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## What Is CFIDS/ME (pronounced "see-fids em-ee")?

Chronic Fatigue Immune Dysfunction Syndrome is also known as Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis or Myalgic Encephalopathy (ME). It is a complex, debilitating, and often disabling illness which affects multiple systems of the body. Most people with CFIDS experience profound exhaustion, post-exertional malaise, sleep disorder, neurological and flu-like symptoms, and cognitive problems such as difficulty thinking, processing, and remembering. The illness may last many months or years. Symptoms may vary in severity and may wax and wane. There is as yet no known definitive one cause. It is likely that there are several triggers that set off a cascading panoply of pathological changes in many of the body's systems. While there is no known cure many of the symptoms can be treated. Some patients show improvement over time, while others may show little improvement or a worsening of symptoms.

CFS/CFIDS/ME affects men, women, and children of all ages, ethnic and socioeconomic groups. A very carefully conducted government-funded study (Jason et al; *Archives of Internal Medicine*, Oct 11, 1999) estimated that there are about 1 million cases of CFS/CFIDS/ME in the US, with a majority of them being women. This study found a prevalence among adolescents and children to be about half that of adults. The study also found the prevalence in women (522 per 100,000) is vastly higher than that for HIV in women (125 per 100,000), lung cancer in women (63 per 100,000) and breast cancer in women (43 per 100,000). The study suggested that a high percentage of cases remain undiagnosed as a result of some patients' lower economic and medically uninsured status. A recent (2008) study by the Centers for Disease Control & Prevention (CDC) now estimates the prevalence to be almost two million cases in the US, with 80% of them undiagnosed. However that study used a revised version of the 1994 CDC case definition, and probably over-estimates the prevalence.

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## How Is CFIDS Diagnosed?

CFS/CFIDS/ME often resembles other illnesses, including Lyme disease, multiple sclerosis, mononucleosis, primary depression, mitochondrial disease and lupus. Currently, CFS/CFIDS/ME in the US is usually diagnosed according to the US Centers for Disease Control & Prevention's (CDC) 1994 research definition. The definition first requires that other illnesses which could explain a patient's symptoms be ruled out. A diagnosis is based on the presence of the following:

1. Unexplained, persistent or relapsing chronic fatigue that is of new or definite onset; that is not relieved by rest; results in substantial reduction in previous levels of occupational, educational, social, or personal activities.

2. Four or more of the following symptoms at the same time, all of which have persisted or recurred for six or more consecutive months after the onset of the fatigue:

- Short-term memory or concentration problems severe enough to greatly affect occupational, social, educational, or personal activities
- Sore throat
- Tender lymph nodes in the neck or underarm area
- Muscle pain
- Multiple joint pain without redness or swelling
- Headaches of a new type or severity
- Unrefreshing sleep
- Worsening of symptoms after exertion even up to a day or two later.

A much more accurate diagnosis criteria for CFIDS/ME is given in the [2003 Canadian definition](#). Please see our detailed Diagnosis section for more information.

## Other Important CFIDS Symptoms

In addition to the 1994 CDC diagnostic list, there are additional symptoms of note. Onset of the illness is often sudden (a few days to a few weeks.) Common symptoms with their incidences are on the following list compiled from information provided by famous CFS/CFIDS/ME clinicians.

### **Most Common Symptoms of CFS/CFIDS/ME**

- Exhaustion, made worse by physical exercise (100%)
- Low-grade fever in early stages (60-95%)
- Recurrent flu-like illness (75%)
- Frequent pharyngitis (sore throats) (50-75%)
- Joint and muscle pain (65%)
- Severe muscle weakness (40-70%)
- Stiffness (50-60%)
- Post-exertional fatigue & flu-like symptoms (50-60%)
- Multiple sensitivities to medicines, foods, and chemicals (40-60%)
- Severe nasal & other allergies (often with worsening of previous mild allergies) (40-60%)
- Frequently recurring, difficult to treat respiratory infections (40-60%)
- Dyspnea (labored breathing or hunger for air) on exertion
- Painful lymph nodes (especially on neck and under arms) (30-40%)

### **Neurological Symptoms**

- Sleep disorders & unrefreshing sleep (50-90%)
- Headaches (35-85%)
- Visual blurring (50-60%)
- Intolerance of bright lights
- Paresthesias (numbness or tingling feelings) (30-50%)
- Dizziness/ Lightheadedness (30-50%)
- Ringing in the ears
- Impaired cognition (50-85%)
- Attentional difficulties
- Calculation difficulties
- Memory disturbance
- Spatial disorientation
- Saying the wrong word

### **Other Symptoms**

- Worsening of premenstrual symptoms (70% of women)
- Nocturia (excessive urination during the night) (50-60%)
- Tachycardia (abnormal rapid heart action) (40-50%)
- Chest pain (25-40%)
- Cough (30-40%)
- Weight gain (50-70%)
- Nausea, especially in earlier stages (50-60%)
- Diarrhea, intestinal gas or irritable bowel (50%)
- Intolerance of alcohol
- Night sweats (30-50%)
- Dry eyes (30-40%)
- Dry mouth (30-40%)
- Rash (30-40%)
- Frequent canker sores (30-40%)
- Herpes simplex or shingles (20%)
- Symptoms worsened by extremes in temperature

*(Statistics compiled from data by: Paul Cheney MD, Anthony Komaroff MD, Charles Lapp MD, Daniel Peterson MD)*

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## What Causes CFIDS?

The cause of CFS/CFIDS/ME is not yet known, but current research shows strong evidence of immune, neuroendocrine, and circulatory system dysfunction. Research indicates that some parts of the immune system may be in an overactive state, while other parts of the system may be in an underactive state. There is convincing evidence that viruses are associated with CFS/CFIDS/ME in many cases.

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## How Is CFIDS Treated?

Since there is no known cause or cure, treatment is targeted to relieve specific symptoms, such as pain and sleep disorder. Experienced CFIDS/ME clinicians are treating patients with both conventional and alternative approaches. Experimental treatments are being evaluated in clinical trials. Patients need to assess their treatment options carefully for safety and effectiveness. (See our detailed [Treatment](#) section.)

Because some patients can show lower tolerance and/or hypersensitivity to medications, treatment should be started at low doses with gradual increases as appropriate. Since anesthesia can also trigger hypersensitive reactions, caution must be exercised.

Important lifestyle changes include: increased rest, decreased and carefully paced activity ("living in your energy envelope"), exercise only as tolerated, stress control, balanced nutrition, improved sleep, and identifying effective coping strategies. Patient and family support groups, as well as counseling, can be very helpful. It is vital to find a physician who understands CFIDS/ME, and is willing to develop an individualized treatment program.

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## What About Kids?

Children develop CFS/CFIDS/ME, but they are often misdiagnosed. An accurate pediatric definition of CFS/CFIDS/ME has only been in existence since 2006. Children tend to experience symptoms of short-term memory and concentration problems, dizziness, light-headedness, abdominal pain, rash, fever, and chills. They frequently experience profound fatigue as well, although they may have difficulty expressing their complaints or judging the severity of their condition. Thus, some people may incorrectly perceive that the child is developing progressive learning and social difficulties rather than a physical illness. (Please see our [Children & Youth](#) section for more information.)

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## More Resources

[Clinical Guides to Diagnosis and Treatment](#)

[Dr. Anthony Komaroff, The Latest Research on CFS, summary of lecture April 24, 2010](#)

[The CFIDS Initiation—A Primer for New Patients](#)

[CFIDS Self-Care: The Basics](#)

[The Physical Basis of CFS](#)

[Complementary & Mainstream Treatment Approaches](#)

[On the Morbid Fascination with Psychiatric Morbidity](#)

[Links to other sites with information about CFS/CFIDS/ME](#)

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