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Chronic Fatigue Syndrome

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WHAT IS CHRONIC FATIGUE SYNDROME?

We all get tired. Many of us have felt depressed at times. But the mystery known as chronic fatigue syndrome (CFS) is not like the normal ups and downs we experience in everyday life. The early sign of this illness is a strong and noticeable fatigue that comes on suddenly and often comes and goes or never stops. You sometimes feel too tired to do normal activities or are easily exhausted with no apparent reason. Unlike the mind fog of a serious hangover, to which researchers have compared CFS, the profound weakness of CFS does not go away with a few good nights of sleep. Instead, it slyly steals your energy and vigor over months and sometimes years.

HOW DOES CFS BEGIN?

For many people, CFS can begin after a bout with a minor illness such as a cold, or an intestinal bug. Often, people say that their illnesses started during a period of high stress. In others, CFS develops more gradually, with no clear illness or other event starting it.

WHAT ARE THE SYMPTOMS?

Unlike influenza symptoms, which usually go away in a few days or weeks, CFS symptoms either hang on or come and go frequently for more than 6 months. Symptoms can include

- Headache

- Tender lymph nodes
- Fatigue and weakness
- Muscle and joint aches
- Inability to concentrate

WHO GETS CFS?

CFS was once called “yuppie flu” because those who sought help for and caused scientific interest in CFS in the early 1980s were mainly well-educated, well-off women in their 30s and 40s. Since then, doctors have seen the syndrome in people of all ages and social and economic classes from several, mostly English-speaking, countries around the world. Similar illnesses, known by different names, date back at least to the late 1800s.

Still, for unknown reasons, CFS is diagnosed two to four times more often in women than in men. In addition, some members of the medical community and the public do not know about or are skeptical of the syndrome.

HOW MANY PEOPLE HAVE CFS?

Because there is no specific laboratory test or clinical sign for CFS, no one knows how many people are affected by this illness. The Centers for Disease Control and Prevention (CDC) estimates, however, that as many as 500,000 people in the United States have CFS or a CFS-like condition.

WHAT CAUSES CFS?

While no one knows what causes CFS, for more than a century, doctors have reported seeing illnesses similar to it. In the 1860s, Dr. George Beard named a similar or identical syndrome “neurasthenia” because he thought it was a nervous disorder with weakness and fatigue.

In the mid-1980s, health experts labeled the illness “chronic EBV” infection when laboratory clues led scientists to wonder whether the Epstein-Barr virus (EBV), one of the causes of infectious mononucleosis, might be causing this group of symptoms. Evidence soon cast doubt on this theory.

HOW IS CFS DIAGNOSED?

Health care providers find it difficult to diagnose CFS because it has the same symptoms as many other diseases. When talking with and examining you, your health care provider must first rule out diseases that have similar symptoms. In follow-up visits, you and your provider need to watch for any new cues or symptoms that might show that the problem is something other than CFS.

When other diseases are ruled out and if your illness meets other criteria as well, your health care provider can diagnose you with CFS (see The CFS Case Definition).

THE CFS CASE DEFINITION

Scientific studies on EBV sparked new interest in the syndrome among medical researchers. They realized they needed a standard way to describe CFS so they could more easily compare research results.

In the late 1980s, CDC brought together a group of CFS experts to tackle this problem. Based on the best information available at the time, this group published in the March 1988 issue of the scientific journal, *Annals of Internal Medicine*, symptom and physical criteria—the first case definition—with which scientists could evaluate CFS study patients.

Not knowing the cause or a specific sign for the disease, the group agreed to call the illness “chronic fatigue syndrome” after its primary symptom. “Syndrome” means a group of symptoms that occur together but can result from different causes. (Today, CFS also is known as myalgic encephalomyelitis, postviral fatigue syndrome, and chronic fatigue and immune dysfunction syndrome.)

After using this definition for several years, CFS researchers realized some criteria were unclear or unnecessary. An international group of CFS experts reviewed the criteria for CDC, which led to the first changes in the case definition. This new definition was published in the same journal in December 1994.

In addition to revising the CFS case criteria—which reduced the required minimum number of symptoms to four out of a list of eight possible symptoms—the newer report also proposed a conceptual outline for studying the syndrome. This outline recognizes CFS as part of a range of illnesses that have fatigue as a major symptom. Although primarily intended for researchers, these guidelines should help health care providers better diagnose CFS.

Despite the existence of case definitions, the causes of CFS remain essentially unknown, and the only way to make the diagnosis is to rule out other causes of the same symptoms. This can be particularly difficult because many patients with CFS also have major psychiatric illnesses such as depression, and some of these conditions and the medicines used to treat them can cause some of the CFS symptoms.

HOW CAN I COPE WITH AND MANAGE THE ILLNESS?

Learning how to manage your fatigue, in spite of your symptoms, may help you improve the level at which you can function as well as your quality of life. A rehabilitation medicine specialist can evaluate you and teach you how to plan activities to take advantage of times when you usually feel better.

The lack of any proven effective treatment can be frustrating to both you and your health care providers. Scientists are currently conducting studies to evaluate such treatments as cognitive-behavioral therapy (a psychological therapy) and graduated exercise therapy. While early results look promising, these therapies do not work for everyone, and often induce improvement but not cure. If you have CFS, health experts recommend that you try to maintain good health by

- Eating a balanced diet and getting adequate rest
- Exercising regularly but without causing more fatigue
- Pacing yourself—physically, emotionally, and intellectually—because too much stress can aggravate your symptoms

The course of CFS varies from person to person. For most people, CFS symptoms reach a certain level and become stable early in the course of illness and thereafter come and go. Some people get better completely, but it is not clear how frequently this happens. Emotional support and counseling can help you and your loved ones cope with the uncertain outlook and the ups and downs of this illness.

Treatment

Antidepressants sometimes help to improve sleep and relieve mild, general pain in people with CFS. Because adequate doses of an antidepressant often increase fatigue, health care providers may have to start with a low dose and increase it very slowly or prescribe another type of antidepressant. Some people with CFS benefit from medicines used to treat acute anxiety as well as other nervous system problems such as dizziness and extreme tenderness in the skin. You should work closely with your health care provider to find a medicine, or a combination of medicines, that works well for you and that your body can tolerate. For more information on treatment, contact CDC (see below).

CONCLUSION

CFS is a disease of unknown cause. Early results of new treatment methods appear promising, but it is too soon to tell how well these treatments will work, and for how many CFS patients. Because CFS can be a serious illness that affects many aspects of daily living, you should consult a qualified doctor who can evaluate you and help you manage your illness.

MORE INFORMATION

MedlinePlus
National Library of Medicine
1-888-FIND-NLM (1-888-346-3656) or 301-594-5983
<http://medlineplus.gov>

Agency for Healthcare Research and Quality
Office of Communications and Knowledge Transfer
540 Gaither Road, Suite 2000
Rockville, MD 20850
<http://www.ahrq.gov>

Centers for Disease Control and Prevention
Atlanta, GA 30333
1-888-232-3228 or 404-639-1388
<http://www.cdc.gov>

Disability Benefits

Clearinghouse on Disability Information
Office of Special Education and Rehab Services
U.S. Department of Education
Room 3132, Switzer Building Washington, DC 20202
212-205-8241

Social Security Administration
Call your local social security office or
1-800-772-1213

<http://www.ssa.gov>

National Organization of Social Security Claimants' Representatives (lawyer referral)

6 Prospect Street Midland Park, NJ 07432
1-800-431-2804

<http://www.nosscr.org>

Finding a Health Care Provider.

University-affiliated medical schools may help in locating health care providers who can evaluate symptoms or who can provide an appropriate referral.

Health Professional Organization

American Association for Chronic Fatigue Syndrome
325 Ninth Avenue
Box 359780
Seattle, WA 98104
206-781-3544

<http://www.aacfs.org>

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