Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Patients' Pamphlet

What is ME/CFS?

ME/CFS is an acquired illness that affects all body systems; predominantly the neurological, endocrine and immune systems. It can be severely debilitating.

How is ME/CFS Classified in the World Health Organization's (WHO) International Classification of Diseases (ICD)?

In the WHO's ICD-10, published in 1992, Post-Viral Fatigue Syndrome was assigned the number G93.3 and classified as a disease of the nervous system. Benign myalgic encephalomyelitis is included in this category. Illnesses cannot be classified in more than one category, thus, ME/CFS cannot be classified under any category of illness other than a disease of the nervous system.

What Causes ME/CFS?

Most people led a healthy, active lifestyle before they became ill. In many cases a viral infection, such as a flu or upper respiratory infection, initiates ME/CFS. Instead of recovering from the "flu-like" illness, the patient's health continues to deteriorate and s/he develops the many symptoms of ME/CFS. Multiple factors that stress the neurological, immune and endocrine systems may be involved, including environmental pollutants, physical trauma, immunization, and anesthetics. On rare occasions ME/CFS has developed in less than a week following a blood transfusion.

How Common is ME/CFS?

The Statistics Canada Community Health Survey[i] indicated that the prevalence of adults diagnosed with Chronic Fatigue Syndrome in Canada was 341,126 in 2003. A large American study by L. Jason indicated that approximately 422 per 100,000, or 0.42%, of adults have ME/CFS, however, it is thought to be under-diagnosed. It is more common than AIDS (12 per 100,000), breast cancer (26 per 100,000), and lung cancer (33 per 100,000).

Who Gets ME/CFS?

ME/CFS affects all age groups, including children, all racial/ethnic groups, and all socioeconomic strata. As in many autoimmune illnesses, it is more common in females.

Why is ME/CFS More Common in Females?

This is not fully understood. However, circulatory factors may play a role. Females have a smaller heart and lower blood volume than males. Not only does a female of the same weight as a male have almost 20% less blood volume, but their capacity to produce red blood cells is also approximately 20% less than males. Red blood cells carry oxygen and nutrients to the tissues and pick up waste and toxins to be eliminated. Many pathogens cannot survive in an oxygen-rich environment. Thus, females have less blood volume to cope with pathogens and toxin. Beyond these gender differences, ME/CFS patients have a significantly reduced circulating blood volume.

How is ME/CFS Diagnosed?

The patient must meet all 7 criteria.

Clinical Definition of ME/CFS

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

2. 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.

3. Sleep Dysfunction: There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

4. 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.

5. Neurological / Cognitive Manifestations: **Two or more** of the following difficulties should 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 – and/or emotional overload, which may lead to "crash" periods and/or anxiety.

6. At Least One Symptom from Two of the Following Categories:

a) Autonomic Manifestations: orthostatic intolerance – neurally mediated hypotension, postural orthostatic tachycardia syndrome, delayed postural hypotension; light-headedness; 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.

7. The illness must persist for at least 6 months although a preliminary diagnosis may be made earlier.

Other illnesses will be excluded.

What is it Like to Have ME/CFS?

Have you ever had a flu so severe that you sleep all day and every time you try to get up, you are so weak you have an urgent need to lie down before you fall down? That is what the acute stage of ME/CFS is like, but it lasts for months or years. A simple activity such as taking a shower can be so exhausting that you have to go back to bed. Some wonder how it is possible for someone to sleep so much and still be exhausted. Research studies indicate that ME/CFS patients do not get into the deep stages of sleep, where the body restores itself. Some patients are so severely affected that they are bedridden for months or years and are dependent on others for their care. Others are housebound and may require a wheelchair for mobility.

In the chronic stage, the majority of patients have some periods of time during the day that they can function but not at the level that they did before they became ill. They may sleep a lot of the time, or have insomnia, and are usually exhausted. The smallest amount of physical or mental activity can cause flu-like symptoms, severe fatigue, and worsening of other symptoms. Cognitive difficulties become more pronounced – the patient's responses are slower, less coherent, more confused, and they have difficulty recalling information and words. Recovery from reactive symptoms can take a day, weeks, or more.

Patients face many physical, mental, educational, social, and emotional challenges, which also affect their family and work opportunities. One thing that makes ME/CFS so difficult to manage is that symptoms fluctuate from day to day and from hour to hour, even when the patient is able to do limited activity. Many remain too ill to work, while others with milder ME/CFS are able to work part-time. Children and youth may require special educational considerations or study at home, as they are able. Social activities may become severely reduced. It is important that the patient's meaningful others remain understanding and supportive.

How do ME/CFS Patients Respond to Exercise?

Even though post-exertional malaise/fatigue is a hallmark feature of ME/CFS, patients are often prescribed exercise without sufficient care.Research studies have confirmed that ME/CFS patients do not respond to exercise the same way healthy people do. Some examples are:

Response to Exercise	Healthy People	ME/CFS Patients
Sense of wellbeing	Invigorating, antidepressant effect	Malaise, fatigue, worsening of symptoms.
Resting heart rate	Normal	Elevated
Heart rate at maximum workload	Elevated	Reduced heart rate
Maximum oxygen uptake	Elevated	Approximately ½ of sedentary controls
Age-predicted target heart rate	Can achieve it	Can **NOT** achieve it
Heart functioning	Increased	Suboptimal
Cerebral blood flow	Increased	Decreased
Body temperature	Increased	Decreased
Respiration	Increased	Decreased
Cognitive processing	Normal, more alert	Impaired
Oxygen delivery to the muscles	Increased	Reduced
Gait Kinematics	Normal	Abnormalities
Recovery period	Short	Days or weeks

What Precautions Must be Taken Before Exercising?

- Medical management must be optimized.
- Total illness burden must be assessed.
- Risk factors and pain generators must be determined and addressed.
- The reality of biological dysfunctions and limitations must be acknowledged.
- Activity boundaries and fluctuations must be recognized and accommodated.
- The treating doctor knows the patient best and should direct and coordinate all rehabilitative efforts.
- All rehabilitation personnel must be knowledgeable about ME/CFS.

What is an Appropriate Exercise Program?

Exercise is not recommended for all patients.

- Exercise must be individualized.
- Begin at a comfortable level and progress slowly. Some patients can only begin with a few minutes.
- Patients must have autonomy over the intensity and pacing of the exercises.
- Start with stretching and gentle exercising.
- ME/CFS patients must NOT be pushed towards age-predicted heart rates. This is potentially DANGEROUS as the heart may be operating at a sub-optimal level and may not be able to accommodate the stress.

What Can I Do to Help Myself?

- **Education:** Become knowledgeable about ME/CFS.
- **Early warning signs:** Pay attention to how you feel, and take your temperature before and after an activity. If your temperature drops, you have done too much. Become aware of things that aggravate your symptoms, and how long you can do an activity.
- **Listen to your body and trust your feelings:** Pace your physical and mental activities; do what you can without aggravating your symptoms; stop before you “crash”, and rest when you need to.
- **Keep your body warm:** Your temperature is often below normal and fluctuates. When you are cold, take a warm shower, wrap yourself in warm blankets, and rest.

What is the Natural Course of ME/CFS?

Early diagnosis and treatment may lessen the severity of ME/CFS in some patients. Children have a much higher recovery rate than adults do. Usually there is a plateau between six months and six years. However, some improve while the health of others gradually deteriorates. Severe complications and other illnesses may also develop. Numerous studies indicate that fewer than 10% of adults fully recover**.**

Is There a Cure for ME/CFS?

Presently there is no known cure. However, there have been a number of exciting breakthroughs in research in the past few years. The discovery of a breakdown in one of the body’s antiviral defense pathways may lead to a laboratory test for ME/CFS. It is hoped that further research developing out of these findings will lead to improved treatment and a possible cure.

What are Some Areas of Research?

- **Neuropathy and brain imaging**: There is disruption in the communication between the brain and the other body systems. Abnormal levels of some of the body's chemical messengers have been found. There is significantly less blood flow and metabolism in parts of the brain. Small lesions have been found in the brain.
- **Neurocognitive dysfunction:** Research indicates brain dysfunction in many cognitive and verbal tasks.
- **Memory*:*** There is dysfunction in the part of the brain that regulates new memory production, so events may erroneously be thought to be new.
- **Sensory information** is mismanaged.
- **Autonomic nervous system:** There is dysfunction of the body's regulating and stabilizing systems.
- **Cardiac abnormalities:** A number of abnormalities have been found in the heart. There is also a marked reduction in the circulating blood volume. Many patients have neurally mediated hypotension or tachycardia.
- **Abnormalities in the immune system:** There is often significant activation of parts of the immune system. Poor cellular function with significant abnormal activity of the natural killer cells, that form part of the body's antiviral defense system, has been established.
- **Antiviral defense pathway:** There is dysfunction in an antiviral defense pathway. Some of the molecules are being abnormally cleaved. A test measuring the ratio between the normal weight molecules and the cleaved molecules can distinguish ME/CFS patients from healthy controls and FMS patients.
- **Infectious agents:** ME/CFS patients likely have many active infections but it has not been determined if they are a cause or a result of the immune dysfunction.

Reference:

1. Carruthers BM, Jain AK, De Meirleir KL, Peterson DL, klimas NG, Lerner AM, Bested AC, Flor-Henry P, Joshi P, Powles ACP, Sherkey JA, van de Sande MI.
   MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME: Clinical Working Case Definition, Diagnostic and Treatment Protocols. *Journal of Chronic Fatigue Syndrome* 11(1):7-116, 2003.
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   http://www.haworthpressinc.com/store/product.asp?sku=4958
2. Carruthers BM and van de Sande MI. **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document.** *Carruthers & van de Sande* 2005/2006.

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