



Making
the
invisible
visible

MEET REAL CANADIANS LIVING WITH BRAIN INJURY

By Lauren Bentley

We spoke to real Canadians living with brain injuries so we could tell their stories. Driven by our commitment to ensuring the research we fund leads to real impact for Canadians living with brain conditions, Brain Canada is proud to present the following stories from nine survivors of brain injury.

Brain injuries are diverse, complicated, and for many, life-altering. Nearly every brain injury survivor we talked to told us the same thing: they felt invisible.

Though some survivors carry external signs of their injury, many of the most common symptoms – from language and memory loss to cognitive fatigue, environmental sensitivities, and splitting headaches – can be difficult for survivors to articulate and can remain hidden from others. In addition, nearly two-thirds of those with the worst brain injuries deal with depression or other mental health challenges in the years following an injury.

According to Brain Injury Canada, nearly four percent of Canadians – or more than 1.5 million people – are living with a brain injury.¹ These are classified as “traumatic” when they come from a physical injury to the head, and “acquired” when the result of a stroke or other illness. The majority of brain injuries are the results of accidents or illness, but many people each year are injured from failed suicide attempts.²

Many felt like the severity of their injury was recognized too late, stunting their recovery, or noted months- or years-long gaps in getting connected to resources. Nearly everyone said they had to do their own research – many while dealing with debilitating cognitive side effects – to self-advocate for the care they needed.

¹“Statistics on Brain Injury.” Brain Injury Canada, 2022.

<https://braininjurycanada.ca/en/statistics/>, accessed Dec. 2022.

²“Brain Injury Information.” Ontario Brain Injury Association, 2023.

<https://obia.ca/resources/brain-injury-information/>, accessed Dec. 2022.

Seeing The Invisible Disability

Rob Staffen was standing at the back of the crowded room at the St. Marys Golf and Country Club, his family business. It was the second annual fundraising event for the Brain & Mind Matters Community Fund, which he and his family founded to provide grants to charitable organizations that support people with brain injuries near his hometown of St. Marys, Ont. The charity was inspired by Rob's own story: in 2012, he suffered a traumatic brain injury (TBI) while cycling in Joshua Tree National Park.

Rob's daughter, in her early 30s at the time, stood at the microphone. "I have had two dads," she told the crowd. "Dad 1.0 and Dad 2.0." Rob was shocked – two dads? Had his brain injury really changed him that much?

"I looked to my wife, Sharon, whom I've known since grade 10, to confirm," he says. "She said that after the accident, it was like falling in love with someone new."

"After I got out of the hospital, you could never tell by looking at me that I was injured," Rob says, though he has dealt with severe cognitive fatigue, personality changes, anxiety, tinnitus, and high sensitivity to light and sound for years.

Rob was fortunate: he was able to get immediate in- and out-patient care at Parkwood Institute in London, Ontario, where their Pacing Points Program was critical for his recovery. But the waitlist for care can be years long.

"TBIs are way more serious than we think," Rob says. "We need to start helping people earlier."

Another hurdle is navigating the return-to-work process with employers and insurance companies. Some survivors feel pressured to return to work before they are ready in order to keep their jobs or are burdened by having to "prove themselves" as disabled to insurance companies to receive benefits.



Rob Staffen recommends the *MyBrainPacer* app developed by St. Joseph's Health Care London, Ont. (www.mybrainpacer.ca) to regulate activities during the recovery period after experiencing a TBI. "There are resources out there," he says, "but they need to be better known."

Those who want to continue working may find employers unable or unwilling to accommodate their fluctuating abilities.

Rob, an entrepreneur with a family business, avoided these types of difficulties with employers. But for him and many others, a complex web of challenges remains for life.

Ten years after his accident, Rob is back to work and back on his bike. But he lives differently now: he has to manage his energy to avoid cognitive overload, and take a more holistic approach to his time, carefully assessing what is most important.

"A brain injury never leaves you. You just have to figure out how to live with it for the rest of your life," he says. "It's a lifetime commitment to get better." •

"After I got out of the hospital, you could never tell by looking at me that I was injured."

You Will Never Be The Same Person Again

“When you have a brain injury, you lose a lot of yourself the day of the accident.”

Last year, Barb Aldan finished a quilt. That might seem like a simple thing. In fact, it should have been, as she had always been adept at sewing. But that changed five years ago, when she was driving on a country road near her home in Trent River, Ont. It was the first snowfall of the season.

Less than 15 minutes from her house, another car spun out of control. Her SUV was hit three times – at the front of the car, the driver’s side door, and the passenger door.

After being freed from her car, she went into shock and was rushed to the hospital where she was treated for her physical injuries. But even after her body healed, she knew something wasn’t right. She could no longer concentrate and began to experience memory and communication issues. She was plagued by nausea and balance issues. Barb was known as being very diplomatic, yet suddenly she found herself with no filter: “I would say things that would horrify me.”

Particularly difficult was realizing she could no longer do simple things she loved, like cooking or sewing.

“When you have a brain injury, you lose a lot of yourself the day of the accident,” she says. This was confirmed when her counsellor at the Ontario Brain Injury Association later told her, “You will never be the same again. Pick the things that you like about yourself and get rid of the rest. Try to keep moving forward.”

Her primary care physician and other general practitioners she spoke to had little experience with brain injuries. Barb had trouble articulating what was going on. Six months later, she had a meltdown in her doctor’s office and finally got referred to the Ontario Brain Injury Association.

“The world doesn’t know what a brain injury is, because you can’t see it. And unfortunately, when you have it, you can’t express it until you finally realize what the heck’s going on,” she says.

Barb describes the moment she finally was diagnosed with a moderate brain injury through a neuropsychiatrist 18 months after the accident. “It was life-changing,” she says. The accident had affected her relationships, her mental health, and her self-confidence. She even lost her job – when she went back to work two months after her accident, she learned her job had been divided among three other employees.

Once she got her diagnosis, she began the difficult journey to love the new person she had become – with the help of a committed circle of friends and her supportive husband. It also meant setting goals for herself, like finishing that quilt. Last year, Barb found a mentor who worked with her step by step through the project, which she had started before the accident. It was a huge accomplishment.

“I’m totally different than who I was before. But I think I’m a better version of myself,” she says. “You have to work at it to make it happen. Doctors right from the emergency department to family doctors need to become more knowledgeable when it comes to brain injuries so that they can truly understand what their patient is going through.” •

Barb Aldan has learned a great deal about brain injuries since her TBI. She draws support from her involvement with the Peterborough Brain Injury Association, regular lectures from an occupational therapist, and a monthly ladies support group.



The Incredible Power of Neuroplasticity

Stéphane Rouleau used to be an ultramarathoner and a cross-country mountain biker with Olympic potential.

He'd had a few concussions in the past – each time, the doctor would have him sign a form promising that he would buy a new helmet, then he would sleep it off. Then, one night, he passed out while sitting in his car after a first date.

“I was a cardio machine, and funnily enough, I had a stroke,” Stéphane says.

The stroke was caused by a carotid dissection, the most common cause of stroke in people under 50. It was bad enough that he was told he would never walk again.

But Stéphane was determined. He worked with a physiotherapist and eventually regained his ability to walk. Just over a year later, he was back at work.

Stéphane has had a remarkable recovery. But it wasn't easy. The first year, he slept almost nonstop. Four and a half years after the stroke, he still deals with memory issues and muscle atrophy on his left side. He also has a significant visual impairment, which means he has to be tested annually to keep his driver's license – a test that makes him increasingly anxious, as he lives in a small town, Paris, Ont., with few transportation options.

And of course, he has to protect his head, which means no more high-risk sports. Though he misses his high-intensity lifestyle, Stéphane says he feels “healthier, smarter, wiser, and better” since his stroke.

“I used to take crazy risks,” he says, describing himself as an adrenaline chaser and a workaholic. “The stroke made me realize that I have only one life to live. I have to take care of it. Because if I'm not there for me, how can I be there for others?”

He credits his successful recovery to his attention to health and nutrition, his physical condition before his injury, and one key ingredient: neuroplasticity, or the brain's ability to regrow new pathways to compensate for damaged or lost cells. At one time, it was thought that adult brains were stagnant; now we know this is not true, a fact that offers incredible hope



“The stroke made me realize that I have only one life to live. I have to take care of it. Because if I'm not there for me, how can I be there for anyone else?”

After a stroke that weakened his left side, Stéphane Rouleau says he slept nearly nonstop for almost a year. Now, he is meticulous about nutrition and fitness to support his recovery.

to TBI patients, though research in the area is still scarce.

This is particularly remarkable in Stéphane's case. A while after the stroke, a doctor showed him a picture of his brain: a chunk of the right hemisphere was gone. His brain had figured out how to work around the lost section to regain function.

“I would like fellow survivors to know that there is hope,” he says. “There is another life after the injury.” •

A Lonely Path That Impacts Everyone

Many of the brain injury survivors we talked to noted how lonely the experience was. "You are on such an individual journey," says Nicole Hagley, who survived a biking accident that left her with a life-altering TBI in July 2020.



Nicole Hagley, an educator, past national athlete, and now yoga instructor, is still actively recovering from a bike accident two years ago. "We need people to understand the diversity of the brain, and the fact that no two brain injuries are the same."

"Once my face healed, then I came into the world of an invisible disability."

"Even though you have an amazing circle of care around you, you're going through this all on your own. And you can't process it, so you can't articulate what's happening to you, and what you're feeling."

Though her two children are now young adults, Nicole says her brain injury reminded her of the toddler years, when the inability to communicate comes out in emotions and fits of frustration: "I would just melt," she describes.

Despite the lonely journey, Nicole recognizes that brain injuries deeply impact a survivor's entire community. "My relationships have been profoundly impacted during this journey of recovery," she says. "Overnight, all of my home tasks and responsibilities were thrust upon my husband and children. Similarly, my workplace duties, as an educator and Department Head, also needed transferring to colleagues, impacting professional relationships."

Her family is still working through their own personal traumas that have stemmed from the accident.

"It has taken, and continues to take, a great personal and emotional effort to process and manage the guilt of knowing your accident has caused so much pain," says Nicole.

During the bike accident, Nicole's sunglasses embedded into her face, requiring surgery. "Once my face healed, then I came into the world of an invisible disability."

Today, Nicole has healed enough to look normal and perform social norms. But every day is still a struggle. "I can't process information in the moment," she says. A task that used to take seconds, like writing an email, can take 15 minutes or more.

The world, Nicole says, can simply be too loud. As she recovered, she longed for quiet where the chaos in her brain could calm down. Eventually, through the help of yoga, meditation, and physiotherapy, along with the unflagging support of her family and care providers, she is on the path to healing. "There is still a way to go in this healing, yet I can't believe how far I have come." •

From Injury To Advocacy

In early 2011, on a Sunday morning, Bob was heading out to play golf with his friends when he got a headache. He waved down an unmarked police car and told the officer he was in severe pain.

“That’s all I remember,” he says. He woke up a few days later in a sterile hospital room, alone and hooked up to machines. He had had a cerebral hemorrhage – a brain bleed – and nearly died.

Despite the severity of his condition, he was sent home and told to rest up. He knew he didn’t feel right, but he figured he would just push through until he felt better. “I thought I would just snap out of it,” he says. Eventually he quit his job so he could fully recover. But he never did.

Five years after his incident, Bob finally found a nurse practitioner who recognized what was going on: he had a severe brain injury. From there, he finally found resources and support to help him begin healing.

His losses in those five years were huge. Bob found himself with no savings, limited mobility, and mental health struggles. Because he couldn’t participate in the activities he used to love, he lost friends. He felt like he was in a permanent daze.

After living comfortably for many years before his brain injury, he has had to figure out how to live in one of the country’s most expensive cities, Toronto, on a limited disability income and the six hours he works a week as an outreach worker. His own financial insecurity post-injury means he now understands what it is like to struggle to keep food on the table. He is housed – but he knows many with brain injuries who are not. In fact, Brain Injury Canada estimates that 50 per cent of unhoused people have experienced a brain injury.³

In the intervening years, Bob has become an advocate for tenants’ rights, people living on disability, and those experiencing food insecurity. Motivated to help others in similar situations, Bob is using the energy he has to illuminate the interconnections between injury and food, housing, and employment insecurity to elected officials, city councillors, and social justice groups.

“It’s important that we have a voice at the table and our voices be heard. Every single person’s voice is important. Many individuals with brain injury don’t want to talk about it... because of the stigma that comes along with it,” he says.

He wants Canadians to recognize that many people on disability – including those with brain injury – are navigating near impossible situations. Some can no longer drive, yet they can’t afford the bus and don’t have the energy to walk. They might struggle to find jobs that can accommodate their limited energy, yet for many, doing even a small amount of work contributes immensely to their recovery.

It’s a series of complicated choices that Bob wants to bring to light, advocating for better solutions from the government and more empathy from everyday Canadians. •

“It’s important that we have a voice at the table and our voices be heard.”



After losing nearly everything after surviving a spontaneous brain bleed, Bob Murphy is now an advocate for those on disability and experiencing food scarcity.

³ “Statistics on Brain Injury.” Brain Injury Canada, 2022. <https://braininjurycanada.ca/en/statistics/>, accessed December 2022.

“I Am Not My TBI”

When we spoke over a video call with Nathalie B. Morin for this interview, she was lying in bed, with her nose taped after a physiotherapy treatment.

For Nathalie, some of the most difficult parts of her TBI are expressing herself and loneliness.

“I’m more isolated... and it’s difficult to interact with people. Even with friends on the phone, sometimes I just have to say, ‘I gotta go.’”

Prior to 2015, she experienced seven car accidents involving head injuries. Then, in 2015, she had a bike accident while training for a triathlon that led to a severe TBI, as well as a number of physical complications. These range from a displaced septum and sphenoid bone, which are still being treated, to bulging discs and sacroiliac injuries that keep her bed ridden, as she is unable to sit for lengthy periods of time.

Despite knowing about her previous head injuries, after the bike accident Nathalie’s ER doctor sent her home, dismissing her injury by saying “kids fall all the time.” But as the days wore on, her condition deteriorated. A month later, she could barely walk. She knew something was seriously wrong.

Nathalie, a lifelong government employee, worked for two-and-a-half years before she couldn’t do it anymore, unable to perform her duties. After years of seeing numerous specialists and health care providers, she compiled multiple, voluminous medical reports and was approved for long-term disability, which was followed by her approval for medical retirement in 2021.

“I aim to have the best quality of life, even if I feel like I’m a professional patient sometimes,” she says.

The grueling experience of getting disability and medical retirement made her realize how important it was to be aggressively proactive in advocating for her needs.

Even with the best insurance, the cost of quality care can be expensive. Nathalie, for example, receives thorough free care from an Ottawa-based concussion clinic, but other important supplementary services, from physiotherapy to speech-language pathology, are all out-of-pocket, requiring significant personal financial investment. For Nathalie, that means living simply so she can invest any extra income into her health.

Nathalie says that managing all the paperwork involved with her complicated care and daily life is excruciating – she needs help with it all. Like many survivors, she struggles to fill out forms and keep track of complex processes.

“Now, when I talk to someone on the phone, I just say, ‘I have a brain injury,’” she describes, hoping to elicit patience and help from the person on the other end.

“TBI patients are not normal,” she says. “The wires in the fuse box could fry at any time. But because you’re functional at a certain level, people don’t always appreciate how we struggle.” These struggles include loneliness, emotional volatility, and more. “I push as much as I can,” she says. “But when I crash, I crash.”

It’s a lot to manage. But Nathalie – who has always been a fighter – is adamant, “I am not my traumatic brain injury. The important thing is not to give up. If you give up on yourself, you give up on life.”

She credits her health care team with sticking with her through her many challenges. She looks forward to a future in which she can manage better and enjoy life even more. But for today, she tries to practice gratitude for what she does have. “There’s no perfection,” she says. “But I can still enjoy my coffee in the morning.” •



Photography: Owen Egan & Joni Dufour

A Soccer Player Turned Brain Health Advocate

Jay Randhawa was – quite literally – at the top of his game before a brain injury changed everything. At 23, he was playing pro soccer in Portugal and in peak physical fitness. When COVID hit he was told to come home to Toronto. He started playing with a semi-pro team to stay in shape as he waited out the pandemic.

During his first game with the new team, Jay went for a header to defend against a corner kick. As his head made contact with the ball, another player's head made contact with his.

The result was an astounding injury that nearly cost him his life: his brain smashed against the side of his skull, creating a median displacement of 7 mm – the average displacement in a serious brain injury is 3 mm. His doctors told his sister, a nurse, that he had a 20 per cent chance of survival. If he did survive, they said, he would be permanently disabled.

Jay went into a coma for a month and, unbeknownst to him, had three craniotomies for two brain bleeds.

After he became more aware of what was going on, he entered a dark time. He was 23, paralyzed on his right side, and covered in tubes. On top of that, he struggled to accept that his pro soccer days were over. At times, he became so aggressive the nurses had to restrain him.

In rehab, something changed. He had to start his life over at ground zero, but as a natural athlete, he knew how to push himself and take care of his body.

Today, Jay has made a near-complete recovery. But after being at the pinnacle of his career, he can no longer play soccer. He still struggles to regulate his emotions, and has bad days.

“For a brain injury, the recovery is lifelong,” he says.

Though he is no longer on the pitch, Jay still has a passion for soccer, which he channels into coaching young players and training athletes.



Jay Randhawa suffered a head injury during a soccer game that ended his career. He credits his faith in God for giving him strength throughout his recovery. “When you face adversity and opposition, you have two choices,” he says. “Stay down and give up or get up and fight!”

He is currently working on a pilot program for integrating brain health into athletic training. “People just don’t know enough about the brain,” he says. “Before my injury, I didn’t know anything about the brain.” He has spent hours researching brain health – and says he is astounded that he, as a top-level pro athlete, had never learned about the connections between exercise, nutrition, and the brain.

And for the 10-year-old children he coaches through his company, 5P Elite Training? “We don’t do any headers in practice,” he says. He is an advocate for safer sports for kids – and he wants them to take care of their brains from the start. •

“Before my injury, I didn’t know anything about the brain.”

The Crisis For Caregivers



Susan Marsh, whose daughter suffered a catastrophic TBI, is adamant about preserving the dignity of those with invisible disabilities. "Just because people have disabilities doesn't allow the able-bodied to tell somebody what they can and cannot do."

"It felt like she wasn't 'disabled enough,' and in many people's eyes, she looked 'fine.'"

When Susan's 15-year-old daughter, Sydney, was in a car accident, it changed the life of their entire family.

In the hospital, Susan saw her mild-mannered, introverted daughter become aggressive, combative, and physical with the nurses.

In the emergency room, Sydney initially was diagnosed with a mild concussion, a dramatic underestimation of the real damage. For the first few months, Sydney was unable to go to school, and slept nearly all the time – even falling asleep in the middle of eating. When she did start going to school, she needed extra support, including a learning strategist, speech pathologists, and a neurophysiologist, just to name a few.

Over the next few years, Susan and her family witnessed Sydney, who is Métis with ancestral ties to Kapawe'no First Nation, Treaty 8, transform from a diligent and collaborative student to someone they hardly recognized.

Sydney lost her close friends and began hanging out with people who introduced her to high-risk behaviour. Sydney became increasingly impulsive and started self-medicating in unhealthy ways. Her mental health deteriorated, leading to erratic and volatile behaviour and leaving her deeply suicidal.

Eventually, she saw a neuropsychologist and was diagnosed with a catastrophic brain impairment. Finally getting the proper diagnosis helped Susan and her family discover better resources and support for her daughter – and win a legal case to help pay for her treatment.

But the results of the accident have permanently altered the lives of Susan and her husband, as well as their two other children.

Sydney, now 28, still deals with impulse control, mood swings, difficulty planning, low self-confidence, and cognitive fatigue. Because of the extent of her injury while her brain was in a critical period of development, recovery for Sydney is a complicated, ongoing process. Against all odds and with the unrelenting support of her mother, Sydney – who at one point considered dropping out of high school – earned her bachelor's degree in psychology with a minor in neuroscience and mental health. She is currently finishing her diploma in Mental Health and Addictions, and is on a work placement with accommodations.

Susan contrasts the system of support for Sydney to young people with physical disabilities. "If she had [an extreme physical impairment], we would get 24-hour care," she says. "It felt like she wasn't 'disabled enough,' and in many people's eyes, she looked fine," Susan describes, even though Sydney's injury has required Susan and her husband to be on-call around the clock for more than a decade.

For Susan and other parents of kids with brain injuries, processing the dramatic changes in their children can be exhausting and devastating.

"It's a mental health crisis for the caregivers too. There's nobody to support us," she says. •

Support, Attitude, Motivation

The person who pulled Peter Kyriakides out of his darkest moments was his grandfather.

More than a decade ago, Peter was driving in Northern Ontario when he hit black ice and slammed into a tree. “The car was a pancake,” he says. Miraculously, he got out of the car and walked to the nearest house for help.

Back home, he started having concussion symptoms, but figured they would wane. Five months later, he fell in the bathtub and finally went back to the hospital.

“I never came out of the hospital the same way again,” he says.

Peter's brain was severely inflamed, and he had a TBI. He also got an infection from a spinal tap at the hospital, and ended up in a coma for ten days.

When he finally went to rehab, he was in a catatonic state. “I spent a year there recouping and trying to understand what happened. But I didn't want to live anymore. I told friends to kill me,” he says.

But every day, his grandfather would visit him, telling Peter not to give up. This consistent support and encouragement helped Peter through his darkest moments.

“I realized, I could stay the way I was and make everyone miserable around me. Or I can do the best I can with what I have. So, I chose to do the best I can,” he describes.

After three years of rehab, Peter was finally able to return home.

Today, Peter mostly uses a wheelchair and deals with lingering effects from the intense trauma his brain experienced. But he's building a new life that's shaped by what he's learned from his brain injury.

“Before my injury, I was pretty superficial. I was into fast cars, motorcycles, making money, and partying. Now over time, I've recognized how precious life is. It's not about getting things and partying and superficial things that have nothing substantial to them. Life just has so much more meaning than that,” he says.

One of the main things he hopes Canadians realize about brain injury? “Not all brain injuries are the same. Every injury is unique as the brain itself,” he says. “And the brain is not fixed. We can do so much to help our brains.” Like so many survivors we talked to, Peter emphasized the potential within each person to heal – but also recognized it takes a lot of patience, acceptance, and support from others to get there. He uses the acronym SAM – support, attitude, motivation – to encourage others on their own healing journeys.

“The first thing we need is support,” he says, thinking about his grandfather. “Once the support was there, I was able to change my attitude. When I changed my attitude, I had motivation to get better.” •

“The first thing we need is support. Once the support was there, I was able to change my attitude.”



Peter Kyriakides, who survived a life-threatening trauma to the brain, sees a desperate need for more mentors and coaches for patients. He wonders if paying survivors to mentor others could fill gaps in the system. “It could change the whole game,” he says.

Engaging Survivors To Improve Research

Thanks to the generous support of the Galati Family and their gift of \$850,000, Brain Canada is introducing a pioneering project on traumatic brain injury (TBI) to ground its funded research in the needs of diverse stakeholders.

“For people with a brain injury, there is no map,” says Dr. Anneliese Poetz, Senior Program Manager, Knowledge Mobilization for Social Innovation, who is leading the effort at Brain Canada. “To achieve research impact, you need to put the time and effort into finding out what the actual problems and priorities are.

“We’re encouraging research outcomes that directly help people and can better improve practice and policy,” Poetz says. “What we learn from stakeholders in this process will be used to inform the research agenda at Brain Canada and beyond well into the future. This approach is a significant step forward in improving patient lives with targeted research. Things should be easier for people, not harder.”

Led by Matthew Galati, a Canadian physician and brain injury survivor, the Galati family founded Brain Changes Initiative. Together, Brain Changes Initiative and Brain Canada are partnering to double their impact and support bold brain research in TBI. A new funding program will be announced later this year, informed by the input and feedback from people living with brain injury.

“We are energized by this new approach,” says Viviane Poupon, President and CEO of Brain Canada. “Engaging stakeholders in this way aligns with Brain Canada’s mission to advance a better understanding of the brain – and to improve the lives of Canadians directly affected by brain disease or injury.”

Offering Hope To Others

The people we talked to are using their own experience to help others. Many, like Rob, Barb and Peter, have served as mentors for brain injury patients and their families. Bob is on the West Park Hospital Patient Family Advisory Committee, making sure patient voices become part of the decision-making process, and the Brain Injury Society of Toronto Advisory and Advocacy Committee. Nicole, an educator, is

using her personal experience to help influence and change the policies and expectations for students and staff coming into school after acquiring a concussion or traumatic brain injury. And of course, everyone who shared their stories here and through other brain injury awareness platforms are bringing hope and visibility to brain injuries. Thank you.

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