



**UNDERSTANDING MYALGIC ENCEPHALOMYELITIS (M.E.),  
also known as CHRONIC FATIGUE SYNDROME (CFS)  
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Myalgic Encephalomyelitis is a severe chronic illness that is sometimes more commonly known as Chronic Fatigue Syndrome. It is also called M.E. or ME/CFS for short. A person with ME/CFS has a number of serious symptoms other than chronic fatigue. The illness affects the brain, central nervous system, heart, muscles and endocrine system. It is considered a neurological and an immune system disorder. Some ME/CFS symptoms are similar to the illness known as Fibromyalgia and many people with ME/CFS also have Multiple Chemical Sensitivities, so Canadians need research and improved services for all three related illnesses.

Based on the Canadian Community Health Survey results for 2005, 334,000 Canadians had ME/CFS and 390,000 had been diagnosed with a similar illness known as Fibromyalgia (FM). Since many symptoms overlap, some patients may be initially diagnosed with FM and then later diagnosed with ME as newer symptoms appear. Some patients will be told they have both illnesses, as research is still evolving so we can better separate the two illnesses. Therefore, statistics sometimes talk about the number of Canadians with ME or FM as one combined figure.

In 2006, the Centers for Disease Control and Prevention (CDC) in the U.S. estimated that less than 20% of those affected have been accurately diagnosed. Studies also usually leave out children who have ME/CFS. It is becoming very clear, therefore, that ME/CFS is one of the most common life-changing disabilities in Canada and that the number of Canadians who are actually ill is much higher than statistics show. Perhaps as few as 10%-25% of patients have been properly diagnosed. Here's how ME/CFS compares to other chronic disabling illnesses:

### COMPARISONS WITH OTHER CHRONIC DISABLING ILLNESSES

#### Number of Canadians with the Illness in 2005

Diabetes	1,324,874	(Canadian Community Health Survey, 2005)
Heart Disease	1,288,009	(CCHS, 2005)
M.E. /Fibromyalgia*	723,598	(CCHS, 2005)
Multiple Chemical Sensitivities (MCS)*	598,535	(CCHS, 2005)
Cancer	370,763	(CCHS, 2005)
Effects of Stroke	297,547	(CCHS, 2005)
Alzheimer's and other Dementias	280,000	(Canadian Institutes of Health Research, 2005)
Physically Disabled Children/Youth	155,000	(CCHS, 2005)
Parkinson's Disease	100,000	(Health Canada / Parkinson's Society, 2005)
HIV/AIDS	58,000	(Public Health Agency of Canada, 2005)
Multiple Sclerosis	55,000	(MS Society of Canada, 2006)

\* As some patients may be diagnosed with more than one of these conditions, the CCHS reports 1,135,225 Canadians have at least one of these conditions, almost as many patients as have heart disease or diabetes

## THE DEVASTATING IMPACT OF ME/CFS

- ME/CFS and Fibromyalgia are now second only to Diabetes and heart disease in the number of people affected by serious chronic illness and yet we spend significantly less on ME and FM research and services compared to all of the other chronic illnesses mentioned above.
- The illness can attack at any age but most people are adults and 70% are women. (It is common for some neurological and immune system disorders to affect more women than men.) However, ME/CFS does not discriminate; it affects people of both sexes and all racial and ethnic backgrounds, as well as all education and income levels.
- Most people living with ME/CFS cannot work for long periods of time and many must give up their jobs, often for life. Their income can drop drastically and many live on disability payments of less than \$15,000 a year. ME/CFS costs the Canadian economy billions of dollars in disability payments, healthcare costs and lost taxes.
- The social cost of Myalgic Encephalomyelitis can also be high: family and financial stresses, lost dreams and relationships, and sometimes depression *in response to* the illness. Early diagnosis, combined with good healthcare and support from family, friends and workplaces are essential.
- Children may recover faster than adults, often after three years. The average time for adults who recover from ME/CFS is seven years. Most adults never fully recover. It is rare to find people with ME/CFS still able to work, even part-time, if they are still symptomatic after 10 or more years. Canada has confirmed cases of more than 25 years. There may be periods of fewer symptoms, like with Multiple Sclerosis (remission) but the person often relapses, sometimes suddenly, after an infection, surgery, fall, anaesthetic, even a vaccination, events that trigger the neuro-immune system.

## DIAGNOSIS:

There is no one test that can diagnose Myalgic Encephalomyelitis but accurate diagnosis is possible. The handbook *A Clinical Case Definition and Guidelines for Medical Practitioners* is the Canadian standard for diagnosis. A diagnosis is based on a set of symptoms that must last for 6 months or longer for adults and 3 months for children. A physician must also rule out other illnesses where fatigue, muscle pain, sleep disorders and immune problems are common. Most patients undergo extensive blood work and months of tests before a diagnosis is made. While symptoms can begin gradually, for many the onset of symptoms is sudden. Most people were previously healthy and many can identify the month or even the day when their life changed. While we do not know all of the triggers for ME/CFS, we do know that viral illnesses are implicated for about 70% of those diagnosed, while accidents and damage to the spine or central nervous system and drug/chemical exposures are other likely causes. For most people, ME/CFS illness begins with severe physical fatigue. People may sleep for hours or days upon time, but mostly in the early stages. People with ME/CFS find even the smallest physical activity exhausting and painful. More symptoms begin to emerge.

## SYMPTOMS:

**All of these key symptoms must be present before a diagnosis of ME/CFS can be considered:**

- **Fatigue:** Symptoms usually begin with new, significant, unexplained, and persistent fatigue that affects both physical and mental abilities. The fatigue can be so overwhelming that

performing the smallest task can lead to exhaustion. After the initial outbreak, the fatigue can ease over time or might come and go in cycles, but normal energy levels do not return.

- **Loss of Stamina and Muscle Strength:** Sometimes called “post-exertional malaise or fatigue”, this means that the slightest physical or mental activity might require a recovery period of 24-hours or longer. There is pain or fatigue that is out of proportion with the activity; recovery from a simple walk can feel like recovery from a marathon.
- **Sleep Dysfunction:** The amount of sleep is disturbed and the quality is unrefreshing. Studies clearly show brain wave changes that disrupt the key levels of deep sleep, and sometimes reverse the sleep rhythm so nighttime sleeping is difficult and people are sleepy throughout the day.
- **Pain:** There is significant pain that affects muscles and joints, is often widespread throughout the body, and can change location over time. People with ME/CFS develop headaches that can be regular and severe.

### **Several of these key symptoms must also be present:**

- ME/CFS affects the immune system, with swollen glands, recurrent sore throat and a constant flu-like feeling.
- Loss of appetite or unexplained weight loss, especially in the early stages.
- Inability to concentrate or confusion with mental tasks. There may be short-term memory loss, and difficulties processing information or word retrieval. People with ME/CFS often call this “brain fog”.
- An inability to focus the eyes. There is extreme sensitivity to lights and noise.
- Disorientation, including spatial disorientation may occur. There may be problems with motor coordination, balance or walking.
- Paleness, dizziness and even a feeling of fainting when standing can occur together. Young people are more likely to faint. The heart rate can rise dramatically from walking. People can feel extreme fatigue from standing or even sitting for long periods without lying down or changing position. People with M.E. cannot undergo stress tests as even a small increase in the heart rate can cause problems with blood pressure, dizziness and other symptoms.
- Heart problems may develop, including significant heart rhythm changes (arrhythmias).
- Many are also diagnosed with irritable bowel syndrome. People experience abnormal nausea, bowel or bladder problems, bloating and diarrhea.
- Loss of temperature control may occur, leading to some of these symptoms: extremely low body temperature, especially with activity; feelings of feverishness; cold legs, feet and hands; sweating, especially regular night sweats or other changes while asleep.
- Over time, people can develop new “allergic-like” reactions to foods, fragrances, chemicals, medications they used to tolerate and to fragrances and chemicals in their environment. This is often known as Multiple Chemical Sensitivities, although many people with MCS do not have ME/CFS
- Even as people start to recover, any new illness or increase of activity can cause “crashes” and a relapse of symptoms. Regular “pacing” of activities with slow increases over many months or years may be necessary for even partial recovery.

***THERE IS CURRENTLY NO KNOWN CURE FOR ME/CFS  
but NEW RESEARCH, EARLY DIAGNOSIS, TREATMENT OF SYMPTOMS  
AND FOLLOWING GUIDELINES FOR PACING DOES MAKE A DIFFERENCE***

We can help. Contact the MEAO Info Line for more information.

Disclaimer: Our organization has reviewed reliable information in preparing this document but medical information is constantly changing. We urge you to review our materials with a qualified health care provider.