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Schaumburg man doesn't let his loss of speech crush his spirit



Looking to his wife, Mary Beth, to supply the words, Steve Riedner points to photographs and drawings of what he wants to say. The 63-year-old Schaumburg man suffers from Primary Progressive Aphasia, a dementia that initially attacks the part of the brain that processes language and speech.

JOE LEWNARD | STAFF PHOTOGRAPHER



Using notebooks, photographs and a whiteboard helps Steve Riedner communicate with his wife, Mary Beth. The 63-year-old Schaumburg man suffers from Primary Progressive Aphasia, a dementia that initially attacks the part of the brain that processes language and speech.

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While a rare brain disorder called Primary Progressive Aphasia is robbing Steve Riedner of the ability to say “I love you,” the Schaumburg man still manages to get that message across to Mary Beth, who has been his wife for nearly 39 years and now is also his caretaker.

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By [Burt Constable](#)

The sight of me standing outside his front door in Schaumburg sends Steve Riedner into one of his belly-shaking, blue eyes-a-twinkling chuckles. He points to the jaunty, herringbone tweed newsboy hat on my head, reaches into his closet and pulls out an identical cap.

The very idea that I’d wear the same hat as Steve — a flag-flying, lifetime NRA member and Vietnam veteran who enthusiastically challenges some of my opinions — gets me to giggling, too. Then Steve puts it into words.

“Tay dot den den tane net not be de da,” a grinning Steve says, his cadence and expression giving me the impression that he might be meaning to say, “You’ve got the same hat as me now, so you can start following my lead on the important issues.”

Or maybe not, says Mary Beth, a better translator of Steve’s intent based on her almost 39 years of being married to the man.

When we last got together in 2007, Steve had just been diagnosed with Primary Progressive Aphasia, a rare, incurable form of dementia that strikes people as young as in their 40s and destroys the brain’s ability to communicate. Five years ago, he told a funny story about how his unknowing switch of another B-word for the word “beach” created some awkward moments on a vacation, and he’d point out his flubs, such as using “hapdicapped” for “handicapped,” “conversed” for “convinced,” and “profasiftive” for “pervasive.”

Now, it’s rare when the 63-year-old utters the word he intends. But he has moments.

“It’s things,” Steve says during a more coherent chat on Friday. He scampers into another room and returns with the framed shirt he wore on his first solo flight as a private pilot.

He grabs old newspaper clippings showing him with the photos he took of Bob Hope during Steve's days on the crew of a prop plane during the Vietnam War.

"I can read," Steve says slowly, before pointing to his head. "I just can't get it out da."

Steve originally attributed his messed-up syntax on being in his 50s. In 2002, doctors thought he'd had a stroke, but couldn't find any evidence of that. It would be another four years before he was diagnosed with PPA.

"Even among specialists, only a few are well-informed about this condition," says Dr. Marsel Mesulam, director of the Cognitive Neurology and Alzheimer's Disease Center at Northwestern University's Feinberg School of Medicine and the researcher who first identified the disease in 1982. He discovered that, unlike the generalized dementia of Alzheimer's disease, PPA initially targets the part of the brain that controls speech and language abilities.

"It's like a brush fire. It starts in a certain place and things spread," says Mesulam.

"It starts very subtly. Sometimes the person is the only one to recognize the change."

Often within five to 15 years, PPA destroys communication and starts killing off brain cells that control other functions. Researchers discovered how the disease progresses.

"We know a lot," says Mesulam, "but we can do very little."

There is no cure or even standard treatment that has proved effective. Some patients, including Steve, take medications developed for Alzheimer's patients,

"There's always hope," Mesulam says.

A tool-and-die maker who appreciated logical arguments, took care of his home, cherished his freedoms and loved being his own man, Steve has had to sell his extensive gun collection, including the pistols he used to compete in fast-draw competitions. He got rid of his motorcycle. He stopped driving the car. The TV remote and the microwave now stump him.

"Dressing is starting to become a problem," says Mary Beth, whose patience and love clearly mean a lot to Steve, who just has trouble expressing it. Giving him time to organize for the attempt, Mary Beth counts to three and slowly says, "I love you."

"I low two yow," Steve says back.

"It doesn't come out right, but I know what's he's thinking," Mary Beth says with a smile.

Their three grown children and two grandchildren visit and are very supportive, Mary Beth says. They understand how cruel the disease can be, even robbing Steve of the ability to say his wife's name.

"It usually sounds like Monnie," Mary Beth says. She makes photo books and notebooks where Steve can point to communicate. She writes things on an erasable white board. Even so, Steve sometimes just shrugs and says, "I don't know."

"It's not his memory," Mary Beth says as Steve struggles to come up with the name of his father, who died last year at age 92.

"La la el da," stammers Steve, who nods when Mary Beth says, "Elmer."

A sign that was his father's has the phrase "Always Something" burned into the wood. Steve points at the saying, points at the hearing aid in his one "good" ear, moves his hands as if he's coaxing words to come forth, shrugs when they don't and then laughs.

"His attitude helps me so much," Mary Beth says. One Saturday a month at the Elk Grove Village Public Library, she attends a support group gathering with a dozen suburbanites coping with loved ones suffering from PPA.

Steve still laughs at jokes and likes to watch TV. He strikes a pose with his hands at waist-level.

"That's 'The Rifleman,'" Mary Beth says. "He loves old westerns — 'Gunsmoke,' anything with John Wayne."

Steve goes to the gym and gets together for breakfast and other outings two or three times a week with his buddies.

"He's got great friends," Mary Beth says.

A conference March 24 at Northwestern University's Chicago campus will educate families and professionals on the latest methods to care for people diagnosed with PPA and other diseases under the umbrella of Frontotemporal Degeneration.

"Last year we had over 250 people from 22 states, Canada and Ireland," notes Darby Morhardt, a clinical research social worker and director of education at Northwestern. A fundraiser for the center includes a volunteer's participation in next month's Hustle Up the Hancock. For information about the conference, the fundraiser, PPA or other dementia issues, visit brain.northwestern.edu.

When Mary Beth says that Steve wants to donate his brain to research after he dies, Steve nods and indicates that he wants his story told.

"Most hup pom people see it and hep mo mo," Steve says.

“He says that is why we’re doing this, to help people,” Mary Beth says.

Steve, who always described himself as a “spiritual” person, has a mantra that he must depend on his wife to put into words.

“Thy will be done,” Mary Beth says.

“That’s it,” Steve says, who acknowledges that he is not the one in control of his own fate. “It just goes on and don day nad.”