

Respect for Autonomy

COMMON QUESTIONS

- What factors should be considered when determining if an individual with Alzheimer's disease has capacity to understand?
- What are the ethical considerations of taking away a person's right to autonomous decision-making?
- When should health care providers engage surrogates to assist with decision-making for a person with Alzheimer's disease?

BACKGROUND INFORMATION

Concern for the autonomy of a person with dementia requires an assessment of an individual's capacity to understand the relevant options and consequences of a particular task or decision in light of one's own values. Judgments of capacity in a specific area are routinely made informally by health care professionals and family members. They may also be made by legal professionals when judging whether a person with dementia has capacity to understand and complete advance directives and other legal documents. Decision-making capacity is generally task specific and different from a formal legal pronouncement made by a judge that a person is incompetent to manage his or her own medical, legal or financial affairs. State laws can vary in regard to legal determinations of competence.

Such assessments of capacity can be straightforward and 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 capacity may not be definitive because a person may fluctuate in his or her ability to understand and reason. Even the person with somewhat advanced dementia may have periods of lucidity that allow for significant decision-making.

In almost all cases, judgments of capacity to make medical decisions can be accomplished without the need for legal proceedings. The standard definition of capacity for medical treatment decisions includes the essential element of the ability of the person with Alzheimer's disease or another dementia 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, and 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 capable decisions. Neither law nor ethics allows interference with a capable 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 decision-making incapacity. False accusations of incapacity or incompetence can leave a person with Alzheimer's disease feeling worthless and hopeless.
- Caregivers should seek the least restrictive alternative when a person is incapable in a specific area.
- Persons with decision-making capacity have a moral and legal right to reject or accept any medical treatment. Many people with mild or moderate dementia retain this capacity and their rights should be protected.
- Reasonable indecision or change of mind about medical decisions does not in and of itself indicate incapacity if it is consistent with the persons prior statements and beliefs.
- When more serious decisions are being considered, especially those that may involve medical decisions or other issues involving safety, assessment tools are recommended to determine capacity.
- 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 sound 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 capable.
- The wishes of a person with dementia should be considered whenever possible and until safety becomes an issue.
- Health care providers should engage surrogates designated via health care and durable powers of attorney to participate in the disease management process and address safety concerns if they assess the person with dementia incapable of independently managing their health care-related decisions. If no surrogates are available, a judicial action may

be needed to review whether legally appointed assistance (such as a guardian) is needed to assist with decision-making and supervision.

- Judgments of incapacity should reflect the mental condition of the person with dementia, not the needs or intolerance of others.
- 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 incapacity 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 capable of making his or her own decisions. People diagnosed with Alzheimer's disease should also be encouraged to draft a durable power of attorney for business and financial matters; 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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Respect for Autonomy Bibliography

Black, B.S., Kass, N.E., Fogarty, L.A., & Rabins, P.V. (2007, July-August). Informed consent for dementia research: The study enrollment encounter. *IRB*, 29(4), 7-14).

Black, B.S., Rabins, P.V., Sugarman, J., & Karlawish, J.H. (2010, January). Seeking assent and respecting dissent in dementia research. *American Journal of Geriatric Psychiatry*, 18(1), 77-85.

de Boer, M.E., Hertogh, C.M., Droes, R., Jonker, C., & Eefsting, J.A. (2010, March). Advance directives in dementia: Issues of validity and effectiveness. *International Psychogeriatrics*, 22(2), 201-208.

Howe, E.G. (2006, Winter). Do we undervalue feelings in patients who are cognitively impaired? *Journal of Clinical Ethics*, 17(4), 291-301.

Kane, M.N. (2001, March-April). Legal guardianship and other alternatives in the care of elders with Alzheimer's disease. *American Journal of Alzheimer's disease and Other Dementias*, 16(2), 89-96.

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- Kapp, M.B. (2001, November). Legal interventions for persons with dementia in the USA: Ethical policy and practical aspects. *Aging & Mental health*, 5(4), 312-315.
- 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.
- Kazuko, M., & Shimanouchi, S. (2014, June 13). The decision making and communication capacities of older adults and dementia: A population based study. *Open Nursing Journal*, 7, 17-24.
- Kim, S.Y.H., Kim, H.M., Langa, K.M., Karlawish, J.H.T., Knopman, D.S., & Appelbaum, P.S. (2009, January 13). Surrogate consent for dementia research: A national survey of older Americans. *Neurology*, 72(2), 149-155.
- Murray, L.M., & Boyd, S. (2009, March). Protecting personhood and achieving quality of life for older adults with dementia in the U.S. health care system. *Journal of Aging and Health*, 21(2), 350-373.
- Pierce, R. (2010, February). A changing landscape for advance directives in dementia research. *Social Science & Medicine*, 70(4), 623-630.
- Powers, B.A. (2003, November). The significance of losing things for nursing home residents with dementia and their families. *Journal of Gerontological Nursing*, 29(11), 43-52.
- Sabat, S.R. (2005, November-December). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*, 39(11-12), 1030-1035.
- Sailors, P.R. (2001, Spring). Autonomy, benevolence, and Alzheimer's disease. *Cambridge Quarterly of Healthcare Ethics : CQ : The International Journal of Healthcare Ethics Committees*. 10(2), 184-193.
- Stocking, C.B., Hougham, G.W., Danner, D.D., Patterson, M.B., Whitehouse, P.J., & Sachs, G.A. (2008, October). Variable judgments of decisional capacity in cognitively impaired research subjects. *Journal of the American Geriatrics Society*, 56(10), 1893-1897.
- Tan, J.O., & Hope, T. (2006, January 14). Mental health legislation and decision making capacity: Capacity is more complex than it looks. *British Medical Journal: Clinical Research*, 322(7533), 119.
- Trachsel, M., Hermann, H., & Biller-Andorno, M. (2014, June). Cognitive fluctuations as a challenge for the assessment of decision-making capacity in patients with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 30(4), 360-363.
- Tweedle, F. (2009, August 13 - September 9). Covert medication in older adults who lack

decision- making capacity. *British Journal of Nursing*, 18(15), 936-939.

Whitney, S.N., & McCullough, L.B. (2007, July). Physicians' silent decisions: Because patient autonomy does not always come first. *American Journal of Bioethics*, 7(7), 33-38.

Woods, B., & Pratt, R. (2005, September). Awareness in dementia: Ethical and legal issues in relation to people with dementia. *Aging & Mental Health*, 9(5), 423-429.