



A response to the BC Framework for Accessibility Legislation Consultation From the ME | FM Society of BC

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The ME | FM Society of BC (the Society), a BC non-profit run by patients, carers and their families, was formed to help, support and advocate on behalf of patients with myalgic encephalomyelitis (ME) and/or fibromyalgia (FM).

Myalgic encephalomyelitis (ME), also referred to as ME/CFS, is a disabling chronic neuroinflammatory spectrum condition which affects more than 77,000 British Columbians¹. Women are more likely to be diagnosed with ME than men², and an estimated 2 in 100 children suffer from the disease³. Those affected experience a substantial loss of physical and/or cognitive functioning resulting in an inability to sustain employment and lifelong disability. It is estimated that more than 50% of persons with ME are disabled⁴ and up to 75% are unable to work or attend school regularly. Twenty-five percent are fully homebound or bedridden⁵.

Fibromyalgia (FM) is a chronic, complex illness characterised by widespread musculoskeletal pain accompanied by fatigue, sleep, memory impairment and other issues impacting approximately 90,000 British Columbians¹. A person with FM suffers from a wide variety of symptoms, which can fluctuate in degree of severity or remain constant.

¹ Statistics Canada unpublished *Canadian Community Health Survey (CCHS)* reports that just over 560,000 patients were diagnosed with ME/CFS in 2015

² US Center for Disease Control and Infection, [Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: What is ME/CFS?](#) (website)

³ US Center for Disease Control and Infection, [Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: ME/CFS in Children](#) (website)

⁴ Institute of Medicine Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington, DC: The National Academies Press; (2015). Available online at: <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>

⁵ Pendergrast T, Brown A, Sunnquist M, Jantke R, Newton JL, Strand EB, Jason LA. [Housebound versus nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome](#). *Chronic Illn.* 2016;12(4):292–307

While both diseases can be very disabling, ME is the more severe of the two. Both diseases often overlap and share many of the same accessibility challenges. For the purposes of this submission, we will focus on ME, letting it be known that the issues and suggestions we submit are shared for both diseases.

Myalgic Encephalomyelitis (ME) and Disability

The United Nations Convention on the Rights of Persons with Disabilities defines persons with disabilities as “*those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*” (Article 1)

Despite the prevalence and severity of ME, patients are faced with systemic barriers to access a variety of government benefits and services, including healthcare, due to the lack of recognition of the disability brought on by the disease.

In a study published in March 2018, researchers concluded that: “*people with ME/CFS were measurably more disabled than PWMS [people with multiple sclerosis] or HCs [healthy controls] These findings should encourage the health community to recognise the disabling effects of ME/CFS, to 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.*”⁶

LONG-TERM IMPAIRMENT & ME

At this time, there is no known cure and few treatments that alleviate ME symptoms. The prognosis for ME is considered to be poor with only a minority (a median estimate of 5%) returning to pre-morbid levels of functioning⁷. The majority of patients remain significantly impaired. Consequently, ME is considered a serious complex chronic disease, indefinitely creating disability in patients' lives.

ME SYMPTOMS AND IMPAIRMENTS

- **Post exertional malaise:** The defining symptom of myalgic encephalomyelitis is post exertional malaise (PEM). Following exertion which exceeds their energy envelope, people living with ME experience a profound drop in their energy level and an increase in their symptomatology. This drop, or “crash” can have onset immediately or even 24 to 48 hours following an episode of overexertion, and can last for days, weeks or months. In some cases overexertion can lead to a relapse or permanent worsening of the illness.

PEM makes accessibility and disability accommodation essential for ME patients in order to prevent overexertion and the worsening of symptoms and disability that can result.

⁶ *Functional Status and Well-Being in People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Compared with People with Multiple Sclerosis and Healthy Controls*, Kingdon, C.C., Bowman, E.W., Curran, H. et al. *PharmacoEconomics Open* (2018) 2: 381. <https://doi.org/10.1007/s41669-018-0071-6>

⁷ Cairns, R.; Hotopf, M. (Jan 2005). *A systematic review describing the prognosis of chronic fatigue syndrome*. *Occupational Medicine (Oxford, England)*. 55 (1): 20–31. doi:10.1093/occmed/kqi013. ISSN 0962-7480. PMID 15699087.

- **Energy metabolism disruption:** Patients also experience fluctuating energy due to disruptions in energy metabolism⁸. This means that patients work on very limited amount of energy, and while some are able to walk, other use all of their energy simply to manage their daily care. Social and cognitive activities are equally taxing.

This reduced energy envelope raises the risk of triggering post exertional malaise and the increased disability which accompanies that symptom. It is essential that persons living with ME remain well within their fluctuating energy envelope, a task that is extremely challenging.

- **Sensory overload:** Sensitivities to light, sound, vibration and odours can trigger symptoms that last for days or weeks. Even a simple telephone conversation can be overwhelmingly exhausting to a person with ME. Those most severely affected live solitary lives in dark and quiet rooms.
- **Cognitive impairment:** Most persons living with ME or fibromyalgia suffer from cognitive impairment. For those with ME, this can be one of the worst symptoms, making it challenging to navigate bureaucracies, paperwork, information and social situations. Form filling and self-advocacy become particularly difficult for ME patients, with the risk of mental overload leading to post exertional malaise, further reducing their physical and mental capacity.
- **Cardiovascular issues:** Inability to tolerate an upright position due to orthostatic intolerance (OI), neurally mediated, hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), palpitations with or without cardiac arrhythmias, light-headedness/dizziness. This is one of the most disabling symptoms of ME and one which requires special accessibility accommodations.
- **Other disabling symptoms:** Some of the most common symptoms of the disease are pain in the muscles and joints, unusual headaches, gastrointestinal symptoms, muscle weakness, autonomic, endocrine and immune system dysregulation and unrefreshing sleep.

SEVERITY OF 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 for ME, and very few patients fully recover.

Adults with ME experience a profound decrease in the quality of life, impairment in daily activities, and inability to retain employment status. Twenty-five 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 schooling⁹. On average, ME patients score more poorly on quality of life surveys than those with multiple sclerosis, stroke, diabetes,

⁸ *Metabolic features of chronic fatigue syndrome*, Robert K. Naviaux, Jane C. Naviaux, Kefeng Li, A. Taylor Bright, William A. Alaynick, Lin Wang, Asha Baxter, Neil Nathan, Wayne Anderson, Eric Gordon. Proceedings of the National Academy of Sciences Sep 2016, 113 (37) E5472-E5480; DOI: 10.1073/pnas.1607571113

⁹ G Kennedy, C Underwood, & JF Belch, *Physical and Functional Impact of Chronic Fatigue/Myalgic Encephalomyelitis in Childhood, Pediatrics*, 125: 6 (2010) 1324-1330.

renal failure, lung disease, heart failure and some cancers¹⁰. More severe cases are compared to end stage AIDS or cancer, only it can go on for years¹¹.

BURDEN OF THE DISEASE

The burden of this disease and its medical and economic costs are in fact significantly greater than other chronic disease categories. This is not only due to ME's devastating impact on multiple body systems and the patient's daily life, but also due to delays in diagnosis, failures of treatment, and profound errors in the treatment of comorbidities. In turn, these are compounded by the misunderstanding of the disease and concomitant stigma and bias.

Obstacles to ME Accessibility

TRADITIONAL OBSTACLES

Transportation: Those able to leave their home face obstacles of transportation as driving or public transit use may be impossible. Many in our community use wheelchairs or mobility scooters, however public transportation may prove impossible due to long commute times (aka milk run), sensory overload, motion sickness, and other factors such as difficulty in retrieving the mobility device, ability to get out of their home and whether there are stairs to maneuver.

Housing: Housing is a challenge for most people in British Columbia, especially for those with disabilities. But for those with an invisible disability such as ME, which is stigmatised and misunderstood, the challenge is mostly insurmountable, forcing those living with ME to reside in harmful homes. Stairs, sounds and smells can all trigger post exertional malaise, as can the search for housing itself and arguing with government officials to make a case for the right to such housing.

When these obstacles are overcome, challenges often arise navigating the destination, and once more individuals are facing sensory overload issues in locations such as shopping malls, grocery stores, coffee shops, and sports arenas.

SYSTEMIC OBSTACLE TO ACCESSIBILITY: STIGMA

At the core of the UN Convention of the Rights of Persons with Disabilities is the undertaking by State Parties to “ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities **without discrimination** of any kind on the basis of disability.” (Article 4).

¹⁰ Nacul L, et al. *The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers*. BMC Public Health. 2011;11:402

¹¹ Falk Hvidberg M, Brinth LS, Olesen AV, et al. (2015) *The health-related quality of life for patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)*. PLoS ONE 10: e0132421

While much is being done in British Columbia to address this commitment to those with visible disabilities, those who comprise the disability underclass are excluded. That underclass includes those with INVISIBLE disabilities such as ME. The inability to stand or sit for any length of time, or the possession of an energy envelope that is exquisitely small, or the inability to tolerate sensory stimulation, are all disabilities which those without ME cannot see.

The result of this lack of visible proof of disability, along with the lack of a biomarker, is that people with ME experience stigma and bias. Either the disease itself is called into question, or the person living with the disease is accused of malingering or exaggerating. ME is often dismissed as “chronic fatigue” and trivialised as “everybody's tired”.

Despite the recent advances in research^{12,13} many in the medical community, insurance industry, government and other services continue to deny the very existence of ME.

Denial of the devastating impact of the disease has ramifications that result in systemic barriers for the individuals living with ME on a day-to- day basis.

- **Systemic lack of knowledge.** There is close to a universal lack of awareness of ME throughout the healthcare system, government, support services and the public. This is reflected in a lack of ME directed government policy, funding decisions, strategic initiatives and services, with impacts that cascade throughout government and health care systems, and result in an absence of accessibility accommodations for persons living with ME.
- **Lack of medical care.** It typically takes a BC resident 5 years to be diagnosed with ME as physicians in BC are unfamiliar with the disease or its diagnostic criteria. This delay all too often leads to devastating consequences. Ignorant of the nature of the disease and disability it imposes, patients are encouraged to exercise and push themselves, rather than to rest and operate within their now-limited energy envelope, often causing patients to become housebound or bedridden. All this could be avoided if medical practitioners recognised and were knowledgeable about ME, and accommodations were made for the disabilities and limitations created by the disease.

The Complex Chronic Disease Program at BC Women's Hospital is the only provincial program that recognises and deals with ME. It is a referral program with a two and a half year wait list. Once admitted to the program patients are eligible for services for only 18 months, despite the disease being a lifelong condition. The result is that those fortunate enough to enter the program are left unable to access equitable and safe health care for most of their life with the illness. The rest of the ME population fares even worse.

- **Barriers to Income Assistance and Support for ME.** Typically in order to qualify for most disability supports or benefits the individual must demonstrate that they have done everything possible to maximize their functional Independence. This is the paradox of ME: Individuals with ME need to conserve their energy and plan for future energy

¹² Komaroff AL. *Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome*. JAMA. 2019;322(6):499–500. doi:<https://doi.org/10.1001/jama.2019.8312>

¹³ An excellent summary of current ME Research has been created by Jaime Selzer at #MEAction: [ME Research Summary 2019](#)

expenditure. Therefore to maintain optimal functioning they need to consistently do less than they are able. To do otherwise results in increased levels of disability.

However this management strategy is not approved by current eligibility requirements, which do not make accommodation for ME. Further, ME patient's abilities can fluctuate from day to day, casting doubt on the veracity of their reported symptoms.

As a result, disability insurance, pension plans, supports to individuals with disabilities, in-home caregiving, residential care situations all have eligibility requirements that tend to exclude individuals with ME despite high levels of disability. Typically this results in individuals living in poverty, substandard housing, and relying on informal support networks for caregiving.

- **Harmful environments.** Most notable are the following environments that can exacerbate symptoms of ME and act as barriers to access.
 - ◇ Hospital emergency and treatment rooms and wards that are loud and bright, not allowing ME patients who require it to lie down, with staff unfamiliar with ME, often resulting in traumatic experiences for the patient.
 - ◇ Loud government offices with fluorescent lighting.
 - ◇ Long lineups required to access services, often with nowhere to sit or stand while waiting, often in noisy, bright environments.
 - ◇ Handydart trips that extend over an hour as other people are picked up and dropped off.
 - ◇ Public transport, street noises, and traffic each create sensory overload.
 - ◇ All environments where scents are not modified and designated scent free. Most ME patients have environmental sensitivities such that a person wearing scented hand cream or use of commercial cleaning products can trigger ME symptoms.
- **Lack of housing options.** Few individuals with ME meet the eligibility requirements for long term care or assisted living. For those who do qualify, it is difficult to find a facility that can accommodate their needs. For others, poverty forces them into inadequate housing that exacerbates their disability, having to deal with stairs, noise, cigarette smoke, chemical or mold exposures, which can trigger symptoms, worsen their condition and can create insurmountable barriers to functioning. Severity of illness can force people to stay in harmful accommodations as they are too ill to search for appropriate housing, let alone to make the move.
- **Lack of support resources.** Few individuals living with ME qualify for home care, support to access compounded medications (required due to sensitivities to medications), transportation to and from the hospital, ME appropriate rehabilitation services, assistance with complimentary supports like dietitians, complementary health services, purchase of a wheelchair, and dietary supplements. These are fundamental resources, essential for ME patients in stabilizing their health status as much as possible.

- **Lack of accommodation in employment or schools.** For those individuals who are able to continue to work at a reduced intensity, it is important that employers understand their legal obligation to accommodate the disability. However, pressure from insurance companies forces most patients to continue with a workload they are unable to sustain, causing a worsening of their illness and increase of disability, even in cases where doctors who are knowledgeable about the disease prescribe a reduction or cessation of work. In many cases, insurance companies force patients to submit to harmful exercise therapies, causing irreparable damage to patients' health.

School environments and educational activities have multiple barriers for the child or teen with ME. As with adults, ME is not accepted as real by many schools, who in turn fail to accommodate students with ME. Too often the concerns about access fall on deaf ears and are interpreted as an "overprotective family" issue.

In summary, the stigma associated with ME is profound. It results in discrimination on a systemic level and challenges individuals on a daily basis, posing significant barriers to participation, eligibility, and treatment.

It is the challenge of having an invisible disease or disability, that is doubted by service providers, employers, gatekeepers for various entitlements, and even family and friends. It is the challenge of being asked if the symptoms are real or exaggerated. It is the challenge of being told the disease is psychosomatic. It is the challenge of being accused of malingering, of not trying to cooperate with psychiatric interventions, of lacking in effort to heal.

It is the challenge of knowing that treatments are ineffective, inadequate and inappropriate; and that some exacerbate symptoms. It is the challenge of being ineligible for benefits.

It is the challenge of having your integrity questioned as you seek the assistance to which you are entitled, and an equitable opportunity for participation in the rights and privileges of citizenship.

Recommendations

To this end, we stress that this legislation must address the inequities associated with invisible disabilities like ME and the many barriers to access to all the privileges of citizenship, inter alia: medical care, rehabilitation services, income and food security, housing, transportation and home care.

As a signatory of the UN Convention on the Rights People with Disabilities, Canada and British Columbia has an obligation to uphold its principles and implement policies that put into practice the Articles of the Convention. If they do not do so, they will fail to address the needs of the most profoundly disabled among us. As such it will be merely window dressing and continue to perpetuate the inequities and indignities, and condone the current neglect.

The measure of whether or not this legislation is successful needs to be whether it creates access for those with the most barriers, those for whom barriers to access are a profound and constant struggle.

Our recommendations with respect to a BC framework for accessibility legislation consultation:

1. Establish an independent office to investigate and report to the Legislature on systemic bias in response to complaints from individuals.

Currently, most individuals who feel that they have been unfairly treated or excluded are directed to make a complaint to the agency which has treated them in a discriminatory manner. This does nothing to address systemic bias and rectify discrimination. It perpetuates the myth that it is something inherent in the individual and fails to address the issues of invisible disability and, more specifically, those associated with ME. The new legislation must hold bodies accountable for this insidious systemic discrimination.

2. Engage in a comprehensive awareness raising campaign to reduce the multiple barriers to access and inclusion experienced by persons with invisible disabilities, including ME.

Work with the ME community to develop and implement this awareness raising campaign targeted at government officials, decision-makers, schools, community and health care workers. For too long people living with ME have struggled with access on multiple fronts because of systemic bias which fails to accommodate their invisible disability. The UN Convention on the Rights of Persons of Disabilities is clear about the obligation of the State with respect to the prevention of discrimination.

3. Creation of a public awareness campaign to educate British Columbians about the disabling nature of many invisible illnesses, including ME.

Whether it be fatigue, orthostatic intolerance, pain or any other invisible disability, British Columbians who face these challenges face the added challenge of dealing with the skepticism of those in the community who cannot see or are ignorant of these disabilities. Those living with invisible disabilities such as ME deal with this skepticism when parking in a handicapped parking spot or parking a mobility scooter and then walking, when cancelling plans and appointments at short notice, or when asking for help. A public awareness campaign would help to change how those with invisible disabilities are viewed, creating a more supportive and caring environment for members of our community who desperately need help and understanding.

4. Conduct a review of systemic barriers to access of government supports and services for British Columbians living with ME

As part of a comprehensive myalgic encephalomyelitis strategy for the province of British Columbia, the Ministry of Social Development & Poverty Reduction needs to conduct a review of systemic barriers to access of government supports and services, across

ministries. Where necessary, measures to rectify inequities and address long-standing neglect should be implemented.

5. Recognition of invisible disabilities such as ME by BC businesses and service providers operating in British Columbia

The Ministry of Social Development & Poverty Reduction is to develop and implement regulations applicable to BC businesses and service providers that reflect the respectful, non-discriminatory intent and tone of the UN Convention as it applies to invisible disabilities.

6. Ensure that invisible disabilities such as fatigue, orthostatic intolerance, sensory sensitivity and pain are recognised and accommodated

In the same way that ramps and automatic doors allow British Columbians with physical disabilities to access buildings and services, the availability of invisible disability safety spaces - quiet, low light environments with places for lying flat - could enable those living with ME to also access buildings and services.

7. Modify eligibility requirements for income support and benefits to accommodate unique ME disabilities

Overexertion is to an ME patient what sugar is to a diabetic. At some point disability prevents ME patients from being able to work full-time without causing harm to their health. In these cases, ME patients require accommodations to make it possible to work part-time.

For most ME patients, however, the reality is that they are unable to work at all. In order to prevent becoming bedbound, patients must be able to access income support and benefits to afford to stop working altogether. Currently, the energy required to attempt to gain these financial supports is more than many patients have to spare. Eligibility requirements discriminate against those with invisible disabilities, especially when ignorance about the disease causing the disability is high.

The result is that many ME patients are left impoverished, suffering from food and housing insecurity. The situation is particularly untenable for those who have families.

8. Modify eligibility requirements for home care to accommodate unique ME disabilities

Post exertional malaise combined with a reduced energy envelope means that ME patients require accommodations for daily living in order to prevent the harmful results of overexertion. Home care is required for severe patients to prevent overexertion and worsening of symptoms or a permanent decline in health, and needs to include assistance with cooking, cleaning, shopping, laundry and other domestic chores.

9. Provide a publicly subsidised ride service that accommodates British Columbians living with ME

Currently, HandyDART trips can extend over an hour as other people are picked up and dropped off. They do not cater to the needs of severely ill ME patients who need to attend medical appointments and other important events. Compliance with the UN Charter for Persons with Disabilities would require that accommodations be made to allow such transportation to be made available to all British Columbians with disabilities.

10. Creation of a yearly provincial conference: Accessibility for Invisible Disabilities

At the Accessibility for Invisible Disabilities conference disability and patient groups, decision-makers and stakeholders will come together to identify the special needs of the invisible disability community, brainstorm and strategize solutions, and assess the success of implementation of these solutions over time.

Many thanks for the opportunity to make this submission. We look forward to being part of future discussions and planning to address accessibility legislation and policy, in particular how it pertains to invisible disabilities, myalgic encephalomyelitis and fibromyalgia.

Sincerely,

Board of Directors

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