

Speaking out on aphasia

SUE TIFFIN

Staff Reporter

In the first hours after a massive stroke affected one third of Barb Thibault's brain, her doctor told her husband that she'd be dead within 36 hours.

Instead, almost five years to the day of the ischemic stroke that at first left her unable to walk, talk, or independently care for herself, the feisty, humorous, strong-willed woman sits alongside her partner and grandchild, both who she learned over time to remember and recognize, and the speech therapist she met in the first few days at the hospital.

It's not immediately apparent that Thibault has experienced any sort of medical event – neurologists will look at her inches-thick file, then at her, and back at her file in surprise – except that sometimes she switches pronouns as she speaks, and her family will seemingly subconsciously make hand motions for numbers when they say them, helping to give a visual when there is a disconnect with the audio.

And then 40 minutes into the interview, Thibault begins purposefully sharing examples of what her aphasia can sound like.

"Chihuahua," says her granddaughter, Maleeka Fortier.

"She-wanna-wanna," says Thibault, in an attempt to repeat the word.

"Rhinoceros," says Bob Wilson, her husband.

"Rhino-isserin," says Thibault, clearly focusing intently and becoming frustrated as she speaks.

"Mosquito is another one," says Fortier.

"Mushskwashesidin?" asks Thibault, then motioning for everyone to wait, "I've got the word."

Her family pauses as she attempts to pull the word intact from her brain to her mouth, until Wilson sounds it out: "Mo, ski, does," he says, enunciating each syllable, tracing the letters on the table as Thibault watches closely. "She can visually see the word mosquito."

"I can see the word mosquitoes," says Thibault, and then excitedly, "I've got it!"

Usually the result of a stroke or brain injury, aphasia is a communication disability that causes language impairment, affecting the way a person understands or uses language. It can affect people in different ways, from anomic aphasia, in which speech is understood but words are difficult to find, to Wernicke's aphasia in which a person can speak fluently but with sentences sometimes filled with jargon, to global aphasia, in which people can speak few recognizable words and might also have challenges with reading and writing. According to the Aphasia Institute, more than 100,000 Canadians have aphasia, including what Alison Mack, Thibault's speech language therapist, estimates to be a handful of people in Haliburton County.

"The primary thing I want people to know about aphasia is the person they knew is still there [cognition is intact]," she said. "Aphasia has impacted their language ability. However, with a little instruction, it's amazing how well people can learn to communicate with someone with aphasia."

Thibault said she remembers nothing at the point of the major stroke. She remembers Wilson telling her he thought she was having a stroke, she laughed, and then the world went blank. She was aware in the hospital but didn't recognize her visitors, and was frustrated with her lack of speech, at first being able to com-



Barb Thibault, front, had a major stroke five years ago this Oct. 6. She noted the support of speech therapist Alison Mack, left, granddaughter Maleeka Fortier and husband Bob Wilson in helping her to recover, and deal with the challenges of aphasia, an acquired communication disorder that impairs a person's ability to process language. /SUE TIFFIN Staff

municate in writing with her left hand. "I didn't know anybody," she said. "I was scared all the time. Bob would come, and I'm standing, thinking, why is he here all the time, I don't even know him. Maleeka, I don't know her. And I'm looking, and my whole world is gone, everything."

Through extensive rehabilitation and perseverance that her family acknowledged and encouraged, Thibault began regaining skills, including speech. Fortier was only eight, but the girl visited her grandmother and showed her how to play Hangman, the word game.

"Every night she helped me, an hour a day," said Thibault. "I didn't know what I was doing, but I was doing it. She was doing it, and I was doing it."

During her stay in the hospital, she learned she would become a great-grandmother for the first time when her grandson told her she had to get better so she could meet his baby. "I remember that Lincoln told me that he and Holly were having a baby, but I didn't understand what a baby is," Thibault said, becoming emotional at the thought of what she might have missed had she not survived.

But besides surviving, she thrived. Wilson advocated in the hospital to help ensure she had what she needed, even when that meant going home for dinner just three weeks after the stroke. "She started writing first," said Wilson. "I want to go home." He told the doctor his wife wanted to go home, just as she was starting to walk.

"So we're about to leave, and she says, 'make dinner,'" he said. "I said, 'yes, I'm going to make dinner.' Then she pointed at herself, 'make dinner.'"

That night she found what she needed at the grocery store, got home on a leave from the hospital and made dinner.

"She made spaghetti from scratch," said Wilson, half in amazement and half in acknowledgement of Thibault's determination. "Like, homemade sauce from scratch."

Mack said Thibault can speak to what aphasia is in a way that most people who have aphasia cannot.

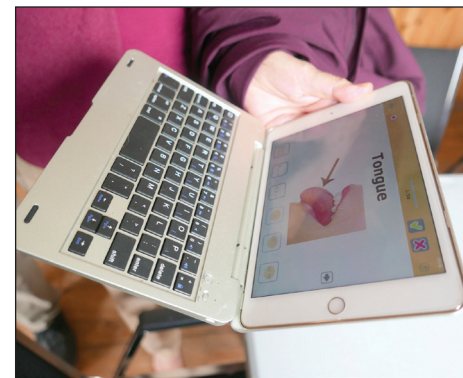
"People with aphasia can't usually say what it's like to have aphasia," said Mack, and to Thibault: "You have aphasia, but you can talk enough for the rest of the world to start to hear."

Thibault said aphasia can create challenges when people don't understand her, don't recognize that she has a disability or don't have patience in trying to better comprehend her communication. Besides some words being difficult for her to pronounce, she said that although she can use number words fluently, when she hears them they are muffled, requiring adaptations including multi-modal communication exhibited by her family, and by medical professionals when they text rather than call appointment scheduling.

"Every day it's a fight," she said. "I don't care what everyone says. I know I talk really good, but I'm not perfect. Not the way I used to be. It's a fight every day. Especially people don't understand what's wrong with you, what happened to you. Sometimes my brain is saying the right things, my mouth is saying something else. I've got to be very slow sometimes when I'm upset or whatever, I've got to really think, but every day is a fight."

Mack said more supports are needed for people with aphasia, and for the families who support them.

"In 1985, Rick Hansen started his Man in Motion tour and since then the public's awareness of people with physical disabilities has changed a lot," she said. "Buildings are now constructed with ramps to get access and many buildings have been retrofitted to have accessibility ramps. But when it comes to communication impairment, the public doesn't have the same awareness and knowledge. We need to start building 'communication ramps' for people with communication disabilities. Community awareness and knowledge builds empathy within a



Alison Mack shows Barb Thibault a program used to help people affected by aphasia, an acquired communication disorder that impairs a person's ability to process language.

community but also a public confidence to step forward rather than to step away from people dealing with communication issues."

"My brain, sometimes I'm getting frustrated because of the numbers," said Thibault. "Or I have to ask someone else to help me. Or I don't remember sometimes. I was a really smart woman until the stroke."

"You still are," said Wilson. "You just have a hard time getting things out."

"I'm a strong woman, I know I am," said Thibault. "But smart, my memory's gone."

"Barb is a force unto herself," said Mack, later. "That she has been able to wire and [has] re-wired her brain to do what she can do, defies my descriptive abilities."

Wilson said it's essential that people who have experienced a stroke are supported by hospital staff and family members, noting he saw some people in the hospital whose families were not always there for them. "Never give up," he said.

"You just have to take time and help them understand what they're going through," said Fortier, who is 14 now. "You've got to be there for them. If you were in that position you wouldn't want someone giving up on you or ignoring you all the time. You can't just stop talking to someone if they have problems. You've got to help them through it ... you have to have people there for you."

"It's a struggle every day, every day," said Thibault. "I'm so lucky to be loved by my family. It's most important. Just tell people, sometimes speech is not the same. People are different, especially if people have had a stroke or any brain injuries, it could be anything. Stop and listen. Listen."

Aphasia Camp 2019 will be held at Camp Wanakita this weekend, bringing together people with aphasia and their families to enjoy a camp atmosphere and be with others with similar life experiences.

"The camp will be what the camp is, it's a different experience for everybody," said Mack. "Part of the advantage of having 10 volunteers from Haliburton come to that camp is so 10 people in the county will get to know what aphasia is. Now we'll have 10 people with lots of experience, a whole weekend of experience, working with lots of different types of aphasia, and learning to use the different techniques. Sometimes it helps just to slow down, or repeat every once in awhile, some people write key words, or pictures, or gestures ... or hangman."

The March of Dimes Aphasia Camp 2019 runs from Oct. 4 to 6 at YMCA Wanakita in Haliburton. For more information about the camp, contact Mara Manzato, camp coordinator, March of Dimes Canada, at 416-571-0467.

Birders aflutter over varied thrush visitor

JENN WATT

Editor

A bird rare to Ontario is creating a flap at Bark Lake Leadership and Conference Centre as a steady migration of birders make their way to check out the varied thrush that has taken up residence outside the office.

Program manager Joe Fortin said at first staff didn't know they had anything special coming to the feeder, but wondered about the bird that looked a bit like a robin and an oriole.

"We eventually reached out to a Facebook community called Ontario Birds with a really bad, blurry photo and quite quickly one of them replied back with yes, that's a varied thrush. Then the floodgates were open and folks [were] commenting," he said. "Once we had a name and a confirmed ID we were able to do a little legwork using the All About Birds website from Cornell University. We found out this isn't a typical bird you'd find in northeastern North America."

The varied thrush, a songbird with bright orange breast, blue-grey back with orange stripes over the eyes, is typically found on the west coast of North America.

"Varied thrushes hop on the ground or low in shrubs and trees," the All About Birds website says. "They eat mainly insects and other arthropods in the summer and switch to nuts and fruit in fall and winter. On breeding territories, male varied thrushes sit on exposed perches to sing their haunting, trilling songs."

Local birder Ed Poropat happened to be at Bark Lake Leadership and Confer-



A vibrantly coloured varied thrush sits in a tree outside Bark Lake Leadership and Conference Centre in Irondale. The rare bird made its way to Haliburton County from the Pacific coast and has been attracting dozens of birders to see it. /Photo by Joe Fortin

ence Centre when the songbird was spotted and has been back a few times since.

"I think of it as a west coast rainforest bird, preferring damp, coniferous mountain slopes. It is a bit of a wanderer in the fall and winter, though, and they show up almost every year in Ontario, even as far as [Newfoundland]," he wrote in an email to the *Echo*. "Usually only one or two, but who really knows! As far as rarity goes, it is certainly a bird that draws much attention in the east, since only a few seem to

be found each year. They will visit feeders for fallen seed, although they are normally berry and insect eaters. I suspect there have been well over 100 people from all over the province to see the one at Bark Lake."

On a weekend earlier this month, Fortin estimates between one and two dozen birders showed up with their professional camera equipment to see the varied thrush. He enjoyed meeting the community of bird enthusiasts, who were

cognizant of the bird's space and took the opportunity to visit with each other.

"It's such an amazing community. The birders that have been coming up have been so respectful, keeping their distance," he said. "Last weekend we had a couple of young folks, maybe 10 or 12 years old, a random birder [let] them use their multi-thousand-dollar scope to look at this bird up close from a safe distance."

Although the varied thrush is used to warmer climates, Poropat said it will be fine as long as it has food to eat.

"It can survive here, as long as there is food present. If not, it will simply move on in search of better areas to feed," he said.

Prior to this year, there had been one varied thrush spotting reported in Haliburton County, several years ago in West Guilford. However, this year there has actually been a second varied thrush in the county.

Following the publication of Poropat's article in *County Life* about the planned Minden Christmas Bird Count, he received an email from a man in Miner's Bay saying he saw a male varied thrush at his feeder. It appeared again during the bird count on Dec. 14 – "a first for Minden [Christmas Bird Count]!" Poropat said.

Fortin said the Bark Lake staff intend to keep the food plentiful all winter long and hopes the bird stays put until spring.

"I would hope that as long as we keep the feeder stocked and keep it fed and make it feel safe here, it will make it through the winter," he said, "and then hopefully find its way back out west with tales of the awesome time it had in the Haliburton area."

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For peat's sake: preserving wetlands in the Haliburton Highlands

JENN WATT

Editor

Mapping wetlands is one of the first steps to providing them legal protection, prohibiting development that could hinder their ability to filter water, mitigate flooding, safeguard wildlife, and sequester carbon.

On the heels of a recent mapping project in Minden Hills on behalf of the Haliburton Highlands Land Trust, biologist Paul Heaven spoke at an Environment Haliburton/HHLT event in Haliburton Jan. 14 about the different types of wetlands that exist, why they're important and what threatens their existence.

With the assistance of a federal government grant, the land trust evaluated the Kendrick Creek Wetland Complex, accounting for 840 hectares (about 2,076 acres) from the Barry Wetland to Snowdon Park to Gelert. Heaven said the land is provincially significant; when the paperwork is complete, that designation will afford the property protections against development.

Evaluation projects are crucial to preserving wetlands, Heaven said.

"By getting a good mapping base and fully understanding where our wetlands are, how much wetland we actually have, might avoid conflicts where one consultant is saying 'there's no wetland there,' one is saying 'it is there,' the planner's in the middle going, 'where do I go from here?'" Heaven said.

Kendrick Creek was a test project and the land trust hopes that more mapping will follow.

He specified that the wetland mapping is different from the LiDAR mapping that is underway. Wetlands don't all look the same. Depending on how much the water



Attendees of biologist Paul Heaven's talk on wetlands participate in an interactive demonstration on how wetlands help reduce flooding. The funnels represent the lakes, each flowing into the next, until they get to the bottom, which represented the amount of water rushing into downtown Minden. Sponges represented wetlands and participants were asked to place them in the funnels to reduce the flow of water. /JENN WATT Staff

stagnates, they can be quite fluid, as in the case of marshes, or relatively solid, as you might find in a bog.

"When you're looking at a black spruce swamp on a treed landscape, the level's the same, it's not necessarily a dip or anything, it's a flat surface," he said.

Heaven explained to the group that there are four types of wetlands: marshes,

fens, bogs and swamps.

Peat, created in bogs and fens from dead plant material, looks a lot like soil, but is actually nutrient-rich and has a long history with humans. When burned, it can create a heat source and people have used it for cooking and home heating. It's also good for agriculture, adding nutrients to the soil.

Heaven said it takes about 1,000 years for one metre of peat to accumulate and when he's doing his work on wetlands, he'll often sink his auger 10 metres into the peat.

"Some of the stuff I'm pulling up is actually 10,000 years old," he said.

"If you're looking at that peat and you see a leaf or a seed in that, that leaf or seed could be 10,000 years old."

Peat also has a gloomier history in Europe, where it seems it was a favoured resting place for corpses – particularly of people who were murdered. Heaven said many well-preserved bodies have been found in bogs overseas.

The Lindow Man, for example, was discovered in 1984 in a bog in northwest England. Reporting suggests he was a man in his 20s, with evidence of strangulation and trauma to the head and cuts on the throat. It's estimated he died between 2 BC and 119 AD.

"They're not rotting; they're thousands of years old, but they're not rotting at all," Heaven said of the bodies found. (Many animals have also been discovered in bogs, perhaps stepping in the wrong spot and sinking in.)

Heaven said there are guidelines to keeping wetlands healthy, including keeping a vegetation buffer and a sizeable setback between the wetland and any residence, using floating docks or pier-supported docks, and refraining from activities that would alter the drainage.

He said he worried about the activity of some off-road vehicles, which are being built with waterproof features, encouraging riders to take them through swamps and marshes.

"Taking an ATV through a wetland not only destroys the habitat, it completely changes the hydrology of that wetland," he said.

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