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1-800-994-9662

TDD: 1-888-220-5446

Chronic Fatigue Syndrome

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.

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 a

bout of infectious mononucleosis (mono), the “kissing disease” that drains your energy. 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, CFS symptoms include:

- 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
- feeling discomfort or “out-of-sorts” for more than 24 hours after being active
- headaches of a new type, pattern, or strength
- tender lymph nodes in the neck or under the arm
- sore throat

Many people with CFS report other symptoms too, ranging from a constant cough to feelings of depression. If you think you may have CFS, talk to your doctor.



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Q: How common is CFS? Who gets it?

A: Experts think as many as half a million Americans have a CFS-like condition. The exact number of people with CFS is not known. CFS can affect people of all ages, racial/ethnic backgrounds, and economic statuses.

More women than men are diagnosed with CFS. But, it is not known for sure that this illness affects more women than men. It may be that women talk to their doctors more often about things like tiredness and pain.

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. And many signs of CFS are also signs of other illnesses or medical treatments.

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
- 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.

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 and 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.
- **Regular exercise** can lessen body aches and joint and muscle pain and increase your energy level. **Be sure to talk to your doctor before starting an exercise plan.** Your doctor can help you create a plan that is right for you. Don't exercise too much. Too much exercise can cause more tiredness.



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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** can help with allergy symptoms, such as runny nose and itchy eyes.
- **Antidepressants** can help improve sleep and ease pain.

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 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. Here are some things you can do that may help you to feel better:
- See the "For more information..." section at the end of this FAQ for a

list of organizations that can help you cope with CFS.

- **Talk therapy** can 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. The Centers for Disease Control and Prevention (CDC) developed guidelines to help you find a good CFS support group. Also 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.

Social Security Administration

Phone Number: 1 (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...

You can find out more about chronic fatigue syndrome by contacting the National Women's Health Information Center at 1-800-994-9662 or the following organizations:

Centers for Disease Control and Prevention (CDC) Chronic Fatigue Syndrome Information

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

Chronic Fatigue and Immune Dysfunction Syndrome Association of America

Phone Number(s): (704) 365-2343

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

National CFIDS Foundation

Phone Number(s): (781) 449-3535

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

International Association for Chronic Fatigue Syndrome

Phone Number(s): (847) 258-7248

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

Social Security Administration

Phone Number(s): 1 (800) 772-1213
(toll free)

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

The Trans-NIH Working Group on Chronic Fatigue Syndrome

Internet address:

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

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