

Claudia K.

My story

Office renovations in 2010 brought on the end of my “used-to-be” when I began to develop an overwhelming list of symptoms with fluctuating severity, some of them “mainstream” and some rather strange. After numerous fruitless tests, my doctor’s advice was reduced to “Don’t feel like you have to be sick”, and a subtle hint at my aging.

My doctor did refer me to specialists for some of my symptoms. I patiently waited, usually for months, to see them: respirologists, gastroenterologists, rheumatologists, an allergist, a dermatologist, a physiotherapist, ENT specialists, a neuro-ophthalmologist, psychologists etc. – each focusing on their area of expertise through the lens of their specialized knowledge - dots that didn’t get connected.

For years I was left looking for answers to questions no one else seemed to be asking. Sometimes people around me thought I was going crazy; sometimes I myself was sure I had. Until a nurse-friend of mine handed me an article she had received from a patient with similar symptomatology. Through it I found out about the Complex Chronic Diseases Program at the Women’s Hospital. With a hopeful heart I initiated a referral, earning myself a spot on their ... drumroll ... two year plus waitlist! My doctor had never heard of the Program.

I eventually wrote her a letter, attaching the Canadian Consensus Criteria for ME as well as the Central Sensitization Model. In our follow-up conversation, she told me she had not been the only one who didn’t believe me, something I had sensed all along. But then again ... how could she? Nobody, it seemed, had taught her about Myalgic Encephalomyelitis in medical school.

Seven years after the 2010 incident I finally received the correct diagnosis of ME/CFS. But because ME is lacking so much equality compared to other diseases, I had by then lost not just my ability to work, but also a big chunk of my trust in the medical profession, any illusion about certain insurance provider’s “fair processes” as well as too much of my mental health.

What I have gained however; is an unbreakable determination to rebuild the level of wellbeing I once had the luxury to take for granted. I have fine-tuned my self-awareness. I have developed deep gratitude for my friends and family, my chosen care providers, nature, and the many little things which make life the big deal that it is.

Plus, I have gained insight into our medical-political system with its oh-so-much room for improvement.

Therefore, this “My MLA and ME” advocacy initiative caught my attention, because – as Jon Bon Jovi would say: “When you can’t do what you do, you do what you can.”