



# Fibromyalgia: The Mystery of Chronic Pain

By Sue Romanick, MD

The journey of one patient's quest to be treated for fibromyalgia shows how difficult the condition is to diagnose due to its complex symptoms and a healthcare environment that often prevents providers from both seeing and treating these patients.

**P**ain can be mysterious — especially the pain of a chronic, widespread condition called fibromyalgia. Imagine the following situation: A patient is experiencing severe, debilitating pain associated with fatigue and is unable to work or concentrate in school. She is baffled; the doctors are baffled. She desperately seeks help, but instead she receives the ultimate insult: She is turned away from each medical clinic that she phones! She then turns to the Internet and is suddenly given hope while being bombarded by powerful advertising slogans such as: "Finally, a cure for fibromyalgia!" Gradually, as the months and years roll by, as treatments are tried and discarded, these slogans appear to look like empty promises.

When Marie first walked in, I could tell that I was simply yet another doctor in the long line of doctors she had already seen. Marie's otherwise pretty face was a mixture of frustration, fatigue and skepticism. She narrowed her eyes as I entered the examination room. Attempting to be upbeat as I approached her, I extended my hand as I introduced myself. To my surprise, she simply looked away. Her hands remained in her lap.

### Chronic Pain Is Not Just Any Pain

Everyone has experienced some sort of pain. Pain teaches children to "be more careful next time." They learn that a bandage is temporary and will come off as soon as things get better. Despite the pain, there is hope that things will get better. But it can be different with chronic pain. Unfortunately, with chronic pain, patients may suffer a loss of hope.

To some, fibromyalgia is something to dread. Many patients who have done their own research before landing in my clinic have pleaded with me: "Don't tell me I have fibromyalgia!" Others weakly mumble: "Fibromyalgia doesn't really exist, does it?"

I wish I could say that Marie simply belonged to yet another group of patients whose healthcare providers had casually tossed out a blanket statement: "It's all in your head" followed by "Just live with it." These are patients I can passionately empower in short order. However, Marie's case was more troubling. Marie had not even managed to get through the door of any of the medical clinics that she had phoned for help. You see, in response to her being asked each time what her purpose was for calling, she had replied: "I have fibromyalgia." And, each time, the same curt reply followed: "I'm sorry, we don't treat fibromyalgia." This included clinics with rheumatologists, the very specialists trained to treat fibromyalgia in addition to pains associated with arthritis! Even more shocking, Marie had failed to get into medical clinics in two other cities before she finally made it to my clinic. Incredibly, it had taken Marie three months of phoning around for a medical appointment before she first presented to my medical clinic.

### Fibromyalgia: A "Real" Disease

By definition, fibromyalgia is a chronic pain condition. Patients often describe their pains as muscular and diffuse. Classically, the pain distribution has been both above and below the navel, and involving both the right and left side of the body. In 1990, the American College of Rheumatology (a branch of adult or internal medicine

overseeing healthcare providers responsible for diagnosing and managing pain and arthritis, as well as autoimmune disorders) recognized fibromyalgia as a specific, valid diagnosis. In addition, an official diagnostic code was assigned to this medical condition.

However, having just one diagnostic code doesn't mean that one patient's fibromyalgia presents with the same symptoms as another's. The variety of symptoms encountered in patients with fibromyalgia can fool both patients and doctors alike. It's no small wonder that the diagnosis of fibromyalgia has been looked upon suspiciously by some, including healthcare providers! For example, some chronic pain patients report multiple awakenings at night. At times, a formal sleep study may uncover specific sleep apnea. Other patients with fibromyalgia report intermittent bowel upset that may be referred to as "irritable bowel syndrome." Still others report "fibrofog," which is a popular term to describe mental foginess that can lead to diverse memory issues such as forgetting dates or words, or even misplacing items. Yet other patients may report restless legs syndrome, which causes a need to shift legs repeatedly in the evening. Commonly, when given a form to check off symptoms experienced in multiple organ systems, patients having fibromyalgia characteristically check off an impressive list.

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I sat down in front of Marie, scanning with amazement the intake form we had requested she complete as a new patient in our clinic. There wasn't a spot of space left on the page to list any more symptoms! She had not only checked off all possible symptoms but had added more in the margins. These included generalized muscular pains, severe fatigue, headaches, dry eyes, constipation, diarrhea and cold fingers, among many others. Mornings were the worst. She woke up daily feeling as if she had been "run over by a truck." These pains were not brought on by any specific injury. If she tried to exercise, it would make her hurt more. She felt increasingly miserable and began to chase answers as she methodically searched for medical help. But why was it so difficult for her to get help?

## The Trouble with Diagnosis

Certain pains can be diagnosed quickly. Diagnosing a stroke, stomach ulcer, heart attack or inflamed gallbladder is generally pretty straightforward. A doctor or healthcare provider orders a test or a battery of tests. The result is some sort of objective (measurable) evidence clearly showing that something is abnormal. Just how “abnormal” this test (or tests) turns out to be may guide how aggressive the treatment needs to be. What will it be? Surgery? Pills? Just wait and see? The benefits of any treatment have to be weighed against the risk or potential side effects of the treatment. But how does one approach treatment of a seemingly widespread condition when it’s hard to prove on paper that you have it?

### *The variety of symptoms encountered in patients with fibromyalgia can fool both patients and doctors alike.*

Fibromyalgia doesn’t cause an abnormality in a blood test. It doesn’t lead to an abnormal X-ray. And, it doesn’t lead to an abnormal brain scan. In fact, the mysterious pains of fibromyalgia leave no traces in standard medical tests. Yet, the pain can be so debilitating that patients feel they are unable to work or, for some, even get out of bed.

Marie was armed with pages and pages of carefully documented symptoms (which healthcare providers refer to as the “history”) and test results that included \$3,000 worth of blood tests, in addition to a brain MR scan that had cost more than \$1,000. It was an impressive bill, but the pain was no better. Indeed, Marie’s search for help had begun many years before. One doctor had worried that she could have multiple sclerosis. Another had diagnosed her with chronic fatigue syndrome. Worse still, she had been told by another: “It’s all in your head.” I really couldn’t blame Marie for looking like she dreaded coming to yet another medical appointment for her next medical opinion.

So, what can patients do when there is no one reliable test for a condition that can be as debilitating and confusing as fibromyalgia? In Marie’s case, the answer came in steps. Step

No. 1 was to step back and take a look at all the symptoms Marie was reporting and to, literally, question whether these symptoms were truly due to a unifying diagnosis of fibromyalgia. So, the problem solving, or detective work, began.

Marie’s pains had gradually increased over a 10-year period. She had had a tough life living in farm country and had suffered from severe emotional stressors. Things got even rougher in the tight economy, and worries were keeping her awake most nights. She knew deep down inside that the stress was really starting to get to her. She even noted some skin rashes and dandruff appeared to be getting worse. Her pains had gotten so bad that she didn’t want to be touched. She also tried to avoid being hugged. Not only did she have pain in the morning, but some of her joints were so stiff that a warm shower was needed to help limber them up. Marie was scared of taking narcotics, but that seemed to be the only solution that had been offered by her general healthcare provider after over-the-counter painkillers just weren’t enough to handle the pain.

At first, Marie appeared dazed when I commented that she appeared to be a victim of discrimination. I quickly added that it wasn’t the kind of discrimination she might be thinking about. I explained that it appeared there were actually a few medical conditions going on with her, but because Marie named just one of them whenever she had called for a medical appointment, that appeared to have shut rather than opened doors. The trouble was, this interfered with her getting help with her other medical conditions. Now, Marie appeared perplexed but hopeful.

Step No. 2 was labor intense. Page by page, I meticulously reviewed Marie’s stack of lab tests. It was futile to look for a fibromyalgia test, as I know it doesn’t exist. On the other hand, I know that there are a number of conditions that can lead to widespread chronic pain that is not explainable by previous injury or due to fibromyalgia. Furthermore, I know that some of these conditions could be associated with fatigue.

With new energy, I poured through the tests looking for specific evidence of conditions that mimic fibromyalgia. For example, Marie’s hormones appeared to be OK — both thyroid and estrogen. A slow thyroid can lead to muscular pain. Menopause, a state of low estrogen, can interfere with sleep, which can affect pain threshold. We talked about this, and Marie was at the age where her hormone levels could be fluctuating. Next, I considered vitamin D deficiency. This is an issue that has been receiving a lot of press, particularly in climates where there isn’t a lot of daily sunshine. Vitamin D deficiency can cause muscle

**Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid**  
**Initial U.S. Approval: 2010**

**INFORMATION FOR PATIENTS**

**These highlights do not include all the information needed to use Hizentra safely and effectively. See full prescribing information for Hizentra.**

-----**INDICATIONS AND USAGE**-----

Hizentra is an Immune Globulin Subcutaneous (Human) (IGSC), 20% Liquid indicated for the treatment of primary immunodeficiency (PI) in adults and pediatric patients 2 years of age and older.

**INFORMATION FOR PATIENTS**

This patient package insert summarizes important information about Hizentra. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare professional, and it does not include all of the important information about Hizentra. If you have any questions after reading this, ask your healthcare professional.

**What is the most important information I should know about Hizentra?**

Hizentra is supposed to be infused under your skin only. DO NOT inject Hizentra into a blood vessel (vein or artery).

**What is Hizentra?**

Hizentra (Hi – ZEN – tra) is a prescription medicine used to treat primary immune deficiency (PI). Hizentra is made from human plasma. It contains antibodies, called immunoglobulin G (IgG), that healthy people have to fight germs (bacteria and viruses). People with PI get a lot of infections. Hizentra helps lower the number of infections you will get.

**Who should NOT take Hizentra?**

Do not take Hizentra if you have too much proline in your blood (called “hyperprolinemia”) or if you have had reactions to polysorbate 80. Tell your doctor if you have had a serious reaction to other immune globulin medicines or if you have been told that you also have a deficiency of the immunoglobulin called IgA. Tell your doctor if you have a history of heart or blood vessel disease or blood clots, have thick blood, or have been immobile for some time. These things may increase your risk of having a blood clot after using Hizentra. Also tell your doctor what drugs you are using, as some drugs, such as those that contain the hormone estrogen (for example, birth control pills), may increase your risk of developing a blood clot.

**How should I take Hizentra?**

You will take Hizentra through an infusion, only under your skin. Make sure that the infusion is not into a blood vessel. You will place up to 4 needles into different areas of your body each time you use Hizentra. The needles are attached to a pump with an infusion tube. It usually takes about 60 minutes to do one infusion. You will need to have infusions once a week.

Do not use Hizentra by yourself until you have been taught how by your doctor or healthcare professional.

**What should I avoid while taking Hizentra?**

Vaccines may not work well for you while you are taking Hizentra. Tell your doctor or healthcare professional that you are taking Hizentra before you get a vaccine. Tell your doctor or healthcare professional if you are pregnant or plan to become pregnant, or if you are nursing.

**What are possible side effects of Hizentra?**

The most common side effects with Hizentra are:

- Redness, swelling, itching, and/or bruising at the injection site
- Headache/migraine
- Nausea and/or vomiting
- Pain (including pain in the chest, back, joints, arms, legs)
- Fatigue
- Diarrhea
- Stomach ache/bloating
- Cough
- Rash (including hives)
- Itching
- Fever and/or chills
- Shortness of breath
- Dizziness

Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Tell your doctor right away if you have any of the following symptoms. They could be signs of a serious problem.

- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain, swelling, warmth, redness, or a lump in your legs or arms. These could be signs of a blood clot.
- Numbness or weakness of an arm or leg or one side of your face. Sudden confusion, or trouble speaking or understanding.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of a brain swelling called meningitis.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a blood problem.
- Chest pains or trouble breathing.
- Fever over 100°F. This could be a sign of an infection.

Tell your doctor about any side effects that concern you. You can ask your doctor to give you more information that is available to healthcare professionals.

**How do I use Hizentra?**

Infuse Hizentra only after you have been trained by your doctor or healthcare professional.

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cramping or even widespread pain. We also considered Marie's specific past history. We discussed that there were elements in her history that could place her at risk for chronic hepatitis B, hepatitis C or HIV infection. These tests were missing from her records, so these would be worthwhile tests still to be ordered.

## *The physical exam for fibromyalgia classically has shown the presence of specific fibromyalgia tender points.*

Hidden among the pages of an impressive \$3,000 lab workup was a surprise. One of Marie's lab tests documenting inflammation was very abnormal. Because inflammation (classically producing warmth, swelling or pain somewhere in the body) is not typical of fibromyalgia, I suggested to Marie that there was probably more than one condition going on. Slowly, Marie's eyebrows lifted and her eyes opened wide, as I could tell her hopelessness and resignation were slowly being replaced by the feeling that knowledge and control were closer to being within her own grasp.

The physical exam for fibromyalgia classically has shown the presence of specific fibromyalgia tender points. The examiner may check 18 different points on the patient's body, and then record a score such as 14 out of 18 in the medical chart. The examiner presses gently on a spot just until the fingertip (or fingernail) starts to turn white (blanch). However, tender spots on physical examination are not enough to make a diagnosis of fibromyalgia. A history of chronic pain is one of the additional items necessary for diagnosis. To illustrate why: Two of the locations classically checked for fibromyalgia, each at the widest part of the hips, can be painful to touch due to local hip inflammation (bursitis). Interestingly, there has never been any proof that the number of tender points reliably decreases with treatment even when the patient is feeling much better. Not surprisingly, there has been some controversy surrounding the role of the tender points when diagnosing fibromyalgia.

One of the most important achievements of Marie's first

visit was to validate that she did, indeed, have fibromyalgia. She had the classic history of chronic pains with disordered sleep, multi-systemic complaints and all of her tender points being very tender to light touch. However, the second most important achievement of her first visit in my clinic was to discover why she had been unable to shake my hand as I had entered the examining room at the beginning of the visit.

I was aghast. Marie's physical examination revealed severe swelling in every finger of each hand. In fact, some of her fingers looked like little sausages. In the medical profession, this is called "dactylitis." What was particularly worrisome to me was that Marie had reported having had this dramatic swelling progress the past few months during which time she actually needed aggressive therapy but was unable to access medical care because she had been repeatedly turned away for another reason.

### **Identifying What Needs Treating and How**

I was grateful that Marie had finally found her way into my clinic so that I could begin itemizing the issues needing to be addressed. However, it was not because of the fibromyalgia but because of her inflammatory arthritis (related to her aforementioned rashes) that we would have to move fast in order to get aggressive medication approved for her by her health insurance. We urgently needed to prevent severe joint damage in her hands from worsening. I pointed out that even the inflammation in her labs supported a sense of urgency. Understandably, Marie was devastated to learn of the second diagnosis. But, I reassured her that by her coming in, we could take immediate, aggressive steps to prevent joint damage.

It was important that Marie understand that it was not her fibromyalgia that I was worried about. Yet, I did reassure her that we would be taking steps to help her learn how to control the pain from her fibromyalgia. In fact, by discussing how we approach treatment of fibromyalgia in general, I could tell that Marie would be feeling a lot better by the time her first appointment came to a close. I started by explaining that the first important concept to convey when treating fibromyalgia was that it is a real diagnosis and deserves proper medical attention. We discussed that lifestyle changes, working on optimizing sleep quality, setting realistic goals and choosing appropriate forms of exercise are all very important. Marie began to understand that the answer to fibromyalgia was not simply in writing a prescription.

Important considerations before starting medication for fibromyalgia include correcting certain vitamin deficiencies, ensuring that there are no underlying, undiagnosed

chronic conditions and evaluating the patient for side effects arising from current medications. Marie had been exposed to several adverse childhood experiences that appeared to be impacting her coping skills with certain family members and her ability to manage current financial worries. Therefore, we talked about the role of counseling, to which she appeared to be very amenable. I explained that stress management or counseling could play a key role in helping her gain control over her fibromyalgia.

It was important that I address Marie's concerns about narcotic therapy. Scientific studies have shown that patients requesting narcotics for chronic pain syndromes, which include fibromyalgia, migraine headaches, irritable bowel syndrome and pelvic pain, have a greater likelihood of having been exposed to emotional, sexual and/or physical abuse. I shared my bias with Marie that narcotics should not play a prominent role in the routine, chronic management of fibromyalgia. In fact, in my own practice, I avoid their use in treating fibromyalgia whenever possible.

Therefore, we discussed medication alternatives that, unlike the medication she would need for her severe hand arthritis, do not work by addressing inflammation. Instead, we talked about nonaddictive pain medications that are not narcotics, but some of which are thought of as antidepressants or muscle relaxants, as well as others that are frequently used for pain originating in nerves. I made it clear that such medications can take several months to really become effective against the pain.

By the end of the visit, Marie's diagnoses had names, and she had come to terms with the fact that fibromyalgia was only one of them. She understood that control over her fibromyalgia pain was within her reach but that it would take time. She appreciated hearing that psychosocial elements in addition to lifestyle would be at least as important as any medication taken for fibromyalgia. Finally, in understanding her medical conditions better, she was in a stronger position to start setting realistic goals for herself.

### **Pitting Patients Against the Healthcare Environment**

It's no small wonder that, when working with such a complex collection of symptoms, healthcare providers are truly challenged. Not surprisingly, office visits often run into overtime. Meanwhile, other patients don't like to be kept waiting. But, let's take one step back to focus on the larger picture: Healthcare providers are burdened with new guidelines dictating the flow of, and reimbursement for, an office visit. Indeed, healthcare is evolving into tight, efficient, low-cost medicine. Sadly, this means that practicing good,

old-fashioned bedside manner with both compassion and comprehensiveness may be going the way of the dinosaurs. The result? Patients may find themselves being turned away.

And what about these patients who really need help? They have more trouble finding it. Of course, they turn to the Internet where they may fall victim to modern-day snake oil salesmen who tout their wares with empty promises. Even some of the scientific studies published in reputable journals are surprisingly inaccurate in the facts presented. It is truly a "buyer beware" environment in which those burdened by pain can fall victim yet a second time. Remember, reaching for that "magic bullet" can start a slippery slide into diminishing hope.

After Marie's first visit, she left knowing that part of the answer lay in her own hands. We discussed appropriate exercises for her fibromyalgia that, in her case, included tai chi or warm-water aquatics. I recommended that she pace herself but try to develop a routine of gentle exercises at least three times per week. We addressed her diet and lifestyle. Simply, Marie's understanding of how the traumatic situations in her past were contributing to the pains she was experiencing now as an adult appeared to empower her. We focused on how her new knowledge could be used to make future lifestyle decisions. Meanwhile, I answered her questions about the role of medication for her fibromyalgia compared with medication required for her unfortunate aggressive form of arthritis. She and I both agreed that her new knowledge about herself formed the first step in her healing process.

As Marie was leaving, I gently placed my hand on her right shoulder and said that I was so sorry that it had taken her so long for her to find my clinic. I added, however, that I really felt confident that we now formed a team to get her back on the right track. I figure her smile in response meant that she agreed. ■

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*Editor's note: The name of this patient has been changed to protect her privacy.*