

# money matters

Helping a person with dementia  
make financial plans



# financial plans for a person with dementia

Putting financial plans in place is important for everyone, but understanding money matters is especially vital for a person with dementia.

Dementia is a general term for the loss of memory, decision-making and other intellectual abilities serious enough to interfere with daily life. Alzheimer's disease is the most common form of dementia.

Upon diagnosis, family and friends should help the individual with dementia make financial plans. The sooner planning begins, the more the person with dementia may be able to participate in decision making.





**The Alzheimer's Association has identified costs you may face as your family member lives with dementia. Inside, you'll also find different ways to help cover those costs.**

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*\*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 the diagnosis has been made. 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 in place all of the information, resources and support you'll need.

## **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

At this point, 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.

Be prepared. Visit [elearning.alz.org](https://elearning.alz.org) to take the free Alzheimer's Association e-learning course: *Legal and Financial Planning for Alzheimer's Disease*



## **Discuss financial needs and goals**

After the diagnosis, determine financial needs and goals. Discussing these early on enables the person to still understand the issues and to clarify his or her wishes.

Involve all 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 might be pooled to provide necessary care.

## **Get professional assistance**

Now is also a good time to find the professionals you will need. They will be valuable sources of information and assistance. Start by contacting the Alzheimer's Association. Our staff can provide you with lists of professionals, including qualified attorneys, financial planners and accountants.

## Financial advisers

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

- Identify potential financial resources
- Identify tax deductions
- Avoid bad 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 for the person with dementia, be sure to consider his or her:

- Age
- Types of assets
- Types of insurance
- Tax issues
- Long-term health outlook
- Future care needs

## 2. costs you may face

Begin planning a long-term budget immediately. 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.

Costs may include:

- Ongoing medical treatment for Alzheimer's-related symptoms, diagnosis and follow-up visits
- Treatment for other medical conditions
- Prescription drugs
- Personal care supplies
- Adult day care services
- In-home care services
- Full-time residential care services

To learn about care options in your area, contact the Alzheimer's Association or visit the Alzheimer's Association Community Resource Finder at [communityresourcefinder.org](https://www.alz.org/communityresourcefinder).



### 3. how to cover the costs

A number of financial resources may be available to help cover the 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 active any existing health care plans that meet his or her needs.

Medicare covers inpatient hospital care and some of the doctors' 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.

If the person with dementia is younger than 65, Medicare can provide coverage if he or she has been on Social Security disability for at least 24 months.





Medicare provides some home health care, including skilled nursing care and rehabilitation therapy, under certain conditions.

Medicare will only pay for up to 100 days of skilled nursing home care under limited circumstances. However, custodial long-term nursing home care is not covered. Medicare will pay for home or inpatient hospice care for qualified people who are terminally ill.

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 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**

Call **800.633.4227**

Visit **medicare.gov**

or find your state’s SHIP at **shiptalk.org**

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

More important, 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 health care reform law 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/national/documents/Preexisting\\_Condition\\_Insurance\\_Plans.pdf](http://alz.org/national/documents/Preexisting_Condition_Insurance_Plans.pdf)** for more information.

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'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.

## 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 upon diagnosis, carefully review the policy to find out:

- Is Alzheimer's disease covered? Most policies say they cover it, but take a closer 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.

## Work-related and personal resources

### Employment

In the early stages of dementia, it's often possible for a person to continue working. This may mean adapting job duties to fit the current ability level.

The **Americans with Disabilities Act (ADA)** offers limited protection to those with Alzheimer's. The ADA requires that companies with at least 15 or more employees make "reasonable" accommodations for job applicants and employees with physical or mental disabilities. For example, an employer may switch the worker to a less demanding job or reduce work hours.

Be sure the employer is educated about Alzheimer's disease and its symptoms. If you think the person with dementia has been treated unfairly at work, first try to resolve the issue with the employer. If that doesn't work, you can file a claim under the ADA through the federal Equal Employment Opportunity Commission or under your state's disability law.

### Employee benefits

If the person with dementia continues to work:

- Review the employer's benefits handbook
- Ask the benefits specialist what benefits may be available, e.g., the employer may provide paid sick leave or other short-term disability benefits (usually for one year or less)
- Keep written confirmation of all benefits

The employee may be able to convert an employer-provided life insurance policy to an individual plan. If the person with dementia is still working, he or she may have available a **flexible spending account**. This allows payment for out-of-pocket medical expenses with pretax dollars, for potential savings of about 20 to 30 percent.

## 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.

## Personal savings, investments and property

Investment assets such as the following can be sources of income:

- 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. These programs provide income support or long-term care services to people who are eligible.

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

A worker who is 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 the Compassionate Allowance Initiative, those with younger-onset Alzheimer's disease are considered eligible for SSDI as long as they meet all





other criteria. They are 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.

### **Supplemental Security Income (SSI)**

SSI guarantees a minimum monthly income for people who:

- Are age 65 or older,
- Are disabled or blind, and
- Have very limited income and assets — these 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 you think he or she qualifies 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**

Application checklist

**[alz.org/documents/national/SSDI/checklist.pdf](https://www.alz.org/documents/national/SSDI/checklist.pdf)**

## 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 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 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 results 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 [communityresourcefinder.org](https://www.alz.org/communityresourcefinder)
- Local Area Agency on Aging or the  
Eldercare Locator:  
Call **800.677.1116**  
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

- *Taxes and Alzheimer's disease*, available at [alz.org](https://www.alz.org)
- Your tax adviser
- Internal Revenue Service (IRS):  
Call **800.829.1040**  
Visit [irs.gov](https://www.irs.gov)

## Financial help that you provide

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.

### 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.

### In-home care

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.



## Support services in your community

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



**Learn more about financial issues and planning by contacting the Alzheimer's Association or the following resources:**

**Alzheimer's Association Alzheimer's Navigator™**  
[alzheimersnavigator.org](http://alzheimersnavigator.org)

**Alzheimer's Association free e-learning course:**  
*Legal and Financial Planning for Alzheimer's Disease*  
[elearning.alz.org](http://elearning.alz.org)

**BenefitsCheckUp**  
[benefitscheckup.org](http://benefitscheckup.org)

**Eldercare Locator**  
[eldercare.gov](http://eldercare.gov)  
800.677.1116

**Financial Planning Association**  
[fpanet.org](http://fpanet.org)  
800.322.4237

**Internal Revenue Service**  
[irs.gov](http://irs.gov)  
800.829.1040

**National Academy of Elder Law Attorneys**  
[naela.org](http://naela.org)

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# 10 quick tips money matters

- 1** Don't put off talking about finances and future care wishes.
- 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** Work-related salary/benefits and personal property should be considered as potential income.
- 7** Find out for which government programs you are eligible.
- 8** Learn about income tax breaks for which you may qualify.
- 9** Explore financial assistance you can personally provide.
- 10** Take advantage of low-cost and free community services.

**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®.**

For information and support,  
contact the Alzheimer's Association:

**800.272.3900**  
**alz.org**

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