

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Make the Diagnosis

The most important thing a doctor can do to help their patient is to make the diagnosis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome (ME/CFS). Currently only 20 % of patients are getting diagnosed because doctors have never been taught. In this article I will lay out the step-by-step process that is needed in order to make a diagnosis of ME/CFS successfully and to rule out other diseases that can cause fatigue, pain, cognitive dysfunction, immune dysfunction, autonomic dysfunction and sleep disorders.

Treatable Active Disease Must First Be Ruled Out with Laboratory Tests or Investigations:

Endocrine Disorders:	Rheumatological Diseases: Systemic Lupus, Rheumatoid Arthritis	Anemia: Iron Deficiency, other treatable forms
Addison's Disease	Infectious Diseases: HIV, Lyme Disease, Hepatitis, TB	Severe obesity (BMI greater than 40)
Cushing's Syndrome	Substance Abuse	Iron Overload
Diabetes	Neurologic Disorders: MS, Parkinson's Disease, Myasthenia Gravis, B12 deficiency	Cancer
Hypothyroidism Hyperthyroidism	Primary Psychiatric Disorders	Treatable Sleep Disorders: Apnea, Narcolepsy

The best way to rule out many of the above diagnoses is by doing screening the blood work as listed below.

Screening Laboratory Testing for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

The patient must have a detailed history and physical examination plus blood work. The following blood tests are suggested by current clinical case definitions to rule out readily treatable conditions that may be contributing to the symptoms of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

Blood Test and (disease ruled out)

CBC (anemias, leukemias, hemoglobinopathies, blood loss, infection)

TSH, free T3, free T4 (hypothyroidism)* Special Case on requisition

Fasting Glucose (diabetes, impaired glucose tolerance)

Electrolytes (pituitary or metabolic imbalances)

Cholesterol and Triglycerides (metabolic screen if overweight)

ALT, GGT (liver diseases, alcohol abuse, viral illnesses, toxicity)

Alkaline Phosphatase (cancers, liver disease, bone pathology)

C-reactive protein (measure of inflammation) * Order CRP and ESR on different dates

ESR (connective tissue disorders e.g. polymyalgia rheumatica)

ANA and Rheumatoid Factor (autoimmune diseases)

Immuno-electrophoresis (immunodeficiency, multiple myeloma)

Ionized Calcium (parathyroid dysfunction, malignancy with bone metastases, inadequate intake or absorption problems, renal tubular disease)

Phosphate (parathyroid dysfunction)

Urinalysis (chronic urinary tract infections, diabetes, nephropathies)

B12 (low values seen in vegans and those with poor GI absorption e.g. Celiac)

Iron studies: ferritin, serum iron, iron binding capacity, percent saturation (deficiency, anemia of chronic diseases, hemochromatosis)

Anti-tissue transglutaminase (celiac screen)

Urea, creatinine, eGFR (renal disease)

Cortisol am and pm (Addison's and circadian rhythm shift)

Lyme tests

Virology studies: Chronic Hepatitis Panel (B and C), CMV, EBV, Mycoplasma

The details of fatigue, post-exertional fatigue, sleep disorder etc. are essential. Using the Functional Capacity Scale plus a detailed Activity Log that the patient has filled out the previous week helps the doctor to understand exactly what the patient is capable of doing on an hourly and daily basis. See attached Functional Capacity Scale plus a detailed Activity Log. Normal energy is 9-10/10. Anything below this is not normal. Look at the pattern on the activity log and see if after doing an activity the patient has a relapse of their symptoms or crashes in bed for the next few hours or days. This is typical of post-exertional fatigue.

As the patient's history is reviewed from a questionnaire that they have previously filled out and from Appendix 4, you will then have enough information to check the positive findings on the ME/CFS Clinical Diagnostic Criteria Worksheet See attached. Yes, patients with ME/CFS are poor historians because they have cognitive dysfunction with poor short term memories, difficulty concentrating and slowed processing, so a questionnaire completed before the visit is essential for you to complete the patient's history.

This will likely happen over several sessions in a family practice office where complex medicine is time constrained. Just think how much easier the diagnosis of ME/CFS will be after we get a blood test for it.

In the meantime using the criteria works. This is my approach to diagnosing patients with ME/CFS. I have been using it successfully to diagnose patients with ME/CFS for the last twenty-five years.

After you have used the forms once, it gets easier. You have permission to use all the forms with your patients.

Your patients will thank you for diagnosing them and not telling them they are "just depressed". It is the most important thing you can do for your patient - it validates their experience with the illness ME/CFS and brings such relief to know that it is a real physical illness that has pushed their world upside down.

All the best to you.

Sincerely,

Alison

Alison C. Bested MD FRCPC
Hematological Pathologist
Clinical Associate Professor
Faculty of Medicine
University of British Columbia

1265 Morningside Avenue, Suite 107
Toronto ON M1B 3V9

Functional Capacity Scale

COMPLETING YOUR ACTIVITY LOG:

- Write (using ink) in each hourly time slot 1. **your activity** using one word (e.g. dressed, made bed, nap) and 2. an **energy scale number** from the Functional Capacity Scale below as you are doing it throughout the day.
- Rest is defined as lying down, eyes shut, meditating or sleeping.
- You may change the times on the left hand side of the log to suit your usual daily schedule.

YOUR ACTIVITY LOG:

- Keep it in a handy place.
- Complete it every day.
- Take your completed logs to your doctor/other health care provider at follow-up visits.
- Your logs assist your doctor/other health care provider to adjust your treatment plan as needed.
- Completed logs may reassure your insurance company of your active ongoing participation in your treatment.

FUNCTIONAL CAPACITY SCALE:

The Functional Capacity Scale incorporates energy rating, symptom severity, and activity level. The description after each scale number should help you to rate your functional capacity every hour of each day.

- 0 = No energy, severe symptoms including very poor concentration; bed ridden all day; cannot do self-care (e.g. need bed bath to be given).
- 1 = Severe symptoms at rest, including very poor concentration; in bed most of the day; need assistance with self-care activities (bathing).
- 2 = Severe symptoms at rest, including poor concentration; frequent rests or naps; need some assistance with limited self-care activities.
- 3 = Moderate symptoms at rest, including poor concentration; need frequent rests or naps; can do independent self-care but have severe post exertion fatigue.
- 4 = Moderate symptoms at rest, including some difficulty concentrating; need frequent rests throughout the day; can do independent self-care and limited activities of daily living (e.g. light housework, laundry); can walk for a few minutes per day.
- 5 = Mild symptoms at rest with fairly good concentration for short periods (15 minutes); need a.m. and p.m. rest; can do independent self-care and moderate activities of daily living, but have slight post exertion fatigue; can walk 10-20 minutes per day.
- 6 = Mild or no symptoms at rest with fairly good concentration for up to 45 minutes, cannot multitask; need afternoon rest; can do most activities of daily living except vacuuming; can walk 20-30 minutes per day; can do volunteer work – maximum total time 4 hours per week, with flexible hours.
- 7 = Mild or no symptoms at rest with good concentration for up to ½ day; can do more intense activities of daily living (e.g. grocery shopping, vacuuming) but may get post exertion fatigue if 'overdo'; can walk 30 minutes per day; can work limited hours, less than 25 hours per week; no or minimal social life.
- 8 = Mild intermittent symptoms with good concentration; can do full self-care, work 40 hours per week, enjoy a social life, do moderate vigorous exercise three times per week.
- 9 = No symptoms with very good concentration, full work and social life; can do vigorous exercise three to five times a week.
- 10 = No symptoms, excellent concentration, over achiever (sometimes may require less sleep than average person).

NUMBER OF USABLE HOURS / DAY = Number of hours NOT asleep or resting/meditating with eyes closed.

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Dr. Lynn Marshall

Activity Log

Name: _____ Date Commencing: _____

DAY	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
SLEEP: Write number of hours slept and quality 1 = very poor 2 = poor 3 = fair 4 = good 5 = very good							
Functional Capacity Scale: Record your activity and energy rating every hour using the scale 1-10/10							
Activities: (please specify)							
6 a.m.							
7 a.m.							
8 a.m.							
9 a.m.							
10 a.m.							
11 a.m.							
12 p.m.							
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.							
6 p.m.							
7 p.m.							
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.							
# of minutes walked							
# of usable hours / day							

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with your patients.
Dr. Rosemary Underhill

We encourage you to copy this log for use

ME/CFS Signs and Symptoms are patient specific (APPENDIX 4):

Circulatory System

- neurally mediated hypotension (NMH)
- postural orthostatic tachycardia syndrome
- delayed orthostatic hypotension
- light-headedness
- palpitations
- fluid retention
- extreme pallor
- bruising

Digestive System

- lump in throat
- nausea
- heart burn
- abdominal pain
- irritable bowel syndrome

Neuroendocrine System

- loss of thermostatic stability –subnormal body temperature or diurnal fluctuations
- hot flashes
- excessive sweating or night sweats
- feelings of feverishness
- feelings of cold extremities
- anorexia or abnormal appetite
- marked weight change
- hair loss

Musculoskeletal System

- myalgia
- muscle cramps, particularly in legs
- chest pressure and pain
- arthralgia
- TMJ

Nervous System

- persistent fatigue
- lack of endurance
- migraines or new onset headaches
- seizure like phenomena

Sensory

- hypersensitivity to pain
- hyper-responsiveness to noxious
- perceptual & dimensional distortions
- feeling of burning or swelling
- overload phenomena
- loss of cognitive map
- altered taste and/or smell

Cognitive

- difficulties processing information
- concentration problems
- confusion
- difficulties with word retrieval
- word mix-ups
- short-term memory difficulties
- slowness in cognitive processes

Motor and Balance

- muscle weakness or paralysis
- poor balance, ataxia & tandem gait
- clumsiness & tendency to drop things
- difficulty in tandem gait
- atypical numbness or tingling

Sleep Disturbances

- sleep disturbance-hyper or insomnia
- non-refreshing sleep

Visual and Auditory Disturbances

- photophobia
- visual changes or eye pain
- double, blurred or wavy vision
- dry or itchy eyes
- hyperacusis & cocktail party phenomena

Neuropsychological

- loss of adaptability
- worsening of symptoms with stress
- emotional flattening or personality change
- anxiety &/or panic attacks
- reactive depression

Immune System

- tender lymph nodes
- recurrent sore throat
- recurrent flu-like symptoms
- new sensitivities to medications, chemicals

Reproductive System

- dysmenorrhea
- PMS or irregular menstrual cycles

Respiratory System

- exertional dyspnea
- sinusitis
- persistent cough & wheezing

Urinary System

- urinary frequency, bladder dysfunction

Reference: Carruthers, Bruce, et. al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome 2003; Vol. 11(1): 7-115.

Name _____

Date _____

1. **Fatigue:** 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 Fatigue:** There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional fatigue and/or malaise and/or pain and a tendency for other associated symptoms within the patient's cluster to worsen. There is a pathological slow recovery period – usually 24 hours or longer.
3. **Sleep Dysfunction:*** There is unrefreshed sleep or sleep quantity or rhythm disturbance such as reversed or chaotic diurnal sleep rhythm.
4. **Pain:** * There is a significant degree of myalgia. Pain can be experienced in the muscles and joints and is often 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 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”¹ periods and/or anxiety.
6. **At Least One Symptom from Two of the Following Categories:**
- Autonomic Manifestations:** orthostatic intolerance-NMH, POTS, delayed postural hypotension, vertigo; light-headedness, extreme pallor; nausea and IBS; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmia; palpitations, and exertional dyspnea.
- Neuroendocrine Manifestations:** loss of thermostatic stability-subnormal body temperature and/or marked diurnal fluctuation, sweating episodes, recurrent feeling of feverishness and cold extremities; intolerance to heat and cold; marked weight change-anorexia or abnormal appetite; loss of adaptability and tolerance for stress, worsening of symptoms with stress and a slow recovery.
- Immune Manifestations:** tender lymph nodes, recurrent sore throat and flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.
7. **The illness persists for at least six months in adults.** It usually has a distinct onset,**although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

1. “Crash” refers to a temporary period of immobilizing physical and/or mental fatigue.

Exclusions: Rule out active disease processes that explain the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction with patient history, physical exam laboratory testing or imaging. These include: Addison’s disease, Cushing’s syndrome, hypothyroidism, hyperthyroidism, iron deficiency, iron overload syndrome, other treatable forms of anemia, diabetes mellitus, cancer, treatable sleep disorders including upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyositis, and polymyalgia rheumatica; neurological disorders such as MS, Parkinson's disease, myasthenia gravis and B12 deficiency; infectious diseases such as TB, chronic hepatitis, Lyme disease, AIDS; primary psychiatric disorders and substance abuse. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if the patient meets the criteria otherwise.

Co-Morbid Entities: Fibromyalgia syndrome, myofascial pain syndrome, temporomandibular joint syndrome, irritable bowel syndrome, interstitial cystitis, irritable bladder syndrome, Raynaud’s phenomenon, prolapsed mitral valve, migraine, allergies, multiple chemical sensitivities, thyroiditis, sicca syndrome, depression, Hashimoto’s, etc. Such co-morbid entities may occur in the setting of ME/CFS. Others such as IBS may precede the development of ME/CFS by many years, but then become associated with it. The same holds true for migraines and depression. Their association is thus looser than between the symptoms within the syndrome. ME/CFS and FMS often closely connect and should be considered to be “overlap syndromes”.

Idiopathic Chronic Fatigue: If the patient has unexplained prolonged fatigue but has insufficient symptoms to meet the criteria for ME/CFS, it should be classified as idiopathic chronic fatigue.

_____ Patient meets the criteria for ME/CFS

_____ Patient meets the criteria for Idiopathic Chronic Fatigue

Reference: Carruthers, Bruce, et. al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome 2003; Vol. 11(1): 7-115.

Physician's Signature

Date

Physician's Stamp:



References:

1. Bruce M Carruthers MD, CM, FRCPC; Anil Kumar Jain, B Sc, MD; Kenny L De Meirleir, MD, Ph D; Daniel L Peterson, MD; Nancy G Klimas, MD; A Martin Lerner, MD, PC, MACP; Alison C Basted, MD, FRCP C; Pierre Flor-Henry, MB, Ch B, MD, Acad DPM, FRC (Psych), CSPQ (Psych); Pradip Joshi, BM, MD, FRCPC; Ac Peter Powles, MRACP, FRCPC, ABSM; Jeffrey A Sherkey, MD, CCFPC; Marjorie van de Sande, B Ed, Grad Dip Ed. **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols.** Journal of Chronic Fatigue Syndrome 11(1) 2003, pages 7-115. <http://mefmaction.com/images/stories/Medical/ME-CFS-Consensus-Document.pdf>
2. Friedberg F, Bateman L, Basted A, Davenport T, Friedman K, et al. International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis ME/CFS: Primer for clinical practitioners. Chicago, IL: IACFS/ME, 2014:50 pages. <http://iacfsme.org/ME-CFS-Primer-Education/News/News-Related-Docs/2014/ME-CFS-Primer-for-Clinical-Practitioners-%282014-rev.aspx>
3. Basted, Alison C. and Marshall, Lynn M. [Review of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: an evidence-based approach to diagnosis and management by clinicians](#) [Reviews on Environmental Health, Volume 30, Issue 4](#). November 2015: pages 223-249.