A crucial test for Alzheimer's

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It's painful to watch Peter Kenney take a memory test.

"Can you tell me what year it is?" asks Alyssa Bergey, a research assistant at the Memory and Alzheimer's Treatment Center at Johns Hopkins Hospital.

Kenney's brow wrinkles in thought, but after a minute, confusion clouds his eyes and he shakes his head.

"How about what season it is?" she presses on. "The month?"

Kenney, 78, thinks on it a while, then shakes his head.

"Today's date?" she asks.

"Today's date I don't know," his soft voice murmurs. He rubs his head and says, "It's baffling."

Bergey pulls objects one at a time from a box and asks him to identify them: a baby's rattle, a stethoscope, a comb.

No, no and no.

She asks if he knows where he is today. "Do you know what state you're in?"

He replies, "A state of confusion." And the tension in the room breaks.

Kenney, from Timonium, Md., has been coming to Hopkins since 2003, four years after his primary care doctor diagnosed him with Alzheimer's disease after running him through a battery of similar mental exercises, says Ann, Kenney's wife of 56 years. She says that despite his advanced condition, he has retained a sense of humor and a sweetness unmatched in most advanced patients, who can become highly anxious, belligerent or passive.

Alzheimer's is a brain disease that causes the memory to slowly erode, eventually ending in death. When symptoms of dementia appear, it's not uncommon for patients to seek out memory centers such as the one at Johns Hopkins to find out what's going on.

Though a good medical history, a physical and cognitive tests are typically the first type of work-up a person receives, there are an increasing array of methods for evaluating brain function earlier and more accurately, says Alzheimer's Association chief medical and scientific officer Bill Thies.

Tests for biomarkers -- substances in the body such as proteins that indicate underlying disease -- hold promise. They include newer and more complex MRI and PET scan imaging, not widely used yet, which can measure the size of brain regions and can look for the amyloid plaques and tau tangles that are the physical hallmarks of the disease, Thies says. Genetic tests for certain "risk genes" also can be conducted.

The availability, accuracy and value -- especially early on -- of such Alzheimer's tests are subject to debate because effective treatments have yet to be found, he says.

"This whole scene will change when and if we develop more effective treatments," says Ron Petersen, director of the Mayo Clinic Alzheimer's Disease Research Center.

Listen to a half-dozen patients and their loved ones tell their diagnosis story and you'll hear stories laced with words such as "frustration," "shock," "relief." Many families say they wish the testing process were more succinct and the devastating news rendered with more sensitivity.

Most families, like the Kenneys, say they became frustrated by the months-long process it took to figure out that Alzheimer's was the culprit. Ann Kenney said she brought it up with her husband's doctor numerous times over a year before he tested her husband.

Some families have flat-out tactless diagnosis experiences.

Carol Blackwell, who blogs for USA Today with her husband, Alzheimer's patient Bob Blackwell, says she was present when his mother was diagnosed with Alzheimer's 21 years ago. "Bob and I took her to the doctor, who is a family friend, to be tested. He said, 'Bobby, your mother is as nutty as a fruitcake.'"

Carol said Bob's diagnosis four years ago at age 64 wasn't dispensed as harshly, but it was lacking in comfort. "Handing you a sheet of paper with some general information after they've just knocked you over with a bowling ball isn't very helpful. There definitely should be counseling along with it," Carol says.

The extended diagnosing period is a result of the fact that no Alzheimer's test is 100 percent accurate yet, says Marilyn Albert, a professor of neurology at Johns Hopkins School of Medicine. So answers come from only a composite picture that the multiple tests piece together.

"We don't have a single, simple test the way we do for prostate cancer, for example. You have to do a series of evaluations," says Albert, who says the tests also help rule out other causes of cognitive decline -- such

as cardiovascular and thyroid problems -- which sometimes can be reversed with treatment.

Without a brain biopsy done during an autopsy that can reveal plaques and tangles, it's impossible to know for sure whether Alzheimer's is the root cause, she says. Even then, it's still considered a probable diagnosis, she says, noting that at least 10 percent of people believed to have Alzheimer's while alive turn out not to have the diagnosis on autopsy.

Experts are desperate to step up early diagnosis because the nation is on the crest of an Alzheimer's epidemic, if not already there, as Baby Boomers grow older, Thies says. According to an Alzheimer's Association report this year, 5.3 million people have the disease, and that number is projected to run as high as 16 million by 2050.

To streamline diagnosis, about a year and a half ago the National Institute on Aging and the Alzheimer's Association organized a project to review the body of knowledge about Alzheimer's and possibly revise diagnosis criteria.

Researchers and clinicians on the project presented preliminary reports at the annual Alzheimer's Association conference in Honolulu this summer, suggesting continued use of basic tests -- including pen and pencil tests -- but also the addition of biomarker and neuroimaging techniques, including spinal taps to measure proteins in cerebrospinal fluid that indicate Alzheimer's is present.

Thies says new diagnostic recommendations could be published early next year.

At medical centers such as Georgetown, scientists already are using biomarker methods to glean more information about the brains of dementia patients, says Scott Turner, director of the Memory Disorders

Program at Georgetown, but technologies are not available everywhere. New diagnostic criteria would likely change that, Thies says.

Petersen says most doctors probably wait too long before they make a solid diagnosis of Alzheimer's because, until more definitive diagnostic testing is available, they'd rather err on the side of caution. Once a diagnosis is made, it can affect health insurance and long-term-care policies, work status and social standing.

But conversely, an early diagnosis can help families feel less alienated, says Gary Kennedy, director of Geriatric Psychiatry at Montefiore Medical Center in the Bronx, N.Y. "Many physicians abhor making the diagnosis because they fear we have nothing to offer. I disagree," he says. "Working with the family and patient to accept the diagnosis and plan for the future is rewarding."

Ann Kenney says she's glad they found out earlier rather than later, because the medical support helps. But it's Peter's sweet disposition that makes the strain of caring for him less trying than what some families endure.

As she watches Peter, once an accomplished pianist, pluck out Peg o' My Heart on the table in front of him as if it were a piano keyboard, and half-whisper, half-hum the words, their eyes meet and a loving glance passes between them for a moment before Peter's hands fumble and his train of thought is lost.

RANGE OF TESTS FOR ALZHEIMER'S

So far, no single test offers an indisputable diagnosis, not all tests are widely available, and some are still being evaluated for use as Alzheimer's tests. Some examples:

Cognitive: This neuropsychological test is typically one of the first exams that a primary care doctor or memory center specialist will give to people who exhibit signs of dementia. Questions range from whether you know the date and state to identifying certain objects and writing a letter.

Genetic: Doctors look for "risk" genes, such as ApoE4, in DNA by examining blood and saliva.

Spinal tap: Fluid is drawn from the spine so doctors can look for changes in signature proteins, amyloid beta and tau, that indicate brain cell death.

MRI: Magnetic resonance imaging uses radio waves and a strong magnetic field to produce detailed images of your brain that, for example, indicate brain volume, specifically any changes in the hippocampus, where the earliest signs of Alzheimer's can be detected.

CT: With computerized tomography, X-rays pass through your body from many angles to create a cross-sectional image, or slices, of your brain. The procedure can help doctors rule out tumors, bleeding and other causes of dementia.

PET scan: Positron emission tomography uses an injection of a radioactive material that binds to chemicals that travelin the brain. A scanner tracks the radioactive material, which illuminates parts of the brain not functioning properly, such as areas dense with amyloid plaque.

Sources: Bill Thies, Alzheimer's Association; Ron Petersen, Mayo Clinic