revokes the power of attorney.

DURABLE POWER OF ATTORNEY

This designates another person to act on the principal's behalf and includes a durable clause that maintains the power of attorney after the principal becomes incapacitated. The POA will terminate if revoked or if the principal dies.

SPECIAL OR LIMITED POWER OF ATTORNEY

The agent has specific powers always limited to a specific area. An example is a power of attorney that grants the agent authority to sell a home or other piece of real estate.

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.

Many people will want at least two powers of attorney—one for finances and one for health care—because many states impose different guidelines for these separate POAs. You and your loved one can get help with POAs by consulting with an elder law attorney. The National Academy of Elder Law Attorneys can help you find a local professional.

Alzheimer's is an irreversible, fatal brain disease that damages nerve cells and slowly robs people of their memories, thinking skills, and ability to complete simple daily tasks.

CARING FOR YOURSELF

Taking care of your own well-being is a very important part of caregiving. Caregiving is a selfless act and it can take a mental, physical, and emotional toll. As demands grow, dementia caregivers often report feelings of sadness, stress, guilt, anger, isolation, and depression. If these emotions persist, the caregiver can experience burnout.

Don't neglect your own health. Caregivers provide the best care when they are healthy and properly managing stress.





THE 10 SIGNS OF CAREGIVER STRESS

The Alzheimer's Association has prepared a list of 10 signs of caregiver stress to help you recognize and identify potential problems.

59% of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, and up to 40% report symptoms of depression.

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 OR FRUSTRATION THAT HE OR SHE CAN'T DO THE THINGS THEY USED TO BE ABLE TO DO.

"He knows how to get dressed—he's just being stubborn."

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?"

5 DEPRESSION* THAT BREAKS YOUR SPIRIT AND AFFECTS YOUR ABILITY TO COPE.

"I don't care anymore."

6 EXHAUSTION THAT MAKES IT NEARLY IMPOSSIBLE TO COMPLETE NECESSARY DAILY TASKS.

"I'm too tired for this."

7 SLEEPLESSNESS CAUSED BY A NEVER-ENDING LIST OF CONCERNS.

"What if she wanders out of the house or falls and hurts herself?"

8 IRRITABILITY THAT LEADS TO MOODINESS AND TRIGGERS NEGATIVE RESPONSES AND ACTIONS.

"Leave me alone."

9 LACK OF CONCENTRATION THAT MAKES IT DIFFICULT TO PERFORM FAMILIAR TASKS.

"I was so busy, I forgot my appointment."

10 HEALTH PROBLEMS THAT BEGIN TO TAKE A MENTAL AND PHYSICAL TOLL.

"I can't remember the last time I felt good."

* Depression is among the most treatable of mental disorders, according to the American Psychiatric Association. With proper treatment, almost all people with depression gain some relief from their symptoms.



STRESS MANAGEMENT

To help avoid caregiver burnout, consider these tips from the Alzheimer's Association:

KNOW WHAT COMMUNITY RESOURCES ARE AVAILABLE

Adult day programs, in-home assistance, visiting nurses, and meal delivery are a few services that can help. The Alzheimer's Association Community Resource Finder ([communityresourcefinder.org](https://www.alz.org/communityresourcefinder)) is a good place to start.

GET HELP AND FIND SUPPORT

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

As the disease progresses, new caregiving skills may be necessary. The Alzheimer's Association offers programs to help you better understand and cope with the behaviors and personality changes that often accompany Alzheimer's.

TAKE CARE OF YOURSELF

Visit your doctor regularly. Try to eat well, exercise, and get plenty of rest. Making sure that you are healthy can help you be a better caregiver.

ARE CHILDREN INVOLVED?

Dementia doesn't involve only those afflicted and their caregivers. It affects everyone in the family. Without help in understanding how dementia progresses, children and teens may feel scared or confused. It's important to take time to talk with them about what is happening to their loved one with dementia.

WAYS TO HELP CHILDREN AND TEENS COPE

- Offer comfort and support.
- Provide opportunities for them to express their feelings.
- Let them know their feelings are normal.
- Educate them about the disease and encourage them to ask questions.
- Respond honestly to their questions.
- For more information, visit: [alz.org/living-with-alzheimers/talking-to-kids-and-teens.asp](https://www.alz.org/living-with-alzheimers/talking-to-kids-and-teens.asp).



\$1.1 trillion

Alzheimer's costs by 2050
without a medical breakthrough.

CREATING THE FINANCIAL STRATEGY

After gaining a better understanding about the three stages of decline—and after taking a moment to remember to make your own well-being a priority—you can now focus on designing a financial strategy for your loved one. To help guide you through the process, researchers at the Massachusetts Institute of Technology (MIT) AgeLab identified five subjects to explore when discussing financial strategies and Alzheimer’s disease.

Work with a financial professional to draft and execute the strategy.





FIVE AREAS OF FOCUS

The MIT AgeLab's framework covers distinct financial management issues and caregiving plans, including assets, income and insurance, intentions, banking administration, and care management.

When crafting a strategy, it's important for you and the financial professional to understand the source and destination of your loved one's money so you can help when the individual is no longer able to communicate his or her wishes. Ideally, you'll have these conversations before cognitive decline develops, or in the mild decline stage of Alzheimer's.

While financial considerations can seem secondary when you're focused on providing quality care to a loved one, creating a stable financial foundation is critical to providing the level of care the person deserves.

1 in 3 seniors die with Alzheimer's or another dementia.



ASSETS

1. **The first thing to do when meeting with a financial professional is to ensure he or she has a complete view of your loved one's assets and how they are managed.**

The professional should also clearly understand the person'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. Medicaid eligibility requirements stipulate 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 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 an attorney examine the situation.

QUESTIONS TO ASK:



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 financial professional to complete or update your loved one's existing financial profile to include all identified assets.

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. Consider working with a financial professional or attorney before making any decisions. When warranted, it's important to remember assets must be transferred five years before applying for Medicaid or the applicant will be deemed ineligible. Medicaid eligibility information for each state can be found on the Medicaid website.

Have you considered selling your house or downsizing?

The federal government's Housing for Senior Citizens section on USA.gov lists resources that may help with this discussion. More housing-specific information can be found in the answers to questions under "Intentions" on page 21. The Administration for Community Living, which provides links to specific state area agencies on aging, may also be helpful.

 For more information on these resources, reference the [Toolkit For a Loved One With Dementia](#).



INCOME AND INSURANCE

2. After reviewing assets, the focus should shift to your loved one's income and insurance policies.

You and the financial professional 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 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 (SSDI), are only available to those under 65.

QUESTIONS TO ASK:

Q: 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.

Let's review your employee benefit package. Does your current health insurance plan cover care for conditions like dementia and Alzheimer's disease?

Consider asking the financial professional to help you review the policy.

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.

For more information on these resources, reference the [Toolkit For a Loved One With Dementia](#).



INTENTIONS

3. A dementia diagnosis is a devastating life event, and it's difficult for most people to think about disease progression.

But talking about this early on, while still in the mild stage of cognitive decline, can help you learn your loved one's wishes and help reduce stress later.

Talk about where the person wants to live as the disease progresses, how he or she wants care to be managed and delivered, and how your loved one wants to ensure his or her finances will be safe. As time passes, the person may be less able to make these decisions and articulate what he or she wants. Knowing intentions about care, living arrangements, and desire to protect income for other family members will better prepare you and the financial professional to design an effective strategy, as well as give you and your family peace of mind.

QUESTIONS TO ASK:

Q: 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. 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.

Have you thought about where you want to live as the disease progresses?

The National Aging in Place Council offers links to services that can help with this decision.

Several other helpful online resources include A Place for Mom®, SeniorAdvisor.com®, Caregiverlist®, Eldercare Locator, and the Alzheimer's Association Community Resource Finder.

Have you arranged for a power of attorney for finances and health care?

As dementia progresses, the individual will lose legal capacity. If your loved one loses legal capacity before executing a durable power of attorney, legal proceedings may be needed to appoint a guardian or conservator. Transamerica's [Guide to Guardianship, Powers of Attorney, and Advance Health Care Directives](#) provides more information.

For more information on these resources, reference the [Toolkit For a Loved One With Dementia](#).



BANKING AND ADMINISTRATION

4. As your loved one's health declines, 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 duties, you should allow the financial professional to help ensure all banking and fiscal obligations are being met.

One method to manage your loved one's finances is to establish a convenience bank account, which allows authorized individuals to make transactions on behalf of the owner. Some families use joint accounts, but these can invite fraud because joint owners can withdraw money for their own benefit. Also, money in a convenience account transfers to the estate when the account owner passes. Money in a joint account, on the other hand, transfers to anyone named on the account. This is known as the "right of survivorship."

QUESTIONS TO ASK:

Q: Have you thought about adding services to your bank account such as direct deposit, automatic bill pay, late notifications, or overdraft protection? Have you considered establishing a representative payee for government benefits?

The Social Security website features a representative payee page to help you and your loved one.

Have you thought about using a convenience bank account?

Check to see whether your bank offers this type of account or to learn about alternatives.

Remember, it's prudent to avoid joint accounts. In most states, money in a joint account automatically transfers to those named on the account upon the death of a joint owner. This could cause an unintended inheritance and friction within the family. Consider talking with a financial professional or an attorney before making a decision.

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 association's website also provides consumers with questions to ask before hiring a daily money manager.

 For more information on these resources, reference the [Toolkit For a Loved One With Dementia](#).



CARE MANAGEMENT

5. Finally, you'll need to talk about how to finance and facilitate care, especially when the disease progresses and caregiving demands intensify.

Ask 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 the person is determined to stay home, work with the financial professional to understand the costs associated with modifications or renovations that could be needed to make the home more accessible. The professional may be able to suggest free or low-cost community care and care-management options. Your loved one may be involved in these decisions in the mild decline stage, but you may need to work directly with the professional if the disease has advanced to the point where the person can no longer participate in discussions.

QUESTIONS TO ASK:

Q: 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' "Long Term Care" page lists several resources designed to help maturing adults and their families plan for long term care, including links to locating benefits, finding home care or assisted living, and connecting with veteran's services.

Have you considered hiring a geriatric care manager?

The Aging Life Care™ Association 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.

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.

▮ For more information on these resources, reference the [Toolkit For a Loved One With Dementia](#).

\$10.9 billion

The physical and emotional impact of dementia caregiving is estimated to have resulted in \$10.9 billion in health care costs in the United States in 2016.

2017 Alzheimer's Disease Facts and Figures, Alzheimer's Association, 2017

CONCLUSION

Caring for someone living with dementia is a generous act of love, but it can be overwhelming. Financial considerations can seem secondary when your primary concern is providing quality care to a loved one, but it's critical to have a stable financial foundation to administer the level of care the person deserves.

When developing a financial strategy for a loved one living with Alzheimer's or other dementias, it's important to work with a financial professional who has experience helping those afflicted. You and your loved one's financial professional should draft strategies as soon as possible—before legal capacity is lost—so the person with dementia can participate in discussions and disclose his or her wishes. It's also important to be aware of caregiver burnout. You will be less likely to provide effective care if you neglect your own mental, physical, and emotional well-being. The ultimate goal is to help your loved one live in a comfortable and dignified manner.





ACKNOWLEDGMENTS

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THE MIT AGE LAB

agelab.mit.edu

The MIT AgeLab 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

alz.org

24/7 Helpline: 800-272-3900

The Alzheimer’s Association, formed in 1980, is the 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 the global dementia crisis 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.

STEVEN A. STARNES, MBA, CFP®

Steven Starnes is a Certified Financial Planner™ with Grand Wealth Management in Grand Rapids, Michigan. His grandmother was diagnosed with Alzheimer’s in 2004, his first year as a financial professional. Through this experience, Starnes recognized the value of his services to families affected by the disease, and he has since helped many 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.



TRANSAMERICA®

Make every day count.

To learn more about the Transamerica Caregiver's *Field Guide to Financial Strategies for Those Living With Dementia* series and to get support materials:

 **Visit:** [Transamerica.com/dementia](https://www.transamerica.com/dementia)

 **Contact:** Your Financial Professional

MIT AgeLab

Transamerica is proud to collaborate with the Massachusetts Institute of Technology's innovative AgeLab to educate and encourage caregivers as they help loved ones make financial decisions about their future.

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