How Do We Explain Fibromyalgia to Others?

by BARBARA LEECH

Explaining Fibromyalgia

I have friends and family who have no idea I have fibromyalgia. It simply feels like too much work or embarrassment for me to try and explain it to them.

I fear they will not give the disorder, or me, the respect we deserve, nor will they understand the gravity of what I go through each day. It may be seen as just another ailment I have; a “there she goes again” confession.

The people close to me know I have lupus. Some even know I also have Hashimoto’s thyroiditis. But few know that on top of those two illnesses, I have been diagnosed with fibromyalgia.

This, in part, is my own reluctance to try and find ways to articulate and adequately explain what it is, and why I have these three debilitating conditions together. I mean, it sounds like I am collecting them, right?

I worry it would raise doubts in some people’s minds, especially those who have no idea what fibromyalgia is or what it does. I fear they won’t believe how sick I am and what I struggle with. It makes me feel small, so until recently I have simply avoided telling most people.

Why Don’t We Talk About Fibromyalgia?

Fibromyalgia was the first of my three life-altering conditions to appear and be diagnosed. I was 27 and suffering from many odd symptoms that included joint and muscle pain and a fatigue so extreme it was a struggle to keep going each day.

Now my doctor believes I also had lupus at the time, but it would not be diagnosed until I was 40.

The doctor I had back then who diagnosed the fibromyalgia did little to explain to me what it was. He simply told me I had fibro and prescribed duloxetine (Cymbalta), which he said was used to help relieve nerve pain in people with diabetes or ongoing pain due to medical conditions.

I told some people I knew about my diagnosis and I learned quickly that most people did not believe fibromyalgia is real; even my primary care doctor at the time seemed to discount it. So, I simply stopped talking about it.

One can only take so many eye rolls and looks of disbelief. Though I knew it was real, and with fibromyalgia causing me pain every day, dealing with other people’s doubt was very hurtful. I learned to say nothing to avoid being looked at like I was crazy or making things up.

But recently there has been a lot of actual medical documentation and articles written by the medical community about fibro, which has spurred greater knowledge and acceptance. People are starting to get the fact that this is a very real condition, so I have started to come out of my protective shell.

My outlook has changed and I find myself feeling like it is time to tell people I have fibro and be willing to explain to them what it is. Knowledge is power.

How to Explain Fibromyalgia to Others

If you are like me, getting started is the hardest part. Where do we begin?

Here are a few tips to follow on how to tell people you have fibro and how to explain what this often confusing condition is and does.

Next page: explaining your condition and what it does to your body.

How to Explain Fibromyalgia to Others

Explaining What Fibromyalgia Is

Once you tell people of your fibro diagnosis, you will find though many people have heard of it, they have no idea what it is.

I say this: “Fibromyalgia is defined as a disorder characterized by widespread pain, which causes many symptoms like extreme fatigue, sleep issues, memory loss and even affects the mood. It is essentially a very painful, exhausting, joy-killing disease, for which there is no cure and little can be done to treat it.”

Explain how fibro differs from other conditions — for example, polymyalgia vs fibromyalgia — and try your best to explain fibro in terms of how it impacts you.

How Fibromyalgia Affects the Body

I say this: “Researchers believe fibromyalgia amplifies painful sensations by affecting the way your brain processes pain signals. So my body feels extreme pain, even though I have done nothing to injure or hurt myself, but the pain felt is debilitating and real.”

Good and Bad Days of Fibromyalgia

People do not seem to understand there are good days and bad days. The uncertainty of not knowing what each day will bring wears on us deep down.

I say this: “I have days where it is less painful to move — perhaps I rested the day before and ate properly and a small miracle occurred. It is not horrible all the time.

But it is unpredictably horrible. Happy occasions and celebrations become one more thing you must get through or manage. Spontaneity vanishes as you must plan ahead for everything.

I have to plan to do things on a day when I wake up and the pain level is in check, so I think I can handle all that is required. Other people take the ability to do all of that, with no planning or weighing their health that morning, completely for granted. I no longer have that luxury.”

I know that what I do on a good day, will probably come back to bite me the next.

I say this when people ask why I’m fine one day and can barely move the next: “Often when I tackle a day as if I don’t have fibro, I will hurt badly the next day and may be so exhausted I will struggle to get through the following day, or two, or three.

That one good day can be one that makes me regret my time of joy. Essentially, often I am punished for enjoying the good days.”

Fibromyalgia, Negativity and Depression

I tell people depression is a natural part of having fibro. Being in extreme pain on a regular basis, and feeling punished for doing the simplest things in life, brings about an associated response. If you pay for having fun and being happy with pain and suffering, eventually you come to anticipate the negative before it even arrives.

So it affects the way you experience the good days a well. This affects your outlook on life and the future, whether you want it to or not.

I have finally reached a point in my life where I will not hide the fact I have fibromyalgia out of fear of how others will react. What others think is not my problem; it is theirs and is a reflection on their character, not mine.

I back up what I tell people with facts, refer them to legitimate sources, and answer their questions honestly. That is all any of us can do and I believe the more we do so, the greater public awareness there will be.