

## Still beyond ?Sick and Tired?

by BROCK WEIR

It's often said an ounce of prevention is worth more than a pound of cure.

While we might collectively roll our eyes at a cliché that is almost threadbare at this point, I think we can all agree that there is a lot of truth in the statement.

If we hadn't already a few short years ago, most of us would certainly subscribe to that now, having spent the bulk of the last three of those years masking up and using more hand sanitizer in that window than we already had in our lives up to that point.

It may have been inconvenient, and, if you're still following these common-sense preventatives, they still are, but is it effective?

Well, that's been the debate for the entirety of this journey ? but I'll say out of personal experience that since face masks found new life outside a dentist's office, much like the renaissance of the nearly-forgotten and disused QR code, I've experienced a significant drop in the number of colds and bouts of flu I'd get with each passing year.

Of course, nothing is foolproof ? that was clear from the get-go ? and, being up to date on what needs to be up to date, I've gone through two very minor bouts with COVID myself that I have been fortunate enough to bounce back from pretty quickly.

But I'm all too aware that others haven't been as lucky.

As the world seems to be moving past COVID, thanks in no small part to the World Health Organization declaring last week that the virus is no longer a global emergency, there are many others in our communities for whom ?moving past? is simply not an option.

Long COVID is a very real concern and one that has been put under increased focus as of late.

There are still many unanswered questions and treatment options being explored, but this exploration isn't limited strictly to the causes and effects of Long COVID; research has shown that it shares similarities with other diseases that have, until quite recently, been largely dismissed or forgotten.

This Friday, May 12, marks Myalgic Encephalomyelitis (ME) Awareness Day.

Also known as Chronic Fatigue Syndrom (CFS), this early definition of ME has presented something of a challenge, suggesting that it is simply a matter of being tired, a condition solved by a good night's sleep.

That is far from the case.

?It's not just fatigue,? says the United States' Centres for Disease Control and Prevention. ?ME/CFS is a serious, long-term illness. Those affected are unable to perform their usual activities and suffer from profound fatigue that is not relieved by rest. A distinguishing feature is post-exertional malaise (PEM), which is the worsening of symptoms after physical or mental activity. Other symptoms include unrefreshing sleep, dizziness, problems thinking and concentrating, worsened memory, and pain.?

Almost seven years ago in this space, I shared a little about a Toronto-based friend who has lived with ME for more than a decade. Having witnessed first-hand the aforementioned symptoms and a gradual decline in what he feels able to accomplish, ME ? and CFS ? has become a cause close to my heart and one that I have followed with great interest.

But I've also followed it with a degree of frustration as the powers-that-be have been, well, frustratingly slow in taking on the

challenge of addressing this very important need.

On a fall afternoon, members of the MillionsMissing movement held a "lie-in" to drive their point home to the federal Health Minister of the day. At the time, the MillionsMissing organization said there were nearly half-a-million ME patients in Canada, over a quarter of whom are housebound or bedbound. There were no Health Canada-approved drugs to manage the disease, adversely affecting 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 the healthcare system's victims," said Elizabeth Sanchez, the mother of a daughter living with ME, in a statement following the demonstration.

A recent article in The Atlantic stated that "many cases of long COVID are effectively ME/CFS by another name. The exact number is hard to define, but past studies have shown that five to 27 per cent of people infected by various pathogens, including Epstein-Barr virus and the original SARS develop ME/CFS. Even if that proportion is 10 times lower for SARS-CoV-2, the number of Americans with ME/CFS would still have doubled in the past three years."

Now that there are clear parallels being drawn between ME and Long COVID, parallels that are, most importantly, being recognized, I'm hopeful that momentum is now in favour of both making existing treatments more accessible and getting new treatments to market.

This Friday will be illuminating as the MillionsMissing organization hosts an event in Washington DC to continue to highlight the similarities between the two diseases.

"We are telling the story of ME and Long COVID: the connection between, that the neglect of ME led to this moment, that we know we need: patient inclusion, treatments, urgent action and support services," said the American branch of MillionsMissing ahead of the event.

I know I will be watching, and I hope the powers-that-be on both sides of the border do as well.

At the height of COVID we all complained about being "sick and tired of being sick and tired," but as so many of us continue the shift back to normalcy, millions don't have that luxury. At the height of the pandemic, we also looked for silver linings anywhere we could when hope seemed dim. While long COVID is an unfortunate reality, if the interest in finding treatments and cures for it results in benefits for other diseases, those that have been dismissed for far too long, I think we can all put that in the win column.

But only time " and action " will tell.