

"We've documented, as have others, that the level of impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well-known very severe medical conditions."

Dr. William Reeves, Chief of Chronic Viral Diseases Branch - CDC

#### What is ME?

• Myalgic Encephalomyelitis, or Chronic Fatigue Syndrome (ME/CFS) is a neurological disease that affects multiple systems in the body: muscles, brain and central nervous system, endocrine system, autonomic system, and immune system. Exciting new research into viruses known as MLV and XMRV may lead to new diagnostic criteria and possibly even treatments in the next few years.

#### What is FM?

• Fibromyalgia (FM) is a chronic pain condition involving areas of the body with increased sensitivity to pressure along with other severe symptoms such as fatigue, irritable bowel and bladder, cognitive and memory dysfunction, to name a few. FM patients also suffer from non-restorative sleep and thus awaken unrefreshed with potentially stiffened and painful muscles.

#### What is MCS?

- Multiple Chemical Sensitivities (MCS) or Environmental Sensitivities (ES) occur when people become sensitive to substances or phenomena in their everyday environment at levels well below what "normal" people would consider acceptable. Sensitivity reactions can be triggered by scented products, detergents, paints, cigarette smoke, pets, plants, foods, etc. Multiple organ systems are affected, and usually neurological impairments are experienced along with runny eyes and nose, headaches, fatigue, pain, breathing, and digestive problems. They can be overwhelming and result in social isolation.
- Over 440,000 Ontarians suffer from ME, FM and/or MCS (Canadian Community Health Survey, 2005). Most are unable to work, attend school, or engage in even the simplest day-to-day tasks or social activities for months or years on end, some for the rest of their lives. Those that do recover take an average of 7 years.
- ME, FM and MCS are sometimes grouped together for treatment since patients have many symptoms in common. The MEAO likewise is providing services to all three illness communities.
- These diseases are found throughout the world and affect people of all races, backgrounds, income levels, etc. It is common for neurological diseases to show marked sex differences, and for these illnesses there is a strong sex difference with more females affected than males. The first outbreak usually occurs in teens and young adults. Most current patients are now in their forties or fifties, having been ill for 10-25 years.
- It is believed that ME is caused primarily by a triggering infection, or is otherwise triggered by an accident or injury that damaged the brain and central nervous system. FM is believed to be triggered by central nervous system damage or brain injury caused by physical trauma or infection.

- Most people with these illnesses never fully recover. Some of those who are chronically ill will experience unrelenting symptoms and be housebound for years. Most patients describe a Relapsing and Remitting pattern, not unlike Multiple Sclerosis, with serious disability still present even during the "remitting" periods. The quote above by the Chief of the CDC indicates the severity of ME.
- Canadian researchers and clinicians have been some of the lead experts in creating the diagnostic criteria for ME, FM and MCS and our diagnostic manuals are known worldwide as the "Canadian Consensus Documents". Ironically, Canada spends less money, per capita, on these illnesses than most other industrialized nations.

## A Brief Description of ME Symptoms

from "A Clinical Case Definition and Guidelines for Medical Practitioners: An Overview of the Canadian Consensus Document". Edited by Carruthers and Van de Sande.

1. The illness must persist for at least 6 months. All of the first group of symptoms must be present.

**FATIGUE:** The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

## **POST-EXERTIONAL** MALAISE AND/OR

**FATIGUE:** There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period – usually 24 hours or longer.

#### **SLEEP DYSFUNCTION:**

There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

**PAIN:** There is a significant degree of myalgia. Pain can

be experienced in the muscles and/or joints, and is often widespread and migratory in nature. The pain may also have neuralgic qualities. Often there are significant headaches of new type, pattern or severity.

## 2. Neurological/Cognitive Manifestations (two or more of the following will be present).

confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances – e.g. spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory, e.g. photophobia and hypersensitivity to noise.

3. At least one symptom from two of the following categories will be present.

# a) AUTONOMIC **MANIFESTATIONS:**

orthostatic intolerance –

neurally mediated hypotension, postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; lightheadedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.

## b) NEUROENDOCRINE **MANIFESTATIONS:** loss

of thermostatic stability – subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities: intolerance of extremes of heat and cold; marked weight change anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress.

## c) IMMUNE **MANIFESTATIONS:**

tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise. new sensitivities to food, medications and/or chemicals