

Physician's Guide to Fibromyalgia

This short guide accompanies my patient-directed book *Healing Fibromyalgia*, which is based on my experience treating more than 1,600 fibro patients.

Because of the nature of this condition, and the frequent necessity of prescription drugs, I wasn't quite sure how to get the reader's primary care physician involved. Virtually all fibro patients need professional expertise at hand.

And then I thought: I'll write a short guide and offer it free. The book buyer can print it out and hand it to her doctor (you'll also find a printable PDF version at our website, wholehealthchicago.com).

And now, she and I have our collective fingers crossed that you'll read it.

In the very next section you'll encounter some startling facts about fibro, including these two: epidemiologists estimate 10 to 14 million people currently fulfill the accepted diagnostic criteria for fibro...and that about 80-90% of that group are undiagnosed.

This huge group of undiagnosed fibro patients are struggling mightily with their lives--family, relationships, careers, and activities of daily living all compromised by fibro.

For that reason and this one, I urge you to read this guide: a typical fibro patient suffers needlessly for five years and is seen by four physicians before someone says to her, "This looks like fibro."

You could be that doctor.

A fibro diagnosis is neither rare (more women have fibro than have diabetes) nor particularly difficult to make. I sketch out the protocols for you below. What sets fibro apart from the rest of what we all learned in medical school is that it is not a disease with abnormal tests and tissue pathology, but instead the normal physiologic fight-or-flight response gone utterly and completely awry.

This absence of positive tests has done a major disservice to fibro patients. They're endlessly told "we can't find anything wrong with you" and dismissed as chronic complainers.

Your patient bought the book because someone, perhaps you, told her she might have fibro. Maybe she pieced together symptoms that had been a mystery and diagnosed fibro herself (many women do). Perhaps the diagnosis was suggested by her chiropractor, massage therapist, or a friend. Possibly her sister was diagnosed with fibro and she

realized she had the same symptoms herself...or she took an online quiz and her eyes widened when she read her score: You likely have fibromyalgia.

Twenty years ago, I decided to open a medical center that combined conventional and alternative therapies. As the internist, I was the “straight man” to a bevy of very interesting and compassionate “other” healers like chiropractors, acupuncturists, massage therapists, and herbalists.

Desperate for help, having been literally turned away from conventional medical offices (“I think you should see a good psychiatrist”), women began arriving with longstanding fibro and chronic fatigue symptoms. These two conditions, essentially two sides of the same coin, have been our commonest diagnoses by far.

The protocols presented here are based on our 1,600 fibro patients and divided into mild, moderate, and severe categories. If you have any questions, I’m happy to hear from you.

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Part 1: What is Fibromyalgia?

Fibro is a chronic muscular pain syndrome. Based on what we all learned about *disease* in medical school, fibro is not a disease. The muscles in a fibro patient are completely normal. No enzyme elevation, no autoimmune antibodies, no abnormal nerve conduction. When biopsied, fibro muscles look like what they are: muscle.

The primary symptoms of fibro are chronic (over three months) widespread muscle pain, a sense of profound fatigue (previously known as chronic fatigue syndrome), and unrefreshing (non-restorative) sleep. For a condition as potentially disabling as fibro, it is astonishing that so many years elapsed between its original description in 1816, the criteria for diagnosis from the American College of Rheumatology in 1990, and the release of the first FDA-approved but decidedly problematic drugs (because of side effects) Lyrica™, Savella™, and Cymbalta™ in 2008 and 2009.

Even now, when I travel the country and give talks on fibro to physician groups, I am frequently met with skepticism about the very existence of this condition. Audience members who tell me they “never see any fibro patients” are discomfited to be told that statistically 7% of their female patients probably have fibro. What is going on here?

Let me review some interesting facts about fibro in terms of actual numbers:

- Epidemiologists estimate that 10 to 14 million people currently fulfill the accepted diagnostic criteria of fibro.

- Because there are no positive tests to diagnose fibro and a physician must rely on his or her clinical acumen, approximately 80-90% of these 10 to 14 million are undiagnosed, often for years.
- The condition occurs mainly in women (96%), approximately 7% of the female population of the US.
- More women have fibro than have diabetes.
- Fibro occurs world-wide, estimated to affect 200 million women on the planet.
- The disbelief in fibro's very existence among physicians comes from the flaw in medical education that in order to be real, a condition must have verifiable pathology, positive tests, or visible tissue pathology. Fibro has none of these.

The online survey called WE FEEL (Women Expressing Fibromyalgia's Effects on their Everyday Lives), conducted by Harris Interactive among 508 women diagnosed with fibro, revealed the following data:

- 85% of women with fibro consider it a significant burden in their lives.
- 64% felt their symptoms were not taken seriously by their health care provider.
- A typical fibro patient sees four separate physicians before she learns her diagnosis.
- Not infrequently, once a woman learns she has fibro she is told "we don't know much about this condition, there's not a lot to do for it."
- As her years with undiagnosed fibro continue, her symptoms progressively worsen. Most women wait for their symptoms to reach an intolerable level before seeking the right help and finally getting their diagnosis. This usually averages five years, but can take even longer.
- If treatment is delayed and symptoms are allowed to worsen, fibro becomes progressively more difficult to treat successfully. The three FDA-approved drugs demonstrate just a 45% success rate in relief of symptoms, and this 45% occurs in patients who have not suffered years and years of fibro.
- Fibro symptoms can begin at any age. Children as young as eight have been reported with fibro.
- Fibro severely impacts a woman's family life, her relationships, her career, and all activities of daily living.

The reason for the delay in making a fibro diagnosis is our own professional discomfort with this condition. One survey among physicians revealed that roughly 60 to 70% of physicians didn't feel confident when making a diagnosis of fibro. Fibro breaks the rules of how we were all taught to diagnose any condition. We were told that when a patient presents with symptoms, we begin by performing a physical examination and then, based on our working clinical diagnosis and our knowledge of pathophysiology, we order tests, including blood tests, imaging studies, and biopsies.

Positive test results confirm our clinical suspicions and we can begin appropriate treatment. *Negative test results* either steer us down an alternative diagnostic path or

allow us to tell our patient the single most common sentence heard by fibro patients: We can't find anything wrong with you. All your tests are normal.

Sadly and often based on some serendipitously borderline positive lab test result, fibro patients are incorrectly misdiagnosed with an unrelated condition. It is not unusual to encounter fibro patients who have undergone needless surgery or received unnecessary medication. For example:

- A large rheumatology department near my office routinely starts fibro patients with weakly positive ANA levels on a lupus protocol.
- Patients are not uncommonly started on anti-inflammatory medications for alleged rheumatoid arthritis based on a borderline elevated sedimentation rate (and negative rheumatoid factor).
- Chronic pelvic pain (a common fibro symptom) is treated as interstitial cystitis or even, if a small fibroid is noted on ultrasound, the patient is advised to have (and often undergoes) an utterly useless hysterectomy.
- Because of fibro tender points on the anterior chest wall, fibro patients have undergone coronary angiograms. One patient with fibro, panic attacks, and tachycardia underwent an ablation procedure.
- Patients undergo unnecessary (and always unsuccessful) cervical and/or lumbar disc surgery with spinal fusion. Several years ago, one prominent group of neurosurgeons "discovered" that both fibro and chronic fatigue was caused by Chiari malformation (small foramen magnum pressing on the brain stem). Their barbaric procedure uselessly opened dozens of foramina. Naturally, no one improved.

Most commonly, fibro patients are simply written off as depressed. Of course, depression is a normal emotional response for anyone with untreated chronic pain and fatigue who has been told "nothing is wrong." Since SSRIs do have marginal benefits for fibro, the patient thinks "maybe I was just depressed after all" until her fibro starts getting worse. Psychiatrists regularly see patients with fibro referred to them by both primary care physicians and rheumatologists. They virtually never believe depression alone is responsible for all the symptoms experienced by the patient.

Fibromyalgia defined

If you ever hear someone say "We don't know the cause of fibro," don't accept that answer. We now know exactly what is happening with fibro, why some women are victims and others not. We know the physiology and we now have a good understanding of a variety of treatments and why and how these treatments work.

Fibro is a syndrome affecting primarily women who have a heightened sensitivity to painful stimuli (abnormal pain processing) and feel more pain to any noxious stimulus (pain amplification). A physician can observe these phenomena clinically by performing tender point examination (see below) or simply inflating a blood pressure cuff to 180 mm/Hg on a fibro patient. She will complain of significant pain and appear distressed

(tearfulness, diaphoresis), while the same procedure done on a person without fibro causes no appreciable response. If, at a later date, the doctor were to ask “How long did your tender points hurt after the examination?” he or she shouldn’t be surprised to hear the patient was uncomfortable for several hours.

A person’s susceptibility to fibro is genetic and involves both diminished levels of the neurotransmitter serotonin and an increased release of pain transmitters (glutamate, substance P) per noxious stimuli.

Serotonin and its role in fibro

The neurotransmitter serotonin, present in both the central nervous system and the GI tract, acts as our “factory-installed” stress-buffering system. Likely as an effect of evolution, the male level of serotonin as stress buffer is three to four times that of a female. This means a woman is more susceptible to stress, both physically and emotionally.

Were we to measure serotonin levels in both men and women, we would see a pair of bell-shaped curves, some women in the “low-male” range, some men in “high-female.” It is the very low-serotonin women at the far left of the bell-shaped curve who are most vulnerable to stress. These women go through life like walking open wounds with the whole world as salt shaker. It is from this population we find the women most susceptible to developing fibro.

Low-serotonin stress susceptibility disorders

- Female predominance
- Familial disposition, multigenerational
- Usually triggered by stressful events in a woman’s biography
- Can begin in childhood
- Worsen during winter (reduced sunlight reduces serotonin production)
- Worsen whenever blood levels of estrogen are diminishing (premenstrual days, postpartum, perimenopause)

Psychological manifestations of low-serotonin stress susceptibility disorders

- Depression
- Generalized anxiety disorder and/or panic attacks
- Obsessive thinking
- Compulsive behavior patterns
- Social anxiety disorder
- Post-traumatic stress disorder (especially abuse during childhood)
- Phobias

As every clinician has observed, after 4 to 6 weeks of treatment with any serotonin-enhancing medication, most patients report varying degrees of improvement. This is their

stress buffer on the rise. It is accepted good medical practice that taking steps to lower stress through psychological counseling will enhance the effectiveness of antidepressant medication: Anxiety, depression → raise stress buffer (SSRI) + reduce stress (counseling) → clinical improvement

Women often unconsciously self-treat their low-serotonin symptoms with:

- Exercise (regular exercise raises serotonin)
- Sunlight (sun exposure raises serotonin)
- Carbohydrates (raise serotonin)

Physical manifestations of low-serotonin stress susceptibility disorders

A variety of physical symptoms often accompany the patient's psychological symptoms. Not infrequently, physical symptoms may be the only manifestation of "stress" exceeding the stress buffering system. These symptoms may be interpreted by both patient and physician as disease, but despite symptom severity tests are normal and no disease is found (unless a separate disease is found).

Physical symptoms are all part of the physiologic stress response, the fight-or-flight in a constant "on" state.

- Muscle tightness in neck and upper back ("I carry my stress in my neck and shoulders").
- Tension and migraine headaches.
- Jaw clenching, jaw grinding, and TMJ.
- Fibromyalgia itself ("My muscles are tight everywhere, like a suit of armor"). **See below for diagnostic criteria of fibromyalgia.**
- Irritable bowel syndrome (bloating, frequent indigestion, constipation, diarrhea, abdominal cramping).
- Chronic pelvic pain and dyspareunia.
- Premenstrual dysphoric disorder.

When to suspect fibromyalgia

Keep in mind that fibromyalgia is Greek for "muscle pain."

- Widespread symmetrical muscle pain present for longer than 3 months.
- Presence of anatomically defined "tender points" (see next section). A positive tender point means that significant pain is induced by 4.4 kg of fingertip pressure. Tender points *must have a left-right symmetry, and must be above and below the waistline.* The patient must demonstrate pain in 11 of the 18 defined tender points to fulfill the diagnostic requirements for fibro. (Note: the tender-point criteria remains useful despite being eliminated recently by the American College of Rheumatology as being too vague and subjective to establish a fibro diagnosis.)
- Muscle stiffness.

- Unrefreshing (non-restorative) sleep.
- Chronic tiredness (chronic fatigue syndrome).
- Decreased overall sense of well-being.
- Cognitive dysfunction (“fibro fog”).
- Depression.
- Tenderness of musculoskeletal structures and skin.
- Persistence of pain after noxious stimuli ceases.
- Allodynia (pain from normally non-noxious stimuli).
- Family history of low-serotonin stress susceptibility issues.
- History of physical or sexual abuse as a child (applies to 25 to 30% of all fibro patients).
- No evidence of joint inflammation or positive lab test results.

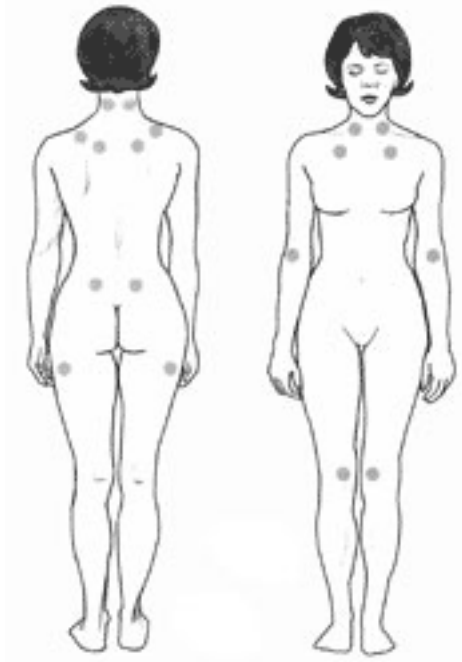
Testing for tender points

Use the accompanying diagram to locate tender points. Place your index finger on a hard surface and press until blood is drained from your nail bed. This is approximately 4.4 kg of pressure.

Press each of the tender points with 4.4 kg of pressure. A “positive” tender point will elicit a dramatic response from your patient (“Ow! Hey, that hurts.”). By the fourth tender point, if fibro is present your patient will most definitely not want any more points tested.

Once you are comfortable with your diagnosis, during follow-up visits you need not retest tender points.

The tender points of fibromyalgia



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The Fatigue of fibromyalgia

- Unchecked by an adequate serotonin stress-buffering system, the patient's protracted stress triggers non-stop stimulation of her hypothalamic-pituitary-adrenal (HPA) axis. Also affected in the HPA axis are thyroid and ovary.
- Adrenal depletion ("adrenal fatigue"): measurable low DHEA, low cortisol, sluggish response to ACTH stimulation, low norepinephrine. Symptoms: fatigue with afternoon crash, orthostatic hypotension, salt craving.
- Thyroid depletion ("thyroid fatigue"): low TSH, low free T3, low basal body temperature (97.6 or lower). Symptoms: cold hands and feet, dry skin/hair, outer third of eyebrows thinning, weight gain, mental sluggishness.
- Ovarian depletion: low estradiol and progesterone. Symptoms: PMS, lack of libido.
- Other sources of fatigue: inefficient sleep, depression.
- This fatigue is what we all know as Chronic Fatigue Syndrome (CFS), so popular in the 1970s and 1980s as the "yuppie flu." A support group of chronically fatigued patients renamed the condition CFIDS (chronic fatigue immune dysfunction syndrome), although there has never been any research consistently linking chronic fatigue with any infection or any immune dysfunction.

Co-morbidities prevalent with fibromyalgia

- Headaches, tension and migraine (10-80% of fibro patients)
- Major depressive disorder (20-25%)
- Temporomandibular joint disorder (75%)
- Irritable bowel syndrome (30-80%)
- Multiple chemical sensitivities, both environmental and medication triggers (33-55%)
- Chronic pelvic pain, vulvodynia, dyspareunia (20%)

Fibro as a disability

Self-reported by patient herself as “can do with much difficulty” or “unable to perform.”

- Heavy household tasks (70% of fibro patients)
- Lifting, carrying 25 lbs without help (60%)
- Strenuous activities (55%)
- Walk one mile (50%)
- Climb one flight of stairs (44%)
- Light household tasks (36%)

The role of a second neurotransmitter, norepinephrine

- Neurotransmitter present in both brain and adrenal gland.
- Plays key role in fight-or-flight response.
- Depleted during protracted adrenal stress in patient with low-serotonin stress susceptibility.
- Low levels associated with depression, apathy, brain fog, increased susceptibility to pain.

Lab tests of fibro patient will demonstrate physiologic changes of protracted stress in a genetically susceptible person (male or female, but usually female). There is *no evidence* of pathology or inflammation with fibro except when a patient has two separate diagnoses (e.g., fibro and rheumatoid arthritis). Physiologic “positive” lab tests:

- Low serotonin.
- Diminished hypothalamic-pituitary-adrenal (HPA) function with adrenal and thyroid “fatigue.”
- Sluggish adrenal response to ACTH stimulation.
- Adrenal fatigue: low norepinephrine, low cortisol, low DHEA.
- Thyroid fatigue: low TSH, low or low-normal free T3, T4. Low basal body temperatures (97.6 or lower).

Summary

- Fibro usually begins in a genetically susceptible low-serotonin woman who has endured a period of protracted stress (family stresses, financial stresses, relationship stresses, etc.).
- The women in her family usually have a history of any of the low-serotonin stress susceptibility disorders listed above and/or a history of SSRI use.
- The patient herself may have experienced any of the low-serotonin disorders following stressful episodes in her life. Taking a biographically oriented history will reveal much information in this regard.
- 25% of fibro women experienced emotional, physical, or sexual abuse as children.
- During and after her period of relentless stress, her muscles chronically tightened painfully as if she is trying to defend herself--almost as if she is creating a suit of armor with her muscles.
- Her unchecked fight-or-flight response depletes her thyroid and adrenal glands.
- From chronic pain she becomes depressed, sleeps poorly, is fatigued, and suffers cognitive difficulties.
- Because her tests are negative, she is written off as depressed and a “whiner.” Eventually her symptoms worsen to the extent of rendering her eligible for disability status.

Part 2: When to Suspect Fibromyalgia

If you are a primary care physician, 5 to 7% of your female patients either have fibro or are at significant risk for developing it.

The actual diagnosis of fibro (as described in Part 1) is a clinical one, based on the history you obtain and your physical examination. No lab tests are needed to diagnose fibro. **You do not need to refer any fibro patient to a specialist of any kind.** The American College of Rheumatologists actually discourages fibro referrals. Mayo Clinic no longer accepts fibro or chronic fatigue patients. This one is all yours!

1. Suspect fibro every time a patient (especially female) says:

“I feel achy all over.”

“My shoulders and neck feel really tight.”

“I’m getting these headaches...”

“I am so tired all the time.”

“I have these backaches. I’ve been seeing a chiropractor, but...”

“I just can’t seem to get enough sleep. I wake up tired.”

“I’m depressed.”

“I just don’t feel well and I know you told me everything is normal.”

Get her up on the table, check her tender points, order basic lab as part of a routine fatigue work-up (blood count, metabolic profile, thyroid profile, sed rate, rheumatoid factor). If she has painful tender points, you have diagnosed fibro

2. If you have an opportunity to review pertinent biographical data, ask about family history of depression, anxiety, SSRI use, fibromyalgia, chronic fatigue, migraines, IBS, and other low-serotonin stress susceptibility disorders.

If you suspect fibro, bring up the childhood abuse issues obliquely, saying something like “With this particular condition, it turns out a lot of the patients had really stressful childhoods, with emotional, physical, and even sexual abuse problems. Looking back on your childhood, would you say yours was a happy one or a stressful one?”

Women who were abused as children rarely reveal this (especially to a male physician), but they will be grateful to any physician who brings this painful issue into the open. If an abuse issue is present, I myself then say to the patient, “Imagine the posture of a little girl (you) when her abuser comes home.” She will likely hunch her shoulders together protectively. I then say, “That’s the way your body has learned to deal with stress, tightening your muscles. That is fibromyalgia.”

3. If your patient is being treated for anxiety or depression, always ask about any chronic physical symptoms, especially muscle pain and fatigue. These patients seem to never volunteer physical symptoms to their therapists. The therapists rarely ask and virtually never check their client for tender points.

Lab tests to order if you suspect fibro

Beyond the standard fatigue panel mentioned above, I routinely order two lab tests and instruct patient on a self-test, mainly to demonstrate to the patient herself what is happening in her body.

1. Pharmasan (formerly NeuroScience) has developed insurance-reimbursable tests that measure levels of neurotransmitters and adrenal function. You will dispense a kit to your patient containing a small bottle for urine (second morning specimen) and four small vials for salivary samples throughout a single day.

Your patient collects the specimens as instructed and mails them directly to the lab.

- Urine: neurotransmitters>specifically serotonin and norepinephrine.
- Saliva: cortisol levels throughout a single day and DHEA.

The results most often confirm what you have inferred: low serotonin and norepinephrine, low DHEA, and low cortisol. (Treatment of any abnormalities follows in Part 3.)

2. Instructions on self-testing for thyroid fatigue using a basal thermometer. After five days of taking her basal temperature on waking (use the five days following first day of menstrual flow to avoid the temperature rise of ovulation), if her average is 97.6 or lower, she has mild hypothyroidism *even with a normal TSH*. Basal temperature testing was a standard means of diagnosing hypothyroidism during the years before the introduction of the TSH measurement in the 1960s. It remains just as useful in this situation in which the pituitary is “fatigued” and unable to produce elevated levels of TSH. (Treatment of any abnormalities follows in Part 3.)

Part 3: Treating Fibro

When treating fibro, it helps to remember how we treat diabetes, another condition affecting millions of Americans. We base our approach to a diabetic depending on the severity of the situation. Mild diabetes really requires only lifestyle changes (weight loss, exercise). Moderate diabetes moves to the oral hypoglycemics. Severe diabetes necessitates adding insulin.

It’s pretty much the same with fibro: mild, moderate, severe.

Step 1: Categorize the severity of your patient’s fibro.

Mild fibro: Her symptoms have been around one year or less. The stress she knew she carried in her neck and shoulders is now constant and she feels achy over her entire body. She is not disabled, is continuing her usual daily activities, but is aware her symptoms are beginning to interfere with her day-to-day enjoyment of life. She is often too tired after work to consider any evening activities and turns down invitations as “too tired.” Although your physical exam will show “positive” tender points, she is startled by their presence. “Wow! That hurts! I didn’t know that was there!”

Moderate fibro: Symptoms usually present less than five years, but are now daily. She awakens stiff, tired, and feeling “old.” Your exam reveals painful tender points. She is in pain through the entire day and her daily activities are a struggle. This patient has usually been to several physicians and one may have actually suggested fibro as a diagnosis, but said something like “We don’t know much about it” and written her an antidepressant.

Severe fibro: Symptoms longer than five years. Chronic daily severe muscle pain. This patient doesn’t even want her skin touched during an exam and a tender point exam will almost invariably bring on sweating and tears. She moves stiffly and slowly and her face is that of a patient in chronic pain. She has often left her job, and is considering or may

already be on disability. If married, her husband does most of the housework. Her fibro dominates her life.

Step 2 (applies to all levels of severity): Educate your patient about fibro.

Studies have shown that simple patient education can actually reduce severity of symptoms. Although her fibro was likely triggered by some definable stressor, now years have passed and the stressor is the fibro itself. Once your patient understands that fibro is not a disease, but rather a genetic susceptibility causing her to overreact to stress, she will be less frightened about the possibility of being disabled for the rest of her life. By breaking this stress>pain>increased stress>increased pain cycle, her muscles can start to relax on their own.

Emphasize that because of her unique sensitivity to stress, her muscles have created a suit of armor over her body. Reassure her that fibro does not lead to any disease and that her symptoms can be brought under control. Do caution her that she can't change her genes and she may experience episodic flare-ups of fibro that may necessitate treatment. Common triggers for "fibro-flares" are new stresses in her life, hormonal changes like menopause, physical injury (e.g., a whiplash-inducing auto accident), or even changes in the weather.

Urge your patient to faithfully follow the stress-reduction steps presented in my book, *Healing Fibromyalgia*.

Step 3 (applies to all levels of severity): Consider psychotherapy, especially cognitive behavioral therapy (CBT) if available.

No shortage of studies has confirmed that CBT does help fibro symptoms, teaching your patient to reframe the way she thinks and acts about stressful situations including fibro pain. The major advantage of CBT is that results can begin in as few as four to six sessions and the average number of total sessions is just 16.

Step 4 (applies to all levels of severity): Refer your patient to a physical therapist or chiropractor who is familiar with fibro.

Although exercise will definitely help fibro, most patients respond to the suggestion "Go exercise," by thinking "Who is he kidding?" Remember, fibro patients are tired and depressed and they hurt.

Mild and moderate fibro: Write a physical therapy prescription for a graded exercise program (to recondition her muscles) and authorize six to eight hour-long sessions of specific forms of massage called *myofascial release* and *deep tissue therapy*. Unlike Swedish massage, which essentially kneads and rubs the muscles, deep tissue work presses into the chronically contracted muscle knots of fibro. Myofascial release stretches the muscles and the tight fascia that is binding them.

Severe fibro: Begin graded exercise only. These patients are simply in too much pain to tolerate myofascial release and deep tissue work. Once symptoms have been controlled with medication, you can prescribe these additional massage therapies.

Step 5 (applies to all levels of severity): My book--*Healing Fibromyalgia*--provides in detail a healthful eating program for fibro.

Please encourage your patient to follow it. Basically, she will replace simple carbohydrates (white flour, sugar) with complex ones, reduce saturated fats, and eliminate junk foods. Sometimes fibro is worsened by gluten, so I encourage all patients to try going one month gluten-free to determine if this may be contributing to symptoms (instructions for the gluten elimination and reintroduction trial are included in the book). Because most fibro patients are overweight, your patient will be encouraged to keep a careful eye on her daily calorie intake.

Step 6: Medications for fibro.

Surveys of physicians who regularly treat fibro have shown that a typical patient with moderate-to-severe symptoms is frequently taking **six separate prescriptions a day** to keep her symptoms under control. These are commonly:

- One of the FDA-approved fibro medications (Lyrica, Savella, Cymbalta)
- A muscle relaxant (Flexeril, Soma, Skelaxin)
- A sleep med (Ambien, Lunesta)
- A pain med (Vicodin, Tramadol, OxyContin)
- An antidepressant (Lexapro, Effexor)
- An “energizer” (Provigil, Nuvigil)

However, this degree of polypharmacy would only apply to a small number of especially severe fibro patients. Since fibro patients are all chemically sensitive (susceptible to side effects from any or all medications), the best idea is to use as few medications as possible and, for mild cases, rely initially on the lifestyle change therapies described above.

Mild fibro

Because I have had two decades of experience using nutritional supplements in lieu of prescription drugs, I treat mild fibro with the following regimen of five supplements:

- **St. John’s wort** 450 mg twice a day (a very mild SSRI).
- **5 Hydroxytryptophan** 100 mg at bedtime (precursor to serotonin, helpful for sleep).
- **D,L Phenylalanine + L Tyrosine** 500 mg daily (many brands available for these amino acids, which are norepinephrine precursors).

Note: Taken together, these three supplements create very mild and side-effect-free versions of Savella and Cymbalta.

- **Theanine** 100 mg three times a day (an amino acid derivative of green tea that acts as mild, non-sedating anxiolytic and muscle relaxant).
- **Magnesium/malic acid** (many brands): A popular over-the-counter combination for fibro. Magnesium acting as a muscle relaxant, malic acid (the same one from Krebs Citric Acid cycle) to improve energy and sense of well-being.

AND

1. **If basal temperatures average 97.6 or lower**, start Armour thyroid ½ gr. (30 mg.) or Synthroid 50 mcg each morning. This is basically a physiologic dose of replacement hormone and can be discontinued in 6 to 9 months. This small dose will not induce hyperthyroid symptoms or pose any risks.

2. **Based on cortisol and DHEA levels from Pharmasan Labs**, if cortisol levels are low, start Cortef 10 mg in AM, 5 mg in afternoon and/or DHEA 10 mg each morning.

Note: This is basically a physiologic replacement dose of cortisone and has minimal anti-inflammatory effect. I generally continue this after about three months of good pain control (the chronic pain itself being responsible for adrenal “fatigue”). Once her pain has been controlled and her stress reduced, her adrenal function will normalize on its own. Remember there is no adrenal “disease” (like Addison’s disease) only “fatigue.”

Moderate fibro

Generally, the mild nutritional supplements used for mild fibro will not be sufficient to control symptoms of moderately severe fibro (although many patients, remembering side effects they’ve experienced in the past, may prefer to try nutritional supplement therapy for several weeks). When switching from supplements to medications, I discontinue the St. John’s wort, 5HTP, and the D,L Phenylalanine/Tyrosine. Unlike prescription SSRIs or SNRIs, these supplements do not need to be tapered. Drug recommendations for moderate fibro follow directly.

FDA-approved fibro drugs: Savella and Cymbalta

Although completely different molecules, Savella and Cymbalta work alike, by raising both serotonin and norepinephrine (DNRI=dual neurotransmitter reuptake inhibitors). I am uncertain why both manufacturers state something along the lines of “we don’t know how these work.”

Raising serotonin will raise your patient’s stress buffer, just like any SSRI. Raising norepinephrine restores levels to her depleted adrenal, increases energy, and improves pain control. That’s how they work.

Having used both medications in hundreds of fibro patients, let me warn you against the package insert of FDA-approved dosing instructions. With both Savella and Cymbalta, the recommended starting doses for both are too high and ramp-up to maintenance too quick for most fibromyalgia patients to tolerate. Following the guidelines will usually result in side effects of sufficient severity for your patient to abandon her medication. If the drugs are taken as per the insert, your patient's norepinephrine will rise too quickly and she'll feel extremely nauseated. The key to these medicines: *go slowly!*

Savella

Instead of Forest Labs recommendation to reach maintenance (50 mg BID) in seven days, **allow six weeks to reach this dose.** At this rate, she will feel maximum benefit at eight weeks.

I write three separate prescriptions for Savella, cleverly numbering them #1, #2, and #3:

Prescription #1 Savella 12.5 mg Disp. 60. One tab qhs x 5 nights, followed by one tab BID x 7 days, followed by one tab in AM, two tabs qhs x 7 days, followed by two tabs BID until supply is used up.

Then fill Prescription #2 Savella 25 mg Disp 60. One tab BID x 7 days, then one tab qAM and 2 tabs qhs X 14 days, then two tabs BID until supply used up.

Lastly fill Prescription #3 Savella 50 mg BID (maintenance).

Notes

- If severe nausea develops with any dose increase, return to the previously tolerated dose and remain there for two weeks before attempting to increase it again.
- If good relief occurs at a lower dose than 50 mg BID, simply remain there.
- If Savella fails to offer good relief, consider adding a small dose of Lyrica (see below) or even OxyContin (10-20 mg q 12 hr).

Cymbalta

The same gradual increase as Savella is necessary:

Prescription #1 Cymbalta 20 mg Disp 30 (maximum allowed by insurance)

Prescription #2 Cymbalta 30 mg Disp 30

Prescription #3 Cymbalta 60 mg Disp 30

Note

- Make sure your patient fills these on different days or they will all be denied by her insurer.

Week one: Cymbalta 20 mg qAM

Week two: Cymbalta 30 mg qAM

Week three: Cymbalta 40 mg qAM (two 20s)

Week four: Cymbalta 50 mg qAM (one 20 mg and one 30 mg)

Week five: Cymbalta 60 mg qAM (maintenance)

Notes

- If severe nausea develops with any dose increase, return to the previously tolerated dose and remain there for two weeks before attempting to increase it again.
- If good relief occurs at a lower dose than 50 mg BID, simply remain there.
- If Cymbalta fails to offer good relief, consider adding a small dose of Lyrica (see below) or even OxyContin (10-20 mg q 12 hr).

Lyrica

This is a medication for all neuropathic pain, originally approved for diabetic and herpetic neuropathy. For fibro patients, it works by reducing the release of pain modulating neurotransmitters (glutamate and Substance P).

Side effects can be troubling and include dizziness, nausea, brain fog, ataxia, and weight gain. This last is especially problematic as most fibro patients are already overweight. They must be warned about this side effect and advised to watch their weight carefully, reducing calories if needed. (I cannot guarantee your personal safety when your patient learns that the 25 lbs she added in a year is from the med you prescribed.)

Like the other fibro medications, package insert directions ramp the dose up too quickly. Lyrica comes in many capsule sizes: 25 mg, 50 mg, 75 mg, 100 mg, 150 mg.

Prescription #1 Lyrica 25 mg Disp 60
Prescription #2 Lyrica 50 mg Disp 60
Prescription #3 Lyrica 75 mg Disp 60
Prescription #4 Lyrica 150 mg Disp 60 (maintenance)

Again, remind the patient not to fill all prescriptions on the same day or they will be denied by her insurer.

Start at 25 mg at bedtime and increase by 25 mg weekly until you reach maintenance at 150 mg BID. A smaller maintenance dose will suffice if this is being used in combination with Savella or Cymbalta

A USEFUL TIP: A very effective and well-tolerated medication schedule is to combine Savella or Cymbalta with Lyrica, using half doses of each. This actually makes good pharmacologic sense: Savella/Cymbalta raise serotonin/norepinephrine, while Lyrica blocks release of pain modulators. Since these may take several weeks to show clinical benefit, I also prescribe Tramadol ER, 100-200 mg each morning, to give my patient more immediate pain relief.

Notes

- If severe nausea develops with any dose increase, return to the previously tolerated dose and remain there for two weeks before attempting to increase it again.
- If good relief occurs at a lower dose than 50 mg BID, simply remain there.
- If Savella fails to offer good relief, consider adding a small dose of OxyContin (10-20 mg q 12 hr).

For patients with moderate fibro, I add:

Flexeril (cyclobenzaprine) 10 mg OR Trazodone 50 mg at bedtime to deepen sleep and relax muscles.

AND

Tramadol ER 100-200 mg in the morning for all-day pain relief. As the Savella/Cymbalta/Lyrica take effect, this can be discontinued. When you prescribe Tramadol with Savella or Cymbalta, you will invariably receive a telephone call from the pharmacist concerned about serotonin syndrome issues. I have never seen this and when I attended a fibro meeting in New York, none of the 250 physician attendees had ever seen it either.

If the Tramadol is ineffective, I will allow the patient Vicodin 5-10/500 up to TID or OxyContin 10-20 mg q 12 hr. Again, these can be lowered or even discontinued in the future.

For patients with severe fibro:

These patients are virtually incapacitated by their chronic pain and pervasive exhaustion. They are depressed and frustrated by their steady functional decline. Interestingly, though you'll not see many men with fibro, when you do encounter them their fibro is usually in this "severe" category, because they usually have postponed for years (and sometimes decades) seeing anyone for help.

These patients are not difficult to manage provided you are willing to prescribe opioids for the non-cancer pain of fibro. Because fibro patients are extremely sensitive to medications, relatively small doses of opioids can have dramatic beneficial effects. You are using them to break the pain>stress>more pain>more stress cycle while simultaneously adjusting serotonin, norepinephrine, and the pain-modulating neurotransmitters (glutamate and substance P) with Savella, Cymbalta, and/or Lyrica.

Even in the best cases, published studies on these three FDA-approved fibro meds show efficacy rate of only 45%. That means 55% of fibro patients taking these meds do not attain good relief. If Savella/Cymbalta aren't working, add Lyrica, or vice versa, but don't give up. Adding opioids here can really help.

If, for whatever reason, you feel reluctant prescribing opioids for severe fibro pain, then refer your patient to a pain specialist. Please do not allow your patient to spend her life in pain because of a personal bias against these highly effective medications.

Therefore, for severe fibro patients, follow all the steps described for moderate fibro (including Savella/Cymbalta and/or Lyrica and the Flexeril) except instead of Tramadol ER, prescribe:

OxyContin 10 mg every 12 hours and give your patient permission to increase her dose to 20 mg every 12 hours after a week if she is not feeling improvement. You can also allow her up to three (no more) Vicodin 5/500 per day for breakthrough pain.

Re-evaluate her status in about two weeks (if she is taking 2 to 10 mg OxyContin tablets twice a day, she will be running out of medication). This particular dose (i.e., OxyContin 20 mg q 12 hr, with up to three Vicodin 5/500 per day for breakthrough pain) works nicely for the majority of my severe fibro patients.

Approximately 10% require 30 mg q 12 hr and 5% 40 mg q 12 hr. I never go beyond 40 mg every 12 hours. No matter how severe a patient's fibro pain may be, that particular dose--40 mg q 12 hr--is the limit. Virtually no one wants more and were they to ask for more I say, "After 1,600 fibro patients, I know pretty much how much OxyContin is needed. More is not better." Instead, I would prescribe additional physical therapy,

myofascial release, and increase Savella, Cymbalta, or Lyrica, but I never increase the opioids beyond this dose.

If, after several months, the OxyContin appears to be less effective, using an online dose comparison chart you can switch to Opana ER, Avinza, Fentanyl patches, or Kadian. The goal, however, is to start lowering doses after several pain-free or at least pain-reduced months. I generally reduce OxyContin by 5 to 10 mg per week. If patients have been following all the lifestyle suggestions, physical therapy exercises, stress reduction techniques, etc, most severe fibro patients can be tapered off their OxyContin in a year and off their FDA-approved meds in 1 ½ to 2 years. They are cautioned about the possibility of “fibro flares” but not to lose heart as these flares are almost always temporary events.

Other medications to consider for moderate and severe fibro

Amrix 15 mg is an extended-release form of cyclobenzaprine (Flexeril) and currently undergoing clinical trials for fibro. In my own experience, I find this an excellent choice and am sure it will get its FDA approval. Using Amrix has allowed me to avoid opioids or keep the opioid dose low. However, Amrix is very expensive and many insurers balk at paying for Amrix as maintenance therapy.

Xyrem (sodium exacerbate) Clinical trials on what is a reconfiguration of the date-rape drug from the 1970s (gamma hydroxybutyrate) actually showed efficacy in relieving fibro pain by increasing depth of sleep. However, despite good data the FDA quite reasonably turned down the application, fearing widespread abuse potential. In my own experience, Xyrem is effective for those patients who report fibro prevents them “from ever sleeping deeply” and when the regular hypnotics (Ambien, Lunesta, etc.) don’t work.

N.B. A recent price increase by Jazz Pharmaceuticals, makers of Xyrem, has pretty much eliminated it from my fibro armamentarium. \$4,200 a month. Need I say more?

Butrans (buprenorphine) This is an opioid derivative absorbed through skin and administered as a skin patch once weekly. Sizes are 5, 10, and 20 mcg per hour. The patients I have started on Butrans uniformly reported “no relief” at 5 mcg/hour and “very good” pain relief at 10 mcg/hour. I have not needed to increase it beyond that dose.

Provigil, Nuvigil These are FDA-approved for chronic daytime sleepiness and shift worker sleep disorder. These medications are frequently prescribed off-label for chronic fatigue syndrome, which is essentially the fatigue component of fibro. Patients take this on arising (usually ½ tablet of the lowest dose will suffice) and report sufficient energy and mental clarity to continue through a workday.

Conclusion

To me, one of the most interesting questions to ask ourselves about fibro concerns the status of women in our society. If fibro is essentially an unchecked stress response and 96% of fibro patients are female, have we really made life so stressful for half the occupants of our planet that they need antidepressants and opioids simply to survive?

When we prescribe a serotonin-boosting *anything*--whether it's for anxiety, depression, or fibro--we are essentially raising a person's stress-buffering system. But women given antidepressants report feeling "numb" and "like zombies." Artists on antidepressants report losing their creative spark.

It well may be that the low serotonin level in women (and probably artists as well) places the human stress buffer where it actually should be. After all, women are more intuitive and more sensitive to color, texture, and sensation. They are compassionate in a way that men simply are not.

We need to consider what fibro is trying to say to us about the status of women on our planet, and about the real status of ourselves.