Sabrina Says Listen To Your Body

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My name is Sabrina Sena and I am an acupuncturist from New Jersey. I was diagnosed with syringomyelia in August of 2001. About 10 months prior to my diagnosis, I began experiencing occasional pinching pains down my right arm. It began above my elbow, and traveled down to my little finger. It was really no more than a nuisance at that time, so I dismissed it. I was a full time graduate student studying Traditional Chinese Medicine (acupuncture and Chinese herbs), and working part-time as well, so I just didn't feel like I had the time to see a doctor. Especially over minor pain in my little finger. But in the following months, the pain started occurring more frequently and with more intensity, especially after lifting weights. So, finally when I was off from school in the summer of 2001, I went to see my doctor. Little did I know, things were about to change forever.

My X-Rays and EMG were of course basically normal, they thought I just had a pinched nerve, and ordered some physical therapy. After all, what could be that wrong with a 24 year old who is going around walking and talking just fine? But I wasn't satisfied, and my instincts are usually pretty good. I insisted that I have an MRI, so my orthopedist sent me for one. The entire time I was in that machine, I couldn't shake the feeling that something was terribly wrong. The MRI technician confirmed my fears when he handed me my films and said, "Make sure your doctor sees these right away."

Uh Oh! Right away? Why? I found out 2 days later in my orthopedist's office. He sat me down, and said "You have a syrinx. It goes from your brainstem down to T3. You need a second MRI, and you have to see a neurosurgeon as soon as possible because I'm not qualified for this." Well, what was I supposed to do with that information? He gently tried to explain to me what a syrinx was, and what the possible causes were. But I was in total denial. It was like he was telling me about someone else. As soon as I got home, I did what you're never supposed to do. …looked it up on the internet! There was nothing even slightly reassuring in the information I found. Pictures of Bobby Jones saying how disabled he became with syringomyelia before he died don't exactly make you warm and fuzzy inside. However, I was able to get he name of a neurosurgeon who had experience with this condition.

So, I made an appointment with him, and had a 2nd MRI in the meantime. When I went to see the surgeon, he looked at my MRI's and said, "Well, you have a tumor in your spinal cord. The good news is that it's benign. The bad news is it's in a really bad spot. You need to have surgery next week." He also said, "You're going to ask me if you can be paralyzed, and the answer is yes." This had to be a mistake. What on earth was going on?! I just had a little pain in my pinky, what are they talking about?! But then everything clicked. Symptoms I had for years (weakness in my legs, terrible pain in my neck and upper back, loss of balance) that I just attributed to stress or carrying my book bag, were all tied together now. I was terrified. You know, they say when a person is having a heart attack, one thing they describe in a feeling of impending doom. Well, I can tell you that it doesn't just happen if you're having a heart attack. It was more or less my perpetual state until they rolled me into the operating room.

I had my surgery on September 10, 2001. Unfortunately, the first thing I remember was waking up on September 11th to find the whole world upside down. My own world, and the world outside. The pain I was in was unimaginable. It felt like every nerve ending in my body was on fire. I couldn't move. It hurt to breathe. I wasn't paralyzed, but I've never experienced my entire body being in that kind of pain. The hospital was locked down because they were expecting victims from the World Trade Center. It was like a nightmare I couldn't wake up from.

Since then, things have gotten better. The tumor was removed, but unfortunately some nervous tissue went with it. I have pins and needles and decreased sensation from the chest down. And my right hand has been endearingly renamed "the claw" by my family. The syrinx hasn't completely collapsed, but it is smaller, and I'm not on any medications. I don't want to take medications for something that's a lifelong condition. I don't want live like that.

I finished graduate school in August 2004, and I practice acupuncture in NJ. Chinese Medicine has been a Godsend to me. I found that regular acupuncture treatments really help to mitigate the pain in my neck and back. The pins and needles are what really get to me, though. They're unrelenting. It feels like I'm hooked up to an electrical socket. They're stubborn to treatment, but we do the best we can. Not too many people understand how painful numbness can be. My husband, family, and friends have been more than supportive of me. It's hard on them sometimes because I look fine. Walking isn't too bad, I just get fatigued really easily sometimes. But they listen when I need to vent now and then and don't hold it against me if I'm distant or cranky. Most days I'm just grateful to have use of my legs. When I was rehabbing from the surgery I saw so many people in worse shape than I am. Young teenagers with their entire lives ahead of them, who will never walk again because they jumped into a pool the wrong way. If they can smile, so can I. It really puts things in perspective. Considering how things could have turned out, I'm very lucky. The tumor was occupying so much space in my cord, that if I kept ignoring it I could be in a wheelchair right now. (Not too practical for an acupuncturist.) So, if I have one thing to pass on, it's this……

LISTEN TO YOUR BODY! You know better than anyone if something is wrong, and follow through. Life is way to short. You can deal with anything once you know what it is you're dealing with.

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

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