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National Fibromyalgia & Chronic Pain Association

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You Don't Have to Look Sick to Be Sick: Understanding Fibromyalgia

by Marijke Vroomen Durning

Fibromyalgia (FM) is a mysterious and frustrating illness. People who have FM can feel intense pain from every day injuries, such as paper cuts or stubbed toes. The pain from serious injuries can last for months, even years. What makes it even tougher is that people with FM don't look sick. The illness is invisible, which makes it difficult for people to understand. I know because I have FM.

What is fibromyalgia?

"Fibromyalgia is a multiple system disorder," says C. Jessie Jones, PhD, Health Science Director of the Fibromyalgia and Chronic Pain Center in Fullerton, CA, who also has FM. "This is why it is so hard to find something to treat it." It affects your energy, ability to sleep, bowel function, and more. But, the most common and life-altering issues with FM are the constant pain and exhaustion.

Although FM is now recognized as a medical problem, some experts still disagree on its classification. It is considered to be a soft-tissue disorder, because of the pain in the muscles and tendons, the tissues that connect muscle to bone. But FM also could be a neurosensory disorder because of how sensations are sent to and received by the brain. Some experts even say FM is not an illness or disorder at all. "Fibromyalgia is not a disease," says Hal S. Blatman, MD, Director of the Blatman Pain Clinic in Cincinnati, OH, and au-

thor of *Winners Guide to Pain Relief*. "It is a condition of being that describes the problems the person has."

Why is there pain?

Researchers are slowly making progress in learning why people with FM have so much pain. This is what they know: Your body detects pain and responds to with neurotransmitters that send impulses between nerves, muscles, organs, and other tissues. When you burn your hand, a neurotransmitter called substance P sends a message to your brain that you have been hurt. Your brain responds and you pull your hand away from the heat. According to four separate studies, including one published in the journal *Arthritis & Rheumatology*, people who have FM have up to three times more substance P than does the general public. The messages to the brain are more intense. At the same time, people with FM have lower levels of another neurotransmitter, serotonin, which affects how the pain is perceived.

People with FM have also too much of another neurotransmitter, glutamate, says Dr. Jones. This adds to the confusion the body faces when dealing with pain. "The glutamate makes you hypervigilant," she points out. "This is your fight-or-flight response and causes you to feel more pain." This excess of glutamate also explains why many people with FM startle easily. Their body is

always on guard, waiting for the next thing to happen.

Daniel J. Clauw, MD, Director of the Chronic Pain and Fatigue Research Center and Director of the Michigan Institute for Clinical and Health Research at the University of Michigan, describes FM this way: "The volume control is set too high. Pain and other sensory information are amplified by the system." Using Dr. Clauw's example, this is how I explained it to my husband one day: "My senses are magnified. My body is hypervigilant. Sounds are louder, lights are brighter, and touches that should be gentle or soft are irritating or painful. Worst of all, a pain that you may feel is minor, can be close to unbearable to me."

How is fibromyalgia diagnosed?

There is no exam that can identify FM. Doctors must run several tests before they can consider FM. Once other diseases have been ruled out, the doctors rely on criteria issued by the American College of Rheumatology to make the final diagnosis. They review the patient history to see how long the pain has been present and what type of pain it is. Until recently, the doctors checked for specific tender points all over the body. If the patient had 11 tender points out of a possible 18, FM became the diagnosis. This part was removed from the criteria in 2010.

The testing process is discouraging.



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I would be frustrated every time the tests came back negative, suggesting there was nothing wrong. I knew there was something wrong. I didn't want to be sick, but I wanted a diagnosis, something that I could fight. When my doctor finally told me that I had FM, I cried. I now had proof of what I knew all along. There was something wrong. This wasn't all in my head. This was real. The National Fibromyalgia Association says it takes an average of five years to get an accurate diagnosis. For me, it took 30.

Who gets FM?

Fibromyalgia affects up to 10 million American adults. Children can and do get FM, but no one knows how many are affected.

More women have FM, but it is not really understood why. One explanation could be that women have higher levels of glutamate than men, says Dr. Jones. These levels can be raised even higher as a result of certain behaviors, such as smoking, drinking alcohol, eating too much protein, or experiencing too much stress. However, doctors are finding that more men do have FM than originally thought.

The original criteria of checking patients for tender points were developed in 1990, but doctors learned that this was biased against men. "What we didn't know in 1990 when the criteria were published, was that women are quite a bit more tender than men," explains Dr. Clauw. "So, if you use the threshold of 11 tender points in the general popu-

lation, very few men have 11 tender points. Men are innately less tender." By eliminating this part of the diagnostic criteria in 2010, FM is going from a disease that was about 90 to 95 percent female to about 65 percent female.

Does FM run in families? There does seem to be evidence that it might, much like heart disease can run in the same family. Dr. Blatman, who believes that fibromyalgia is a condition caused for the most part by consuming "bad" foods, such as wheat, potatoes, sugar, and fruit juices, looks at it from another point of view. He says that people in the same

family eat the same types of food. "What you eat is more important than your genetic structure," Dr. Blatman says. "What you eat will turn genes on and something else you eat will turn things off."

Fibromyalgia help

Treatments for FM depend on what symptom you need to manage. For some people, pain may be relieved through non-medical approaches, even some lifestyle changes. "People have to play an active role in their treatment," says Dr. Clauw. They need to take responsibility for getting educated, eating well, and getting exercise.

Exercise may be the last thing on your mind if you're having pain or you are exhausted, but there is evidence that moderate exercise does help provide relief in many ways, from keeping your body flexible to producing endorphins, another neurotransmitter, that can help relieve pain. Dr. Jones understands the reluctance to exercise, but she still advises it and exercises herself. "I can be out of shape and in pain or I can be in shape and in pain," she says. The trick is to start slowly and gently, allowing your body to adapt.

Healthy eating when you have FM is vital, say all three doctors. "The human body is a high performance biochemical vehicle, designed to run on Ferrari racing oil and racing gas," says Dr. Blatman. "If you fill it with old Quaker State oil from your grandpa's basement and 20 octane gas from down the street, you will not be going around the circle as fast as the big



"Fibromyalgia is a multiple system disorder."

boys." Consider your body as a Ferrari.

Alternative medicine

Dr. Blatman uses the holistic approach in FM management. He advises diet changes and provides prolotherapy (injections into the ligament or tendon), trigger point injections, and joint injection therapy, among other treatments. Other alternative therapies include massage therapy, physiotherapy, exercise, yoga, cognitive therapy, acupuncture and acupressure, herbs, and nutritional supplements, among others.

Traditional medicine

Traditional Western medicine may include using prescription drugs that have been approved for treatment of FM or medications that work directly on the troubling symptom.

Living with FM is not easy, but now that the medical community has recognized FM as a true illness and as people become more educated, there is hope that those who are suffering won't have to wait five years – or thirty years – before they are diagnosed and treated. For more information on fibromyalgia, visit the National Fibromyalgia Association & Chronic Pain Association at <http://fmcpaware.org>. •



Marijke Vroomen, RN, is Montreal, Canada-based health writer who has been living with fibromyalgia as long as she can remember and blogs at <http://med-healthwriter.blogspot.ca>.

Here are some suggestions to help you manage fibromyalgia pain. Not all approaches help everyone, but with some trial and error, you may find something that works for you.

Lifestyle Changes

• Diet

Some experts recommend increasing intake of vitamin B6, which is found in foods such as poultry, fish, beans, and dark green leafy vegetables. The United States MyPlate program offers good advice on healthy eating.

• Exercise

Low-impact exercises, such as swimming, yoga, or Tai Chi, can be helpful. Exercise helps keep your muscles strong and flexible and can help improve your sleep and mental well-being.

• Get enough quality sleep

Use your bedroom for sleep and sexual activity only. Avoid caffeine and alcohol in the late afternoon and evening. Avoid napping and don't exercise too close to bedtime.

Complementary and Alternative Medicine Therapies

Acupuncture, massage therapy, cognitive therapy, biofeedback, and trigger point injections, are some of the more popular alternative therapies, to name a few.

Herbs and nutritional supplements

Some herbs and nutritional supplements may reduce FM symptoms. If you are taking medications, be sure to check with your pharmacist to avoid interactions between anything you consume.

Prescription Medications

Fibromyalgia Medications

Currently, there are three FDA-approved medications for FM: pregabalin (Lyrica), duloxetine (Cymbalta), and milnacipran (Savella). Lyrica seems to work on the nerve signals, while Cymbalta and Savella work on the nerve transmitters.

Pain relievers and relaxants

Nonsteroidal anti-inflammatories (NSAIDs), such as naproxen, may help relieve pain. Certain muscle relaxants may be prescribed to help you sleep, which may reduce pain the next day.

Antidepressants

It is not understood why, but some antidepressants are effective in treating chronic pain. These are usually the ones that affect the serotonin levels.

