

ETHICAL ISSUES IN ALZHEIMER'S DISEASE

Suicide and Assisted Suicide

COMMON QUESTIONS

- How is refusal and withdrawal of medical treatments different from assisted suicide?
- Are there more appropriate alternatives to physician-assisted suicide?

BACKGROUND INFORMATION

Alzheimer's disease is a devastating illness that robs individuals of their sense of self and imposes an enormous financial and emotional burden upon family and caregivers. Because of the disease's impact and because many people perceive the care options as limited, Alzheimer's disease has become a focus in the debate over physician-assisted suicide and euthanasia. The policies that emerge from this debate will have monumental significance for people with dementia, for social attitudes toward the task of providing care, and for the quality of care that is available to people at the end of their lives.

A discussion of the Association's position on the issue depends on a clarification of terms and a review of other Association viewpoints about end-of-life decisions. An assisted suicide involves a still competent person with an early diagnosis of Alzheimer's ending his or her own life with the use of prescribed pills or some other poison. Euthanasia would involve another person acting as the agent directly causing death in the patient no longer able to do so for himself or herself.

These two acts are not the same as refusing or withdrawing treatments. Consistent with medical practice and law, the Association emphasizes that

refusal or withdrawal of treatment is not to be equated with either assisted suicide or euthanasia. When treatment is withheld or withdrawn, the intent is not to kill but to unburden the person from a technological assault on a natural dying. If the person lives on, he or she will still be cared for well and attentively, often with a hospice philosophy, which focuses on providing comfort and treating pain.

The Association asserts that the refusal or withdrawal of any and all medical treatment is a moral and legal right for all competent Americans of age. This right can be asserted by the competent patient in legal documents concerning end-of-life care or by a family surrogate acting on the basis of either "substituted judgment" (what would the patient have wanted) or "best interests" (what seems the most humane and least burdensome option in the present).

ASSOCIATION POSITIONS

The issue of assisted suicide and Alzheimer received national attention in 1990, when Michigan pathologist Jack Kevorkian assisted in the suicide of Janet Adkins, a 54-year-old woman diagnosed with probable Alzheimer's. In response to the circumstances, the Association issued *A Statement by the Alzheimer's Association Regarding the Suicide of Alzheimer Patient Janet Adkins*. The brief but clear statement must be quoted in full:

We are very saddened by the tragic case of Janet Adkins. We believe that hers was a very personal decision; however, we must also affirm the right to dignity and life for every Alzheimer patient and cannot condone suicide.

This tragedy epitomizes the desperation that individuals with Alzheimer's disease and their families feel when the diagnosis is Alzheimer's—an incurable disease. We hope that the discussion surrounding the Janet Adkins case will help stimulate further action on the part of the federal government to support research into discovering the cause of this devastating illness and, therefore, prevent such desperate acts.

It is tragic that Janet Adkins chose to take her life. We want others in her situation to know that there are services and programs available to assist such patients and families in coping with Alzheimer's disease, and we encourage them to seek professional help.

Since that time, the debate has continued and many people have voiced their agreement and disagreement with the Association's position. In 1998 the Alzheimer's Association national newsletter, *Advances*, published a letter from Ron Adkins, Janet's husband. In the letter he explained the decision that his wife had made. Excerpts from the letter follow:

My wife, Janet Adkins, was excited by life. She was a woman of many ideas and interests. She was a talented musician and an avid reader. She liked pushing the limit and trying new things, such as trekking through Nepal.

When she was diagnosed with Alzheimer's disease at age 53, she was devastated. She weighed the options of letting the disease take her mind and body or exiting early with the assistance of a doctor while her intellect was still intact. We had openly discussed end-of-life issues, and her choice was not to let the disease progress. . . .

We made an informed decision and a personal choice, one that was right for Janet. Most importantly we openly discussed end-of-life issues together as a family. I encourage others to do the same.

The Association continues to affirm that the most needed response to the possibilities for suicide and assisted suicide, as in the case of Janet Adkins, is the assurance that no person with Alzheimer's will be made to endure unwelcome efforts to prolong dying in the advanced stage of the disease or discomfort due to the lack of treatment for pain. It is the fear of burdensome over-treatment that must be eliminated by clinical practices and laws that respect and encourage the choice of a natural dying.

In 1998 the Association's Public Policy office issued a statement entitled *Physician-Assisted Suicide: What Does it Mean to People with Alzheimer's Disease?* The statement concludes as follows:

Physician-assisted suicide will continue to raise complex ethical and legislative questions in years to come, particularly for people suffering from Alzheimer's disease. While the furor surrounding physician-assisted suicide has the potential to polarize American society, the debate has also focused the Alzheimer's Association on improving end-of-life services. By providing families with better end-of-life care options, we as a society will be better equipped to tackle the issue of physician-assisted suicide. More importantly, the creation of such options will help reduce the suffering and grief associated with the final stages of Alzheimer's disease.