

The Definition & History of Myalgic Encephalomyelitis (M.E.)

[LINK](#)

*This monograph was prepared for the Amsterdam M.E. Conference September 2015. It has not been adequately spell and grammar checked by my staff. For this I apologize to the readers. There are undoubtedly errors also in composition but the story is essentially valid, as is the much overlooked history Of Myalgic Encephalomyelitis.
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CANADIAN GUIDELINES EXTRACT

[Link to ME Society of America](#)

The Canadian Expert Consensus Panel has published a medical milestone, the first clinical case definition for the disease known as myalgic encephalomyelitis/chronic fatigue syndrome. This definition is clearly a vast improvement over the CDC's 1994 Fukuda criteria, which led to misunderstanding in both research and treatment modalities by making "fatigue" a compulsory symptom but by downplaying or making optional the disease's hallmark of post-exertional sickness and other cardinal ME/CFS symptoms. In sharp contrast to the Fukuda criteria, this new clinical case definition makes it compulsory that in order to be diagnosed with ME/CFS, a patient must become symptomatically ill after exercise and must also have neurological, neurocognitive, neuroendocrine, dysautonomic, and immune manifestations. In short, symptoms other than fatigue must be present for a patient to meet the criteria. This case definition, which incorporates some of the current research on dysautonomia, cardiac, and immune problems, was published in the Journal of Chronic Fatigue Syndrome, Vol. 11 (1) 2003.

To access this document, which includes the diagnostic and research-overview parts of the ME/CFS case definition in PDF format, [click here](#). PDF files require the use of an Adobe Acrobat Reader. If you do not already have one, it is available as a free download [here](#). For an HTML excerpt containing criticisms of Cognitive Behavior Therapy (CBT) and Graded Exercise Therapy (GET), [click here](#). The complete 109-page article "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols," J of Chronic Fatigue Syndrome, Vol. 11 (1) 2003, pp. 7-116, from which the above linked excerpt was taken, is available for a fee from the Haworth Document Delivery Service -- 1-800-HAWORTH. The complete article contains additional information on treatment protocols and disability issues, as well as the full references. The article can also be ordered on-line [here](#).

It is summarized as follows:

1. POST-EXERTIONAL MALAISE AND FATIGUE: There is a loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional fatigue, malaise and/or pain, and a tendency for other symptoms to worsen. A pathologically slow recovery period (it takes more than 24 hours to recover). Symptoms exacerbated by stress of any kind. Patient must have a marked degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level. [Editor's note: The M.E. Society prefers to use "delayed recovery of muscle function," weakness, and faintness rather

than “fatigue.” Further, we disagree that the muscle dysfunction is “unexplained.” See our M.E. Definitional Framework and researchers’ medical explanations on this website.]

2. SLEEP DISORDER: Unrefreshing sleep or poor sleep quality; rhythm disturbance.

3. PAIN: Arthralgia and/or myalgia without clinical evidence of inflammatory responses of joint swelling or redness. Pain can be experienced in the muscles, joints, or neck and is sometimes migratory in nature. Often, there are significant headaches of new type, pattern, or severity. [Editor’s note: neuropathy pain is a common symptom and should be added here as well.]

4. NEUROLOGICAL/COGNITIVE MANIFESTATIONS: Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, difficulty with information processing, categorizing, and word retrieval, intermittent dyslexia, perceptual/sensory disturbances, disorientation, and ataxia. There may be overload phenomena: informational, cognitive, and sensory overload -- e.g., photophobia and hypersensitivity to noise -- and/or emotional overload which may lead to relapses and/or anxiety.

5. AT LEAST ONE SYMPTOM OUT OF TWO OF THE FOLLOWING CATEGORIES:

AUTONOMIC MANIFESTATIONS: Orthostatic Intolerance: e.g., neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension, vertigo, light-headedness, extreme pallor, intestinal or bladder disturbances with or without irritable bowel syndrome (IBS) or bladder dysfunction, palpitations with or without cardiac arrhythmia, vasomotor instability, and respiratory irregularities. [Editor’s note: low plasma and/or erythrocyte volume should be added as another explanation for orthostatic intolerance in this disease. We also hold that more cardiac symptoms should be listed such as left-side chest aches and resting tachycardias, which, in addition to low blood volume, have also been documented in the research. The full text of the case definition does suggest 24-hour Holter monitoring, and when tachycardias with T-wave inversions or flattenings are present that they not be labeled as nonspecific since they aid in the diagnosis of ME/CFS. See the above link to access the diagnostic part of the document.]

NEUROENDOCRINE MANIFESTATIONS: loss of thermostatic stability, heat/cold intolerance, anorexia or abnormal appetite, marked weight change, hypoglycemia, loss of adaptability and tolerance for stress, worsening of symptoms with stress and slow recovery, and emotional lability.

IMMUNE MANIFESTATIONS: tender lymph nodes, sore throat, flu-like symptoms, general malaise, development of new allergies or changes in status of old ones, and hypersensitivity to medications and/or chemicals.

6. The illness persists for at least 6 months. It usually has an acute onset, but onset also may be gradual. Preliminary diagnosis may be possible earlier. The disturbances generally form symptom clusters that are often unique to a particular patient. The manifestations may fluctuate and change over time. Symptoms exacerbate with exertion or stress.

This summary is paraphrased from Dr. Kenny van DeMeirleir's book Chronic Fatigue Syndrome: A Biological Approach, February 2002, CRC Press, pg. 275. A few edits and

suggestions were added by the M.E. Society of America. As we have noted, the M.E. Society of America holds that this is the best case definition so far, although it is not perfect. Listing more cardiac and neurological symptoms (e.g., chest pain, left-side chest aches, tachycardia, and neuropathy pain), and emphasizing muscle weakness and faintness instead of “fatigue,” would have more accurately represented the symptomatology and vastly improved the criteria (please see our M.E. Definitional Framework on this website). Nevertheless, the Canadian Consensus Panel clinical case definition more accurately represents the experience and manifestations of the disease than other current case definitions. Again, for the 30-page diagnostic ME/CFS case definition [click here](#).

Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Panel

1. Dr. Bruce M. Carruthers, lead author of the consensus document; co-author of the draft of the original version of the ME/CFS clinical definition, diagnostic and treatment protocols document; internal medicine.
2. Dr. Anil Kumar Jain co-author of the draft the original version of the ME/CFS consensus document, affiliate of Ottawa Hospital, Ontario.
3. Dr. Kenny L. De Meirleir, Professor Physiology and Medicine, Vrije Universiteit Brussel, Brussels, Belgium; ME/CFS researcher and clinician; organizer of the World Congress on Chronic Fatigue Syndrome and Related Disorders; a board member of the American Association for Chronic Fatigue Syndrome; and co-editor of Chronic Fatigue Syndrome: Critical Reviews and Clinical Advances (Haworth)
4. Dr. Daniel L. Peterson, affiliate of the Sierra Internal Medicine Associates in Incline Village, Nevada; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the International Chronic Fatigue Syndrome Study Group
5. Dr. Nancy G. Klimas, Clinical Professor of Medicine in Microbiology/Immunology/Allergy and Psychology, University of Miami School of Medicine; ME/CFS researcher and clinician; a board member of the American Association for Chronic Fatigue Syndrome; and member of the federal CFS Coordinating Committee
6. Dr. A. Martin Lerner, staff physician at William Beaumont Hospital in Royal Oak, Michigan; Clinical professor and former chief of the Division of Infectious Diseases at Wayne State University’s School of Medicine; and ME/CFS researcher and clinician
7. Dr. Alison C. Basted, haematological pathologist; former head of the Division of Haematology and Immunology at the Toronto East General and Orthopaedic Hospital; affiliate of the Environmental Health Clinic and Sunnybrook & Women’s College Health Sciences Centre, Toronto, Ontario; ME/CFS researcher and clinician
8. Dr. Pierre Flor-Henry, Clinical Professor of Psychiatry, University of Alberta; Clinical Director of General Psychiatry and Director of the Clinical Diagnostic and Research Centre, both based at Alberta Hospital in Edmonton, Alberta, Canada; ME/CFS brain researcher
9. Dr. Pradip Joshi, internal medicine, Clinical Associate Professor of Medicine at Memorial University of Newfoundland in St. John’s, Canada
10. Dr. A. C. Peter Powles, Professor Emeritus, Faculty of Health Science, McMaster University, Hamilton; Professor, Faculty of Medicine, University of Toronto; Chief of Medicine and Sleep Disorders Consultant, St. Joseph’s Health Centre, Toronto; Sleep Disorder Consultant at the Sleep Disorder Clinic at St. Joseph’s Healthcare, Hamilton, and Central West Sleep Affiliation, Paris, Ontario
11. Dr. Jeffrey A. Sherkey, family medicine, affiliate of the University Health Network, Toronto, Ontario; and diagnosed with chronic fatigue syndrome nearly 10 years ago

12. Marjorie I. van de Sande, Consensus Coordinator; and Director of Education for the National ME/FM Action Network, Canada

This definition was hosted and coordinated by the National ME/FM Action Network of Canada, led by Lydia Nielson. The M.E. Society would like to thank the Canadian group for the many years of work that went into this important project.