



Fibromyalgia -- A Guide for Patients

David A. Nye MD, 13Aug95

What is fibromyalgia?

Fibromyalgia is a common and disabling disorder affecting 2-4% of the population, women more often than men. Despite the condition's frequency, the diagnosis is often missed. Patients with fibromyalgia usually ache all over, sleep poorly, are stiff on waking, and are tired all day. They are prone to headaches, memory and concentration problems, dizziness, numbness and tingling, itching, fluid retention, crampy abdominal or pelvic pain and diarrhea, and several other symptoms.

There are no diagnostic lab or x-ray abnormalities, but a physician can confirm the diagnosis by finding multiple tender points in characteristic locations. Fibromyalgia often runs in families, suggesting an inherited predisposition. It may lie dormant until triggered by an injury, stress, or sleep disturbance. It is closely related to the chronic fatigue and irritable bowel syndromes. Some have suggested that these are all just different facets of the same underlying disorder.

What causes it?

Fibromyalgia has mistakenly been thought to be either an inflammatory or a psychiatric condition. However, no evidence of inflammation or arthritis has been found, and it is now believed that depression and anxiety when present are more often the result than the cause of fibromyalgia.

There is better evidence that fibromyalgia is due to an abnormality of deep sleep. Abnormal brain waveforms have been found in deep sleep in many patients with fibromyalgia. Fibromyalgia-like symptoms can be produced in normal volunteers by depriving them of deep sleep for a few days. Low levels of growth hormone, important in maintaining good muscle and other soft tissue health, have been found in patients with fibromyalgia. This hormone is produced almost exclusively in deep sleep, and its production is increased by exercise.

I should point out though that while this is my personal favorite among the theories of the cause of fibromyalgia, there are several other viable ones, and at this time there is probably not a majority of fibromyalgia researchers that supports any one theory.



How is it treated?

Taking medication by itself has relatively little effect on fibromyalgia symptoms. Successful treatment requires active involvement of the patient in his or her care, including:

- 1) Medication to improve deep sleep.
- 2) Regular sleep hours and an adequate amount of sleep.
- 3) Daily gentle aerobic exercise.
- 4) Avoidance of undue physical and emotional stress.
- 5) Treatment of any coexisting sleep disorders.
- 6) Patient education.

If any of these steps are omitted, the chance of significant improvement is greatly reduced.

Medications

A number of medications have been used to improve sleep in fibromyalgia. The oldest of these is amitriptyline (Elavil), a medication first used to treat depression. Amitriptyline and related medications probably work by improving the quality and depth of deep sleep rather than by any effect on mood. As amitriptyline has a number of bothersome side effects, such as weight gain, dry mouth, and fuzzy-headedness, I rarely try it first. Other often-prescribed medications with less bothersome side effects include trazodone (Desyrel), diphenhydramine (Benadryl), cyclobenzaprine (Flexeril), alprazolam (Xanax), carisoprodol (Soma), and 5-hydroxytryptophan.

Medication is started at a low dose and gradually increased until you sleep well at night and feel good during the day, encounter unacceptable side effects, or reach the prescribed maximum dose. Starting low and slow helps minimize initial side effects such as dizziness and morning grogginess. By two to four weeks, most patients find that the side effects are settling down and the fibromyalgia symptoms are starting to improve.

It often takes a lot of fiddling with the dose to get it exactly right, and it frequently will be necessary to try several medications in succession or sometimes in combination. Some patients find that certain of these medications cause stimulation rather than sedation, as if one has had too many cups of coffee. When this "paradoxical effect" occurs it will be necessary to switch to another medication. The medication may become less effective after a period of time and the dose may then need to be increased slightly. Most patients will need to continue on medication indefinitely.



There are several herbal and other "alternative" remedies that some patients feel are helpful. While I can't recommend them simply because they haven't been adequately studied for efficacy or long term harm, I don't discourage patients from using them if they find them helpful.

Regular sleep

Patients with fibromyalgia must get to bed by the same time every night and get enough sleep. Staying up just one hour late may cause an exacerbation that lasts for several days. Many patients with fibromyalgia have exacerbations triggered by the change over to or from Daylight Savings time. Try to make the switch in fifteen minute increments every few days instead of by one hour overnight. I have had no success getting patients truly feeling well who work off shifts that prevent them from having a consistent bedtime or require that they sleep during the day.

Exercise

Daily gentle aerobic exercise is very important. While patients who try to do too much exercise too soon or of the wrong type will make themselves temporarily worse, most patients who don't begin a daily aerobic exercise regimen will never notice much improvement. Aerobic exercise is defined as exercise that gets your heart rate up to a target heart rate for the duration of the exercise period. Heart rates are measured in beats per minute. It is accurate enough for our purposes just to take your pulse for 6 seconds and multiply by 10. The aerobic target heart rate is calculated from the following formula:

$$(220 - \text{age} - \text{rhr}) \times .6 + \text{rhr}$$

where age is your age in years and rhr your resting heart rate, determined by taking your pulse when you wake up but before getting out of bed. A good place to feel your pulse is at the wrist turned palm up, next to the large bone on the thumb side at the end of your forearm. If you are exercising hard enough you should be able to feel your heart beating and can just count that. For most people, the aerobic target heart rate is at about the point where they can no longer sing but can still talk comfortably.

Exercise seems not to work through conditioning of muscles but rather through a direct, possibly hormonal effect on pain and sleep, which explains why you don't need to exercise painful muscles for the pain in them to decrease. Daily exercise is essential. Patients who have been exercising regularly and then miss a day usually find that their fibromyalgia symptoms are significantly worse for the next day or two.



The kind of exercise is unimportant. Just make sure to pick something that doesn't make you hurt worse. It may take trying several different kinds before finding one or more types that agree with you. Popular kinds include walking, a water exercise program, regular or exercise bicycles, other exercise equipment, and *gentle* aerobic dance. Jogging, vigorous aerobic dance, and weight lifting tend not to be very good choices. If your pain is mainly in your legs or back, exercise just your arms or try exercising in the water.

While many patients insist that they get plenty of exercise at work, doing housework, or in their yard, it is rarely the right kind. Effective exercise must result in a sustained elevation of the heart rate, and these incidental kinds of exercise are usually stop and go and may instead increase your pain. You need to set aside a time specifically for daily exercise.

Particularly if you are out of shape, start out with just 3-5 minutes of exercise and gradually increase as tolerated, shooting for twenty to thirty minutes. Take a few minutes to stretch your muscles, then start out slowly, increasing to full speed after a minute or two. Slow down again for the last minute or two and repeat the stretches. There are five recommended stretches, each done for 20 seconds a side. They should be gentle and painless. Hold onto a tree or post for support for #s 3-5:

- 1) Shrug your shoulders in a circular motion.
- 2) Reach your arm over your head and bend to the opposite side.
- 3) Bend forward with your legs straight.
- 4) Pull your foot towards your buttock while standing on the other leg.
- 5) With your feet flat on the ground and one foot ahead of the other, lean forward, bending just the front knee.

Exercise is most effective if done in the late afternoon or early evening. If you absolutely can't do it then, exercising earlier in the day is better than not exercising at all, but you will probably need to exercise longer for the same effect. Don't exercise just before bed as this may interfere with sleep.

Some patients find that exercise provides an immediate benefit, making them feel more alert and comfortable for several hours. If you experience this effect, you may want to try exercising on awakening and at noon as well. Some patients for whom this works may not need medication.



Avoid physical and emotional stress

Too much physical activity of the wrong kind will make you feel worse. Rather than doing housecleaning, yard work, or other physical activity all on one day, break up the task so that you do a half hour or an hour every day until it is done. While it is difficult to learn to do this, it is essential that you be able to sense when you have reached your limit and stop. By pacing yourself, you will be more productive overall. You need to be able to say no to family and friends when you are not up to some outing or other activity. Don't take on extra responsibilities if you can avoid it.

Stress also worsens fibromyalgia symptoms. If you have ongoing problems with depression or anxiety, consider seeking help for them from your family doctor or a psychiatrist. Anxiety and depression may arise as symptoms of fibromyalgia and in turn cause insomnia, leading to worsening of the underlying problem. Relaxation techniques or a chronic pain program can also help lower your stress level and are of proven benefit in treating fibromyalgia.

Treat other sleep disorders

Several other sleep disorders besides insomnia may aggravate fibromyalgia. Almost half of men with fibromyalgia and some women have obstructive sleep apnea. In this condition the patient snores loudly and has periodic pauses in breathing after which he starts breathing again with a snort. Periodic limb movements of sleep is a condition in which patients jerk or kick every 30 to 90 seconds for long periods during the night. Patients may be completely unaware of either of these conditions until the spouse complains. Not only will it be difficult to get fibromyalgia symptoms to improve without treating other sleep disorders, but if sleep apnea is left untreated it may lead to accidental death or injury as well as early strokes or heart attacks. Be sure to tell your physician about these problems if you notice them.

Other common sources of repeated sleep disturbance are a spouse's snoring and young children. If the spouse drinks alcohol in the evenings or is overweight, then avoidance of alcohol after supper or weight loss may eliminate snoring. Avoiding sleeping on the back will often help. At the very least, the patient can wear earplugs. Children are harder to put off but fortunately most soon outgrow their need for care at night.



Miscellaneous factors

It is important to avoid prescription tranquilizers and sleeping medications of the benzodiazepine group. While these may help you get to sleep, they suppress deep sleep and therefore often make fibromyalgia symptoms worse the next day. Alcohol and narcotic pain medications taken in the evenings have the same effect on deep sleep and should be avoided. Some patients have noticed that certain foods may trigger fibromyalgia symptoms much as they may migraines. Some have found that a diet low in fats and simple sugars helps. If you suspect that some food make you worse, try avoiding it and see if that makes a difference.

Patients with fibromyalgia should probably give up caffeine completely as even one cup in the morning can sometimes disrupt sleep at night and may also directly increase muscle pain and headaches. If you are drinking more than a cup a day you should taper yourself off caffeine-containing beverages over two weeks or so to minimize withdrawal symptoms such as headaches.

Support and education

Patients who make the effort to learn as much as possible about this disorder usually do better than those who don't. I recommend that you keep this handy and re-read it periodically. Fibromyalgia sufferers often elicit less sympathy and support than they deserve from family, friends, and employers because of the lack of outward evidence of disease. Many have been told by physicians that there is nothing wrong with them or that it is "all in your head" which can be very demoralizing. For these reasons, and just because it is good to know that you are not alone, attending a support group can be valuable. There are local chapters in most areas now of the Fibromyalgia Network. This organization also produces a newsletter worth subscribing to. Contact them at:

Fibromyalgia Network
PO Box 31750 Tucson, Az. 85751-1750
info line: (520) 290-5508
fax: (520) 290-5550

For those of you with internet access, alt.med.fibromyalgia, a Usenet newsgroup devoted to fibromyalgia, is a great place for information and support.



Staying in remission

While fibromyalgia is not curable, most patients with a little work can make it to the point where they feel substantially better most of the time. Even with good results from treatment however brief relapses are common, perhaps caused by staying up as little as one hour late one evening, skipping exercise, a disruption in your routine, increased stress, a storm front moving in, or often for no apparent reason. You will do best if you "give in to it" when this happens and try to get extra rest. Ibuprofen or naproxen and hot baths may help at these times. If at all possible, try not to stop exercising when this happens, even if you have to back off on the amount a little. Once you have had a period of feeling relatively well, it should be possible to get you back to that point again by identifying what derailed you and correcting the problem.

The fibromyalgia tender points

To qualify for a diagnosis of fibromyalgia, patients must ache all over and have tenderness in at least 11 of these 18 spots when 4 kgs. of pressure are applied.



Location of FMS tender points:

- 1) Attachment of neck muscles at the base of the skull
- 2) Midway between neck and shoulder
- 3) Muscle over upper inner shoulder blade
- 4) 2 cms below side bone at elbow
- 5) upper outer buttock
- 6) Hip bone
- 7) Just above knee on inside
- 8) Lower neck in front
- 9) Edge of upper breast bone



How to find a fibromyalgia specialist

If you are not one of the lucky few whose primary doctor is knowledgeable about fibromyalgia or at least willing to work with you and learn about it, you will need to see a fibromyalgia specialist. Unfortunately, finding one is often difficult. They can be found in many different specialties. Most are rheumatologists or physiatrists (physical medicine rehabilitation specialists), but you can't assume that any given rheumatologist or physiatrist will be able to help. Some are internists, anesthesiologists, or neurologists.

The best way to find a fibromyalgia specialist is to get a referral from the Fibromyalgia Network (see above) which keeps a list of recommended doctors and also go to a local fibromyalgia support group meeting and ask for recommendations. It is best to do both because the FMNet list is incomplete. Those of you out there who already have good fibromyalgia specialists please let the FMNet know. A fibromyalgia specialist will be able to perform a tender point exam (without which it is impossible to make the diagnosis), will tell you that it is not possible to cure fibromyalgia but that most patients can be helped substantially, and will appear to enjoy treating it.

David Nye MD (nyeda@uwec.edu), Midelfort Clinic, Eau Claire, WI