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The incurable dementia that strikes younger people

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Tragedy may be looming, but love set up camp long ago in this Schaumburg home.

The simple pleasure of letting Mary Beth, his wife of 34 years, know how he feels about her is something Steve Riedner cherishes.

"How many more opportunities am I going to have to tell her, 'I love you'?" Riedner says, hinting at the sad silence in their forecast.

"I'm going to know anyway," his wife says.

A critical thinker with strong opinions, Riedner has contributed to several of my columns over the years. When moments of confusion and being tongue-tied became more frequent in his mid-50s, Riedner chalked it up as "a sign of getting old."

The tool-and-die maker, who spent part of his youth flying missions in a prop plane through the jungles of Vietnam, didn't realize how dire his situation had become until he found himself rooting for a brain tumor.

"I know there's about four things it could be — tumor, stroke, thyroid problem or a brain disease," Riedner, 58, says of communication problems that began in 2001. "I was hoping for the tumor, because they could cut that out and I'd be good to go."

A tad overweight with a cholesterol level of 270, Riedner originally was told by his doctor that he had had a stroke. But tests didn't show any evidence of that.

Even with speech therapy, his word confusion worsened.

That's when doctors diagnosed Riedner with primary progressive aphasia, a rare and incurable form of dementia that strikes people as young as in their 40s and destroys the brain's ability to communicate.

While people are familiar with Alzheimer's, which attacks the memory, "PPA is very different," says Dr. Marsel Mesulam, a researcher and professor at Northwestern University who first identified the disease.

"The disease attacks not the memory, but the language part of the brain," Mesulam says.

"Patients don't forget events. They forget words. You show them an object, and they can't tell you what the object is called, even simple things."

Sitting at his kitchen table trying to explain what that is like, Riedner tells how he caused a stir during one of his motorcycle trips. The group stopped at a hotel and wanted to swim in the lake.

"I wanted to ask the ladies at the counter if they had a beach in the back, and it didn't come out that way," says Riedner, who was mortified to later find out he had used an offensive slur instead. "I said it three or four times, and I just couldn't get the right word. I felt bad about that because I offended those ladies."

At work, Riedner discovered he had to write down measurements because he'd forget them in the time it took him to study a blueprint and turn toward his manufacturing machines. Unrelated to his dwindling abilities, Riedner fell victim to companywide layoffs in 2003.

Now at home with Mary Beth, who heads the library at Roosevelt University, he takes an Alzheimer's drug that sometimes helps for a bit. He makes lists of common words that he's forgotten, although he admits that it's difficult to look up words because he can't even recall the first letter. Writing is a lost art.

"A couple sentences is a couple hours' time because I can't get close enough for spell check," Riedner says.

He usually can't recall the name of his disease. So he tells people he's had a stroke "and then everybody is very nice," Riedner says.

"Patients with Alzheimer's forget that they forget. Patients with PPA are pretty aware and very frustrated at their inability to communicate," Mesulam says.

Riedner says "calakator" when he means calculator, "conversed" instead of convinced, "hapdicapped" for handicapped, and he depends on Mary Beth to translate his jumbles.

"What's the word — profasiftive?" Riedner asks.

"Pervasive," his wife offers.

"I just know you," she adds tenderly in explaining how she understands what her husband wants to say.

The couple have three grown children (Dan, Dave and Debbie) and two granddaughters (Josie, 4, and Audrey, 18 months).

"This is going to be real hard for the family," Riedner says. "You're trapped in your body and that would be terrible. I don't want to put them through that, and I don't want to do it."

But he realizes he doesn't have control.

"I have the love of my family, and they say they'll do that for me," he says, his eyes watery. "So, OK."

The disease progressed quickly for Barbara Caponigri of Schaumburg, who suffered from PPA complicated by a motor neuron disease. A French and Spanish teacher for a junior high, she "was a little off" during a 2003 speech about her volunteer work, remembers her husband, Paul Caponigri. She was not quite 45.

"Words are out of order for a while," Paul Caponigri says. "Then it progressed where she couldn't say a complete sentence. ... The last four months, she started to lose control of her abilities."

She died at age 46, leaving behind her husband and four kids.

The disease affects people differently. "I've had patients I've followed at 10 years or 15 years," Mesulam says.

But there is no cure.

"It's not as if there is something around the corner. This is going to be a tough struggle to find something that works," Mesulam says. "But one never should give up hope. One should remain as active as possible and enjoy all things that are possible and try to react to this new reality."

For Riedner, that means a stint volunteering with mentally disabled adults.

"It came to me that these people don't know how bad they've got it," Riedner says. "We had a great time. I learned a lot from those people. They're finding a way to have pleasure and enjoy the life that they have."

So is Riedner, who takes trips with his wife, is building a sun room onto his house, improving his spiritual side and still voicing his opinions as long as he can.

"I will get to the point where I'll be totally mute," Riedner says solemnly, before adding with a twinkle, "A lot of people are waiting for that."

His wife laughs.

"His sense of humor is still there," she says.

To learn the warning signs of PPA or find out more about the disease, check out www.brain.northwestern.edu.

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