

Respect for Autonomy

COMMON QUESTIONS

- What factors should be considered when determining the competence of an individual with Alzheimer's?
 - What are the ethical considerations of taking away a person's right to autonomous decision making?
-

BACKGROUND INFORMATION

Concern for the autonomy of a person with dementia requires an assessment of an individual's competence, or capacity to understand the relevant options and consequences of a particular task or decision in light of one's own values. Judgments of competence in a specific area are routinely made informally by attending physicians, other health care professionals, and family members. Such assessments can be straightforward and based on common sense, particularly when the person is obviously incoherent in conversation, retains little or no information, responds to the same repeated question with opposing statements, and lacks insight into the consequences of a decision or its alternatives. If information is neither grasped nor manipulated, an assessment is not difficult. However, an assessment of competence may not be definitive because a person may be obviously incompetent one day but competent the next. Even the person with somewhat advanced dementia may have periods of lucidity that allow for significant decision making.

In almost all cases, judgments of competence to make medical decisions can be accomplished without the need for legal proceedings. The standard

definition of competence for medical treatment decisions includes the essential element of the patient's ability to understand the nature, purpose, risks, benefits, and alternatives of the proposed treatment. More specifically, a patient needs to be able to demonstrate the following abilities:

1. appreciate that he or she has a choice;
2. understand the medical situation and prognosis, the nature of the recommended care, the risks and benefits of each alternative, and the likely consequences; and
3. maintain sufficient decisional stability over time, in contrast to the profound vacillation that indicates an absence of capacity.

ASSOCIATION POSITIONS

In general, allowing the person with Alzheimer's disease to feel that his or her autonomy is being respected, to the extent possible, is ethically important and the appropriate alternative to unnecessary coercion. A consistent theme across discussions of the Ethics Advisory Panel is that people with dementia should be allowed to exercise their remaining capacities for choice, consistent with their cultural expectations. Denying this free exercise challenges their independence and dignity.

It is obligatory to protect a person with dementia from seriously harmful consequences, but it is equally obligatory to respect his or her competent decisions. Neither law nor ethics allows interference with a competent person's choices purely on the grounds that the caregiver or another individual knows what is best for the patient. The following principles should be considered to protect an individual's need for autonomy:

1. Diagnosis of Alzheimer's disease alone is not an indication of incompetence. False accusations of incompetence can leave anyone feeling worthless and hopeless.
2. Caregivers should seek the least restrictive alternative when a person is incompetent in some specific area.
3. Competent people have a moral and legal right to reject any medical treatment. Many people with mild or moderate dementia retain this right, and it should be protected.
4. Reasonable indecision or change of mind about medical decisions does not in and of itself indicate incompetence.
5. A person with Alzheimer's may lack capacities to drive, handle financial affairs, or live independently in the community, but he or she may still have the capacity to make competent decisions about place of residence and medical care. The individual can find it distressing to have wishes overridden in areas in which he or she is still competent.
6. Appointment of a legal guardian for specific tasks, such as financial affairs, might allow a person with Alzheimer's to maintain a degree of independence and exercise autonomy over other matters.
7. Judgments of incompetence should reflect the mental condition of the person with dementia, not the needs or intolerance of others. Individuals may be unwelcome in the community because they are remiss about hygiene, uninhibited, inclined to mishaps, and unable to keep their residences in good appearance. The reaction of

the public to such circumstances should not be the basis of an assessment of competence.

8. In some cultures, collective decision making within the family prevails, and autonomous decisions are deemed inappropriate. In such circumstances, it is appropriate for the patient, family, physician, and other interested parties to clarify soon after a diagnosis of Alzheimer's how these values will play a role in future decisions as the disease progresses.

Special considerations: It is important to plan for the global incompetence of advanced dementia through the use of legal documents, especially the durable power of attorney for health care, which assigns decision-making authority on medical matters to a particular person once the individual with Alzheimer's is no longer competent. People diagnosed with probable Alzheimer's disease should also create estate wills that describe how their property will be dealt with after death and living wills that establish their wishes concerning end-of-life care and the use of life-support systems.

The Ethics Advisory Panel discussed the ethics of using electronic tracking devices for people with Alzheimer's. Such devices, while intended to ensure the safety of the person with Alzheimer's, may be perceived as infringement on personal autonomy. The panel felt that using these devices is acceptable so long as they do not violate the express wishes of a competent individual. Also, these devices should not be of a permanent nature, or implanted into the person with Alzheimer's.