

alzheimer's  association[®]

money matters

Helping the person
with dementia
settle financial issues



the compassion to care, the leadership to conquer



Putting financial plans in place is important for everyone, but settling money matters is especially vital for the 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.

Once a person is diagnosed, family and friends should help the person make financial plans. The sooner plans can begin, the more the person with dementia may be able to participate.



The Alzheimer’s Association has identified costs you may face as your loved one lives with dementia. Inside, you’ll also find different ways to help cover those costs:

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***Money matters** 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 helping the person with dementia put financial plans in place as soon as the diagnosis has been made. Careful planning can help secure a healthy financial future for both of you.

As the caregiver, you may be responsible for a wide range of 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 go over all financial and legal documents, even if you're already familiar with them. This is especially crucial if you've not been involved in the family's legal or money matters up to this point.



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

Ask the person with dementia if he or she knows where the documents might be filed.

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.



Discuss your loved one's wishes

After the diagnosis, ask the person with dementia about his or her financial needs and goals.

Have this discussion as early as possible, while the person is still able to understand the issues and to tell you what his or her wishes are.

Gather family members and close friends to talk with the person about putting financial and care plans in place.

Encourage the sharing of caregiving duties. Supporting a person through this illness should not be tackled alone.

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 your local Alzheimer's Association office. Our staff can match you with the right professional services, 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

Also, ask the financial adviser whether he or she is familiar with elder care or terminal-illness issues.

Legal advisers

Seek an experienced elder law attorney to help:

- Address estate planning issues
- Prepare legal documents

If you cannot afford legal assistance, 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



Review your own finances

The person with dementia may not have all the money he or she will need to pay for care. Consider whether you are able to provide some financial assistance and, if so, how much you may wish to contribute.

- Review your own assets, such as savings, investments and insurance plans.
- If the person with Alzheimer's depends on you for money, you may be eligible for medical expense deductions and dependent care credits on your tax return.
- Consider what plans need to be in place in case something happens to you. Your role in providing financial support is now more important than ever.
- You may need to increase your own life insurance or disability insurance to provide a financial safety net for yourself and anyone else who depends on your income.
- This situation often calls for changing your priorities, including your approach to investing. Financial advisers who have experience working with terminally ill clients can help you make decisions about how to adjust your investments.

2 *Costs you may face*

Begin planning a long-term budget now. 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, including diagnosis and follow-up visits
- Treatment for other medical conditions associated with aging
- Prescription drugs
- Personal care supplies
- Adult day care services
- In-home care services
- Full-time residential care services

These costs vary – sometimes drastically – depending upon where you live.

Housing costs can have a major financial impact.

Explore housing options now, including what each will cost and how they might be paid for:

- **Nursing homes** average \$42,000 a year, but can run \$70,000 or more in some areas
- **Assisted living** within an Alzheimer's unit may cost less than nursing home care, but it may not be appropriate for the late stages of the disease
- **Hospice** in the home is an option during the final months of the disease

When making decisions, involve the person with dementia as much as reasonably possible. Your financial adviser can help design a plan that's unique to the person's financial needs – both immediate and long-term.



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, others in the future.

Insurance

Health-care coverage

Because most people diagnosed with dementia are age 65 or older, the No. 1 source of their health coverage is usually **Medicare**.

However, private insurance, a group employee plan or retiree health coverage may also be in effect. No matter what 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. Beginning Jan. 1, 2006, Medicare will also cover 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.

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



The person with dementia may be able to choose a **“managed care” form of Medicare**, such as:

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

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

To learn about the many Medicare options, and whether they are right for the person with dementia, read each plan carefully. You can also contact your State Health Insurance Assistance Program (SHIP) for free one-on-one help and publications. Call us at 1.800.272.3900, and ask for the SHIP location nearest you.

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 1.800.633.4227

Visit www.medicare.gov or find your state’s SHIP at www.medicare.gov/contacts/static/allStateContacts.asp



If the person with dementia is **younger than 65 years old** (considered *early-onset Alzheimer's*), he or she most likely will have private insurance, a group employee health plan or perhaps retiree medical coverage.

If he or she changes policies, check how soon expenses from Alzheimer's disease will be covered under the new policy.

Most policies do not cover “pre-existing conditions” for up to a year. However, these exclusion periods (when coverage is not provided) don't apply in all cases.

The exclusion period won't apply if the person:

- Has been covered for the past 12 or 18 months, depending on the policy,
- Has already met an exclusion period, and
- Has not been without health coverage for more than 62 days

COBRA may be another option for a person younger than age 65.

COBRA 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 his or her 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 more to cover administrative costs.

COBRA can be especially helpful until the person with dementia:

- Gets new coverage through an employer, or
- Becomes eligible for Medicare

You must activate the COBRA option within 60 days of when the person with dementia leaves work or has work hours reduced.

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.

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 benefits from a personal disability policy are not taxed as income.

Long-term care insurance

Find out if the person with dementia has a long-term care insurance policy. Few people do.

If so, carefully review the long-term care policy to find out:

- Is Alzheimer's disease covered? Most policies say they cover Alzheimer's disease, 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, custodial care 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?

Unfortunately, after symptoms of Alzheimer's disease appear, it is usually no longer possible to purchase many types of insurance, like disability and long-term care insurance.



Life insurance

Life insurance can be a valuable 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 may 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

The person with dementia may still like to continue working. This is often possible in the early stages of the disease. It may mean adapting job duties to fit his or her current level of ability.

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. For example, 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

Retirement plans include:

- Individual retirement accounts (IRAs)
- Annuities

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

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

The person with dementia 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 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 the person with dementia becomes disabled or blind. (See "Government assistance" on pages 21 and 22.)



Personal savings, investments and personal property

Investment assets like these can be sources of income:

- Stocks
- Bonds
- Savings accounts
- Real estate
- Personal property, such as jewelry or artwork

For example, a home could be sold and the money invested.

Or the equity in the 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 for SSDI, 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.

Family members also may be eligible to receive SSDI benefits.

File for SSDI benefits as soon as possible:

- Benefits do not begin until the sixth full month of disability.
- The Social Security Administration often takes a long time to decide whether to approve a claim.
- It's not unusual for disability applicants to be rejected initially. Be prepared to appeal. Your professional advisers can assist in this process.

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 1.800.772.1213

Visit www.ssa.gov



Medicaid

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

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, so choices are limited.)

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. For example, giving away assets can delay Medicaid eligibility for nursing home care.

Be sure you are fully aware of the legal and financial results of transferring property and wealth. Check with your legal adviser before you proceed.

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 www.cms.hhs.gov/medicaid



Veterans benefits

Veterans may qualify for government benefits, including health and long-term care. These benefits often change, so call a Veterans Affairs benefits counselor or visit the VA Web site for the latest information.

Learn more about veterans benefits

Contact the Department of Veterans Affairs:

Call 1.877.222.8387 for health care benefits

Call 1.800.827.1000 for general benefits

Visit 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

- Local Alzheimer's Association office
- Local Area Agency on Aging or the Eldercare Locator:
Call 1.800.677.1116
Visit 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

- Alzheimer's Association publication, *Taxes and Alzheimer's disease*, available from your local chapter or at www.alz.org
- Your tax adviser
- Internal Revenue Service (IRS):
Call 1.800.829.1040
Visit 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.

If you're considering cutting back on your work hours to increase the time you spend caregiving, examine how this will affect your income. Review the expenses you listed earlier. Make sure the reduced income will still cover expenses.

If you hire a professional to work in your home to help with caregiving, 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

- Your local Alzheimer's Association office
- Eldercare Locator:
Call 1.800.677.1116
Visit www.eldercare.gov
- Your local religious organization
- Hospital social worker or discharge planner

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

10 quick tips for the caregiver

Money matters

- 1 Don't delay in asking what your loved one's wishes are
- 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

The Alzheimer's Association, the world leader in Alzheimer research, care and support, is dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer's.

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

1.800.272.3900

www.alz.org

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