

What is FMS?

Fibro refers to fibrous tissue – ligaments and tendons, **myo** refers to muscle, and **algia** refers to pain. Fibromyalgia involves widespread pain of the muscles, ligaments, and tendons. A syndrome is a set of signs and symptoms that are seen together.

What Causes FMS?

There appears to be a genetic factor involved in some patients. A physical trauma, such as a whiplash or spinal injury, can trigger FMS in some patients. In other cases it comes on gradually with no known cause.

How Common is FMS?

Studies estimate that between 2% and 10% of the general population have FMS. It is two to five times more common than rheumatoid arthritis.

Who Gets FMS?

FMS affects all age groups, including children, all racial/ethnic groups, and all socioeconomic strata. It is most common between the ages of 35 to 50. As in many painful conditions, such as arthritis, there is a higher prevalence of FMS in females.

Why Do More Females Get FMS Than Males?

All the mechanisms are not fully understood. Females generally have a more flexible and delicate skeleton, longer necks, and thinner, less massive muscles than males. This makes females more prone to neck and spinal injuries. The ligaments of the sacroiliac and pubic joints are stretched during pregnancy and childbirth, making them less stable and more prone to lower back injury. Females have less tolerance for pain than males, as females produce more of some brain chemicals that increase pain signals and less of some other brain chemicals that decrease pain signals.

What is the Clinical Case Definition of FMS?

You must have:

- **Widespread pain that lasts at least 3 months.** Widespread means that there is pain above and below the waist, and on both sides of the body.
- **11 or more of the 18 defined tender points.**

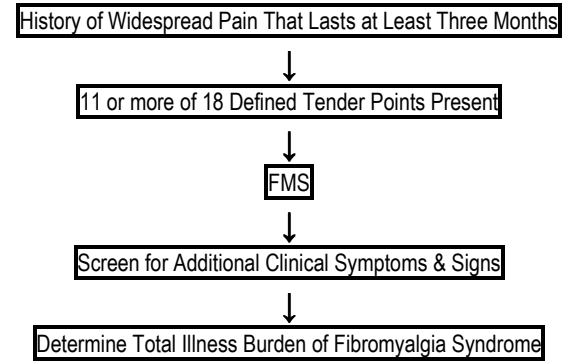
Additional Clinical Symptoms & Signs: can contribute importantly to the patients' burden of illness. Two or more of these features are usually present in most FMS patients by the time they seek medical attention. On the

other hand, it is uncommon for any individual FMS patient to have all of the associated symptoms or signs. As a result, the clinical presentation of FMS may vary somewhat, and the patterns of involvement may eventually lead to the recognition of FMS clinical subgroups. These additional clinical symptoms and signs are not required for the research classification of FMS but they are still clinically important. For these reasons, the following clinical symptoms and signs are itemized and described in an attempt to expand the compulsory pain criteria into a Clinical Case Definition of FMS.

- **Neurological Manifestations:** Neurological difficulties are often present such as hypertonic and hypotonic muscles; musculoskeletal asymmetry and dysfunction involving muscles, ligaments and joints; atypical patterns of numbness and tingling; abnormal muscle twitch response, muscle cramps, muscle weakness and fasciculations. Headaches, TMJ disorder, generalized weakness, perceptual disturbances, spatial instability, and sensory overload phenomena often occur.
- **Neurocognitive Manifestations:** Some neurocognitive difficulties usually are present. These include impaired concentration and short-term memory consolidation, impaired speed of performance, inability to multi-task, and/or cognitive overload.
- **Fatigue:** There is persistent and reactive fatigue accompanied by reduced physical and mental stamina, which often interferes with the patient's ability to exercise.
- **Sleep Dysfunction:** The patient experiences unrefreshing sleep. This is usually accompanied by sleep disturbances including insomnia, frequent nocturnal awakening, nocturnal myoclonus, and/or restless leg syndrome.
- **Autonomic and/or Neuroendocrine Manifestations:** These manifestations include cardiac arrhythmias, neurally mediated hypotension, vertigo, vasomotor instability, sicca syndrome, temperature instability, heat/cold intolerance, respiratory disturbances, intestinal and bladder motility disturbances with or without irritable bowel or bladder dysfunction, dysmenorrhea, loss of adaptability and tolerance for stress, emotional flattening, lability, and/or reactive depression.
- **Stiffness:** It is common for generalized or regional stiffness that is most severe upon awakening and typically lasts for hours, to occur. Stiffness can return during periods of inactivity during the day.

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What is the Clinical Diagnostic Procedure?



Why Are Clinical Symptoms and Signs Included in the Clinical Definition?

For research purposes, widespread pain and tender points are the only criteria needed to meet the definition of FMS. In a clinical setting, once the patient has met the criteria of FMS, it is important to assess all the patient's symptoms related to the illness in order to establish the patient's total illness burden.

What are Tender Points?

There are specific, distinctive points on the body called tender points. When they are touched with a force that is not painful to healthy people, the tender points produce pain in FMS patients. Many of the tender points are where ligaments, tendons, or muscles attach to bones.

What Do Painful Tender Points Indicate?

Just as a painful left arm can indicate malfunction of the heart, the painful tender points indicate that there is dysfunction in the central nervous system related to pain processing. FMS patients have higher levels of some chemicals that increase pain signals to the brain and lower than normal levels of some other chemicals that decrease pain signals. This results in miscommunication between the brain and the body. Unopposed pain signals are being sent to the brain and from the brain to the body.

Do FMS Symptoms Appear Suddenly?

There is often a known trigger such as a physical trauma, but the symptoms of FMS usually take several weeks to months to develop. The widespread pain and tender points usually develop first. Many of the other clinical symptoms develop more gradually.

What is it Like to Have FMS?

Do you recall the fairy tale where the princess could feel a pea under her mattress? FMS patients are extremely sensitive to pain and the pressure of a fold in their night - clothes may cause enough pain to wake them up. How many minutes can you hold a muscle in a flexed state before it becomes tired – 5, 10, 15 minutes? Many FMS patients are living with muscles that are permanently contracted and relentlessly pulling on their joints. Their constantly stressed joints are unstable and have abnormal movement, and sometimes are pulled out of alignment. This puts more stress on the muscles, which in turn puts more stress on the joints, and so the vicious circle continues. Their body can become lopsided over time. They have difficulty sleeping, and do not spend sufficient time in the deep states of sleep that are needed for restore the body. They wake up in pain, stiff, and exhausted - feeling like they have been hit by a truck. They have impaired cognitive functioning, and symptoms of ANS/endocrine origin. The severity of FMS can range from mild to debilitating.

How Are Ligaments and Tendons Involved?

Although the pain is most often felt in the muscles and joints, ligament and tendons are also sensitive to pain. When injured, they are difficult to heal as they have a limited blood supply, particularly where they attach to the bone. Lax or injured ligaments do not hold the joints in place properly so there is abnormal joint movement.

Why Are My Muscles So Tight?

When there is abnormal movement of a joint, muscles around the joint tend to react by contracting in order to help stabilize the joint and prevent further damage. Muscles that are shortened from spasm are dysfunctional and chronically fatigued.

Should I Exercise?

Although patients are usually told to exercise, there is no evidence that it will help reduce pain. On the other hand, you want to remain as active as possible without worsening your condition. An important consideration is the extent of dysfunction of the muscles and ligaments. Lax or injured ligaments cause abnormal joint movement, which in turn causes the muscles to tighten and shorten. These muscles are dysfunctional and must be warmed and stretched before any exercising. If they are not stretched and released, strengthening exercise can cause further shortening and dysfunction of the muscles.

What Precautions Must be Taken Before Exercising?

- **Medical management** of your symptoms must be under optimal control.
- **Total illness burden** must be assessed.
- **Risk factors and pain generators** must be determined and addressed.
- **Disturbances and limitations of function are a biological reality** that must be acknowledged.
- **Activity boundaries and fluctuations** must be recognized and accommodated.
- **The treating doctor knows the patient best** and should direct and coordinate rehabilitative efforts.
- **All rehabilitation personnel** must be knowledgeable about FMS.

What Kind of Exercise Program is Recommended?

Exercise is not recommended for all FMS patients.

- Exercise must be individualized.
- Begin at a comfortable level and go slow.
- Patients must have autonomy over the intensity and pacing of exercise.
- Stretching and gentle exercising are best.

Why Have I Gained Weight?

Weight gain is common. An under-active thyroid is three to twelve times more common in FMS patients than in the general public. Some medications commonly used for FMS cause weight gain. Patients are also less active due to their pain.

What Can I Do to Help Myself?

- **Education:** Become knowledgeable about FMS.
- **Early warning signs:** Pay attention to how you feel, and take your temperature before and after an activity. If your temperature drops, you have done too much. Become aware of which things aggravate your symptoms and how long you can do an activity.
- **Listen to your body and trust your feelings:** Pace your activities, do what you can without aggravating your symptoms, stop before you "crash", and rest when you need to.
- **Keep you body warm:** It is important to keep warm as your muscles tend to stiffen when they are cold.

What is the Natural Course of FMS?

Some patients experience some improvement over the years while other experience worsening of symptoms and

functional disability. Generally, the course remains stable, patients continue to be symptomatic, and do not improve overall.

Is There a Cure?

There is no known cure for FMS, but your doctor will be able to help lessen the severity of some of your symptoms.

What are Some Areas of Research?

- **Central nervous system (CNS) imaging:** Research indicates that many of the abnormalities found in FMS are associated with abnormalities in the CNS.
- **Autonomic nervous system (ANS):** Studies indicate that there are a number of abnormalities in the regulation and stabilizing roles of the ANS.
- **Sleep dysfunctions:** Sleep studies indicate that patients do not get into the deep restorative stages of sleep, and suffer insomnia and/or early wakening.
- **Neurocognitive dysfunctions** may be related to poor sleep as deep sleep strengthens short-term memory and new memory consolidation.
- **Mismanagement of sensory information:** Hypersensitivity to noise, light, and fast-paced or confusing environments, and disruption of motor information have been documented.
- **Skeletal muscle dysfunction** has been studied.
- **Pain and neurochemicals:** Research has found increased levels of some CNS chemicals that amplify pain and decreased levels of chemicals that decrease pain.
- **Neuroendocrine:** Hormone deficiencies and dysfunction of some of the neuroendocrine axes have been found.

Reference: Jain AK, and Carruthers BM, co-editors. van de Sande MI, Barron SR, Donaldson CCS, Dunne JV, Gingrich E., Heffez DS, Malone DG, Leung F Y-K, Romano TJ, Russell IJ, Saul D, Seibel DG. **FIBROMYALGIA SYNDROME: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols. A Consensus Document.** *Journal of Musculoskeletal Pain* 11(4):3-107, 2003. Printed simultaneously in, **The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners.** Editor: Russell IJ. *Haworth Medical Press*, 2004. ISBN 0-7890-2574-4. Clinical Definition reprinted with permission. © Copyright 2004 Haworth Press Inc., Binghamton, NY. Available from The Haworth Press Delivery Service: 1-800-429-6784, orders@haworthpressinc.com www.haworthpress.com
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The National ME/FM Action Network

Is a Canadian registered, non-profit organization dedicated to advancing the recognition and understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia Syndrome through education, advocacy, support and research.

Our logo, Canadian geese flying in formation, portrays working cooperatively and supporting each other.

We do not react to unfairness, we act for change.

- **National ME/FM Awareness Day:** In 1994 we successfully lobbied the federal government to proclaim May 12th as National ME/FM Awareness Day.
- **First Clinical Consensus Documents for ME/CFS and FMS,** including the first clinical definitions and diagnostic and treatment protocols, were published. The National ME/FM Action Network spearheaded the drive for the development of these clinical consensus documents, which are considered clinical milestones.
- **Disability Tax Credit Application Form:** We lobbied to revise the wording of the application form, and have applications reviewed with a decision made at the time of submission. These revisions were implemented.
- **Symposiums:** We have sponsored symposiums featuring world renowned clinicians and researchers.
- **Research Studies:** Our members have participated in numerous international research studies.
- **Petitions and Letter Campaigns:** We have sponsored campaigns to effect positive change in the attitudes, policies and practices of government, medical regulating bodies, business, and the media. Although we are an independent organization, we work cooperatively with all ME/CFS and FMS societies and support groups.
- **Independent Medical Examination (IME) Registry:** A registry of disability applicants who have attended IMEs is being developed to give us the necessary data bank of fair and unfair reports to enable us to make appropriate recommendations for change in the way IMEs are done.
- **National Doctor and Lawyer Rosters**
- **Educational Materials** have been developed.

There is still much work to be done.

Please help us help you by becoming a member! \$25.00 membership includes our newsletter "Quest".

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FIBROMYALGIA SYNDROME (FMS)

National ME/FM Action Network
512, 33 Banner Road
Nepean, Ontario K2H 8V7, Canada
Phone 613-829-6667
Fax 613-829-8518
Email: ag922@ncf.ca
Web: www.mefmaction.net

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