

MONEY MATTERS

MAKING FINANCIAL PLANS
AFTER A DIAGNOSIS OF DEMENTIA



THE IMPORTANCE OF FINANCIAL PLANNING

After receiving a diagnosis of Alzheimer's disease or another dementia, the need for and cost of future care may not be immediately considered. Financial planning often gets pushed aside because of the stress and fear the topic evokes. However, financial stress can be reduced by preparing for care costs. The sooner planning begins, the more the person with dementia may be able to participate in decision-making.

10 KEY TIPS

1. Discuss finances and future care wishes soon after a diagnosis.
2. Organize and review important documents.
3. Seek help from well-qualified financial and legal advisers.
4. Estimate possible costs for the entire disease process.
5. Look at all of your insurance options.
6. Find out for which government programs you are eligible.
7. Learn about income tax breaks for which you may qualify.
8. Explore financial support you can personally provide.
9. Take advantage of low-cost and free community services.
10. Consider how personal property and work-related benefits can become a source of income.



CONTENTS

- 1. Getting started..... p.2
- 2. Costs you may face..... p.4
- 3. How to cover costs..... p.5
- 4. Considerations for individuals
with younger-onset p.11
- 5. Support services in your
community p.16

This brochure is meant to provide general financial information, not to take the place of professional financial or legal advice. New developments — such as legislative and regulatory changes — may affect its accuracy. Consult a professional before making decisions.

1. GETTING STARTED

Begin putting financial plans in place as soon as possible after a diagnosis to help secure your financial future. In addition to planning for the cost of care, consider ongoing financial duties, such as:

- » Paying bills.
- » Arranging for benefit claims.
- » Making investment decisions.
- » Preparing tax returns.

Gather financial and legal documents

Carefully review all financial and legal documents, even if you're already familiar with them.

Legal documents include:

- » Living wills.
- » Medical and durable powers of attorney.
- » Wills.

Financial documents include:

- » Bank and brokerage account information.
- » Deeds, mortgage papers or ownership statements.
- » Insurance policies.
- » Monthly or outstanding bills.
- » Pension and retirement benefit summaries.
- » Social Security payment information.
- » Stock and bond certificates.
- » Other sources of monthly income, e.g. rental property, sale of stocks, interest.

It may also be helpful to identify which necessary documents are not yet in place. Professional financial and legal advisers can assist you.

Discuss financial needs and goals

Talking about financial needs and goals early on enables the person with Alzheimer's to understand the issues, clarify his or her wishes and participate in making financial and care plans. If friends and family can help, encourage the sharing of caregiving duties and discuss how finances could be pooled to provide and cover the costs of care.

Seek professional assistance

Find professionals who can provide planning information and assistance. Start by contacting the Alzheimer's Association® to discuss the type of assistance you may require.

Financial advisers

Professional financial planners and estate planning attorneys can help you:

- » Identify potential financial resources.
- » Identify tax deductions.
- » Analyze your investment portfolio with long-term care needs in mind.

When selecting a financial adviser, consider:

- » Professional credentials.
- » Work experience.
- » Educational background.
- » Membership in professional associations.
- » Areas of specialty.

Make sure to ask the financial adviser if he or she is familiar with elder care or long-term care planning.

Legal advisers

Seek an experienced elder law attorney to help:

- » Address estate planning issues.
- » Prepare legal documents.

If you cannot afford legal assistance, contact the Alzheimer's Association to find out if pro bono (no cost) legal aid is available in your community.

Look at factors that affect income

When making financial plans, be sure to consider:

- » Age of the person with dementia.
- » Types of assets.
- » Types of insurance.
- » Tax issues.
- » Long-term health outlook.
- » Future care needs.

LEARN MORE

Visit [alz.org/education](https://www.alz.org/education) to take our free online workshop: *Legal and Financial Planning for Alzheimer's Disease*.

2. COSTS YOU MAY FACE

Create a long-term budget. Consider all of the costs you might face now and in the future. Keep in mind that Alzheimer's is a progressive disease and the person's needs will change over time. While medical or other forms of insurance may cover some of these costs, they may not cover all.

Costs may include:

- » Prescription drugs.
- » Personal care supplies.
- » Adult day care services.
- » In-home care services. Note: If you hire a professional caregiver to work in your home, you may be responsible for paying his or her

Social Security and unemployment taxes. Consult with your financial advisor for specific information.

» Full-time residential care services.



3. HOW TO COVER COSTS

Various insurance options and benefits may be available to help cover costs throughout the course of the disease. Some may apply now, while others may help in the future.

Health care coverage

Medicare is the primary source of health care coverage for most individuals 65 and older. However, private insurance, a group employee plan or retiree health coverage may also be in effect. No matter the age of the person with dementia, it's vital to keep active any existing health care plans that meet his or her needs.

Medicare covers:

- » Inpatient hospital care, some doctor fees and other medical services for people with Alzheimer's disease who are 65 and older. Medicare Part D also covers many outpatient prescription drugs.
- » A person with dementia who is younger than 65 and has been on Social Security disability for at least 24 months.
- » Some home health care, including skilled nursing care and rehabilitation therapy, under certain conditions.
- » Up to 100 days of skilled nursing home care under limited circumstances.
- » People who are terminally ill and qualify for home or inpatient hospice care.

Medicare does not cover:

- » Long-term care.
- » Personal aides to assist with daily activities.

Medicare Advantage allows you to choose "managed care," such as:

- » Medicare health maintenance organization (HMO).
- » Preferred provider organization (PPO).
- » Point of service (POS) plan.

These forms of Medicare provide services not covered by traditional Medicare, and usually have limits on which hospitals, doctors and other health care providers you can use.

Read each plan carefully. Learn about the many Medicare options and decide whether they are right for the person with dementia. You can also contact your State Health Insurance Assistance Program (SHIP) for free, one-on-one help.

You may be able to supplement the person's Medicare coverage with Medigap insurance, which fills certain gaps in Medicare coverage, such as paying for coinsurance or other items.

Long-term care insurance

Long-term care insurance generally needs to be in place before a dementia diagnosis. Once an individual is diagnosed, review the policy carefully to find out:

- » Is Alzheimer's disease covered?
- » When can the person with dementia begin to collect benefits? Most policies require a defined level of physical or cognitive impairment, such as needing assistance with daily activities.
- » What is the daily benefit and is it adjusted annually for inflation?
- » How long will benefits be paid?
- » Is there a maximum lifetime payout?
- » What kind of care — such as skilled nursing home, assisted living and licensed home care — will the policy cover?
- » Is there is an elimination period before coverage begins?
- » Are there any tax implications involved?



Life insurance

Life insurance can be a source of cash. You may be able to borrow from a life insurance policy's cash value. Or the person with dementia may be able to receive part of the policy's face value as a loan. This is called a viatical loan and is paid off upon the person's death.

Some life insurance policies offer accelerated death benefits. This means that some of the insurance benefits can be paid out if the insured person is not expected to live beyond the next six to 12 months because of a terminal illness. The payout may run as high as 90 to 95 percent of the policy's face value and will not be taxed as income. Find out if any policies contain a waiver of premium rider. That means that the insured, if disabled, does not have to pay premiums to continue coverage.

Medicaid

Medicaid is a state-administered program jointly funded by federal and state governments.

Medicaid pays for:

- » Medical care for people with very low income and asset levels.
- » Long-term care for people who have used most of their own money for care-related costs, under most circumstances.

Most Medicaid dollars go toward nursing home care, but select states have home and community-care options for some people who qualify for nursing home care. (Note: Not all nursing homes accept Medicaid.)

In most states, Medicaid will pay for hospice care. If the person with dementia is eligible for Supplemental Security Income (SSI), he or she is usually automatically eligible for Medicaid. Those not on SSI must have minimal income and assets, as determined by each state.

There are specific guidelines about protecting spouses from impoverishment (the depleting of finances) in determining income and asset levels. The person with dementia should be careful about giving away assets to family members in order to qualify for Medicaid, as strict laws govern this area. Check with your legal adviser to be sure you are fully aware of the legal and financial consequences.

Veterans benefits

Those who served in the military for any period of time may qualify for government benefits, including health and long-term care.



Other public programs

Many states fund services including:

- » Adult day care.
- » Respite care.
- » Meal programs.
- » Caregiver support.
- » Other in-home services.

LEARN MORE

For more information about insurance options and benefits, contact these agencies:

» Medicare

- > Call **800.633.4227** or visit **Medicare.gov**.
- > Visit **SHIPtalk.org** to find your State Health Insurance Program.

» Medicaid

- > Visit **Medicaid.gov**.
- > Call the Centers for Medicare and Medicaid Services (CMS) at **877.267.2323** to obtain your state's Medicaid contact information.

» Veterans benefits

- > Contact the Department of Veterans Affairs. Call **877.222.8387** for health care benefits or **800.827.1000** for general benefits. Or, visit **VA.gov**.

» Public programs

- > Visit the Alzheimer's Association Community Resource Finder at **alz.org/CRF**.
- > Contact your Local Area Agency on Aging or the Eldercare Locator. Call **800.677.1116** or visit **Eldercare.gov**.

» Tax issues

- > Consult your tax adviser.
- > Contact the Internal Revenue Service (IRS). Call **800.829.1040** or visit **IRS.gov**.

Tax benefits for caregivers

The Internal Revenue Service (IRS) offers some financial benefits to caregivers, including:

- » Income tax deductions.
- » Income tax credits.

The person with dementia is likely considered a caregiver's dependent for tax purposes. If so, you may be allowed to itemize his or her medical costs. Keep careful records of all medical expenses. You may be entitled to the Household and Dependent Care Credit if you need to pay someone to care for the person with dementia so you can work. This credit can be subtracted directly from the tax shown on your return.

4. CONSIDERATIONS FOR INDIVIDUALS WITH YOUNGER-ONSET

For individuals diagnosed with younger-onset Alzheimer's — those under age 65 — certain insurance and governmental benefits should be considered. The federal government provides premium subsidies to low- and moderate-income individuals to help them purchase insurance, and offers subsidies to businesses that provide health insurance coverage to retirees aged 55 to 64.

Insurance companies are required to:

- » Issue insurance to all individuals who want to purchase it, thus ending pre-existing condition exclusions.
- » Renew the policy to any enrolled individual wishing to renew.
- » Maintain insurance for individuals who pay their premiums, therefore ending the practice of rescinding the insurance coverage of high-cost individuals.

- » Limit the premiums charged to older individuals to no more than three times the amount charged to younger individuals.

Work-related and personal resources

If diagnosed with Alzheimer's while still employed, educate yourself about the benefits available through your employer so you can maximize them before you leave your job.

Employer-offered benefits may include:

COBRA

Another option for a person younger than 65 may be COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985). COBRA applies to employers with 20 or more employees.

Under COBRA, an employee may continue group plan coverage for up to 18, 29 or 36 months, depending on the circumstances, if he or she:

- » Leaves the employer.
- » Has work hours reduced to the point that he or she no longer qualifies for the health plan.

The insured employee must pay the full cost of coverage, plus up to 2 percent to cover administrative costs. COBRA can be especially helpful until the person with dementia:

- » Gets new coverage through an employer or spouse.
- » Becomes eligible for Medicare.
- » Receives coverage through the Affordable Care Act.

You must activate the COBRA option within 60 days of when the person with dementia receives notice from his or her insurer that COBRA is an option. Some private health care plans will extend coverage under a disability extension of benefits, meaning although the medical plan may lapse, an insured individual's disability (in this case, Alzheimer's) remains covered.

Disability insurance

Disability insurance provides income for a worker who can no longer work due to illness or injury. The insurance plan must be in place before symptoms of Alzheimer's disease appear.

With an employer-paid disability policy, 60 to 70 percent of a person's gross (total) income may be provided. Employer-paid disability benefits are taxed as income. If the person with dementia bought a personal disability policy, then the benefits paid will be the amount he or she chose. The personal disability policy benefits are not taxed as income.

Processes differ across policies so check yours to determine next steps.

Retirement benefits

Benefits from retirement plans can provide critical financial resources, even if the person with dementia hasn't reached retirement age.

Retirement plans include:

- » Individual retirement accounts (IRAs).
- » Annuities.

Pension plans typically pay benefits before retirement age to a worker defined as disabled under the plan's guidelines.

The person may also be able to withdraw money from his or her IRA or employee-funded retirement plan before age 59½ without paying the typical 10 percent early withdrawal penalty.

This money is typically considered regular income, and taxes will have to be paid on the amount withdrawn. In that case, if withdrawals can be delayed until after the person leaves work, income taxes due will likely be less because he or she will likely be in a lower income-tax bracket. Social Security benefits are also available before retirement age if Social Security disability requirements are met.

Flexible spending account

If the person with dementia is a dependent under tax rules, you might be able to use your own workplace flexible spending account. This money can cover the person's out-of-pocket medical costs or dependent care expenses in some cases.

Family and Medical Leave Act

If you work for an employer with 50 or more employees, you may be able to use the federal Family and Medical Leave Act (FMLA) to help balance your caregiving responsibilities. FMLA allows you to take up to 12 weeks of unpaid leave each year to provide caregiving. Most workers are guaranteed to keep their jobs.

Paid time off

Some employers provide limited paid time off and/or allow flexible scheduling.

Personal savings, investments and property

Investment assets, like the following, can be income sources:

- » Stocks.
- » Bonds.
- » Savings accounts.
- » Real estate.
- » Personal property, such as jewelry or art.

Equity in a home may be converted into income through a process called a reverse mortgage. This loan allows an individual age 62 or older to convert some of the equity in his or her home into cash, while remaining the homeowner. The amount the person is eligible to borrow is generally based on:

- » His or her age.
- » The home's equity.
- » The lender's interest rate.

Reverse mortgages do not have an impact on Social Security or Medicare benefits, but they may affect the person's ability to qualify for other government programs.

Government assistance

In addition to Medicare, the person with dementia may qualify for a number of public programs that provide long-term care services or income support to people who are eligible.

Social Security Disability Income (SSDI)

A worker younger than age 65 may qualify for Social Security disability payments. To do so, the person must meet the Social Security Administration's definition of disability. Generally, this means proving that:

- » The person with dementia is unable to work in any occupation.
- » The condition will last at least a year or is expected to result in death.

Through SSDI's Compassionate Allowance Initiative, those with younger-onset Alzheimer's disease are considered eligible for SSDI as long as they meet all other criteria. The person with dementia is also fast-tracked to a favorable decision, which significantly shortens the time it takes to start receiving benefits.

After receiving SSDI benefits for at least 24 months, the person with dementia will qualify for Medicare benefits. SSDI can provide the person and his or her family with disability payments if he or she is "insured," meaning worked long enough and paid Social Security taxes.

Supplemental Security Income (SSI)

SSI guarantees a minimum monthly income for people who meet all of the following requirements:

- » Age 65 or older.
- » Disabled or blind.
- » Very limited income and assets (qualifying levels vary from state to state).

To qualify for SSI benefits, the person with dementia must meet the Social Security Administration's definition of disability. If he or she may qualify for SSI benefits, begin the application process as quickly as possible after the diagnosis — SSI payments begin upon approval of the application.

LEARN MORE ABOUT SSDI AND SSI

- » Call **800.772.1213** or visit **SSA.gov**.
- » Use our application checklist:
alz.org/SSchecklist.

5. SUPPORT SERVICES IN YOUR COMMUNITY

Many community organizations provide low-cost or even free services. It can be helpful to explore these resources in your community before you need them. Some services offered include:

- » Respite care.
- » Support groups.
- » Transportation to social events.
- » Meals delivered to the home.

Seek support from:

- » Alzheimer's Association 24/7 Helpline
Call **800.272.3900** (TTY: 866.403.3073).
- » Community Resource Finder
Visit **alz.org/CRF**.
- » Eldercare Locator
Visit **Eldercare.gov**. Call **800.677.1116**.
- » Your local faith-based organization.
- » Hospital social worker or discharge planner.
- » BenefitsCheckUp
Visit **benefitscheckup.org**.
- » Financial Planning Association
Visit **FPANET.org**. Call **800.322.4237**.
- » Internal Revenue Service
Visit **IRS.gov**. Call **800.829.1040**.
- » National Academy of Elder Law Attorneys
Visit **NAELA.org**.



ALZHEIMER'S ASSOCIATION COMMUNITY RESOURCE FINDER

Visit **Community Resource Finder** (**alz.org/CRF**) to find Alzheimer's and dementia resources, community programs and services in your area.



alz.org/care

The Alzheimer's and Dementia Caregiver Center provides reliable information and easy access to resources, including:

- » Alzheimer's Navigator® – Assess your needs and create customized action plans of information and support.
- » Community Resource Finder – Find local resources.
- » ALZConnected® – Connect with other caregivers who can relate to your situation.



alz.org/education

Free online workshop:

- » *Legal and Financial Planning for Alzheimer's Disease*



alz.org/findus

We're in communities across the country.



800.272.3900

24/7 Helpline – Available all day, every day.
(TTY: 866.403.3073)

alzheimer's association®

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our 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.

Our vision is a world without Alzheimer's disease®.

800.272.3900 | alz.org®

This is an official publication of the Alzheimer's Association but may be distributed by unaffiliated organizations and individuals. Such distribution does not constitute an endorsement of these parties or their activities by the Alzheimer's Association.