



4woman.gov

800-994-WOMAN (9662)

888-220-5446 (TDD)

The National Women's Health Information Center

A project of the U.S. Department of Health and Human Services, Office on Women's Health



Frequently Asked Questions about Chronic Fatigue Syndrome

What is Chronic Fatigue Syndrome (CFS)?

Having chronic fatigue syndrome, or CFS, means more than just getting tired. With the busy lives American women lead, we all get tired from time to time. But, the fatigue with CFS is extreme and overwhelming, and doesn't get better with bed rest. And, it is often made worse with physical or mental activity.

This illness seems to happen all of a sudden – one day you may notice that you are very tired and can't manage your normal activities. Your energy level is lower and you often get tired for no reason. You may also feel weak and have muscle pain, difficulty focusing, or *insomnia* (not being able to sleep). After you engage in physical activity or exert yourself, you may feel tired for more than 24 hours. The extreme fatigue may then come and go, giving you times when your energy level is normal. Sometimes, though, the extreme tiredness never stops, leaving you feeling exhausted and depleted all the time. You notice that you can't get done in a day what you normally would have been able to, before having this condition. CFS is diagnosed only when other possible causes of the fatigue are ruled out, and the fatigue has lasted for at least 6 months. There are treatments to help a person cope with CFS, some of which include medication. Sometimes CFS goes away on its own or a person can have long periods of time, even years, without symptoms.

What causes CFS?

No one knows for sure what causes CFS. For more than 100 years, doctors have reported seeing illnesses like CFS. Some causes of CFS offered over the years by health experts include *anemia* (low iron in the blood); *hypoglycemia* (low blood sugar); environmental allergies; and *candidiasis* (yeast infection) in the entire body.

Sometimes CFS develops on its own, for no reason. But, most persons with CFS say that it started after having a cold, bronchitis, hepatitis, or an intestinal virus. It can also follow a bout of *infectious mononucleosis* (mono), the "kissing disease" that drains the energy of many teenagers and young adults. Some persons with CFS say their illness began after a time of extreme stress, such as the loss of a loved one or undergoing major surgery.

It can be hard to figure out if a person has CFS. This is because many illnesses have extreme fatigue as a symptom and many treatments, such as chemotherapy, can cause extreme fatigue.

What are the signs of CFS?

CFS symptoms either stay with a person or come and go for more than 6 months. Initial symptoms can feel like you have the flu. Besides extreme fatigue and weakness, CFS symptoms include:

- Headaches of a new type, pattern, or intensity
- Tender lymph nodes

- Sore throat
- Muscle pain or aches
- Pain or aches in several joints without swelling or redness
- Not being able to concentrate, focus, or remember
- Feeling tired even if sleeping
- Feeling discomfort or “out-of-sorts” after physical exertion

How common is CFS? Who gets it?

The Centers for Disease Control and Prevention estimates as many as half a million Americans have a CFS-like condition. In the early 1980s it was first called the “yuppie flu” because mostly well-educated women with high incomes in their 30s and 40s sought help for CFS-like symptoms. It is now known that this illness affects people of all ages, racial/ethnic backgrounds, and economic situations. And, it isn't just an American illness – people all over the world are affected by CFS.

More women than men are diagnosed with CFS. But, it isn't known for sure that this illness affects women more than men. Women may be more likely than men to talk to their doctors about symptoms like exhaustion and pain.

How would my health care provider know if I have CFS?

There has been much debate among CFS experts about a standard way to define CFS. This is because the cause for CFS is not known and there is no one standard symptom. Your health care provider will first do a physical exam and order any needed tests. She or he will rule out the presence of any other diseases or problems that may have CFS-like symptoms, such as *multiple sclerosis* and *systemic lupus erythematosus* (autoimmune diseases). To be diagnosed with CFS, you must have severe chronic fatigue for 6 months or longer, with other medical conditions ruled out by a provider, and 4 or more of the symptoms bulleted out in the question “*What are the signs of CFS*” in this FAQ.

How is CFS treated?

Right now, there is no treatment that works to cure CFS. The good news is there are things you can do to feel better, increase the level at which you can function, and improve your quality of life.

Talking with your health care provider about treatments for your symptoms, along with ways to manage your fatigue, is a good place to start. And, building a good relationship with your provider is key to managing your illness over time. This will help you to talk more freely with your provider about your symptoms, which can improve the treatment of your illness. Keep in mind your provider may need to learn more about CFS to better help you. If you feel your provider doesn't know a lot about CFS or has doubts about whether it is a “real” illness, see another provider for a second opinion. Try a local university medical school or research center for help with finding providers with expertise in CFS.

Medications can work to relieve the symptoms of CFS. *Nonsteroidal anti-inflammatory drugs*, or *ibuprofen* (Advil, Motrin, Alleve), can help with body aches, headaches, and muscle and joint pain. Non-drowsy *antihistamines* can relieve allergy symptoms, such as runny nose and itchy eyes. While there is no proof these practices help, some people report symptom relief with massage, acupuncture, and chiropractic care. Physical activity and exercise can also help with symptom relief, but be sure to talk with your provider about developing an activity and exercise program that's best for you. For some people, physical activity and exercise can worsen symptoms. (See next question on “*What can a person do to cope with CFS?*” for more information on physical activity and exercise.)

Drugs used to treat depression, or *antidepressants*, are sometimes used to treat CFS. This is because studies have found that people with *fibromyalgia*, an illness similar to CFS, get relief from taking these drugs. Some experts believe these drugs improve the quality of sleep, helping decrease fatigue with CFS. Two types of antidepressants are most often prescribed by providers – *low-dose tricyclic antidepressants* or the newer *selective serotonin reuptake inhibitors* (SSRIs).

What can a person do to cope with CFS?

When you have CFS, learning how to pace yourself and manage or avoid physical and emotional stress is important. Physical activity helps you to feel better not just physically, but emotionally as well. Regular exercise can lessen body aches, joint and muscle pain, and increase energy. But, be careful not to over do it. Too much exercise can end up causing more fatigue. As you build up strength over time, you may be able to increase the intensity of your exercise program. Physical therapists and rehabilitation medicine specialists can help you develop an exercise program and a daily activity plan that won't be too stressful or something you can't handle.

Cognitive behavioral therapy is a special treatment that can help you to change the way you think about your condition. It also helps you to develop ways to improve both your daily functioning and quality of life.

Yoga, stretching, and self-hypnosis are some alternative treatments that some people report help with CFS. Keep in mind that there are many alternative treatments, dietary supplements, and herbal remedies touted to cure illnesses like CFS, which can end up doing a person more harm than good. Remember to always keep your health care provider informed of the other health care professionals and alternative practitioners you are seeing.

Having an illness for which there is no cure can cause psychological stress and even depression for some people. It is normal to feel cranky, sad, angry, and frustrated with an illness that causes extreme fatigue and pain. *Psychotherapy* (sometimes called “talk therapy”) can help you learn how to manage your feelings about this difficult illness. It may also be helpful to join a support group, where you can talk with other people who are going through the same thing. See the “*For more information...*” section at the end of this FAQ for referrals to consumer organizations that can help you to cope with CFS.

If a person becomes so disabled with CFS that they can no longer work, they can contact the Social Security Administration for help with disability benefits. There are two social security programs that have the same medical requirements for disability payments – the Social Security Disability Insurance Program and the Supplemental Security Income (SSI) Program. Your prior work history will determine if you can receive Social Security disability. SSI payments are made on the basis of financial need. Contact the Social Security Administration toll-free at (800) 772-1213 or check out their web site, <http://www.ssa.gov> for more information.

What is the latest research on CFS?

Both the National Institutes of Health and the Centers for Disease Control and Prevention have research programs to fund CFS studies. Researchers are focusing on doing more long-term studies with people with CFS, to look at changes in CFS symptoms over short- and long-time periods. The *neuroendocrine system*, which is involved in how the body reacts to stress, is also being studied. The role of hormones, *cytokines* in particular, in the body may also provide clues about how the body responds to stress, as well as CFS. Studies are also being done to look for the presence of infectious agents in people with CFS, and how the body responds to these agents.

Researchers are looking at how disturbed sleep and pain reactions affect CFS. Some experts think that disrupted sleep may cause many of the symptoms of CFS. Others think that women may experience pain differently than men, as well as have different reactions to drugs. CFS-related depression caused by disturbed sleep is also being studied. And, research into fatigue is being done, which may help develop better approaches to dealing with fatigue.

For more information...

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

Center for Disease Control 24-Hour Chronic Fatigue Syndrome Voice Information System

Phone Number(s): (888) 232-3228

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

Chronic Fatigue and Immune Dysfunction Syndrome Association of America

Phone Number(s): (800) 442-3437

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

National Institute of Allergy and Infectious Diseases

Phone Number(s): (301) 496-5717

Internet Address: <http://www.niaid.nih.gov/>

National CFIDS Foundation

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

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

National Chronic Fatigue Syndrome and Fibromyalgia Association

Phone Number(s): (206) 313-2000

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

American Association for Chronic Fatigue Syndrome

Phone Number(s): (206) 781-3544

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

This FAQ was developed from chronic fatigue syndrome fact sheets of the National Institute of Allergy and Infectious Diseases and the Centers for Disease Control and Prevention.

All material contained in the FAQs is free of copyright restrictions, and may be copied, reproduced, or duplicated without permission of the Office on Women's Health in the Department of Health and Human Services; citation of the sources is appreciated.

This FAQ has been reviewed by Eleanor Z. Hanna, Ph.D., of the Office of Research on Women's Health, National Institutes of Health.

September 2002