

BROCK'S BANTER: Beyond 'Sick and Tired'?

By Brock Weir

'Pretty soon, I'm just going to be a head on a skateboard.'

That was the typically tongue-in-cheek way a friend of mine explained his predicament.

Sure, many of us try to throw a bit of humour or self-deprecation into explaining away the binds we sometimes find ourselves in, but generally speaking, our binds are often temporary ' and usually pretty funny in retrospect.

That is most definitely not the case for him.

It is a challenge he lives with every day, sure in the knowledge there are potential solutions just out of reach and that, at the end of the day, is the root of the problem.

The predicament in question was finding the wherewithal to get through a peaceful demonstration in Toronto to help facilitate a solution. But, when you're mad as hell and you're not going to take things lying down, how are you going to make a difference if the thing you feel like most in the world is lying down?

Well, why not? Lie down. It creates a hell of a visual.

He lives every day with myalgic encephalomyelitis (ME), commonly known as, for better or worse, Chronic Fatigue Syndrome (CFS). Those living with it say 'CFS' is something of a misnomer, a term which can conjure up derision and eye rolls from people who might think it can be solved simply by a good night's sleep. If only it were that simple.

Before striking up this friendship, my experience with ME/CFS was strictly limited: a very good but distant friend living in San Diego ' and Bea Arthur.

Dorothy Zbornak, as played by Arthur in the Golden Girls, battles CFS. When the show first aired in the late 1980s, CFS was still a largely unknown quantity and her continual, inexplicable exhaustion is misdiagnosed by countless doctors until one finally comes to the correct diagnosis.

The episode, inspired by the struggles of the episode's writer, Susan Harris, served to highlight CFS to a massive North American audience but, after the two part 'very special episode,' Dorothy's uphill battle was never mentioned again.

Outside of the magic world of television, those living with CFS and ME can't go back to their regularly scheduled program after sweeps week.

They fight the fight every day and now they are looking to get someone in their corner.

Several people living with ME/CFS gathered in Toronto last month to make a bold statement to Federal Health Minister Jane Philpott that more ' anything ' needs to be done to foster the research and treatment of ME and CFS, and make it easier for those living with them to take part in exciting and evolving treatments closer to home.

Donning the evocative red t-shirts of the Millions Missing movement, impacted GTA residents lay down their shoes ' and themselves ' not for a sit-in, but a 'sick-in' to make their point. They were not alone. On September 27, similar protests took place in 10 U.S. States, England, Wales, Northern Ireland, Germany, the Netherlands, Norway, Australia, and Argentina.

'Today, we are taking our sickness to the streets for all to see, especially Health Minister Jane Philpott, as she is the only one who can stop the ongoing harm ME patients experience from the health care system,' said ME patient Scott Simpson in a statement.

According to #MillionsMissing, ME symptoms are multi-system, disabling and include: unrelenting exhaustion, sensory overload, cognitive impairments, and muscle and joint pain. The cardinal symptom is 'post-exertion neuroimmune exhaustion,' meaning patients experience flu-like and neurological symptoms after what seems to be just a bit of effort. The World Health Organization classifies ME as a neurological illness.

The organization says there are nearly half a million ME patients in Canada, over a quarter of whom are either housebound or bedbound. Currently, there are no Health Canada-approved drugs to manage the disease, adversely impacting each individual's quality of life compared to others living with chronic illness who have the benefit of approved drugs to alleviate their symptoms.

'Between the harmful treatment, the near-zero research funding, and stigma from physicians which leads to a denial of treatments, Canadian ME patients truly are healthcare system victims,' contended Elizabeth Sanchez, in a statement, whose daughter Jasmine, a former dancer and university student has been bedbound for over three years.

Ahead of their protest, participants said their main purpose was to get the attention of Minister Philpott, our neighbouring Member of Parliament for Markham-Stouffville. Members of the campaign say they have submitted more than 7,000 emails to the Minister and other MPs which have largely gone unacknowledged.

'Minister Philpott could stop some of this harm tomorrow with a simple announcement for physicians to use the internationally respected Canadian Criteria Consensus for ME,' noted Mr. Simpson. 'We're asking her to stop the harm perpetuated by the healthcare system on ME patients by creating a national strategy for ME.'

It is yet to be seen how far their efforts last month might go in encouraging the government to 'stop the harm,' but their efforts gained significant attraction on social media.

Personally, I was moved by the photos posted by my friend in question, and those of his fellow protestors, and I was not alone.

Truth be told, I was also amused by some of the shots, including one of him and a friend 'a man who does not suffer from ME but was there in solidarity' with beaming grins.

Aha, I joked, you look way too happy and energized to be in a sick-in. This was explained away with the fact both men brought copious amounts of candy and desserts to keep the energy levels high. Still, I questioned whether carrying out a protest such as this on a sugar high might not be ideal in driving home the message 'similar to Dorothy's mother, Sophia, pondering whether her daughter getting gussied up before her appointments might be shooting herself in the foot.

'That's the problem,' she said. 'You don't look sick.'

The people participating in the protest didn't look sick, but knowing what I know now, appearances are most definitely deceiving.

They are people one would never guess are sick, and I wonder how many Aurorans are simply going about their day, outwardly looking fit and healthy, yet remain undiagnosed, or are suffering in silence, and/or remain unaware there are millions of people out there experiencing the same struggle.

And more still more campaigning to have something done about it.

If you have a story to share of your own journey, I can be reached at brock@auroran.com.