



BACKGROUND:

Revised April 2021

The unmet health care needs of
British Columbians living with
MYALGIC ENCEPHALOMYELITIS (ME)

The ME/FM Society of BC is working to support people with Myalgic Encephalomyelitis (ME) and Fibromyalgia (FM) throughout British Columbia
mefm.bc.ca

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Introduction

More than 77,000 British Columbians live with ME¹ (myalgic encephalomyelitis²), a devastating, chronic neuro-inflammatory disease impacting multiple systems in the body. For patients with ME, the burden of disease is greatly increased (over most other chronic disease categories) with significantly higher social, medical and economic costs because of delays in diagnosis, failure to treat and errors in treatment of comorbidities.

The misconception in health care that ME is psychologically induced has led to a lack of recognition of the biological nature of the disease and the severity of its effects, which has in turn resulted in a system that is poorly equipped to diagnose, treat or support ME patients, and may as a result, cause harm³. The devastating impact of this inadequate health care delivery on the lives of ME patients cannot be overstated, as it affects their lives medically, financially, socially and emotionally.

Given the prevalence and impact of the disease, and in a majority; permanence of the disability it imposes, the burden on the economy includes: health care costs for a large group of patients with no positive health outcomes; loss of productivity; and tens of thousands of BC residents missing from their communities. ME also impacts physician resources due to limited knowledge of the disease resulting in multiple visits over months or years in order to receive a proper diagnosis.

Service Plan: Ministry of Health

The Ministry's 2018/19 - 2020/21 Service Plan recognises chronic disease as "the largest cause of death and disability" representing "the largest proportion of the burden of diseases..." In order to adequately address the issues associated with chronic disease, the Ministry will be interested in incorporating the needs of the 77,000 British Columbians with ME, 25 percent of whom are homebound or bedridden. It is urgent that collaboratively, we begin to address the unmet healthcare needs of the ME community.

Our Society's Mandate

The ME/FM Society of BC (The Society) is a BC charity, run by patients, carers and their families, formed to help and

¹ Statistics Canada unpublished Canadian Community Health Survey (CCHS) reports that just over 560,000 patients were diagnosed with ME/CFS in 2015.

² Also referred to as ME/CFS, chronic fatigue syndrome or systemic exertion intolerance disease (SEID) .

³ The [Workwell Foundation](#) are leaders in the understanding of the impact of GET on ME patients. Their work was heavily relied upon by the Institute of Medicine for understanding of the link between over exertion and post exertional malaise in ME/CFS. See the Workwell Foundation's open letter to medical practitioners "[Opposition to Graded Exercise Therapy \(GET\) in ME/CFS](#)"

support patients with myalgic encephalomyelitis (ME) and/or fibromyalgia (FM). ME is also referred to as ME/CFS, chronic fatigue syndrome or Systemic Exertion Intolerance Disease (SEID).

Our Society goals include: to collaborate with the government to determine the unmet needs of ME patients in British Columbia; to increase funding for health and support services for patients; to educate and raise awareness of the disease in the medical community. We receive minimal provincial or federal government funding. The Society has helped people understand their illnesses and seek and obtain appropriate medical help and treatments, where available.

Background

What is ME?

ME is a systemic neuroinflammatory condition, usually with an acute infectious onset, characterized by a marked reduction in functioning and a severe worsening of symptoms after even minimal exertion. It is a devastating multi-system disease that causes dysfunction of the neurological, immune, endocrine and energy metabolism systems. The most typical symptoms include: cognitive impairment, muscle pain and headaches, severe sleep disturbances, sensitivity to light/sound/touch/smell, muscle weakness, digestive issues, inability to tolerate an upright position, difficulty breathing, body temperature fluctuations, and post exertional malaise (PEM), which is the hallmark symptom of the illness. PEM results whenever a person with ME overexerts (which could be as little as going to the bathroom or talking for too long), involves the delayed onset of worsening of most symptoms, and which can last hours, days, weeks or even months.⁴

How disabling is the disease?

ME is a spectrum disease, with all people with ME experiencing a substantial loss of physical or cognitive functioning. There is no known cure, and very few patients fully recover. Adults with ME experience a profound decrease in their quality of life, impairment in daily activities, and inability to retain employment status. The 25 percent of patients with severe ME are housebound and even bedridden and require assistance for basic functioning. Many adolescents living with ME are unable to continue their schooling⁵. On average, ME patients score more poorly on quality of life surveys than those with multiple sclerosis, stroke, diabetes, renal failure, lung disease, heart failure and some cancers⁶.

⁴ [*Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Redefining an Illness, Report Brief, February 2015*](#), Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Board on the Health of Select Populations, Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C.

⁵ G Kennedy, C Underwood, & JF Belch, [*Physical and Functional Impact of Chronic Fatigue/Myalgic Encephalomyelitis in Childhood*](#), Pediatrics, 125: 6 (2010) 1324-1330.

⁶ In a study published in March 2018, [*Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls*](#), researchers concluded that: *people with ME/CFS were measurably more disabled than PWMS or HCs in this study population. Furthermore, employment and income data are consistent with loss of functional status. These findings should encourage the health community to recognise the disabling effects of ME/CFS, to*

More severe cases are compared to end stage AIDS or cancer, only it can go on for years.

Prevalence

According to the 2015 Canadian Community Health Survey, there are just over 560,000 Canadians living with ME⁷. Canada has the highest prevalence of ME globally. 1.9% of the Canadian population have been diagnosed with ME or chronic fatigue syndrome⁸.

Stigma

"I've had patients who met post-traumatic stress disorder criteria ... where their trauma was their interaction with their physician. They came to a doctor with Chronic Fatigue Syndrome [M.E.]; they left with PTSD."

Dr. Nancy Klimas, Nova Southeastern University

Despite the severity and prevalence of ME, patients are subjected to bias and invalidation of their illness by health professionals, institutions, government, insurance companies and even their families.

Many patients can go undiagnosed or misdiagnosed for years, as the disease lacks an acknowledged biomarker and is poorly understood by most health care professionals. Recent research is pointing towards energy metabolism abnormalities⁹, brain inflammation¹⁰ and abnormal exercise response¹¹, just to name a few areas that deserve further research and confirmation of promising research. Lack of a viable biomarker feeds the stigma inflicted on ME patients. As with MS and Parkinson's Disease in the past, this has led to patients mistakenly labelled as having a somatoform

advocate for the needs of people with ME/CFS, and to investigate strategies to address the cost of the disease to both individuals and society.

⁷ In the [2015 Canadian Community Health Survey](#) statistics include chronic fatigue syndrome and myalgic encephalomyelitis. C. Rusu, M. E. Gee, C. Lagace, M. Parlor, *Chronic fatigue syndrome and fibromyalgia in Canada: prevalence and associations with six health status indicators*. Health Promotion and Chronic Disease Prevention in Canada. Research, Policy and Practice, 35: 1, (2015) 3-11

⁸ Jason, L. A., Porter, N., Hunnell, J., Rademaker, A., & Richman, J. A. (2011). CFS prevalence and risk factors over time. *Journal of Health Psychology*, 16(3), 445–456. <https://doi.org/10.1177/1359105310383603>

⁹ [Insights into myalgic encephalomyelitis/chronic fatigue syndrome phenotypes through comprehensive metabolomics](#). Dorottya Nagy-Szakai, Dinesh K. Barupal, Bohyun Lee, Xiaoyu Che, Brent L. Williams, Ellie J. R. Kahn, Joy E. Ukaigwe, Lucinda Bateman, Nancy G. Klimas, Anthony L. Komaroff, Susan Levine, Jose G. Montoya, Daniel L. Peterson, Bruce Levin, Mady Hornig, Oliver Fiehn, W. Ian Lipkin. Scientific Reports, 2018; 8 (1) DOI: [10.1038/s41598-018-28477-9](https://doi.org/10.1038/s41598-018-28477-9)

¹⁰ [2016 Ramsay: Research Team 1 Update](#), Solve ME/CFS Initiative, 18 Feb 2018

¹¹ [Cardiopulmonary Exercise Test Methodology for Assessing Exertion Intolerance in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#), Staci Stevens, Chris Snell, Jared Stevens, Betsy Keller and J. Mark VanNess. Front. Pediatr., 04 September 2018

disorder.

However, the evidence is in that ME is a real and serious biological disease¹². The prestigious U.S. Institute of Medicine's 2015 comprehensive report, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Redefining an Illness*, concluded that:

The primary message of the committee's report is that **ME/CFS is a serious, chronic, complex, systemic disease**... Many people with ME/CFS report difficulty completing everyday tasks, and at least one quarter have been home- or bed-bound at some point as a result of their illness. The total economic costs of ME/CFS are estimated at \$17 to \$24 billion annually. Many health care providers are skeptical about the seriousness of ME/CFS, mistake it for a mental health condition, or consider it a figment of the patient's imagination. **Misconceptions or dismissive attitudes on the part of health care providers make the path to diagnosis long and frustrating for many patients. The committee stresses that health care providers should acknowledge ME/CFS as a serious illness that requires timely diagnosis and appropriate care.**¹³

Stigma also means that once a patient is labelled with ME, other symptoms are often ignored or attributed to ME, delaying the diagnosis of other conditions, such as lupus, cancer, vasculitis, cardiomyopathy and POTS.¹⁴ And when patients are labelled with the term "chronic fatigue syndrome", a variety of stereotypes are perpetuated, along with misunderstanding of the illness and dismissive attitudes from health care providers and the public⁴.

Stigma also impacts quality of life in a number social, economic and health indicators.

2014 CANADIAN COMMUNITY HEALTH SURVEY: UNMET HEALTH CARE NEEDS

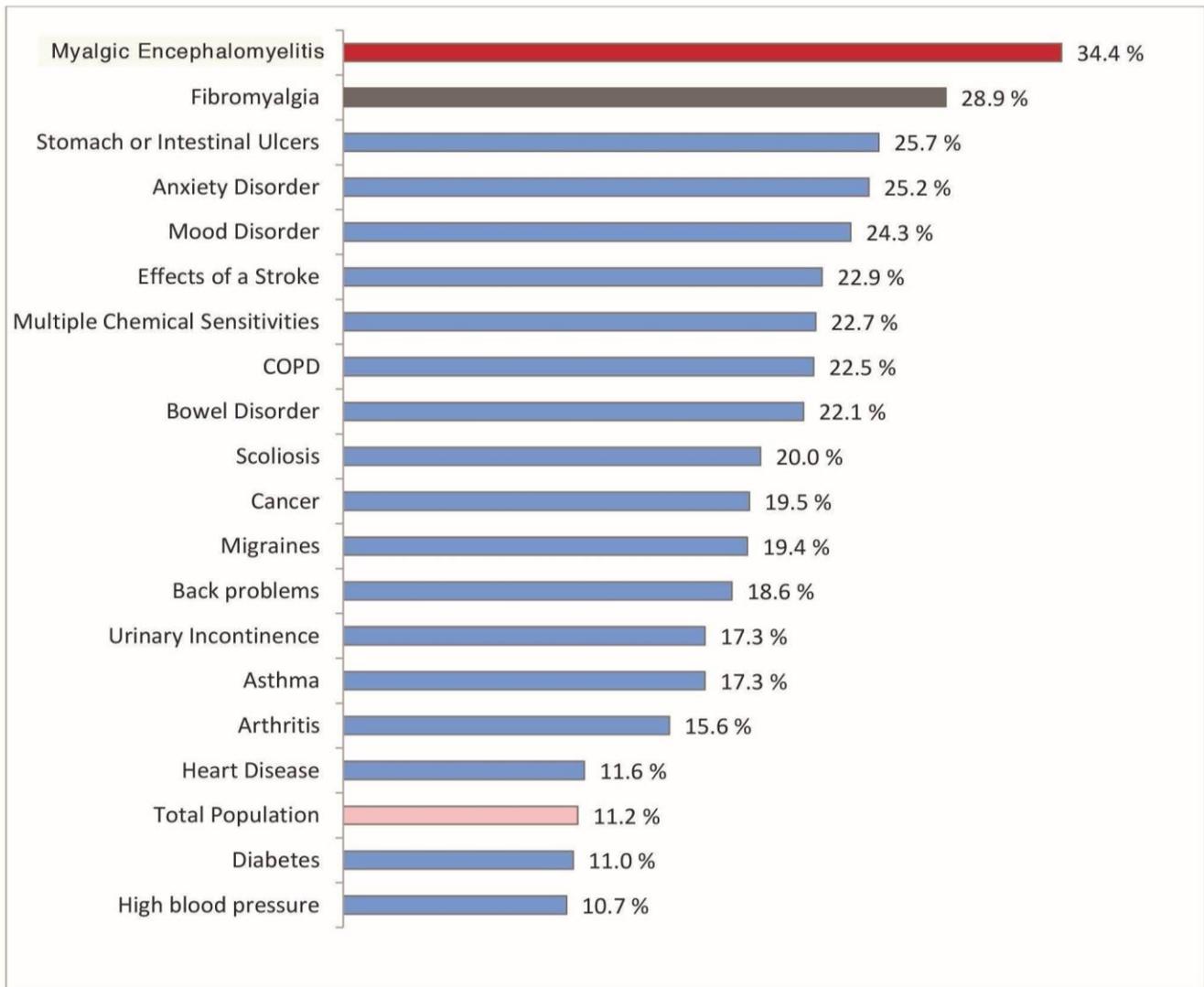
Canadians aged 12 and older reporting unmet health care needs according to their chronic health condition¹⁵

¹² Solve ME/CFS Initiative, *Research Highlights from 2018 So Far: Notable Study Developments* - June 21, 2018

¹³ *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Redefining an Illness, Report Brief, February 2015*, Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Board on the Health of Select Populations, Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C. Full report here: <https://www.nap.edu/read/19012/chapter/1>

¹⁴ J. Castro-Marrero, M. Faro, L. Aliste et al., *Comorbidity in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Nationwide Population-Based Cohort Study Comorbidity in CFS/ME*, *Psychosomatics*. 2017 Sep - Oct;58(5):533-543. doi: 10.1016/j.psych.2017.04.010. Epub 2017 Apr 21

¹⁵ Adapted from National ME/FM Action Network, *Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia Findings from the 2014 Canadian Community Health Survey*.



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File
 COPD = Chronic Obstructive Pulmonary Disease (including Chronic Bronchitis and Emphysema)
 Arthritis = ages 15+ , COPD = ages 35+; Urinary Incontinence = ages 25+

Lowest quality of life of patients living with chronic disease

The Canadian Community Health Survey clearly indicates that Canadians living with ME score the worst on metrics for health and social programs of all Canadians living with chronic diseases: highest unmet health care needs, lowest income, and highest food insecurity.

After reviewing the findings for the three surveys [2010, 2012, 2014], we can state that those with ME/CFS consistently fared badly for indicators reflecting the health and

social systems... **According to the CCHS data, those with ME/CFS in Canada remain under-served and in great need.** Margaret Parlor, National ME/FM Action Network¹⁶

The situation is worse for those with severe ME

The severely affected comprise 25% of the ME population¹⁷. Housebound or bedridden, they are too ill to seek medical help or to look for financial or personal support. For example, the BC Women's Hospital Complex Chronic Diseases Program, with the only ME program in the province, does not treat the severely ill. While the severely ill have the greatest and most desperate need, they are in practice excluded from receiving health care.



High rates of suicide

The medical, financial and personal neglect endured by ME patients, added to the pain and suffering of the disease itself, result in a high rate of suicide among people living with ME¹⁸. Some patients look to suicide as their only treatment option.

Severe ME patient, Whitney Dafoe, bedridden by the disease for years, having his hair shaved by his father, the world-renowned geneticist, Ron Davis, PhD. (Courtesy of Whitney's family) [More here](#)

BC ME Patients' Unmet Health Care Needs

Lack of research funding

A dire lack of research funding has prevented the identification of a cause or biomarker for the disease at this time. Since the Institute of Medicine's 2015 report, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*, interest in and funding for ME research has slowly grown, but is still far from equitable when compared with research funding for other comparably disabling diseases.

Lack of funding for Canadian research

Until August 2019, Canadian Federal funding for ME research has been virtually non-existent. The result has been that

¹⁶ National ME/FM Action Network, [Commentary: Under-Served and in Great Need](#), Margaret Parlor, Quest Newsletter 112, Fall 2017.

¹⁷ [Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Redefining an Illness, Report Brief, February 2015](#), Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Board on the Health of Select Populations, Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C. Full report here: <https://www.nap.edu/read/19012/chapter/1>

¹⁸ [Risk of due to neglect amongst people living with myalgic encephalomyelitis/chronic fatigue syndrome in Spain: First Spanish Study](#), Juan Jiménez-Ortiz, LigaSFC May 12, 2016

research capacity is severely limited as very few scientists enter the field, choosing instead well-funded research areas.

Canadian Institutes of Health Research funding 2015-2016¹⁹

\$158.58	vs.	\$0.11
Average per patient CIHR funding for four major chronic diseases ¹		Per patient CIHR funding for ME/CFS

¹ Multiple Sclerosis, Parkinson's Disease, Epilepsy, Alzheimer's

The [CIHR's announced on August 22nd 2019, that \\$1.4 million funding](#) is to be invested over 5 years in a new national network that will create critically needed biomedical research for biomarkers, as well as for causes and treatments for ME. The announcement was welcomed by the ME community (watched by hundreds on Livestream), and is a starting point for establishing an ME research collaborative to encourage new and young researchers to enter the ME research field.

While ME patients deserve and need much more funding for research, and have deserved and needed this for decades, as Dr. Moreau, lead on the ME collaborative research project, [was quoted saying on CBC](#): "This \$1.4 million is just the beginning of something... We know we need much more money, for sure, but yesterday's announcement was a big step for all of us."

There are a multitude of areas where research is desperately needed, including epidemiological, economic and social impact studies of the disease. We need the provincial government to join federal efforts to invest in research for an illness which has devastated thousands of Canadian lives.

Years to get a diagnosis

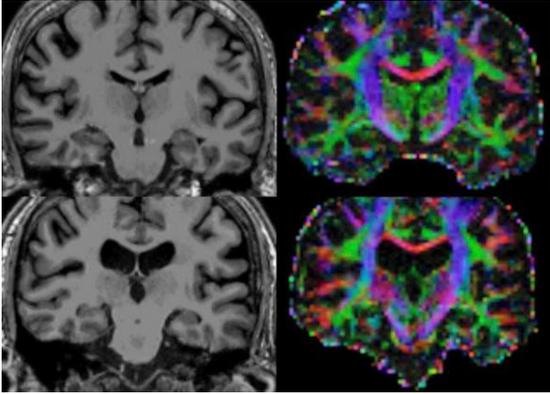
The Institute of Medicine's comprehensive Report on ME, *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Redefining an Illness* identified that "*many people struggle with symptoms for years before receiving a diagnosis... Although many health care providers are aware of ME/CFS, they may misunderstand the disease or lack knowledge about how to diagnose and treat it. Such gaps in understanding lead to delayed diagnoses and inappropriate management of patients' symptoms.*" In particular, the report noted that "**many individuals have yet to be diagnosed because the majority of doctors are not familiar with the globally accepted Canadian Consensus Criteria which outlines the diagnostic criteria for ME.**"²⁰

[Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: An Overview of the Canadian Consensus Document](#), known as the **Canadian Consensus Criteria**, was published in 2003 and developed by international ME experts with the support of Health Canada. Despite the global acceptance of the CCC, most Canadian doctors are still unfamiliar with the criteria and unable to properly diagnose patients.

¹⁹ Thanks to [Millions Missing Canada](#) for this graphic.

²⁰ *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Redefining an Illness*, Report Brief, February 2015, Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Board on the Health of Select Populations, Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C.

Lack of appropriate treatments



BC Women’s Hospital Complex Chronic Diseases Program (CCDP) was set up in 2012 as a provincial referral centre to help manage BC patients with ME, fibromyalgia, chronic Lyme disease, and multiple chemical sensitivities. With an estimated 77,000 ME patients in BC, only a small percentage have access to the provincial program. Despite the lack of awareness of the program in the medical community, it has maintained a 23 - 28 month wait list of over 1500 patients. Given the prevalence of the disease, this number represents the tip of the iceberg. The program currently only offers symptom and chronic disease management.

When a patient is admitted into the program after waiting an average of two years, they are advised that they can only access the program for 12 months. This effectively means that for a disease that is for the most part permanent for our patient population, patients only receive care for 12 months. When patients are discharged, they are returned to their family physician who often is not sufficiently trained to address the complexities of the illness, nor the patient’s comorbidities. Patients are then unable to access treatments which could improve quality of life and are again in the position of having to deal with their disease by themselves, even when more concerning symptoms develop. As new information about the disease and its treatment comes available, very few family physicians stay up-to-date and patients continue to receive outdated care, if any at all. Some patients are too ill to attend the self management program following a two year waitlist, others have navigated their own care during the waiting period and identified self management protocols on their own.

While there are no Health Canada approved treatments for ME, international experts commonly provide antivirals, immunomodulators and other treatments helpful to patient subsets. Patients in British Columbia, however, do not have access to appropriate testing or treatment within the provincial health care system. Those that can afford to, go to great lengths and great expense to access treatments not available through MSP, many going out of the country.

Shortage of knowledgeable health care professionals

As there is no medical specialty responsible for ME, patients spend years with clinical referrals to specialists not trained to diagnose or treat the illness. The responsibility of providing care for patients with this very complex disease, and its common co-morbid conditions, is then left to family practitioners.

The **Ontario Task Force on Environmental Health** noted that there is a critical shortage of primary care physicians and nurses in Ontario knowledgeable about ME²¹. The situation is the same, if not worse, in British Columbia. Our Society is aware of many patients seeking medical support who have waited an average of 4- 6 years for a diagnosis, with many waiting even longer.

Lack of proper medical guidance has patients being prescribed harmful and outdated treatments, such as graded exercise therapy (GET) or cognitive behaviour therapy (CBT), the result of medical biases which still deem the illness psychological and the use of obsolete and erroneous information. Physicians, unaware or skeptical of the severe

²¹ **Care Now: An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)**. Final Report of the Ontario Ministry of Health Task Force on Environmental Health, December 2018

implications of ignoring post exertional malaise (PEM)²², encourage patients to push through their symptoms, causing them to “crash” (relapse) for days, weeks, months and sometimes years²³.

The CCDP at BC Women's Hospital has slowly developed the capacity to diagnose and educate patients and their family physician, assisting with disability income and insurance applications. However, the program suffers from the same shortage of knowledgeable health care professionals as in the rest of the province.

Outside of this provincial program there are only two known family physicians in the province who specifically indicate they are knowledgeable about ME. Both practices are oversubscribed, with one no longer taking new patients.

As in other Canadian jurisdictions, ME is not taught to physicians at any point in their undergraduate, graduate or professional education.

The results of this ME education gap:

- Patients are abandoned by their health care system, left to their own devices to learn about the disease and manage it, exhausting what little energy reserves they have in order to research the disease on the internet.
- Patients wait years for a diagnosis.
- Lack of physician education means patients have a poorer outcome and it leaves both patients and physicians frustrated.
- Patients are then blamed for not getting better., accused of malingering.
- Without validation of the illness by a medical professional, employers, families and friends doubt the credibility of the patient’s health concerns
- Patients suffer further emotional and psychological injury from dealing with a neglectful, even disdainful, health care system.

No billing or diagnostic code for ME in BC

There are no diagnostic or billing codes for ME in British Columbia. Without an appropriate billing or diagnostic code which recognises the complexity of the illness and the difficulty to diagnose and treat the condition, medical practitioners do not have the extra time required to spend with patients.

The lack of a billing code makes it difficult to attract new physicians to a practice that focuses on a disease with the complexity of ME. Patient issues and their chronicity, require physician time over and above what is compensated under the current billing system. We need to incentivize physicians to provide appropriate care to ME patients.

Lack of a diagnostic code also means that there is no recording of statistics tracking the number of patients, and no study to understand longitudinal progress and epidemiology of the disease.

²² Post exertional malaise (PEM), also referred to as post-exertional neuroimmune exhaustion, is an exacerbation of some or all of an individual's ME/CFS symptoms after physical or cognitive exertion, or orthostatic stress that leads to a reduction in functional ability. PEM often puts the patient in relapse that may last days, weeks, or even longer. The Institute of Medicine has classified PEM as the hallmark symptom of ME. [Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Redefining an Illness, Report Brief, February 2015](#), Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Board on the Health of Select Populations, Institute of Medicine of the National Academies, The National Academies Press, Washington, D.C.

²³ [Cognitive-behavioural therapy for chronic fatigue syndrome: neither efficacious nor safe](#), Frank Twisk and Lou Corsius, British Journal of Psychiatry, Volume 213, Issue 2, August 2018, pp. 500-501

Hospitals are unsafe places for ME patients

Lack of knowledge of ME among health care professionals makes hospitals and diagnostic testing locations unsafe for ME patients²⁴:

- Patients face long-lasting trauma from their interactions with health care professionals in hospitals
- Noise, light, movement, smells can be painful and too much for many patients, often leading to pain, sensory overload and prolonged relapse.
- The expectation to communicate or to move can be impossible for an ME patient who is acutely sick and requiring hospital attention.
- Disease-specific accommodations are not made for most patients who need to lie down as they cannot deal with upright positions for any length of time.
- ME patients typically are very sensitive to medications and have dietary issues, and it is essential for health care practitioners to be aware of them. Drug reactions can lead to surgical complications. Ignorance of these disease-specific issues can contribute to adverse events and worsens the patient's condition for weeks, months or years.

²⁴ [*Chronic fatigue syndrome in the emergency department*](#), Christian R Timbol, James N Baraniuk, Volume 2019:11 Pages 15—28.

This U.S. study confirms the experiences with Emergency Rooms that our BC community has repeatedly shared with our Society. The study concludes: "*A barrier to care was the lack of knowledge of ED staff about CFS [also known as ME, myalgic encephalomyelitis, ME/CFS], and focus on psychosomatic etiology so that 43% of patients were told, "It is all in your head".*"

Economic costs of ME

- Thousands of British Columbians living with ME are missing from their jobs, their community, their families.
- Studies have indicated that people living with ME are more disabled than people affected by multiple sclerosis (MS), and that ME impacts patients' ability to work more so than patients with MS²⁵.
- Lack of an early diagnosis means patients do not learn to avoid activities which will worsen their condition, increasing their disease burden and need for medical and personal supports. Without a diagnosis, many patients are denied disability insurance and forced to continue to work until they are so ill as to be totally incapacitated.
- Lack of treatments and knowledgeable health care practitioners force patients to turn to alternative treatments or out-of-country medical, all paid for out of the patient's pocket.
- With four times the number of patients as affected by MS, the economic impact of ME on the BC economy is very significant.

ME patients have difficulty receiving disability income and insurance

People with disabilities living in British Columbia may be eligible for:

- Provincial Disability Assistance;
- Canada Pension Plan Disability Benefit;
- Employment Insurance sickness benefits (Federal);
- Accumulated sick time;
- Employer or self-purchased private insurance.

The process of applying for financial support can be onerous, complex and exhausting, creating an overwhelming barrier for many ME patients, in particular those suffering from cognitive impairment. Often the family physician is not supportive or lacks proper training to require paperwork for ME patients' disability application forms. The physical effort involved in this application process is a barrier for those who are severely ill. Eligibility is generally based on an individual's capacity to function, not taking into account the volatility of the symptoms due to PEM. The application process proves a huge stress to patients, especially those who have little to no financial recourse and little emotional support while they are at the lowest point in their lives.

Eligibility for provincial disability income is based on a person being able to open a file with the Ministry of Social Development & Poverty Reduction, then applying for and receiving a person with disability designation (PWD). The bias against the disease, lack of a biomarker and knowledge of diagnostic criteria, and lack of understanding of the physiological changes preventing ME patients from working, results in people living with ME having to fight to establish their PWD status and /or receive disability income. Patients often spend years ruining their health for financial support, often losing the battle.

²⁵ [*Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls*](#), Caroline C. Kingdon, Erinna W. Bowman, Hayley Curran, Luis Nacul, Eliana M. Lacerda.

Delayed diagnosis (it can take years for patients to receive a diagnosis²⁶) can also prove a barrier for many private health insurance plans, which place limits on time of application from onset of illness. Applications are often denied, forcing patients to go through a protracted appeals process. In cases where an ME diagnosis is accepted and claims approved, many private insurance companies and employers often **pressure ME patients to engage in “rehabilitation” activities which are in fact harmful**, at best triggering PEM, and in many cases causing a long-term worsening of the illness. Rehabilitation is prescribed by health care professionals who are not experts in ME, very often going against the recommendations of expert physicians. Patient non-compliance with these harmful activities often leads to accusations of malingering and rejection of a claim or application. These experiences are a source of trauma for patients, and often repeated on a yearly basis as patients are required to submit yearly updates on their condition.

Many patients spend all their savings seeking legal help to deal with denied claims. The resulting financial burden leads to worsened health, poverty, anxiety, stress, depression and sometimes suicide.

Lack of home support and care services

Given the dangers that overexertion can pose to ME patients, assistance for daily living is the equivalent for the more seriously ill patients of providing insulin for diabetes patients.

The lack of in-home support and care services pose high levels of stress on patients, forcing them to overexert and constantly trigger post exertional malaise (PEM) or even a relapse¹⁶. The fluctuations of the disease and the uniqueness of the disability caused by overexertion makes it extremely difficult for patients to be approved for home care.

Stigma for ME also means that some families are not supportive. Families are very often influenced by the physician’s assessment and are told to encourage the patient to become more active. They may not understand that the illness is biological and not psychosomatic. In such cases families too often place pressure on patients to get back to work and take care of themselves.

Families and caregivers who are supportive are often subjected to stress, as they receive no financial support for caring for the family member with ME. Patients with children are particularly hard hit, with family breakdown, poverty, and food insecurity resulting.

²⁶ [*Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Redefining an Illness, Report Brief, February 2015*](#), p. 16

Appendices

Additional resources on ME:

- Our Society's website hosts additional listings on the latest research on ME. Find large research summaries and linked to individual topics of research [here](#).
- Our Society has collected a few personal stories of living with ME in British Columbia. Patient, family, caregiver stories can be read [here](#).
- The US Center for Disease Control hosts various information to support health care professionals and individuals living with ME/CFS. Please access [here](#).
- Diagnosis remains one of the largest challenges for patients. Here are a few starting points:
 - Diagnosis and Management of Myalgic Encephalomyelitis and Chronic Fatigue Syndrome is a 10-minute instructional video on diagnosing and treating ME. The film is used as part of a Continuing Medical Education Program for ME (USA). [Watch here](#).
 - For more detailed information on diagnostic criteria visit: [Canadian Consensus Criteria](#) and [History](#)
- *Unrest* is an award-winning feature documentary that was shortlisted for the 2018 Academy Awards for Best Documentary Feature. The film is an intimate, visceral view into the hidden world of severe ME, taking us along a personal journey through the illness and the medical system. Connections with patients, clinicians and researchers around the world, telling a compelling, enlightening and informative story that leaves audiences in awe. (Copies available from most local libraries)
 - A short (17min) TedTalk from Documentarian is available [here](#).

Contact:

info@mefm.bc.ca

www.mefm.bc.ca