

Legal and Financial Planning for People with Alzheimer's Disease

FACT SHEET

Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease (AD). Legal and medical experts encourage people recently diagnosed with a serious illness—particularly one that is expected to cause declining mental and physical health—to examine and update their financial and health care arrangements as soon as possible. Basic legal and financial instruments, such as a will, a living trust, and advance directives, are available to ensure that the person's late-stage or end-of-life health care and financial decisions are carried out.

A complication of diseases such as Alzheimer's is that the person may lack or gradually lose the ability to think clearly. This change affects his or her ability to participate meaningfully in decision making and makes early legal and financial planning even more important. Although difficult questions often arise, advance planning can help people with AD and their families clarify their wishes and make well-informed decisions about health care and financial arrangements.

When possible, advance planning should take place soon after a diagnosis of early-stage AD while the person can participate in discussions. People with early-stage AD are often capable of understanding many aspects and consequences of legal decision making. However, legal and medical experts say that many forms of planning can help the person and his or her family even if the person is diagnosed with later-stage AD.

There are good reasons to retain the services of a lawyer when preparing advance planning documents. For example, a lawyer can help interpret different State laws and suggest ways to ensure that the patient's and family's wishes are carried out. It's important to understand that laws vary by State, and changes in situation—for instance, a divorce, relocation, or death in the family—can influence how documents are prepared and subsequently maintained.

Legal, Financial, and Health Care Planning Documents

When families begin the legal planning process, there are a number of strategies



Alzheimer's Disease Education & Referral (ADEAR) Center
A Service of the National Institute on Aging
National Institutes of Health
U.S. Department of Health and Human Services



and legal documents they need to discuss. Depending on the family situation and the applicable State laws, some or all of the following terms and documents may be introduced by the lawyer hired to assist in this process. Broadly speaking, these documents can be divided into two groups:

- documents that communicate the health care wishes of someone who may no longer be able to make health care decisions
- documents that communicate the financial management and estate plan wishes of someone who may no longer be able to make financial decisions

Advance Directives for Health Care

Advance directives for health care are documents that communicate the health care wishes of a person with AD. These decisions are then carried out after the person no longer can make decisions. In most cases, these documents must be prepared while the person is legally able to execute them.

A **Living Will** records a person's wishes for medical treatment near the end of life. It may do the following:

- specify the extent of life-sustaining treatment and major health care the person wants
- help a terminal patient die with dignity
- protect the physician or hospital from liability for carrying out the patient's instructions
- specify how much discretion the person gives to his or her proxy (discussed below) about end-of-life decisions

A **Durable Power of Attorney for Health Care** appoints a designated

person, sometimes called an agent or proxy, to make health care decisions when the person with AD no longer can do so.

Depending on State laws and the person's preferences, the proxy might be authorized to:

- refuse or agree to treatments
- change health care providers
- remove the patient from an institution
- decide about making organ donations
- decide about starting or continuing life support (if not specified in a living will)
- decide whether the person with AD will end life at home or in a facility
- have access to medical records

A Do Not Resuscitate (DNR) Order

instructs health care professionals not to perform cardiopulmonary resuscitation if a person's heart stops or if he or she stops breathing. A DNR order is signed by a doctor and put in a person's medical chart.

Access to private medical information is closely regulated. The person with AD must state in writing who can see or use personal medical records.

Advance Directives for Financial and Estate Management

Advance directives for financial and estate management must be created while the person with AD still can make these decisions (sometimes referred to as "having legal capacity" to make decisions). These

directives may include some or all of the following:

A **Will** indicates how a person's assets and estate will be distributed upon death. It also can specify:

- arrangements for care of minors
- gifts
- trusts to manage the estate
- funeral and/or burial arrangements

Medical and legal experts say that the newly diagnosed person with AD and his or her family should move quickly to make or update a will and secure the estate.

A **Durable Power of Attorney for Finances** names someone to make financial decisions when the person with AD can no longer do so. It can help people with AD and their families avoid court actions that may take away control of financial affairs.

A **Living Trust** provides instructions about the person's estate and appoints someone, often referred to as the trustee, to hold title to property and funds for the beneficiaries. The trustee follows these instructions after the person no longer can manage his or her affairs.

The person with AD also can name the trustee as the health care proxy through the durable power of attorney for health care.

A living trust can:

- include a wide range of property
- provide a detailed plan for property disposition
- avoid the expense and delay of probate (in which the courts establish the validity of a will)

- state how property should be distributed when the last beneficiary dies and whether the trust should continue to benefit others

Who Can Help?

Health Care Providers—Health care providers cannot act as legal or financial advisors, but they can encourage planning discussions between patients and their families. Qualified clinicians can also guide patients, families, the care team, attorneys, and judges regarding the patient's ability to make decisions.

Elder Law Attorneys (ELAs)—An ELA helps older people and families:

- interpret State laws
- plan how their wishes will be carried out
- understand their financial options
- learn how to preserve financial assets while caring for a loved one

The National Academy of Elder Law Attorneys and the American Bar Association can help families find qualified ELAs. See the list of resources section at the end of this fact sheet for more information.

Geriatric Care Managers (GCMs)—GCMs are trained social workers or nurses who can help people with AD and their families:

- discuss difficult topics and complex issues
- address emotional concerns
- make short- and long-term plans
- evaluate in-home care needs
- select care personnel

- coordinate medical services
- evaluate other living arrangements
- provide caregiver stress relief

Other Advance Planning Advice

Start discussions early. The rate of decline differs for each person with AD, and his or her ability to be involved in planning will decline over time. People in the early stages of AD may be able to understand the issues, but they may also be defensive or emotionally unable to deal with difficult questions. Remember that not all people are diagnosed at an early stage. Decision making already may be difficult when AD is diagnosed.

Review plans over time. Changes in personal situations—such as a divorce,

relocation, or death in the family—and in State laws can affect how legal documents are prepared and maintained. Review plans regularly, and update documents as needed.

Reduce anxiety about funeral and burial arrangements. Advance planning for the funeral and burial can provide a sense of peace and reduce anxiety for both the person with AD and the family.

Resources for Low-Income Families

Families who cannot afford a lawyer still can do advance planning. The following resources can help:

- Samples of basic health planning documents can be downloaded from State government websites.
- Area Agency on Aging officials may provide legal advice or help.

Other possible sources of legal assistance and referral include:

- State legal aid offices
- the State bar association
- local nonprofit agencies
- foundations
- social service agencies

Summary

Facing AD can be emotionally wrenching for all concerned. A legal expert and members of the health care team can help the person and family address end-of-life issues. Advance health care and financial planning can help people diagnosed with AD and their families confront tough questions about future treatment, caregiving, and legal arrangements.

Steps for Getting Your Affairs in Order

- **Gather everything you can about your income, property, investments, insurance, and savings.**
- **Put copies of legal documents and other important papers in one place.** You could set up a file, put everything in a desk or dresser drawer, or just list the information and location of papers in a notebook. If your papers are in a bank safe deposit box, keep copies in a file at home. Check regularly to see if there's anything new to add.
- **Tell a *trusted* family member or friend where you put your important papers.** You don't need to tell this friend or family member your personal business, but someone should know where you keep your papers in case of emergency. If you don't have a relative or friend you trust, ask a lawyer to help.

Overview of Medical, Legal, and Financial Planning Documents	
Medical Document	How It Is Used
Living Will	Describes and instructs how the person wants end-of-life health care managed
Durable Power of Attorney for Health Care	Gives a designated person the authority to make health care decisions on behalf of the person with AD
Do Not Resuscitate Form	Instructs health care professionals not to perform CPR in case of stopped heart or stopped breathing
Legal/Financial Document	How It Is Used
Will	Indicates how a person's assets and estate will be distributed among beneficiaries after his/her death
Durable Power of Attorney for Finances	Gives a designated person the authority to make legal/financial decisions on behalf of the person with AD
Living Trust	Gives a designated person (trustee) the authority to hold and distribute property and funds for the person with AD

For More Information

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250
800-438-4380 (toll-free)
www.nia.nih.gov/Alzheimers

A service of the National Institute on Aging, the ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to AD. Staff members answer telephone, email, and written requests and make referrals to local and national resources. The ADEAR website offers free publications in English and Spanish, email alert and online *Connections* newsletter subscriptions, the AD clinical trials database, the AD Library database, and more. Additional helpful resources include:

- Legal and Financial Issues: A List of Resources at www.nia.nih.gov/Alzheimers/Publications/legal.htm

- AD Lib (searchable online database) at www.nia.nih.gov/Alzheimers/Resources/SearchHealthLiterature

Eldercare Locator

800-677-1116 (toll-free)
www.eldercare.gov

Families often need information about community resources, such as home care, adult day care, and nursing homes. Contact the Eldercare Locator to find these resources in your area. The Eldercare Locator is a service of the Administration on Aging.

National Institute on Aging Information Center

P.O. Box 8057
Gaithersburg, MD 20898-8057
800-222-2225 (toll-free)
800-222-4225 (TTY/toll-free)
www.nia.nih.gov/HealthInformation
www.nia.nih.gov/Espanol

This service of the NIA offers many helpful publications, including:

- *Age Page: Getting Your Affairs in Order*

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- *End of Life: Helping with Comfort and Care*
 - *So Far Away: Twenty Questions for Long-Distance Caregivers*

National Library of Medicine MedlinePlus

<http://medlineplus.gov>

Search for:

“Advance Directives”

“End-of-Life Issues”

NIH Senior Health

www.nihseniorhealth.gov

Visit this senior-friendly website from the National Institute on Aging and the National Library of Medicine offering health information for older adults. Special features make it simple to use. For example, you can click on a button to have the text read out loud or to make the type larger.

Other Organizations

AARP

601 E Street, NW

Washington, DC 20049

888-OUR-AARP (888-687-2277; toll-free)

www.aarp.org/Families/legal_issues

Aging with Dignity

P.O. Box 1661

Tallahassee, FL 32302-1661

888-5WISHES (888-594-7437; toll-free)

www.agingwithdignity.org

Alzheimer's Association

225 N. Michigan Avenue, Suite 1700

Chicago, IL 60601-7633

800-272-3900 (toll-free)

866-403-3073 (TDD/toll-free)

www.alz.org

American Bar Association

Commission on Law and Aging

740 15th Street, NW

Washington, DC 20005-1022

202-662-8690

www.abanet.org/aging

Family Caregiver Alliance

180 Montgomery Street, Suite 1100

San Francisco, CA 94104

800-445-8106 (toll-free)

www.caregiver.org

National Academy of Elder Law Attorneys

1604 North Country Club Road

Tucson, AZ 85716

520-881-4005

www.naela.org

National Association of Professional Geriatric Care Managers

1604 North Country Club Road

Tucson, AZ 85716

520-881-8008

www.caremanager.org

National Hospice and Palliative Care Organization

NHPCO Marketplace

1700 Diagonal Rd., Suite 625

Alexandria, VA 22314

800-658-8898 (toll-free)

877-658-8896 (Spanish/toll-free)

www.caringinfo.org/AdvanceDirectives