Talking About Fibromyalgia

by DINA NEWTON-EDWARDS

Emotions and The Importance of Talking About Fibromyalgia

I received my diagnosis of fibromyalgia about three months after the onset of symptoms. During that three-month period I was coping with fibromyalgia fatigue — and I didn't even know it.

I was tired all of the time and was falling asleep frequently. The fatigue was so bad that I would even drop off to sleep whilst typing on my iPad or halfway through a row of knitting.

Sleep was dominating my life, preventing me from taking part in my usual social activities. I felt as though I was letting people down even though I was trying to explain what was happening. Life was passing me by.

During that time I was desperate for the fatigue to be due to post-infection malaise, even though my doctor had mentioned that he thought it more likely that it was fibromyalgia. I kept as positive an attitude as I could – I would not admit to myself that there really was a possibility that it could be fibromyalgia, even though I told people that was what it might be. It’s good to keep a positive attitude, right? Well, no, actually. Not in my case.

When my GP gave me the diagnosis my initial reaction was one of profound disappointment. I was disappointed that I had fibromyalgia, but what was almost worse was that my optimism, the positive attitude that I had concentrated so hard on having, had been a waste of time. All that effort for nothing.

When I arrived home from the surgery I explained to my partner what the GP had said. I don’t think he knew what to think about the news. He knew less than I did about fibromyalgia, and I didn’t know much! As for me, by the time I had arrived home, I was feeling as though I had been given a life sentence. I was pretty scared, I can tell you.

Finding a Way to Share

Within 24 hours of being told I had FM, I knew I needed to write a blog diary about it. The feeling was a compulsion and I have a habit of following those compulsions when I have them. Consequently, I set up my online Fibro Diary on 13 November 2014. I have found that by writing the diary I am able to work through my feelings about having FM and about the reactions I am faced with from other people.

For me, it is important to be honest with my close family and closest friends about my FM and how it is affecting me. If I’m not honest, how will they know how I am? My Fibro Diary gives me the opportunity to explain how I am feeling in my own words, without interruption. It gives me time to explain in a way that helps me to cope with the illness, and also that, I hope, will help those closest to me to understand how it is affecting me, both physically and mentally.

I have time to choose the words and phrases that I think will best convey what I am attempting to say. It’s not always possible to do that when conversing with others, as they will be putting their own interpretation on what I am saying and projecting it back to me. I don’t want that. I don’t need that.

I need those close to me to see, and hear, and understand what I am trying to explain. I need to be allowed to speak in my own words – and I also need them to listen. I don’t need platitudes or sage advice. I am coping with my fibromyalgia on a day-to-day basis and, although sometimes I complain, it is working well for me.

Next page: the dangers of bottling up your feelings

The Dangers of Suppressing Emotions

I don’t know whether other people react in a similar way to me when they are given their diagnosis, but I am willing to bet that they feel the need to share their thoughts and feelings in some way. There are so many ways to do that and it is important that each person finds the way that is best for him or her. Bottling up one’s feelings is not a sensible option, in my view. Believe me, I know! I spent a lifetime (well, nearly 45 years) bottling up my feelings and I have the scars to prove it!

I have long-term depression and anxiety. I had several periods of depression prior to it settling in for the long haul and have tried different therapies to alleviate the symptoms, with varying degrees of success. I had developed a pretty strong fortress within which to bury my feelings and it took a huge amount of work, firstly, to access those feelings, and, secondly, to learn not to automatically bury them there when I am troubled.

Hence, my need to find an outlet for my feelings about my diagnosis and its likely effect on my future. As I say, for me, my Fibro Diary fulfils that need.
In my view, it is vital for everyone with a chronic condition such as fibromyalgia to find some way of giving vent to their feelings about both their diagnosis and the effects of the condition on their lives. These are vast, life-altering situations, not only for the sufferer, but also for those closest to him or her.

Since my diagnosis, I have found very many places online offering help, advice, resources and somewhere to talk. There are sites giving information about FM, including the latest thinking on possible causes and treatments, forums, support groups and more.

Although I haven’t really used sites like those, I have used one called Patients Like Me, which allows me to keep a record of how I am physically, my medication, my mood and many other aspects of my health. I have found it particularly useful when visiting my GP to be able to look back over any given period to see how I have been. I know I could keep a written record, but I also know I wouldn’t keep it up. The beauty of that site is how simple it is to use: I receive a daily email with a link to click.

I have found that I don’t particularly wish to talk to other sufferers about my FM. FM affects everybody differently and I think I am coping with mine fairly well by writing my Fibro Diary blog. I think I am slightly afraid that sharing with other fibro sufferers will mean that I am confronted by aspects and symptoms of fibro that I don’t want to know more about at the moment. It is my version of “Ostrich Syndrome,” i.e. burying my head in the sand.

I am extremely lucky in that I have very little pain, at the moment. The thought of suffering excruciating pain scares me witless so I don’t want to spend my life worrying about it – there will be plenty of time for that when or if it happens. Does that make me selfish? I don’t know, but it sure as hell stops me from being overwhelmed by fear of FM and that, for me, is definitely a very good thing.