

September 15, 2021

Briefing Note for BC Provincial Treasury Board, Select Standing Committee on Finance

Cc: Premier John Horgan, Minister of Health Adrien Dix, Deputy Minister of Health Stephen Brown, Official Opposition Critic, Shirley Bond, Health Critic Renee Merrifield.

**Subject: Equitable Access to Healthcare for ME Patients in British Columbia:
Diagnosis and Incentivized Billing codes for Myalgic Encephalomyelitis Essential for BC**

Issue: Myalgic encephalomyelitis (ME), is a devastating, chronic, multi-system disease. Approximately 600,000 individuals in Canada and 77,000 British Columbians suffer from ME. It affects children, adolescents and adults of all ages.¹

Currently, BC has one provincial resource for these patients, the Complex Chronic Diseases Program (CCDP) at BC Women's and Children's Hospital. The waitlist for this program has consistently been over 24 - 30 months, since its inception in 2014 and offers a 1-year enrollment for a disease that has only a 5% remission rate, lasts a lifetime with no known cure, and seriously impacts all aspects of life. Program intake excludes children and is not accessible or structured for patients with severe ME. Even the leadership of the CCDP acknowledges that relying on one single program cannot be the path forward to improved and acceptable care for the tens of thousands of British Columbians struggling with this debilitating illness.

GPs and other clinicians outside of the CCDP are generally unaware or ill-informed about ME (see ME in BC [full report](#)). For those who do recognize ME, there is no ME-specific billing code, so they are not paid to properly treat ME as the full, complex disease it is, with the time needed to provide effective care: doctors can only bill to treat patients for individual symptoms in short sessions. While some physicians will commit their own time and energy to quality care at considerable personal cost, many patients are turned away or limited to low-value, in-and-out visits with no help for effective, ongoing illness management.

To make things worse, physicians are also unable today to register a specific diagnosis: at this time, ME falls under the generic diagnostic category of "Complex Chronic Disease" in BC. Having no specific ME diagnostic code hides the prevalence and devastating impact of ME by not tracking ME patients in the system or collecting ME-specific counts and statistics. This lack of ME-specific data in BC impedes access to research funding and negatively impacts clinical priorities.

The lack of a specific ME diagnostic code and incentivized billing code only serves to maintain and exacerbate the existing gaps in ME awareness within the medical community, and impede effective care for already desperately underserved BC ME patients.

¹ See [what is ME](#) from the Canadian Institutes of Health Research; and the unpublished 2015 Statistics Canada Community Health Survey.

Myalgic Encephalomyelitis facts:

- ME is a complex chronic disease that presents with a wide range of symptoms, including chronic cycles of debilitating exhaustion, pain, nausea, confusion and “brain fog,” inability to concentrate, powerful light/food/sound sensitivities, lightheadedness and passing out (POTS), and other neurological, physical and cognitive impacts.
- 75% of those affected are unable to work/attend school and 25% are homebound or bedridden.²
- ME is triggered by viral infections in the majority of patients. Many scientists speculate that the COVID-19 “long-haulers” may now have ME.³ The symptoms are very similar. This could add a significant number of new ME patients to our communities, all requiring care.⁴
- 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 severe ME may be bedridden, have trouble communicating, and require: complete darkness, complete silence, complete isolation, a feeding tube and catheter.
- ME presents differently in different people:
 - 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 continuous decline. Few patients have stable 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.⁵

Considerations:

- For ME patients to get the help they require over their lifetime, GPs and other primary clinicians all over BC must be empowered to record a correct diagnosis, offer (and be compensated for) appropriate visits and treatments, and provide suitable ongoing management and care. It is a fact that current general codes do not support many of the most effective management approaches and safe, effective treatments for ME patients.
- Creating ME-specific diagnostic codes and incentivized billing is a powerful way to: create general awareness among clinicians; encourage early and accurate diagnosis; allow clinicians to provide the critical early and ongoing treatments to their ME patients they cannot easily provide using today’s codes; and generally fill the substantial gap in existing care in BC.

² [A Conversation about Myalgic Encephalomyelitis](#) by Dr. Nina Muirhead of Canadian Institutes of Health Research (2021).

³ [Working together to understand long-term effects of COVID-19](#) (2021)

⁴ Estimates for the U.S. suggest doubling of the numbers of ME/CFS sufferers within a year: [Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?](#) (2021)

⁵ [The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome \(ME/CFS\)](#) (2015)

- Canada already has one of the leading globally-recognized diagnostic criteria frameworks for ME, making developing a diagnostic code easier.⁶
- With the speculation that many of the thousands of BC COVID 19 “long-haulers” may now have ME, being able to make a specific ME diagnosis, counting and tracking patients, and clinicians being compensated for proper care is even more critical for the wellbeing and productivity of our BC ME patients and their families and caregivers.
- ME needs elected representatives and key financial and health committee members to stand with BC patients with ME by approving funding for change that will improve the lives of this large, suffering, and mainly invisible population.

Conclusion:

To improve the wellbeing, quality of life and productivity of BC’s thousands of suffering ME patients, BC clinicians must be able to diagnose, count, track and support BC’s ME patients.

- Only by tracking ME with a specific diagnostic code will we understand the scope and scale of this devastating illness, and understand the needs of the ME population.
- Only with incentivized billing for clinicians will our medical community be able to provide the right treatments and management options to their ME patients.

By supporting and sharing with colleagues the proposals here to create and fund an ME-specific diagnostic code and incentivized billing code for BC clinicians, you can help to move ME out of the shadows, improve ME awareness, and give hope and help to our over 77,000 BC patients and friends and family members with this debilitating complex disease.

Recommendations:

1. Help prioritize and fund the development of an ME-specific diagnostic code for BC clinicians.
2. Lobby to implement and fund incentivized billing codes for \$100 per person annually - an MSP expenditure of \$7.7 million if every ME patient in BC was receiving dedicated care for their disease.
3. Share and champion the asks in this brief and the related “Fund, Develop and Incentivize CME modules on ME for BC physicians ” brief with colleagues and key ministers and committee members to increase awareness of ME among legislators and begin to provide tangible help to your constituents suffering from ME.

Further Information:

- *Fund, Develop and Incentivize CME modules on ME for BC physicians* - a brief with the ME/FM Society of BC’s other proposed actions on improving care for ME patients: [this document is found on the following webpage.](#)

⁶ [One-page summary](#) of the Canadian Consensus Criteria completed by the CCDP. For a longer summary, see [ME - A Clinical Case Definition and Guidelines for Medical Practitioners: An overview of the Canadian Consensus Document \(2005\)](#)

- *Backgrounder: The Unmet healthcare needs of British Columbians living with Myalgic Encephalomyelitis* (2021) - ME/FM Society of BC policy brief outlining the current state of ME care in BC: [see here](#).
- *M.E. in BC: how the healthcare system for M.E. impacts clinicians and patients - A preliminary project examining the unmet needs of British Columbians living with Myalgic Encephalomyelitis (ME)* (2021) - ME/FM Society of BC community pilot project report: [short report](#); [long report, including patient stories](#)
- *A Conversation about Myalgic Encephalomyelitis* by Dr. Nina Muirhead, Canadian Institutes of Health Research: <https://cihr-irsc.gc.ca/e/52474.html>

Contact: Please Reach out to Hilary Robertson, Co-Chair of the Board, ME/FM Society of BC by email at hilary.robertson@mefm.bc.ca, or ask to meet with us in person to discuss details, including our plans, estimated effort, and resources.