

# End of Life: Helping With Comfort and Care

## Dementia At the End of Life

As they reach the end of life, people suffering from conditions like [Alzheimer's disease](#) (AD) or Parkinson's disease can present special problems for caregivers. People live with these diseases for years, becoming increasingly disabled. Because they do not die soon after they are diagnosed, it can be hard to think of these as terminal diseases. But they do contribute to death.

Illnesses like Alzheimer's disease make it difficult for those who want to provide supportive care at the end of life to know what is needed. Because people with advanced [dementia](#) can no longer communicate, they cannot share their concerns. Is Uncle Bert refusing food because he is not hungry or because he's confused? Why does Grandma Ruth seem agitated? Is she in pain and needs medication to relieve it, but can't tell you?

As these conditions progress, they also obstruct efforts to provide emotional or spiritual comfort. How can you let Grandpa know how much his life has meant to you? How do you make peace with your mother if she no longer knows who you are? Someone who has [severe memory loss](#) might not take spiritual comfort from sharing family memories or understand when others express what an important part of their life this person has been. Palliative care or hospice can be helpful in many ways to families of people with dementia.

Sensory connections—targeting someone's 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.

When an illness like Alzheimer's disease is first diagnosed, if everyone understands that there is no cure, then [plans for the end of life](#) can be made before thinking and speaking abilities fail and people can no longer legally complete documents like [advance directives](#). That didn't happen in Ethel's family. She had been forgetful for years, but even after her family knew that AD was the cause of her forgetfulness, they never talked about what the future would bring. As time passed and the disease eroded Ethel's memory and her ability to think and speak, she became less and less able to share her concerns and desires with those close to her. This made it hard for her daughter Barbara to know what Ethel needed or wanted. Barbara's decisions, therefore, had to be based on what she knew about her mom's values and priorities, rather than on what Ethel actually said she would like.

Quality of life is an important issue when making health care decisions for people with Alzheimer's disease. For example, there are [medicines available](#) that might slow the progression of this devastating disease for a short time in some patients, generally early in the illness. However, in more advanced AD, some caregivers might not want these drugs prescribed. They may believe that the

quality of life is already so diminished and that the medicine is unlikely to make a difference. If the drug has serious side effects, they are even more likely to decide against it.

End-of-life care decisions are more complicated for caregivers if the dying person has not expressed the kind of end-of-life care he or she would prefer. Someone [newly diagnosed with Alzheimer's disease](#) might not be able to imagine the later stages of the disease. Ethel was like that. She and Barbara never talked about things like feeding tubes, machines that help with breathing, antibiotics for pneumonia, or transfers to the hospital. So when doctors raised some of these questions, Barbara didn't know how to best reflect her mother's wishes. When making care decisions for someone else near the end of life, it is important to consider how a treatment will benefit the person and what the side effects and risks might be. Sometimes you might decide to try the health care team's suggestion for a short time. Other times you might decide that the best choice is to do nothing.

Alzheimer's disease and similar conditions often progress slowly and unpredictably. Experts suggest that signs of the final stage of Alzheimer's disease include some of the following:

- 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

Because of their unique experience with what happens at the end of life, hospice and palliative care experts might also be of help identifying when someone in the final stage of Alzheimer's disease is beginning to die.

[Caring for people with Alzheimer's](#) disease at home can be demanding and stressful for the family caregiver. [Depression](#) is a problem for some family caregivers, as is fatigue, because many feel they are always "on call." More than half of one group of family caregivers reported cutting back on work hours or giving up their jobs because of the demands of caregiving. Most of those family members taking care of dying Alzheimer's disease patients at home expressed relief when death happened—for themselves and for the person who died. It is important to realize such feelings are normal. Hospice—whether used at home or in a facility—gives family caregivers needed support near the end of life, as well as help with their grief, both before and after their family member dies.

## Questions to Ask

You will want to understand how the available medical options presented by the health care team fit into your family's particular needs. You might want to ask questions such as:

1. How will the approach the doctor is suggesting affect your relative's quality of life? Will it make a difference?

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2. If considering hospice for your relative with Alzheimer's disease, does the facility have special experience with people with dementia?