

Planning for the Future

Legal, Financial and Care Considerations After a Dementia Diagnosis

A diagnosis of Alzheimer's or another dementia is life-changing, and thinking about the future may cause fear and uncertainty. However, it's critical to begin planning for legal, financial and care needs. For the person living with dementia, this process can be an empowering opportunity to voice their wishes. The sooner planning begins, the more they can participate in making these important decisions.

Note: This brochure contains only general information on legal, financial, care and medical issues and is not meant to take the place of professional advice. Laws vary by state and are constantly changing. As a result, we make no warranty or guarantee of the accuracy or reliability of the information contained herein. You should consult a lawyer and/or financial advisor before acting on any information contained herein for advice specific to your situation.

Getting started

Start by thinking about long-term goals. Identify trusted family members or close friends who can provide support and be involved in planning conversations. Alzheimer's is a progressive disease — meaning it worsens over time — so it's vital to begin having these discussions as soon as possible after a diagnosis to ensure the person living with dementia can participate in decision-making as long as possible.

Gather important documents

Organize and carefully review existing legal and financial documents. It's important to access or obtain financial documents that outline existing assets, expenses and incomes so that this information can guide decisions about future care and related costs. Up-to-date legal documents help ensure the person's wishes will be carried out and enable others to act on their behalf when needed.

While making plans, the person living with Alzheimer's should include someone they trust. Share important passwords and the location of key documents with this person in case of an emergency or unforeseen event.

Examples of 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).

Examples of legal documents include:

- Advance directives, which specify decisions about end-of-life care.
- Durable powers of attorney for finances and health care, which allow another person to make financial and health-related decisions when the person living with dementia is no longer able.
- A living will, which expresses the person's wishes for medical treatment near the end of life.
- A standard will, which provides information about how the person's estate will be distributed after death.

Use our worksheet at alz.org/assetsworksheet to get organized.

Seek professional assistance

If the person's financial or legal situation is complex or additional assistance is needed, consider contacting a professional. A financial advisor, such as a financial planner or an estate planning attorney, can help identify potential resources and outline a plan to make financial resources last. A legal professional, such as an elder law attorney, can help navigate legal decisions and documents.

Even if you can't hire a lawyer or financial advisor, many financial and legal forms can be completed without professional help. Planning ahead is beneficial and attainable for every person, regardless of their financial situation.

Visit the Alzheimer's Association & AARP Community Resource Finder (alz.org/CRF), a database of dementia and aging-related resources, to find an elder law attorney in your area. You can also contact your local Area Agency on Aging or use their Eldercare Locator (eldercare.acl.gov; **800.677.1116**) to find free legal resources.

Care Considerations

Building a care team

Take the time now to build a care team: the group of people a person living with dementia will partner with and rely on to provide help, care, support and connection throughout the course of the disease. A care team may include family, close friends, neighbors, doctors, and members of a faith community or other social groups.

Developing a support network can help the person lead a more productive, active and engaged life.

Care options

The type of care needed as the disease progresses will likely depend on how independently the person performs day-to-day tasks. It's never too early to learn about different types of care and explore options. A few common types include:

- **In-home care** — provides services such as medical care and/or assistance with daily activities in the home rather than in a care community.
- **Adult day centers** — offers opportunities to socialize and participate in activities in a safe, supervised setting.
- **Residential care** — offers a communal living environment and, depending on the setting, provides varying levels of care (e.g., retirement housing, assisted living, nursing homes).

Financial Planning

Identifying costs

To prepare for financial needs during the course of Alzheimer's or another dementia, it's important to consider all costs that may arise now and in the future. Since Alzheimer's is a progressive disease, care needs will increase over time. Some typical care costs include:

- Ongoing medical treatment.
- Prescription drugs.
- Personal care supplies.
- Adult day services.
- In-home care services.
- Full-time residential care communities.

In addition to planning for the cost of care, there are many ongoing financial responsibilities to address, including:

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

Covering costs

Start by evaluating current income and spending. Write down how much money comes in and out of accounts each month. This can help the person understand overall patterns and make choices about where to reduce spending, if necessary. Try to set aside more in savings to prepare for unexpected expenses. Even modest monthly savings can make a big difference.

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.

Some common options include:

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.

Medicare will pay for some care costs — but not all — so read each plan carefully. Learn about the many health care options available through Medicare by calling **800.633.4227** or visiting **Medicare.gov**. You can also contact your State Health Insurance Assistance Program (SHIP) for free one-on-one help. Visit **SHIPhelp.org**.

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.

Life insurance

Life insurance can be a source of income. It may be possible to borrow from a life insurance policy's cash value or receive part of the policy's face value as a loan.

Medicaid

Medicaid is a state-administered program jointly funded by federal and state governments. It pays for medical care for people with very low incomes and, with some exceptions, long-term care for people who have used most of their own money for care-related expenses.

Veterans benefits

Those who served in the armed forces for any period of time may qualify for government benefits, including health care and long-term care. Visit VA.gov or contact the Department of Veterans Affairs (call 877.222.8387 for health care benefits or 800.827.1000 for general benefits).

Considerations for younger-onset Alzheimer's

For individuals diagnosed with younger-onset Alzheimer's — those under age 65 — certain insurance and government 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.

If the person is still working, it's critical to learn about and take advantage of the benefits available through their employer before leaving the job.

Resources for younger-onset Alzheimer's:

Visit alz.org/younger-onset for information and resources to help navigate the unique challenges of younger-onset Alzheimer's disease.

Legal Considerations

Legal capacity

During the legal planning process, you may hear the term “legal capacity.” Legal capacity is the ability to understand and appreciate the consequences of one's actions and to make rational decisions. It often pertains to a person's ability to execute (put in place by signing) a legal document. As long as the person living with dementia has legal capacity, he or she should be involved in making decisions about the future.

Legal capacity requirements can vary from one legal document to another. A lawyer can help navigate the requirements to prove capacity for a particular document. Creating a legal document does not mean that the person's rights are immediately revoked. The legal forms completed now will only be implemented when the person living with dementia no longer has the capacity to make decisions.

Legal documents

Legal documents are used to specify the person's wishes and designate people who can act on their behalf in the future. Discuss and be sure the individual living with dementia understands all legal documents before signing them. Review any existing

documents to confirm that the information is accurate and up-to-date.

Advance directives

Advance directives, such as living wills and durable powers of attorney for health care, are legal documents that detail preferences about treatment and care, including end-of-life wishes.

Most people don't need an attorney to prepare advance directives. Many states have designed advance directive templates that you can complete on your own. If planning without the help of a lawyer, these forms can be obtained from the state health department, local library or office supply stores.

Power of attorney

A power of attorney document allows a person (the principal) to name another individual (an agent or attorney-in-fact) to make financial and other important decisions on their behalf once they no longer can. Typically, the agent is a spouse, domestic partner, trusted family member or friend.

The agent is responsible for acting according to the person's wishes and best interests, and should be chosen carefully. Plan to have a thorough conversation with the agent about what the responsibility entails.

Power of attorney documents should be written so that they are "durable," meaning they are valid even if the person living with dementia is unable to make decisions in the future. It is important to have durable powers of attorney for both finances and health care.

Standard will

A standard will provides information about how the person's estate will be distributed upon death. In the will, an executor (person who will manage the estate) and beneficiaries (those who will receive the assets in the estate) may be named. The executor named in the will has no legal authority while the person with dementia is alive.

Living trust

A living trust allows the person to pool financial assets in one place (a trust) and provide instructions about how to handle these resources when they are no longer able. To do this, a trustee must be appointed to follow their instructions.

End-of-Life Decisions

Discussing end-of-life wishes with family and friends may be difficult and emotional. But these conversations and the completion of important legal documents (like advance directives) can offer peace of mind. Some questions the person should consider include:

- Where do I want to spend the end of my life (e.g., at home, in a residential care community, etc.)?
- What are my religious, spiritual or cultural beliefs about the end of life? How can these be respected and honored?
- Do I want all available life-sustaining treatment measures to be taken? Are there any treatments I do not want?

Understanding treatment options

Medical care in the late stage of Alzheimer's may include the use, withdrawal, limitation or refusal of treatment. Advance directives should include the person's wishes regarding life-sustaining treatments. Depending on the situation, aggressive medical care may not always prolong life and may lead to discomfort. Some examples of life-sustaining treatments include: respirators, feeding tubes, IV hydration and cardio pulmonary resuscitation (CPR).

Do not resuscitate (DNR)

A person living with dementia may request that their physician sign a "do not resuscitate" (DNR) form, which is a legal order that instructs medical personnel to not perform lifesaving interventions, particularly if CPR or defibrillation is needed. Without a DNR, health care professionals are required to perform resuscitation.

A DNR order does not affect other types of treatment. For instance, a person can continue to receive chemotherapy, antibiotics, dialysis or any other appropriate regimens.

Some states do not recognize DNR orders initiated out of state, so check local laws. End-of-life wishes should include how the person would like to experience care at this stage. Instead of trying to prolong life, hospice care focuses on dignity, comfort and quality of remaining life. Care can be provided at home, or in a hospital or residential care setting.

Brain autopsy and brain donation

The person may decide to arrange for a brain autopsy or brain donation after death — both may provide scientists with a better understanding of Alzheimer's.

Brain autopsy involves a researcher or physician conducting an examination after death to look for the hallmark plaques and tangles found in brains affected by the disease. Brain autopsy may involve a cost to the family. If you are interested, put plans in place as early as possible.

Brain donation provides an important opportunity to help researchers better understand Alzheimer's and other dementias, which can pave the way for scientific breakthroughs and improved treatments. If you are interested, put plans in place as early as possible. Making arrangements early allows scientists to learn more from the brain and make the most of this precious gift. Visit alz.org/braindonation for more information.

Resources for support:

- Call the **Alzheimer's Association 24/7 Helpline (800.272.3900)** to speak confidentially with specialists and master's-level care consultants.
- Find a support group (alz.org/CRF).
- Join our online community, **ALZConnected** (alzconnected.org), to connect with other people who are facing dementia.
- Contact the Financial Planning Association (FPANET.org; **800.322.4237**).
- Get legal help through the National Academy of Elder Law Attorneys (NAELA.org).

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