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Online information for caregivers of Alzheimer's patients

People with Alzheimer's disease usually experience a delay in length of time from when symptoms first appear until diagnosis. However, it is significant that the delay is measured in terms of years, not months. The Alzheimer's Foundation of America (AFA) wanted to determine why the delay in diagnosis was so lengthy so much of the time. AFA commissioned Harris Interactive to conduct a survey, the results of which were recently released. The full report is available at www.alzfdn.org.

The AFA survey discovered that the typical Alzheimer's patient experiences symptoms for just over 2 years, and visits several doctors before being diagnosed. Of those who participated in the survey, more than half of the caregivers reported a fear of stigma and/or denial as a reason for a delay in diagnosis. This would include the caregiver's own fear of stigma, as well as the patient's fear of stigma. This fear of stigma can result in a delay of diagnosis for up to six years!

A delay in diagnosis, with its attendant delay in treatment, is a serious matter for those individuals with Alzheimer's disease. Elder Law Answers (www.elderlawanswers.com) reports that Eric J. Hall, CEO of the AFA, states that a delay in diagnosis is a setback for Alzheimer's patients and their families, and a long delay is "a serious and unnecessary set back." Getting a diagnosis is essential to managing and treating the disease. Any delay, especially one of years in duration, can result in more emotional distress than is necessary, particularly for loved ones and caregivers of the ill person.

The emotional impact of caring for someone with Alzheimer's disease is intricately connected with the delay in diagnosis due to fear of stigma. Caregivers report that the emotional impact of care outweighs the practical aspects and hardships experienced. It is very difficult watching someone you love lose their ability to function effectively. Caregivers, especially those caring for a parent, worry that they will develop the disease some day. Caring for someone with Alzheimer's disease is, not surprisingly, a life changing experience.

However, the survey reports that caregivers found that they were stronger than they thought. This was particularly noted among the group who reported denial due to fear of stigma. Sixty-four percent of caregivers reported that they felt that they became more compassionate people. Many caregivers, who at first denied the possibility of such a diagnosis, became the most informed caregivers about the disease process and treatment.

Utilizing advocacy groups, such as the AFA, and local support groups are an important part of the caregivers' tools in coping with caring for a loved one with Alzheimer's disease. Denying the disease by not having the ill person diagnosed, also denies the caregiver of sources of vital sources of information, as well as emotional support during a difficult caregiving process.

Lack of long term care planning also contributed significantly to a delay in diagnosis and treatment. Long term care planning does not just include financial planning, although this is important. It also includes failure to execute adequate Power of Attorney documents, Living Wills, and Wills. Caregivers who wish to assist are often powerless to do so. Long term care insurance is also an important component of the plan, which helps ease the financial burden on the caregiver.