



What a Pain!

Have you resigned yourself to dealing with pain?

Does your current treatment regimen fall short?

This article outlines the **drug and nondrug treatment options** most often used to ease the pain of CFS.

Written by a clinician who has treated hundreds of CFS and FM patients, the article may be a good resource to **share with your own doctor.**

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Pain figures in no less than five of the nine “official” criteria for chronic fatigue syndrome used in the United States. This is no news to most CFS sufferers, for many of whom pain is at least as important as fatigue in limiting what they can do. But the spectrum of pain in CFS is very wide. A few people with CFS (PWCs) have little or no pain, only exhaustion and difficulty concentrating. On the other end of the spectrum are the unfortunate ones who, in addition to these symptoms, have pain everywhere, all the time. Despite this, pain has been largely neglected in research on CFS and is routinely undertreated by doctors who treat PWCs. This is a pity because pain can usually be reduced substantially with proper treatment. Sometimes the reduction is sufficient to allow a previously disabled person to return to work and to active participation in family life.

The mechanism of pain in chronic fatigue syndrome is thought to be a disorder in the nervous system, rather than in the organs or tissues where the pain is felt. So pain in a muscle doesn't mean there's something wrong with the muscle; the problem is with the nerves between the muscle and the brain, and in the brain itself. But this emphatically does *not* mean that the pain is “all in the mind!” Rather, it's a disorder of the *information transmission* through the nerves and spinal cord to the brain, causing information that would normally result in a nonpainful sensation (such as the movement of a joint, the pressure of clothing or the sensation of a full bladder) to be “processed” or “amplified” and provoke a feeling of pain. The pathways through which the information travels have been changed or “sensitized,” like a stereo system that has become prone to producing feedback noises instead of just reproducing the music as it ought to.



DRUGS FOR TREATING PAIN IN CFS PATIENTS

Acetaminophen	Sometimes helps a little; try adding to other treatments, especially during pain flare-ups.
Tramadol	Sometimes helps dramatically. To minimize side effects, work up to a full dose in one to two weeks.
Nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen, naproxen, Celebrex	Rarely help much, but are worth trying; nearly all the full effect occurs within a day, so a trial consists simply of one day on a low dose, then one day on a high dose. Long-term use carries small but serious side effects, so this treatment should be discussed with your doctor.
Tricyclic antidepressants (TCAs), such as amitriptyline, doxepin, nortriptyline	Often help sleep as well as pain, but a rather wide dose range has to be explored slowly to minimize side effects, so a trial usually takes about two weeks.
Other antidepressants (SSRIs such as Prozac, Zoloft, Paxil); Effexor, Cymbalta	These antidepressants have been touted for pain, but with low success rates. They probably take several weeks to have full effect, so trying several of them is very time-consuming.
Opioids (hydrocodone, oxycodone, hydromorphone, morphine, methadone, fentanyl)	Our strongest pain medications, these are very safe when used properly. Many doctors wrongly withhold them from PWCs because of needless fears of inducing addiction. This is the only group of pain medicines that commonly benefits PWCs sufficiently to make big changes in their lifestyle, such as returning to work. Both benefits and adverse reactions vary from one opioid to another, so it's generally worth trying several.
Medications for "nerve pain" such as Neurontin, Topamax, Lamictal	Sometimes helpful for shooting, tingling or burning pains. Neurontin is also sometimes helpful when sleep is disturbed by pain, and a trial can be as short as a week. The others take several weeks to work up to the effective dose.
Lidoderm patches	Postcard-sized patches which stick to the skin and deliver lidocaine, a local anesthetic that can help even with quite deep pain, such as pain over the hips that makes it hard to lie on them.
Muscle relaxants, such as Skelaxin, baclofen, Flexeril, Soma, Parafon Forte, Robaxin, Norflex, Zanaflex	Each of these is chemically distinct, so one may work well when the others don't help at all. For each one, the trial period lasts only one to three days, so trying sample packs from the doctor is worthwhile.
Other medications	Various other medications certainly help a few CFS patients. The rule for all of them should be to try them and observe the results carefully to find out as quickly as possible whether they help. This usually takes only a few days.



This pain mechanism is referred to by scientists as a disorder of pain amplification, as pain processing or as central sensitization. Since this represents a change (plasticity) in the way the nervous system works, it is also referred to as a kind of neuroplasticity. These terms are confusing at first, but when readers come across them, they should just remember that they all refer roughly

to the same process: messages traveling in nerves to the brain have become "turned up" so they cause pain, instead of mild nonpainful sensations.

The underlying cause of this process is unknown. The current favorite theory is that proinflammatory cytokines, which are chemicals released in the body in response to infections, become excessive and

uncontrolled in CFS and irritate cells in the nervous system, producing pain amplification and other CFS symptoms. In favor of this theory is the fact that such chemicals, when injected intravenously into fit volunteers, do produce widespread pain and exhaustion, similar to illnesses like influenza—and CFS. However, this is still just a theory. So far it has few implications for

NONDRUG TREATMENTS FOR PAIN IN CFS PATIENTS

Acupuncture	Helps some patients, but few find it worth the time and expense to continue long-term. More often used as a brief course during pain crises. Because of wide variance in the styles and the competence of acupuncturists, word-of-mouth recommendations are probably best when selecting a practitioner.
Massage	Helps some patients during acute pain crises, but may not work as a long-term strategy to control chronic pain. The competency and efficacy of individual massage therapists varies dramatically, so referrals are helpful. Massage can actually exacerbate pain symptoms in some patients.
TENS (Transcutaneous Electrical Nerve Stimulation)	A tiny battery-powered gadget delivers small “buzzing” sensations that sometimes mask a nearby pain. Often used for well-localized pains, such as pain over the hips. Patient rents or buys the device and learns how to use it from a physical therapist.
Heat or cold	Either heat or cold can sometimes help, or worsen, pain in CFS patients. It’s quite safe to experiment on your own with hot and cold packs and stick with whatever clearly helps.
Nutritional supplements	Disappointing to date. Supplements that are touted for pain-relieving properties often don’t work, or only help a small percentage of people, or have such a small effect that patients don’t find them worth the expense. Wildly overpromoted by health food stores, supplement manufacturers and many Internet sites.



treatment, but this may change in the next few years if specific drugs can be developed to inhibit damage by cytokines. Whatever the mechanism is for the pain, it must be quite variable from one person to another to account for the very divergent responses to particular pain medications from one PWC to another.

Thankfully, treatment of pain need not wait upon such research, since it depends not on theories about the underlying cause of the pain, but on the observation that *a wide variety of pain treatments each*

help a few patients with CFS, but no single one of them helps a majority.

The conclusion is obvious: if you want to treat pain in CFS, you have to be prepared to try a number of different remedies in order to arrive at one that might work for you. We have no reliable guides to match treatments with particular patients, or even with particular kinds of pain. It makes sense to try each of the main contenders, with as brief a trial as is necessary to establish if the treatment helps or not.

This is rarely done. Most

doctors try one or two treatments, then give up if neither worked, and patients understandably quickly get discouraged when trying one thing after another.

Another problem, which enormously hinders the process of finding out what helps and what doesn’t, is the practice of having a patient take a drug (or try a treatment such as acupuncture or biofeedback) for far too long as a trial period, even when it could—and should—have been assessed much more quickly. For instance, many pain medications have their full effect within two days, so the trial period is exactly that—two days. To require the patient to stay on the treatment for a month, then come back to see the doctor, is quite wrongheaded, since it wastes time that should have been spent exploring a number of different treatments, and it exposes the patient to unnecessary side effects.

Medications

The table on page 11 shows some of the main pain medications, each of which helps a number of PWCs. This list is based on my own experience of working with CFS patients over almost two decades, and on informal surveys that have been done of doctors specializing in CFS. Proper scientific studies have simply not been done. The closest we have are studies of such treatments used for fibromyalgia (FM), a condition which overlaps so much with CFS that we assume that treatments for FM will help at least some patients with CFS as well.

There are also pharmacologic pain treatments



that don't involve taking tablets. One is to apply medications locally, right where the pain is, in the form of creams or patches. The Lidoderm patch (which requires a prescription), contains lidocaine and is often especially helpful for localized pains. Patches that deliver heat often help back pain, and the newer non-prescription ones can last all day.

Nutritional supplements

PWCs are very familiar with supplements touted to improve energy, but some supplements are also used to treat pain. None of them helps more than a minority of patients. When I suggest to my patients that they try stopping their supplements, most are no worse off for this. But there are exceptions. If you stop taking several supplements and you do feel worse, then it may be best to reintroduce them, one at a time, to try to find out which one was helping.

Other pain treatments

Acupuncture, massage and other "hands-on treatments" sometimes help, but they are costly, inconvenient and very much dependent on the skill of the practitioner. Unfortunately, competent practitioners are not common. To find good ones, I suggest two simple criteria. First, do you know people the practitioner has clearly helped? And second, does he or she promise that only four or five treatments will be needed to tell if it helps? The best practitioners get results very quickly, so beware the ones who want you to sign up for 10 or more sessions even if nothing is getting better after the first few.

The underlying rule for these alternative treatments is the same as for medications: only a minority of PWCs gets a worthwhile response. So if you try one, only do so for a short trial period and only continue if it's clearly helping. Finally,

DID YOU KNOW?

- **The National Pain Care Policy Act (H.R. 1863) is the first comprehensive pain care bill introduced in Congress. You can learn more about the bill and voice your support for this legislation by using the Grassroots Action Center. Just visit www.cfids.org, click on the Capitol building icon on the lower left corner of the page, and follow the prompts from there.**
- **Studies show that it is very rare to get addicted to pain medicine while under the proper supervision of a medical professional. That's because when people are in pain, the body uses medication differently than if they were taking the drug to get high.**
- **Keeping a personal pain journal can be valuable in helping you gather information you can use to effectively communicate with your health care team about your pain and treatment regimen. Your journal should be a record of your daily pain and pain management occurrences, when you experience the least and most pain, what activities modify your pain and the treatment that offers the most relief.**
- **It is estimated that chronic pain affects 15 to 33 percent of the U.S. population, or nearly 70 million people. Chronic pain disables more people than cancer or heart disease, and according to the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), costs more than both combined. JCAHO reports that pain costs the U.S. an estimated \$100 billion a year in medical costs and lost productivity.**
- **A 2004 survey conducted for the American Chronic Pain Association found that 72 percent of people with chronic pain have lived with it for more than three years and 34 percent for more than a decade.**

remember that advertisements for these treatments are not legally controlled, so their promoters are free to make highly exaggerated claims for them.

The bottom line for CFS sufferers is that the best chance for pain relief comes by working patiently through a number of drug and non-drug treatments until you find something that helps. And since many doctors are unfamiliar with this process, you'll probably have to push to get the doctor to persist with it. You may wish to show the tables accompanying this article to your doctor to use as a basis for that enterprise. ■

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