



The Carousel Network

**Chronic Neuroimmune Disease
Information and Support for Sonoma County**
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Fibromyalgia Basics

Fibromyalgia Network

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Answers to questions such as what is fibromyalgia, the symptoms and associated syndromes, possible causes, common treatments, prognosis, and self-help strategies.

The Carousel Network (TCN) offers information on the various diseases and disorders associated with chronic neuroimmune diseases, such as chronic fatigue syndrome, fibromyalgia, multiple chemical sensitivity, autoimmune thyroid disease, etc. The information is intended to help patients and caregivers make informed decisions about the patient's health, diagnostic testing, and treatment in conjunction with their health care practitioners. TCN does not diagnose patients nor recommend specific medical or palliative treatments.

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Membership is \$20/year; make checks payable to The Carousel Network, POB 366, Fulton CA 95439-0366.

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Below is a description of fibromyalgia syndrome (FMS), but because of its substantial symptom overlap with chronic fatigue syndrome (CFS), it can be viewed as applying to chronic fatigue syndrome patients as well.

WHAT IS FIBROMYALGIA SYNDROME?

FMS (fibromyalgia syndrome) is a widespread musculoskeletal pain and fatigue disorder for which the cause is still unknown. Fibromyalgia means pain in the muscles, ligaments and tendons--the fibrous tissues in the body. FMS used to be called fibrositis, implying that there was inflammation in the muscles, but research later proved that inflammation did not exist.

Most patients with fibromyalgia say that they ache all over. Their muscles may feel like they have been pulled or overworked. Sometimes the muscles twitch and at other times they burn. More women than men are afflicted with fibromyalgia, but it shows up in people of all ages.

To help your family and friends relate to your condition, have them think back to the last time they had a bad flu. Every muscle in their body shouted out in pain. In addition, they felt devoid of energy as though someone had unplugged their power supply. While the severity of symptoms fluctuate from person to person, FMS may resemble a post-viral state and this is why several experts in the field of FMS and CFS believe that these two syndromes are one and the same.

SYMPTOMS AND ASSOCIATED SYNDROMES

Pain - The pain of fibromyalgia has no boundaries. People describe the pain as deep muscular aching, burning, throbbing, shooting and stabbing. Quite often, the pain and stiffness are worse in the morning and you may hurt more in muscle groups that are used repetitively.

Fatigue - This symptom can be mild in some patients and yet incapacitating in others. The fatigue has been described as "brain fatigue" in which patients feel totally drained of energy. Many patients depict this situation by saying that they feel as though their arms and legs are tied to concrete blocks, and they have difficulty concentrating.

Sleep disorder - Most fibromyalgia patients have an associated sleep disorder called the alpha-EEG anomaly. This condition was uncovered in a sleep lab with the aid of a machine which recorded the brain waves of patients during sleep. Researchers found that fibromyalgia syndrome patients could fall asleep without much trouble, but their deep level (or stage 4) sleep was constantly interrupted by bursts of awake-like brain activity. Patients appeared to spend the night with one foot in sleep and the other one out of it. In most cases, a physician doesn't have to order expensive sleep lab tests to determine if you have disturbed sleep. If you wake up feeling as though you have just been run over by a Mack truck--what doctors refer to as unrefreshed sleep--it is reasonable for your physician to assume that you have a sleep disorder. It should be noted that most patients diagnosed with chronic fatigue syndrome have the same alpha-EEG sleep pattern and some fibromyalgia-diagnosed patients have been found to have other sleep disorders, such as sleep myoclonus or PLMS (nighttime jerking of the arms and legs), restless leg syndrome and bruxism (teeth grinding). The sleep pattern for clinically depressed patients is distinctly different from that found in FMS or CFS.

Irritable Bowel Syndrome - Constipation, diarrhea, frequent abdominal pain, abdominal gas and nausea represent symptoms frequently found in roughly 40% to 70% of fibromyalgia patients.

Chronic headaches - Recurrent migraine or tension-type headaches are seen in about 50% of fibromyalgia patients and can pose as a major problem in coping for this patient group.

Temporomandibular Joint Dysfunction Syndrome - This syndrome, sometimes referred to as TMJD, causes tremendous face and head pain in one quarter of FMS patients. However, a 1997 report indicates that as many as 90% of fibromyalgia patients may have jaw and facial tenderness that could produce, at least intermittently, symptoms of TMJD. Most of the problems associated with this condition are thought to be related to the muscles and ligaments surrounding the joint and not necessarily the joint itself.

Multiple Chemical Sensitivity Syndrome - Sensitivities to odors, noise, bright lights, medications and various foods is common in roughly 50% of FMS or CFS patients.

Other common symptoms - Painful menstrual periods (dysmenorrhea), chest pain, morning stiffness, cognitive or memory impairment, numbness and tingling sensations, muscle twitching, irritable bladder, the feeling of swollen extremities, skin sensitivities, dry eyes and mouth, frequent changes in eye prescription, dizziness, and impaired coordination can occur.

Aggravating factors - Changes in weather, cold or drafty environments, hormonal fluctuations (premenstrual and menopausal states), stress, depression, anxiety and over-exertion can all contribute to symptom flare-ups.

POSSIBLE CAUSES

The cause of fibromyalgia and chronic fatigue syndrome remains elusive, but there are many triggering events thought to precipitate its onset. A few examples would be an infection (viral or bacterial), an automobile accident or the development of another disorder, such as rheumatoid arthritis, lupus, or hypothyroidism. These triggering events probably don't cause FMS, but rather, they may awaken an underlying physiological abnormality that's already present in the form of genetic predisposition. What could this abnormality be? Theories pertaining to alterations in neurotransmitter regulation (particularly serotonin and norepinephrine, and substance P), immune system function, sleep physiology, and hormonal control are under investigation. Substance P is a pain neurotransmitter that has been found by repeat studies to be elevated threefold in the spinal fluid of fibromyalgia patients. Two hormones that have been shown to be abnormal are cortisol and growth hormone. In addition, modern brain imaging techniques are being used to explore various aspects of brain function--while the structure may be intact, there is likely a dysregulation in the way the brain operates. The body's response to exercise, stress and simple alterations in position (vertical versus horizontal) are also being evaluated to determine if the autonomic nervous system is not working properly. Your body uses many neurotransmitters, such as norepinephrine and epinephrine, to regulate your heart, lungs and other vital organs that you don't have to consciously think about. Ironically, many of the drugs prescribed for FMS/CFS may have a favorable impact on these transmitters as well.

COMMON TREATMENTS

Traditional treatments are geared toward improving the quality of sleep, as well as reducing pain. Because deep level (stage 4) sleep is so crucial for many body functions, such as tissue repair, antibody production, and perhaps even the regulation of various neurotransmitters, hormones and immune system chemicals, the sleep disorders that frequently occur in fibromyalgia and chronic fatigue patients are thought to be a major contributing factor to the symptoms of this condition. Medicines that boost your body's level of serotonin and norepinephrine--neurotransmitters that modulate sleep, pain and immune system function--are commonly prescribed. Examples of drugs in this category would include Elavil, Flexeril, Sinequan, Paxil, Serzone, Xanax and Klonopin. A low dose of one of these medications may be of help. In addition, nonsteroidal, anti-inflammatory drugs (NSAIDs) like ibuprofen may also be beneficial. Most patients will probably need to use other treatment methods as well, such as trigger point injections with lidocaine, physical therapy, acupuncture, acupressure, relaxation techniques, osteopathic manipulation, chiropractic care, therapeutic massage, or a gentle exercise program.

WHAT IS THE PROGNOSIS?

Long term follow-up studies on fibromyalgia syndrome have shown that it is chronic, but the symptoms may wax and wane. The impact that FMS can have on daily-living activities, including the ability to work a full-time job, differs among patients. Overall, studies have shown that fibromyalgia can be equally as disabling as rheumatoid arthritis. On the other hand, follow-up of people meeting the chronic fatigue syndrome criteria indicates that as many as 40% may significantly improve but few are thought to completely recover from this syndrome. Longer term follow-up studies are not available to indicate whether these "improved" CFS patients later relapse with an increase in symptoms. A preliminary follow-up study by the CDC (Centers for Disease Control) reveals that for those individuals with chronic fatigue syndrome who do not recover or significantly improve after five years duration, their most prominent symptom changes from fatigue to muscle pain with concentration problems (sounds a lot like the permanent syndrome of fibromyalgia but the CDC is not checking patients for tender points).

According to a research study by Dedra Buchwald, M.D., people who meet the criteria for both FMS and CFS tend to be at the more severe end of the spectrum of symptoms and are more likely to become work-disabled. Buchwald says her findings underscore the importance of recognizing concurrent fibromyalgia and chronic fatigue syndrome (*Rheumatic Disease Clinics of North America* 22(2):219-243, 1996).

SELF-HELP STRATEGIES

Lifestyle modifications may help you conserve your energy and minimize your pain. Learn what factors aggravate your symptoms and avoid them if possible. Join your local support group and become informed about your condition by subscribing to *Fibromyalgia Network* newsletter (click on red catalog button above). In this newsletter, you will read about research findings, new treatment options, and tips on coping with fibromyalgia and chronic fatigue syndrome. You may also contact Fibromyalgia Network for a listing of patient contacts and physician referrals. Our phone number is: (800) 853-2929. Other educational materials may be ordered from Fibromyalgia Network as well (<http://www.fmnetnews.com>).

DIAGNOSTIC CRITERIA FOR FM AND CFS

FIBROMYALGIA SYNDROME (FMS)

For the most part, routine laboratory testing reveals nothing about fibromyalgia or chronic fatigue syndrome. However, upon physical examination, the fibromyalgia patient will be sensitive to pressure in certain areas of the body called tender points. To meet the diagnostic criteria, patients must have:

- A. Widespread pain in all four quadrants of their body for a minimum of three months
- B. At least 11 of the 18 specified tender points

These 18 sites used for diagnosis cluster around the neck, shoulder, chest, hip, knee and elbow regions. Over 75 other tender points have been found to exist, but are not used for diagnostic purposes.

While many chronic pain syndromes display symptoms that overlap with fibromyalgia, the 1990 ACR multi-center criteria study (published in the February 1990 issue of *Arthritis and Rheumatism*) evaluated a total of 558 patients, of which 265 were classified as controls. These control individuals weren't your typical healthy "normals." They were age and sex matched patients with neck pain syndrome, low back pain, local tendinitis, trauma-related pain syndromes, rheumatoid arthritis, lupus, osteoarthritis of the knee or hand, and other painful disorders. These patients all had some symptoms that mimic FMS, but the trained examiners were not fooled--they hand-picked the FMS patients out of the "chronically ill" melting pot with an accuracy of 88%. FMS is not a wastebasket diagnosis!

Although the above criteria focuses on tender point count, a consensus of 35 FMS experts published a report in 1996 saying that a person does not need to have the required 11 tender points to be diagnosed and treated for FMS. This criteria was created for research purposes and many people may still have FMS with less than 11 of the required tender points as long as they have widespread pain and many of the common symptoms associated with FMS. Commonly associated symptoms include:

- fatigue
- irritable bowel (e.g., diarrhea, constipation, etc.)
- sleep disorder (or sleep that is unrefreshing)
- chronic headaches (tension-type or migraines)
- jaw pain (including TMJ dysfunction)
- cognitive or memory impairment
- post-exertional malaise and muscle pain
- morning stiffness (waking up stiff and achy)
- menstrual cramping
- numbness and tingling sensations
- dizziness or lightheadedness
- skin and chemical sensitivities

CHRONIC FATIGUE SYNDROME (CFS)

Chronic fatigue syndrome is diagnosed using the CDC 1994 guidelines published in the *Annals of Internal Medicine* 121(12):953-959. A copy of this article can be downloaded from the CDC (Centers for Disease Control and Prevention) Internet site at: <http://www.cdc.gov/ncidod/diseases/cfs/defined.htm>

To meet the criteria, patients must have:

A. Fatigue

Severe, unexplained fatigue that is not relieved by rest, which can cause disability and which has an identifiable onset (i.e., not lifelong fatigue). It must be persistent or relapsing fatigue that lasts for at least six or more consecutive months.

B. Four or more of the following symptoms:

- impaired memory or concentration problems
- tender cervical or axillary lymph nodes in neck region (note that they do not have to be swollen but just tender; this can be a problem for people with FMS who have tenderness in these areas as well)
- sore throat (but may not show signs of infection)
- muscle pain
- multi-joint pain (but not arthritis)
- new onset headaches (tension-type or migraine)
- unrefreshing sleep (wake up in the morning feeling unrested)
- post-exertional malaise (fatigue, pain and flu-like symptoms after exercise)

NOTE: Five of the above eight criteria relate to pain and are often present in FMS as well. For both the fibromyalgia and chronic fatigue syndrome criteria, patients should be evaluated for other problems that could cause pain and fatigue, such as low thyroid function, low iron stores, arthritis and many other medical conditions. If any of these problems are found and corrected, but the individual still meets the FMS criteria, these other disorders (FMS and CFS) are viewed as co-existing and deserving of special medical attention. Unfortunately, the CDC criteria excludes people with other medical problems such as hypothyroidism and lupus, but it is okay to have the tender points of FMS or a mild case of depression/anxiety.

As a patient, you are deserving of medical care if the CFS symptoms persist and you should pursue therapy options with your doctor. However, when it comes to research studies or prevalence figures determined by the CDC, you will not be included as a CFS patient if you have any other co-existing medical condition (other than FMS and mild depression/anxiety). On the other hand, FMS is viewed as a distinct clinical entity that stands on its own, regardless of whether a person has other medical problems. This may be one reason why the prevalence figures for FMS (2% of the general population) are so much higher than CFS (roughly 0.5% of the general population).

FIBROMYALGIA COPING TIPS

Effectively dealing with chronic fibromyalgia pain and fatigue from day to day requires an armament of coping strategies. A few self-help tips have been spliced from several of the past issues of *Fibromyalgia Network* newsletter in hopes that they might be of assistance to you.

Talking to other people with fibromyalgia or chronic fatigue syndrome may assist you in finding better ways to cope. Finding knowledgeable health care providers in your town may also be of benefit, especially for minimizing your frustrations.

- Handling demands on your time requires learning to say no effectively and using a "To Do" list. How should you approach it? Eliminate non-essential activities and ask loved ones for their help whenever possible. Take comfort in knowing that many healthy people, not impacted by the symptoms of FMS, don't make it through their "To Do" lists either!
- Andrea Sime, LCSW recommends the following anger coping technique to her patients. When discussing an angry situation use "I statements." For example, "I feel angry or frustrated when I try to tell you how difficult it is for me to do the things I previously was able to do (housework, childcare, work outside the home, social activities, etc.). I would really appreciate it if you would stop what you are doing and listen to me when I talk to you. Try to understand my feelings."
- Are you taking care of yourself? Here's a self-care quiz created by Katrina Berne, Ph.D. She recommends that you take time to ask yourself two important questions:

- What do I need to do more of in my life?
 - What do I need to do less of in my life?
- Don't hesitate to ask yourself these questions as time progresses or as your situation changes. Think of the answers as part of the structural foundation for building your coping skills.
 - Receiving better health care may require you to scrutinize your doctor, and there are ways to do this. Competence, fear of being sued and influence of financial incentives, and other factors can affect the way your physician treats you. In the older, more traditional fee-for-service system, the more your doctor did, the more they got paid. Timothy McCall, M.D., author of *Examining Your Doctor*, says: "In managed care, the financial incentives are turned on their head! Now physicians are often being paid more for doing less." If you want to interpret your doctor's recommendations, McCall says you need to follow the money trail.
 - Minimize daily hassles that waste your time. A study by Chris Henriksson, O.T., Ph.D., of Sweden, evaluated 250 days worth of diaries filled out by 94 FMS/CFS patients. What did she find? Personal care activities gobbled up 30% more time for people with FMS/CFS, compared to healthy people. Find ways to do tasks more efficiently and to simplify your lifestyle.
 - Hurdling painful flare-ups can be like learning how to ride a roller coaster. You need to anticipate symptom flare-ups to head them off before they become too overwhelming. The moment you sense your pain is starting to intensify, try various strategies that help keep you calm despite the bumpy road ahead.
 - Persistent pain, fatigue and your other symptoms can add stress to your life. Force yourself to take it easy on days when your symptoms are particularly bad. Also keep in mind that stress can be cumulative--it builds up throughout the day, throughout the week. If your workload and commitments start to pile up, learn to say "No."
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Related Books and Other Resources

TCN Handouts:

Fibromyalgia & Chronic Fatigue Syndrome: Related Syndromes?
 It's A Guy Thing: Men with CFS/FM
 HMO Patient Self-Defense Kit

Books:

From Fatigued to Fantastic. Jacob Teitelbaum, MD
 The Fibromyalgia Handbook. Harris H. McIlwain, Debra Fulghum Bruce
 The Fibromyalgia Survivor. Mark J. Pellegrino
 The Neuroscience and Endocrinology of Fibromyalgia. Stanley R. Pillemer

Websites:

Fibromyalgia Network: www.fmnetnews.org
 Melissa Kaplan's Chronic Neuroimmune Diseases: www.anapsid.org
 Chronic Fatigue Syndrome & Fibromyalgia: chronicfatigue.about.com
 American College of Rheumatology: www.rheumatology.org/