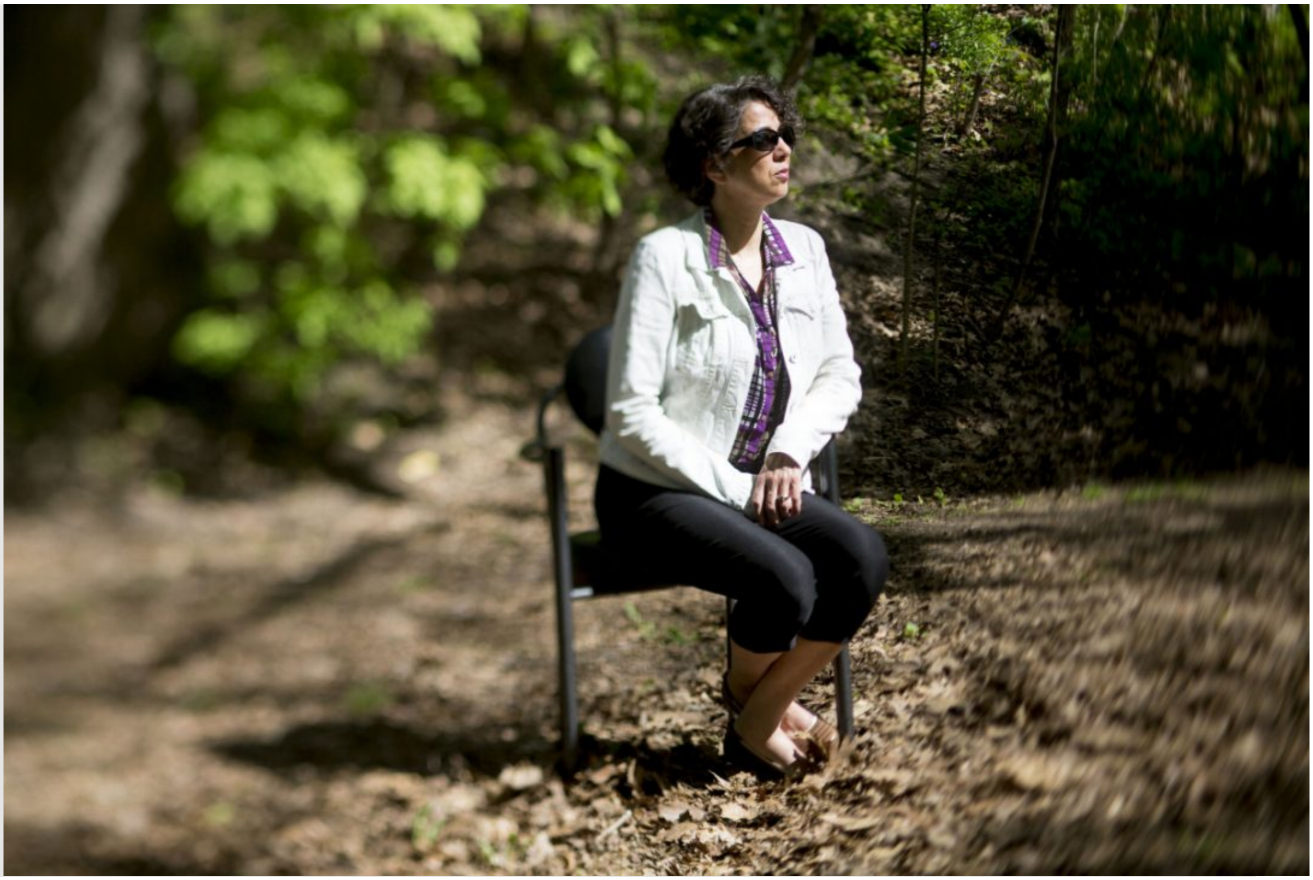
Life in the shadows of the concussion debate

It’s not just pro athletes: thousands of people suffer the mysterious after-effects of concussions, which can last years and turn lives upside down. With Ontario set to pass a bill to establish youth concussion protocols, we look at some of their stories.



Writer Julia Nunes describes her post-concussion symptoms: "It's like jogging on a bum knee all day long, knowing the thing could blow at any second." (CARLOS OSORIO / TORONTO STAR) |

By **JULIA NUNES** Special to the Star, Sun., June 5, 2016

I’m in the kitchen pouring rice into a cup when my husband asks a question. I look towards him but my brain can’t do two things at once. The rice hits the floor. Thousands of grains scatter under the counter, the oven, the fridge. I grab a broom but can’t focus. My neurons are in overdrive: dinner is late, I have to get downtown but I can’t drive that far and the 45-minute streetcar ride seems daunting.

This is the new me. The old me ran a half-marathon and researched a book while working towards a master’s degree and writing TV scripts to pay the bills.

The new me gets flustered cooking rice. This is what concussion has made of me. And I hate every second of it.

“Just go,” my husband says, taking the broom from my hand. “Go to your workshop.”

So I do. It’s about, of all things, persistent symptoms of concussion.

* * *

A brain injury is hard to grasp second-hand. Even my closest friends don’t really get it. Everyone get headaches. Everyone gets tired. Lots of people forget where they parked the car. The difference is qualitative. I walk around constantly aware that my head isn’t right. It’s like jogging on a bum knee all day long, knowing the thing could blow at any second. But you can rest a bad knee by sitting down. A bad head follows you everywhere.

On good days, I fight through the brain fog and write in spurts at the computer. I run around a bit with my kid. On bad days, the fatigue is crushing. There’s this pressure in my head as if a blunt object is expanding inside my cranium, straining to get out. If I do too much — walk too far, read for too long, forget to pace myself — a piercing headache erupts. Every day is a calculation: how much will be too much?

When symptoms like mine linger, it’s called post-concussion syndrome or PCS. Over time, you learn what your brain can’t handle: loud noises (air brakes, espresso machines, wailing children including your own), crowded spaces (dinner parties, food courts, stadiums) and anything requiring focus. Sometimes just following a recipe can make my head spin.

Ten months post-injury, I still live like this. So do tens of thousands of Canadians.

Pro athletes own the concussion debate but the rest of us live in the shadows — minus the multimillion-dollar salaries and billion-dollar lawsuits — just waiting for our brains to heal.

And unlike Sidney Crosby, we’re invisible.

It’s a full house at the workshop. A few dozen people sit on folding chairs in a conference room at Toronto Western Hospital. We all look healthy enough. But many have been suffering for years. And many have had multiple concussions. With each hit, the brain becomes more vulnerable to the next.

My troubles started with a pup tent, a raucous game of hide-and-seek and a head-on collision with my preschooler. Four years later, a freak accident: two people fell on my head, knocking me backwards on a patio couch. It wasn’t a monumental crash but the next day I could barely stand.

At the workshop, we learn that 85 per cent of people recover from a concussion within three months. Research can’t yet tell us why we’re the unlucky minority. It also can’t tell us how to heal. “Currently, there is no accepted standard of care/treatment,” the handout tells us starkly. We’re encouraged to try exercise, meditation and cognitive behavioural therapy to cope with symptoms.

In a lively Q & A, people ask about vestibular therapy, nerve blockers, vitamins, acupuncture, physiotherapy, chiropractic — anything that might help. The answer is always the same: no supporting research but try it if you'd like.

I've tried some of these with little success. "If there's a magic bullet out there, I think I'd know about it," my specialist says patiently. He's a leading concussion clinician and researcher. I'm just now coming to accept what he's said all along: rest between activities, take it easy, be patient.

I'm not naturally inclined to any of those things. But I'm luckier than most. I have excellent doctors, a supportive family and (barely) enough family income to survive my loss of pay. I'm otherwise healthy. And I haven't endured the stress of battling skeptical insurance companies or lengthy legal cases in which I must convince others that my injury is real.

I'm getting better. But I'm still so far from who I was.

After the workshop, in a crowded elevator, a young woman (a yoga instructor pre-injury), punches numbers into her phone. "I forgot my password!" she announces brightly. "I do that all the time now."

We all share a chuckle. "You've gotta laugh," she says. Then the elevator doors open and we disperse, vanishing into the crowds on Dundas St. W.

The doctors' view

Every year Canadians sustain about 200,000 concussions. With roughly 15 per cent resulting in post-concussion syndrome, that's 30,000 new cases each year.

"It's a gigantic number," says Dr. Charles Tator, a renowned neurosurgeon and concussion researcher at Toronto Western Hospital. "We think it is a significant public health issue."

Tator’s schedule is crammed with PCS patients, each suffering in their own way. “It is profoundly disruptive no matter what stage in life you are. If you’re a kid then it prevents you from going to school and learning … If you’re in the working population you can’t work.” Symptoms can be so life-altering that depression and anxiety take hold. “The mental health issues of PCS are very severe in many people.”

The demand for help outstrips supply: too few skilled specialists, too few treatment options, too few research dollars. Even reliable information is hard to come by, which is why Tator helped create the workshops I attended.

“There just isn’t a lot out there for people having more persistent symptoms,” says Dr. Lesley Ruttan, the workshop leader and a neuropsychologist at the Toronto Rehabilitation Institute. “It can be a difficult system to navigate.”

Despite rising awareness of concussion in sport, PCS remains largely invisible and poorly understood. Invisible because its sufferers wear no casts or bandages, meaning support can be elusive. And invisible because its effects on the brain continue to evade modern science. No blood test or scanner can reliably detect it. No drug or therapy can reliably treat it. Tator’s prescription for patients is by nature imprecise: a graduated return to activity as symptoms allow.

“We’re starting from almost zero,” he says. “We don’t even understand where in the brain concussion occurs … It’s not surprising that treatments are not available.”

The vacuum has filled with inconsistent medical advice and unproven, often pricey treatments.

“You’re seeing lots of concussion clinics popping up here and there, and there may be claims made,” Dr. Ruttan says. “We really want to recommend to people to be cautious and to understand that it’s complex. Further research is certainly needed to try and decipher what’s happening in people when symptoms are more persistent.”

Here’s just a hint of what we still don’t know about PCS:

- Why do some people struggle for years while others recover quickly?

“Not much is known about susceptibility,” says Tator. Women seem to be more susceptible but the reasons are unclear, perhaps related to thinner neck muscles providing less stability for the head. There may also be a genetic link. (My son and I, for example, both suffer from PCS.) “We’re looking for the responsible genes, but so far they’re not apparent.”

- Does the type of hit or location of the brain injury matter?

“Not enough research has been done,” says Tator. Multiple concussions may be a factor but “that’s debatable.” His data suggest that 20 per cent of people with PCS have had just one concussion. Smaller “sub-concussive” hits accumulated over many years without apparent symptoms may play a role.

- How does concussion affect the brain?

Is PCS a biochemical injury only or are there structural changes that have yet to be detected? Understanding the mechanisms of injury is the first step to better diagnostics and treatments.

“We need a lot of both fundamental research and clinical research,” Tator concludes. “But it’s not cancer, it’s not heart disease. We’re not a Canadian favourite. We’re way down the list.”

David Bourque, 60, suffered repeated concussions that forced him to end his career as a clarinetist with the Toronto Symphony Orchestra. One night during a performance of Shostakovich, he says, he started to play a solo and "I'm not sure what came out." (CARLOS OSORIO)

‘Everybody was looking at me strangely’

David Bourque, 60, musician

On a sunny day in June, David Bourque miscalculated a turn on a country road. His motorcycle skidded and he flew 15 metres in the air, landing in a ditch. When he came to, he hurt everywhere. “I should have been killed. There was pavement in my helmet,” he recalls. “Clearly it wasn’t my time.”

At the hospital overnight, they watched for signs of organ damage and prescribed painkillers for five fractured ribs. But no one mentioned anything about brain injury. “They sent me home with no head injury routine and no follow-up.”

At first, Bourque attributed the confusion and spacey feeling in his head to the painkillers. Doctors said his symptoms were normal. He soon went back to work, as a clarinetist with the Toronto Symphony Orchestra.

To his surprise, he couldn’t perform. Suddenly, at 53 and at the peak of his musical career, he was like a ninth grader, playing wrong keys and rhythms, forgetting fingerings. One night during a performance of Shostakovich’s *Symphony No. 11*, he hit a long, fast clarinet solo. “I’m not sure what came out,” he says, still sounding astonished. “Everybody was looking at me strangely.”

Bourque had been in car accidents before and taken hard hits playing hockey in his youth, even dislocating his jaw. But he’d never had symptoms like this. He kept performing, somehow muddling through until he slowly started to recover.

Then, a year after his crash, on holiday in Paris with his girlfriend, the top of his head hit a low-hanging window frame. He tried to shake it off with a walk but somehow couldn’t make his way across the road. “That,” he says, “was the beginning of the end.”

His memory worsened, he was often confused and couldn’t follow conversations. He forgot the names of musical pieces. “People say, ‘Oh, that happens all the time.’ And I say, ‘Not like this it doesn’t.’ I know the name of the piece. It’s in here,” he says, tapping his forehead, “inside a little door that’s locked.”

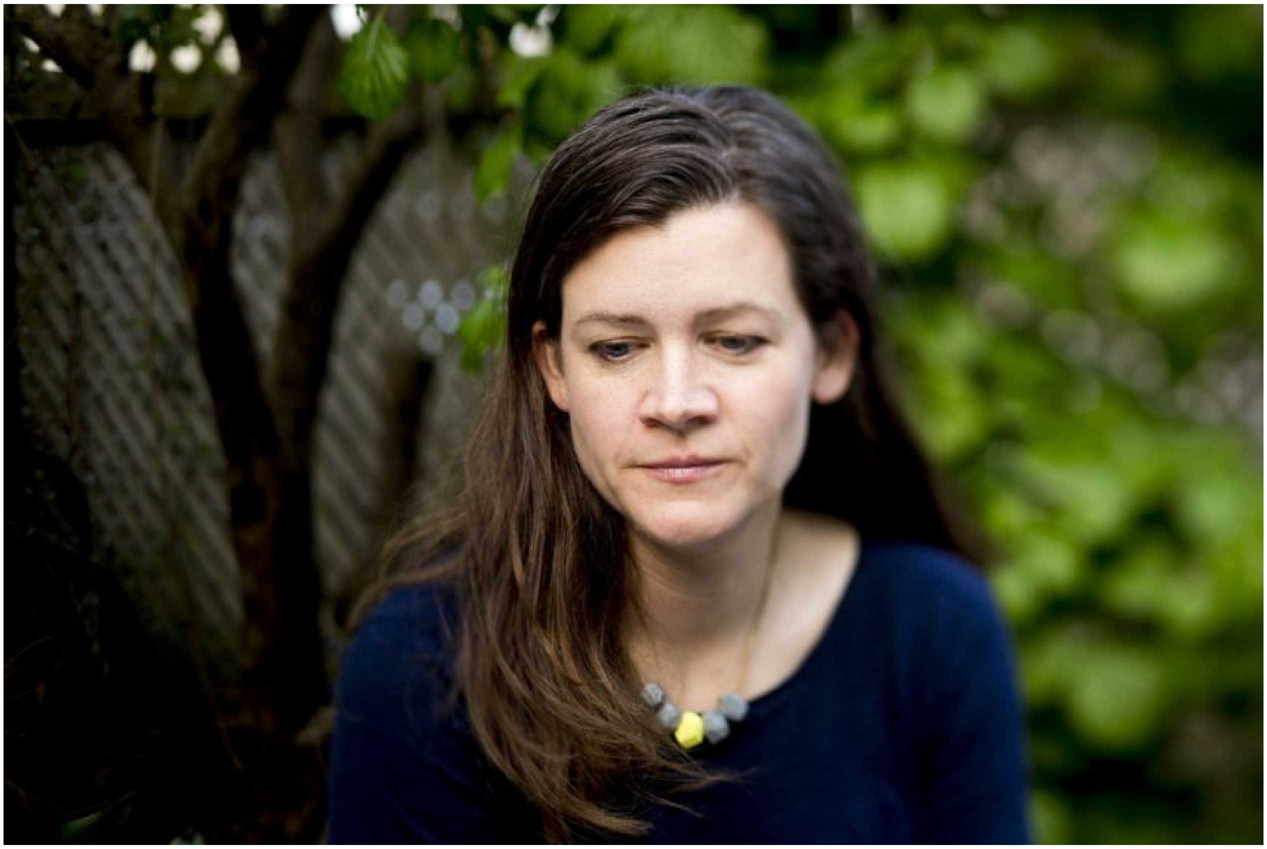
Doctors call this “loss of executive function” and at times it reduced him to tears. He struggled with depression. And after a few months of trying, he stopped working.

For nine months he lived with no income while the insurance company processed his disability claim, then denied it, then denied an appeal. He considered a lawsuit but the added stress, he says, “would likely prolong and even worsen symptoms. The insurance companies count on this.”

Finally, at 56, David Bourque put down his clarinet. He retired from the TSO. “I’ve not played great music with great players in an orchestra setting since then,” he says quietly. “And I never will.” He equates the grief to the death of his father. “To think that I could never play a Mahler symphony again … It was a really significant loss.”

Since his concussion, Bourque has learned to live with all kinds of loss. His girlfriend split, his sister became estranged. But with proper medical care — including a sleep study that revealed a drastic disruption in sleeping patterns, quickly repaired with a few months of medication — many symptoms have subsided. His depression is in check. “My soul is intact.”

What does he want people to know about living with PCS? “People say ‘Ah, well, you’re just faking.’ You can think whatever you want, but this is very real. And it is extraordinarily difficult.”



Laurie Carmichael, 43, suffered a single concussion a year and a half ago when she tripped on a sidewalk. Her symptoms have improved since then, but she still can't return to recreational running. (CARLOS OSORIO)

‘I’m not Sidney Crosby’

Laurie Carmichael, 43, senior program adviser, Ontario government

As falls go, Laurie Carmichael’s was unremarkable. Walking to a restaurant, turning to speak to her husband, she caught a boot on an uneven sidewalk and toppled sideways. “Just a totally clumsy, spastic move but I fell down kind of hard.”

At lunch she felt nauseous and fuzzy-headed. She returned to work but struggled.

But a concussion it was, confirmed a few days later by a family doctor who instructed her to take it easy mentally and physically. No mean feat for a woman with a full-time job and two young children. She took a few days off work but it was December: the kids had school concerts, she had a work deadline and she admits, “I was kind of addicted to my iPhone.”

In the weeks ahead, she couldn’t escape the headaches, light and noise sensitivity. She took sporadic days off work. She closed the office blinds, dialled down the computer screen brightness. “By the end of the day I was really struggling.”

Home offered little respite. “We’re a busy household and there’s always lots of volume.” Told to avoid another fall, she gave up skating and skiing with the kids. A lifelong recreational runner, she now found even a dash to the streetcar could be too much.

“I always felt a bit like people thought I was exaggerating. Even a few weeks after, there was always people that would say ‘Really? Are you seriously still feeling symptoms?’ … or ‘I had concussions before and I got right back into the swing of things.’ I just felt like I was weaker.”

Six months in, she tried a short run. “I swear I felt nauseous for almost three weeks after.”

Now, a year and a half after her fall, Carmichael is much improved. Her symptoms are manageable. But she still gets headaches. And she still can’t run. It’s her “new normal” — a place she never expected to be.

“I’m not Sidney Crosby. I’m not a pro athlete,” she says. “You feel like you’re in a space that you don’t belong.”

Identical twins Tim, left, and Trevor Bullen. After each suffering concussions in recent years, they must conserve their energy carefully to get through a day. Researchers have speculated on a genetic link in post-concussion syndrome. (CARLOS OSORIO)

‘It’s like your body is in molasses’

Trevor Bullen, 48, high school vice-principal

Tim Bullen, 48, recruitment executive

Excited teens hover outside the vice-principal’s office at Riverdale Collegiate: an identical twin is in the house. Students giggle at the matching shaved heads, broad shoulders, big smiles. But the VP, Trevor Bullen, and his brother share something else that no one sees.

Tim Bullen was first to the concussion dance, almost three years ago, at the back of a whitewater raft when it took a five-metre drop. His head whipped back and that’s all it took. “It wasn’t a real head hit.”

Almost a year later, Trevor was standing at a school fundraiser and nursing a cold. His wife cracked a joke and he laughed — so hard it triggered a massive coughing fit. He passed out, falling backwards, his head striking a buddy’s knee on the way down.

It was Trevor’s first diagnosed concussion, Tim’s third.

“I did it for him,” Trevor says.

Tim laughs. “He just wanted to join the party.”

Life post-concussion has been anything but.

Jocks since childhood, they both took blows to the head playing school football and other sports with no lingering effects. But this is different.

“There isn’t a time of day where I’m like ‘Oh, I don’t feel concussed,’” Tim says plainly.

Push too hard and debilitating fatigue takes hold. “It’s like your body is in molasses,” Trevor explains. “To get across a room is a concerted effort.”

But both have demanding jobs and teenagers at home. Tim co-partners a business. Sometimes he works from home, takes a nap then works some more.

Both must carefully manage their days, their energy — or they wind up in bed with the curtains closed. It’s hard for family to understand. “Internally you’ve changed,” says Trevor, “and externally it doesn’t look that way.”

“It just takes away who you are,” Tim says. “You were a big, strong, active, strapping person … We used to play basketball every Monday night. Running was a big thing we both liked to do. And those days are gone.”

Both have tried multiple therapies, exercise and doctors. They're positive-minded guys and they do what they can. But for all they share, there is one difference:

"I've kind of in a way resigned myself," says Tim. "I don't think it'll ever go away."

Trevor is "a little more optimistic. I've seen improvement every year, so hopefully we keep moving forward …

"Hopefully down the road there'll be that magic pill that we take and feel instantly better."

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