

<http://online.wsj.com/article/SB10001424052702304791704577418173565087592.html>

# The Curse of a Diagnosis

## Is Early Detection Useful If a Disease Has No Cure? An Alzheimer's Dilemma

*By Melinda Beck*

*Updated May 22, 2012 at 1:12 pm ET*

*Malibu, Calif.*

If you were in the early stages of Alzheimer's disease, would you want to know?

That question will haunt a growing number of people and their families as scientists devise more ways to diagnose the degenerative brain disease before it causes severe symptoms, but still can't prevent or cure it.

Linda Dangaard underwent a spinal-tap test last year confirming suspicions of early Alzheimer's disease at age 56. Allowing his wife to be tested "was the biggest mistake of my life," says Colin Dangaard, age 70. Even though she is still functional and vibrant and works in the family's Malibu saddle-importing business, the diagnosis cost her her driver's license, many of her friends and much of her self esteem, her husband says. "Her golden years were ripped out from under her by a diagnosis that I think is cruel, because there's nothing anybody can do about it."

"It feels like a bomb has gone off in my life," says Mrs. Dangaard, who concedes that she sometimes gets confused and repeats herself. "I also ask myself, 'Why me?' I eat right. I exercise. No one else in my family has this."

Traditionally, the only way to confirm Alzheimer's was with an autopsy, when the disease's characteristic plaques and tangles are found in a patient's brain. Before that, doctors diagnose it on the basis of symptoms, once they rule out other explanations. But experts say the plaques and tangles start forming 10 to 20 years before symptoms appear.

New tests are emerging that can detect those early brain changes, and more are on the horizon. Last month, the Food and Drug Administration approved a radioactive dye, Amyvid, that makes brain plaque visible on a PET scan. It is expected to be available this summer.

The spinal-tap test that Mrs. Dangaard had measures changes in the cerebrospinal fluid associated with the brain plaques and tangles. It has been available for several years, but used mainly in research settings.

Neither test is covered by insurance or Medicare, and neither is definitive alone. Negative findings reduce the likelihood that cognitive impairment is due to Alzheimer's. But 20% to 30% of people over 65 have some plaques in the brain and many are cognitively normal. It is unclear if they will ever develop the disease.

Genetic tests can identify gene variations that raise the risk of Alzheimer's to varying degrees. One rare variation virtually guarantees that a carrier will develop Alzheimer's at an early age; their offspring have a 50% chance of inheriting it. Researchers are testing a drug that could potentially prevent Alzheimer's in a large Colombian clan that carries the gene variation. As in many research trials, family members won't be told who has it and who doesn't, since the knowledge can be devastating without effective treatments.

Linda and Colin Dangaard with their horses and one of their dogs at their Malibu, Calif., ranch. ILLUSTRATION: MICHAL CZERWONKA FOR THE WALL STREET JOURNAL

For patients already experiencing memory problems, the ethical issues are different,

experts say. It pays to have a medical evaluation, since many treatable conditions can cause dementia-like symptoms. Once those are ruled out, neurologist John Ringman at the University of California, Los Angeles, says he typically asks patients with mild cognitive impairment if they want to know if it is likely to progress to Alzheimer's—even though the knowledge won't change their treatment. "Some people say, 'Doc, I want to know everything.' Other people say, 'If it isn't going to affect the treatment, I should just live my life.' "

Mrs. Dangaard's sister, Dawn Coffee, says it was Linda who first raised concerns about her tendency to repeat herself several years ago. Mrs. Coffee and their mother—all of whom work in the Dangaards' business—were concerned as well, so they encouraged her to investigate.

Her primary-care doctor found that she had a severe deficiency of vitamin B-12, which can mimic Alzheimer's. B-12 injections helped a little, but when her symptoms persisted, they consulted a neurologist, Paul Dudley. He conducted more tests, including two MRIs, which were inconclusive, and suggested they seek a more definitive diagnosis at UCLA. Still, Dr. Dudley found enough evidence of dementia that he notified state health authorities, as required by California law, triggering a review of her driver's license.

At UCLA, Mrs. Dangaard fared poorly on tests of memory and word recognition. But her age and the insight she displayed weren't typical of Alzheimer's, so Dr. Ringman suggested the spinal tap. "I wanted to make sure I hadn't missed anything," such as an infection or inflammation in the spinal fluid, he says. (Drs. Ringman and Dudley both had the Dangaards' permission to discuss her case.) The spinal tap found levels of beta amyloid protein and tau "consistent with Alzheimer's disease," he says. And given her scores on the cognitive tests, he adds, "it isn't what I'd call the early stages—she has significant dementia."

Mr. Dangaard disputes that his wife is significantly impaired and says the diagnosis has done more damage than the disease. "Sure, she can't do the complicated ordering that she used to do in our business, but there are lots of other things she does very well," he says.

Losing her driver's license has been particularly hard. "It is like house arrest in California," he says. Mrs. Dangaard attempted to win it back but failed the written test. Mr. Dangaard

blames the stress of the situation and says she misses only one or two questions out of 220 when he quizzes her at home. "She can out-Sudoku me," he says.

Mrs. Dangaard jokes that while her short-term memory can be hazy, "I figure if I keep doing those tests over and over again, eventually they'll be in my long-term memory and I won't have a problem." Asked if she thinks she has Alzheimer's, Mrs. Dangaard says, "I guess my wiring is a little off. But knowing it is worse than having it."

Her husband says, "There's no way this diagnosis benefits people who have it. It just crushes your spirit."

Her sister has a different view. "I love my sister dearly. We've been best friends all our lives. But she's gotten worse and he's in denial," says Mrs. Coffee, who says that disagreements over Linda's condition have caused a rift in the family.

Experts in caring for Alzheimer's patients say it is typical for family members to disagree in such cases. It is also typical for people with Alzheimer's to remain highly functional in some areas of life and deteriorate in others. "Patients often work very hard to compensate for it, but there comes a point where they can't hide it anymore," says Lori Bliss, a care manager at Senior Concerns, a nonprofit organization that serves adults with special needs in nearby Thousand Oaks, Calif.

As devastating as it is, an early diagnosis can give families time to plan and let patients participate in financial, legal and health-care arrangements. The course of the disease is often unpredictable. Some people work and remain independent for years after a diagnosis. "Families should let people with Alzheimer's do as much as they can and be there as a safety net," says Norma Featherston, a senior care consultant at the Alzheimer's Association in Ventura County, Calif. Staying active and connected socially is vital to patients' well-being, particularly in the early stages, she adds.

That is one thing everyone agrees on in Linda Dangaard's case: "I just want her to live every day and be as happy as she can be," her husband says.

**Write to Melinda Beck at [HealthJournal@wsj.com](mailto:HealthJournal@wsj.com)**

