

Care Partner Information

Alzheimer's Disease and Related Dementia Caregiving Tips

Honoring Last Wishes

When a person is diagnosed with dementia, there are important decisions to be made. These are often called “end-of-life decisions.” But, they are really decisions that need to be made as soon as possible, long before someone’s actual end of life. These decisions help the doctors and family know exactly what kind of medical care a person should get during their last few months of life. They describe what kinds of treatment they want or don’t want. They may also say when to stop treatment. These decisions are made with “advance directives.”

Advance directives are written forms that make a person’s wishes known for when they are no longer able to make their own decisions. The forms can also name someone who the person trusts as their decision-maker when they can no longer make their own decisions.

Advance directives help patients and families prepare for the future. They give families peace of mind knowing they have followed their loved one’s wishes. It allows them to honor and respect the person’s beliefs and wishes.

The two types of advance directives are:

Living Will	A legal document that states the person’s wishes about the medical treatments they would want to have, or would not want to have.
Durable Power of Attorney for Health Care	A legal document in which the person chooses a trusted partner, family member, or friend to make medical decisions for them when they are no longer able to make their own decisions.

Why Are Advanced Directives Important For People With Dementia?

People with dementia will lose the ability to make end-of-life decisions. It is important that people with dementia fill out their advance directives before they lose that ability so they can continue to be in charge of their life.

This Care Partner Information page is part of a series on caregiving tips. They are written to help family and community caregivers, direct care workers and promotoras care for someone with Alzheimer’s disease or related dementias. The information in the series offers general advice and does not distinguish between the different types of dementia.

If someone is dying and doesn't have advance directives, the family must make decisions based on what they think the person would want. This can be very hard for families because often not everyone agrees on what the person with dementia would have wanted.

Advance directives are an important way to know what the person would want for themselves. Although it can be hard to talk about these things, having these discussions and filling out the forms allows you to know what they want and honor their wishes.

End-Of-Life Treatment Choices

Making choices about treatment can be very tough. Families often want to see their loved one eating and drinking because they think that is a sign of health. They might ask about feeding tubes or IV fluids because they think this will make the person feel better. However, not eating and drinking is normal at the end of life. Feeding tubes and IVs can actually be uncomfortable for the person with dementia.

So, it is important to know the types of treatment choices that a family may face for a loved one with late-stage dementia. Families can refuse, limit, or stop any of these treatments—but only if there are advanced directives or a durable power of attorney for health care.

Treatment Choices	What Is It?	What To Think About
Feeding Tubes	Putting tube through the nose into the stomach to feed someone who is no longer able to eat or swallow.	Tube feeding does not help patients feel better or live longer. There is no benefit.
IV Fluids	Giving someone fluid through a tube into their veins when they are no longer able to drink.	This can prolong dying and make it more uncomfortable. For this reason, IVs are often not recommended.
Antibiotics	Using antibiotics to treat an infection such as a pneumonia or urine infection.	Antibiotics might not help the person's condition. Dying from an infection can be a peaceful way to die.
Respirators	A breathing tube put into the lungs so a machine can breathe for a person if they can't breathe on their own.	A breathing machine can cause a lot of discomfort and stress.
CPR (Cardiopulmonary Resuscitation)	Trying to bring a person back to life when their breathing or heartbeat has stopped.	CPR is not recommended for people who have late-stage dementia because it just prolongs the dying process.
Comfort Care or Palliative Care	Often given by hospice, this special care focuses on reducing pain or discomfort and provides caregiver support.	This very helpful care doesn't mean doing nothing. It means giving special care to assure that the person doesn't suffer.

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