

## **CFS – AN INVISIBLE AND DEBILITATING ILLNESS**

Chronic fatigue syndrome (CFS), also known as chronic fatigue immune dysfunction syndrome (CFIDS), myalgic encephalomyelitis, or myalgic encephalopathy (ME), is an emergent illness and as such remains unfamiliar to the public and medical communities. CFS as it is now known was described in the scientific literature for the first time 18 years ago, yet we still do not know very much about this illness.

CFS is a complex multisystemic illness that compromises the immune, neuroendocrine, and autonomic nervous systems. The Centers for Prevention and Disease Control estimates that 4 million Americans have CFS and about 80% to 85% of this population has not been diagnosed properly. The illness has been misunderstood even by the medical professionals who attempt to treat it as depression or hypochondriasis. Over a decade ago, here in the United States, it was called “the yuppie flu” because the majority of the individuals being diagnosed with CFS were “white, upper-class females.” This view changed quickly when researchers discovered that the illness occurs most often in people in their 40s and 50s, in lower income individuals, and in minorities.

In some countries, such as Japan, Canada, Australia, and the United Kingdom, this syndrome is known as myalgic encephalomyelitis or encephalopathy— names that could be better associated with a physiological cause.

## **WHAT IS CFS?**

CFS is a combination of subjective symptoms that are, in general, expressed by the patient, and it is characterized by a physically and mentally debilitating fatigue lasting at least 6 months with a significant reduction in occupational, social, and personal activities. It does not improve with rest and might get worse by engagement in physical activities. CFS has characteristic symptoms, including muscle and joint pain, problems with memory and concentration, nonrefreshing sleep, and influenza symptoms.

It affects multiple systems, among them the nervous system that includes the [hypothalamic- pituitary-adrenal \(HPA\) axis](#), with low levels of cortisol. Researchers have also found abnormalities in the [autonomic nervous system](#) that affect heart rate and blood pressure.

In the immune system, there is an increase in the [natural killers T-cells](#) (NK-T) and [cytokines](#), but it is not clear whether this reflects an abnormal response to an infectious agent or the lack of an adequate response.

## **WHAT ARE THE SYMPTOMS?**

According to the CDC, clinicians should consider a diagnosis of CFS if the two following criteria are met:

1. Unexplained, persistent fatigue that is not due to ongoing exertion, is not substantially relieved by rest, is of new onset (not lifelong), and results in a significant reduction in previous levels of activity.
  
2. At least four of the following symptoms are present for 6 months or more:
  - Impaired memory or concentration
  - Postexertional malaise (*extreme, prolonged exhaustion and exacerbation of symptoms following physical or mental exertion*)
  - Unrefreshing sleep
  - Muscle pain
  - Multijoint pain without swelling or redness
  - Headaches of a new type or severity
  - Sore throat that is frequent or recurring
  - Tender cervical or axillary lymph nodes

### **Other Common Symptoms**

- Irritable bowel, abdominal pain, nausea, diarrhea, or bloating
- Chills and night sweats
- Brain fog
- Shortness of breath
- Visual disturbances (blurring, sensitivity to light, eye pain, or dry eyes)
- Allergies or sensitivities to foods, alcohol, odors, chemicals, medications, or noise

- Difficulty maintaining upright position (orthostatic instability, irregular heartbeat, dizziness, balance problems, or fainting)
- Psychological problems (depression, irritability, mood swings, anxiety, or panic attacks)

## **WHO IS AT RISK FOR CFS?**

CFS could affect anyone; there is not a relationship between ethnicity and socioeconomic status among those with this syndrome. It is more common in adults than in children. Among these adults, women are 3 to 5 times more likely to have CFS.

## **WHAT IS THE PROGNOSIS?**

CFS is characterized by a pattern of relapse and remission over long periods of time, but it is not clear yet how long this illness lasts. Some patients recover after 2 to 4 years, whereas others remain ill for decades. Recovery and/or remission is in the range of 5% to 10%.

Researchers have found some factors that provide a better prognosis for patients whose symptoms began abruptly with mild fatigue and those who do not have a psychiatric illness. Dr. James Jones from the CDC stated “that patients who were ill for two years or less were more likely to improve,” making early detection and

treatment of CFS of utmost importance. The longer a person is ill before diagnosis, the more complicated the course of the illness appears to be.

## **DIAGNOSIS**

There is no laboratory test or biomarker to diagnose CFS. This disease could resemble many other disorders, including mononucleosis, fibromyalgia, Lyme disease, lupus, multiple sclerosis, primary sleep disorders such as narcolepsy or sleep apnea, and hypothyroidism. Health professionals need to exclude other illnesses before a diagnosis can be confirmed. Because there is no diagnostic lab test for CFS, it is a diagnosis of exclusion.

## **WHAT CAN I DO?**

If you think you may have CFS, make a list of your symptoms and identify what makes your symptoms worse. Bring this list to your family physician to help you engage him or her in your treatment. Ultimately, you will probably have to see a CFS specialist for help. There are many websites that have important information on CFS. Click on [P.A.N.D.O..R.A](#) or go to [www.pandoranet.info](http://www.pandoranet.info) and click on the “resources/links” and on the empowerment group pages. As a CFS patient, you will need to empower yourself through personal knowledge, determination, and resilience. These resources will contribute to your overall treatment and wellness. It is important to engage your family, employer, and caregiver early in the process through advocacy so the image of this complex and mysterious illness is taken seriously.

## TREATMENT

There is not one single cause known for CFS, and there is no cure. There are many current therapy courses that can alleviate the primary symptoms. Pain relievers are commonly used as well as antidepressants and medications that affect the [central nervous system](#).

Pharmacological therapy is directed toward the relief of specific symptoms experienced by the individual patient through the use of the most cost-effective treatment and drugs that act on multiple body systems and symptoms in an attempt to reduce the unwanted side effects. Initial small dose increments of medications are important because many CFS patients are very sensitive to medications, particularly agents acting on the central nervous system. It is important to monitor your symptoms and note improvements and/or side effects. It is crucial to find the best overall treatment.

It is recognized that a well-balanced diet should be part of the treatment for all chronic illnesses, so it is important to maintain a balanced and healthy diet. Such a diet can be used beneficially to strengthen the ailing immune system of people suffering from CFS. [Omega 3](#) and foods rich in vitamin B-12 and magnesium are recommended. A once a day vitamin is recommended by most CFS specialists as well as other supplements that might lead to overall wellness. It is important to remember, however, that nutritional supplements cannot take the place of good diet

and nutrition. Inform your family or specialist physician of the names of supplements you take to be sure there are no interactions with your medications.

Alternative therapies should be discussed with your health care professional. Some herbal remedies could interact with the nervous system drugs; therefore, it may be harmful to you, make sure to include them on the medications lists given to your physician. It is advisable to avoid herbal remedies such as comfrey, ephedra, kava, germander, chaparral, bitter orange, licorice root, yohimbe, and any other supplements that might interact and be potentially dangerous.

Although considered controversial by many within the patient advocacy community, cognitive behavioral therapy can help patients and their families to understand the illness and how to live with it. Working with a cognitive behavioral therapist, patients with CFS can examine beliefs, concerns, and coping behaviors and modify these as necessary to manage the illness more effectively. It is not a cure but an effective tool for patients with any chronic illness.

Exercise and physical therapy play a controversial role in the treatment of CFS, and recently, researchers have shown that graduated exercise taught by a rehabilitation specialist with full knowledge of CFS will help with muscle tone, flexibility, and muscle pain. Some patients are afraid to engage in any kind of exercise because of their past experience and lack knowledge in this area.

It is important to start slowly and increase slowly, gradually escalating both the level of activity and the duration. One to 2 minutes of stretching, slowly and in short periods of 3 to 5 minutes followed by 5 minutes of rest. Patients can increase their exercise time by one minute every 7 to 10 days, but no more than 10 minutes at a time. If you feel worse after exercising for several weeks, quit the exercise. Current researchers investigating exercise are addressing many of patients' concerns and examining the possibility that exercise can be integrated into long-term treatments programs without side effects.

## **FAMILY ISSUES**

CFS will take a toll on families. Sexual and intimacy issues can be exacerbated by the fatigue and side effects of medications. Loss of employment, disability issues, and financial expenditures can create serious personal hurdles for patients with CFS. Quality of life is one of the primary concerns of patients. It is important that individuals with CFS address these issues as effectively as they can. Cognitive behavioral therapy can be an important tool in this area.

## **CFS AND PREGNANCY**

Presently, there is no substantial and extensive research information about pregnancy and CFS. Young women with CFS will not find extensive resources in reproductive health or information that could guide them during pregnancy. It is not

possible to determine who will feel better or worse during pregnancy. In some studies some women have improved during pregnancy and worsened after. Other women have the opposite experience. We could say that pregnancy is not a contraindication for patients with CFS. Currently, there is no research-based evidence showing that mothers can pass CFS on to their child.

**According to the 2006 Winter issue of the *CFIDS Chronicle*, these are the top 10 discoveries about the biology of CFS:**

1. CFS is not a form of depression. Many patients with chronic illness become depressed because of the impact of the illness on their lives.
2. There is a state of chronic, low-grade immune activation in CFS. There is evidence of activated T-cells.
3. There are poorly functioning natural killer cell (NK) cells. White blood cells are important in fighting viral infections.
4. Using MRIs, researchers have found abnormalities in white matter of the brain in CFS patients just below the cerebral cortex.
5. Abnormalities in brain metabolism that affect temporal lobes have been found.
6. Abnormalities in the neuroendocrine system in the brain, particularly depression of the hypothalamic-pituitary-adrenal (HPA) axis as well as the hypothalamic –prolactin axis have been noted.
7. Cognitive impairment, especially information-processing efficiency and memory/attention are present.

8. Abnormalities in the [autonomic nervous system](#) have been found, including a failure of the body to maintain blood pressure several minutes after a person stands up, abnormal response of the heart rate when standing, and unusual pooling of blood in the veins of the legs.
9. Researchers have discovered expression of genes that are important in energy metabolism of individuals with CFS.
10. There is evidence of more frequent latent active infection with various herpes viruses and enterovirus in patients with CFS.

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