MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME

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What is ME/CFS?

Imagine a flu that simply refuses to go away. Your body aches. Your mind is foggy, your arms seem to weigh two hundred pounds. You're exhausted, but you can't seem to fall asleep. When you do sleep, you wake up no more rested than before. A shower is an ordeal, fixing breakfast a marathon.

Such is life for people with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome. ME/CFS is a complex physical illness. It is characterized by debilitating fatigue, post-exertional malaise, pain, cognitive problems, sleep dysfunction and an array of other immune, endocrine, neurological and autonomic symptoms.

Who Can Get ME/CFS?

People of all ages and both genders suffer from ME/CFS. It is more common in women. Men get it. Children get it. It occurs across all ethnic and socioeconomic groups. Most people who contract ME/CFS led healthy and active lifestyles before they became ill.

According to the Canadian Community Health Survey of 2010, more than 411,000 Canadians have been diagnosed with ME/CFS. The illness is still not well known but this is changing.

What Causes ME/CFS?

The exact cause of ME/CFS is currently unknown. It may result from a combination of factors including genetic predisposition. While it often appears to be triggered by a viral infection, like the flu, there are many other potential triggers including bacteria, parasites, immunization, trauma or environmental toxins. In some people, onset is gradual with no known triggering event.

Is There A Cure?

At present there is no cure for ME/CFS. Research is being done in many areas including the study of pathogens, immune system abnormalities, genetics and disruptions at the cellular level. Scientists have gained a better understanding of how ME/CFS affects the body. Researchers are working on developing diagnostic tests and on studying the effectiveness of different treatments.

How is ME/CFS Diagnosed?

Each of the following criteria is needed for a diagnosis. Criteria must have persisted for 6 months, 3 in children.

1. Debilitating Fatigue: unexplained, persistent, or recurrent physical and/or mental fatigue that reduces activity levels

2. Post-Exertional Malaise and/or Fatigue: Mild exertion (physical or mental) is followed by a worsening of symptoms such as fatigue and pain. Onset may be delayed and recovery is slow.

3. Sleep Dysfunction: Sleep is unrefreshing. There may be disturbance in sleep quantity or rhythm including daytime hypersomnia or nighttime insomnia.

4. Pain: Pain can be experienced in the muscles and/or joints and is often widespread and migratory in nature. Often there are significant headaches.

*5. Neurological / Cognitive Impairment: (must have 2 or more symptoms)** Symptoms include (but are not limited to) short-term memory loss, poor concentration, disorientation, sensory disturbances (sight, sound, touch), balance problems, muscle weakness.

*6. Autonomic / Neuroendocrine / Immune Manifestations: (at least one symptom from two of these three categories)** Symptoms include light-headedness, cardiac arrhythmias, irritable bowel symptoms, low body temperature, weight change, reduced tolerance for stress, tender lymph nodes, recurrent sore throat, general malaise, food sensitivities.

Other illnesses must be excluded. Testing should be done to rule out other major illnesses while recognizing that co-existing conditions are possible.

* Refer to publication no. 1 on the back for a more complete list of symptoms.

Treatment / Management

Symptoms as well as "functional capacity" vary widely among ME/CFS patients. There are some who are bedridden, some who can function at a limited level and some who can work part or full time but have limited activities beyond work.

If you believe you have ME/CFS, you should discuss your symptoms with your doctor. It may be helpful to take medications to treat symptoms such as pain, sleep dysfunction, low blood pressure, anxiety ... etc. Consider including a naturopathic doctor as part of your health care team.

Managing your illness will mean lifestyle adjustments. The good news is that, with careful management, most people will see improvements in symptom severity, functional capacity and quality of life.

Improving Sleep

Even small improvements in sleep will help. Try to find techniques that will improve sleep time and quality. Establish a routine; create a quiet environment; avoid getting overtired; try herbal remedies. Many find it helpful to take medication to assist sleep. It may be helpful to consult a sleep specialist.

Managing Your "Energy Envelope" / Pacing

All ME/CFS patients are familiar with the "push" and "crash" cycle. You feel good so you try to resume normal activities, you overexert yourself, your symptoms return, you're exhausted, you crash. It takes a long time to recover.

Living within your "energy envelope" - the optimal zone of activity - means being as active as you are able without exceeding the limits that trigger your symptoms.

Pacing involves careful observation of your energy limits, what time of day you function best, what activities trigger your symptoms. You will need to pre-plan your day. Decide how many hours in a day you can function. Break up tasks, take rests, alternate between mental and physical activities, stop activities before you are tired. Learn to delegate.

Energy is not only physical, it is expended for mental and emotional events as well. By managing your physical, mental and emotional energies and living within your energy envelope you can reduce symptoms, gain stability and gradually increase functionality.

Nutrition

It can be difficult to prepare meals when dealing with limited energy but a good balanced diet is essential. Do not forget to eat as your body needs fuel to function. Many ME/CFS patients suffer from food sensitivities. Patients get symptom relief when they eliminate offending foods from their diet. It will require trial and error to find which foods bother you but some common sensitivities include wheat, dairy, corn and refined sugar.

Mind and Body

As in any illness, it is important to understand there is a connection between the mind and the body. While they will not cure ME/CFS, many therapies are available that help to reduce stress, induce relaxation, generate positive thinking and gain a sense of control. Before starting any therapy ensure your therapist fully understands that your illness is real and serious and that they are using a collaborative approach.

You may benefit from activities such as meditation, breathing exercises and restorative yoga or from therapeutic activities such as writing and art.

Exercise / Physical Activities

Research suggests exercise or physical activity is not tolerated well by those with ME/CFS because the aerobic (long-term) energy system is impaired.

Be as active as you are able but understand this differs for everyone. For some, simple daily activities like making a meal will exceed their physical capacity. For others, short term physical activities may be tolerated as long as there is a significant rest period after each.

A heart rate monitor may help ensure you do not exceed your capacity. Walking short distances several times can be better than one long walk. Even if you are severely ill, you may benefit from some assisted range of motion and strengthening exercises.

Some points to remember:

- Start low, go slow, take breaks
- Be very careful not to aggravate symptoms
- Know your limits and stop before you reach them
- Be realistic. Your goals will be different than before you became ill.

Get Support

One of the biggest challenges people with ME/CFS face is a lack of understanding from friends, family and even the medical community. ME/CFS can be very isolating and people with it may feel they are alone.

- It is important that friends, family, colleagues and caregivers are understanding and supportive. They too can become knowledgeable about ME/CFS.
- Look for and join a support group in your area or online.

THE NATIONAL ME/FM ACTION NETWORK

is a Canadian, registered, nonprofit organization dedicated to advancing the recognition and understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia through education, support and research.

The network celebrated its 20th anniversary in 2013. By becoming a member, you can stay up to date on news and events while supporting our efforts.

View these publications on our website:

1. **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document.** *Carruthers BM & van de Sande MI. 2005/2006.*
2. **Chronic Fatigue Syndrome Myalgic Encephalomyelitis A Primer for Clinical Practitioners.** ***IACFS/ME 2012***
3. **TEACH-ME A Sourcebook for Teachers of Young People With Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS) .** *Bell DS, Carruthers BM and the TEACH-ME Task Force. 2nd Edition 2005*
4. **Canada Pension Plan Disability Application & Appeals Guide for Canadians with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS).** *Neilson LE, Parlor M, Wodak J. 2012*

Other Recommended Reading:

Bested AC, Logan AC, Howe R. **Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia.** *2nd ed. Cumberland House 2008*

Stein E. **Let Your Light Shine Through.** *Stein 2012*
Available at http://EleanorSteinMD.ca