



Chronic Fatigue Syndrome

<http://www.womenshealth.gov>

1-800-994-9662

TDD: 1-888-220-5446

Q: What is Chronic Fatigue Syndrome (CFS)?

A: A person with CFS feels completely worn-out and overtired. This extreme tiredness makes it hard to do the daily tasks that most of us do without thinking — like dressing, bathing, or eating. Sleep or rest does not make the tiredness go away. It can be made worse by moving, exercising, or even thinking.

CFS can happen over time or come on suddenly. People who get CFS over time get more and more tired over weeks or months. People who get CFS suddenly feel fine one day and then feel extremely tired the next. A person with CFS may have muscle pain, trouble focusing, or insomnia (not being able to sleep). The extreme tiredness may come and go. In some cases the extreme tiredness never goes away. The extreme tiredness must go on for at least 6 months before a diagnosis of CFS can be made.

CFS is sometimes called chronic fatigue and immune dysfunction syndrome (CFIDS). It is also sometimes called myalgic encephalomyelitis (mye-AL-jik en-SEFF-ah-loh-mye-LYE-tiss), or ME.

Q: What causes CFS?

A: No one knows for sure what causes CFS. Many people with CFS say it started after an infection, such as a cold or stomach bug. It also can follow infection with the Epstein-Barr virus. This is the same virus that causes infectious mononucleosis (sometimes called “mono”). Some people with CFS say it started after a time of great stress, such as the loss of a loved one or major surgery.

It can be hard to figure out if a person has CFS because extreme tiredness is a common symptom of many illnesses. Also, some medical treatments, such as chemotherapy, can cause extreme tiredness.

Q: What are the signs of CFS?

A: The signs of CFS can come and go or they can stay with a person. At first, you may feel like you have the flu. As well as extreme tiredness and weakness, main CFS symptoms include:

- Feeling very tired for more than a day (24 hours) after physical or mental exercise
- Forgetting things or having a hard time focusing
- Feeling tired even after sleeping
- Muscle pain or aches
- Pain or aches in joints without swelling or redness
- Headaches of a new type, pattern, or strength
- Tender lymph nodes in the neck or under the arm
- Sore throat



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The symptoms above are the main signs of CFS. CFS symptoms may also include:

- Visual disturbances (blurring, sensitivity to light, eye pain)
- Psychological symptoms (irritability, mood swings, panic attacks, anxiety)
- Chills and night sweats
- Low grade fever or low body temperature
- Irritable bowel
- Allergies and sensitivities to foods, odors, chemicals, medications, and noise/sound
- Numbness, tingling, or burning sensations in the face, hands, or feet
- Difficulty sitting or standing straight up, dizziness, balance problems, and fainting

Symptoms of CFS vary widely from person to person and may be serious or mild. Most symptoms cannot be seen by others, which makes it hard for friends, family members, and the public to understand the challenges a person with CFS faces. If you think you may have CFS, talk to your doctor.

Q: How common is CFS? Who gets it?

A: Experts think at least one million Americans have CFS. Fewer than 20 percent of these cases have been diagnosed, however.

Women are four times as likely as men to develop CFS. The illness occurs most often in people ages 40 – 59. Still, people of all ages can get CFS. CFS is less common in children than in adults. Studies suggest that CFS occurs more often in adolescents than in children under the age of 12.

CFS occurs in all ethnic groups and races, and in countries around the world. People of all income levels can develop CFS, although there is evidence that it is more common in lower-income than in higher-income persons. CFS is sometimes seen in members of the same family, but there is no evidence that it is contagious. Instead, it may run in families because of a genetic link. Further research is needed to explore how this happens.

Q: How would my doctor know if I have CFS?

A: It can be hard for your doctor to diagnose CFS because there is no lab test for it. Also, many signs of CFS are also signs of other illnesses or side effects of medical treatments. All cases are diagnosed by the 1994 Centers for Disease Control (CDC) definition, which is also sometimes called the “Fukuda criteria” after the name of a leading researcher in the field. Children with CFS can be diagnosed by a new pediatric case definition, which differs from the adult definition.

If you think you may have CFS, see your doctor. Your doctor will:

- Ask you about your physical and mental health.
- Do a physical exam.
- Order urine and blood tests, which will tell your doctor if something other than CFS might be causing your symptoms.
- Order more tests, if your urine and blood tests do not show a cause for your symptoms.



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- Classify you as having CFS if:
 1. You have been extremely tired for 6 months or more and tests do not show a cause for your symptoms

AND

 2. You have 4 or more of the symptoms listed in the section “What are the signs of CFS?” in this FAQ.

This process can take a long time (even years), so try to be patient with your doctor. While these tests are being done, talk to your doctor about ways to help ease your symptoms. Although CFS is not a form of depression, many patients develop depression as a result with dealing with a long-term illness.

Q: How is CFS treated?

A: Right now, there is no cure for CFS. But there are things you can do to feel better. Talk to your doctor about ways to ease your symptoms and deal with your tiredness. You might also try these:

Lifestyle changes:

- Try to stop or do less of the things that seem to trigger your tiredness. For a week or two write down what you do each day. Note when you feel really tired. Then, look over this list to find out which activities tend to tire you out. An occupational therapist can help you by looking at your daily habits and suggesting changes to help you save energy. Your doctor can help you find an occupational therapist near where you live.
- At the end of the day, try thinking about how much energy you

think you had that day, and how much energy you actually used that day. If you keep these two amounts of energy similar over time, you may slowly gain more strength and energy. Think about which activities are most important to you, and which activities you do not need to do as often. Make sure to tell other people in your life how much energy you can actually use each day. They can help make sure you don't do too much. It is important to remember that energy can mean mental, emotional, or physical energy.

Medications:

- Over-the-counter pain relievers such as Advil, Motrin, or Aleve can help with body aches, headaches, and muscle and joint pain.
- Nondrowsy antihistamines (an-tee-HISS-tah-meens) can help with allergy symptoms, such as runny nose and itchy eyes.
- Prescription medications like doxepin (DOCKS-ih-pin) or amitriptyline (am-ih-TRIP-tah-leen) can help improve sleep.

Some people say their CFS symptoms get better with complementary or alternative treatments, such as massage, acupuncture, chiropractic care, yoga, stretching, or self-hypnosis. Keep in mind that many alternative treatments, dietary supplements, and herbal remedies claim to cure CFS, but they might do more harm than good. Talk to your doctor before seeing someone else for treatment or before trying alternative therapies.

Also, keep in mind that your doctor may need to learn more about CFS to better help you. If you feel your doctor



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doesn't know a lot about CFS or has doubts about it being a "real" illness, see another doctor for a second opinion. Contact a local university medical school or research center for help finding a doctor who treats people with CFS.

Q: What can I do to cope with CFS?

A: It's normal to feel cranky, sad, angry, or upset when you have an illness like CFS. Some things that might help you to feel better include:

- See the "For more information" section at the end of this FAQ for a list of organizations that can help you cope with CFS.
- Consider talk therapy to help you learn how to deal with your feelings.
- Join a CFS support group. Sometimes it helps to talk with people who are going through the same thing. See the "For more information" section at the end of this FAQ for a list of organizations that can help you find CFS support groups.

Q: What if I can't work because of CFS?

A: If you can't work because of CFS, get in touch with the Social Security Administration for help with disability benefits. It can be hard to get these benefits on your own. Working with a lawyer who specializes in disability benefits could make this process easier.

Social Security Administration

Phone Number: (800) 772-1213 (toll free)

Internet Address: <http://www.ssa.gov>

Q: What is the latest research on CFS?

A: Both the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) fund CFS studies. Today, we have a much better understanding of CFS, but researchers are still searching for the cause(s). They also are looking for ways to prevent CFS and for the best ways to ease CFS symptoms. In time, research findings will be used to develop a cure for CFS. ■



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For more information

For more information on chronic fatigue syndrome, call womenshealth.gov at 1-800-994-9662 or contact the following organizations:

Centers for Disease Control and Prevention (CDC) 24-Hour Chronic Fatigue Syndrome Voice Information System

Internet Address: <http://www.cdc.gov/cfs/>

Chronic Fatigue Syndrome Advisory Committee (CFSAC)

Phone Number: (202) 690-7650

Internet Address: <http://www.hhs.gov/adv-comcfs>

Chronic Fatigue and Immune Dysfunction Syndrome Association of America

Phone Number: (704) 365-2343

Internet Address: <http://www.cfids.org>

National CFIDS Foundation

Phone Number: (781) 449-3535

Internet Address: <http://www.ncf-net.org>

The Trans-NIH Working Group on Chronic Fatigue Syndrome

Phone Number: (301) 402-1770

Internet Address: <http://orwh.od.nih.gov/cfs.html>

International Association for CFS/ME

Phone Number: (847) 258-7248

Internet Address: <http://www.iacfsme.org/>

National Chronic Fatigue Syndrome and Fibromyalgia Association

Phone Number: (816) 737-1343

Internet Address: <http://www.ncfsfa.org/>

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