

Chronic Fatigue Syndrome

Chronic fatigue syndrome (CFS), also referred to as myalgic encephalomyelitis (ME) or ME/CFS, is a complex, chronic illness that affects about 1 million Americans. Women are two to four times more likely than men to be diagnosed with ME/CFS. People with ME/CFS experience a range of symptoms that makes it hard to do the daily tasks that most of us do without thinking — like dressing or bathing. Currently, there are no Food and Drug Administration-approved treatments specific to ME/CFS. Usually, treatments focus on relieving the symptoms.

Q: What causes ME/CFS?

A: No one knows for sure what causes ME/CFS. Many people say it started after a flu-like illness or other infection, such as a cold or stomach bug. It also can follow infection with the Epstein-Barr virus (the virus that causes mononucleosis or “mono”). Some people with ME/CFS report that it started after a time of great physical stress, such as following surgery.

Q: What are the symptoms of ME/CFS?

A: The main ME/CFS symptoms include:

- Feeling extremely exhausted for over 24 hours after physical or mental exercise
- Not feeling refreshed after sleeping, or having trouble sleeping
- Having a hard time concentrating, or problems with attention and memory
- Feeling dizzy or faint when sitting up or standing (due to a drop in blood pressure)
- 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 that is constant or goes away and comes back often

These symptoms may get worse after activities that use mental or physical energy. The symptoms may come and go or they may last for weeks, months, or years.

Q: How is ME/CFS diagnosed?

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

- Ask about your physical and mental health.
- Do a physical exam.
- Order lab tests based on your symptoms, such as urine and blood tests, which will tell your doctor if something other than ME/CFS might be causing your symptoms.
- Order tests that check for problems found in people with ME/CFS.
- Classify you as having ME/CFS if:
 1. You have the main symptoms for ME/CFS, including extreme fatigue or exhaustion that does not go away and prevents you from doing the things you want and need to do for you and your family; exhaustion that comes after mental or physical exercise, sleep problems, and pain.

And

2. You have had the extreme fatigue and other symptoms for 6 months or longer (3 or more months for children and adolescents).

And

3. You and your doctor cannot find another explanation for your symptoms.

Q: How is ME/CFS treated?

A: Right now, there is no cure or FDA-approved treatments for ME/CFS. But, there are things you and your doctor can do to help ease your symptoms. Because the symptoms of ME/CFS vary from person to person, the management plan you discuss with your doctor may look very different from the plan of another person with ME/CFS.

Q: I don't have insurance. How can the Affordable Care Act help me?

A: If you're uninsured or have been denied coverage in the past for ME/CFS, the Health Insurance Marketplace may be able to provide you with access to affordable coverage. With health insurance plans in the Marketplace, you can no longer be refused coverage just because you have a pre-existing health condition. Medicaid and the Children's Health Insurance Program (CHIP) also can't refuse to cover you or charge you more because of a health condition. They also can't charge women more than men. Learn more about the Affordable Care Act and the Health Insurance Marketplace at Healthcare.gov.

For more information...

For more information on ME/CFS, call the OWH Helpline at 800-994-9662 or contact the following organizations:

FEDERAL GOVERNMENT

- **Agency for Healthcare Research and Quality (AHRQ)**
 - Chronic fatigue syndrome/myalgic encephalomyelitis. A primer for clinical practitioners (<http://www.guideline.gov/content.aspx?id=38316>)
- **Centers for Disease Control and Prevention (CDC)**
Phone Number: 800-232-4636
www.cdc.gov/cfs/
- **Chronic Fatigue Syndrome Advisory Committee, HHS**
www.hhs.gov/advcomcfs/index.html

• Social Security Administration

- Revised Social Security Ruling about Evaluating Cases Involving Chronic Fatigue Syndrome for Social Security Disability (http://www.socialsecurity.gov/OP_Home/rulings/di/01/SSR2014-01-di-01.html)

• Trans-NIH ME/CFS Research Working Group, NIH

www.orwh.od.nih.gov/research/me-cfs/

ME/CFS ORGANIZATIONS

- **International Association for CFS/ME**
Phone Number: 847-258-7248
www.iacfsme.org
- **Massachusetts CFIDS/ME & FM Association**
Phone Number: 617-471-5559
www.masscifds.org



- **ME/CFS Forums**
www.mecfsforums.com
- **New Jersey ME/CFS Association, Inc.**
helpdesk@njcfsa.org
www.njcfsa.org
- **Organization for Fatigue & Fibromyalgia Education & Research (OFFER)**
www.offerutah.org
- **Patient Alliance for Neuro-endocrine-immune Disorders Organization for Research and Advocacy (PANDORA)**
Phone Number: 231-360-6830
www.pandoraorg.net
- **Phoenix Rising**
www.phoenixrising.me
- **Rocky Mountain CFS/ME & FM Association**
Phone Number: 303-423-7367
www.rmcfaf.org/index.html
- **Solve ME/CFS Initiative**
Phone Number: 704-365-2343
www.solvecfs.org
- **Wisconsin ME/CFS Association, Inc.**
Phone Number: 608-834-1001
www.wicfs-me.org

ME/CFS RESEARCH INSTITUTES

- **Chronic Fatigue Initiative**
www.cfinitiative.org
- **Institute for Neuro Immune Medicine at Nova Southeastern University**
Phone Number: 800-541-6682
www.nova.edu/nim/index.html
- **ME-CFSCommunity**
www.cfsknowledgecenter.ning.com
- **Open Medicine Institute**
Phone Number: 650-691-8633
www.openmedicineinstitute.org
- **ProHealth**
Phone Number: 800-366-6056
www.chronicfatiguesupport.com
- **Simmaron Research**
Phone Number: 775-298-0030
www.simmaronresearch.com
- **Solve ME/CFS Initiative**
Phone Number: 704-365-2343
www.solvecfs.org
- **Stanford ME/CFS Initiative**
www.chronicfatigue.stanford.edu
- **Whittemore Peterson Institute for Neuro-Immune Disease**
Phone Number: 775-682-8250
www.wpinstitute.org

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Content last updated: September 4, 2014

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