

Ethical Considerations

Issues in Death and Dying

For an individual with Alzheimer's disease, advance planning is essential to fulfilling end-of-life wishes. The physicians and care team play an important role in initiating discussion with the individual and family regarding these wishes.

Even though Alzheimer's disease can run a course of up to 20 years, it is terminal. Ideally, the physician and care team should discuss values and preferences related to death and dying with all older persons on a regular basis. Early discussion will help to clarify the individual's wishes before the onset of dementia.

Advance Directives

Individuals have a moral and legal right to limit or forgo medical or life sustaining treatment (including the use of artificial feeding, mechanical ventilators, cardiopulmonary resuscitation, antibiotics, dialysis and other invasive technologies). Individuals who lack decision-making capacity have the right to have surrogates use advance directives to assure this right.

The two common forms of advance directives are a living will and a durable power of attorney for health care. A living will states the individual's choices for future medical care decisions. The durable power of attorney allows the individual to designate a surrogate, usually a trusted family member, to make specific treatment decisions for them. The surrogate should make decisions consistent with what they think the individual's wishes would have been. In the absence of written advance directives, care providers should try to learn about the individual's wishes from family members as a basis for making their decisions.

Every state now legislatively recognizes advance directives. State legislation creates procedural mechanisms to effectuate rights that are guaranteed by the federal constitution. Both the living will and durable power of attorney for health care are authorized in most states and the District of Columbia. However, issues within the statutes regarding the use or withdrawal of artificial nutrition and hydration vary from state to state.

Treatment Withdrawal/Refusal

If there is an identified surrogate, families should be contacted and involved in the decision-making process. Care providers should work closely with the family, in cases where a substitute judgment must be made, to interpret advance directives. If there is a lack of knowledge about the individual, care providers should base a decision on what they feel is in the best interest for that individual. If necessary, the importance of respecting the individual's wishes should be clarified for the family. Clinical ethics consultants or the facility's ethics committee may offer assistance in facilitating consensus.

An individual's right to refuse or withdraw any treatment, including treatment for life-threatening illness (infections, hemorrhaging, heart attacks, etc.), is not the same as assisted suicide or euthanasia. In fact, aggressive medical treatment may seem torturous to the individual because of his or her lack of orientation to the surroundings and lack of understanding of the intentions of care providers.

(Continued on back page)

(Continued from front page)

Hospice Care

During the terminal stages of Alzheimer's disease, hospice care can be particularly beneficial to individuals with Alzheimer's disease and their family members. Hospice, which is normally offered to individuals who are expected to live less than six months, includes comprehensive palliative care and support services, including bereavement counseling for family members.

Aggressive life-sustaining treatments such as artificial nutrition and hydration, antibiotics and cardiopulmonary resuscitation are not normally recommended for hospice patients. However, it is important to assess the person's need for pain medication, since many persons with Alzheimer's disease may be unable to verbally communicate their discomfort.

Hospice care is a benefit paid, for those eligible, by Medicare and Medicaid, and often by private insurance. Most hospice patients are cared for in the home, but some reside in long-term care settings. Despite the appropriateness and benefit for persons with Alzheimer's disease and their families, and their eligibility for the Medicare hospice benefit, very few persons with Alzheimer's disease receive hospice care. Physicians, care professionals and families can change this by generating awareness of the importance of hospice to the individual in the terminal stages of Alzheimer's disease.

The care providers should:

- ▶ *Facilitate early communication with older patients to understand their end-of-life wishes.*
- ▶ *Respect the end-of-life wishes of the individual.*
- ▶ *If these wishes conflict with the care provider's personal beliefs, consideration should be given to the transfer of care to another provider.*
- ▶ *Confer with ethics consultants or ethics committees in cases where there is no consensus with the family.*
- ▶ *Refer families to the Alzheimer's Association for services such as support groups and information on area programs and services.*

ALZHEIMER'S ASSOCIATION:

Through its nationwide network of chapters, the Association offers a broad range of programs and services for people with the disease, their families, and caregivers. These services include support groups, telephone helplines, educational seminars, advocacy programs, and a variety of print and on-line resources on the disease, caregiving approaches, and current research.

Research into the causes, treatment, and prevention of Alzheimer's disease will create new options for treatment and care. The Alzheimer's Association, the largest private funder of Alzheimer research, is dedicated to supporting scientists who are making advances toward conquering this disease.

For more information or to locate the chapter nearest you, call:

(800) 272-3900

This fact sheet was adapted for the Alzheimer's Association from the "Fairhill Guidelines on Ethics of the Care of People with Alzheimer's Disease: A Clinical Study," prepared by Stephen G. Post, Ph.D. and Peter J. Whitehouse, M.D., Ph.D.