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Diagnosis of Alzheimer's isn't always accurate

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Martin Rosenfeld, 90, of Farmington Hills and daughters Cookie Gonik, left, and Shelley Rosenberg rest easier since learning why he was confused. Alzheimer's was feared, but the big problem turned out to be sleep apnea. / SUSAN TUSA/Detroit Free Press



By **Robin Erb**
Detroit Free Press Medical Writer

His loved ones dreaded what might be next: a diagnosis of Alzheimer's.

Martin Rosenfeld had called too many times -- confused and frustrated -- from a parking lot outside his synagogue, after driving there in the middle of the night for services that wouldn't begin for hours.

Once a meticulous pattern-maker in the clothing industry, he now nodded off mid-conversation. Spilled things. Mumbled.

"We'd be getting calls all night long. He'd say, 'What time is it? Can I get up now?' " said his daughter, Shelley Rosenberg, whose husband, Don Rosenberg, chairs the Alzheimer's Association -- Greater Michigan Chapter.

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Rosenfeld's confusion, which turned out to be caused partly by sleep apnea, reflects what the head of Wayne State University's Institute of Gerontology worries is a growing trend in the number of Americans being wrongfully assumed -- even medically misdiagnosed -- with Alzheimer's, the most common form of dementia and perhaps the most feared disease of old age.

"It's a real problem. If you're older and you get a label of Alzheimer's -- even a hint that you have Alzheimer's -- there's no more critical thinking about it. You're written off by a lot of people," said Peter Lichtenberg, head of the institute and a clinical psychologist who has testified in several probate cases in which a person's mental capacity was at issue.

Lichtenberg, in a December paper for the journal *Clinical Gerontology*, highlighted two case studies: in one, a man's bouts of confusion and agitation in his late 70s were caused by illness and painful cellulitis, not Alzheimer's; in the other, an 87-year-old woman, who seemed suddenly confused, was suffering from depression.

Lichtenberg's paper builds on research elsewhere that suggests that the difficulty in pinning down Alzheimer's makes misdiagnosis too easy. The research is based mostly on small studies but also on an ongoing, long-term study supported by the National Institute on Aging, which is part of the National Institutes of Health. In cases reviewed so far, about one-third of Alzheimer's diagnoses were incorrect, according to the lead researcher, Lon White.

"The diagnosis was dead wrong one-third of the time, and it was partially wrong a third of the time, and it was right one-third of the time," White said.

The project, called the Honolulu-Asia Aging Study, has been under way since 1991 and focused on the precise brain changes linked to Alzheimer's disease and other types of dementia. Pathologists examined the brains of 852 men born between 1900 and 1919, about 20% of whom were diagnosed with Alzheimer's.

In the cases carrying an Alzheimer's diagnosis, two-thirds of the brains exhibited the types of lesions closely linked to Alzheimer's. Half of those featured other problems, as well, such as scarring on the hippocampus, the part of the brain responsible for memory, White said.

That didn't mean that those without the Alzheimer's lesions were otherwise healthy, "but what we're calling Alzheimer's is very often a mixture of different disease processes," White said.

Lichtenberg said his concerns about misdiagnosis in no way lessen the enormity of Alzheimer's impact.

"I don't know how vast a problem it is, but I see it too often," Lichtenberg said.

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The Alzheimer's Association estimates that 5.4 million Americans are living with Alzheimer's. Lichtenberg's grandmother had the disease. A picture of her, dancing, sits in his office at Wayne State.

But understanding how often Alzheimer's and other dementia are misdiagnosed is hard to quantify. Sometimes, that's because loved ones have not yet noticed a decline; sometimes, they don't want to face the possibility, Lichtenberg said.

Rosenfeld's most pressing problem was severe sleep apnea that had aggravated the more manageable symptoms of undiagnosed Lewy-body dementia. Lewy-body dementia causes a visual processing disorder, disrupts the ability to organize, plan and focus and can cause sleep problems and hallucinations.

A breathing machine at night made a dramatic difference, said Shelley Rosenberg: "I'm thrilled. He is what he used to be. I have my father back."

Some too quick to judge

It's a difficult balance for the Alzheimer's Association: trying to raise awareness and boost early intervention efforts for Alzheimer's and other dementias, while also cautioning families and clinicians not to jump to conclusions.

Diagnosing Alzheimer's is tricky and is done, in part, by ruling out other health problems, such as an undetected stroke or brain tumor.

Even well-meaning doctors can be too quick to judge, especially when confronted by worried loved ones listing Mom's memory lapses, said Jennifer Howard, executive director of the Alzheimer's Association -- Michigan Great Lakes Chapter.

An expert evaluation by an interdisciplinary team that includes a geriatrician and neurologist is crucial, she said.

"The brain is not just a physical structure. It's this incredible computer. It's constantly computing where resources are needed and redirecting, depending on energy is coming from and what task you need to do," said Rhonna Shatz, director of Behavioral Neurology at Henry Ford Hospital in Detroit.

For that reason, a common urinary tract infection, a sudden change in blood pressure or depression are all stresses on an older brain that, combined with other problems, can quickly short-circuit it, Shatz said.

The result is acute confusion or delirium that, to an untrained eye, may look like Alzheimer's disease.

"Pulling these things apart and the need for a real diagnosis -- that's important so people can live the best quality of life as possible for as long as possible," said Howard at the Alzheimer's Association.

Other factors missed

In the case of Al Edelson, a former Wayne State professor and cancer survivor, the confusion was really the result of a regular cocktail of 18 medications prescribed for a variety of health issues.

In his mid-70s, the once sharp-witted, effervescent professor of instructional technology began to withdraw, family members said. For years, he and his wife traveled frequently, but he began to be more comfortable remaining near his family's Huntington Woods home.

In the hours before their 5 a.m. departure for a trip to Britain aboard the Queen Mary 2 several years ago, Edelson was wide awake, anxious.

"He said, 'I think I need to cancel this.' It was 2 a.m. I said, 'I will never forgive you,' " his wife, Joanna Edelson, recalled, chuckling.

But the change had become undeniable: Usually at ease dancing with his wife or leading group conversations, the now-retired professor was awkward and withdrawn on the ship, Edelson said.

Eventually, a doctor gave the diagnosis of Alzheimer's.

"The problem is that when you're older and you have a lot of medical conditions, no doctor speaks to the other doctor, and that's basically what happened," said Edelson, a retired teacher.

After consulting with other doctors, family members scaled back Al Edelson's drugs. They were amazed.

"It was like he came out of a coma," his wife said.

When he died in December, having just turned 80, the cause was pneumonia, Joanna Edelson said: "Dementia did not kill my husband."

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More Details: Is it Alzheimer's?

Unlike delirium, which usually comes on fast and sets off alarm bells for loved ones, Alzheimer's disease moves through the brain slowly, seemingly shutting off switches one by one.

Diagnosing it isn't easy. There is no blood test, no telltale brain scan. Even the brain anomalies common in an Alzheimer's patient - - plaques (abnormal clusters of a protein called beta-amyloid) and tangles (twisted strands of a protein called tau) -- are shared by those who have no symptoms at all. That means diagnosing Alzheimer's is about ruling out other problems and relying on changes observed over time.

Among the conditions that might bring on temporary, but dangerous, delirium:

- Urinary tract infections
- Medications
- Stroke or vascular disease

- Fever, illness
- Depression
- Blood pressure changes
- Surgery
- Drug or alcohol use
- Tumors

For more information, go to <http://www.alz.org/> or call 800-272-3900.

More Details: Common terms and what they mean

Sorting through confusion begins with understanding that some changes may be temporary.

Terms to know:

- **Delirium:** Temporary but acute mental confusion. Can be life-threatening. Involves a sudden onset of symptoms -- anxiety, disorientation, tremors, hallucinations and incoherence -- and can be caused, especially in elderly people, by illness and infection, changes in blood pressure, reactions to medication or vitamin deficiency.
- **Dementia:** More permanent medical condition that disrupts brain function. Includes Alzheimer's disease, but also vascular dementia (from a stroke or blood vessel disease in the brain), severe alcoholism, depression, delirium, Huntington's disease and inflammatory diseases such as syphilis, tumors and Parkinson's disease. Symptoms include anxiety, paranoia, personality changes, lack of initiative and difficulty acquiring new skills.
- **Alzheimer's:** The most common form of dementia. Proceeds in stages over months or years and gradually destroys memory, reason, judgment, language and the ability to carry out simple tasks.

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