BROCK'S BANTER: A few simple words

By Brock Weir

We live in an age of economics ? well, as far as our words are concerned.

The days where we were encouraged to wax lyrical on any number of subjects, the flowerier the better, are long gone.

Those days have been replaced with an age of expediency where it is both desirable and encouraged to cram complex thoughts into just a few hundred characters, bite-sized, slightly pre-digested, for mass consumption on social media.

Don't get me wrong, it is something of an art, and it always has been; after all, everyone from Blaise Pascal to Winston Churchill has been quoted as saying something along the lines of, ?Excuse this long letter, I didn't have time to write a short one.?

Whoever actually said it, and whoever actually started this trend, it seems as much as we focus on boiling down our thoughts into a wafer-like appetizer we are getting further and further away from truly considering the impact that just a few words can have.

A weekend ago, I was stuck by the elation a friend and his circle felt hearing just two simple words come out of the mouth of Federal Health Minister Ginette Petipas Taylor. Those words had, in their view, been a long time coming.

?I am enthusiastic, creative, love beauty in all its forms and eccentricities equally,? writes my friend, Jeffery Smith for the Wall of Missing.

The Wall of Missing is a collection of photos, vignettes and biographies of people across Canada who have been struck down with Myalgic Encephalomyelitis, better known as ME, and previously known by the misnomer Chronic Fatigue Syndrome.

?I devour history, and style, and classic films. I hope I am kind, equitable and I fight for equality for all. I am grateful and know I am blessed. I am the creator of magazines, art, and occasionally writing. I am sarcastic and love black humour, but I am an optimist who believes that we, like Martin Luther King, can make the world a kinder place if we try and care.

?I have been ill with ME since September 1996. That was my D-Day; the day my world, life and productivity practically stopped. I hope I am still all of those things, though I have access to little of it anymore. Most days I am a faint shell of that person, like someone with advanced Alzheimer's.

?I grew up gay in a small hockey town in
the 1970s and learned about injustice and inequality early. Even though I could stay hidden, people of colour and other races could not and I developed a deep empathy for those being unfairly prejudiced against. In my 20s, I developed a rich and full life with my loving partner Dave, wonderful friends and the ongoing love of my parents.

?In September 1996, I got a flu that never
went away. I went from 100 per cent capacity to about 20 per cent and am now less than that. I am always dizzy, have cognitive breakdown and tremors throughout my body when standing for more than a minute. I am unable to achieve anything but the most basic self-care on most days.

?It would take me years to find out that
my Epstein Barr was constantly reactivating, leaving me ill daily as someone in the last stages of AIDS or cancer ? but frozen in that state. I changed jobs six times, moving down to less responsibility due to the cognitive disfunction before becoming too ill to work at all and ending up on long-term disability.

?I had three GPs over the years in Canada.
One said it could be Chronic Fatigue Syndrome (CFS), but that may not exist. The other said CFS was imaginary and the third said I probably had ME, but there was no diagnoses or treatment here, only anti-anxiety meds and antidepressants.?

Jeff went to the Chronic Fatigue Syndrome
in Stanford, California about five years ago, where he received a battery of blood tests, undertook a number of interviews and examinations that, after 18 years, were still not available in Canada while millions like Jeff continued to get sicker and sicker.

Those trips for treatment to California
cost him thousands of dollars out of pocket, but he said it was worth the hardship.

?I needed hope, support, diagnosis and
treatment, and none of this was available here,? he said. ?Although my illness continues to progress, I have met the bravest, most fierce and loving souls in the ME community that inspire me to not give up when I don't have it in me to face the future so deeply impaired.?

What Jeff often doesn't realise is that, through
him, I too have met one of the bravest, most fierce and loving souls, so I was buoyed when it seemed the quest for hope and support received a shot in the arm.

That shot in the arm came from a direction some people might not understand: the simple fact that the Minister of Health voiced the word ?M.E.? for the very first time.

It might seem small, but for the dozen-or-so weary advocates taking a stand at a health forum in Toronto over the weekend hosted by MP Rob Oliphant, it was almost the dawn of a new day; after all, previous Health Ministers have, apparently, fallen short of that mark.

They came with a mission: to advocate Ontario Health Minister Christine Elliott and her Federal counterpart to create a centre of excellence in ME/CFS care, education and research in Ontario, as well as to establish a transitional implementation committee to provide leadership in the initial phases of putting this plan into action.

?I hear you,? said the Minister Petipas Taylor. ?I know that there are challenges and I know when it comes to the levels of investments, they haven't been huge, but as a government I am committed that I certainly want to pay closer attention to this and if there is any way that we would be able to meet in Ottawa to discuss this matter even further I would be more than happy to meet with you and get a better sense of your requests, and also to get a better sense of the situation.?

We can only hope this meeting transpires and leads to concrete action from the top down.