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For Alzheimer's, Detection Advances Outpace Treatment Options

By [GINA KOLATA](#)

When Awilda Jimenez started forgetting things last year, her husband, Edwin, felt a shiver of dread. Her mother had developed [Alzheimer's](#) in her 50s. Could his wife, 61, have it, too?

He learned there was a new brain scan to diagnose the disease and nervously agreed to get her one, secretly hoping it would lay his fears to rest. In June, his wife became what her doctor says is the first private patient in Arizona to have the test.

"The scan was floridly positive," said her doctor, Adam S. Fleisher, director of brain imaging at the [Banner Alzheimer's Institute](#) in Phoenix.

The Jimenezes have struggled ever since to deal with this devastating news. They are confronting a problem of the new era of Alzheimer's research: The ability to detect the disease has leapt far ahead of treatments. There are none that can stop or even significantly slow the inexorable progression to [dementia](#) and death.

Families like the Jimenezes, with no good options, can only ask: Should they live their lives differently, get their affairs in order, join a clinical trial of an experimental drug?

"I was hoping the scan would be negative," Mr. Jimenez said. "When I found out it was positive, my heart sank."

The new brain scan technology, which went on the market in June, is spreading fast. There are already more than 300 hospitals and imaging centers, located in most major metropolitan areas, that are ready to perform the scans, according to Eli Lilly, which sells the tracer used to mark plaque for the scan.

The scans show plaques in the brain — barnaclelike clumps of protein, beta amyloid — that, together with dementia, are the defining feature of Alzheimer's disease. Those who have dementia but do not have excessive plaques do not have Alzheimer's. It is no longer necessary to wait until the person dies and has an autopsy to learn if the brain was studded with plaques.

Many insurers, including [Medicare](#), will not yet pay for the new scans, which cost several thousand dollars. And getting one comes with serious risks. While federal law prevents insurers and employers from discriminating based on genetic tests, it does not apply to scans. People with brain plaques can be denied long-term care insurance.

The Food and Drug Administration, worried about interpretations of the scans, has required something new: Doctors must take a test showing they can read them accurately before they begin doing them. So far, 700 doctors have qualified, according to Eli Lilly. Other kinds of diagnostic scans have no such requirement.

In another unusual feature, the F.D.A. requires that radiologists not be told anything about the patient. They are generally trained to incorporate clinical information into their interpretation of other types of scans, said Dr. R. Dwaine Rieves, director of the drug agency's [Division of Medical Imaging Products](#).

But in this case, clinical information may lead radiologists to inadvertently shade their reports to coincide with what doctors suspect is the underlying disease. With Alzheimer's, Dr. Rieves said, "clinical impressions have been misleading."

"This is a big change in the world of image interpretation," he said.

Like some other Alzheimer's experts, Dr. Fleisher used the amyloid scan for several years as part of a research study that led to its F.D.A. approval. Subjects were not told what the scans showed. Now, with the scan on the market, the rules have changed.

Dr. Fleisher's first patient was Mrs. Jimenez. Her husband, the family breadwinner, had lost his job as a computer consultant when the couple moved from New York to Arizona to take care of Mrs. Jimenez's mother. Paying several thousand dollars for a scan was out of the question. But Dr. Fleisher found a radiologist, Dr. Mantej Singh Sra of Sun Radiology, who was so eager to get into the business that he agreed to do Mrs. Jimenez's scan free. His plan was to be the first in Arizona to do a scan, and advertise it.

After Dr. Sra did the scan, the Jimenezes returned to Dr. Fleisher to learn the result.

Dr. Fleisher, sad to see so much plaque in Mrs. Jimenez's brain, referred her to a psychiatrist to help with anxiety and suggested she enter clinical trials of experimental drugs.

But Mr. Jimenez did not like that idea. He worried about unexpected side effects.

"Tempting as it is, where do you draw the line?" he asks. "At what point do you take a risk with a loved one?"

At Mount Sinai Medical Center in New York, Dr. Samuel E. Gandy found that his patients — mostly affluent — were unfazed by the medical center's \$3,750 price for the scan. He has been ordering at least one a week for people with symptoms ambiguous enough to suggest the possibility of brain plaques.

Most of his patients want their names kept confidential, fearing an inability to get long-term care insurance, or just wanting privacy.

A woman from New Zealand was told by one doctor that she had Alzheimer's and by another that she had [frontotemporal dementia](#), a rare brain disease that strikes people at younger ages than Alzheimer's and progresses faster. She had a scan. The result was clear — no significant accumulation of plaques. She had frontotemporal dementia. Unfortunately, Dr. Gandy said, there was nothing he could offer her, not even a clinical drug trial.

A man given a diagnosis of [Parkinson's disease](#) was totally immobile and demented. Could he have had Alzheimer's all along?

A scan showed he did.

Dr. Gandy's first patient, Alexander Dreyfoos, an 80-year-old electronics engineer and businessman, was one of the very few willing to be open about his experience. He is independently wealthy and was not worried about privacy or insurance.

But he was very worried about Alzheimer's. His mother, who died at age 79, had it. "I watched her deteriorate to the point where she couldn't even recognize me," Mr. Dreyfoos said. And he had begun seeing signs that his [memory](#) was slipping.

"A few years ago, I realized I wasn't at the top of my game," he said.

Mr. Dreyfoos had his DNA sequenced by a commercial company and learned that he had a gene, ApoE4, that increases the risk of Alzheimer's. At Massachusetts General Hospital, he learned he had shrinkage of his brain — typical of Alzheimer's. After doctors tested his memory and reasoning, he said, they told him he was right to worry.

Finally, Mr. Dreyfoos went to Dr. Gandy at Mount Sinai, looking for an experimental treatment for the Alzheimer's he was sure he had. Dr. Gandy also suspected he had the disease, but suggested a scan.

The scan did not show an abnormal accumulation of amyloid. As far as Dr. Gandy is concerned, Mr. Dreyfoos does not have Alzheimer's.

Mr. Dreyfoos was surprised, "wonderfully so," he said.

Dr. Gandy said that as many as 30 percent of people who seem to have Alzheimer's turn out not to have it when they get the scan. But those who get bad news struggle to cope.

Desperate to slow the progression of his wife's disease, Mr. Jimenez is now giving her turmeric, coenzyme Q10, astaxanthin, krill oil, ginkgo biloba and coconut oil — remedies he found on the Internet. There is no good evidence they work, and each costs about \$5 to \$15 a month. But, Mr. Jimenez says: "What am I going to do? People feel so helpless with this disease that they are willing to try anything."

He worries about the future and how they will survive financially. He wonders if it might have been better not to know the diagnosis.

"It is financially, emotionally and spiritually draining," Mr. Jimenez said. "Everything hangs by a thread."