



Briefing note for MLAs in BC

April 13, 2021

Subject: Myalgic Encephalomyelitis in British Columbia

Purpose: Patients with ME are requesting support from provincial MLA's to improve awareness, education and care.

Issue: There are an estimated 77,000 British Columbians with myalgic encephalomyelitis (ME)¹. In BC, it can take several years for a patient to receive a diagnosis. Despite its prevalence, many in the medical community are unaware or ill-informed about the disease. As a result, patients are often misdiagnosed, receiving inappropriate or harmful treatments. Many patients report neglect or abuse by the healthcare system.

Currently, BC has one provincial resource for these patients, the Complex Chronic Diseases Program at BC Women's and Children's Hospital. The waitlist for this program has consistently been over 24 – 30 months for the past several years. For some patients, they can't find a family doctor willing to refer them. The program itself offers group medical and complementary modality visits for self-management education and 1:1: medical consultation appointments for a 1 year enrollment. Prior to COVID, all program activities and appointments required in-person visits. Even with virtual care, many patients fall too ill while on the waitlist to attend, or self-educate themselves on the basic content offered during this waitlist period. For patients who can attend, after 1 year they are then discharged and return to limited medical support in the community.

Background: ME is a complex chronic disease that presents with symptoms in multiple body systems. According to the World Health Organization, ME is a neurological disease. ME greatly impacts one's life: 75% of those affected are unable to work and 25% are homebound or bedridden. The disease is triggered by viral infections in the majority of patients. Many scientists are speculating that the individuals who show long-term symptoms of the COVID-19 virus may now have ME. The symptoms are very similar. Thus, it is unknown how many more patients will join the current ME patients in our communities.

The cardinal symptom of ME is post-exertional malaise (PEM). PEM is a flare of symptoms and/or the appearance of new symptoms after exertion, often presenting about 24 hours after the triggering event. While PEM is often studied in relation to physical activity, cognitive overexertion or sensory overload may also initiate PEM.

People with ME experience a substantial loss of physical and/or cognitive function. Someone with mild ME may be able to work full-time with accommodations; someone with very severe ME may be bedridden, have trouble communicating, and may require: complete darkness, complete silence, complete isolation, a feeding tube and catheter. For many patients, ME is a relapsing-remitting condition, with significant fluctuations in their well-being from day to day, week to week, and month to month. For others, it is progressive with a continuing decline of

¹ Statistics Canada unpublished Canadian Community Health Survey (CCHS) reports that just over 560,000 patients were diagnosed with ME/CFS in 2015.

health and diminished capacity of daily living. A few patients experience a stable presentation of symptoms.

Several studies have shown that patients with ME have a suicide rate approximately 5 times higher than national averages due to untreated pain, loss of income and career, loss of independence and the lowest quality of life of any chronic illnesses. The average person with ME scores as more disabled on quality of life surveys than those with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure, and cancer.

Considerations:

- The ME/FM Society of BC is reaching out to MLA's to increase awareness of this disease. Now and over the next year, patients involved with the Society will contact MLAs to offer personal perspectives on this pervasive, yet misunderstood and under supported disease.
- As legislators it is a responsibility to be informed about the issues constituents face. Support and awareness for ME was indicated in multiple sections of the 2020 Select Standing Committee on Finance and Government Services. Continued momentum is necessary to improve the lives of ME patients and their families.
- Getting health care “right” is deeply challenging, as there is no perfect solution to all. ME patients know that many illnesses have come before ME, such as HIV and MS. It is time for ME to receive attention and see change. All this begins with ME awareness. This is where we require your assistance. ME needs elected representatives to step up and stand *with* us.

Conclusion:

ME in BC needs provincial awareness, leadership and support. It is a choice to help or ignore 77000 British Columbians, their families, their caregivers and their doctors to achieve better health, better quality of life and better contributions to our society.

Recommendation:

MLAs increase their awareness and education on the needs of ME patients in their community by joining the MLA and ME campaign initiated by the ME/FM Society of BC.

Further Information:

- To read our policy brief outlining the current state of ME care in BC, *Backgrounder: The Unmet healthcare needs of British Columbians living with Myalgic Encephalomyelitis (2019)*, please visit [here](#).
- To view our recent community pilot project report (Convene Report - Short, Long and Summary Graphics : *Examining the Unmet Needs of British Columbians Living with Myalgic Encephalomyelitis - Mapping a provincial needs assessment (2021)*, please visit: <https://www.mefm.bc.ca/our-research>