

HEALTH & SCIENCE

Dementia doesn't always signal Alzheimer's

The degenerative brain disease known as frontotemporal dementia often escapes diagnosis for years, mimicking instead psychiatric and movement disorders.

By Susan J. Landers, *AMNews* staff. April 21, 2008.

Washington -- Dementia in people younger than 65 isn't always the result of early-onset Alzheimer's disease. Frontotemporal lobar degeneration, or FTLN, an umbrella term that covers several brain disorders, is another cause of early dementia, although one that is not widely recognized.

The announcement last fall by Sen. Pete Domenici (R, N.M) that he has FTLN placed a spotlight on the condition, at least momentarily. However, FTLN remains very much in the shadow of Alzheimer's.



Members of panel on "Early Dementia: Research, Practice and Policy Perspectives," at the Annual Conference of the American Society on Aging, in Washington, DC, March 28, 2008. (Pictured L-R) Sandra Weintraub, PhD, Northwestern University Feinberg School of Medicine; Katie Maslow, MS, Alzheimer's Assn.; Helen-Ann Comstock, Founder, AFTD; and Darby Morhardt, MS, LCSW, Northwestern University Feinberg School of Medicine.

About 250,000 Americans are believed to have FTLT, and 250,000 to 640,000 are estimated to have early-onset Alzheimer's.

Neither disorder can be cured. Although Alzheimer's is diagnosed fairly readily, FTLT is frequently misdiagnosed as a psychiatric or movement disorder, according to presenters at the Annual Conference of the National Council on Aging and the American Society on Aging held March 26-30 in Washington, D.C.

FTLT often occurs when people are in their 40s and 50s, about a decade earlier than Alzheimer's disease. Its unexpected appearance can place a tremendous burden on younger families with teens living at home, and work and income issues to be resolved. Its cause is not known.

Both Alzheimer's disease and FTLT cause brain cells to die. However, because they affect different regions of the brain, each triggers distinct abnormalities, said Sandra Weintraub, PhD, professor of psychiatry, behavioral sciences and neurology at Northwestern University's Feinberg School of Medicine in Chicago.

FTLT destroys areas of the brain that govern behaviors, while the hallmark of Alzheimer's is loss of memory, according to the Assn. for Frontotemporal Dementias, an advocacy and educational group in Philadelphia. The association was founded in 2002 by Helen-Ann Comstock, whose husband had Pick's disease, an FTLT subtype.

The pattern of damage becomes obvious after death when an autopsy is performed. While Alzheimer's causes early damage to the hippocampus and then more extensive damage to the entire brain, it is the frontal and temporal lobes that are hard hit by FTLT.

"We need greater awareness, accurate diagnoses and knowledgeable medical professionals," said Comstock. The level of knowledge about FTLT today is about where information on Alzheimer's disease was 30 years ago, she noted.

A person with early FTLT is more likely to exhibit poor organizational skills, loss of initiative or emotions -- symptoms a family member is likely to detect first. However, since language and memory may remain intact, diagnosis can be difficult. A physician may think the individual is depressed. "The last thing on their mind is dementia," said Dr. Weintraub. Comstock's husband, who had a PhD in math and taught at a university, was initially diagnosed with bipolar disorder.

FTLT patients frequently undergo personality transformations. For example, a quiet person may suddenly become boisterous and exhibit inappropriate behavior. A patient may have difficulty walking, experience rigidity and tremor, or muscle atrophy and weakness. A misdiagnosis of Parkinson's disease is not uncommon.

But an accurate diagnosis is important because medications used to treat other conditions may be harmful to a person with FTLT, according to advocates. Plus, a proper diagnosis of early-

onset Alzheimer's can trigger a course of medications that may at least slow the disease's progress.

Although there are no medications proven to be effective specifically for FTLD, some clinicians prescribe selective serotonin reuptake inhibitors or acetylcholinesterase inhibitors. Both prolong the activity of neurotransmitters in the brain. Antioxidants, such as vitamin E, may also be used because these substances are thought to slow progression of damage to brain cells in general.

Finding proper care

Both early-onset Alzheimer's and FTLD cause additional family turmoil when it comes to finding long-term care because these patients are so much younger than the average nursing home patient, said Darby Morhardt, a research associate professor at Northwestern's Feinberg School of Medicine.

Nursing homes sometimes don't accept patients younger than 65, Morhardt said. Plus the odd behavior of some FTLD patients may make it difficult for staff to control them.

Even when services are available, they may not be appropriate. "The evidence suggests that younger people have different needs," she said. People in their 40s and 50s are active, and frequently no programs exist for them, even in adult day-care facilities, said Morhardt.

The lack of public awareness of FTLD also can trigger unhelpful responses, she added. The patient may be arrested after an angry outburst or disability benefits may be denied because the disease has been misdiagnosed. Families also cite problems negotiating the health care system. "The medical community isn't there for them," said Morhardt, who has conducted a survey of caregivers.

Support for family members caring for patients at home has long been cited as an unmet need. Groups such as the AMA have called on medical schools and residency programs to prepare physicians to assess and help manage caregivers' stress and for research and education aimed at reducing the burden on family caregivers.