

# Do I fit the International Consensus Criteria?



## Questionnaire for patients over age 18

**Disclaimer:** This questionnaire does not replace the full International Consensus Criteria (ICC) document or the primer. It is based on the symptoms of the criteria and should not be used as a substitute for medical advice from a licensed medical professional. This document is for informational purposes. Consult a physician experienced in diagnosing ME. It is important to evaluate for other diseases before assigning a diagnosis of ME. (ICD code G93.3).

According to the ICC a six month waiting period is NOT required for diagnosis of ME. Removing the waiting period is very important so ME patients can be advised to get complete rest as soon as possible in order to get the best possibility of improved health.

### **Must have Post Exertional Neuroimmune Exhaustion (PENE)**

PENE is physical inability to produce sufficient energy on demand.

The following are signs you have PENE:

1. Marked, rapid physical and/or cognitive fatigability in response to exertion, which may be minimal such as activities of daily living or simple mental tasks, can be debilitating and cause a relapse.
2. Post-exertional symptom exacerbation: such as acute flu-like symptoms, pain and worsening of other symptoms
3. Post-exertional exhaustion: may occur immediately after activity or be delayed by hours or days
4. Recovery period is prolonged, usually taking 24 hours or longer. A relapse can last days, weeks or longer
5. Low threshold of physical and mental fatigability (lack of stamina) results in a substantial reduction in pre-illness activity level.

*Symptom severity must result in a significant reduction of pre-illness activity level.*

The 2 day Cardio Pulmonary Exercise Test available at Workwell Foundation (California) and Ithaca College (New York) is a 2 day CPET specifically designed to look for inability to repeat physical activity two days in a row.

If you aren't sure if you have PENE, watching the following video may help you answer the question. Video by Mark VanNess explaining an abnormal physiological response to exertion and the 2 day test: <https://www.youtube.com/watch?v=FXN6f53ba6k&app=desktop>

**Do you have PENE:** \_\_\_ Yes \_\_\_ No

**If YES, go to next section.**

**If NO, stop quiz. You do not fit this criteria.**

# Do I fit the International Consensus Criteria?

## SECTION 2

Check off the ones that apply to you.

### Neurocognitive Impairments

- Difficulty processing information:** *slowed thought, impaired concentration such as confusion, disorientation, cognitive overload, difficulty with making decisions, slowed speech, acquired or exertional dyslexia*
- Short-term memory loss:** *difficulty remembering what one wanted to say, what one was saying, retrieving words, recalling information, poor working memory*

### Pain

- Headaches:** *such as chronic, generalized headaches often involve aching of the eyes, behind the eyes or back of the head that may be associated with cervical muscle tension; migraine; tension headaches*
- Significant pain** *can be experienced in muscles, muscle-tendon junctions, joints, abdomen or chest. It is non-inflammatory in nature and often migrates. In other words have generalized hyperalgesia, widespread pain (may meet fibromyalgia criteria), myofascial or radiating pain.*

Definitions:

**Hyperalgesia:** *increased sensitivity to pain*

**Myofascial:** *pertaining to a muscle and its sheath of connective tissue, or fascia*

### Sleep Disturbance

- Disturbed sleep patterns:** *such as insomnia, prolonged sleep including naps, sleeping most of the day and being awake most of the night, frequent awakenings, waking much earlier than before illness onset, vivid dreams/nightmares*
- Unrefreshed sleep:** *awaken feeling exhausted regardless of duration of sleep, day-time sleepiness*

### Neurosensory, perceptual and motor disturbances

- Neurosensory and perception:** *inability to focus vision, sensitivity to light, noise, vibration, odor, taste and touch; impaired depth perception*
- Motor:** *muscle weakness, twitching, poor coordination, feeling unsteady on feet, ataxia*

Definitions:

**Ataxia:** *Inability to coordinate muscle activity*

Did you check at least one box in at least three categories in section 2? \_\_\_ Yes \_\_\_ No

**If YES, go to next section.**

**If NO, continue for possible atypical ME criteria.**

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## SECTION 3

Check off the areas that apply to you.

- Flu-like symptoms** *may be recurrent or chronic and typically activate or worsen with exertion. Such as sore throat, sinusitis, cervical and/or axillary lymph nodes may enlarge or be tender*
- Susceptibility to viral infections** *with prolonged recovery periods*
- Gastro-intestinal tract:** *such as nausea, abdominal pain, bloating, irritable bowel syndrome*
- Genitourinary:** *such as urinary urgency or frequency, excessive urination at night*
- Sensitivities to food, medications, odors or chemicals**

Did you check at least three boxes in section 3? \_\_\_ Yes \_\_\_ No

**If YES, go to next question.**

**If NO, continue for possible atypical ME criteria.**

## SECTION 4

Check off the ones that apply to you:

- Cardiovascular** - *inability to tolerate an upright position - orthostatic intolerance, neurally mediated hypotension, postural orthostatic tachycardia syndrome, palpitations with or without cardiac arrhythmias, light-headedness/dizziness*
- Respiratory** - *air hunger, laboured breathing, fatigue of chest wall muscles*
- Loss of thermostatic stability** - *subnormal body temperature, marked diurnal fluctuations; sweating episodes, recurrent feelings of feverishness with or without low grade fever, cold extremities*
- Intolerance of extremes of temperature**

Did you check at least one box in section 4? \_\_\_ Yes \_\_\_ No

**If you have answered YES to each section, you fit the International Consensus Criteria for Myalgic Encephalomyelitis.**

**If you answered no in section 2, 3, or 4 you may have atypical ME.**

**Atypical myalgic encephalomyelitis:** *meets criteria for PENE (section 1) but has a limit of two less than required of the remaining criterial symptoms. Pain or sleep disturbance may be absent in rare cases.*

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**Note: pediatric symptoms vary - See source at this link for pediatric:**

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/full>

**Link to the International Consensus Primer for Physicians which lists tests and treatment options for those who fit the ICC:**

[http://sacfs.asn.au/download/me\\_international\\_consensus\\_primer\\_for\\_medical\\_practitioners.pdf](http://sacfs.asn.au/download/me_international_consensus_primer_for_medical_practitioners.pdf)