CFI Chronic Fatigue Initiative

FAQ: What Is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome (CFS) is a debilitating disease that entails neurologic, immunologic and endocrinologic dysfunctions and is characterized by overwhelming fatigue often aggravated by physical or mental exertion. It does not improve with rest. A carefully defined subgroup of CFS is myalgic encephalomyelitis (ME); ME is the more common name for the disease in Europe.

What Are The Causes And Risk Factors?

The exact causes of CFS/ME have yet to be identified despite 25 years of research, and diagnostic tests do not exist. It is not directly caused by other medical conditions.

According to the National Institutes of Health and the Canadian Consensus Criteria case definition, as published in the Journal of Chronic Fatigue Syndrome, some theories suggest CFS/ME may be due to viral reactivation or some other source of systemic and/or brain inflammation, such as autoimmunity. Potential causes of chronic infection include:

- Epstein-Barr Virus
- Human Herpesvirus-6 and 7
- Entrovirus
- Cytomegalovirus
- Lentivirus
- Chlamydia
- Mycoplasma
- Inflammation in the nervous system due to a faulty immune system response

However, findings have been mixed and there is no conclusive support for any one pathogen. Age, previous illness, stress, genetics and environmental factors may also play a role in the development of CFS/ME.

What Are The Diagnostic Criteria?

There are a number of case definitions but there are two that are widely used in chronic fatigue syndrome/myalgic encephalomyelitis research: the Fukuda criteria (1994) and the Canadian case definition (2003). Now, a third recently formulated case definition is also available, the International Consensus Criteria (2011).

<u>1994 CDC (aka Fukuda) Criteria</u>

According to the CDC criteria, a patient with CFS/ME will meet the following criteria:

1. Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities.
2. The concurrent occurrence of four or more of the following eight symptoms, all of which must have persisted or recurred during six or more consecutive months of illness and must not have predated the fatigue:
    - self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities
    - sore throat that's frequent or recurring
    - tender cervical or axillary lymph nodes
    - muscle pain
    - multi-joint pain without swelling or redness
    - headaches of a new type, pattern, or severity
    - unrefreshing sleep
    - post-exertional malaise (extreme, prolonged exhaustion and sickness following physical or mental activity) lasting more than 24 hours

<u>2003 Canadian Consensus Criteria</u>

According to the CCC, a patient with CFS/ME will meet the following criteria:

1. Fatigue: 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: 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. Pathologically slow recovery period-usually 24 hours or longer.
3. Sleep Dysfunction: Unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.
4. Pain: Significant degree of myalgia. Pain experienced in the muscles and/or joints, and often widespread and migratory in nature. Significant headaches of new type, pattern or severity often present.
5. Neurologic/Cognitive Manifestations: Two or more of the following difficulties:
    - confusion
    - impairment of concentration and short-term memory consolidation
    - disorientation
    - difficulty with information processing, categorizing and word retrieval
    - perceptual and sensory disturbances e.g., spatial instability and disorientation and inability to focus vision

    Ataxia, muscle weakness, and fasciculations are common. Overload phenomena (cognitive, sensory – e.g., photophobia and hypersensitivity to noise – and/or emotional overload) may lead to "crash" periods and/or anxiety.
6. At least one symptom from two of the following three categories:
    a. Autonomic Manifestations:

- orthostatic intolerance-neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension
- lightheadedness
- 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 typically has a distinct onset, although it may be gradual.

<u>2011 Myalgic Encephalomyelitis: International Consensus Criteria</u>

This case definition more carefully defines a subgroup of CFS, myalgic encephalomyelitis. According to the ICC, a patient with ME will meet the following criteria:

1. Postexertional neuroimmune exhaustion. Characteristics are as follows:
   - 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
   - postexertional symptom exacerbation: e.g. acute flu-like symptoms, pain and worsening of other symptoms
   - postexertional exhaustion may occur immediately after activity or be delayed by hours or days
   - recovery period is prolonged, usually taking 24 hours or longer. A relapse can last days, weeks or longer
   - low threshold of physical and mental fatigability (lack of stamina) results in a substantial reduction in pre-illness activity level
2. Neurological impairments. At least one symptom from three of the following four symptom categories:
   a. Neurocognitive impairments
      - difficulty processing information: slowed thought, impaired concentration. E.g. confusion, disorientation, cognitive overload, difficulty with making decisions, slowed speech, acquired or exertional dyslexia

- short-term memory loss: e.g. difficulty remembering what one wanted to say, what one was saying, retrieving words, recalling information, poor working memory

b. Pain
   - headaches: e.g. 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 noninflammatory in nature and often migrates. E.g. generalized hyperalgesia, widespread pain (may meet fibromyalgia criteria), myofascial or radiating pain

c. Sleep disturbance
   - disturbed sleep patterns: e.g. insomnia, prolonged sleep including naps, sleeping most of the day and being awake most of the night, frequent awakenings, awaking much earlier than before illness onset, vivid dreams/nightmares
   - unrefreshed sleep: e.g. awaken feeling exhausted regardless of duration of sleep, day-time sleepiness

d. Neurosensory, perceptual and motor disturbances
   - neurosensory and perceptual: e.g. inability to focus vision, sensitivity to light, noise, vibration, odour, taste and touch; impaired depth perception
   - motor: e.g. muscle weakness, twitching, poor coordination, feeling unsteady on feet, ataxia

3. Immune, gastro-intestinal and genitourinary impairments. At least one symptom from three of the following five symptom categories:
   - flu-like symptoms may be recurrent or chronic and typically activate or worsen with exertion. E.g. sore throat, sinusitis, cervical and/or axillary lymph nodes may enlarge or be tender on palpitation
   - susceptibility to viral infections with prolonged recovery periods
   - gastro-intestinal tract: e.g. nausea, abdominal pain, bloating, irritable bowel syndrome
   - genitourinary: e.g. urinary urgency or frequency, nocturia
   - sensitivities to food, medications, odors or chemicals
4. Energy production/transportation impairments. At least one symptom:
   - cardiovascular: e.g. 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: e.g. air hunger, laboured breathing, fatigue of chest wall muscles
   - loss of thermostatic stability: e.g. 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

Pediatric considerations:
(Please note that there is also an international pediatric case definition. The link is posted on http://iacfsme.org/Portals/0/pdf/pediatriccasedefinitionshort.pdf).
Per the ICC: Symptoms may progress more slowly in children than in teenagers or adults. In addition to postexertional neuroimmune exhaustion, the most prominent symptoms tend to be neurological: headaches, cognitive impairments, and sleep disturbances.

1. Headaches: Severe or chronic headaches are often debilitating. Migraine may be accompanied by a rapid drop in temperature, shaking, vomiting, diarrhea and severe weakness.
2. Neurocognitive impairments: Difficulty focusing eyes and reading are common. Children may become dyslexic, which may only be evident when fatigued. Slow processing of information makes it difficult to follow auditory instructions or take notes. All cognitive impairments worsen with physical or mental exertion. Young people will not be able to maintain a full school programme.
3. Pain may seem erratic and migrate quickly. Joint hypermobility is common.

What Is The Treatment?

As there is currently no universal treatment or cure for CFS/ME, treatment is aimed at relieving symptoms on a case by case basis. For information regarding possible treatments, a CFS/ME patient should consult with a physician or a medical professional.

What Is The Prognosis For Recovery?

Each individual's experience with CFS/ME is unique. Some patients are able to maintain somewhat active lifestyles within certain constraints, while others have difficulty leaving their bed or house. Some research has shown that 25 percent of patients are severely disabled.

The long-term prognosis for patients with CFS/ME varies. While some patients completely recover within six months to a year, others feel like they never fully recover their pre-CFS/ME condition. There is little scientific data on outcomes; it is an area that needs further study.

Sources

http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002224/

http://www.cdc.gov/cfs/

Carruthers BM et al. "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols." *Journal of Chronic Fatigue Syndrome* 11.1 (2003): 7-36.

Carruthers BM et al. "Myalgic Encephalomyelitis: International Consensus Criteria." *Journal of Internal Medicine* 270.4 (2011): 327-338.