



**Fibromyalgia symptoms, diagnosis, treatment, and research**

**A National Fibromyalgia Partnership Publication**

\* \* \* \* \*

© Copyright 2001, National Fibromyalgia Partnership, Inc. (NFP)  
140 Zinn Way, Linden, Virginia 22642-5609 USA. Website: [www.fmpartnership.org](http://www.fmpartnership.org)

This document may be photocopied and distributed in its entirety for educational purposes without permission. It may not be reprinted in any publication or on any website or other electronic media.

The *FM Monograph* is provided for informational and educational purposes only, and no endorsement of any treatment program is intended or implied. For your own protection, always consult a medical professional before starting a new treatment.

## What Is Fibromyalgia?

Fibromyalgia (or "FM" for short) is a complex, chronic condition which causes widespread pain and fatigue as well as a variety of other symptoms. The name fibromyalgia comes from "fibro" meaning fibrous tissues (such as tendons and ligaments), "my" meaning muscles, and "algia" meaning pain. Unlike arthritis, FM does not cause pain or swelling in the joints. Rather, it produces pain in the soft tissues located around joints and in skin and organs throughout the body. Because FM has few symptoms that are outwardly visible, it has been nicknamed "the invisible disability" or the "irritable everything" syndrome.

The pain of FM usually consists of diffuse aching or burning described as "head-to-toe", and it is often accompanied by muscle spasm. Pain can vary in severity from day to day and change location, becoming more severe in parts of the body that are used the most (i.e., neck, shoulders, and feet). In some people, it can be so intense that it interferes with the performance of even simple tasks, while in others it may cause only moderate discomfort. Likewise, the fatigue of FM also varies from person to person ranging from a mild, tired feeling to the exhaustion of a flu-like illness. FM is not physically crippling nor does it interfere with a person's expected life span. Although the exact prevalence of FM in the U.S. population has not been thoroughly studied, conservative estimates place the total between 4 and 6 million. Other experts believe the true number is closer to 10 million.<sup>1</sup> An estimated 80% of sufferers are women, most of them working age, so FM has obvious consequences in terms of employment and family stress. FM also occurs in all other age groups as well as in men, and it exists in all races worldwide.

## Symptoms/Syndromes Associated With FM

In addition to pain and fatigue, a number of symptoms/syndromes are usually associated with FM. Like pain/fatigue, their severity may wax and wane over time, and individuals may differ in the extent to which they are troubled by them. Typically, patients suffer from one or more of the following:

**Stiffness:** Body stiffness is usually most apparent upon awakening and after prolonged periods of sitting or standing in one position. It may also coincide with changes in relative humidity.

**Increased Headaches Or Facial Pain:** Head/facial pain is frequently a result of extremely stiff or tender neck/shoulder muscles which refer pain upwards. It can also accompany temporomandibular joint (TMJ) dysfunction, a condition which occurs in an estimated one-third of those with FM and which affects the jaw joints and surrounding muscles.

**Sleep Disturbances:** Despite sufficient amounts of sleep, FM patients may awaken feeling unrefreshed, as if they have barely slept. Alternatively, they often have trouble falling asleep or staying asleep. The reasons for the non-restorative sleep and other sleep difficulties of fibromyalgia are unknown although early FM research in sleep labs documented disruptions in the deep (delta) sleep of some patients.

**Cognitive Disorders:** Those with FM report a number of cognitive symptoms which tend to vary from day to day. These include difficulty concentrating, "spaciness" or "fibro-fog", memory lapses, difficulty thinking of words/names, and feeling overwhelmed when engaged in multiple tasks.

**Gastrointestinal Complaints:** Digestive disturbances, abdominal pain, and bloating are quite common with FM as are constipation and/or diarrhea. Together these symptoms are usually known as "irritable bowel syndrome" or IBS. FM patients may also have difficulty swallowing food. Researchers think this may be a result of abnormalities in smooth muscle functioning in the esophagus.<sup>2</sup>

**Genito-Urinary Problems:** FM patients may experience increased frequency of urination or increased urgency to urinate, typically in the absence of a bladder infection. Some may develop a chronic, painful inflammatory condition of the bladder wall known as "interstitial cystitis"(IC). Women with FM may have more painful menstrual periods or experience a worsening of their FM symptoms during this time. Conditions such as vulvar vestibulitis or vulvodynia, characterized by a painful vulvar region and painful sexual intercourse, may also develop in women.

**Paresthesia:** Numbness or tingling, particularly in the hands or feet, sometimes accompanies FM. Also known as "paresthesia", the sensation can be described as prickling or burning.

**Myofascial Trigger Points:** A significant number of people with FM have a neuromuscular condition known as "myofascial pain syndrome (MPS)" in which very painful spots (trigger points) form in taut bands in muscles or other connective tissue, often as a result of repetitive motion injury, prolonged poor posture, or illness. Not only are these spots very painful but they also refer pain to other parts of the body in very predictable ways. Unlike FM which affects the entire body, MPS is a localized condition which occurs in very specific areas, typically the neck, shoulders, or lower back. TMJ is considered a form of MPS.

**Chest Symptoms:** Individuals with FM who engage in activities involving continuous, forward body posture (i.e., typing, sitting at a desk, working on an assembly line, etc.) often have special problems with chest and upper body (thoracic) pain and dysfunction.<sup>3</sup> The pain may cause shallow breathing and postural problems. They may also develop a condition known as costochondralgia (also referred to as costochondritis) which causes muscle pain where the ribs meet the chest bone and is frequently mistaken for heart disease. Persons with FM are also prone to a largely asymptomatic heart condition known as mitral valve prolapse (MVP) in which one of the valves of the heart bulges during a heartbeat causing a click or murmur. MVP usually does not cause much concern unless another cardiac condition is also present. (Note: Anyone experiencing chest pain should immediately consult a physician.)

**Dysequilibrium:** FM patients may be troubled by light-headedness and/or balance problems for a variety of reasons. Since fibromyalgia is thought to affect the skeletal tracking muscles of the eyes, "visual confusion" and nausea may be experienced when driving a car, reading a book, or otherwise tracking objects. (Difficulties with smooth muscles in the eye may also cause additional problems with focus.)<sup>4</sup> Alternatively, weak muscles and/or trigger points in the neck or TMJ dysfunction may cause dizziness or dysequilibrium. Researchers at Johns Hopkins Medical Center have also shown that some FM patients have a condition known as "neurally mediated

hypotension" which causes a drop in blood pressure and heart rate upon standing with resulting light-headedness, nausea, and difficulty thinking clearly.<sup>5</sup>

**Leg Sensations:** Some FM patients may develop a neurologic disorder known as "restless legs syndrome" (RLS) which involves a "creepy crawly" sensation in the legs and an irresistible urge to move the legs particularly when at rest or when lying down. One recent study suggests that as many as 31% of FM patients may have RLS.<sup>6</sup> The syndrome may also involve periodic limb movements during sleep (PLMS) which can be very disruptive to both the patient and to her/his sleeping partner.

**Sensory Sensitivity/Allergic Symptoms:** Hypersensitivity to light, sound, touch, and odors frequently occurs among those with FM and is thought to be a result of a hyperactive nervous system. In addition, persons with FM may feel chilled or cold when others around them are comfortable, or they may feel excessively warm. They may also have allergic-like reactions to a variety of substances accompanied by itching or a rash or a form of non-allergic rhinitis consisting of nasal congestion/discharge and sinus pain. However, when such symptoms occur, there is usually no measurable immune system response like that found in true allergies.<sup>7</sup>

**Skin Complaints:** Nagging symptoms, such as itchy, dry, or blotchy skin, may accompany FM. Dryness of the eyes and mouth is also not uncommon. Additionally, fibromyalgia patients may experience a sensation of swelling, particularly in extremities (i.e., fingers). A common complaint is that a ring no longer fits. However, such swelling is not like the joint inflammation of arthritis; rather, it is a localized anomaly of FM of unknown cause.

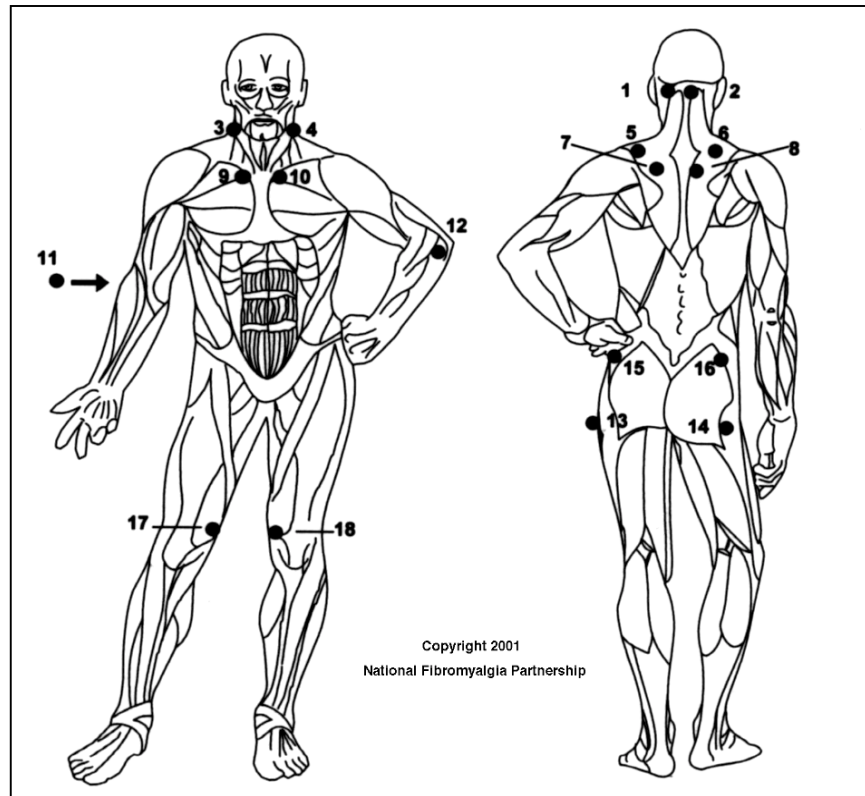
**Depression And Anxiety:** Although FM patients are frequently misdiagnosed with depression or anxiety disorders ("it's all in your head"), research has repeatedly shown that fibromyalgia is not a form of depression or hypochondriasis. Where depression or anxiety do co-exist with fibromyalgia, treatment is important as both can exacerbate FM and interfere with successful symptom management.

## Official Diagnostic Criteria

Fibromyalgia has had a long, if rather obscure, history as an illness. Masquerading behind numerous medical aliases, FM has existed throughout history and throughout the world. It was only in 1990 that official diagnostic criteria for FM were established by the American College of Rheumatology (ACR).<sup>8</sup> They include:

**(1) A History of Widespread Pain:** Chronic, widespread, musculoskeletal pain lasting longer than three months in all four quadrants of the body. ("Widespread pain" is defined as pain above and below the waist and on both sides of the body.) In addition, axial skeletal pain (in the cervical spine, anterior chest, thoracic spine, or low back) must be present.

**(2) Pain in 11 of 18 Tender Point Sites on Digital Palpation:** There are 18 tender points that doctors look for in making a fibromyalgia diagnosis (see Figure 1). According to the ACR requirements, a patient must have 11 of the 18 to be diagnosed with fibromyalgia. Approximately four kilograms of pressure (or about 9 lbs.) must be applied to a tender point, and the patient must indicate that the tender point locations are painful



**Figure 1: Fibromyalgia Tender Points Identified By  
The American College Of Rheumatology in 1990**

(at digital palpation with an approximate force of 4 kg)

- (1 & 2) Occiput:** bilateral, at the sub-occipital muscle insertions.
- (3 & 4) Low Cervical:** bilateral, at the anterior aspects of the inter-transverse spaces at C5-C7.
- (5 & 6) Trapezius:** bilateral, at the midpoint of the upper border.
- (7 & 8) Supraspinatus:** bilateral, at origins, above the scapula spine near the medial border.
- (9 & 10) Second Rib:** bilateral, at the second costochondral junctions, just lateral to the junctions on upper surfaces.
- (11 & 12) Lateral Epicondyle:** bilateral, 2 cm distal to the epicondyles.
- (13 & 14) Gluteal:** bilateral, in upper outer quadrants of buttocks in anterior fold of muscle.
- (15 & 16) Greater Trochanter:** bilateral, posterior to the trochanteric prominence.
- (17 & 18) Knee:** bilateral, at the medial fat pad proximal to the joint line.

(Source: Frederick Wolfe, M.D., et al., "The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia: Report of a Multicenter Criteria Committee," *Arthritis & Rheumatism*, Vol. 33, No. 2, February 1990, pp. 160-172.)

## National Fibromyalgia Partnership, Inc.

As the ACR criteria suggest, a fibromyalgia diagnosis requires the "hands-on" evaluation of a patient by a skilled medical professional, typically a rheumatologist, though other medical specialists are becoming very knowledgeable in this area. As patients are not usually aware of the specific anatomical origins of pain in their bodies, self-diagnosis is not advised. Because routine laboratory and x-ray testing is usually normal in fibromyalgia patients, a complete medical history and physical exam are crucial for a correct diagnosis. Since FM symptoms mimic several other diseases (for example, systemic lupus, polymyalgia rheumatica, myositis/polymyositis, thyroid disease, rheumatoid arthritis, multiple sclerosis, and others), it is necessary to rule out those conditions before a FM diagnosis is made. While a diagnosis of fibromyalgia does not preclude the co-existence of another condition, it is important to ensure that no other condition is mistaken for fibromyalgia so that appropriate treatment may be initiated.

### Limitations of the ACR Diagnostic Criteria

In the absence of diagnostic laboratory tests or x-rays, the ACR diagnostic criteria were a milestone in the recognition and study of fibromyalgia. For the first time, researchers around the world could identify and study FM patients using standardized measures. Patients who had fallen through the cracks of medical science could finally be diagnosed. Nevertheless, the criteria were not without their drawbacks.<sup>9</sup>

First, the tender point paradigm suggested that FM patients only experience pain in anatomically specific sites on the body. However, later studies, such as those reported by Granges and Littlejohn in 1993,<sup>10</sup> began suggesting that individuals with FM are sensitive to painful stimuli throughout the body, not merely at the ACR-identified locations. Today, extensive body pain is commonly associated with FM.

Secondly, it quickly became evident that patient tenderness varied day-by-day and month-by-month. As a result, tender point counts on some days could be below the required 11 while on other days they might surpass it. Furthermore, patients did not always manifest pain in all four body quadrants. Some had unilateral pain; others had pain solely in the upper or lower halves of the body.

Thirdly, the tender point exams conducted by medical professionals are subject to human error. When performed incorrectly (at the wrong anatomical point or with an incorrect amount of digital palpation), they yield erroneous results. Unfortunately, the tender points of fibromyalgia are also sometimes confused with the trigger points of myofascial pain syndrome. Not uncommonly, FM is mistaken for MPS and vice versa. The search continues for a foolproof laboratory marker for FM. Meanwhile, the ACR criteria are still the most widely used diagnostic tool for fibromyalgia.

### What Causes Fibromyalgia?

Although the cause of fibromyalgia is not currently known, research has already uncovered significant clues. For example, it is known that FM often develops after a physical trauma (i.e., an accident, injury, or severe illness) which appears to act as a trigger in predisposed individuals. Such

## National Fibromyalgia Partnership, Inc.

a trauma may affect the brain and central nervous system which in turn produce the condition that we know as fibromyalgia. During 1997, a team of investigators led by Israeli researcher Dan Buskila, M.D., reported on a study of the relationship between cervical spine injuries and the onset of fibromyalgia which found that FM was 13 times more likely to occur following a neck injury than an injury to the lower extremities.<sup>11</sup> New research by Stuart Donaldson, Ph.D.; Mary Lee Esty, Ph.D.; and Len Ochs, Ph.D., suggests that FM may actually be a "CNS Myalgia" (central nervous system myalgia) caused by a traumatic brain injury which results in abnormalities in the functioning of the brain and central nervous system.<sup>12</sup>

Not all cases of FM can be considered post-traumatic FM, as frequently no apparent "trigger" can be identified. For this reason, researchers continue to explore a number of avenues which might explain what causes fibromyalgia. There is already evidence of a strong familial pattern in many cases of FM, with fibromyalgia often following the female side of the family. Exciting new genetic studies are now underway to investigate genetics and fibromyalgia.<sup>13</sup> Additionally, current research by neurosurgeon Michael Rosner, M.D., and others is examining the extent to which FM patients suffer from Chiari malformation and cervical spinal stenosis, conditions which may be responsible for the symptoms experienced by a subset of FM patients. Still other investigators believe that fibromyalgia is caused by an infectious microorganism, such as a virus or mycoplasma.<sup>14</sup>

Once, researchers believed that something must be wrong with the muscles of FM patients because they seemed to be the origin of so much pain and dysfunction. In fact, FM's former name, "fibrositis", literally meant inflammation of the muscles and soft tissue. However, later studies ultimately found no inflammation or nerve injury. Today, researchers generally concur that FM is a condition which is centrally mediated by the brain and not a disease of the periphery. Increasingly, they have identified abnormalities in the levels of various neurochemicals in the brain. Perhaps best known is the study by I. Jon Russell, M.D., Ph.D., of the University of Texas Health Science Center in San Antonio, which demonstrated that the brain neurochemical Substance P, the agent which signals the brain to register pain, exists in FM patients at a level that is three times higher than in normal controls.<sup>15</sup> Also of interest is why the neurotransmitter serotonin, which modifies the intensity of pain signals entering the brain, appears to be deficient in patients with FM. Many of the medications currently used to treat fibromyalgia work to counteract this deficit. As it becomes increasingly clear that there are significant abnormalities in pain processing in fibromyalgia, researchers are trying to determine whether the problem is an exaggerated brain/body reaction to basically normal stimuli (allodynia) or a magnified response to real pain stimuli (hyperalgesia).<sup>16</sup>

Recently, a great deal of interest has been directed at the neuroendocrine system and the abnormal status of such neurotransmitters/neurochemicals as calcitonin-gene-related peptide, noradrenaline, endorphins, dopamine, histamine, and GABA. Hormones of the hypothalamus, pituitary, and adrenal glands are thought to be dysfunctional, too.<sup>17</sup> Research by Leslie Crofford, M.D., at the University of Michigan at Ann Arbor suggests that FM is a "stress-associated syndrome" (since it often occurs following physically or emotionally stressful events and is also exacerbated by them) with disturbances in the major stress response systems, the hypothalamic-pituitary-adrenal axis, the sympathetic nervous system, and very likely, the autonomic nervous system.<sup>18</sup> It also supports earlier ground-breaking research conducted by Robert Bennett, M.D., at the Oregon Health Sciences University, which found that the growth hormone axis is abnormal in individuals with FM. Mexican researchers Carlos Abud-Mendoza et al., studied a subset of fibromyalgia patients

## **National Fibromyalgia Partnership, Inc.**

who didn't respond well to conventional therapy and found they actually suffered from a form of subclinical hypothyroidism that was not detected by routine lab tests. The hypothyroidism was believed to be rooted in a central nervous system dysfunction.<sup>19</sup>

### **Fibromyalgia: A New Perspective**

Not long ago, medical researchers viewed fibromyalgia as a discrete medical entity. Increasingly, however, FM is being seen as a condition which overlaps significantly with certain other systemic illnesses and regional conditions that affect particular body organs. One of the earliest proponents of this view was University of Illinois researcher Muhammad Yunus, M.D., who developed the concept of Central Sensitivity Syndromes (CSS). CSS is an umbrella term for a number of associated conditions that share common clinical characteristics and a similar biophysiological mechanism. Dr. Yunus includes nine conditions in addition to fibromyalgia: chronic fatigue syndrome (CFS), irritable bowel syndrome (IBS), tension-type headaches, migraine headaches, primary dysmenorrhea, periodic limb movement disorder, restless legs syndrome (RLS), temporomandibular joint (TMJ) pain and dysfunction syndrome, and myofascial pain syndrome (MPS).

According to Dr. Yunus, members of the CSS family share certain common symptom characteristics (i.e., pain, fatigue, poor sleep, hyperalgesia, absence of structural tissue pathology, etc.); have common demographic features (i.e., female predominant); and exhibit neurohormonal dysfunctions which result in central sensitivity which in turn causes "amplified, widespread, and persistent pain."<sup>20</sup>

With this new perspective, the long list of symptoms/syndromes associated with fibromyalgia can be seen in a special context rather than as one long, baffling list of seemingly incongruent complaints. When FM and allied conditions are viewed as part of a spectrum, new, coordinated, multi-disciplinary approaches to research and treatment can be undertaken. Researchers and patients still disagree on the extent to which systemic conditions like FM, chronic fatigue syndrome, Gulf War syndrome, and multiple chemical sensitivity are similar, or even identical, conditions. Interestingly, Dr. Robert Bennett also points out that while FM patients are unlikely to develop another rheumatic or neurological disease, it is not at all unusual for patients with well established conditions like rheumatoid arthritis, Sjögren's Syndrome, or lupus to develop FM.<sup>21</sup> Other researchers have identified overlaps between FM and conditions such as inflammatory bowel disease and Lyme disease. More research will be necessary to unravel these puzzles.

### **Fibromyalgia and the NIH**

In the United States, the principal federal government entity responsible for funding fibromyalgia research is the National Institutes of Health (NIH). Within the NIH, the institute most active in FM research is the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), though a number of other institutes and offices are increasingly taking an interest in various aspects of the condition and are earmarking research dollars for FM research.

## National Fibromyalgia Partnership, Inc.

While still one of the smallest institutes in the NIH, NIAMS has devoted increased attention to fibromyalgia research in recent years. Most notably, in July 1996 it sponsored a scientific workshop on the neuroscience and endocrinology of fibromyalgia which brought together veteran fibromyalgia researchers as well as leading experts in the basic sciences of chronic pain, neuroendocrinology, circadian rhythms, and sleep disorders to help articulate research needs and opportunities and identify gaps in current knowledge. During the latter part of 1999, the NIAMS, along with three other NIH Institutes,\* awarded \$3.6 million in research grants for fibromyalgia to 15 investigators as part of its March 1998 Request for Applications (RFA), *Basic and Clinical Research on Fibromyalgia*. Of particular interest to the Institute were studies on the pathogenesis and clinical manifestations of FM.

## Fibromyalgia Management

Because there is currently no "magic pill" for fibromyalgia, treatment aims at managing FM symptoms to the greatest extent possible. Just as individual manifestations of fibromyalgia vary from patient to patient, so do successful forms of treatment (e.g., what works for one patient may not work for another). In addition, medical practitioners often have different preferences as to treatment. Because successful FM treatment can involve a variety of medical professionals, patients usually benefit from a coordinated, team approach to disease management. The most common treatment strategies, used alone or in combination, are the following:

### Medication

Although a number of medications are now available to treat fibromyalgia, two drugs, amitriptyline (Elavil) and cyclobenzaprine (Flexeril) remain quite popular and are helpful to many patients. Both have the advantage of having undergone extensive clinical testing for effectiveness in the treatment of fibromyalgia. Although prescribed for the treatment of depression in much higher dosages, the tricyclic antidepressant amitriptyline is often useful in low doses to fibromyalgia patients because it addresses the serotonin deficiency which often accompanies FM and helps control pain and promote sleep. The medication cyclobenzaprine is a muscle relaxant which has proved helpful in the treatment of FM muscle pain and spasm. Both drugs are usually taken at bedtime, or earlier in the evening if they produce a "hangover" effect the next day. For those patients who do not tolerate these drugs well, many other similar-acting medications are available (i.e., doxepin, nortriptyline, trazadone, etc.).

A relatively new group of medications which help to keep serotonin available in the system longer after it is secreted in the brain are the Selective Serotonin Reuptake Inhibitors (SSRI's). These medications tend to be reserved for FM patients who are also suffering from depression. The SSRI's include: fluoxetine (Prozac), sertraline (Zoloft), and paroxetine (Paxil), among others. Because side effects may include nervousness or insomnia, SSRI's are often prescribed at low dosages early in the day and are sometimes combined with a (sedating) tricyclic antidepressant at night.

\*The three other institutes included: The National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Dental and Craniofacial Research (NIDCR), and the Office of Research on Women's Health (ORWH).

## National Fibromyalgia Partnership, Inc.

Non-steroidal anti-inflammatory drugs (NSAIDs) are another class of medications which can be somewhat helpful in taking the edge off of pain. NSAIDs include aspirin and ibuprofen (among others), available in both prescription and non-prescription form. Caution must be exercised when using these drugs over long periods of time since they can cause gastrointestinal (GI) bleeding and ulcers.

A new type of NSAID known as a COX-2 inhibitor has also appeared in the marketplace recently. Currently available by prescription only, it is manufactured in two forms under the brand names of Celebrex (Searle Pharmaceuticals) and Vioxx (Merck). Unlike other NSAID's, these drugs carry a much lower risk of GI side effects.

Also effective in treating FM pain are analgesics like acetaminophen (Tylenol) or stronger narcotic analgesics (i.e., codeine, methadone, morphine, etc.). The latter tend to be prescribed much less frequently due to their side effects and potentially addictive qualities and are often reserved for FM patients who are experiencing painful flare-ups or who do not respond well to other pain medications. A newer drug, tramadol (Ultram), has proven popular and effective as a pain reliever for many patients in recent years. Individuals using Ultram should be aware that this drug may sometimes cause allergic reactions in persons sensitive to codeine medications. A small number of patients have also reported having seizures after taking it.<sup>22</sup>

Benzodiazepines like diazepam (Valium), alprazolam (Xanax), lorazepam (Ativan), and clonazepam (Klonopin) are often used in conjunction with low levels of ibuprofen to treat the anxiety as well as the muscle spasms that many FM patients experience. Clonazepam is helpful in treating restless legs syndrome. These drugs act as mild tranquilizers and have muscle relaxant properties. Like the narcotic analgesics, benzodiazepines can cause physical dependency and must be administered with care.

Although regular sleep medications are not generally used on a long-term basis for FM patients because they tend to impair the quality of deep sleep, the drug zolpidem tartrate (Ambien) is sometimes prescribed for short intervals to persons having severe sleep problems.

While the aforementioned drugs remain the mainstay of general FM treatment, physicians are utilizing several other drugs (many of them new) for the treatment of particular symptoms and syndromes: pramipexole for restless legs syndrome, alosetron (Lotronex) for irritable bowel syndrome, gabapentin (Neurontin) for nerve pain, and tizanidine hydrochloride (Zanaflex) for muscle spasm.

## Physical Rehabilitation

A wide variety of hands-on "bodywork" therapies are available to individuals with FM. Some can only be provided by trained physical rehabilitation professionals familiar with fibromyalgia; others may be practiced at home, under the guidance of a professional. The most widely used therapies are the following:

**Massage:** Often combined with ultrasound and/or the application of hot/cold packs, massage may be performed in a number of ways and is useful in soothing and increasing blood circulation to tense, sore muscles. It can also help remove built-up toxins like lactic acid and re-educate muscles and joints which have become mechanically misaligned.

**Myofascial Release:** A technique developed by physical therapist John Barnes, myofascial release is a very gentle form of bodywork designed to relieve restrictions and tightness in connective tissue (fascia). When properly performed, it often decreases connective tissue's pull on bones, allowing muscle fibers to relax and lengthen and organs to expand.<sup>23</sup>

**Trigger Point Therapy:** A technique designed to break up the trigger points associated with myofascial syndrome, sustained pressure is usually applied by a therapist. When trigger points cannot be broken up by this method, patients may be sent to a physician for trigger point injections.

**Craniosacral Therapy:** Developed by Dr. John Upledger, craniosacral therapy is "a gentle, non-invasive method of evaluating and enhancing the function of the craniosacral system, the environment in which the brain and spinal cord function...this manual therapy encourages the body's natural healing mechanisms to improve the operation of the central nervous system, dissipate the negative effects of stress, enhance health, and strengthen resistance to disease". Patients can perform a form of craniosacral therapy at home using a "stillpoint inducer", a product which can be purchased commercially or fabricated by knotting two tennis or racquet balls into a sock. The inducer is placed along the back of the head at the line of the ear, for gradually increased lengths of time (usually 2-20 minutes).<sup>24</sup>

**Flexyx Neurotherapy Systems (FNS):** A new FM treatment stemming from the research of Len Ochs, Ph.D.; Stuart Donaldson, Ph.D.; and Mary Lee Esty, Ph.D.; Flexyx Neurotherapy uses EEG-monitored, low frequency radio waves to treat FM patients who have suffered a traumatic brain injury.<sup>25</sup> Patients first have a brain mapping performed to identify areas of the brain which have been injured and are functioning abnormally in terms of brain wave activity. After a series of FNS treatments are administered by a specially trained professional, followup physical rehabilitation work is done to restore proper muscle balance, promote optimum posture, and address other neuromuscular problems.

**Chiropractic:** As explained by chiropractor Eric Terrell, D.C., "Chiropractic philosophy recognizes that the nervous system via the brain, spinal cord, and nerves connects to every part of the body and controls all bodily functions." Chiropractic care works to remove misalignments in the vertebrae, "unchoke" nerves, and allow the body to heal naturally.<sup>26</sup>

**Osteopathy:** A system of therapy founded by Andrew Taylor Still, osteopathy proposes that the body is often able to effectively cope with disease on its own as long as it is in a normal structural relationship, has a favorable environment, and suffers no nutritional deficits. Osteopathy uses generally accepted physical, medicinal, and surgical methods of diagnosis and therapy (including the prescription of medications) while placing chief emphasis on the musculoskeletal system. FM patients may receive manipulation (bodywork) as part of a comprehensive treatment plan.

**Stretching:** Gentle stretching can be performed by physical therapists and/or practiced by patients at home. Several videotapes have been specially created for FM patients for this purpose. Stretching is important because it helps to relieve muscle tension and spasm. In difficult to treat areas, "spray and stretch" techniques can be used to apply a spray coolant to sore muscles, deadening pain while the muscles are stretched. Patients can also perform stretching exercises using a "Theraband", a long elasticized strip which is manipulated in a number of ways, or an oversized, inflatable "Swiss ball" over which they can extend themselves in different ways to stretch and strengthen tight muscles.

**Aerobic Exercise:** Low-impact aerobic exercise is very important for fibromyalgia patients to prevent muscle atrophy (wasting), to promote the circulation of blood containing oxygen and other nutrients to muscles and connective tissue, and to build strength and endurance. Examples of low-impact exercise include walking, warm water walking/exercise, and the use of treadmills or cross-country ski machines. More and more, gentle exercise programs designed specifically for fibromyalgia and other chronic pain conditions are being offered through local health/recreation centers, the Arthritis Foundation, and by videotape. A cardinal rule for fibromyalgia patients is to start extremely slowly and conservatively and build up exercise tolerance in increments. Most medical professionals also suggest that patients find a form of exercise they like so that they will stick to it on a regular basis. However, should a FM patient find that exercise repeatedly causes high levels of pain, a consultation with a physical rehabilitation therapist (i.e., physical therapist, chiropractor, etc.) may be indicated. These professionals can help restore normal physiological relationships between muscles and joints, thereby paving the way for successful exercise.

## Complementary Therapies

A number of other approaches have proven useful in the management of fibromyalgia:

**Postural Training:** While the various forms of bodywork described above can help patients reduce pain and relax muscles, posture or movement training is often required to undo lifelong bad habits which increase pain and to reeducate muscles/joints that have become mechanically misaligned. Physical therapists can help with posture while professionals trained in the "Alexander Technique" can provide movement training. FM patients who have significant problems with foot pain resulting from poor posture or body mechanics may also benefit from special shoe inserts (orthotics) prescribed by a podiatrist.

**Occupational Therapy:** When job-related tasks contribute to pain (i.e., repetitive movements, uncomfortable work stations, etc.), an occupational therapist can help by suggesting/designing improvements. For example, for FM patients who work at a computer, ergonomic keyboards, chairs, and other products may provide significant relief.

**Relaxation Therapy:** Not surprisingly, the pain and related symptoms of fibromyalgia cause significant stress to the body. Recent research suggests that, physiologically, FM patients simply do not process stress well. Thus, effective stress management programs are recommended. Among those used for fibromyalgia are: biofeedback, watsu, meditation, breathing exercises, yoga, tai chi, progressive relaxation, guided imagery, and autogenic training. Patients need to receive initial

## National Fibromyalgia Partnership, Inc.

training for many of these but can often continue practicing the concepts they have learned on their own. Books, audiotapes, and classes are widely available to help.

**Nutrition:** Nutritional therapy for fibromyalgia can be helpful in counteracting stress, ridding the body of toxins, and restoring nutrients which have been malabsorbed or robbed from the body. Simple approaches may include the use of vitamin/mineral supplements to combat stress, replace deficiencies, and support the immune system. Nutritionists commonly urge fibromyalgia patients to limit the amount of sugar, caffeine, and alcohol they consume since these substances have been shown to irritate muscles and stress the system. More sophisticated nutritional programs using diet, toxin cleansing, and supplementation generally require a nutritionist familiar with FM who tests patients to determine their particular nutritional needs. As with other fibromyalgia treatments, a specifically designed nutritional plan that works well for one patient may prove disastrous for another.<sup>27</sup> Unfortunately, a number of unproven "miracle" diets and supplements are advertised for FM and should be investigated carefully by patients before use. When starting a new nutritional program, it is important to inform your physician as some supplements and foods cause serious, or even dangerous, side effects when mixed with certain medications.

**Acupuncture:** While a number of alternative remedies have been offered for FM management, very few have been rigorously studied in clinical settings. Acupuncture, a treatment which involves the insertion of small needles at specific anatomical points identified as conducive to energy, has received more scrutiny than most. In November 1997, the National Institutes of Health convened a Consensus Panel on Acupuncture which issued a statement indicating that (1) pain from musculoskeletal conditions and (2) nausea were the entities most successfully treated by acupuncture.<sup>28</sup> In February 1998, the NIH Office of Alternative Medicine, along with NIAMS and several other institutes/offices, announced the "Acupuncture Clinical Trial Pilot Grants" designed to increase the quality of clinical research evaluating the efficacy of acupuncture for the treatment or prevention of fibromyalgia and several other diseases/conditions.

**Cognitive/Behavioral Therapy:** As trite as it may sound, attitude is often one of the strongest predictors of how well a patient is able to manage FM. Research has shown that patients who are not actively engaged in taking charge of their illness simply aren't as likely to get better. Those who unknowingly adopt maladaptive illness behaviors (i.e., hopelessness, victim mentality) are less likely to aggressively seek help through exercise, physical therapy, or medications. Getting better with FM can be very tough, but patients should not give up. Constructive help is available. If negative thinking is a problem, cognitive/behavioral therapy (via classes, audiotapes, and or individual counseling) can be a beneficial resource.

**Common Sense:** Individuals with FM can make a meaningful contribution to their own treatment by learning how their bodies respond to fibromyalgia. For example, do certain activities (especially those involving repeated or prolonged muscle use) tend to exacerbate FM? If so, how can they be modified or replaced and thus better tolerated? Do certain types/levels of activity cause delayed pain reactions a day or two later? Also crucial is learning to pace yourself, take frequent breaks, and/or say "No" to requests that simply cannot be accommodated on a particularly bad day. If certain commitments cannot be avoided, try to get extra rest before and after to aid in recovery. While these ideas sound simple in theory, they are often difficult to implement.

## National Fibromyalgia Partnership, Inc.

**Self Tolerance:** It is all too easy for individuals with FM to be excessively hard on themselves. After realizing that they are unable to accomplish all they once did, they can become overly critical or disparaging of themselves in their "self-talk". Guilt may also become a problem as they must depend on friends and family to a greater extent for help with daily activities while "letting them down" by saying "no" to social outings when symptoms are severe. If surrounded by people who don't "believe in" fibromyalgia, patients may wonder if their FM really IS just a figment of their imagination or is somehow "their fault". And, if a helpful treatment regimen is not discovered right away, they may feel discouraged or worry that others think they just aren't trying hard enough to feel better.

Newly diagnosed patients need to know that it is not their fault that they have fibromyalgia. FM is a legitimate, medically recognized condition which is being actively researched every day. Public awareness of FM is rapidly increasing, too. It takes enormous energy as well as courage to adjust to FM and find treatments that work well without wasting precious energy on guilt, self-deprecation, and doubt.

Rheumatologist and FM specialist Russell Rothenberg, M.D., has words of hope to share. Just because someone starts out with severe symptoms doesn't mean that (s)he cannot find worthwhile improvement with a skillfully devised and comprehensive treatment program. "Patients need to know that medication, judicious rest, exercise, physical therapy, and good diets can do more than just control the symptoms of fibromyalgia; they can control the disease process as well. There is no cure for FM, but people do get better! Hopefully, as better medications that are more specific for fibromyalgia are developed, and people are diagnosed earlier in their illness, more individuals with fibromyalgia will go into remission, or at least partial remission, and feel better."<sup>29</sup>

## References

1. Muhammad Yunus, M.D., "What's New in Fibromyalgia Syndrome? A Review of Abstracts Presented in the 1996 American College of Rheumatology Annual Scientific Meeting: Part 1", *The Fibromyalgia Times*, Vol. 1, No. 4, Winter 1997, p.4.
2. Daniel Clauw, M.D., "Update on the Physiology and Management of Fibromyalgia Syndrome," seminar presentation hosted by the National Fibromyalgia Partnership (formerly the Fibromyalgia Association of Greater Washington, Inc.) on 11/10/97, Bethesda, MD.
3. See "Thoracic Pain and Dysfunction," *Fibromyalgia Frontiers*, Vol. 5, # 2, Spring 1997.
4. Clauw, *ibid*.
5. Bou-Holaigah, M.D., et al., "Provocation of Hypotension and Pain During Upright Tilt Table Testing in Adults with Fibromyalgia," *Clinical and Experimental Rheumatology*, Vol. 15, 1997, pp.239-246.
6. Muhammad Yunus, M.D., "Fibromyalgia and Other Overlapping Syndromes: The Concept of Dysregulation Spectrum Syndrome," seminar presentation hosted by the National Fibromyalgia Partnership (formerly the Fibromyalgia Association of Greater Washington, Inc.) on 11/10/97, Bethesda, MD.
7. Daniel Clauw, M.D., "New Insights into Fibromyalgia," *Fibromyalgia Frontiers*, Vol. 2, # 4, Fall 1994.
8. Frederick Wolfe, M.D., et al., "The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia: Report of a Multicenter Criteria Committee," *Arthritis & Rheumatism*, Vol. 33, No. 2, February 1990, pp. 160-172.
9. Clauw, *ibid*.
10. G. Granges and G. Littlejohn, "Pressure Pain Threshold in Pain-Free Subjects, in Patients with Chronic Regional Pain Syndromes, and in Patients with Fibromyalgia," *Arthritis & Rheumatism*, May 1993, Vol. 36, #65, pp. 642-6.

## National Fibromyalgia Partnership, Inc.

11. D. Buskila, M.D., et al., "Increased Rates of Fibromyalgia Following Cervical Spine Injury: A Controlled Study of 161 Cases of Traumatic Injury," *Arthritis & Rheumatism*, Vol. 40, No. 3, March 1997, pp. 446-52.
12. Stuart Donaldson, Ph.D., et al., "Fibromyalgia: A Retrospective Study of 252 Consecutive Referrals," *Canadian Journal of Clinical Medicine*, Vol. 5, # 6, June 1998.
13. For example, in 1999, NIAMS/NIH awarded a grant to Case Western Reserve University (Cleveland, OH) researcher Jane Olsen, M.D., for her project entitled, "Mapping Genes for Fibromyalgia Syndrome." In addition, researchers Muhammad Yunus, M.D., and Debra Buchwald, M.D., have also been very active in the study of genetics and FM.
14. See "Study of Mycoplasma in Gulf War Vets May Provide Clues for FMS/ CFS." *Fibromyalgia Frontiers*, Vol. 7, #3, July/August 1999, pp. 1-11.
15. I. Jon Russell, M.D., Ph.D., et al., "Elevated Cerebrospinal Fluid Levels of Substance P in Patients with the Fibromyalgia Syndrome," *Arthritis & Rheumatism*, Vol. 37, No. 11, November 1994, pp.1593-1601. See also "Cerebrospinal Fluid (CSF) Substance P (SP) in Fibromyalgia (FM): Changes in CSP SP Over Time, Parallel Changes in Clinical Activity," *Arthritis & Rheumatism*, Abstract Supplement, Vol. 41, #9, September 1998.
16. J. Fransen, R.N., and I.Jon Russell, M.D., Ph.D., *The Fibromyalgia Help Book: Practical Guide to Living Better with Fibromyalgia*, St. Paul, MN: Smith House Press, 1996, pp. 25-26.
17. Muhammad Yunus, M.D., "Dysfunctional Spectrum Syndrome: A Unified Concept for Many Common Maladies," *Fibromyalgia Frontiers*, Vol. 4, No. 4, Fall 1996, p. 3.
18. Leslie J. Crofford, M.D., et al. "Neurohormonal Perturbations in Fibromyalgia," *Baillieres Clin Rheumatology*, Vol. 10, No. 2, May 1996, pp. 365-78. See also, Leslie J. Crofford, M.D., "The Hypothalamic-Pituitary-Adrenal Stress Axis in the Fibromyalgia Syndrome," *Journal of Musculoskeletal Pain*, The Haworth Press, Vol. 4, No. 1/2, 1996.
19. Carlos Abud-Mendoza et al., " Hypothalamus-Hypophysis-Thyroid Axis Dysfunction in Patients with Refractory Fibromyalgia," *Arthritis & Rheumatism*, Abstract Supplement, Vol. 40, #9, September 1997.
20. Muhammad Yunus, M.D., "Central Sensitivity Syndromes: A Unified Concept for Fibromyalgia and Other Similar Maladies," *JIRA*, Vol. 8, # 1, March 2000. See also Muhammad Yunus, "Fibromyalgia and Other Overlapping Syndromes: The Concept of Dysregulation Spectrum Syndrome," seminar hosted by the National Fibromyalgia Partnership (formerly the Fibromyalgia Association of Greater Washington, Inc.) on 11/10/97, Bethesda, MD., and Muhammad Yunus, "Dysfunction Spectrum Syndrome: A Unified Concept for Many Common Maladies," *Fibromyalgia Frontiers*, Vol. 4, No. 4, Fall 1996.
21. Robert Bennett, M.D., "An Overview of Fibromyalgia for Newly Diagnosed Patients," Website of the Oregon Fibromyalgia Foundation, [www.myalgia.com](http://www.myalgia.com).
22. Ortho-McNeil Pharmaceutical, Letter to Health Care Professionals, 3/20/96.
23. Hanna Meyer, L.M.T., C.N.M.T., Presentation hosted by the National Fibromyalgia Partnership (formerly the Fibromyalgia Association of Greater Washington, Inc.) on 3/7/98.
24. Sue Muris, PT, "Exploring Body Work for FM Self-Care," *Fibromyalgia Frontiers*, Vol. 4, No. 3, Summer 1996, p.4.
25. See "EEG-Driven Stimulation: Hitting the 'Reset Button' in Fibromyalgia Patients," *Fibromyalgia Frontiers*, Vol. 6, #4, July/August 1998, and "CNS Myalgia: A New Paradigm for Fibromyalgia," *Fibromyalgia Frontiers*, Vol. 7, #3, September/October 1999.
26. Eric D. Terrell, D.C., "Chiropractic & Chronic Pain", *Fibromyalgia Frontiers*, Vol. 5, No. 4, Fall 1997.
27. "Panel on Nutrition," a speaker presentation hosted by the National Fibromyalgia Partnership (formerly the Fibromyalgia Association of Greater Washington, Inc.) on 6/4/97 featuring Virginia Inglese, M.A., R.D., CEDS; Sam Makoul, BCCN; Marti Pattishall, and Victoria Wood, M.P.H., R.D.
28. *Complementary and Alternative Medicine at the NIH*, Vol. 5, No. 1, January 1998.
29. Russell Rothenberg, M.D., "To The Newly Diagnosed Patient," *Fibromyalgia Frontiers*, Vol. 3, No. 1, Winter 1995, p. 7.

**The *FM Monograph* is available in booklet form from the National Fibromyalgia Partnership. To order, visit our online store or write for a catalog: NFP, Inc., 140 Zinn Way, Linden, VA 22642.**