ME | FM Society of BC

Evidence for Change

Survey Findings from 1,045 BC Patients

An accessible summary of the largest examination of healthcare experiences for patients with ME/CFS, Fibromyalgia, Lyme Disease, and Long COVID ever conducted in British Columbia.

This document translates comprehensive survey research into clear, digestible findings designed for patients, caregivers, and community advocates.

What This Document Contains:

Validation

Comprehensive data showing you are not alone in your struggles with the healthcare system

Evidence

Statistics and patient voices documenting systemic failures and gaps in care

Hope

Proof that quality care IS possible when the right conditions exist

Action

A clear path to join the movement demanding provincial healthcare reform

By patients, for patients

Contents

This document is an accessible summary of findings from a comprehensive survey of **1,045 patients** with recognized conditions including **ME/CFS, Fibromyalgia, Lyme Disease, and Long COVID** across BC.

We've translated academic research into clear, patient-centered findings that validate your experiences and provide evidence for systemic healthcare change. This summary highlights the key findings that matter most to our community.

For complete methodology, detailed statistical analysis, and comprehensive data, the full detailed survey report is available separately.

Contents:

Additional Resources:

Full Survey Report: **https://www.mefm.bc.ca/survey-report-2025**

- ME|FM Society of BC: **https://www.mefm.bc.ca**

United Voices: Understanding these illnesses in BC

This comprehensive survey, gathering **1,045 voices from every region of British Columbia**, offers unprecedented insight into the experiences of patients living with ME/CFS, Fibromyalgia, Lyme Disease and Long COVID. It's a powerful statement: **you are not alone**, and your experiences are valid. What you're about to see not only validates your journey but provides the crucial evidence needed to demand real change.

Who Participated?

- 1,045 British Columbians with ME/CFS, fibromyalgia, Lyme disease, and/or Long COVID across all health authorities. 65.7% have more than one of these illnesses One-third have been ill for 20+ years, highlighting the chronic, long-term nature of these conditions
- Our participants represent diverse communities: urban, rural, and suburban.
- Patients include those accessing specialized clinics AND those managing care through family physicians, ensuring a broad perspective.
- The survey was conducted anonymously and confidentially to encourage honest and open reporting.

This critical initiative was supported by: The National ME | FM Action Network, BC Lyme Society, and ME Victoria Association.

Academic Survey Author: Kelly Lautt, BA, MA, PhD (ABD), Director at ME|FM Society of BC

Key Findings

Healthcare System Failure

93%

Negative Patient Experiences

Of 1,045 patients surveyed, 93% reported negative experiences with the healthcare system.

75%

Providers Lack Basic Knowledge

75% of patients reported their healthcare providers lack basic knowledge about their conditions.

This overwhelming percentage of negative patient experiences directly correlates with patients reporting that their healthcare providers lack basic knowledge about these complex conditions. This indicates a systemic failure rooted in inadequate provider education, leading to profound impacts on patient care and wellbeing.

However, There Is Hope

The good news? Citing being believed, knowledgeable practitioners, and sufficient 1:1 time and attention, 40% of respondents reported at least one positive experience - proving appropriate care is possible with the right support.

93% Of ER Users Had Negative Experiences

93%

Negative ER Experiences

Harmful advice, dismissal, trauma

Of the patients found in the original survey who used emergency services, 93% reported negative experiences in emergency departments—including harmful advice, dismissal, and medical trauma that left many patients feeling afraid to seek additional help.

> "The ER doctor told me to exercise more when I was literally unable to walk or care for myself. I felt so dismissed, and it became clear that I would find no real help for my pain here."

Financial Devastation

When the public system fails, patients are forced into financial crisis. The cost of managing these conditions without adequate healthcare support is devastating.

Out-of-Pocket Care

Providing for medical necessities, even when forced to pay out-of-pocket, despite lacking any federal or local support.

Supplements & Treatments

Purchasing uncovered medications and therapies, often at prohibitive costs.

Travel Costs

Securing specialized care and treatments not available locally, requiring extensive and costly travel arrangements.

Lost Income

Loss of income due to extended illness, disability, and discrimination in employment.

> "I've spent thousands on private care, supplements, anything that might help because the public system offers nothing. I'm going bankrupt with no health insurance."

Medical Gaslighting Reality

Dismissal and disbelief are not isolated incidents—they are daily experiences for the vast majority of patients across all care settings.

> "They don't believe in the illness and feel like everything that I'm telling them is made up"

> "I've been sick for 8 years. I've seen 15 doctors. Still, I have no diagnosis, no treatment plan, and no hope. Just debt and despair."

Caregiver Impact

Families Bear the Burden

Caregivers report having to advocate constantly for basic respect and care, translate medical information and symptoms, witness medical trauma inflicted on loved ones, and sacrifice their own health and careers to provide support that the system fails to offer.

- Constant advocacy for basic respect
- Medical translation and interpretation
- Witnessing trauma inflicted by the healthcare system
- Personal health and career sacrifices

> "The system makes it almost impossible for us to advocate for ourselves. It forces those who are already sick and exhausted to fight for every bit of care. That's why allies and advocates are so important."

Resources for Caregivers

Download our comprehensive Caregivers Toolkit with specific strategies and resources for supporting loved ones affected by ME/CFS and related conditions: **https://www.mefm.bc. ca/toolkits**

When Care Works: Hope in the Data

The survey reveals a critical finding: positive experiences DO happen when the right conditions are met.

93%

Had At Least One Positive Experience

Almost every respondent (93%) reported at least one positive healthcare experience - proving that good care isn't impossible, it's just far too rare.

When patients encountered providers who believed them, had knowledge about their condition, and gave sufficient time and attention, they reported:

- Proper diagnosis (often after years of searching)
- Helpful treatment plans
- Support with financial applications
- Validation and respect

The Problem Isn't That Good Care Can't Exist

The problem is that positive experiences are vastly outnumbered by negative ones. While 93% had at least one positive experience, negative experiences dominated overall, leaving patients exhausted, traumatized, and without consistent support.

Good care exists. We need to scale it.

> "Finally one person who believed me, who even knew what I had. I barely even cared if they could actually help. I just wanted someone to validate me!"

Alternative Healthcare Providers

Positive

77% of patients who saw alternative practitioners (occupational therapists, physiotherapists, naturopaths, and mental health professionals) reported positive experiences.

These providers tend to:

- ✓ Believe patients and treat them respectfully
- ✓ Take time to discuss experiences and symptoms
- ✓ Provide one-on-one appointments
- ✓ Willingly prescribe or refer for helpful care

The Solution Isn't Impossible

This data proves we know what works - we need to scale it. When providers have knowledge, time, and belief in their patients, care improves dramatically.

What Patients Need Most

Survey respondents clearly identified their top healthcare priorities:

Top Priority: Knowledgeable One-on-One Care

Quick access to highly skilled, supportive healthcare professionals who can provide:

- Fast, accurate diagnosis
- Ongoing care and treatment plans
- Effective management of high-impact symptoms

Healthcare Providers Who Believe

Professionals who:

- Truly listen and validate patient experiences
- Recognize the physiological (not psychological) basis of these conditions
- Understand the severity and disability impact of illnesses like ME/CFS

Provider Education & Information

Up-to-date, evidence-based education for both primary care providers and specialists on complex illnesses such as ME/CF chronic fatigue syndrome and fibromyalgia

Financial Support & Coverage

Assistance with securing resources like insurance coverage, disability benefits, and other financial aid

Virtual One-on-one Appointments

Accessible online appointments for individuals unable to attend in-person consultations due to illness severity.

What Patients Value Less (But Still Appreciate)

Group sessions and online information are helpful as supplements, but patients prioritized direct, individual medical care over these options.

> "Group sessions addressing the challenges of ME/CFS are valuable, but access to a physician who truly understands the illness and is up-to-date on research is paramount."

> "While helpful for general wellness, holistic and alternative therapies should complement, not replace, evidence-based medical care."

One-Page Summary for Healthcare Providers

Print and bring this to your appointments

PATIENT HEALTHCARE EXPERIENCE SURVEY

Key Findings from 1,000+ BC Patients with ME/CFS, Fibromyalgia, Lyme & Long COVID

Full Survey Report

The Crisis

- 93% negative healthcare experiences
- 75% said their healthcare providers lack basic knowledge about their conditions
- 75% experienced simply not being believed
- 35% reported having experienced 11 or more different types of negative healthcare experiences

But Solutions Exist

- ✓ Being believed and having their symptoms validated
- ✓ Providers with knowledge about their condition
- ✓ Sufficient time and attention from their doctor or healthcare team

The problem isn't that good care is impossible - it's that negative experiences often vastly outnumber positive ones, leaving patients feeling unheard and unseen.

Key Concepts for Providers

> **Post-Exertional Malaise (PEM):** Symptom worsening minutes to hours after physical or mental exertion, often delayed by 24-72 hours. This can last for days or weeks. Rest and pacing are key for management.
>
> **Chronic vs. Acute Illness:** Conditions like ME/CFS and Fibromyalgia are chronic illnesses. They require long-term, compassionate management, not just acute care.

What Helps Patients

- Belief and validation
- Accurate diagnosis and appropriate treatment strategies
- Holistic symptom management
- Compassionate support

What Harms Patients

- Dismissal or disbelief of symptoms
- Being told to "push through" fatigue or other symptoms
- Invalidating symptoms as psychosomatic

Resources & Support

ME | FM Society of BC

Web: www.mefm.bc.ca
Email: info@mefm.bc.ca

Your Voice Matters: Join the Movement

If you are interested in further advocacy consider joining us in our My MLA and ME initiative.

Learn more: **https://www.mefm.bc.ca/my-mla-and-me-outreach-campaign**

Together, we are:

- Engaging healthcare organizations across BC
- Advocating for policy changes at the provincial level
- Building a community of informed, empowered patients

Your individual advocacy matters. Collective advocacy changes systems.

Other Ways to Take Action:
Share the Survey

- Post on social media using #MyDataStory
- Share the one-page provider summary (page 12) with your healthcare team
- Send to your local health authority:
  - Find contact information: **https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities/regional-health-authorities**

Connect With Community

- Join patient support groups:
  - ME|FM Society support groups: **https://www.mefm.bc.ca/support-groups**
- Share your experiences and resources with other patients
- Support others in their advocacy

Together, through My MLA and ME and other advocacy work, we will use this evidence to create the care we deserve.

Key Links:

- My MLA and ME: **https://www.mefm.bc.ca/my-mla-and-me-outreach-campaign**
- Become a member: **https://www.mefm.bc.ca/become-a-member**
- Full Survey Report: **https://www.mefm.bc.ca/survey-report-2025**