Telling the Truth in Diagnosis

COMMON QUESTIONS

- What are the implications of a person with Alzheimer’s knowing or not knowing their diagnosis?
- What impact might the values and expectations of a particular culture have on diagnostic disclosure?

BACKGROUND

Telling a patient the truth about a diagnosis of Alzheimer’s disease or other dementia 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 mention the disease by name, expectations for the future and the fact that while the condition cannot be cured, its symptoms can be treated. Moreover, diagnostic truth-telling allows the individual with dementia and his or her family the opportunity to plan for the future.

Many experienced health care professionals have experienced the agonizing discussions with 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 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 POSITION

The Association asserts that so long as a person retains his or her competence to understand, it is important to tell the truth in a supportive manner. 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:

- Plan for optimal life experiences in remaining years of intact capacities.
- Prepare legal and financial documents concerning care in more advanced stages of the disease.
- Build a supportive care team.
- Consider possible enrollment in research programs.
- Participate actively in Alzheimer’s support groups.
Telling the truth in diagnosis allows an individual to prepare legal documents, called advance directives, which 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 person with Alzheimer’s or the stated wishes of the family. Diagnostic truth-telling also allows an individual to make his or her wishes known regarding participation in research and future care needs.

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 can be considered a burden to the patient. Some cultures are less individualistic in their orientation to ethical decision-making, and the preferred approach is for a group or family to make the decisions. It is important for health care professionals to be sensitive to cultural preferences, but in all cases the individual with dementia should be involved to the fullest extent possible.

**PRINCIPLES FOR A DIGNIFIED DIAGNOSIS**

The Alzheimer’s Association’s Early Stage Advisory Group created a document titled Principles for a Dignified Diagnosis in 2009 that offers guidance for health care professionals on providing a dignified diagnosis of Alzheimer’s disease.

Talk to me directly, the person with dementia. I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.

Tell the truth. Even if you have don’t have all the answers, be honest about what you do know and why you believe it to be so.

Test early. Helping me get an accurate diagnosis as soon as possible gives me more time to cope, plan and live to my fullest potential.

Deliver the news in plain but sensitive language. This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.

Coordinate with other care providers. I may be seeing more than one specialist — it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don’t have to repeat any tests unnecessarily.

Explain the purpose and validity of different tests. Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long
it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

Give me tools for living with this disease. Please don’t give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me and I need to know not only about medical treatment options, but also what kinds of support resources are available in my community. If possible, please put me in contact with a qualified counselor.

Work with me on a plan for healthy living. Medication may help modify some of my neurological symptoms, but I am also interested in recommendations for keeping myself as healthy as possible in other ways, through diet, exercise and social engagement.

Recognize that I am an individual and the way I experience this disease is unique. This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

Alzheimer’s is a journey, not a destination. Treatment doesn’t end with the writing of a prescription. Please continue to be an advocate, not just for my medical care, but for my quality of life as I continue to live with Alzheimer’s.

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Telling Truth in Diagnosis Bibliography


