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## **Advice from an FM Expert**

*Editor's Note: We suggest you pass this article on to your treating physicians. Much of Dr. Bennett's treatment protocol also applies to individuals with CFIDS/ME, as the two conditions closely parallel each other.*

If you are reading this you probably have a common syndrome of chronic musculoskeletal pain called fibromyalgia (FM). This chronic pain state is caused by abnormalities of sensory processing within the spinal cord and brain. As such you will usually experience a bewildering array of bodily and psychological problems that can seldom be "cured". However, armed with both patience and knowledge, many FM patients can be helped to live with less pain and be more productive. In my own evolving experience of dealing with this problem, I can identify seven aspects of management that are of importance for your doctor to successfully manage your FM.

### **My Advice to Doctors who care for FM Patients**

1. Realize that FM patients are going to be a chronic challenge.
2. Be non-judgmental and prepared to be an advocate.
3. Understand the pathophysiological basis for symptoms.
4. Analyze and treat pain complaints in a systemic approach.
5. Recognize and treat psychological problems at an early stage.

6. Recognize associated syndromes of disordered sensory processing.

7. Involve all FM patients in a program of stretching and gentle aerobic exercise.

### **Treatment of Pain**

Pain is the primary over-riding problem for most of you. Many of the problems you experience are largely a secondary consequence of having chronic pain. When pain is even partly relieved, FM patients experience a significant improvement in psychological distress, cognitive abilities, sleep and functional capacity. A total elimination of pain is currently not possible in the majority of FM patients. However, worthwhile improvements can nearly always be achieved by a careful systematic analysis of the pain complaints.

As a generalization, FM-related pain can be divided into general pain (i.e., the chronic background pain experience) and focal pain (i.e., the intensification of pain in a specific region—usually aggravated by movement). The latter is probably a potent driving force in the generation of central sensitization. Attempts to break the pain cycle, to enable patients to be more functional are especially important.

In general, most FM patients do not derive a great deal of benefit from non-steroidal anti-inflammatory drugs (NSAID) preparations or acetaminophen, although NSAIDs are very useful in the treatment of associated joint pain problems such as osteoarthritis. Prednisone and other steroids have been shown to be ineffective in the long-term treatment of FM.

### **General Pain**

The use of NSAIDs (e.g., ibuprofen, aspirin, etc.) is usually disappointing. It is unusual for FM patients to experience more than a 20% relief of their pain, but many consider this to be worthwhile. Narcotics (propoxyphene, codeine, and oxycodone) often provide a worthwhile relief of pain. In most patients, concerns about addiction, dependency and tolerance are ill-founded. Ultram (Tramadol) and Ultracet (Tramadol + Tylenol), are the most useful pain medications in many patients. They both have the advantages of having a low abuse potential

and are not a prostaglandin inhibitor. Tramadol reduces the epileptogenic threshold and it should not be used in patients with seizure disorders.

Currently, opiates are the most effective medications for managing most chronic pain states (Friedman OP 1990, Portenoy 1996). Their use is often condemned out of ignorance regarding their propensity to cause addiction, physical dependence and tolerance (Melzack 1990, Portenoy *et al* 1997, Wall 1997).

While physical dependence (defined as a withdrawal syndrome on abrupt discontinuation) is inevitable, this should not be equated with addiction (Portenoy 1996). Addiction is a dysfunctional state occurring as a result of the unrestrained use of a drug for its mind-altering properties. Manipulation of the medical system and the acquisition of narcotics from non-medical sources are common accompaniments. Addiction should not be confused with "pseudo-addiction". This is a drug-seeking behavior generated by attempts to obtain appropriate pain relief in the face of *under-treatment* of pain.

Opiates should never be the first choice for pain relief in FM, but they should not be withheld if less powerful analgesics have failed. In my experience many FM patients want to try opioid medications, but then give up on them due to unacceptable side effects, such as mental fog, increased tiredness, dizziness, constipation and itching.

### **Local Pain**

Although you are experiencing widespread body pain—a manifestation of central sensitization—you will also have multiple areas of tenderness in muscles—so called "myofascial trigger points." The severity of pain and the location of these "hot spots" typically varies from month to month, and the judicious use of myofascial trigger point injections and

spray and stretch (see section on focal pain) is worthwhile in selected patients. It is often worthwhile for your physician to identify the most symptomatic points for myofascial therapy. The steps involved in the injection of trigger points are:

1. Accurate identification of the trigger point.
2. Identification and elimination of aggravating factors.
3. The precise injection of the myofascial trigger points with 1% procaine (a local anesthetic).
4. Passive stretching of the involved muscle after the local anesthetic has taken effect; this is often aided by spraying the overlying skin with an ethyl chloride spray. In most FM patients, this myofascial therapy needs to be repeated over a period of several weeks and occasionally over several months.

Unresponsiveness is usually due to failure to eliminate an aggravating factor, imprecise injection of the trigger point, or failure to inject satellite trigger points. Trigger points are usually injected with 3 to 5 ml of 1-% procaine. Please note that these are not "steroid shots."

Performing "myofascial spray and stretch" often enhances the efficacy of trigger point injections immediately after the injections. Spray and stretch consists of an application of a vapocoolant spray, such as ethyl chloride over the muscle with simultaneous passive stretching. A fine stream of the spray is aimed toward the skin directly overlying the muscle with the active trigger point. A few sweeps of the spray are passed over the trigger point and the zone of reference. This is followed by a progressively increasing passive stretch of the muscle.

Evaluation by an occupational and physical therapist often provides worthwhile advice on improved ergonomics, biomechanical imbalance and the formulation of a regular stretching program. Hands-on physical therapy treatment with heat modalities is reserved for major flares of pain, as there is no evidence that long-term therapy alters the course of the disorder. The same comments can be made for acupuncture, TENS units and various massage techniques.

### **Treatment of Sleep Disorders**

Non-restorative sleep is a problem for most of you and contributes to your feelings of fatigue and seems to intensify your experience of pain. Effective management involves (1) ensuring an adherence to the basic rules of sleep hygiene, (2) regular low grade exercise, (3) adequate treatment of associated psychological problems (depression, anxiety etc.) and (4) the prescription of low dose tricyclic antidepressants or TCAs (amitriptyline, trazadone, doxepin, imipramine etc.).

Some FM patients cannot tolerate TCAs due to unacceptable levels of daytime drowsiness or weight gain. In these patients, benzodiazepine-like medications such as Ambien (zolpidem) are usually very useful. Some FM patients suffer from a primary sleep disorder, which requires specialized management. About 25% of male and 15% of female FM patients have sleep apnea. Unless specific questions about this possibility are asked, sleep apnea will often be missed. Patients with sleep apnea usually require treatment with positive airway pressure (CPAP) or surgery. By far the most common sleep disorder in FM patients is restless leg syndrome. This can be effectively treated with L-Dopa/ carbidopa (Sinemet 10/100 mg at supertime) or clonazepam (Klonopin 0.5 or 1.0 mg at bedtime).

### **Exercise for FM**

FM patients cannot afford not to exercise as de-conditioned muscles are more prone to microtrauma and inactivity begets dysfunctional behavioral problems. However, musculoskeletal pain and severe fatigue are powerful conditioners for inactivity. All FM patients need to have a home program with muscle stretching and gentle strengthening, and aerobic conditioning.

There are several points that need to be stressed about exercise in FM patients:

(1) Exercise is health training, not sport's training;

(2) Exercise should be non-impact loading;

(3) Aerobic exercise should be done for 30 minutes each day. This may be broken down into three 10-minute periods or other combinations, such as two 15 minute periods, to give a cumulative total of 30 minutes. This should be the aim—it may take 6-12 months to achieve this level.

(4) Strength training should emphasize on concentric work and avoid eccentric muscle contractions.

(5) Regular exercise needs to become part of the usual lifestyle; it is not merely a 3-6 month program to restore you to health.

Suitable aerobic exercise includes: regular walking, the use of a stationery exercycle or Nordic track (initially not using the arm component). Patients who are very de-conditioned or incapacitated should be started with water therapy using a buoyancy belt (Aqua-jogger). [*We highly recommend ongoing pool exercise programs for both FM and CFIDS/ME patients to reduce pain and to safely increase conditioning.--Ed*

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### Recognition of Secondary Distress

As you suffer from chronic pain there is a distinct possibility that you may develop secondary psychological disturbances, such as depression, anger, fear, withdrawal and anxiety. Sometimes these secondary reactions become the "major problem" for some patients. The prompt diagnosis and treatment of these secondary features is essential to effective overall management of FM patients. Some FM patients develop a reduced functional ability and have difficulty being competitively employed. In such cases your doctor will hopefully act as an advocate in sanctioning a reduced or modified load at work and at home.

Unless you have a severe psychiatric illness (e.g., major depressive illness or a psychosis), referral to psychiatrists is usually non-productive. Psychological counseling, particularly the use of techniques such as cognitive restructuring and biofeedback, may benefit some patients who are having difficulties coping with the realities of living with their pain and associated problems.

### Fibromyalgia Associated Syndromes

It is not unusual for FM patients to have an array of bodily complaints other than musculoskeletal pain. It is now thought that these symptoms are a result of the abnormal sensory processing as described in the previous section. Recognition and treatment of these associated problems are important in the overall management of your FM.

- Chronic fatigue
- Restless Leg Syndrome
- Irritable Bowel Syndrome
- Irritable bladder syndrome
- Cognitive dysfunction
- Cold intolerance
- Multiple Sensitivities
- Dizziness
- Neurally Mediated Hypotension
- Non-restorative sleep (above)

1. **Chronic fatigue**—The common treatable causes of chronic fatigue in FM patients are: (1) inappropriate dosing of medications (TCAs, drugs with antihistamine actions, benzodiazepines etc.); (2) depression; (3) aerobic deconditioning; (4) a primary sleep disorder (e.g. sleep apnea); (5) non-restorative sleep (see above); and (6) neurally mediated hypotension. A new drug called Provigil is of some help when used intermittently for management of fatigue.

2. **Restless leg syndrome**—This strictly refers to daytime (usually maximal in the evening) symptoms of (1) unusual sensations in the lower limbs (but can occur in arms or even scalp) that are often described as paresthesia (numbness, tingling, itching, muscle crawling); and (2) a restlessness, in that stretching or walking eases the sensory symptoms. This daytime symptomatology is nearly always accompanied by a sleep disorder—now referred to as periodic limb movement disorder (formerly nocturnal myoclonus). Treatment is simple and very effective—DOPA / Levodopa (Sinemet) in an early evening dose of 10/100 (a minority require a higher dose or use of the long acting preparations).

3. **Irritable bowel syndrome**—This common syndrome of GI distress that occurs in about 20% of the general population is found in about 60% of FM patients. The symptoms are those of abdominal pain, distension with an altered bowel habit (constipation, diarrhea or an alternating disturbance). Typically the abdominal discomfort is improved by bowel evacuation. Due to abnormal sensory processing these symptoms may be quite distressing to FM patients. Treatment involves (1) elimination of foods that aggravate symptoms; (2) minimizing psychological distress; (3) adhering to basic rules for maintaining a regular bowel habit; (4) prescribing medications for specific symptoms; constipation (stool softener, fiber supplementation and gentle laxatives such as bisacodyl), diarrhea (loperamide or diphenoxylate) and antispasmodics (dicyclomine or anticholinergic /sedative preparations such as Donnatal).

**4. Irritable bladder syndrome**—This is found in 40-60% of FM patients. The initial incorrect diagnoses are usually recurrent urinary tract infections, interstitial cystitis or a gynecological condition. Once these possibilities have been ruled out a diagnosis of irritable bladder syndrome (also called female urethral syndrome) should be considered. The typical symptoms are those of suprapubic discomfort with an urgency to void, often accompanied by frequency and dysuria. In a sub-population of FM patients this is related to a myofascial trigger point in the pubic insertion of the rectus abdominus muscles and may be helped by a procaine myofascial trigger point injection. Treatment involves: (1) increasing intake of water; (2) avoiding bladder irritants such as fruit juices (especially cranberry); (3) pelvic floor exercises (e.g. Kegel exercises); and (4) the prescription of antispasmodic medications (e.g. oxybutinin, flavoxate, hyoscamine).

**5. Cognitive dysfunction**—This is a common problem for many FM patients. It adversely affects the ability to be competitively employed and may cause concern as to an early dementing type of neurodegenerative disease. In practice the latter concern has never been a problem and patients can be reassured. The cause of poor memory and problems with concentration is, in most patients, related to the distracting effects of chronic pain and mental fatigue. Thus the effective treatment of cognitive dysfunction in FM is dependent on the successful management of the other symptoms.

**6. Cold intolerance**—About 30% of FM patients complain of cold intolerance. In most cases this amounts to needing warmer clothing or turning up the heat in their homes. Some patients develop a true primary Raynaud's phenomenon (which may mislead an unknowing physician to consider diagnoses such as Lupus (SLE) or scleroderma). Many FM patients have cold hands and feet, and some have *cutis marmorata* (a lace like pattern of purple discoloration of their extremities on cold exposure). Treatment involves: (1) keeping warm; (2) low-grade aerobic exercise (which improves peripheral circulation); (3) treatment of neurally-mediated hypotension; and (4) the prescription of vasodilators such as the calcium channel blockers (but these may aggravate the problem in patients with hypotension).

**7. Multiple sensitivities**—One result of disordered sensory processing is that many sensations are amplified in FM patients. In general FM patients are less tolerant of adverse weather, loud noises, bright lights and other sensory overloads. Treatment involves being aware that this is an FM-related problem and employing avoidance tactics.

**8. Dizziness**—This is a common complaint of FM patients. Before this symptom is attributable to FM a thorough evaluation for other neurological causes should be pursued (e.g. postural vertigo, vestibular disorders, 8th nerve tumors, demyelinating disorders, brain stem ischemia and cervical myelopathy). In many cases no obvious cause is found, despite sophisticated testing. Treatable causes related to FM include: (1) proprioceptive (awareness of posture, movement, changes in equilibrium) dysfunction secondary to muscle deconditioning; (2) proprioceptive dysfunction secondary to myofascial trigger points in the sterno-cleido-mastoids and other neck muscles; (3) neurally mediated hypotension (see below); and (4) medication side effects. Treatment is dependent on making an accurate diagnosis. In patients in whom no obvious cause is found a trial of physical therapy, concentrating on proprioceptive awareness may prove worthwhile relief.

**9. Neurally mediated hypotension**—Patients with this problem usually have a low blood pressure that does not go up normally on standing or on exercise. Although such patients often have a low ambient BP with postural changes, these findings are not a prerequisite for diagnosis. A tilt table test (sometimes with the infusion of isoproterenol) is the most reliable way to confirm this diagnosis. Treatment involves: (1) education as to the triggering factors and their avoidance; (2) increasing plasma volume (increased salt intake, prescription of flornidol); (3) avoidance of drugs that aggravate hypotension (e.g. TCA's, anti-hypertensives); (4) prevent the involuntary response (prescribe beta-adrenergic antagonists e.g. propranolol (Inderal) or metoprolol (Lopressor) or disopyramide (Norpace), but these agents are only used as a last resort because they reduce exercise tolerance); and (5) minimize the efferent limb of the involuntary response (prescribe alpha-adrenergic agonists e.g. midodrine (Proamatine) or anti-cholinergic agents).

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