

Mansfield mom shares her challenges after a stroke in PBS documentary

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Wicked Local Mansfield

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Mansfield — Before Stephanie Sylvain, 37, had her stroke she could walk with ease. Since her stroke, she walks with a slight limp.

Before Stephanie had her stroke, she could drive a car. After her stroke she still drives, but with some modifications.

Before Stephanie had her stroke, she didn't think twice about carrying on a conversation. After her stroke she can still converse, but often times it is a source of frustration.

Stephanie, a Mansfield resident, is part of the documentary, "After/Words" that recently aired on PBS.

Through portraits of people successfully living with aphasia, the documentary brings public awareness about a condition that many stroke victims live with.

Stephanie and her husband Jayson, along including their children, twins Eva and John, 7, and daughter, Kareana, 10, attended the "After/Words" premiere at the Brattle Street Theatre on March 3 in Cambridge.

The couple agreed to participate in the documentary because they want increase awareness and erase any misconceptions about the disability.

"Aphasia is a loss of communication not intelligence," Stephanie said.

A little over four years ago, on Nov. 13, 2008, Stephanie had a massive stroke. Ironically it was Jayson's birthday.

Then 33, Stephanie said she was sound asleep when the stroke occurred. Her daughter Eva was 3 years old at the time and came into her parent's room at 4 a.m.

"Eva came into the room and I had kicked all the covers off," Stephanie said. "She woke up Jay and said something was happening."

At first, Jayson said, he didn't overreact.

A year earlier, in July 2007, Stephanie had a similar incident that had gone undiagnosed, so he assumed she was having another episode.

"At the time no one could diagnose it and she had the same symptoms again," Jayson said.

He said Stephanie didn't respond when asked if she was okay, and that is when he knew something was wrong.

The ambulance came and brought Stephanie to Sturdy Memorial Hospital in Attleboro then transferred her to Mass General in Boston where she would stay for approximately three weeks.

"I was in a sleep-like state for the first two weeks," Stephanie said.

When she finally came to, her first thought, she said, was of her three children and her husband.

"I was aware of what was going on but couldn't communicate," she said.

What Stephanie didn't know was that she had surgery on Nov. 14, where part of her skull was removed to alleviate the swelling the stroke had caused, Jayson said.

Wearing a helmet to protect her brain, unable to move the right side of her body and unable to speak, Stephanie said things were pretty confusing.

"It was a gradual process," Jayson said. "She started slowly, first opening her eyes then she started to squeeze our hands."

Once the swelling went down and Stephanie was deemed stable, she was released.

Fittingly, Stephanie returned home on New Year's Eve, a new year for her new definition of normal.

Prior to her arrival, Jayson installed handrails from the garage into the kitchen and up the stairs to provide support as Stephanie re-learned how to walk.

"There really was nothing more we had to do," Jayson said. "She adjusted. Stephanie is very self-sufficient."

In the beginning Stephanie wore a leg brace on her weak leg and had to revisit things she spent a lifetime taking for granted — walking, getting dressed, but most importantly talking.

Out of all the setbacks, Stephanie said losing her ability to communicate and being diagnosed with Aphasia, was by far the most difficult to accept.

“Losing speech was the hardest part, I felt trapped,” she said.

Stephanie threw herself into speech therapy. As luck would have it, a close friend and Mansfield resident, Jennifer Higgins was a speech and language pathologist.

Higgins went to Stonehill College with both Stephanie and Jayson where the couple met.

She typically works with children in her sessions, but decided to create a program to help her friend.

“I immediately starting thinking, how can I use my skills to help her,” Higgins said. “When she first came home the main issue was helping her find her words, she knew what she wanted to say but couldn’t get it out.”

Not being able to find the right word is a classic symptom of aphasia, Higgins said, adding that not all strokes produce aphasia, it depends on the severity of the stroke and Stephanie had a massive stroke.

To help Stephanie recall her vocabulary, Higgins used photos of common objects and photo albums of family members to trigger her memory.

“We put labels on everything, from the garage door to the kitchen sink and refrigerator,” Higgins said.

In conversation Stephanie often uses her finger to write in the air or with a pen on a notepad to help her find the word she is looking for.

“It helps to guide her brain,” Higgins said.

She also started taking speech therapy classes at Boston University once a week, which is where she met speech-language pathologist Jerry Kaplan who co-created the “After/Words” documentary.

“Jerry is great,” Stephanie said.

Getting to Boston to take the classes was tricky though as Stephanie still wasn’t driving because of inability to use her right arm and leg. Determined to conquer that barrier, she re-learned how to drive and has her car set up so she can use her left foot.

She admits to taking the back roads to Boston as the highway still intimidates her.

Seeing his wife drive post-stroke was a big moment for Jayson.

“When she decided she was going to drive again, she went out and took lessons,” Jayson said, adding that is just who his wife is, determined.

At home Jayson said he and the kids have adapted to Stephanie’s speech. Because of their familiarity with each other, often times they can fill in the blanks when Stephanie is looking for a word.

“It’s like a Jedi-mind trick,” Jayson said.

Other than the obvious bumps, Jayson said their household is just as normal as anyone else’s complete with messes, dinners, kids, and laundry. If anything, he said, his children are more compassionate.

“At first the kids were a little hesitant to leave her,” he said. “They were afraid something would go wrong when they were gone. But they help her do things like carry the laundry and hold her hand to give her extra balance on uneven terrain.”

Higgins said some in her field believe aphasia patients can only make so much progress, and it typically occurs in the first year after a stroke.

But both she and Jayson dismiss this theory.

“She continues to make progress,” Higgins said. “Some of the things she doesn’t do in a typical way but she’s gonna do it!”

Jayson said if anyone can beat the odds, it is his wife.

“I’m happy with whatever progress she makes. We weren’t sure how far she’d come back but I’m sure she will continue to improve and continue to make progress with her speech,” he said. “She’s persistent if she says she’s going to do it, she’s going to do it.”

As for Stephanie, she doesn’t dwell too much on everything that has happened. Is her life the same as it was before the stroke? No. But she has accepted her new normal and said it’s better than the alternative.

“I’m alive,” she said.



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