Respect for Autonomy

COMMON QUESTIONS

- What factors should be considered when determining the competence of an individual with Alzheimer’s disease?
- 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 be based on common sense, particularly when the person is 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 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 ability of the person with Alzheimer’s disease ability to understand the nature, purpose, risks, benefits and alternatives of the proposed treatment. More specifically, an individual needs to be able to demonstrate the following abilities:

- Appreciate that he or she has a choice.
- Understand the medical situation and prognosis, the nature of the recommended care, the risks and benefits of each alternative and the likely consequences.
- Maintain sufficient decisional stability over time, in contrast to the profound vacillation that indicates an absence of capacity.
ASSOCIATION POSITION

Allowing the person with Alzheimer’s disease to feel that his or her autonomy is being respected is ethically important and the appropriate alternative to unnecessary coercion. The Association asserts 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 person. The following principles should be considered to protect an individual’s need for autonomy:

- Diagnosis of Alzheimer’s disease alone is not an indication of incompetence. False accusations of incompetence can leave a person with Alzheimer’s disease feeling worthless and hopeless.
- Caregivers should seek the least-restrictive alternative when a person is incompetent in a specific area.
- 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.
- Reasonable indecision or change of mind about medical decisions does not in and of itself indicate incompetence.
- A person with Alzheimer’s disease may lack capacities to drive, handle financial affairs or live independently in the community, but retain 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.
- The wishes of a person with dementia should be considered whenever possible and until safety becomes at issue.
- Appointment of a legal guardian for specific tasks, such as financial affairs, might allow a person with Alzheimer’s disease to maintain a degree of independence and exercise autonomy over other matters.
- Guardianship is a legal process where a court determines whether the person with dementia is in need of a guardian to make decisions. A determination of the person’s decision-making ability is made by a physician prior to the guardianship proceedings.

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• 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 or 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.

• In some cultures, collective decision-making within the family prevails, and autonomous decisions are deemed inappropriate. In such circumstances, it is appropriate for the person with dementia, along with his or her family, physician and other interested parties, to clarify (soon after a diagnosis of Alzheimer’s disease) how these values will play a role in future decisions as the disease progresses.

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 disease 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; living wills that establish their wishes concerning end-of-life care and the use of life-support systems; plans for future care needs; and research directives to allow their participation in research studies.

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Karlawish, J.H., Casarett, D.J., James, B.D., Xie, S.X., & Kim, S.Y. (2005, May). The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment. Neurology, 64(9), 1514-1519.


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