



# Introducing CFS

The CFIDS Association  
of America



# What is CFS, or CFIDS?

Chronic fatigue syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS), is a serious and complex illness that affects the brain and multiple body systems. It is characterized by profound exhaustion and extremely poor stamina, problems with information processing and memory, flu-like symptoms, widespread pain in the joints and muscles, sleep problems and numerous other symptoms. CFS can be very debilitating and can last for many years.

CFS is often misdiagnosed or unrecognized, and it can resemble other medical disorders, including mononucleosis, multiple sclerosis (MS), fibromyalgia (FM), chronic Lyme disease, postpolio syndrome and autoimmune diseases such as lupus.

Symptoms vary widely from person to person and fluctuate in severity. Specific symptoms may come and go, complicating treatment and the person's ability to cope with the illness. Most symptoms are invisible to others, which makes it difficult for friends, family members and the public to understand the challenges a person with CFS faces.

## Who gets CFS?

CFS strikes people from every age, ethnic and socioeconomic group. Women account for the majority of cases, but CFS afflicts men and children as well. Studies show that fewer than 20 percent of CFS patients in the United States have been properly diagnosed.

New research conducted by the Centers for Disease Control and Prevention (CDC) indicates that more than four million people in the United States have CFS. The illness is more common than multiple sclerosis, Parkinson's disease, lupus, lung cancer and many other well-known disorders.

## How is CFS diagnosed?

There is no definitive diagnostic test for CFS. Your health care professional will first take a detailed medical history, then perform a complete physical exam. Laboratory tests will also be performed to identify underlying or contributing conditions that require treatment.

A case definition published in the *Annals of Internal Medicine* lists criteria necessary to meet the standard for CFS. The illness can be diagnosed if the patient meets both of the following criteria:

- 1 Clinically evaluated, unexplained persistent or relapsing chronic fatigue that is of new or definite onset (not lifelong), isn't the result of ongoing exertion, isn't substantially alleviated by rest and results in substantial reduction in previous levels of occupational, educational, social or personal activities.
- 2 Four or more of the following eight symptoms, persisting or recurring over at least six consecutive months and not predating the fatigue:
  - Postexertional malaise (extreme exhaustion and/or cognitive difficulties following physical or mental exertion) lasting more than 24 hours
  - Unrefreshing sleep
  - Substantial impairment in short-term memory or concentration
  - Muscle pain
  - Multijoint pain without joint swelling or redness
  - Headaches of a new type, pattern or severity
  - Sore throat
  - Tender lymph nodes

Because there's no diagnostic test or biomarker for CFS, other medical conditions must be ruled out before a diagnosis of CFS can be established. These include a past or current diagnosis of a major depressive disorder with psychotic or melancholic features. Although CFS is *not* a form of depression, many patients often develop secondary depression as a result of dealing with a chronic and debilitating illness.

## Are there other symptoms?

In addition to the diagnostic symptoms just listed, patients may experience a variety of additional symptoms. These may include:

- Visual disturbances (blurring, sensitivity to light, eye pain)
- Psychological problems (irritability, mood swings, anxiety, panic attacks)
- Chills and night sweats
- Low-grade fever or low body temperature
- Irritable bowel
- Allergies and sensitivities to foods, odors, chemicals, medications and noise/sound
- Brain fog; feeling in a fog
- Numbness, tingling or burning sensations in the face or extremities
- Difficulty retaining upright posture, dizziness, balance problems and fainting

## Who can diagnose and treat CFS?

Finding health care professionals who are knowledgeable enough about CFS to diagnose and treat it can be challenging. Physicians, nurse practitioners and physician assistants can all diagnose CFS when they are familiar with the illness. Diagnosis doesn't require referral to a specialist, but people with CFS may not want to limit their health care team to a primary care physician. Many medical professionals—including rheumatologists, pain specialists, allergists, occupational therapists, psychologists, rehabilitation specialists, exercise physiologists and nurse practitioners—work with CFS patients.

Patients who have a good relationship with their current primary care professionals can urge them to learn about the illness. (The Association provides a medical information packet and a CFS Toolkit for providers at no charge.) If a health care provider isn't responsive, local CFS support groups, patients in your area, nurses and other people in the medical field may be able to provide a referral.

## How is CFS treated?

Because there's no cure for CFS, treatment is designed to improve function and quality of life. A treatment approach that focuses on helping patients develop effective coping strategies, manage their symptoms and manage activity levels is now the standard for CFS care. Lifestyle changes—including increased rest, reduced anxiety, changes in diet, nutritional supplements and gentle exercise—are frequently recommended.

Sleep problems, pain, heart rate irregularities, gastrointestinal difficulties, allergies and depression are some of the symptoms which can be relieved through the use of prescription and over-the-counter medications. People with this illness may have unusual responses to medications, so extremely low doses should be tried first and gradually increased as appropriate.

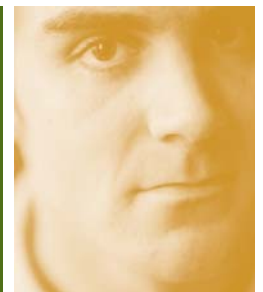
## Does exercise help?

Most CFS patients can't tolerate traditional aerobic exercise or pre-illness levels of activity. Postexertional malaise—a worsening of fatigue and other symptoms following physical or mental exertion—is common in CFS. It's important, however, not to avoid activity altogether because this can lead to deconditioning, which can also make symptoms worse. Limited physical activity, such as gentle stretching and strengthening exercises, and carefully monitored graded exercise will help guard against deconditioning without pushing patients beyond their limits.

## What causes CFS?

The cause of CFS isn't yet understood. Researchers have explored many possibilities over the past 20 years.

**Studies show that 80 percent of Americans who have CFS haven't been diagnosed yet—a staggering statistic. It means millions of CFS sufferers are not receiving much-needed medical care.**



Early investigations focused on the role of several known and novel viruses, but none was found to be the cause. Current thinking suggests there could be a variety of triggers and risk factors that lead to CFS in susceptible individuals. It's now clear, however, that CFS is a physical not a psychiatric illness. Scientists have discovered a number of biologic abnormalities in CFS patients.

Building on the documented abnormalities found in CFS patients, researchers are now focusing on the complex interplay of the immune, neuroendocrine, autonomic and central nervous systems in causing CFS. Powerful new technologies are enabling more sophisticated studies of brain activity, genetic activity and infectious agents to unravel the complexities of CFS.

### Is CFS contagious?

Most people in close contact with CFS patients haven't developed the illness. However, clusters have occurred in families, workplaces, schools and communities. Preliminary research indicates that there may be a familial predisposition or a genetic link. When members of the same family become ill, they're more often blood relatives than spouses. More research is needed to understand how CFS occurs and who is at greatest risk for contracting the illness.

### Do CFS patients get better?

The severity of CFS varies greatly from patient to patient, with some people able to maintain fairly active lives. For others, CFS has a profound impact on work, school and family life. About 25 percent of CFS patients are disabled by the illness. There's often a pattern of relapse and remission, and patients may cycle between different levels of function.

Studies are under way to help learn more about the long-term clinical course of illness and factors that may impact recovery. There is recent research suggesting that CFS patients who are ill for two years or less are more likely to improve, making early diagnosis and treatment of the illness very important. The longer a person is ill before diagnosis, the more complicated the clinical course appears to be.

### Why join the CFIDS Association of America?

The CFIDS Association of America is the nation's leading 501(c)(3) charitable organization dedicated to conquering CFS, and the largest contributor to CFS research aside from the federal government. Since 1987 our efforts in CFS education, awareness, public policy and research have greatly enhanced understanding of this complex and debilitating condition.

Your support of the CFIDS Association of America is critical to sustaining the considerable progress we've made. By becoming a member of the Association, you can help us find definitive answers that will return the men, women and children with CFS to healthy, productive lives.

### Membership Benefits

Your membership helps strengthen and sustain the work of the Association. In return, we offer many valuable benefits, including:

- Annual subscription to our quarterly magazine, the *CFIDS Chronicle*, a trusted source of information on a broad spectrum of CFS-related topics important to patients and to those who care about them
- 10% savings on the CFIDS Association of America's educational materials
- Free listing of local CFS organizations and support groups
- Complimentary copy of the Association's educational pamphlet, "Choosing a Health Care Provider"
- Optional free subscription to our monthly e-newsletter, *CFIDSLink*, which is sent directly to your inbox

Help us speed progress toward improved health for CFS patients by joining the CFIDS Association of America today! For more information, call the Association's resource line at 704-365-2343, or visit [www.cfids.org](http://www.cfids.org).

## Join the Fight Against CFS!

### Annual Membership Dues:

\$35 U.S. (Canada and Mexico, \$45; overseas, \$60)

- New member                       Renewal  
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To begin or renew your membership, or to make a tax-deductible donation, call the Association's resource line at 704-365-2343, fax this form to 704-365-9755, or mail this form to the address below.

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