

alzheimer's  association

MONEY MATTERS

MAKING FINANCIAL PLANS
AFTER A DEMENTIA DIAGNOSIS



THE IMPORTANCE OF FINANCIAL PLANNING

After receiving a diagnosis of Alzheimer's or another dementia, the need for and cost of future care may not be your foremost concern. Financial planning often gets pushed aside because of the stress and fear the topic evokes. However, preparing for future costs can help reduce stress. The sooner planning begins, the more the person living 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 qualified financial and legal advisors.
4. Estimate possible costs for the entire course of the disease.
5. Evaluate all insurance options.
6. Find out if you're eligible for government programs.
7. Research potential income tax breaks.
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. Covering costs p.5
- 4. Considerations for individuals
with younger-onset p.11
- 5. Support services in your
community p.17

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. 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 legal and financial 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.

Identify which necessary documents are not yet in place. Professional financial and legal advisors can assist you.

LEARN MORE

Visit alz.org/education to take our free online workshop, *Legal and Financial Planning for Alzheimer's*.

Discuss financial needs and goals

Talking about financial needs and goals early on enables the person living 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 sharing caregiving duties and discuss how finances could be pooled to help cover care costs.

Seek professional assistance

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

Financial advisors

Professional financial planners and estate planning attorneys can help you:

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

When selecting a financial advisor, consider:

- » Professional credentials.
- » Work experience.
- » Educational background.
- » Membership in professional associations.
- » Areas of specialty.
- » Familiarity with elder care or long-term care planning.

Legal advisors

Seek an experienced elder law attorney to help:

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

If you can't afford legal assistance, contact the Alzheimer's Association to find out if pro bono (free) 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 living with dementia.
- » Assets.
- » Insurance policies.
- » Tax issues.
- » Long-term health outlook.
- » Future care needs.

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 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 in-home caregiver, you may be responsible for paying his or her Social Security and unemployment taxes.)
- » Full-time residential care services.



3. COVERING 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 over the age of 65. However, private insurance, a group employee plan or retiree health coverage may also be in effect. Regardless of age, it's critical to maintain any existing health care plans that meet the needs of the person living with dementia.

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 living 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.
- » Home or inpatient hospice care for certain individuals who are terminally ill.

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 living 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

In order to use long-term care insurance to help cover costs, the policy generally needs to have been in place before the beneficiary is diagnosed with dementia. Once an individual receives this diagnosis, he or she will no longer be able to apply for long-term care insurance coverage.

When reviewing a policy, consider the following:

- » Is Alzheimer's disease covered?
- » When can benefits be collected? 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 an elimination period before coverage begins?
- » Are there any tax implications?



Life insurance

Life insurance can be a source of income. You may be able to borrow from a life insurance policy's cash value or receive part of the policy's face value as a loan. This is called a viatical loan and is paid off upon the insured 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 more than 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, which 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 living 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.

The person living 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 advisor to be sure you are aware of all legal and financial consequences.

Veterans benefits

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



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 & Medicaid Services (CMS) at **877.267.2323** to obtain your state's Medicaid contact information.

» Veterans benefits

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

» Public programs

- > Visit Alzheimer's Association & AARP Community Resource Finder at **alz.org/CRF**.
- > Contact your local Area Agency on Aging or use their Eldercare Locator (**eldercare.gov**; **800.677.1116**) to explore available resources.

» Tax issues

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

Tax benefits for caregivers

The IRS offers some financial benefits to caregivers, including income tax deductions and credits.

A person living with dementia is likely considered a caregiver's dependent for tax purposes. If so, the caregiver may be allowed to itemize the person's medical costs. It's important to keep careful records of all medical expenses.

Caregivers may be entitled to the Household and Dependent Care Credit if they need to pay someone to care for the individual so they can work. This credit can be subtracted directly from the tax shown on their 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 individuals with low to moderate incomes to help them purchase insurance, and offers subsidies to businesses that provide health insurance coverage to retirees age 55 to 64.

Insurance companies are required to:

- » Issue insurance to all individuals who want to purchase it, thereby ending pre-existing condition exclusions.
- » Renew the policy to any enrolled individual wishing to do so.
- » Maintain insurance for individuals who pay their premiums, thereby ending the practice of rescinding the insurance coverage of individuals with costly medical conditions.

- » 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 living with dementia:

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

The COBRA option must be activated within 60 days after the person living with dementia is notified by his or her insurer that COBRA is available. 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 (e.g., Alzheimer's) remains covered.

Disability insurance

Disability insurance provides income for a worker who can no longer work due to illness or injury. In order to use this coverage to pay for costs, the policy 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 living 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 living 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 59^{1/2} without paying the typical 10 percent early withdrawal penalty.

This money is typically considered regular income, and taxes must be paid on the amount withdrawn. If withdrawals can be delayed until after retirement, the person will likely fall into a lower income-tax bracket and owe less in income tax. Social Security benefits are also available before retirement age if Social Security disability requirements are met.

Flexible spending account

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

Family and Medical Leave Act

Caregivers who work for an employer with 50 or more employees may be able to use the federal Family and Medical Leave Act (FMLA) to help balance their caregiving responsibilities. FMLA allows individuals 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, such as the following, can be income sources:

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

Home equity may be converted into income through a reverse mortgage. This loan allows an individual age 62 and older to convert some home equity into cash, while retaining homeownership. 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 living 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)

Workers under age 65 qualify for Social Security disability payments if they meet the Social Security Administration's definition of disability. Generally, this means proving that:

- » The person living 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 review of the individual's claim is also fast-tracked to reduce waiting time for a disability determination.

After receiving SSDI benefits for at least 24 months, the person living 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 he or she worked long enough and paid Social Security taxes.

Supplemental Security Income (SSI)

SSI guarantees a minimum monthly income for people with limited income and assets who also meet at least one of the following requirements:

- » Age 65 or older.
- » Disabled.
- » Blind.

To qualify for SSI benefits, the person living 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**.
- » Refer to 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 what local resources are available to you, even before you need them. Some services offered include:

- » Respite care.
- » Caregiver support.
- » Adult day care.
- » In-home services.
- » Support groups.
- » Transportation to social events.
- » Meals delivered to the home.

Seek support from:

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



alz.org/care

Find 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*



800.272.3900

24/7 Helpline – Available all day, every day.

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®.

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