

end-of-life decisions

Honoring the wishes
of a person with
Alzheimer's disease



Preparing for the end of life

When a person with late-stage Alzheimer's — a degenerative brain disease — nears the end of life and is no longer able to make decisions, families must make choices.

Ideally, the person with dementia has put in place advance directives to specify his or her wishes. Without such directives, or if certain issues have not been addressed, families must make decisions based on what they believe the person would want. End-of-life decisions should respect the person's values and wishes while maintaining comfort and dignity.

The Alzheimer's Association can help you prepare for making end-of-life decisions such as:

- › Advocating for the kind of care that is based on the expressed wishes of the person with dementia
- › Refusing, starting, limiting or ending medical treatments
- › Facilitating care that is focused on comfort
- › Arranging for a brain autopsy





The following information may be helpful for when a person with dementia nears the end of life:

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1. honoring the person's wishes

Advance directives

A person with dementia has the legal right to limit, refuse or stop medical treatments. These wishes are usually expressed through advance directives — legal papers that specify the type of medical care a person wants to receive once he or she can no longer, due to incapacity, make such decisions, and who should make those decisions.

Advance directives should be made when the person with dementia still has legal capacity — the level of judgment and decision-making ability needed to sign official documents or to make medical and financial decisions. These documents should be completed as soon as possible following a diagnosis of dementia. Contact the Alzheimer's Association for information about making legal plans.

If advance directives are not in place, the family must be prepared to make decisions consistent with what they believe the person would have wanted while acting in that person's best interest. Laws may vary by state, but a spouse or adult child may have the right to make the decision to stop medical treatments if no advance directive exists.

Types of advance directives:

Living will

A living will is a set of written instructions that provides specific preferences about the kind of medical treatment a person would or would not want to have. It does not designate someone to make medical decisions on the person's behalf, but rather allows the person to communicate wishes about future care.

Durable power of attorney for health care

A durable power of attorney for health care allows a person to choose a partner, family member or trusted friend to make decisions about care and treatment when he or she is no longer able.

Advance directives forms

Make sure to use the advance directives forms that are recognized in the state where care is, or will be, provided. The Alzheimer's Association can assist you with locating these forms.

Ensure advance directives are followed:

1. Give copies of advance directives to all those involved in decisions

- › Family members
- › Doctors
- › Other health care providers

Have advance directives placed in the individual's medical record. If the person is transferred to a new setting, provide copies to those newly involved in caregiving.

2. Discuss advance directives

Family members should understand, respect and abide by the person's wishes. Discuss these wishes to work out any disagreements and help prevent future conflict or crisis decision making. Advance directives should also be discussed with doctors and other health care providers to ensure they're aware of their patient's wishes.

If a conflict develops between family members, residential care facilities and hospitals often offer social services that can help. You may also consider mediation services as a way to reach consensus. Single people or those in a domestic partnership should designate the appropriate individual to carry out their advance directive if it is not a family member.

3. Stay involved in medical decisions

Work with the health care team to create and follow a care plan based on the advance directives. Make sure you are kept informed of any changes in your family member's condition that may prompt the need for new decisions.

2. understanding treatment options at end of life

Be aware of the range of medical care available when making decisions to use, withdraw, limit or refuse treatment for the person with Alzheimer's. Deciding on treatment options in the late stage of the disease can be one of the most difficult decisions that families face.

Arming yourself with information and discussing options with your care team can be helpful. It's also important to ask the medical team questions and to make sure you understand which treatments are suggested and why they are appropriate.

Aggressive medical care

Individuals who have completed advance directives may have addressed the use of aggressive medical care — measures taken to keep a person alive. The essence of advance directives is to educate the family about what the person wants so that they can make informed decisions.



Respirators

If a person with Alzheimer's is no longer able to breathe independently, a respirator may be used to assist with breathing. While a respirator can help keep a person alive, it may also cause the person's body to undergo unneeded stress and can cause greater discomfort.

Feeding tubes

Feeding tubes are sometimes used if a person has a hard time eating or swallowing, which often happens in late-stage Alzheimer's disease. However, there is no proof that tube feeding has any significant benefits or extends life.

Tube feeding can also result in:

- › Infections
- › Need for physical restraints (the person may try to pull out the tube, causing injury)

There are other ways to feed a person with late-stage Alzheimer's, such as a carefully monitored, assisted-feeding program. For someone who can no longer swallow, an approach focusing on comfort in dying may be most appropriate.

IV hydration

IV hydration — liquid given to a person through a needle in a vein — may temporarily provide fluid when a person can no longer drink, but cannot supply the nutrition needed to stay alive. Increased hydration may also make the person less comfortable because it can cause difficulty breathing.

Lack of hydration is a normal part of the dying process and allows a more comfortable death over a period of days. Using IV hydration can draw out dying for weeks and physically burden the person. If artificial nutrition and hydration are used, families will eventually need to decide if or when these treatments should be stopped.

Antibiotics

Several types of infections, such as pneumonia and urinary tract infections, are common in late-stage Alzheimer's. Antibiotics may be prescribed to treat an infection, but they might not improve the person's condition.

CPR

A family may have to decide whether medical professionals should try to revive a person with cardiopulmonary resuscitation (CPR). CPR is used to restore function when a person's heart and/or breathing stops. It may include mouth-to-mouth breathing or pressing on the chest to mimic heart function and cause blood to circulate.

Consider that CPR:

- ▶ May be painful and traumatic
- ▶ May leave the person in worse condition
- ▶ May not prolong life
- ▶ Is not recommended by many experts when a person is terminally ill

The family can ask the doctor to sign a “do not resuscitate” (DNR) order and place it in the person's medical chart. A DNR order states that no attempts will be made to revive the person.

Comfort or palliative care

Instead of seeking a cure or trying to prolong life, comfort care focuses on dignity and quality of remaining life. It aims to keep the person comfortable and pain-free until life ends naturally.

Comfort care:

- ▶ Does not mean withholding all treatments — a person can continue to receive any necessary medications, for example, for chronic conditions such as diabetes or high blood pressure, as well as those that prevent pain and discomfort.
- ▶ Eliminates medical treatments, tests and procedures that may cause discomfort to the person.

Hospice care

Hospice programs provide comfort care to those in the last stages of terminal illness while also offering support services to families. Care can be provided at home or in a hospital or residential care facility.

A hospice team includes a doctor, nurse, social worker, nurse's aide, clergy and trained volunteers. They work together to address the physical, emotional and spiritual care of the person as well as the family.

For Medicare to cover hospice care, a doctor must estimate that the person has six or fewer months to live. Hospice benefits may be extended if the person lives longer than expected. The Alzheimer's Association can refer you to hospice services in your area.

10 questions about end-of-life care – what to ask the doctor

- 1 What is the treatment for?
- 2 How will it help?
- 3 What are the physical risks or discomforts?
- 4 What are the emotional risks or discomforts?
- 5 Does the treatment match what the person would have wanted?
- 6 Are we doing all we can to uphold dignity?
- 7 Are we doing all we can to give the person the best quality of life?
- 8 Is he or she in pain?
- 9 What can be done to ease the pain?
- 10 When is the best time to ask for hospice care?

3. making informed decisions

When advance directives are not in place or do not address every issue related to end-of-life care, it can be difficult for families to make decisions. Below are some tips to help you through the process.

Focus on the person's wishes

Compare any recommended treatments or actions with the person's wishes for care, or with what you believe he or she would have wanted. For example:

- › Did the person want all available treatment measures or only certain ones?
- › Did the person want medication to fight pain but not infection?

Stay true to the person's values and beliefs

Consider all factors that would influence the person's decisions about treatments, and definitions of quality of life and death, including:

- › Cultural background
- › Spirituality
- › Religious beliefs
- › Family values

Be aware of the differences between your values and beliefs and those of your family member. Make sure that his or her values and beliefs are guiding your decision.

Weigh pros and cons of treatments

Talk with the medical care team about the impact of using or refusing specific care treatments, for example:

- › Will the treatment improve the person's condition or comfort?
- › If so, how long will the treatment benefit the person's condition or comfort?
- › Will the treatment create physical or emotional burdens?

Compare any recommended treatments with the person's wishes for end-of-life care.



Consider where care will be given

Discuss with the care team if and when moving someone to a different setting is best.

Find out if the treatment or care:

- › Can be provided in familiar surroundings
- › Requires transfer to another setting

Sometimes the temporary transfer to a hospital for a procedure, such as putting in a feeding tube, is disorienting and may be harmful to the person with dementia.

Understand the difference between withholding treatment and assisted suicide

You should not think that any refusal or withdrawal of treatment, including tube feeding, antibiotics, CPR or other treatments, is considered assisted suicide (euthanasia). Limiting treatments lets the disease take its natural course and supports the person's comfort and dignity. If aggressive medical treatment is refused or withdrawn, the care team will still provide good physical and emotional care, as well as ensure the person is not in pain.



4. resolving family conflicts

Family members need to take part in ongoing discussions when making decisions on behalf of their relative. Some may disagree about a recommended treatment and get angry or defensive. Or, they may refuse to engage in discussions because they feel the family is “planning for death.”

The following guidelines may be helpful when dealing with family conflict:

Listen to each family member with respect

Family members may have different opinions about end-of-life preferences and quality of care. They may not fully accept that the person is approaching death. Help family members avoid blaming or attacking each other, as this will only cause more hurt.

Involve a third party

A mediator, physician, nurse, social worker, or spiritual leader can be asked to facilitate family meetings and help work through difficult issues.

Cope with your feelings together

The approaching death of a family member is an emotional time for everyone and may cause people to act in unusual ways. Caregivers and their families may want to seek emotional support, particularly during the last stage of the disease.

Contact the Alzheimer's Association about support groups that can assist you and your family members in working through emotions, including: stress, guilt, depression, grief, and anger.

You can also connect with others who relate to your experiences through ALZConnected® (alzconnected.org), an online social networking community powered by the Alzheimer's Association.

5. arranging for a brain autopsy

A brain autopsy involves a researcher or physician examining the brain after death to look for the plaques and tangles found in Alzheimer's-affected brains. It is the definitive way to confirm a diagnosis of Alzheimer's. And, it may provide information researchers can use to better understand the disease.

A brain autopsy may involve cost and special arrangements. Some brain donation programs provide a free autopsy report. Make the decision for an autopsy before the person's death. To learn more about getting a brain autopsy, contact the Alzheimer's Association.

6. terms you should know

Advance directives: Legal papers that specify the type of medical care a person wants to receive once he or she can no longer, due to incapacity, make such decisions and who should be making them.

Aggressive medical care: Care and treatments meant to prolong life when a person is close to death.

Brain autopsy: A scientific examination of brain tissue after death that often allows doctors or researchers to confirm if a person had Alzheimer's or another type of dementia.

Comfort care: Also known as palliative care, refers to care that emphasizes quality of life and dignity by keeping a person comfortable and pain-free until life ends naturally.

CPR or cardiopulmonary resuscitation: CPR is an intervention used to restore function when a person's heart and/or breathing stop. It may include mouth-to-mouth breathing or pressing on the chest to mimic heart function and cause blood to circulate.

Do Not Resuscitate order (DNR): A DNR order, signed by a doctor based on a patient's wishes, instructs medical personnel to not perform life-saving CPR or other procedures to restart the heart or breathing once they have ceased. Once signed, the DNR directive must be placed in the patient's chart.

Durable power of attorney for health care: This document allows a person to choose a partner, family member or trusted friend to make his or her decisions about care and treatment when the person with dementia is no longer able.

Feeding tube: A tube that provides artificial nutrition when a person is unable to eat. The most common type of feeding tube is inserted through an incision in the stomach.

Hospice care: A type of comfort or palliative care provided at home, a hospital or a residential care facility. Hospice care is for an individual who has six or fewer months to live.

IV hydration: Providing liquids through a needle into a person's vein when he or she can no longer drink independently.

Legal capacity: The level of judgment and decision-making ability needed to sign official documents or to make medical and financial decisions.

Living will: Written instructions that provide specific preferences about the kind of medical treatment that a person would or would not want to receive.

Palliative care: See *comfort care*.





alz.org/care

The Alzheimer's and Dementia Caregiver Center provides reliable information and easy access to tools, 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/findus

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



800.272.3900

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

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the compassion to care, the leadership to conquer®

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®.

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