

End-Of-Life Care For People With Dementia

People often live for years with [dementia](#). While it can be difficult to think of these diseases as terminal, they do eventually lead to death. [Caregivers](#) often experience special challenges surrounding the [end of life](#) of someone with dementia in part because the disease progression is so unpredictable. Below are some considerations for end-of-life care for people with dementia.

Making Medical Decisions For People With Dementia

With dementia, a person's body may continue to be physically healthy. However, dementia causes the gradual loss of thinking, remembering, and reasoning abilities, which means that people with dementia at the end of life may no longer be able to make or communicate choices about their health care. If there are no advance care planning documents in place and the family does not know the person's wishes, caregivers may need to make difficult decisions on behalf of their loved one about care and treatment approaches.

When making health care decisions for someone with dementia, it's important to consider the person's quality of life. For example, [medications](#) are available that may delay or keep symptoms from getting worse for a limited time. Medications also may help control some behavioral symptoms in people with mild-to-moderate Alzheimer's or a related dementia. However, some caregivers might not want drugs prescribed for people in the [later stages of these diseases](#) if the side effects outweigh the benefits.



It is important to consider the goals of care and weigh the benefits, risks, and side effects of any treatment. You may need to make a treatment decision based on the person's comfort rather than trying to extend their life or maintain their abilities for longer.

Questions To Ask About End-Of-Life Care For A Person With Dementia

As a caregiver, you will want to understand how the available medical options presented by the health care team fit with the needs of both the family and the person with dementia. You might ask the health care team questions such as:

- Who can help me with end-of-life care for my loved one living with dementia?
- How will your suggested approaches affect their quality of life?
- What are my options if I can no longer manage the care of my loved one at home?
- How can I best decide when a visit to the doctor or hospital is necessary?
- Should I consider hospice at home, and if so, does the hospice team have experience working with people living with dementia?

Being There For A Person With Dementia At The End Of Life

As dementia progresses, caregivers may find it hard to provide [emotional or spiritual comfort](#) to a person who has severe memory loss. However, even in advanced stages of dementia, a person may benefit from such connections.

Sensory connections — targeting someone's senses, including hearing, touch, or sight — may also bring comfort. Being touched or massaged can be soothing. Listening to music, white noise, or sounds from nature seem to relax some people and lessen agitation. Just being present can be calming to the person.



Being There For A Person With Dementia At The End Of Life (cont'd)

[Palliative or hospice care](#) teams may be helpful in suggesting ways for people with dementia and their families to connect at the end of life. They also may be able to help identify when someone with dementia is in the last days or weeks of life.

Signs of the final stages of dementia include some of the following:

- Being unable to move around on one's own
- Being unable to speak or make oneself understood
- Eating problems such as difficulty swallowing

Though palliative and hospice care experts have unique experience with what happens at the end of life and may be able to give a sense of timing, it's hard to predict exactly how much time a person has left.

Supporting Dementia Caregivers At The End Of Life

Caring for people with Alzheimer's or another dementia at the end of life can be demanding and stressful for the family caregiver. [Depression](#) and [fatigue](#) are common problems for caregivers because many feel they are always on call. Family caregivers may have to cut back on work hours or leave work altogether because of their caregiving responsibilities.

It is not uncommon for those who took care of a person with advanced dementia to feel a sense of relief when death happens. It is important to realize such feelings are normal. Hospice care experts can provide support to family caregivers near the end of life as well as [help with their grief](#).

If you are a caregiver, [ask for help](#) when you need it and learn about [respite care](#).



Importance Of Advance Care Planning For People With Dementia And Their Caregivers

Someone newly diagnosed with dementia might not be able to imagine the later stages of the disease. But when a person is first diagnosed with Alzheimer's or another dementia, it's important to make plans for the end of life before the person with the disease can no longer complete advance directives and other important legal documents. End-of-life care decisions are more complicated for caregivers if the dying person has not expressed the kind of care they would prefer.

We Can Help!

Alzheimer's Orange County

Call 844.373.4400

For more caregiver tips

**Visit us at:
www.alzoc.org/resources**

**Information taken from the National Institute on Aging, part of the National Institutes of Health
<https://www.nia.nih.gov/health> | NIH Jan 2022 | Reviewed by AlzOC June 2022**