The Possibility of Fibromyalgia Misdiagnosis

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Fibromyalgia Misdiagnosis

It's not easy to diagnose fibromyalgia. There is no quick test and, if anything, it's more like a process of elimination. To make things even more complicated, fibromyalgia is a condition with lots of symptoms, not all patients experience all the symptoms, and many of the symptoms mimic those of other conditions, such as lupus, rheumatoid arthritis and multiple sclerosis.

As well as experiencing misdiagnosis, it's not uncommon for fibromyalgia patients to suffer from other conditions. Medical professionals often refer to this second illness as a "coexisting condition."

For many fibromyalgia patients managing the condition is like a full-time job. We monitor what we eat, what we do, where we go and how we get there. We look for patterns that link our behavior to our flare-ups, and we change our routines in the hope it will give us the control we crave. So how do we cope with the possibility that maybe, just maybe, we don't have fibromyalgia after all?

Do Your Research

I recently decided I had been misdiagnosed. After seven years with fibromyalgia I decided my medication wasn't helping, my pain felt too severe and I was convinced my doctor had missed something. I went online, Googled my symptoms (we've all done it!) and searched through multiple websites until I was convinced I had rheumatoid arthritis.

If you're going through something similar, my advice at this point is to use trusted websites and be systematic in your research. For many of us, online searching is the step before the doctor's appointment, but that doesn't mean you should listen to the wise words of Yahoo Answers.

Instead, use regulated websites owned by medical professionals or those run by reputable medical associations or charities. Look at multiple sites and try to avoid anecdotal horror stories on web forums that aren't monitored. Instead, use sites like NewLifeOutlook, Patient.Info or Patients Like Me to get a thorough understanding of the patients' experience.

I did all of this, and still couldn't shift the thought that I had rheumatoid arthritis. I was missing a couple of key symptoms but, in my mind, they weren't a big deal and everything else was spot on.

Talk to Your Doctor

It can be embarrassing to go back to your doctor to tell them you think they're wrong. I had been given a fibromyalgia diagnosis, an amitriptyline prescription, and sent on my merry way. What more did I need?

But as the days went on I couldn't shake the feeling that maybe, all those years ago, someone had just got it

wrong.

One day I had a sudden realization: I don't want to be 75 and told I've been treating the wrong condition my whole life, all because I didn't want to offend my doctor. So I booked the appointment and went in with my head held high.

Your relationship with your doctor is two-way, and you must be able to have an open and honest conversation at every appointment. It may feel daunting, but it's so much better than the alternative.

I spoke to my doctor, told him about my suspicions and he asked me to two simple questions. I answered no to both of them and he simply and confidently said, "Then you don't have rheumatoid arthritis."

Understand Your Diagnosis

It's important to understand why you've been diagnosed with fibromyalgia. Although it's often selected via a process of elimination, you have to remember that most other conditions have a very clear pathology. Your neurologist diagnoses you with multiple sclerosis because of the results of your MRI scan. Your rheumatologist diagnoses you with arthritis because of your blood test and X-rays.

Fibromyalgia isn't conclusive so it's hard for us to accept the diagnosis. It seems open to interpretation, subject to change, and that is difficult to cope with.

If you can understand why you've been diagnosed and the range of treatments that are available, it becomes a lot easier to accept. If nothing else, you have the knowledge and power to manage your own condition and control your situation — even if it doesn't feel like it very often.