Coping With Fibromyalgia Doctor Frustrations

by STARLA RICH

Fibromyalgia and Doctor Frustrations

There are many conditions and symptoms associated with fibromyalgia. Some sufferers of FM deal with certain conditions more than others and each person has their own unique journey when dealing with this disease.

But there is one aspect of fibromyalgia that is common among all sufferers — frustration! Each FM sufferer at one time or another has felt the frustration of being misunderstood, of not being heard and not being taken seriously.

It becomes easier to accept why family and friends do not fully understand what an FM sufferer goes through once you realize that not even medical professionals fully understand; which causes patients' lack of clarity about their own disease and conditions.

Medical professionals seem to stand on one side of the fence or the other when it comes to fibromyalgia. Some of them firmly believe that it is a real illness, while others doubt fibromyaliga is real.

Dealing with those who refuse to acknowledge it is so frustrating! So this begs the question, why? Why do they not embrace at least a basic understanding or knowledge of fibromyalgia?

Why Is Diagnosing Fibromyalgia So Difficult?

To put it simply, pain is not something that shows up in an X-ray or blood test. For this reason, diagnosis is difficult when there is no tangible evidence of what is behind the pain. It takes an average of more than two years to get an accurate diagnosis that meets the standard criteria for fibromyalgia.

For even a doctor who is very experienced with fibromyalgia, diagnosing the disease takes time.

Frustration Breeds Frustration

The fact that patients often have difficulty articulating their symptoms is a struggle for doctors in getting the information they need to properly diagnose and treat the FM sufferer.

Over time, we want to avoid being seen as a “whiner” so we become reluctant to talk about symptoms, which can be a serious roadblock for diagnosis.

At some point though, we become a ticking time bomb, to the point where we can’t take it anymore. We're angry and tired of the long diagnostic process and become increasingly desperate when dealing with doctors.

In turn this can backfire and bring more confusion for the physician. Everything becomes convoluted and the doctor finds it difficult to close in on the main symptoms. Like every other relationship in life, communication is key to success between that of a doctor and patient.

Finding the Right Doctor

Those in the inner circle of fibromyalgia understand the struggles and frustrations of finding just the right doctor to walk the fibro journey with you. As an FM sufferer of over 15 years now, I know that frustration firsthand. I have heard it all.

“You are too vivacious to accept disability.” “You look so healthy!” “This is not one of the ‘normal’ symptoms.” “You should just push through and work your job. It might make you feel better!”

And then the worst of all, when you are at your wits end with no relief in sight: “I don’t discuss disability or support alternative schedules concerning your life and career for just fibromyalgia.” To which I wanted to scream back… “JUST FIBROMYALGIA?”

My advice is this: rather than building up more frustration and resentment, or exerting even more of your energy on trying to get certain doctors to understand, continue to push forward to find the right physician.

Easier said than done right? Well here are a few tips concerning a fibro-friendly physician.

Rheumatologists often diagnose fibromyalgia, but for ongoing care, your primary care physician or neurologist may be the ones to walk the journey with you.

It is important to find a doctor who is:

- Experienced in treating fibromyalgia symptoms
- A believer in working with a patient as a team
- Empathetic and a good listener

If you do not have such a doctor that you know well, here are some suggestions:

- Ask friends, family members or co-workers for referrals.
- Learn more about the doctor in regards to their experience with fibromyalgia.
- Ask your doctor if they feel you should see a specialist; rheumatologists, pain specialists and neurologists devote their careers to pain relief.
- Call your health insurance provider to give you a list of healthcare professions near you that your plan covers and will guide you as to proper procedure in seeing a specialist.

Communicate and become a team full of understanding for each other and the frustration will reduce greatly.

Deflating the Frustration Bubble

As I write this article, I am only about 14 hours away from another visit with my physician. Like other FM patients, I hope the visit goes well and feel just a little of that anxiety that I could leave frustrated again.

So what can we do and should we do to help make a doctor’s visit a productive one?

- **Describe your current symptoms in a clear and organized way.** Remember the written list we discussed earlier.
- **Ask questions!** Move past the discomfort you feel talking about your condition and realize the more your doctor knows about you and what you are dealing with, the better they can help.

One of my favorite motivational speakers has a saying: “It all starts and ends with YOU!” There are so many things that are beyond an FM sufferer’s control, but attitude is the one thing that is totally up to you.