

LIVING WITH FIBROMYALGIA, by Julie Wendell

"Mommy, open this, please?", my 3 year old son asked as he handed me a cereal bar early one morning. I tried to tear off the top of the wrapper, but my fingers would not move or grasp the wrapper! Terrified, I tried opening it again, but to no avail. I had lost all strength in both of my hands! As calmly as I could, I asked my 7 year old son to open the cereal bar for his brother. But inside, I was panicking because the weakness in my hands persisted for about an hour. What was happening to me??? Little did I know that the morning of February 10th, 2008 marked the beginning of a myriad of severely painful symptoms. My life was about to drastically change.

Over the course of the next few weeks, I started to experience alarming new symptoms. In addition to the weakness in my hands, I noticed that the joints in my hands were very swollen and stiff. I even took pictures of my hands from all angles to make sure that their odd shape was not just my imagination. I would often feel sharp zinging pains in my extremities, especially in my hands, wrists, knees, and ankles. My muscles and joints ached like I had the flu. There were times when I would be convinced I had a temperature of at least 101, just to find out it was completely normal every time I checked.

My level of fatigue went from "full time single working mother" to "full time single working mother who also ran 100 miles a day". I was physically exhausted from dealing with so much pain every day. To make matters worse, I started noticing that when I woke up each morning, I would not feel refreshed, even after a full straight 6-8 hours of sleep. Instead, it felt like I only slept for one hour each night. So not only was I physically exhausted, I was emotionally drained as well. The overall level of exhaustion was indescribable, the worst I have ever experienced in my life! But I was hoping that whatever was plaguing me would just stop on its own.

One afternoon in April 2008, after I got off work and picked up my kids, I couldn't get home fast enough. My body was overwhelmed with pain like I never felt before. As soon as we walked through the door, I immediately headed for the couch, where I spent the next four days. I had to call my mom to help me take care of the kids. In addition to my existing symptoms, I also suffered from oppressive chest pain, muscles/joints that felt bruised, extreme coldness in my arms and face, and TMJ-like jaw pain. I also had the sensation that my aching spine and pelvis were going to slide out of my body. I cried often, because I had no idea how to cope with these bizarre symptoms. I tried heating packs, ice packs, Tylenol/Advil, but nothing even remotely helped me. My temperature was still normal at 98.6. My mom, who is a nurse, thought maybe I had a virus, but most of the symptoms did not even resemble any virus I had ever had in the past, plus I was not running a fever. Even after the four worst days of feeling severely "sick", most of my symptoms never fully disappeared.

At this point, I was at my wits' end, so I finally decided to get some help. So even though I was terrified of the possible outcomes, I made an appointment to see my primary care physician. After reviewing my list of symptoms and seeing the pictures of my hands, he thought it was very likely that I had rheumatoid arthritis. He immediately referred me to a rheumatologist, who wanted to test me for not only rheumatoid arthritis, but also lupus, mononucleosis, and multiple sclerosis. He ordered some

x-rays of my hands and alot of bloodwork. He also prescribed a week's worth of steroids to see if that would help.

My daily life started becoming a real chore for me. Everything and anything I usually did without a problem was now unbearable or overwhelming. The mornings and evenings were the worst times of day for my pain, fatigue, and weakness. I tried to stay strong, especially for my children, but there were days where I felt like giving up on everything. I tried talking to a few friends and family members about how I was feeling, but they would just say that I was complaining too much and/or accuse me of being a hypochondriac. I had never felt so alone in my life.

The results of the blood tests and x-rays came back the following week and were completely normal. Also, the steroids ended up not helping me at all. Based on these findings, the rheumatologist suggested that I may have fibromyalgia. He prescribed an NSAID called mobic to help with my muscle/joint pain and an anti-convulsant/anti-neuropathy medication called gabapentin to help with my nerve pain. The doctor said that diagnosing fibromyalgia was very tricky because there are no actual diagnostic tools. Instead, the diagnosis is made after everything else has been ruled out. He also wanted to wait and see how the next few months went with the new medications before confirming the suspected diagnosis.

During the following months, both of the medications had made a difference to where my daily activities became more tolerable. I still felt very fatigued, but my quality of sleep seemed to be more restorative (due to the gabapentin). My muscle and joint pain were definitely persistent but they were on more manageable levels (due to the mobic).

When I went back to the doctor in August 2008, he reviewed all of my test results and evaluated me again, then officially diagnosed me with **fibromyalgia**, a syndrome characterized by chronic pain, stiffness, and tenderness of muscles, tendons, and joints (definition by MedicineNet.com). The treatment for fibromyalgia includes pain medication and exercise. The doctor advised me to continue with the medications I was currently taking and to try doing light exercise when possible. He also warned me that my medication combination was not always going to be perfect. He said it may take a few tries with various medications before reaching optimal pain management, and what works for me now may not work for me in a few years. I was completely devastated, knowing that I was going to live with unrelenting complicated pain and severe fatigue for the rest of my life.

Sometimes, in addition to medication and exercise, doctors recommend a gluten free diet to help alleviate fibromyalgia symptoms. Coincidentally, I had already been on a gluten free diet for 4 years already, due to having an auto-immune digestive disorder called Celiac Disease. Unfortunately, being on this diet did not stop me from having fibromyalgia nor had it eased its symptoms. My doctor said that I'm one of the unlucky fibromyalgia patients who was not positively affected by a gluten free diet. Sometimes I like to think that being gluten free has stopped my fibromyalgia symptoms from becoming uncontrollable.

A diagnosis of fibromyalgia carries a negative stigma in society because the symptoms are very vague and are not so clear-cut as other diseases/conditions. I have actually heard people say that there is no

such thing as fibromyalgia, or that the symptoms are fake and they are all in the person's head. It is also widely believed that people who have fibromyalgia just want attention and/or medication. There are many doctors do not recognize fibromyalgia as an actual medical condition. Therefore, people who do have fibromyalgia usually have to see numerous doctors before receiving a diagnosis. Luckily for me, reaching a diagnosis for my symptoms only took 6 months and involved seeing only 2 doctors. Some people suffer for years before finding an answer.

Since my diagnosis, additional symptoms have added themselves onto the original list, such as hypersensitivity to stimuli. For example, if there is too much light or sound, I start feeling very overwhelmed and need to remove myself from the situation. There are times where I cannot be touched, when even my clothes feel like too much overload on my skin and receiving a hug actually HURTS. I also started becoming sensitive to the weather patterns, especially low pressure systems. I jokingly call myself the "human barometer" because I seem to predict rain better than the weatherman! During periods of damp or cold weather, my muscles and joints heavily protest, and in turn, the pain increases substantially. I found that I have a low tolerance for any kind of exercise, it makes me feel worse rather than making me feel energetic and refreshed. I have also developed difficulty with my short term memory and concentration (ie-"fibro-fog"), which has affected all aspects of my life, especially work.

Today, it remains difficult for me to deal with the pain and fatigue that I experience every day with fibromyalgia. My doctor has changed my pain reliever from mobic to tramadol, which is a bit stronger, so my pain is at a tolerable level most of the time. But I definitely have my share of bad days. On a positive note, I have learned a few things from my experience with fibromyalgia. I've learned not push myself to do more than I can handle, but I'm still learning that it's okay to ask for help. I have also learned to prioritize what is actually important and to just take things one day at a time. Having fibromyalgia has made me realize it is so important not to take anything for granted. After my diagnosis, my rheumatologist had pointed out to me that fibromyalgia is not a deadly or destructive disease, which is very fortunate. However, living with chronic pain and fatigue is still a difficult challenge, no matter what the cause or prognosis. Yes, fibromyalgia is REAL.