

# WHAT IS MYALGIC ENCEPHALOMYELITIS

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## **What is Myalgic Encephalomyelitis**

Myalgic Encephalomyelitis (ME), commonly known as Chronic Fatigue Syndrome (CFS) or Chronic Fatigue Immune Dysfunction Syndrome (CFIDS), is a chronic, debilitating condition characterized by disabling levels of fatigue, myalgia (pain), and neurocognitive disturbances.

Although there are no known causes or cures for this disease, it is a universally recognized illness which seriously disrupts the lives of people around the world. As the U.S. Assistant Secretary for Health Dr. P. R. Lee has stated:

“Although we have not yet been able to fully describe the basis for ME, nor do we fully understand the mechanisms of ME, it is very real and it is not the figment of anyone’s imagination. ME is devastating to many who have it.”

### **Living with ME is like...**

People with ME describe the perplexing symptoms they experience in a variety of ways. Some people describe their newly acquired hypersensitivity to noise as sound physically hitting their ear drums literally like a fist. Others can no longer filter out background noise from foreground conversation or sounds. It forces them to strain themselves to concentrate on focusing on the sounds they want to hear. The efforts to attempt this can be extremely exhausting.

For some, it feels like they are walking around with a lead apron (the kind used for dental X-rays), or that they have ankle and wrist weights on all the time. For others, climbing the stairs or walking a short distance can seem overwhelming. While most people do these activities without a thought, people with ME may have so much muscle pain or weakness at times that it seems like they have to consciously tell their legs to move with each step.

Some people with ME will not remember having eaten half an hour before; others may not be able to recall names of people they’ve known well for a long time. Some may confuse which traffic light they are suppose to follow and will go through a red light at their intersection because a light at an intersection farther up the street has turned green. Many people will mix up letters within words and words within sentences. Some who used to be able to read complicated research papers and great literary works before they became ill with ME can’t even comprehend things written for young children.

Some cannot walk for more than 10 minutes before they feel like they will collapse from weakness and nausea. Some may not be able to get out of bed for days. The simplest of tasks, like washing a dish, can feel like the straw that will break the camel’s back. Yet at other times, doing the dishes poses no problem. Others may feel depressed at times, but when, after a nap those depressed feelings have disappeared, they realize it was their fatigue “talking”. The unpredictable fluctuation of symptoms is not only frustrating, but completely baffling to people with ME and those who observe them. At times, such ridiculous, but very real symptoms can make people (both those with ME and others) wonder if they aren’t crazy.

## **Who and how many people ME affects in B.C.**

This complex of bizarre symptoms which makes up ME affects thousands of B.C. residents of all ages with devastating results. ME strikes people from all walks of life: (children, teachers, nurses, doctors, lawyers, actors, musicians, athletes) and affects people from diverse ethnic/race, educational and socio-economic backgrounds.

There have been reports of cluster outbreaks of ME in communities, within families or groups of people who work together in various parts of the world. Some studies indicate that 1% of nurses become ill with ME. Epidemiological studies on the prevalence of ME in the general population vary in their estimates from less than 1 in 1,000 people to 1 or 2 out of every 100 people having ME. A number of recent studies using different methods to gather data concur that the estimates more likely range between 0.2% to 0.42% of the general population.

Applied to B.C.'s population of 4,072,500 in October, 2000, this means that anywhere from 8,000 to 17,000+ British Columbians suffer from ME. In any case, there are few people today who do not know at least one person who has ME.

When one considers that ME doesn't just affect individuals, but also their families, one realizes a lot of people are affected. Businesses and community groups often lose the assistance of very talented and dedicated people who are hit with ME.

## **Duration and Effects**

While many people today commonly complain of fatigue, they are still able to function at work, at home, and in the community. Those with ME, however, suffer from debilitating fatigue and other severe symptoms which make regular employment or daily functioning impossible. Social activities and school work are seriously interrupted for children and youth affected by ME.

ME usually begins with a flu-like occurrence which never ends. Very few people fully recover; most partially recover with symptoms waxing and waning. Because ME so radically affects people's abilities to function in daily life, and because there are no known causes or cures to date, others have a hard time understanding the symptoms those with ME are suffering. It is, in a sense, an invisible disability.

## **Symptomology**

The name Myalgic Encephalomyelitis is used world-wide and indicates a disease affecting the muscles, brain and nervous system (among other functions such as the immune system).

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|-----------|---|--------------|
| Myalgia   | = | Muscle Pain  |
| Encephalo | = | Brain        |
| Myelot    | = | Spinal Cord  |
| Itis      | = | Inflammation |

CFS and CFIDS are the abbreviations used in the U.S. for Chronic Fatigue Immune Dysfunction Syndrome. The difficulty with the term Chronic Fatigue Syndrome is that it doesn't capture the extent of this disabling disease. Chronic fatigue is but one of the symptoms of this syndrome.

Another difficulty with the CFS label is that many people in the "rat race" of modern life think they are always tired or chronically fatigued, yet they are able to push through long commutes to work and through responsibilities at home and in the community on a daily basis. Thus, healthy people have trouble understanding that ME isn't simple exhaustion or tiredness that can be overcome by a good night's sleep or by pushing one's self to do things.

In fact, unrefreshing sleep is one of the symptoms in people who have ME. The fatigue people with ME experience is severe and debilitating. Other chronic, fluctuating symptoms, which vary from person to person, can include:

- flu-like symptoms
- low grade fevers / night sweats
- insomnia / sleep disorder
- muscle pains / spasms
- severe, sudden muscle weakness
- short-term memory loss
- difficulty reading / calculating
- spatial / time disorientation
- speech difficulties (mix up words)
- hot burning skin / prickles
- shortness of breath
- chest pains / palpitations
- headaches / migraines
- heightened sensitivity to light, sound, heat/cold, odors, and allergens
- hypersensitivity to electromagnetic radiation and to + and - emotional stimuli
- chronic sore throat
- easily chilled
- tinnitus (ringing in ears)
- joint pain
- visual disturbances
- brain "fog" / slowed thinking
- difficulty concentrating
- impaired balance / coordination
- gastrointestinal problems
- tingling or numbness
- dizziness / feeling faint
- anxiety attacks
- profound, unending fatigue

### **Criteria for Diagnosis**

In 1994, the Centers for Disease Control in the United States revised its original 1988 case definition for CFS. The criteria for diagnosis is as follows:

The Centers for Disease Control (1994)

Case Definition of Chronic Fatigue Syndrome

A case of the chronic fatigue syndrome is defined by the presence of the following:

1. Clinically evaluated, unexplained, persistent or relapsing chronic fatigue
  - that is of new or definite onset (has not been lifelong)
  - is not the result of ongoing exertion;
  - is not substantially alleviated by rest;
  - and results in substantial reduction in previous levels of occupational, educational, social or personal activities; and

2. The concurrent occurrence of four or more of the following symptoms all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue:

- self-reported impairment in short-term memory or concentration
- severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities;
- sore throat;
- tender cervical or auxiliary lymph nodes;
- muscle pain;
- multijoint pain without joint swelling or redness
- headaches of a new type, pattern, or severity;
- unrefreshing sleep;
- post-exertional malaise lasting more than 24 hours.

### **Possible Triggers, Symptom Patterns, and “Cures”**

Because each person’s experience with ME is unique, individuals exhibit different symptoms in varying intensities. Also, symptoms often fluctuate for no apparent reason and with no easily identifiable patterns. Symptoms can change over time. They can expand and become more complex and severe, while others may diminish or disappear.

Each individual with ME has a unique combination of triggers which may have either led to the illness and/or which can make symptoms worse once a person has ME. Triggers can include:

- exposure to viruses, bacteria, fungi, molds and yeast infections
- exposure to agricultural and industrial chemicals;
- chemicals in paint, rugs, clothing, and cleaning products;
- chemicals in foods: additives, preservatives, food colouring;
- air “fresheners” (including plug-ins), perfumes, deodorants, gas fumes, cigarette smoke;
- odors from fabric softeners, laundry detergents, and anti-static cling dryer sheets which remain in clothes after washing and drying;
- mercury amalgam fillings and drugs;
- stress; a demand to process information within time limits;
- dealing with loss of income, career, sense of productivity and purpose;
- a lack of understanding and support;
- a noisy, bustling environment and a lot of visual motion;
- insomnia and pain (becoming a downward cycle of inability to function).

Some people with ME are severely handicapped, while others are a little more functional at various, though unpredictable, times. After extended periods of rest, people with ME can re-emerge into social activities and look and function fairly well, but only for limited periods of time. (This seeming appearance of health at times contributes to people underestimating the overall severity of symptoms.)

## **Some analogies**

### **Low energy reserves**

It is difficult for some to understand the fluctuating energy levels associated with ME. But it helps to understand energy levels in ME in terms of bank savings and spending. While a person with ME may be able to attend a concert like anyone else, that effort may drastically deplete their energy reserve for a while.

It's like they could afford the \$50 ticket, same as a millionaire, but once that \$50 is spent, they have nothing or little left for anything else, whereas the millionaire can keep on spending with no serious consequences.

Likewise, a person with ME may appear to have the same amount of energy in a given situation as a healthy person, but that doesn't mean they can sustain similar levels of activity over time as a healthy person can. And it may take a long time for their energy reserve, like a bank account, to build up again to allow them another activity "spree".

### **Absurd Assumptions**

Not understanding this principle of inconsistent energy levels, many doctors and psychologists who assess people with ME assume that if they show any evidence of being able to do any little thing they therefore can work full-time! So if a person with ME drives to an appointment, doctors may assume they can drive everyday and in all conditions. They don't understand that the drive and the appointment may wipe the person out for days afterwards.

Making these kinds of assumptions is as absurd as seeing a person dashing for half a block to catch a bus and assuming they can therefore also run a marathon! To avoid jumping to similar absurd conclusions, doctors need to carefully ask people with ME about their energy limits; e.g., how often they can drive a car and in what conditions and at what subsequent energy and pain costs to themselves!

### **MS similarities to ME**

These kinds of unexamined biases by doctors and others are also experienced by people with MS. At times they may be able to function fairly well, but may "crash" for days, weeks, or months afterwards. The only difference is that MS has become a recognized, accepted, "legitimate" illness with proven diagnostic tests, whereas ME hasn't fully reached that status--yet.

But there are some other similarities people with ME share with those who have MS. For a long time, MS wasn't considered a "real" disease, as is often the case now with ME. Also, the range of disability in people with ME is similar to the ranges evident in people with MS. The similarities in symptoms are striking enough that people with ME are sometimes misdiagnosed with MS, and

vice versa. As with MS, some recover, while most do not; and some have remitting/relapsing conditions (often dependent on activity levels) and others get progressively worse.

### **No universal cures**

There are no cures that work for everyone with ME. Drugs, natural remedies, and various treatments often help, but only for limited periods of time. But there are some people who have recovered or improved significantly:

- after changing their diet (such as avoiding carbohydrates or food allergies);
- after chiari surgery (where constriction at the base of the brain is evident);
- by taking certain medications, including anti-viral drugs and very low doses of anti-depressant (anti-inflammatory) drugs;
- from herbal parasite cleanses or by taking herbal or nutritional supplements;
- following removal of dental amalgams, metal crowns and/or root canals;
- after ozone therapy to the blood or following blood electrification treatments;
- unexpectedly after a blood transfusion for unrelated surgery;
- through progressively longer and colder baths;
- through prayer (though rarely instantaneously).

While these methods have helped some, most people with ME have experienced no lasting improvements using the same methods, and some have actually gotten worse in the process.

Further anecdotal evidence suggests that people who immediately go on a program of aggressive rest and are taken care of by others when they first get symptoms of ME, and who stay on such a program for 6 to 18 months, have greater incidences of a full recovery. However, those people who, upon experiencing ME symptoms, continue to push themselves in a feeble attempt to function as they once were able to, rarely recover significantly enough to ever resume normal functioning.

### **Research**

As it eventually did with MS, scientific research is finally giving legitimacy to ME being a physiological disease. There is evidence that oxygen delivery in the blood is severely affected, and some tests have shown that there has been viral damage to the heart or a constriction at the base of the brain.

While ME symptoms resemble those with autoimmune diseases like fibromyalgia, post-polio virus, mononucleosis, and MS, numerous research studies have clearly shown that there are quite distinct biological markers affecting those with ME that significantly differ from those with other autoimmune diseases.

There are also biochemical and other physiological markers which distinguish ME from other diseases which feature fatigue as a symptom and--most importantly in this regard--which distinguish those with ME from those suffering from depression.

## **Financial and quality of life implications**

This latter finding is crucial to those suffering from ME. Doctors often misdiagnose the syndrome as depression, and insurance companies more often than not disallow legitimate ME claims based on doctors diagnosing ME as an emotional disturbance or as malingering. Because so many claimants are denied disability coverage from their unions or insurance carriers, they are forced to go on welfare, provincial disability and/or CPP. Most do not have the energy or financial resources to fight their insurers in court.

As a result of their symptoms, people with ME as a rule experience:

- job loss, loss of their savings and homes;
- poverty which results in difficulties in affording proper housing, treatments, groceries, social and recreational activities, transportation, home care, etc.;
- reduced mobility with impact to grocery shopping, medical visits, etc.;
- that the simplest of tasks become mountains to climb;
- an inability to sufficiently take care of basic chores of cooking and cleaning;
- a high risk of infection due to a compromised immune system which means having to avoid public gatherings and air conditioned buildings and airlines;
- a heightened sensitivity to sensory stimuli which means reducing noise and visual stimuli--silence is often required in one's home (little radio, stereo or TV); also public events, busy malls and traffic areas are generally avoided;
- a hypersensitivity to electromagnetic radiation which means time spent working on computers or watching TV is limited or impossible;
- chemical sensitivities and an intolerance to a wide range of common substances also means less social contact due to perfumes, smoke, gas fumes, etc., which means former levels of participation in community and cultural events are restricted;
- difficulty concentrating and processing (new) information means cognitive tasks suffer;
- hence, an inability to respond to urgent financial, legal and medical matters in a timely manner, resulting in even more stress;
- a hypersensitivity to stress and emotional "fields" so that conflict or even lively parties adversely affect the nervous system, requiring people to limit social contact;
- increased difficulties communicating, relating to others and defending or promoting one's self in terms of one's disabilities, worth, dignity and needs.

These consequences of having ME result in social isolation and having to cope with loneliness. This sense of isolation is compounded by the misunderstandings of doctors, psychologists, family, friends and colleagues. Many people with ME experience divorce as well as alienation from friends, family, and former colleagues who have difficulty fathoming the validity of this bewildering condition.

All these consequences of having ME can lead to bouts of anxiety, despair, and reactive depressions and, in some cases, suicide. Given the seriousness of these situations and the growing number of people with ME having to go on government assistance, ME is rapidly becoming a serious public health concern.

## **Coping with ME**

There are several things people with ME can do to help them cope with their condition.

Learn as much as you can about ME. This web site with its links to other sites can provide much useful information. Your library may have helpful materials. If it is hard for you to use a computer or get to a library, ask a friend to help. Support groups are also a good source of information (as well as important validation).

Try to pace and not over-commit yourself. Listen to what your body tells you it can and cannot do. Try varying activities, and do them for shorter periods and with frequent breaks, so that you don't overtax any one bodily system.

When possible, avoid situations which make you feel worse. Walk away from arguments and situations that are stressful. Rebalance with positive and nurturing activities.

Keep a journal of your symptoms, activities, feelings and medical history (e.g., appointments and tests). Record what makes you feel better and when you feel worse. This will help monitor the disease's course for yourself, your doctor(s), your disability insurance company and your lawyer. It will also provide you with a more objective record of your capabilities and limitations than your poor short-term memory can try to accurately recall.

Find an understanding physician for diagnosis and ongoing treatment. Make sure your doctor believes ME is a valid, physiological illness (albeit with social, economic and psychological consequences). Ask what they know about ME. How willing are they to learn more? (Are they willing to read relevant research articles you may find?). Are they open to alternative medicine treatments that seem to help others? Make sure your doctor thoroughly investigates any new symptoms to exclude other illnesses.

Find people who are willing to listen to, and affirm, you. Explain that you don't want to just talk about symptoms, but that you want to share your continuing or new interests as well. Be sure to listen to their 'stories' as well. Make it clear that you may not be able to carry on conversations for as long as you once might have. Set limits. Don't waste your energy on people who don't want to be convinced. They may be afraid that if this could happen to you it could happen to them, so they'd rather disassociate themselves from you so they don't have to think about that frightening possibility.

Join a local ME support group. Groups can help you and your family and friends understand, affirm and cope with what you are going through, and they can provide an outlet for concerns and fears. They also are a valuable source of information, including who the good local doctors and lawyers are and how to deal with insurance companies. Challenge yourself and your group to be solution-focused to avoid being overwhelmed by ME.

Find out who's willing to help. Ask. Be specific. Don't expect one person to do everything. Perhaps a neighbour will help take care of your garden, a family member might do some grocery shopping, a friend may vacuum for you. Schedule and spread the tasks out over time and among

several people. Find out if local community or religious service organizations help in these ways. If you're on BC Disability, ask your worker what services and 'breaks' are available; they may not volunteer that information on their own.

Find activities that are less demanding than you used to be able to do, but which are still enjoyable and give you a sense of involvement and purpose. If you can no longer read novels, e.g., try reading children's books. Since you likely can't jog or hike, try short walks with breaks or gentle exercises like yoga. Remember, little acts of kindness you do for someone else can go just as far in giving you a sense of joy and purpose as some mega project!

Do something good for yourself each day. Affirm the things you still can do and the positive steps, learning and attitude you take. Use your down times to create good things in your imagination. Befriend yourself.

### **Learning to value yourself and others regardless of illness**

There is no doubt for anyone who has ME that it is a debilitating, and often devastating, illness. Besides the loss of ability come many other losses that must be grieved and dealt with: loss of economic resources, loss of supportive friends and family; loss of self-esteem and meaning. The stress of being misunderstood and maligned is hard to bear. Feeling anxious, angry and despondent are normal reactions, and require the support of others to work through them.

But there can be good learning from all this: learning that worth doesn't need to rely on how much you can produce; learning that there are people who have compassion; learning that the world can still hold beauty despite the pain; learning to slow down and taking time to smell the roses; learning to let go of compulsions to succeed, to prove, to be approved of, in order to just be, and finding that new life, creative forces, and community can arise from that being.

### **MEBC Society**

MEBC is a charitable organization in the province of British Columbia, Canada which is devoted to helping people with ME (and their families, friends and doctors), those with Fibromyalgia (FM), as well as those with related Environmental Illnesses (EI) such as Multiple Chemical Sensitivity (MCS), and Gulf War Syndrome (GWS).

Further details regarding this organization can be found elsewhere on this web site, including information on support groups in B.C. and how volunteers can help the Society to achieve its various goals which include offering practical support, advancing awareness of this disease to the public, governments and the medical community, and raising vital funds to accomplish these goals.