What is chronic fatigue syndrome (CFS)?

The main symptom of CFS is fatigue so profound that it interferes with normal activity. CFS is also sometimes called chronic fatigue and immune dysfunction syndrome, chronic EBV syndrome, or myalgic encephalomyelitis. No one knows what causes it.

What are the symptoms of CFS?

CFS has many symptoms besides fatigue. Other common symptoms are weakness, joint pains, sore throat that keeps coming back, memory loss, trouble concentrating, low fever, and swollen lymph glands. People with CFS sometimes also have vision problems, numbness in the hands and feet, trouble sleeping, confusion, depression, headaches, rashes, and mild infections (like colds and flu) that keep coming back. Some people’s allergies get worse; others become allergic for the first time.

Is CFS a new disease?

No. A similar disease has affected people all over the world for the past 30 or 40 years. In England and other countries, CFS is called myalgic encephalomyelitis. Doctors have seen more and more people with CFS, including a few clusters of cases, over the past five to ten years.

Who gets CFS?

Anyone can get CFS. Children, young adults and the elderly, of both sexes and of all races and incomes, have gotten CFS. However, it is most common among young to middle-aged women.

What causes CFS?

No one knows what causes CFS. We do know that it has nothing to do with AIDS or the virus that causes AIDS.

Is CFS caused by Epstein-Barr virus?

Probably not. Epstein-Barr virus (EBV) causes most cases of mononucleosis, often called “mono.” Most people — with or without CFS — have been infected with EBV even if they never had mononucleosis. Researchers at first thought that CFS was a form of chronic EBV infection. However, blood tests on healthy people showed that they were just as likely to be infected with EBV as people with CFS.

How is CFS diagnosed?

There is no lab test for CFS, so diagnosis depends on symptoms. If a person develops new, lasting, or recurring fatigue which reduces normal daily activity by half for six months or longer, the doctor will suspect CFS. The patient must also have other CFS symptoms (fever, sore throat, headache, swollen glands, weakness, etc.) to fit the definition of CFS. Before diagnosing CFS, the doctor must make sure that the symptoms are not caused by other diseases.
What other diseases can cause the same symptoms?

Many diseases can cause the same symptoms as CFS. These diseases include infections, thyroid disease, multiple sclerosis, tumors and depression, among others. Doctors must rule out these diseases as possible causes of symptoms before diagnosing a patient's problem as CFS.

What is the treatment for CFS?

There is no treatment for CFS itself. Treatment for infections, sleep problems, joint pains, and headaches can relieve some of these symptoms. Plenty of rest and good nutrition can also help.

Does CFS always last a lifetime? Does it always get worse?

No. CFS often gets better, and up to half of the people who have it may fully recover. Many people with CFS find ways to cope with it so they can function better in spite of their symptoms. Researchers are working on CFS to learn more about how long it lasts and what makes it get better or worse.

What should you do if you think you have CFS?

- Get a complete medical exam to make sure your symptoms are not being caused by something else.
- Find a doctor you trust who is sensitive to your needs and problems.
- Lead a healthy lifestyle. Eating right and getting plenty of rest will help. Stop smoking, avoid caffeine, and cut down on alcohol.
- Beware of simple explanations, odd treatments, and claims of miracle cures.
- Find a support group to help you cope with the syndrome.
- Find sources of information about CFS and any new research that might be helpful to you.

Where can you get more information and help coping with CFS?

There are local, regional, state and national groups and organizations that offer information, advocacy, and support for people with CFS. For more information, call or write to:

Massachusetts Chronic Fatigue and Immune Dysfunction Syndrome Association, Inc. (Mass CFIDS)
808 Main Street
Waltham, MA 02154
(617) 893-4415

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