

Appendices Found Online Only:

Appendices: Tools for Clinicians:

1. Functional Capacity Scale
2. ME/CFS Clinical Diagnostic Criteria Worksheet
3. Definition of ME/CFS for Children
4. Activity Log

Appendix 1 : 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:

- Complete it every day and keep it in a handy place
- 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.

Energy Number:

- 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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Please use this with your patients.

Appendix 2 : ME/CFS CCC Clinical Diagnostic Criteria Worksheet*

Name _____ Patient ID _____ Date _____

To diagnose ME/CFS, the patient must have the following clinical symptom criteria:

- Pathological fatigue, post-exertional malaise, sleep problems, pain, two neurocognitive symptoms, and at least one symptom from two of the following categories: autonomic, neuroendocrine, immune
- The fatigue and the other symptoms must persist, or be relapsing for at least six months in adults, or three months in children and adolescents. A provisional diagnosis may be possible earlier
- The symptoms cannot be explained by another illness.

Improved diagnostic accuracy can be obtained by measuring the severity and frequency of the listed symptoms.†

Clinical Criteria Present	Description of Symptoms
Pathological fatigue []	A significant degree of new onset, unexplained, persistent or recurrent physical and/or mental fatigue that substantially reduces activity levels and which is not the result of ongoing exertion and is not relieved by rest
Post-exertional malaise & worsening of symptoms []	Mild exertion or even normal activity is followed by malaise, the loss of physical and mental stamina and/or worsening of other symptoms. Recovery is delayed, taking more than 24 hours
Sleep problems []	Sleep is un-refreshing: disturbed quantity - daytime hypersomnia or nighttime insomnia and/or disturbed rhythm - day/night reversal Rarely, there is no sleep problem
Pain []	Pain is widespread, migratory or localized: myalgia; arthralgia (without signs of inflammation); and/or headache - a new type, pattern or severity Rarely, there is no pain
2 Cognitive symptoms []	Impaired concentration, short term memory or word retrieval; hypersensitivity to light, noise or emotional overload; confusion; disorientation; slowness of thought; muscle weakness; ataxia
At least 1 symptom from 2 of these categories:	
(a) Autonomic []	(a) Autonomic: Orthostatic intolerance; neurally mediated hypotension (NMH); postural orthostatic tachycardia (POTS); light-headedness; extreme pallor; palpitations; exertional dyspnea; urinary frequency; irritable bowel syndrome (IBS); nausea
(b) Neuroendocrine []	(b) Neuroendocrine: Low body temperature; cold extremities; sweating; intolerance to heat or cold; reduced tolerance for stress; other symptoms worsen with stress; weight change; abnormal appetite
(c) Immune []	(c) Immune: Recurrent flu-like symptoms; sore throats; tender lymph nodes; fevers; new sensitivities to food, medicines, odors or chemicals

ME/CFS Clinical Diagnostic Criteria Worksheet (continued)

Symptom Characteristics:

- A sudden onset is most common, but the onset may be gradual
- Symptoms may vary from day to day or during the day
- Relapses and remissions are frequent
- Post-exertional symptom flare-ups may occur immediately or they can be delayed 24 hours or more
- If pain and/or sleep disorder are absent, ME/CFS can be diagnosed if the illness has an abrupt onset

Exclusionary illnesses:

Many other illnesses have symptoms that mimic ME/CFS symptoms. Active disease processes that could explain the major symptoms of fatigue, sleep disturbance, pain, and neurocognitive dysfunction must be ruled out by history, physical examination and medical testing. The following lists some more common, exclusionary conditions:

- **Anemias**
- **Autoimmune diseases** such as rheumatoid arthritis, lupus
- **Cardiac disease**
- **Endocrine disorders** such as diabetes, Addison's disease, thyroid disease, menopause
- **Infectious diseases** such as tuberculosis, HIV/AIDS, chronic hepatitis, Lyme disease
- **Intestinal diseases** such as celiac or Crohn's disease
- **Malignancies**
- **Neurological disorders** such as multiple sclerosis, Parkinson's disease, myasthenia gravis
- **Primary psychiatric disorders** and substance abuse (but not clinical depression)
- **Significant pulmonary disease**
- **Primary sleep disorders** such as sleep apnea.

Non-exclusionary conditions:

- **Some co-morbid entities commonly occur in association with ME/CFS. They include: allergies, fibromyalgia (FM), irritable bowel syndrome (IBS) and multiple chemical sensitivities (MCS)**
- **Any medical condition that has been adequately treated and is under control**
- **Any isolated physical abnormality or laboratory test that is insufficient to diagnose an exclusionary condition.**

ME/CFS and FM are often closely associated and should be considered to be overlapping syndromes. A co-morbid condition may precede the onset of ME/CFS by many years, but then become associated with it.

If the patient has unexplained, prolonged fatigue but has an **insufficient number of symptoms to meet the criteria for ME/CFS**, the illness should be classified as **idiopathic chronic fatigue**.

_____ **Patient meets the criteria for ME/CFS**

_____ **Full criteria not met but patient should be monitored**

Comments:

Provider's Signature

Date

Carruthers BM, et al. ME/CFS: Clinical Working Case Definition, Diagnostic and Treatment Protocols. J CFS 2003;11(1):7-115.

†Jason LA, et al. The development of a revised Canadian Myalgic Encephalomyelitis-Chronic Fatigue Syndrome case definition. American J Biochemistry Biotechnology 2010;6(2): 120-135.

Appendix 3 : Definition of ME/CFS for Children

Jason LA Barker K Brown A. Pediatric Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Rev Health Care. 2012;3(4):257–270.

I. Clinically evaluated, unexplained, persistent or relapsing chronic fatigue over the past 3 months that:

- A. Is not the result of ongoing exertion
- B. Is not substantially alleviated by rest
- C. Results in substantial reduction in previous levels of educational, social and personal activities
- D. Must persist or reoccur for at least three months

II. The concurrent occurrence of the following classic ME/CFS symptoms, which must have persisted or recurred during the past three months of illness (symptoms may predate the reported onset of fatigue).

- A. Post-exertional malaise and/or post-exertional fatigue.
With activity (it need not be strenuous and may include walking up a flight of stairs, using a computer, or reading a book), there must be a loss of physical or mental stamina, rapid/sudden muscle or cognitive fatigability, post-exertional malaise and/or fatigue and a tendency for other associated symptoms within the patient’s cluster of symptoms to worsen. The recovery is slow, often taking 24 hours or longer.
- B. Unrefreshing sleep or disturbance of sleep quantity or rhythm disturbance.
May include prolonged sleep (including frequent naps), disturbed sleep (e.g., inability to fall asleep or early awakening), and/or day/night reversal.
- C. Pain (or discomfort) that is often widespread and migratory in nature. At least one symptom from any of the following:
Myofascial and/or joint pain (Myofascial pain can include deep pain, muscle twitches, or achy and sore muscles. Pain, stiffness, or tenderness may occur in any joint but must be present in more than one joint and lacking edema or other signs of inflammation.)
Abdominal and/or head pain (May experience eye pain/sensitivity to bright light, stomach pain, nausea, vomiting, or chest pain. Headaches often described as localized behind the eyes or in the back of the head. May include headaches localized elsewhere, including migraines.)
- D. Two or more neurocognitive manifestations:
Impaired memory (self-reported or observable disturbance in ability to recall information or events on a short-term basis)
Difficulty focusing (disturbed concentration may impair ability to remain on task, to screen out extraneous/excessive stimuli in a classroom, or to focus on reading, computer/work activity, or television programs)
Difficulty finding the right word
Frequently forget what wanted to say
Absent mindedness
Slowness of thought
Difficulty recalling information
Need to focus on one thing at a time
Trouble expressing thought
Difficulty comprehending information
Frequently lose train of thought
New trouble with math or other educational subjects
- E. At least one symptom from two of the following three categories:
 - 1. Autonomic manifestations: Neurally mediated hypotension, postural orthostatic

tachycardia, delayed postural hypotension, palpitations with or without cardiac arrhythmias, dizziness, feeling unsteady on the feet—disturbed balance, shortness of breath.

2. Neuroendocrine manifestations: Recurrent feelings of feverishness and cold extremities, subnormal body temperature and marked diurnal fluctuations, sweating episodes, intolerance of extremes of heat and cold, marked weight change—loss of appetite or abnormal appetite, worsening of symptoms with stress.

3. Immune manifestations: Recurrent flu-like symptoms, non-exudative sore or scratchy throat, repeated fevers and sweats, lymph nodes tender to palpitation—generally minimal swelling noted, new sensitivities to food, odors, or chemicals.

III. Exclusionary conditions:

A. Any active medical condition that may explain the presence of chronic fatigue, such as:

1. Untreated hypothyroidism
2. Sleep apnea
3. Narcolepsy
4. Malignancies
5. Leukemia
6. Unresolved hepatitis
7. Multiple Sclerosis
8. Juvenile rheumatoid arthritis
9. Lupus erythematosus
10. HIV/AIDS
11. Severe obesity (BMI greater than 40)
12. Celiac disease
13. Lyme disease

B. Some active psychiatric conditions that may explain the presence of chronic fatigue, such as:

1. Childhood schizophrenia or psychotic disorders
2. Bipolar disorder
3. Active alcohol or substance abuse—except as below:
 - a) Alcohol or substance abuse that has been successfully treated and resolved should not be considered exclusionary.
4. Active anorexia nervosa or bulimia nervosa—except as below:
 - a) Eating disorders that have been treated and resolved should not be considered exclusionary.
5. Depressive disorders

IV. May have presence of concomitant disorders that do not adequately explain fatigue, and are, therefore, not necessarily exclusionary.

1. Psychiatric diagnoses such as:

- a) School phobia
- b) Separation anxiety
- c) Anxiety disorders
- d) Somatoform disorders
- e) Depressive disorders

2. Other conditions defined primarily by symptoms that cannot be confirmed by diagnostic laboratory tests, such as:

- a) Multiple food and/or chemical sensitivity
- b) Fibromyalgia

3. Any condition under specific treatment sufficient to alleviate all symptoms

related to that condition and for which the adequacy of treatment has been documented.

4. Any condition, that was treated with definitive therapy before development of chronic symptomatic sequelae.
5. Any isolated and unexplained physical examination, laboratory or imaging test abnormality that is insufficient to strongly suggest the existence of an exclusionary condition.

Appendix 4 : 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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We encourage you to copy this log for use with your patients.