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West Nile's grim realities hit Emory patient

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The illness started subtly.

Twila Jean Starkey had a slight fever. Her energy was low. But she and her husband, Joe, were due in Newnan to spend July Fourth with their grandchildren. A sinus infection, she thought, was not going to stand in their way.

It wasn't a sinus infection. Within two days, Starkey would be in the intensive care unit of Atlanta's Emory University Hospital, too weak to walk or stand or finish a sentence without stopping to take a breath. Within a week, she would be paralyzed: unable to lift her head, close her eyes or breathe on her own.

Eleven weeks later, the 50-year-old Louisiana woman remains at Emory's Wesley Woods Hospital. She has come a long way: She can move her legs and lift her arms from the elbow, and Friday she breathed without machines for almost nine hours.

On Thursday, the Centers for Disease Control and Prevention warned the nation's doctors that in rare cases West Nile virus can paralyze the body like polio. Twila Jean Starkey's case is one of those.

"People think that you will get this and you will either die or you will survive and be OK," Joe Starkey said. "But there is a middle ground here that is very tough, and scary."

The Starkeys have been married for nine years. It is his second marriage, her third, and they have four children and three grandchildren between them. They met at the giant ExxonMobil chemical plant in Baton Rouge, west of where they now live in Hammond, on the north shore of Lake Pontchartrain.

Joe, 58, retired three years ago. He and "TJ," as he calls his wife, bought an RV that hooks onto their pickup. They planned to spend a few years traveling, visiting family and looking for opportunities to do charitable work.

They began the summer traveling: down to Florida in April to see Joe's daughter and back to Hammond in late June to catch granddaughter Haley's dance recital. They left again three weeks later. Haley came along to visit Joe's son Ron and his family in Georgia.

With an RV in tow, it is a nine-hour drive from Hammond to Newnan. By the time the Starkeys arrived, TJ was sick to her stomach and so weak that she tripped and fell. They went twice to the emergency room at a local hospital to get antibiotics and anti-nausea drugs. By the second visit, Joe had to carry his wife into the ER.

A puzzled neurosurgeon called Emory, then summoned an ambulance. Shortly afterward the Starkeys were tearing toward Atlanta, with TJ on oxygen and intravenous fluids and plugged into heart and breathing monitors and Joe in prayer by her side.

They went straight to intensive care.

"She was very calm," Joe said. "She told me: 'I'm not going to make it out of this.'"

Those were among the last words she spoke for more than a month. The paralysis moved swiftly up her body. The fever rose so high that she was placed on a bed of ice to cool her down. Her breathing was turned over to a machine.

The Starkeys are religious people. In the ICU waiting room, Joe --- a tall, bullet-headed man with wire-rimmed glasses and a gentle manner --- clung to his faith.

"It's not that we weren't aware, or weren't frightened, " he said. "But when it's something that you don't have control of, you know the only one who can affect it is the Lord, and you trust he will do that."

The doctors didn't know why TJ was so ill. "All the different things they thought of, just one by one they ruled them out, " Joe said. "It could have been polio, rabies, herpes, Lyme disease." On July 18, a test of her spinal fluid provided the answer: During the three weeks when they stopped in Hammond, TJ had been infected with the West Nile virus.

But the answer didn't lead to a solution. There were no cases of West Nile paralysis in the medical literature --- only a few mentions of "weakness" in some of the first cases in New York in August 1999. Until Thursday, no descriptions of paralysis cases had been published.

Dr. James Sejvar, the CDC neurologist who issued that alert, estimated only 5 percent of the most serious infections develop into paralysis instead of the brain inflammation that doctors have come to expect --- and most of them go unrecognized by doctors.

Researchers do know that some cases of West Nile demand a long recovery time. When Joe began reading up on the disease in a medical library Emory makes available to patients, he discovered how long: from three to 30 months, depending on the severity of the symptoms.

"I thought then that we might be here a year, " he said. "I still think that's probably true."

On July 25, TJ was transferred to Wesley Woods, less than a mile away. For the first few weeks, friendly nurses found Joe chairs and couches to sleep on. He started each morning in the hospital's small lavender-hued chapel. When TJ improved slightly, he left for an afternoon to retrieve their RV from Newnan and move it closer to the hospital. Now he sleeps in it but spends all day with his wife.

They have a routine. Joe starts the day by reading a verse from Psalms. TJ, a fine-boned woman who used to do aerobics daily, works with physical therapists for a single exhausting hour. She can sit in a heavily padded chair if she is lifted into it, but she cannot hold herself up yet. She cannot eat because of the tracheotomy. And though she moves her mouth and forces out a few words in the faintest possible whisper, she still cannot speak.

"She says Dad's getting pretty good at lip-reading, " said Ron Starkey, Joe's youngest child, whose wife, Stacey, trims TJ's nails and brushes her dark hair.

Recently, Joe has had the chance to look back on their experience. In July he had wanted to postpone the trip to Newnan to spare TJ the stress of travel. He is oddly grateful they did not.

"Where we live in Louisiana, it would have been drive an hour this way for an X-ray, drive an hour another way for an emergency room, " he said. "Here everything's in one place. And the people in this facility are so wonderful."

And though his wife came perilously close to death, Joe said, the crisis and the long months of recovery have strengthened his faith instead of undermining it.

"This has been an opportunity to draw closer to God for me and for TJ, " he said. "But I am looking forward to the day we can talk about it. Then it will be much easier."