



Fibromyalgia & Chronic Fatigue Syndrome

An Information Guide

- What Is Fibromyalgia (FM)?
 - How Many People Have Fibromyalgia?
 - What Causes Fibromyalgia?
 - How Is Fibromyalgia Diagnosed?
 - How Is Fibromyalgia Treated?
- What is Chronic Fatigue Syndrome (ME/CFS)?
 - How Many People Have ME/CFS?
 - What Causes ME/CFS?
 - How Is ME/CFS Diagnosed?
 - How Is ME/CFS Treated?

Information presented in this brochure is intended to support Fibromyalgia and Chronic Fatigue Syndrome (ME/CFS) patients to take control of their health. However, we recommend that patients consult with their medical practitioner regarding treatment.

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Fibromyalgia & Chronic Fatigue Syndrome



This guide was created to help patients, families, and physicians better understand the devastating illnesses of fibromyalgia (FM) and Chronic Fatigue Syndrome (ME/CFS). One brochure cannot cover all the important issues and aspects of these illnesses, but we hope the basic questions will be satisfactorily addressed, to open a dialogue between patients and their caregivers. In this limited space, we have presented as much information as possible, and would like to emphasize that this information should in no way undermine the volumes it would take to properly describe the pain, anguish, distress and loss that accompany these horrific diseases.

The name 'chronic fatigue syndrome' was proposed in 1988 by the Centers for Disease Control in a paper describing the diagnostic criteria (Holmes 88), and much of the recent research in this country uses it. I think that few people, especially patients, really like the term. It implies a benign condition of almost no importance in which people are tired, maybe bored, probably because they work too hard or are depressed. But it has become obvious that CFIDS is not a minor or benign illness due to the stresses and strains of daily life. It is a serious, debilitating disease that robs its victims of both their health and their dignity.

Dr. David S. Bell, M.D., [The Doctor's Guide to Chronic Fatigue Syndrome](#)

How can I help myself?

Educate yourself. Utilize the most current and credible information to help you communicate with your health-care practitioner; discuss your findings and concerns so you can work together to implement the right treatment plan for you. You will need to find and work with a health-care practitioner who will tailor a treatment program to address your specific symptoms – including prescribing medications, developing an exercise program, and directing you to appropriate complementary therapies to help you achieve a better quality of life (ProHealth.com's community page features a "Physicians" section to help you find a qualified and respected physician). Complementary therapies you might wish to explore include dietary interventions, nutritional supplementation, massage, acupuncture, neurotherapy, biofeedback, and other alternative treatments.

Where else can I go for information and support?

The Internet is a great tool for conducting research and gathering information. A search from any one of the many internet search engines will lead you to a number of organizations that represent the needs and concerns of ME/CFS and FM patients and work hard to raise awareness, funding and support for these debilitating diseases. Such organizations include ProHealth.com, The CFIDS Association of America, The National Fibromyalgia Partnership, The National Fibromyalgia Association, The National CFIDS Association, and The National Fibromyalgia Research Association, among others.

Finding an understanding, knowledgeable healthcare practitioner and establishing a support system is crucial to the overall well-being of fibromyalgia and ME/CFS patients – this starts with the immediate family, who will need to be educated about the patient's debilitating symptoms and significant limitations. If you have Internet access,

ME/CFS and FM chat rooms and message boards can be a beneficial resource. There are message boards and chat rooms at ProHealth.com where you can join a growing online community of patients and their families to share information, ask questions, debate treatments, and lend and receive support. You can also search an online database to find support groups that meet near you – personal contact with other ME/CFS & FM patients can be very helpful.

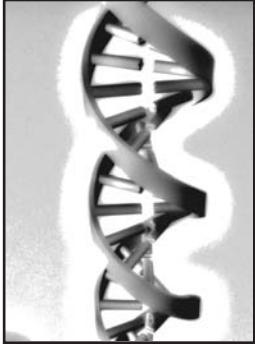
Finding financial support when you need it is important, too. Some patients with ME/CFS and fibromyalgia find that they are unable to work or must reduce their work hours. Such cases may be eligible for Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI).

What is the prognosis?

FM: Long term follow-up studies on FM have shown that it is chronic, but the symptoms may wax and wane. The impact that FM can have on daily-living activities, including the ability to work a full-time job, differs among patients. Overall, studies have shown that FM can be equally as disabling as rheumatoid arthritis.

ME/CFS: Follow-up of people meeting the ME/CFS criteria indicates that possibly 15-30% may improve but few are thought to completely recover from this terrible syndrome. Longer term follow-up studies are not available to indicate whether these "improved" ME/CFS patients later relapse with an increase in symptoms. A preliminary follow-up study by the CDC reveals that for those individuals with ME/CFS who do not recover or significantly improve after five years duration, their most prominent symptom changes from fatigue to muscle pain and concentration problems (source: Massachusetts CFIDS/FM Association Fact Sheet).

Chronic Fatigue Syndrome



What is Chronic Fatigue Syndrome?

The mystery known as Chronic Fatigue Syndrome (ME/CFS) or Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) 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 feel too tired to do normal activities or are easily exhausted with no apparent reason. The profound physical weakness of ME/CFS does not go away with a few nights of

good sleep. Instead, it slyly steals your energy and vigor over months and sometimes years.

ME/CFS was once stereotyped as a new "yuppie flu" because those who sought help for and caused scientific interest in ME/CFS in the early 1980s were mainly well-educated, well-off women in their thirties and forties. Similar illnesses, known by different names, however, date back at least to the late 1800s.

Source: NIH Fact Sheet on Chronic Fatigue Syndrome

How Many People Have ME/CFS?

It has been estimated that approximately 422 per 100,000 persons in the U.S. has ME/CFS.* This means as many as one million people nationwide suffer from the illness. 90% of patients have not been diagnosed and are not receiving proper medical care for their illness.

ME/CFS does not discriminate. It strikes people of all age, racial, ethnic, and socioeconomic groups. Research has shown that ME/CFS is about three times as common in women (522/100,000) as men, a rate similar to that of many autoimmune diseases, such as multiple sclerosis and lupus. To put this into perspective, ME/CFS is over four times more common than HIV infection in women (125/100,000), and the rate of ME/CFS in women is considerably higher than a woman's lifetime risk of getting lung cancer (63/100,000).

*Source: Jason LA, Richman JA, Rademaker AW, Jordan KM, Plioplys AV, Taylor RR, McCready W, Huang CF, Plioplys S: A Community-Based Study of Chronic Fatigue Syndrome. Arch Int Med 1999; 159(18):2129-37.

What Causes ME/CFS?

The etiology of ME/CFS continues to be investigated. Because of the syndrome's heterogeneity, many researchers argue against it being a discrete disease caused by one agent, and instead believe ME/CFS involves a common set of symptoms triggered by different combinations of various infectious and noninfectious factors. Although some ME/CFS patients exhibit any of a variety of immunologic disturbances, no single pattern of disturbances appears consistently, and many patients test in the normal range.

For many people, ME/CFS begins after a bout with a cold, bronchitis, hepatitis, or an intestinal bug. For some, it follows a bout of infectious mononucleosis. Often, people say that their illnesses started following a physical trauma, or during a period of high stress. In others, ME/CFS develops more gradually, with no clear illness or other event triggering it.

"Attitudes and beliefs about one's life and about chronic illness can be impediments to treatment. Measuring your worth by your accomplishments can result in anger and loss of ego when the ability to work is taken away or significantly reduced by CFIDS. There's an over-representation of Type A patients in this disease. A change in belief systems is essential: a change in orientation from 'doing' as a definition of yourself, to 'being' as the definition of yourself. And to orient from recovery to healing."

-Paul Cheney, M.D., leading ME/CFS physician and researcher

How is ME/CFS Diagnosed?

Diagnosis of ME/CFS is complicated by the fact that fatigue is the single most commonly reported complaint, but fatigue is also a feature of countless other conditions. Because of this, a doctor's first goal should be to rule out other illnesses.

"Since December 1988, I have been disabled by a viral illness that targeted my brain. A nationwide research study, in which I was included as a subject, found that the brains of people with this illness (CFIDS) were riddled with 'anatomical holes' that show up as 'bright lesions' on magnetic resonance imaging scans of the subcortical region.' As reported to the American Society for Microbiology and in the Journal of the American Medical Association, researchers 'do not know whether the holes will heal.' Mine have not yet. A spray of holes prickles my brain and nearly everything about me has changed."

-Floyd Skloot, from Chapter 16 of *Stricken: Voices from the Hidden Epidemic of Chronic Fatigue Syndrome*

The Centers for Disease Control (CDC) established certain criteria for diagnosing ME/CFS:

1. Fatigue that is persistent, relapsing or debilitating; does not improve with bed rest; and reduces or impairs average daily activity level by more than 50 percent for a period of at least 6 months. Patient has no previous history of fatigue.

2. The patient has 4 or more of the following symptoms, which must have persisted or recurred during 6 or more consecutive months and predated the fatigue:

- Short-term memory or concentration problems
- Sore throat
- Multi-joint pain without joint swelling or redness
- Muscle pain
- Headaches of a new type, pattern or severity
- Non-refreshing sleep
- Post-exertional malaise lasting more than 24 hours

In addition, a number of other symptoms may also occur: Poor sleep, achiness, brain fog, increased thirst, bowel disorders, recurrent infections, exhaustion after minimal exertion.

How is ME/CFS Treated?

Treating ME/CFS presents a significant challenge to persons with the illness and their physicians. As yet, there is no known cause, cure, or universal treatment for ME/CFS. Until a treatment is developed which will improve all the symptoms of ME/CFS, or correct the underlying cause, therapy is based upon the individual's presenting symptoms.

Pharmacologic therapy is directed toward the relief of specific symptoms (such as pain and sleep problems) experienced by the individual patient, and may include low-dose tricyclic agents, antidepressants (SSRIs), anxiolytic agents, Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), antimicrobials (if the patient has been diagnosed with a concurrent infection), antihistamines (for those with allergies), antihypertensive drugs, and antihypertensive drugs (beta blockers). Many patients find that complementary nutritional therapies are helpful in managing their symptoms, including vitamins and nutritional supplements. Popular choices among ME/CFS patients include NADH, vitamin D, Ginkgo Biloba, Coenzyme Q10, malic acid & magnesium formulas, a complete multivitamin, antioxidants, vitamin B-12, and undenatured whey protein and transfer factor.

Fibromyalgia

"In the past, FMS (fibromyalgia syndrome) symptoms often promoted an incorrect diagnosis of arthritis despite the fact that joints are not involved. Misdiagnosis and delayed diagnosis are common. Most people have symptoms for an average of six years before receiving the correct diagnosis. Because the pain and other symptoms are 'invisible,' people with FMS feel alone even after finally receiving the correct diagnosis. However, FMS is more common than rheumatoid arthritis, epilepsy, or multiple sclerosis, which have received more media attention."

-I. Jon Russell, M.D., Ph.D., leading FM researcher and clinical practitioner, Jenny Fransen, R.N. (from The Fibromyalgia Help Book)

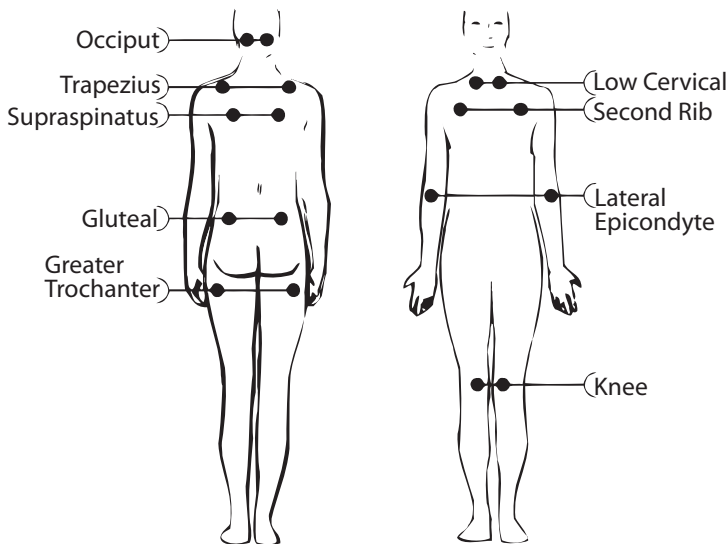


What Is Fibromyalgia (FM)?

Fibromyalgia is a chronic disorder characterized by widespread musculoskeletal pain, fatigue, and multiple tender points. "Tender points" refers to tenderness that occurs in precise, localized areas, particularly in the neck, spine, shoulders, and hips. People with fibromyalgia may also experience sleep disturbances, morning stiffness, headaches, irritable bowel syndrome, anxiety, memory and concentration problems

(cognitive disorders), and other symptoms. The name fibromyalgia comes from "fibro" meaning fibrous tissues (such as tendons and ligaments), "my" meaning muscles, and "algia" meaning pain.

The Tender Points of Fibromyalgia



How Many People Have Fibromyalgia?

According to the National Fibromyalgia Association, fibromyalgia occurs in 3 to 6 percent of the U.S. population. Some experts believe the true number affected is closer to 10 million. It primarily occurs in women of childbearing age, but children, the elderly, and men can also be affected. Fibromyalgia is the second most commonly diagnosed rheumatological disorder after osteoarthritis.

What Causes Fibromyalgia?

Although the cause of fibromyalgia is unknown, researchers have several theories about causes or triggers of the disorder. Some scientists believe that the syndrome may be caused by an injury or

trauma. This injury may affect the central nervous system. Fibromyalgia may be associated with changes in muscle metabolism, such as decreased blood flow, causing fatigue and decreased strength. Others believe the syndrome may be triggered by an infectious agent such as a virus in susceptible people, but no such agent has been identified.

How Is Fibromyalgia Diagnosed?

Fibromyalgia is difficult to diagnose because many of the symptoms mimic those of other disorders. The physician (typically a rheumatologist) reviews the patient's medical history and makes a diagnosis of fibromyalgia based on a history of chronic widespread pain. The American College of Rheumatology (ACR) developed a criteria for fibromyalgia that physicians can use in diagnosing the disorder. According to ACR criteria, a person is considered to have fibromyalgia if he or she has widespread pain for at least three months, in combination with tenderness in at least 11 of 18 specific tender point sites [see illustration of tender points].

In June 2002, a study published in *Arthritis & Rheumatism* scientifically proved what patients have been telling a skeptical medical community for years: their pain is real. To correlate subjective pain sensation with objective views of brain signals, the researchers used a super-fast form of MRI brain imaging, called functional MRI or fMRI, on 16 fibromyalgia patients and 16 people without the disease. As a result, the study offers the first objective method for corroborating what fibromyalgia patients report they feel, and what's going on in their brains at the precise moment they feel it. Lead authors Richard Gracely, Ph.D., and Daniel Clauw, M.D., did the study at Georgetown University Medical Center and the National Institutes of Health, and are continuing the work at the University of Michigan Health System.

How Is Fibromyalgia Treated?

Treatment of fibromyalgia requires a comprehensive approach. The patient, physician, and physical therapist all play an active role in the management of fibromyalgia. Patients may benefit from a combination of exercise, medication, physical therapy, and relaxation. Studies have shown that low-impact aerobic exercise, such as walking and swimming, can improve muscle fitness and reduce muscle pain and tenderness. Heat, massage, and acupuncture may also give short-term relief. Antidepressant medications may help elevate mood, improve quality of sleep, and relax muscles and several drugs have been FDA approved for treatment of Fibromyalgia. Many fibromyalgia patients also benefit from practicing yoga and meditation.

Additionally, many patients find complementary nutritional therapies are helpful. Popular choices among fibromyalgia patients include malic acid & magnesium formulas, 5-HTP, a complete multi-vitamin, glucosamine/chondroitin, natural enzymes (such as Trypsin, Chymotrypsin, Pancreatin, Bromelain, and Papain), essential fatty acids (Omega 3 and 6), Coenzyme Q10, vitamin D, vitamin B12 and NADH.

"There is no 'cookbook recipe' for fibromyalgia syndrome (FMS) or myofascial pain syndrome (MPS). What works well for one of us can be ineffective for another. A medication which puts one person to sleep may keep another awake. Each of us has our unique combination of neurotransmitter disruption and connective tissue disturbance. We need doctors who are willing to stick with us until an acceptable symptom relief level is reached."

-Devin Starlanyl, leading FM and MPS researcher