

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 (CFS), also known as chronic fatigue and immune dysfunction syndrome (CFIDS). 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: In 2003, a Canadian consensus definition was developed for clinical use to diagnose CFS. Some health care providers may use the 1994 International Case Definition, although it was developed as a research case definition. Diagnosis of CFS is a time-consuming process which involves excluding other illnesses with similar symptoms and comparing a patient's symptoms with the consensus/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 Association's Fact Sheet "[Choosing a Health Care Provider](#)" or "[Doc Talk](#)." 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, researchers agree that CFS is not a form of depression or psychiatric illness. All chronic illnesses have significant medical, psychological and social components. CFS 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: Estimates vary, but at least one million Americans have CFS and millions more suffer worldwide. Studies indicate that fewer than 20% of CFS patients in the United States have been properly diagnosed.

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.

Physical 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 CFS patients can help design a highly individualized activity regimen to optimize health and well-being.

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 patients. 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. Unfortunately, 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. Research has shown that people who have CFS for two years or less are more likely to improve. The longer a person is ill before diagnosis, the more complicated the course of the illness appears to be.

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.

FREQUENTLY ASKED QUESTIONS

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. CFS patients 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.

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 allow a CFS patient 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. You can find information about applying for disability benefits in the Legal Issues section of our web site.

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 these feelings 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: In 2007 the CFIDS Association embarked on a new research initiative to increase the pace of progress in CFS research. This expanded research program is accelerating the discovery of biomarkers, better diagnostics and more effective treatments for CFS.

The first formal CFS research network was initiated in January 2009, a collaboration between the CFIDS Association and the National Institutes of Health (NIH), to leverage existing expertise from successful network models like NIH's Biomedical Informatics Research Network and the National Cancer Institute's Early Detection Research Network. This CFS network will impact research and patient care, bringing clinical and academic investigators into closer contact and stronger alignment.

The creation of the [SolveCFS BioBank](#) which collects and stores biological samples (such as blood, tissue, cells and DNA) and clinical information from CFS patients and healthy individuals aged 10 years and older was announced in March 2010. First collaborations have begun and General Enrollment Criteria enable the broad participation by patients diagnosed with CFS by a physician, while ensuring that the population can be narrowed according to criteria for individual studies approved by our Medical Research Advisory Committee. Consistent collection of detailed clinical data and health history is a tremendous resource for CFS research, in addition to the tissue repository.

In February 2012, the CFIDS Association of America announced the new "Research Institute Without Walls" or RIWW, breaking out of the conventional non-profit role of simply sponsoring medical research by becoming a full partner with leading research institutions. This new investment of \$2 million includes the five new grant awards mentioned above, two new projects using resources from a central biobank and [curation of a biomarker "hit list"](#) to guide future research.

Q: What is the CFIDS Association of America?

A: The CFIDS Association 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 was directed to medical research. Since that time, the Association has grown to become the nation's largest and most active charitable organization dedicated to conquering CFS by investing more than \$30.4 million in this important mission.

Information and resources are available to patients, family members, caregivers, support groups, media professionals the general public and health care professionals. The Association focuses its resources on research, policy and communications that will advance understanding, diagnosis, treatment and prevention of CFS.

The Association is committed to providing relevant, up-to-date information about CFS in various formats for readers: [SolveCFS: The Chronicle of the CFIDS Association of America](#), a print publication distributed twice a year; [Research1st News](#), an e-newsletter delivered to subscribers the beginning of each month; and two websites, [www.cfids.org](#) and [www.Research1st.com](#).

Join us in our Mission - for CFS to be widely understood, diagnosable, curable and preventable - by making a tax-deductible [contribution today](#).

Learn more by visiting the CFIDS Association at [www.cfids.org](#)