

Telling the Truth in Diagnosis

COMMON QUESTIONS

- Should the person with Alzheimer's disease be told about his or her diagnosis?
 - What are the implications of knowing or not knowing one's diagnosis?
 - What impact might the values and expectations of a particular culture have on diagnostic disclosure?
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BACKGROUND INFORMATION

Telling a patient the truth about a diagnosis of progressive dementia caused by probable Alzheimer's disease or some other dementia-causing disease should be the usual practice. Doing it sensitively and in a way that avoids unnecessary despair requires more focused attention than it has currently received. Disclosure should usually mention the probable disease by name; expectations for the future; and the fact that while the condition cannot be cured, its effects can be treated.

Many experienced health care professionals have experienced the agonizing discussions of the family about whether to tell the patient about a diagnosis of Alzheimer's only to have the patient say, "That's what I've thought all along." The discovery of inheritance patterns, emerging cognitive-enhancing drugs that are best applied early in the course of disease, the general public awareness of Alzheimer's, and the interest in advance financial and medical planning all contribute to a noticeable swing toward diagnostic truth telling.

ASSOCIATION POSITIONS

The Association asserts that, in general, so long as a person retains his or her competence to understand, it is important to tell the truth in a supportive manner. The Association's key statement on this issue, entitled *Ethical Considerations: Ethical Issues in Diagnostic Disclosure* (1997), includes the following remark:

Disclosing the diagnosis early in the disease process allows the individual to continue to live a quality of life and play an active role in planning for the future. If disclosure of the diagnosis is made after the dementia has advanced, it may no longer be warranted or meaningful.

Truth telling in diagnosis enables the person with Alzheimer's to take several beneficial measures:

1. plan for optimal life experiences in remaining years of intact capacities,
2. prepare legal documents concerning care in more advanced stages of the disease,
3. consider possible enrollment in research programs, and
4. participate actively in Alzheimer support groups.

The Association's statement includes the important argument that disclosing the diagnosis early in the disease process allows the person to "be involved in communicating and planning for end-of-life decisions." Diagnostic truth telling allows an individual to prepare legal documents, called advance directives, that stipulate care preferences for late in the disease when he or she is

not capable of making such decisions. One such document, a durable power of attorney for health care, allows a trusted loved one to make any and all treatment decisions once the person with Alzheimer's becomes incompetent. This advance directive can be effectively coupled with a living will, which allows the person to express a decision on the use of artificial life-support systems and other end-of-life care issues. Without these legal documents, there is a greater chance that an individual will be placed on life-support systems, whether or not such care meets the presumed wishes of the patient or the stated wishes of the family.

Important considerations: While ordinarily it is presumed that the patient is expected to be the "autonomous" decision maker, there are some cultures in which the practice of truth telling for any serious medical diagnosis is considered a burden to the patient. Some cultures are less individ-

ualistic in their orientation to ethical decision making, and the preferred approach is for a group or family to make the decisions. In all cases the individual with dementia should be involved to the fullest extent possible, but in less individualistic cultures, the person's family or group should be approached rather than focusing solely on the individual. Generalizations about culture are not possible because cultures are quite internally diverse and individuals express their preferences and decisions in different ways within their own culture-based values and beliefs.

Even if diagnosis is withheld out of respect for an individual's cultural preferences, the person with dementia should be encouraged to make financial and legal plans for the future. If a living will is not considered appropriate because it hinges on the preferences of the individual, the option of a durable power of attorney for health care can still be offered.

To receive additional Association materials on this topic, log onto the Association's Web site (<http://www.alz.org>) or call (800) 272-3900.

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