

6. To Be or Not to Be

An advance directive is a written document that identifies an individual's wishes regarding medical treatment if that person becomes unable to communicate them to the attending physician. Advance directives are legally recognized throughout the United States, although laws governing their implementation vary from state to state.

“Voluntarily stopping eating and drinking” (VSED) is a provision included in some advance directives to shorten the dying process. There are particular concerns about honoring VSED in advance directives of patients with dementia.

Some religious groups, ethicists, health care professionals, and disability advocates who oppose VSED for patients with dementia raise concerns about honoring their advance directives. In the absence of reaffirmation, they maintain that end of life decisions should always be made in favor of prolonging life, even when the quality of life appears to be severely diminished. They also argue that dementia and the capacity to decide voluntarily are mutually exclusive, rendering the “choice” of VSED invalid. Further, people often live with advanced dementia for years.

Allowing a person with dementia who is otherwise healthy to die by starvation, is effectively slow euthanasia. Although it may not be possible to understand the patient's subjective perception, there is no reason to assume that the individual does not experience pleasure or happiness.

Those who support implementation of VSED in advance directives for individuals with dementia argue that there is no fundamental difference between the advance directive of an individual who is unable to communicate because of dementia, and that of an individual unable to communicate because of another disease or condition. Additional concerns arise when dementia patients require gastrostomy tubes. In addition to the discomfort of insertion and presence of a feeding tube, physicians may order restraints to prevent the patient from pulling out the tube. Restraint is distressing, even for patients with advanced dementia.

According to the Chicago Health and Aging project, almost four out of ten people who reach the age of ninety will develop dementia, and a similar number will experience mild cognitive or functional impairment. As greater numbers of people live longer, thanks to improved nutrition, medical care, and other factors, there will be more people with nonreversible dementia. Many baby boomers who now care for parents with dementia do not want to live with dementia themselves, or to burden their children with caring for them should they develop the disease.

Those who request VSED in the case of dementia in their advance directives face challenges in having their wishes honored. Health care providers may worry that withholding nutrition and hydration to the elderly could result in criminal charges of neglect or abuse.