

Frequently Asked Questions

CHRONIC FATIGUE SYNDROME

Q: Is there a diagnostic test for CFS?

A: No, there is currently no blood, urine or imaging test to diagnose chronic fatigue syndrome. The keys to diagnosis are identifying a characteristic pattern of symptoms and excluding other possible causes. Only a health care professional can diagnose CFS.

Q: How do I get a diagnosis?

A: Although it was developed as a research case definition, the 1994 International Case Definition is the prevailing document used for diagnosis. Diagnosis of chronic fatigue syndrome (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS), is a time-consuming process which involves excluding other illnesses with similar symptoms and comparing a patient's symptoms with the case definition. As yet, there is no indicator or diagnostic test that can clearly identify the disorder.

Q: How do I find a doctor who is knowledgeable about CFS?

A: Start by reading the CFIDS Association of America's brochure, "Choosing a Health Care Provider." A reliable source of referral is often an area support group where people share information about their experiences dealing with local health care professionals with fellow patients.

Q: Is there a cure for CFS?

A: No, there is currently no cure for the illness. However, there are symptomatic and supportive therapies that can be helpful for many patients. With good medical care, improvements in symptoms, function and quality of life are possible.

Q: Is CFS a psychological disorder?

A: No, most researchers now agree that CFS is not a form of depression or psychiatric illness. All chronic illnesses have significant medical, psychological and social components. Chronic fatigue syndrome and depression share a few similar symptoms, which may be one reason for misdiagnosis. However, the physical symptoms of CFS differ greatly than those of depression and can help to differentiate between the two illnesses. While CFS is not a psychological disorder, depression or anxiety may occur as a result of having such a chronic, debilitating illness.

Q: How many people have CFS?

A: A 2007 community-based prevalence study from the CDC indicates that more than 4 million Americans have the illness, yet less than 20% have been diagnosed.

Q: Where can I find a support group?

A: Local support groups may provide help in learning to cope with the many life changes that can occur due to CFS. The CFIDS Association maintains state-by-state listings of CFS support groups. To receive a list of support groups and contacts in your state, e-mail your name and complete mailing address to SupportGroups@cfids.org or send a self-addressed, stamped envelope to the CFIDS Association of America, Attn: Support Group Info, PO Box 220398, Charlotte, NC 28222-0398.

Q: Will exercise, bed rest or diet changes help?

A: There are treatments that can help ease symptoms. These include various medications that are given to help with specific symptoms, such as sleep disturbances or pain, and alternative/complementary therapies such as acupuncture, hydrotherapy, massage, yoga or tai chi.

Excessive activity and aerobic exercise may aggravate CFS symptoms. However, a paced, graded exercise program that is specifically designed for the patient can be beneficial. People with CFS have varying degrees of activity tolerance and must carefully balance activity and rest.

CFS patients with severe symptoms may be bedridden, while others tolerate more activity. Deconditioning is a problem that can easily affect a person who is bedridden or has limited amounts of daily physical activity. A rehabilitation professional familiar with the energy management problems of people with CFS can help design a highly individualized activity regimen to optimize health and well-being for patients.

Because many people with CFS have digestive problems (nausea, pain, irritable bowel syndrome), maintaining adequate nourishment can be a challenge. Many fad diets call for an imbalanced food intake, can create poor nutritional status and should be avoided. Food intolerances are also a problem for a significant number of people with CFS. Speak with your primary care provider and/or a registered dietitian regarding your nutritional concerns.

Q: How long will it take to recover?

A: It's not possible to predict recovery. Some patients recover in small to moderate degrees, while others recover almost fully, but no one knows why. Still others have progressively worse symptoms over time. Very little data exists about recovery rates for CFS. No treatments or physical characteristics of people with the illness have been associated with recovery and, at this time, there are no reliable predictors of how long the illness may last. According to recent CDC research, patients who were ill for two years or less were more likely to improve, and the longer a person is ill before diagnosis, the more complicated the course of CFS appears to be.

FREQUENTLY ASKED QUESTIONS

Q: Should people with CFS donate blood?

A: Donating blood may not be safe for people with CFS because research has shown that many patients have low blood volume and other vascular problems, and removing additional blood could provoke a relapse. Additionally, CFS patients should refrain from donating bone marrow or organs since it's currently unknown whether or not the illness may be contracted in this manner.

Q: Can people with CFS continue working?

A: Yes, some people with the illness continue to work. But this is highly individualized and dependent on symptom severity and the demands of a given job. People with CFS experience a wide spectrum of disability, ranging from people whose symptoms are mild and who are able to work full time, to those who can work part time, to patients who are unable to work at all. A recent CDC study found that 25% of people with CFS are disabled.

Whenever possible, people should be encouraged to continue working because of the benefits to self-esteem and economic security. Decisions about changing employment status need to be considered carefully, obtaining as much information as possible regarding continuation of insurance and disability benefits. Occupational therapists may be helpful by providing tips on energy conservation, joint protection and other functional techniques that may allow a person with CFS to stay in the workplace.

Q: Are people with CFS eligible for Social Security and long-term disability benefits?

A: Yes. Like any other medically certified illness, sickness benefits or disability allowances are an important part of ensuring financial stability for people who are disabled by CFS. For more information about disability benefits, please visit our website at <http://www.cfids.org/resources/legal-issues.asp>.

Q: What can I do about the anger, guilt and fears caused by CFS?

A: These feelings are a common part of coping with a chronic illness. Talk with your primary care provider and/or find a therapist, minister or support group with whom you can voice your feelings. Although periods of sadness that last a day or two are normal, extended periods of feeling sad, hopeless and "down" are troublesome. It's crucial to seek medical help during these times because depression that co-exists with CFS can worsen other symptoms and general well-being.

Q: What is being done about CFS?

A: Federal agencies, such as National Institutes of Health and the U.S. Centers for Disease Control and Prevention, along with organizations like the CFIDS Association of America, encourage and support CFS research and education. The Association's CFS awareness, education, public policy and research programs have been effective in focusing federal attention on CFS-related issues, engaging the scientific community in the study of CFS and improving public awareness of the illness.

Q: What is the CFIDS Association of America?

A: The CFIDS Association of America was founded in 1987 by a small group of individuals intent on fighting back against the disease that had stolen so much of their lives. The first dollar spent by the organization was directed to medical research. Since that time, the CFIDS Association has grown to become the nation's largest and most active charitable organization dedicated to conquering CFIDS/CFS. The Association has invested more than \$25 million in this important mission since 1987.