

Life after injury: supported by strength of spirit, family and a caring helper

Tuesday, November 6, 2018

As Carolyn and Mike Woodward welcome 2019, their goals are simple: to get Mike off his ventilator and ultimately, to bring him home.

Last Christmas Eve, Mike fell down the stairs of their home, sustaining a spinal cord injury that has left him on a ventilator and unable to move from the neck down. When Carolyn first found Mike, he had no vital signs. He actually died once when the paramedics were in their home. They brought him back, but lost him again on the way to the hospital before reviving him again. Their two sons, who were living in Whistler and Calgary, immediately flew back.

"The early days were quite a blur for us: I was dealing with the emotions of such a devastating accident and Mike was not really aware of details. Within three days, we were transferred down to Sunnybrook where we were given the news that if Mike did not undergo spinal cord surgery, he could sustain a brain-stem injury leaving him in a permanently vegetative state," says Carolyn. "As Mike was periodically coherent, it was left to him to make that decision, which, thankfully he did. I spent most days in a daze, not knowing what the next moment would bring. I wasn't sure what the future held and couldn't imagine a future without him by my side."

In those early days, Mike and Carolyn connected with Stephanie Bolton, a Regional Services Co-ordinator with the Spinal Cord Injury Ontario (SCIO) office in Peterborough. Stephanie set up a time to meet with them to provide an overview of what SCIO can offer. Carolyn explains: "Stephanie has many connections and people she can reach out to. And she told us that she would help us connect the dots to where we want to go."

Connecting dots, bridging gaps

SCIO Regional Services Co-ordinators provide clients with information and education on topics such as housing, financial assistance, health, sexuality, equipment, transportation

and travel. They learn about their clients' goals and help to gradually build toward them. Stephanie has helped Mike and Carolyn to set up timely assessments, introduced them to assistance programs and even acted as a courier, bringing equipment to Mike's hospital room to increase his comfort level.

"Sometimes people fall through the cracks and need help navigating the healthcare system and support options," explains Stephanie. "For example, sometimes when I meet people, they've already been given assistive technology supports. But Mike had been told it would be a year or two. I knew we could do better than that, and got moving on setting up his assessments."

Mike is now equipped with speech input software and an eye tracking input device that he can use to direct a mouse pointer. As a result, after nine months in the hospital Mike was able to play his first game of solitaire. Being able to use a computer has boosted Mike's outlook, and the assistive technology will help him reclaim some independence with tasks like composing emails and researching on the internet.

A big step: getting off the ventilator

When Mike's accident happened, he and Carolyn were preparing to transition into retirement. Mike was a Computer Numeric Controlled Machinist, working full time for a research facility and Carolyn, an Administrative Assistant at Lakeridge Health Hospital. They were planning to relocate to the Caribbean in late 2018 to live by the ocean and run a vacation rental property. They had a trip planned for January 2018 to view properties, meet with the bank and file their immigration papers.

Now, Mike's goal is simply to get back home. Currently, he lives at Lakeridge Health, which also happens to be Carolyn's workplace. "Eventually I want to go home, but the resources and care needed for me to be on a ventilator at home would be prohibitive," says Mike. "So, getting off the vent is my biggest first step."

To support this step, Stephanie connected Mike and Carolyn with a previous SCIO client who has successfully come off a ventilator, so they could learn from his experience. This young man had undergone a relatively rare surgery to implant a diaphragm pacing system;

an implant that helps with normal breathing by electronically stimulating the diaphragm muscles and nerves, causing the diaphragm to contract and pull air into the lungs.

Ultimately, Mike decided to go ahead with the surgery, which took place at Toronto Western Hospital in July of 2018. Post-surgery, he has been going through a 'weaning' process. At first, the respiratory therapist took him off the ventilator three times a day, for five minutes at a time. By November, he had reached two four-hour periods per day and continues to work toward the goal of becoming completely "vent free".

"We wouldn't be as far as we are without Mike's strength and the support of our sons. They have moved back to Ontario with their girlfriends to be a part of Mike's rehabilitation," says Carolyn. "And Stephanie has added to our support network. She is another friend who is part of Mike's journey and someone I can rely on. She has truly been a bright light at the end of a dark tunnel, helping us to navigate through a mountain of paperwork, always with a smile on her face and a funny story to share."

A revised retirement dream

"Stephanie also opened our eyes to the Direct Funding program, which would allow Mike to hire his own health care providers and be re-situated back home. This was something neither of us were aware of, and we know many others are not likely to have heard of it," says Carolyn. "We have filed our application and are awaiting a ruling to see if Mike qualifies."

In addition to funding for in-home health care, Carolyn and Mike need to find a new home that they can adapt for Mike. Stephanie has connected them with people living in accessible homes so they can view the properties and understand the options. They ultimately hope to one day bring Mike home to a place by the water, with the potential to run a small rental property for seasonal activities: a revised version of their original retirement plan.

"This is not the future we had planned, but we're now changing the plan," say Mike and Carolyn, who have come so far along the most unforeseen journey over the last year. "With Mike's hard work and determination, we are pushing forward to make it the best we can make it. We're looking forward to what the New Year will bring and are hoping for a brighter 2019."

Would you like to support our work, helping people from the time they sustain a spinal cord injury through recovery and rehab to building a life of independence and choice? <u>Donate now</u>: every donation has a profound, personal impact.

Would you like to learn more about how we can help you or a family member who has sustained a spinal cord injury? Visit the <u>Service Co-ordination section of our website</u>.