MY STORY

By

Karen R. Carpenter

I was diagnosed with Fibromyalgia approximately 8 years ago. After my diagnosis I encountered prejudiced attitudes from doctors, pharmacists and therapists. I was often treated with antagonism and rudeness. I was told my condition was my fault, that I must have a bad home life and if I went to see a psychiatrist my condition would go away. No one was willing to treat my diagnosis or my pain seriously. I was told I would have to learn to live with my pain because, since it would never go away, they not give me any pain medication. Pain was my constant companion. A burning, stabbing, throbbing nightmare. I couldn't sleep, I couldn't eat.

I tried all of the treatments the doctors told me to; acupuncture, physical therapy, massage therapy, ice and heat, hot baths, trigger point injections, biofeedback and every anti-inflammatory on the market as well as other drugs usually prescribed for nerve pain such as Neurontin. I tried all of the treatments multiple times hoping for some relief. I found no relief with any of these treatments. When I told the doctors this over and over, they just looked at me and said well, let's try it again or let's give you a couple more prescriptions (for the stuff that wasn't working in the first place). Most of the medication had really bad side effects: extreme drowsiness, possible liver damage, stomach damage, etc. In spite of these effects, the doctors would put me on the largest dose possible, even though I told them the drugs weren't working.

Meanwhile, I was down to 98 lbs (and I am almost 5' 7"), was out of work and could not function to take care of myself or my family, my marriage was under great stress.

I prayed to die. I wanted to die. I didn't want to go through another day enduring the pain I was in.

I repeatedly went to the doctors and begged for help. I didn't get any. Since the treatments they were prescribing weren't helping, they made me feel that it was my fault these treatments were of no help and that I was a criminal for asking for any pain medication. They added guilt to the burden I was already carrying. They made me feel weak and inadequate. Their attitudes

were unsympathetic and superior. If I changed doctors, they accused me of "doctor hopping" to get the answer I wanted. What I wanted was help.

Finally I was referred to a pain specialist in Maryland (I live in Virginia) through an acquaintance. The pain specialist looked at me and my history and agreed to try me on a pain medication called Oxycontin.

This medicine turned my life around. Even through every day is still a struggle, I now have a fairly normal life. I have a full time job, even though it isn't the job I used to be able to do, and I have a home life for the first time since my illness. The hospital in my area finally passed a "Pain Bill of Rights" for its patients. I thought the dark ages were finally over.

Unfortunately, though I thought I was past most of the prejudice and no longer had to "justify" my pain, recently I found I was wrong. To continue my story, over the last 6 months or so I have had an increase in my pain levels. I returned to my pain specialist and my primary care for instruction. On my last visit to my pain specialist, he indicated that an increase in my medication may be necessary. However, he refused to give it to me. In fact, he told me that he was going to remove me from Oxycontin altogether due to the recent publicity. He said he can't afford the scrutiny and that any increase in my medication would bring adverse attention down on myself and him. He stated that everyone taking Oxycontin is now considered a dealer until proven otherwise and that according to the FDA there are no legitimate uses left for Oxycontin.

Thanks to legislators, newsman and others, patients like myself are being held responsible for the actions of drug addicts and dealers. Why should I be punished because people ***choose*** to abuse this medication (and it is their choice even though many don't believe so), by crushing it and/or injecting it? I have no choice in my pain. I can't choose to have no pain today. Do you blame the car when someone wrecks due to driving drunk? No. Do you punish people who are addicted to alcohol for no other reason than recreation? No. I need this medication to keep my job, to take care of my family, to live. Make the abusers and dealers responsible for their own choices and action and stop punishing the people with legitimate need.

My pain specialist mentioned MsContin and Methadone as possible replacements. I preferred to go with MSContin, if I had to change at all. He said he was not comfortable prescribing the MSContin and would prefer to

give me the Methadone. I asked him if the Methadone did not work as well for me as the Oxycontin could I go back to the Oxy. He said no, definitely not. As a form of implied blackmail, he reminded me that doctors don't usually treat Fibromyalgia with narcotics. Given the progress I have made and the change in my life due to treatment with Oxycontin, I can't understand why doctors refuse to treat Fibromyalgia with narcotics. The pain of people with Fibromyalgia is just as real and legitimate as the pain of people with cancer. The other "reason" for not using narcotics is the possibility of addiction. People are addicted to alcohol and cigarettes. Those things kill and cause cancer and destroy lives everyday and have no medicinal purpose, but I don't see those products being taken off the market.

The wonderful FDA is having a meeting on June 14 & 15 to discuss the merits of people with chronic pain who don't have cancer should be treated with narcotics. My pain is just as real as someone who has cancer and should be treated just as seriously. Obviously, none of those people who object to narcotic pain treatment for chronic pain have had or watched someone suffering from severe, debilitating, chronic pain, pain which can be alleviated with the proper medication. The majority of those people who are abusing this medication have never been legitimately prescribed pain medication for a problem, they are simply addicts and Oxycontin is their drug of choice for the moment. If it is gone, they will simply move on to something else. The only people hurt by taking Oxycontin off the market are the people with a legitimate need, who go through legitimate channels to obtain it.

I have never seen legislators, doctors, and newsman have a national or even statewide meeting on how to help people with chronic, debilitating pain. Why not? Not newsworthy enough? Doesn't carry enough political clout? Why isn't there a national taskforce, or state task forces addressing this problem? I'm sure the Attorney General's Office, who has taken such an interest in the abuse of this drug, couldn't find the time to address the issue of untreated pain in America. It is the silent killer and destroys as many or more families and lives than alcohol and drugs combined. It costs the nation millions and could be alleviated so much more easily than addiction. All it requires is proper, adequate treatment.

I am tired of having to be careful not to upset my doctor or disagree with him, or he might not continue to treat my pain. I tired of not being able to

tell the truth about my pain status for fear my doctor will think I am just after more medication.