

What to Know About Dying With Dementia

People with dementia and Alzheimer's disease typically die from complications that are somewhat treatable -- e.g., pneumonia or other infections -- and families struggle to weigh the pros and cons of treatments. In the final stages of dementia, people lose their ability to control most bodily functions, and they often forget how to swallow and have no interest in eating or drinking. The decision of whether to insert a feeding tube can be very difficult for families to make, because nourishing one another is such an essential part of being human. In these situations, families should be aware that:

- By this stage of the disease, patients are completely dependent on others for their care.
- Using a feeding tube will not slow the progression of the disease, and it is equally likely to prolong or to hasten the dying process. In other words, artificial feeding does not, on average, alter the time of death.
- You can offer small bites of soft food or spoonfuls of water and ice chips if you think it makes your loved one more comfortable.
- Not starting feeding-tube treatment, or ending that treatment, may make you feel like you are withholding life-extending measures from a loved one. Sometimes, though, it feels more like a way to keep machinery from tormenting your loved one. For a person living with a long-term, progressive disease like dementia, both perspectives can be true, and it also is true that you are simply allowing the disease to take its natural course.
- It can be hard to know whether or not your loved one is in pain. Let the care team know about your concerns, and insist that they be addressed.
- Look for subtle changes in behavior or sleep patterns and physical signs, such as bedsores, swelling and fever. Be sure the care team is aware of these issues and that they are treated.