

## *Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: A Pragmatic Approach*



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### *What is ME/CFS?*

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a common, highly disabling, and poorly understood condition affecting 411,500 Canadians 12 and over.<sup>1</sup> The diagnostic criteria require the concurrent presence of postexertional malaise lasting for more than 24-hours, unrefreshing sleep, pain, cognitive or mood symptoms, and two of the following: autonomic, endocrine and immune manifestations.<sup>2</sup> As these criteria are used worldwide, French, Spanish, Italian, German, and Dutch translations are also available.

### *What to do in the absence of RCTs?*

The treatments discussed in this paper have been developed empirically over decades and are widely used, symptomatic approaches for ME/CFS. Space constraints do not permit mention of all beneficial treatments. Due to the general lack of research on ME/CFS, these recommendations lack the rigorous RCT evidence that physicians usually rely on. In deciding whether to try new strategies, physicians must weigh the risks and benefits of the proposed strategy with the risks and benefits of “care as usual.” Research on “care as usual” for ME/CFS highlights lack of success.<sup>3</sup>

### *Emile's Case*

Emile is a 20 year old man who suddenly became ill at age 16 with Epstein-Barr Virus (EBV) infection. He never regained his health. He presents as a thin, pale young man with bags under the eyes. He complains of unrefreshing sleep, musculoskeletal pain, post exertional malaise, and flu like symptoms. Due to low energy and poor memory, Emile was unable to finish high school. He has attempted part-time work a couple of times, but each time his health worsened, and he had to quit. He lives at home and doesn't go out much. His medical and family histories are unremarkable. His family physician has ruled out other conditions and Emile's EBV serology is now negative.

### *1. Rule out treatable contributors to disease*

Many treatable conditions can be confused, or can occur co-morbidly, with ME/CFS, including some sleep disorders, major depressive disorder, celiac disease, some chronic infections, and some rheumatologic conditions. The following two conditions below should also be considered:

#### *Lyme Disease*

The validity of and correct treatment for chronic lyme disease continue to be debated. The symptoms of this syndrome — rash, migratory arthritis, chronic fatigue, neurological and cognitive symptoms, and sensory hypersensitivity — overlap with those of ME/CFS. Deer ticks infected



with *Borrelia burgdorferii*, the causative agent for Lyme disease, exist in every province in Canada.<sup>4</sup> Therefore, patients presenting with a ME/CFS profile who had an outdoor lifestyle or employment should be tested.

### *Toxic Mould*

The health symptoms caused by toxic mould growing in water damaged buildings can be similar to those of ME/CFS. These include skin and breathing problems, as well as autonomic, neurological, and cognitive symptoms.<sup>5</sup> People can become allergic to toxic mould as well as suffer from the effects of inhaled mycotoxins.<sup>6</sup> The mould should be removed. In the absence of visible mould, determining the toxic load in a residence or work place requires the services of a qualified air quality inspector or the use of the Environmental Relative Moldiness Index (ERMI), a new test that quantifies the DNA of mould species in house dust.

### *2. Symptom Management*

In the absence of an etiologically based curative treatment for ME/CFS, the treatment of choice is symptom management. This includes the use of medications and patient self-management (please see Resource). Several resources exist to assist physicians and patients with this, including the Canadian Consensus documents referenced above. An online self-management course developed by American psychologist Dr. Bruce Campbell is available at [www.cfidselfhelp.org](http://www.cfidselfhelp.org). A referenced manual written by this author (Dr. Eleanor Stein), outlining management strategies for ME/CFS and its commonly comorbid conditions, Fibromyalgia and Multiple Chemical Sensitivity is available in downloadable and paper versions through the website [www.eleanorstein-md.ca](http://www.eleanorstein-md.ca). Non-specific self-management groups for chronic illness exist in several locations in

Canada through public health services. Look for “Better Choices, Better Health” groups in your area.<sup>7</sup> The manual developed for these groups is available at booksellers.<sup>8</sup>

### *Some Other Suggestions:*

#### *3. High Dose B12*

High dose vitamin B12 has been used for ME/CFS since the 1950s. One theory is that B12 benefits people with ME/CFS due to its ability to scavenge nitric oxide, thereby decreasing oxidative pathways and causing oxidative damage.<sup>7</sup> Nitric oxide pathways and oxidative damage are known to be augmented in ME/CFS.<sup>9</sup> High dose B12 is taken by injection or nebulizer. The common dose is 10 mg/ml methyl or hydroxy B12, 1 ml two to three times weekly. Most patients can learn to safely administer their own injections. There does not appear to be any ill effect of the increased B12 level that occurs within the first few treatments. Side effects include occasional bruising or soreness at the injection site and the ever-present risk of infection if a sterile technique is not followed. Patients with low platelet levels should use a nebulizer instead of injections.

#### *Note Regarding Cyano B12*

Cyano B12, the commonly used form for repletion of low B12 levels should not be used at a high dosage. Cyano B12 does not increase energy and cognitive function unless there is a B12 deficiency. There is no evidence of such deficiency in patients with ME/CFS.

#### *4. Increasing Blood Volume*

ME/CFS is associated with decreased red blood cell mass, blood volume and symptoms of orthostatic intolerance.<sup>10,11</sup> If blood pressure is low

(below 110/70), heart rate is elevated, and clinical symptoms of orthostatic intolerance exist, increasing blood volume by salt and fluid loading may improve stamina and cognition. A much anticipated study of erythropoetin completed a few years ago failed to find benefit from using this approach. The cheaper and safer method of using oral salt is recommended. A typical dose of sea salt is one-fourth teaspoon up to four times daily plus drinking to satiate thirst. Noniodized salt should be used for this purpose. Patients should use the salt as a drug (*i.e.*, in regular measured amounts) and should measure BP at home to prevent overshooting.

## Back to Emile

Emile joined a self management group online and learned that others with his condition were making progress. He began to take a more active interest in his health. After finding his blood pressure to be below 100/60, his family physician recommended oral salt. Emile found that one-and-a-half teaspoons q.d. in divided doses improves his stamina and memory. B12 injections led to another increase in energy. Emile now feels well enough to plan one outing a week with friends (something sedentary like a movie) and is considering completing a high school course by correspondence. He is still severely disabled, but he feels hopeful for the first time in four years.

## Questions and Answers

### 1. How can I confidently diagnose ME/CFS?

Carefully read the Canadian Consensus document, and make sure the patient in question meets the criteria.

### 2. How do I rule out psychiatric conditions, such as depression?

Read the criteria for each condition and see which fits your patient best. Patients can have both ME/CFS and depression.

### 3. What if the above suggestions don't help?

Review the diagnosis and make sure it is accurate. The Canadian Consensus document for ME/CFS can be found at: [http://mefmaction.com/index.php?option=com\\_content&view=article&id=215&Itemid=262](http://mefmaction.com/index.php?option=com_content&view=article&id=215&Itemid=262) and the Physician's Primer published by the IACFS/ME, the international scientific body for ME/CFS can be found at: <http://www.iacfsme.org/Home/Primer/tabid/509/Default.aspx> both contain many more suggestions.



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## Resource

1. Canadian Consensus for the Diagnosis and Management of ME/CFS <http://www.mefmaction.com/images/stories/Medical/ME-CFS-Consensus-Documents.pdf> (Carruthers *et al.*, 2003). A shorter overview is available at: <http://www.mefmaction.com/images/stories/Overviews/ME-Overview.pdf>. Accessed: Friday, July 6, 2012.