It's Just Tension, By Carol Reber

Ed. Note: *The opinions expressed above are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.*

"It's just tension. I'll give you something for it." This was the diagnosis from my family doctor after I told him I had just returned from vacation and was bed ridden with a blinding headache for the last four days. It started Friday morning. By Friday night I could not lift my head off of the pillow. If I turned my head either way my finger tips felt numb. I was scared but I did not know what to do. The headache continued all weekend until Sunday night when I started getting slowly better. On Monday morning we returned home and I called my doctor right away. I got an appointment that afternoon. He came into the room and leaned against the wall and listened to my complaint. Without even touching me or examining me in any way, he gave me two prescriptions. One for Valium and the other for Tylenol #3. They were good for six months. I had been having headaches for several years and they were getting worse. I had seen probably eight to ten different doctors by this time. None of the others had so blatantly ignored my pain.

It was then that I decided that either my headaches would get better and I did have a mental problem, or they would get worse and, maybe then, someone would believe me or maybe I would just die from a brain tumor or something. I had been having headaches since I was 16. I had been seeing doctors about them since I was 18. Most doctors were not as obvious as the one I was seeing today, but almost all of them suggested tranquilizers for my headaches. Valium was a popular one. A few doctors suggested they might be migraines but none of the medicines they gave me helped at all. What I could not understand was that I did not get the headaches when I was sad or upset. I got them if I laughed too hard, or played too hard. I was 25 years old and these headaches had become a way of life. Don't get too excited. Don't have too much fun or you will suffer for it.

Needless to say, I started seeing a new doctor. I really liked him but I did not mention my headaches to him, nor did I mention my new symptom of dizziness. I did not want him to find out I was a mental case or label me as a hypochondriac. But, one day about three years after I started seeing him and learned to trust him a little, I mentioned I was feeling a little dizzy. Although, he had already examined me and was getting ready to leave the room, he came back and did a neuro check. He became very concerned when he discovered that I had developed nystagmus. He made me stop all medications he had prescribed for a stomach condition he was treating me for and sent me for a battery of tests. After seeing several different doctors, including a neurologist, it was decided there was something wrong. I was told I had multiple sclerosis by all of the doctors except one specialist who thought it was not MS but was a central nervous congenital defect. But he stopped there and did not do any testing or even try to pin down a diagnosis. He said he did not want to label some one so young with a lifetime diagnosis. All the other doctors decided I had MS and I began seeing a neurologist on a regular basis to monitor my "illness".

Life went on. Although, I was not happy about having MS, there was a certain amount of relief in the fact that at least the doctors no longer treated me with a smile, a pat on the back, and a prescription for mood altering drugs. They believed me when I said I was dizzy, or had a headache, or the host of new symptoms that developed over the next 10 years. After a few years my second daughter was born. I was having trouble with my balance by then and I was afraid I could not carry her without falling. I had to purchase a pram so I could use it at home to carry her about. I was convinced I would be in a wheel chair some day but, yet, I felt lucky because I was going to be able to watch my children grow up. There was also a relief knowing what was not wrong. I had thought it was a brain tumor or something terminal. Your mind can make up all sorts of fears when something is going wrong and no one can figure out why.

At the age of 38, my husband got a job transfer and we moved to Ohio. I, of course, had to find new doctors. I started seeing an internist there who listened with great interest to my history. After a full exam he insisted on reviewing all of my old medical records. After his review, he said he did not totally agree with the diagnosis of MS and wanted me to have some new tests done. I balked at first. I had already done all of the tests. I had accepted my diagnosis and I did not want to go through it all again. My internist called me on the phone when I did not make an appointment with the neurologist he had suggested and talked to me for more than half an hour and finally convinced me to see the new neurologist.

On the day of my appointment, I did not have any expectations. I had MS and there was nothing to do about it. This was all a waste of time, but because my doctor insisted, I would allow it. I went into the examining room and the neurologist took a complete history, examined me and said, "I think I know what is wrong with you, and I do not think you have MS. I want to do another MRI and see if I am right before we discuss it". I had the MRI done and two weeks later I went back for a follow up appointment. I still did not believe there was any reason to get excited. I had been ill for 22 years. What made this guy any smarter than all the twenty or so doctors I had already seen. The neurologist came into the examining room and gave me a copy of a page from a book that listed all of my symptoms and said, "You have an Arnold-Chiari Malformation and we can fix it with surgery." He told me that the malformation was visible on the x-rays done 7 or 8 years earlier but it had been misread by the radiologist. In fact, he said that the radiologist had read the current MRI as normal and he had made the radiologist go back and reread the MRI and look specifically for a Chiari malformation. It was only then that he found it.

There was a change in my whole perspective on life. I did not have to look forward to a wheel chair. I was looking toward a cure. The thought of brain surgery really scared my husband. He said to me, "I would rather have you like you are than not have you at all. I can not make the decision whether or not you should have the surgery, but I will support you in what ever you decide." To me there never was any question. I was scared, but a cure was too much to pass up just because I was afraid. I had surgery at the Cleveland Clinic in Ohio in May, 1988. I did not have any complications after the surgery but I can not say it was a breeze.

One day about four months later, I was driving somewhere with my children, and it suddenly hit me, "I'm not sick anymore." It was like a revelation. "I'm not sick anymore". I said it out loud. My daughter looked at me and wondered who I was talking to. "Just myself," I said. She thought I was a little strange but what twelve year old doesn't think her mother is a little strange?

I wish I could say that was the end of my problems. But, unfortunately, it was not. Since I experienced symptoms for 22 years, there has been some permanent neurological damage. I still have the nystagmus that makes it difficult to focus my eyes at times. I will always have very poor balance and some double vision in certain fields. My symptoms have been fairly stable for most of the 15 years since the surgery, however, in the last two years, I have been experiencing a mild increase in symptoms for which I am seeking medical care. But the difference now is the doctors no longer treat me like a poor misfortunate depressed woman. They believe what I tell them. I did not know how to be my own advocate when I was young and in pain and scared. I have learned to demand to be heard. There are many good and caring doctors out there. There are a few who think they are too busy to be bothered. I have learned that the latter kind are not worth wasting time on. I have learned to find doctors who care. I have also learned one more thing and have told it to other people I have met over the years. If you have a medical problem, do not wait and doubt your own sanity. Talk to you doctor. Tell him what is wrong. If he does not listen, find a new doctor. Although, there are a few doctors with whom I will always feel some anger toward because of what I have gone through, I realize that some of the responsibility is mine. There were doctors who would have listened but I quit telling them because I was afraid and I did not have enough confidence in myself to demand their attention.

Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.