Fibromyalgie

FIBROMYALGIA NETWORK
http://www.fmnetnews.com/pages/basics.html
D'après les recherches du Dr Muhammad Yunus, le premier à avoir décrit la maladie au début des années 1990 et à l'avoir nommée.

(cet article n'existe plus en l'état et a été remplacé sur la même page par une version plus courte et simplifiée)

Fibromyalgia Basics

Symptoms, Treatments and Research 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.

1. 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.

1.1. 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.

1.2. 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.

1.3. 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.

1.4. 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 sydnrome 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).

1.5. 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 (all described in the catalog section).

2. DIAGNOSTIC CRITERIA FOR FIBROMYALGIA AND CFS

2.1. Fibromyalgia Syndrome (FMS)

For the most part, routine laboratory testing reveals nothing about fibromylagia 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 (see diagram)

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 foiled--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

2.2. Chronic Fatigue Syndrome (CFS)

Chronic fatigue syndrome is diagnosed using the CDC 1994 guidelines published in the Annuals 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)

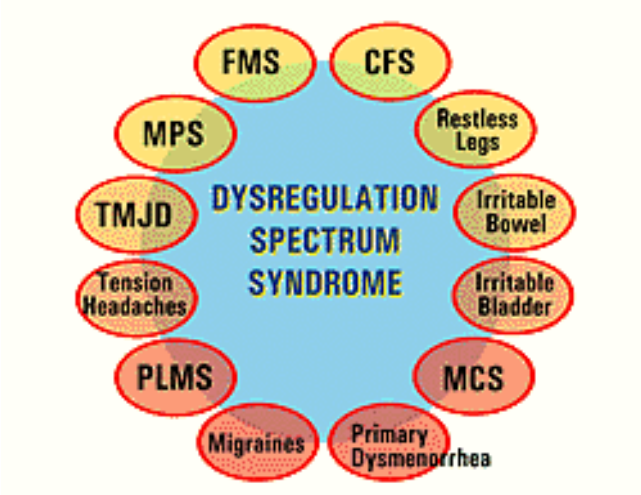
NOTE: Five of the above eight criteria relate to pain and are often present in FMS as well. For both the fibromyalgia and chronic fatigue syndrome criteria, patients should be evaluated for other problems that could cause pain and fatigue, such as low thyroid function, low iron stores, arthritis and 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).

3. Overlapping Syndromes

Fibromyalgia syndrome (FMS), chronic fatigue syndrome (CFS), multiple chemical sensitivity syndrome (MCS), myofascial pain syndrome (MPS), and other conditions form a family of overlapping syndromes. In fact, researcher Muhammad Yunus, M.D., of the University of Illinois College of Medicine claims, most patients have more than one syndrome. Thus, he views FMS and CFS as being part of a larger spectrum of conditions, which he calls Dysregulation Spectrum Syndrome or DSS (see diagram below). Dr. Yunus uses the term dysregulation to mean biophysiological abnormalities, possibly in the neuro-hormonal system.



Backing up Dr. Yunus' commentary are studies by Dedra Buchwald, M.D., of the University of Washington, Anthony Komaroff, M.D., of Brigham and Women's Hospital and Don Goldenberg, M.D., of Newton-Wellesley Hospital. It is always important to keep these overlapping syndromes in mind because the presence of one or more syndromes could impact your treatment. These three researchers have shown that CFS and FMS overlap in patients by as much as 75%. When it comes to MCS, this syndrome is present in roughly 50% of FMS and CFS diagnosed patients.

Most practicing physicians and researchers alike will tell you that the chronic pain diagnosis a person first receives is often colored by their chief symptom complaint. For example, widespread muscular pain is often diagnosed by rheumatologists as FMS. A person who is overcome by extreme fatigue and flu-like symptoms might consult an infectious disease expert and receive the diagnosis of CFS. A person who has severe jaw pain might see a dentist and be told that they have temporomandibular joint dysfunction (TMJD). People who appear to have allergic-type symptoms to a number of chemicals, foods or odors may be informed by an allergist that they have MCS. Similar situations occur with the other conditions in the family of Dysregulation Spectrum Syndrome.

Two common sleep disorders that may be present in FMS/CFS patients are: restless leg syndrome (RLS) and periodic limb movement during sleep (PLMS). According to sleep researcher Harvey Moldofsky, M.D., of the University of Toronto, RLS has been described

as someone playing soccer all night long. The patient's arms and legs just can't stay still. PLMS may feel like a startling response that occurs when you think you have reached the last step going down a flight of stairs and you fling your limbs to catch your balance as you discover that there is one step remaining. Both RLS and PLMS can cause continuous arousal movements during sleep and impede your ability to get a restful night's sleep.

Referring to the specific sleep disorders of RLS and PLMS, Dr. Yunus comments that a sleep study might be helpful if a physician suspected either condition. First of all, it may offer an objective test finding that is lacking for most FMS/CFS patients. Secondly, the treatment for RLS or PLMS is a benzodiazepine with anti-seizure properties such as Klonopin (clonazepam). The most commonly used medications for FMS/CFS, such as tricyclics like Elavil, can actually make this subgroup (30%) of patients worse. Therefore, it is important that you assist your physician by providing accurate symptom information to help identify related syndromes. This can aid in the development of appropriate treatment strategies.

3.1. Research and Treatment Updates

We want to give you ample information about Fibromyalgia Network newsletter and a good idea of the topics we cover. If you click on the "Hot Topic" button to the left, the "article of the month" will appear on your screen as an example of a full-feature article from a previous newsletter issue. Below are short-takes from the October 1997 issue newsletter, followed by a series of news clips from the July 1997 issue. We also have archived articles that may be of interest to you.

Keep up with the latest in research and treatments. Subscribe to Fibromyalgia Network today! The cost is only $25 in the United States, $27 US funds for Canadian residents and $30 US funds for people living outside North America. Just go to the catalog section of this Internet site to order by VISA or MasterCard. If you live in North America, you can simply place an order using our toll-free number: (800) 853-2929.

4. FROM THE OCTOBER 1997 ISSUE:

4.1. Comebacks for Hurtful Comments

People often say the most insensitive and hurtful things when you have an invisible illness. It's inevitable, but what can you do in these awkward situations? Hurtful comments can come from spouses, family members, and friends--some of these people are important to you and you don't want to risk alienating them. We interviewed psychotherapist and rehabilitation specialist Don Uslan, MA, MBA, CRC, of Seattle, WA, to get his take on the problem. "Patients don't need to walk away from people's remarks feeling angry and hurt," says Uslan. If the person really matters to you, he recommends finding a way to say something that will improve your level of communication and understanding with that person. In fact, we presented Uslan with several examples of hurtful comments that FMS/CFS patients regularly hear and he provided us with well thought-out, yet assertive, comebacks for our readers.

4.2. Concentration Problems and What to do About Them

Three research teams have recently published reports on "fibro fog," or what they call cognitive deficits in CFS. The results of each study showed that your concentration problems are not caused by mood or depression. Most interestingly, one team found that CFS patients without coexisting depression scored worse on a battery of cognitive tests than those who also had depression. Yes, concentration difficulties are receiving serious research attention, but the task of jogging your memory each day is still up to you. Cognitive rehabilitation specialist Linda Iger, Ph.D., from Laguna Beach, CA, presents several strategies to help FMS/CFS patients work around some of their cognitive deficit problems.

4.3. Fatigue Factor??

Could there be a chemical produced in your body that causes severe fatigue, malaise (that blah feeling) and brain fog? Researchers are taking a closer look at the affects of interleukin-6. Preliminary studies imply that interleukin-6 may be a fatigue-mediating factor as well as a brain scrambler.

4.4. Hypotension and Pain

Low resting heart rate or low blood pressure may be a sign that your nervous system isn't working right. Johns Hopkins researcher Peter Rowe, M.D., has found an association between hypotension and pain. He is currently working on a drug trial to help alleviate some of the symptoms of hypotension in hopes that it may also clear up many of the symptoms of FMS/CFS. (Several therapies used to treat neurally mediated hypotension are described in our booklet: Getting the Most Out of Your Medicines.)

4.5. What! Can't Tolerate Prozac?

A low dose of Prozac (fluoxetine) in the morning, in combination with a low dose of sedating Elavil (amitriptyline) at night, has been shown in one drug trial on FMS patients to be helpful--at least certainly better than nothing at all. But many patients can't tolerate the side effects of Prozac and its cousin drugs in this class of serotonin re-uptake inhibitors. The research on Serzone (nefazodone) and Effexor (venlafaxine) indicates that they may

be better tolerated than Prozac, with each one touting its special advantages. Find out what they are and whether you wish to talk to your doctor about one of them.

4.6. Is Chiropractic Care For You?

Many chiropractors have been trained to help people with muscle pain. Find out what chiropractic care can do for you and what questions to ask when selecting a chiropractor. Linda Simon, D.C., of Scottsdale, AZ, says you need to look for a better quality of life, and gentle chiropractic treatments that are geared to ease musculoskeletal tension may help you achieve your goals.

4.7. Handling Gloomy Winter Days

One patient wrote to us asking: "How are we supposed to deal with the cold winter days ahead when the sun doesn't shine?" A list of self-help coping tips are provided in the newsletter to assist you in gliding through the gloom this winter. In addition, there is the possibility of St. John's wort, an interesting herb that has been hyped by the media as a "natural" remedy for depression. Rather than experimenting with a health food store herb, you should first read about the research that has been done on St. John's wort.

4.8. How Do You Compare to Other Patients?

In the July 1997 issue of Fibromyalgia Network, we provided readers with a tear-out, postage pre-paid survey to fill out. We analyzed the surveys returned from over 6,000 patients to look at symptoms, triggering events and long-term prognosis. Symptoms may not vary substantially with age, but some people think they are getting better and an equal number feel that they have gotten worse over the years. Details of the 25-question survey are provided.

4.9. US Government-Funded Research on CFS and FMS

The National Institutes of Health, the major biomedical research arm of the US government, spends millions of dollars on researching CFS and FMS. Wouldn't you like to know where the tax dollars are going? There are two special CFS research centers that have been set up by NIH, one is in Seattle, WA, under the direction of Dedra Buchwald, M.D., and the other is in New Jersey, under the direction of Benjamin Natelson, M.D. Each center has an array of ongoing projects, while other researchers (independent of the centers) have received grants to pursue individual projects. As you read about the studies we have highlighted, you will note a blurring of the lines between CFS and FMS. There also seems to be strong focus on identifying possible diagnostic markers for both CFS and FMS--which is good--but much more research is needed before you can hold your head up high and proudly proclaim your diagnosis to the world.