

End-of-Life Care

Caring for someone in the final stage of life is always hard. It may be even harder when the person has Alzheimer's disease. Planning for the end of a person's life and knowing what to expect can make this time easier.

Treatment Decisions

Quality of life is an important issue when making end-of-life health care decisions for a person with Alzheimer's. For example, it is important to consider how a treatment will benefit the person and what the side effects and risks might be. You might decide to try a treatment for a short time, or you might decide that the best choice is to do nothing.

In more advanced Alzheimer's disease, some caregivers might not want certain medicines prescribed. The person's quality of life may be so diminished that the medicine is unlikely to make a difference.

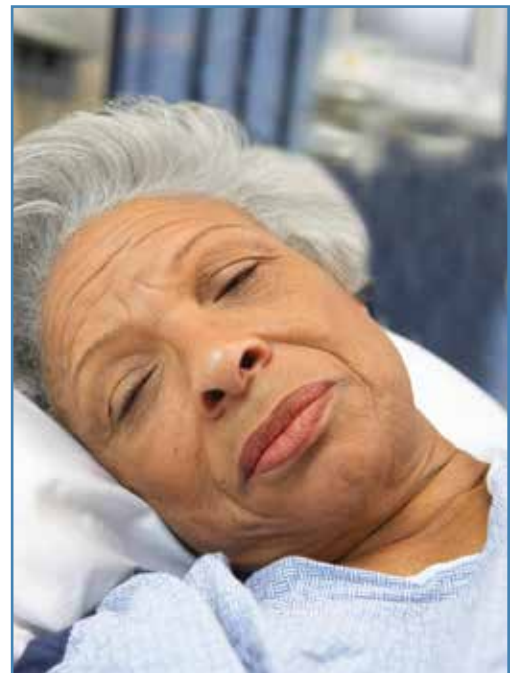
Comfort at the End of Life

Alzheimer's disease and similar conditions often progress slowly and unpredictably. Signs of the final stage of Alzheimer's may include:

- Being unable to move around on one's own
- Being unable to speak or make oneself understood
- Needing help with most, if not all, daily activities
- Eating problems such as difficulty swallowing or no appetite

As a caregiver, you want to make the person as comfortable as possible, but he or she can't tell you how. You may become frustrated because you don't know what to do.

Making connections through senses like hearing, touch, or sight can bring comfort to people with Alzheimer's disease. Being touched or massaged and listening to music, "white" noise, or sounds from nature seem to soothe some people and lessen their agitation.



Sources of Help

Geriatric care managers, grief counselors, and palliative care and hospice staff are trained to help make the person with Alzheimer's more comfortable and to help their families through this time. Geriatric care managers can make home visits and suggest needed services. Counselors can help you understand and deal with your feelings.

Palliative care and hospice services provide care for a very ill person to keep him or her as comfortable and as pain-free as possible. Palliative care provides comfort care, along with any medical treatments a person might be receiving for a life-threatening illness. When a person is near the end of life, hospice care gives family members needed support and help with their grief, both before and after the person with Alzheimer's dies.



For more caregiving tips and other resources:

- **Read** "Caring for a Person with Alzheimer's Disease": www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease
- **Visit** www.nia.nih.gov/alzheimers/topics/caregiving
- **Call** the ADEAR Center toll-free: 1-800-438-4380

Dealing with Emotions

Someone with severe memory loss might not take spiritual comfort from sharing family memories or understand when others express what an important part of their life the person has been. Even so, it's really important to say the things in your heart, whatever helps you to say goodbye.

When the person with Alzheimer's dies, you may have lots of feelings. You may feel sad, depressed, or angry. You also may feel relieved that the person is no longer suffering and that you don't have to care for the person any longer. Relief sometimes may lead to feelings of guilt. All of these feelings are normal.

For more information about end-of-life care, see the NIA booklet "End of Life: Helping with Comfort and Care," www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care.

The Alzheimer's Disease Education and Referral (ADEAR) Center is a service of the National Institute on Aging, part of the National Institutes of Health. The Center offers information and publications for families, caregivers, and professionals about Alzheimer's disease and age-related cognitive changes.

