

**CLINICAL WORKING CASE DEFINITION OF ME/CFS**

*A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine, and immune manifestations; and adhere to item 7.*

- \_\_\_ **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. 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<sup>1</sup> phenomena: cognitive, sensory – e.g. photophobia and hypersensitivity to noise - and/or emotional overload, which may lead to "crash"<sup>2</sup> periods and/or anxiety.
- \_\_\_ **6. At Least One Symptom from Two of the Following Categories:**
  - \_\_\_ **a. Autonomic Manifestations:** orthostatic intolerance - neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), 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 persists for at least six months:** It usually has a distinct onset, \*\*although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 & 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day. \*There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset. \*\*Some patients have been unhealthy for other reasons prior to the onset of ME/ CFS and lack detectable triggers at onset or have more gradual or insidious onset.

**Exclusions:** Exclude **active** disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction. It is essential to exclude certain diseases, which would be tragic to miss: Addison's disease, Cushing's Syndrome, hypothyroidism, hyperthyroidism, iron deficiency, other treatable forms of anemia, iron overload syndrome, diabetes mellitus, and cancer. It is also essential to exclude treatable sleep disorders such as upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus,

<sup>1</sup> "Overload" refers to hypersensitivities to stimuli that have changed from pre-illness status.

<sup>2</sup> "Crash" refers to a temporary period of immobilizing physical and /or cognitive fatigue.