

# money matters

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**Making financial plans  
after a diagnosis of dementia**



## The importance of financial planning

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After receiving a diagnosis of Alzheimer's disease or another dementia, the cost of future care may not immediately come to mind. Financial planning often gets pushed aside because of the stress and fear the topic evokes. However, financial stress can be reduced by planning ahead for care costs. The sooner planning begins, the more the person with dementia may be able to participate in decision making. Learning about the types and costs of care is an important first step.





**There are a number of costs you may face as a result of dementia. It's important to know what to expect and plan ahead.**

<b>1</b>	Getting started.....	<i>p.3</i>
<b>2</b>	Costs you may face.....	<i>p.6</i>
<b>3</b>	How to cover costs.....	<i>p.7</i>
<b>4</b>	Considerations for those living with younger-onset Alzheimer's.....	<i>p.14</i>
<b>5</b>	Support services in your community.....	<i>p.20</i>

*\*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.*

*Money matters was developed from source material created in a collaboration with the National Endowment for Financial Education® (NEFE®). To learn more about NEFE, visit [nefe.org](http://nefe.org).*

# 1. getting started

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Begin putting financial plans in place as soon as possible after a diagnosis. Careful planning can help you secure your financial future. In addition to planning for the cost of care, there are many ongoing financial duties, including:

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

Get started by putting all of the information, resources and support you'll need in place.

## **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 other retirement benefit summaries.
- › Rental income paperwork.
- › Social Security payment information.
- › Stock and bond certificates.

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

## Learn more

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



### **Discuss financial needs and goals**

Discussing financial needs and goals early on enables the person with Alzheimer's to understand the issues and clarify his or her wishes. Involve other concerned individuals as much as possible. Talk about putting financial and care plans in place. If others are available to help, encourage the sharing of caregiving duties. Discuss how finances could be pooled to provide necessary care.

### **Get professional assistance**

Now is also a good time to find professionals who can provide information and assistance. Start by contacting the Alzheimer's Association to discuss the type of assistance you may require.

## Financial advisers

Professional financial advisers, such as financial planners and estate planning attorneys, can help you:

- › Identify potential financial resources.
- › Identify tax deductions.
- › Avoid poor investment decisions that could deplete your finances.

When selecting a financial adviser, check qualifications such as:

- › 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.

## 2. costs you may face

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It's helpful to create a long-term budget. Consider all 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, it will not cover all of them.

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. Ask your financial adviser to be sure.)
- › Full-time residential care services.

### Find local resources

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Care costs vary depending upon where you live. Have a family meeting to discuss how much future care might cost and to make financial plans. Consider using professional legal and financial advisors for guidance.

Visit [alz.org/communityresourcefinder](https://www.alz.org/communityresourcefinder) to locate resources in your area.



## 3. how to cover costs

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A number of financial resources may be available to help cover costs throughout the course of the disease. Some may apply now, while others may help in the future.

### Insurance

#### Health care coverage

Medicare is the primary source of health care coverage for most individuals 65 or 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 any existing health care plans that meet his or her needs active.

Medicare covers:

- ▶ Inpatient hospital care, some doctor fees and other medical items for people with Alzheimer's who are age 65 or 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 qualify for home or inpatient hospice care who are also terminally ill.

Medicare does not cover:

- ▶ Long-term care, including assistance for keeping up 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 and publications.

You also may be able to supplement the person’s Medicare coverage with **Medigap insurance**, which fills gaps in Medicare coverage, such as paying for coinsurance. The more expensive Medigap policies may cover additional items.

## Learn more about Medicare

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- › Call **800.633.4227** or visit **medicare.gov**.
- › Visit **shiptalk.org** to find your State Health Insurance Assistance Program.

## Long-term care insurance

Once an individual is diagnosed with Alzheimer's, he or she will not be able to apply for long-term care coverage. If long-term care insurance is already in place at the time of diagnosis, carefully review the policy to find out:

- › Is Alzheimer's disease covered? Most policies say it is covered, but take a close look to be sure.
- › When can the person with dementia begin to collect benefits? Most policies require a defined level of physical or cognitive impairment.
- › 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 will the policy cover? Examples include skilled nursing home, assisted living and licensed home care.
- › How long after diagnosis will the policy begin to pay? This is often called the **elimination period**.
- › Are there tax implications for getting this money?

## 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 a 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 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. See 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 up most of their own money, under most circumstances.

Most Medicaid dollars go toward nursing home care, but most states have home- and community-care options for some people who qualify for nursing home care. (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 usually is automatically eligible for Medicaid. Those not on SSI must have minimal income and assets. The amount is determined by each state.

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

## Learn more about Medicaid

- › Your state's Medicaid telephone number may be listed in the blue (government) pages of the telephone directory.
- › Call the general information telephone number for your state or county human services or social services department.
- › Visit [cms.hhs.gov/medicaid](https://www.cms.hhs.gov/medicaid).

## Veterans benefits

Those who served in the military for any period of time may qualify for government benefits, including health and long-term care. These benefits often change. Call a Veterans Affairs benefits counselor or visit [va.gov](https://www.va.gov) for the latest information.

## Learn more about veterans benefits

Contact the Department of Veterans Affairs:

- › Call [877.222.8387](tel:877.222.8387) for health care benefits.
- › Call [800.827.1000](tel:800.827.1000) for general benefits.
- › Visit [va.gov](https://www.va.gov).



## Other public programs

Many states have state-funded, long-term care, including:

- › Adult day care.
- › Respite care.

## Learn more about other public programs

- › Alzheimer's Association Community Resource Finder:  
Visit [alz.org/communityresourcefinder](https://www.alz.org/communityresourcefinder).
- › Local Area Agency on Aging or the Eldercare Locator:  
Call [800.677.1116](tel:8006771116).  
Visit [eldercare.gov](https://www.eldercare.gov).

## Tax benefits

Some financial benefits are available for the caregiver from the Internal Revenue Service (IRS):

- › Income tax deductions.
- › Income tax credits.

The person with dementia is likely considered your 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 so you can work. This credit can be subtracted directly from the tax shown on your return.

## Learn more about tax issues

- › Your tax adviser.
- › Internal Revenue Service (IRS):  
Call **800.829.1040**.  
Visit **irs.gov**.



## 4. considerations for those living with younger-onset alzheimer's

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It used to be difficult for individuals with younger-onset Alzheimer's disease (those younger than age 65) to obtain and keep private health insurance. Effective in 2014, the federal government will provide premium subsidies to low- and moderate-income individuals to help them purchase insurance and will offer subsidies to businesses that provide health insurance coverage to retirees aged 55 to 64.

More importantly, insurance companies will be 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, thus 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.

In the interim, the Affordable Care Act, passed in 2010, established Pre-existing Condition Insurance Plans in every state for those who cannot get health insurance because of a pre-existing condition. Visit [alz.org/insurancepdf](http://alz.org/insurancepdf) for more information.

## Work-related and personal resources

If you are diagnosed while still employed, it is critical to 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 age 65 may be COBRA, which stands for the 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.

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**. In other words, even though the medical plan may lapse, an insured individual's disability (in this case, Alzheimer's disease) 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 (overall total) income is usually provided. Benefits paid out of an employer-paid plan 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.

## 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 usually will be 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 probably fall into 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 the 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 off 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. You may be able to adjust your schedule or work fewer hours.

## 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 artwork.

For example, the equity in a home could be converted into income, a process called a **reverse mortgage**. This is a type of home equity loan that allows a person 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 the:

- › Person's age.
- › Home's equity.
- › Lender's interest rate.

Reverse mortgages do not have an impact on Social Security or Medicare benefits, but they may affect qualifying for other government programs.



## **Government assistance**

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

### **Social Security Disability Income (SSDI)**

A worker younger than age 65 may qualify for Social Security disability payments. To qualify, the person must meet the Social Security Administration's definition of disability. Meeting the definition of disability generally 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 he or she has 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:

- › Are age 65 or older.
- › Are disabled or blind.
- › Have very limited income and assets — qualifying asset and income 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**.
- › Visit **ssa.gov**.
- › Use our application checklist **alz.org/SSchecklist**.

### Paying out of pocket

You may choose to pay out of your own pocket for some or most of the care. Review your own resources, such as savings and insurance policies.



## 5. support services in your community

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Many community organizations provide low-cost or even free services, including:

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

### Learn more about support services

- › Alzheimer's Association 24/7 Helpline  
Call **800.272.3900**.
- › Alzheimer's and Dementia Caregiver Center  
Visit **alz.org/care**.
- › Eldercare Locator  
Call **800.677.1116**.  
Visit **eldercare.gov**.
- › Your local religious 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**.

## Support available all day, every day

Contact our 24/7 Helpline at **800.272.3900** for reliable information and referrals.



## Alzheimer's and Dementia Caregiver Center

Visit [alz.org/care](http://alz.org/care) to learn more about all stages of the disease and to get support and find tools to help you navigate through the disease.



## 10 Quick Tips: Money Matters

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1. Discuss finances and future care wishes soon after a diagnosis.
2. Organize and review important documents.
3. Get 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 assistance you can personally provide.
9. Take advantage of low-cost and free community services.
10. Any work-related salary/benefits and personal property should be considered as potential income.



**alz.org/care**

The Alzheimer's and Dementia Caregiver Center provides information and resources, such as:

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



**alz.org/elearning**

Free online workshop:

*Legal and Financial Planning for Alzheimer's Disease*



**800.272.3900**

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



**alz.org/findus**

Chapters in communities nationwide provide support groups, education programs and more.

## alzheimer's association®

The Alzheimer's Association is the world's 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®.**

**800.272.3900 | alz.org®**

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