

## Diagnosis Disclosure

### COMMON QUESTIONS

- What are the implications of a person with Alzheimer's knowing or not knowing their diagnosis?
- Should health care providers disclose a diagnosis of Alzheimer's or other dementias to a designated surrogate if the person with dementia lacks capacity to understand and remember the diagnosis?
- What impact might the values and expectations of a particular culture have on diagnostic disclosure?

### BACKGROUND INFORMATION

Telling an individual the truth about a diagnosis of Alzheimer's disease or another dementia should be the usual practice. Doing it sensitively and in a way that avoids unnecessary despair requires more focused attention than it currently receives. Disclosure should mention the disease by name, outline expectations for the future and share 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 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."

### ASSOCIATION POSITION

The Association asserts that as long as a person retains his or her capacity to understand and appreciate the information relevant to a diagnosis, it is important to fully disclose the diagnosis of Alzheimer's disease or another dementia and its implications in a supportive manner. Disclosing the diagnosis early in the disease process allows the individual make decisions that may enhance his or her quality of life and play an active role in planning for the future. Even when the disease is diagnosed beyond early stage, the person may have some capacity to understand what is happening and efforts should be made to inform the person in a manner he or she can comprehend. If the person with dementia lacks capacity to understand or remember the diagnosis-related information, the health care professional should share this information with the person's surrogate.

Full disclosure of the diagnosis enables the person with Alzheimer's or another dementia to take several beneficial actions:

- 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 enrollment in clinical trials.
- Participate actively in supportive programs and services in the community.

Full disclosure of the diagnosis allows an individual to prepare legal documents, called advance directives, which stipulate care preferences 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 family member or friend to make any and all treatment decisions once the person with Alzheimer's becomes unable. This advance directive may include 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. In addition, state-specific medical orders defining desired treatments can be drafted.

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. Disclosure of the diagnosis also allows an individual to make his or her wishes known regarding participation in research and future care needs.

While it is often presumed that the patient is expected to be the autonomous decision-maker, there are some cultures in which full disclosure 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**

In 2009, the Alzheimer's Association's Early-Stage Advisory Group created Principles for a Dignified Diagnosis, a document that offers guidance to health care professionals in providing a 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 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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### Diagnosis Disclosure Bibliography

- Hamdy, R.C. (2004, January). Alzheimer's disease: To tell or not to tell. *Southern Medical Journal*, 97(1), 1.
- Lee, S.M., Roen, K. & Thorton, A. (2014, May). The psychological impact of a diagnosis of Alzheimer's disease. *Dementia (London)*, 13(3), 289-305.
- Marzanski, M. (2000, April). Would you like to know what is wrong with you? On telling the truth to patients with dementia. *Journal of Medical Ethics*, 26(2), 108-113.
- Mastwyk, M., Ames, D. Ellis, K.A., Chiu, E., & Dow, B. (2014, August). Disclosing a dementia diagnosis: What do patients and families consider important? *International Psychogeriatrics*, 26(8), 1263-1272.
- Pinner, G., & Bouman, W.P. (2002, June). To tell or not to tell: On disclosing the diagnosis of dementia. *International Psychogeriatrics*, 14(2), 127-137.
- Riva, M. (2014, August). Diagnosis disclosure and advance care planning in Alzheimer's disease. *Aging Clinical and Experimental Research*, 26(4), 427-434.
- Whitehouse, P., Frisoni, G., & Post, S. (2004, February). Breaking the diagnosis of dementia. *Lancet Neurology*, 3(2), 124-128.

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