

Is it Alzheimer's? Maybe not

March 3 2011, By Linda Shrieves

Alicia Harper spent years as a missionary, working in Puerto Rico, the Dominican Republic and Mexico, but she faced her greatest challenge six years ago when, at age 69, her mind and body began to falter.

When her children visited, she often sat on the sofa in her Longwood, Fla., home, unresponsive to what was going on around her. A regular churchgoer, she gradually lost interest in attending church. She didn't recognize her own bedroom.

Meanwhile, she was beginning to have trouble walking - and her right hand and right leg often shook.

The diagnosis? Alzheimer's disease.

The reality? Fluid on the brain.

Experts say a significant percentage of those diagnosed with Alzheimer's disease suffer from something else. A study released last week underscored that message.

Researchers in Honolulu autopsied the brains of 426 Japanese-American men who were residents of Hawaii, and who died at an average age of 87. Of those, 211 had been diagnosed with a dementia when they were alive, most commonly Alzheimer's disease.

The study found that about half of the men diagnosed with Alzheimer's did not have sufficient numbers of the [brain lesions](#) characterizing that

condition to support the diagnosis.

For the Harpers, it would take several years - and visits to a handful of doctors - before they discovered Alicia did not have Alzheimer's disease.

Instead, she had normal pressure hydrocephalus. With NPH, patients have a buildup of fluid on the brain - and often experience [memory loss](#), trouble walking and loss of bladder control. As many as 5 percent of those diagnosed with Alzheimer's, Parkinson's disease or some form of dementia may have NPH instead, doctors say.

"We hear it so often, over and over again from families," said Dr. Phillip St. Louis, a [neurosurgeon](#) and director of Florida Hospital's NPH Program. Harper "went to three or four different doctors before they finally found it. And her case is not unusual. But many health-care providers aren't aware of (the condition)."

And that's as frustrating for families as it is for doctors and medical researchers.

After doctors told them Alicia might have Alzheimer's disease, her husband and their four adult children had to accept that she might never be the same.

"To me, it was just a consequence of life," her husband, Nildo, said. "You just have to live with it."

Nildo became both nurse and caretaker for Alicia, a Cuban emigre who had been the glue that held their family together. He couldn't leave the house because he was afraid she might fall.

Alicia doesn't remember much about that time - it's just a hazy memory. "I remember that I wasn't able to walk," she said recently. "And that I

wasn't in charge of the house - the cleaning, the cooking - anymore. I just didn't care."

Her condition continued to worsen. Walking became increasingly difficult - even with a walker. And she couldn't control her bladder.

Finally, a neurologist suggested performing a series of tests on Alicia, including a spinal tap, to see if she had NPH.

The condition is often characterized by how quickly a patient seems to age, St. Louis said.

"Let's say you have Uncle Joe, who you've seen and when you see him six months later, he has trouble remembering things from one minute to the other. And his walking is incredibly bad - he has to use a cane or a walker," said St. Louis. "It's very easy for someone to say, 'Well, he's 70, he's getting old.' But it should be a much more gradual decline."

Neurologists typically conduct memory tests on patients - and follow up with MRI scans of their brains, said Dr. Ashok Raj of the Florida [Alzheimer's Disease](#) Research Center. A neurologist cannot look at an MRI and conclude that a patient has Alzheimer's, Raj said, but "nine times out of 10, an MRI is going to exclude a lot of other memory problems - such as strokes, NPH and tumors."

Added St. Louis, "Doctors should at least do an imaging study to see if there's any reason for this (decline). Many times they don't. They just assume it's Alzheimer's."

Alicia's MRI showed she had enlarged ventricles in her brain - a sign of NPH - but no significant atrophy of the brain, which would have signaled some type of [dementia](#).

The next step? More tests. St. Louis and a team of doctors studied her gait, her cognitive function and then did a spinal tap for three days to see if draining some of the fluid from her brain might help.

Afterward, St. Louis suggested implanting a shunt in her head to continuously drain the excess fluid.

Patients usually experience a slow, but steady improvement in memory, brain function and walking as a result, St. Louis said.

But that didn't happen with Alicia.

The Harpers noticed the change within a week.

Alicia began trying to walk, her hands and legs stopped shaking and she took an interest in life again.

"This is what's so amazing," said Nildo, 81. "The symptoms disappeared like magic - without medication."

Alicia, now 75, still needed physical therapy, to rebuild her strength and improve her walking. But now, a year after her surgery, she no longer uses a walker. And best of all, she seems to have returned to her old self.

She spent Christmas laughing and enjoying the time with her children and eight grandchildren. She began playing solitaire again on the computer, checking out Facebook, playing with her iPod. And even though her hands hurt from arthritis, she sometimes plays the piano again.

She isn't racing around the mall, but she's walking and she's back to bossing Nildo around. "Now," he says, laughing, "she'll even argue with me again."

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