

Long Struggle With Chiari Does Not Define Me

Ed. Note: See Kristen's follow up submission titled [Kristen Checking In](#)

June 30, 2011 - I remember the first time I had a Chiari headache. I was 14 years old and waitressing at a church dinner. I lifted a tray, which wasn't very heavy, but for some reason the strain caused me to feel an intense pain in my head like I had never felt before. I went to my doctor and was told that I had tension headaches. No tests were run, no symptoms were really discussed, to the doctor it was an easy diagnosis. However, my mother and I felt there was more to it. At the age of 14 we couldn't understand what I would be stressed about that would cause such intense pain and why it had come on so quickly. But we went with the doctor's advice of taking over the counter medication as needed.

The problem with that recommendation was that once a headache came on, no medication ever worked. Over time, I realized that the headaches weren't correlated to stressful situations. I wouldn't get one when I was worried about a big test coming up, when I was going for my license, breaking up with a boyfriend or even when my Grandmother was sick. The headaches would come on at strange times, like when I was having fun and laughing so hard that my sides (and head) would hurt. Or when I was picking up something heavy, working out or even when I would have a cold and was coughing. But I would go back to the doctor who repeated: "It sounds like you have tension headaches."

So the headaches became part of my everyday life. Then the back pain started. My back would get so sore I would ask my sister to walk on my back to crack it so at least some pain could be released. I never made the connection between the back pain and the headaches because the back pain was pretty consistent and the headaches would come and go. I remember my mother saying it wasn't normal to experience the pain I did considering how young I was, but I knew nothing different at the time.

After college, I moved to the Lehigh Valley in Pennsylvania and needed to switch doctors. I gave it another attempt, went to a new Family Practice, explained my headaches (still not giving much thought to the back pain) and was told it was stress. My frustration got the best of me and I decided I was done trying. One day in 2002 I was driving home from work, talking to a friend on the phone and I started laughing. The pain in my head came on so quickly and was so intense that I dropped the phone and was truly afraid I was going to crash. A co-worker that also worked for the Family Practice convinced me to try one more time with a different doctor and told me I needed to request an MRI. Reluctantly I agreed, convinced that the MRI would not show anything.

When the results came in, my friend called so she could be the one to tell me the news. Never having heard of an Arnold Chiari Malformation, I didn't really know what to think and kind of shrugged it off. I was scheduled to attend a banquet for work that night but the doctor called as I was walking out the door and explained more about my diagnosis and what treatment lay ahead. I didn't attend the banquet that night. I had never been in a hospital before and the thought of surgery, let alone surgery where they were going to cut open my head and remove part of my skull, was too much for me.

The fortunate part of my story is that the day I was diagnosed was the day that I truly fell for my husband who came to my side that night and has not left. The next day, I called the neurosurgeon my doctor recommended. During that appointment the surgeon told me he was leaving the state because of medical insurance rates in PA, but that he could recommend someone else. So I went to my second neurosurgeon who barely let me finish saying my symptoms before saying I could be treated without surgery and to start taking medication. As I had predicted not even prescription medication worked. Out of frustration I decided to contact a different Neurologist, and this time I took my mother with me. I was 22 at this time and had been resistant to bring "Momma Bear" with me. But I had had enough. My mother asked the doctor about my back pain, something I had long since brushed off. She insisted that the doctor do an MRI of my back to see if any further damage had been done from the Chiari.

The MRI showed a syrinx had developed in my back causing my years of back pain. My doctor suggested I go to another neurologist in Philadelphia who was an old colleague. Although it took some time to get an appointment, he was worth the wait! This doctor did not even open my file until he talked to me about what I was experiencing and what my symptoms were. He then did some of his own evaluations, finally opening up my file. He was the first person to make me feel like I was not overreacting. I was a person dealing with pain that could and should be taken care of. His main concern was the syrinx and taking care of it before it could do more damage. He got me in with a Neurosurgeon within two weeks of our meeting. I am forever grateful to that doctor who "treated me the way he would his own niece."

My first surgery was January 7th 2003. The decompression was done using a bovine patch. I had more staples in the back of my head than I could count, but the pain and pressure were still so intense. For three months I did the rehabilitation as recommended but there was a bubble in the back of my head that caused me to be unable to lay on my back or put any pressure on the back of my head. Unfortunately the patch had leaked and fluid was collecting at the back of my head. On April 16th, I went for my second surgery. The recovery time and overall improvement was drastically different from the first surgery. I was able to return to work after 6 weeks. My neurosurgeon ordered additional MRI's to see if the syrinx had shrunk with the surgeries. Unfortunately it had not changed, and the Surgeon decided it was necessary to perform another surgery. On August 23rd, a spinal shunt was implanted in my back to drain the syrinx. Fortunately, that was the end of my surgeries, but obviously not the end of my struggles with Chiari.

The multiple surgeries had taken their toll on me physically and mentally. Part of the rehabilitation process necessitated focus on my mental

health. I had to deal with Depression as well as Post Traumatic Stress. To this day I struggle with flashbacks as well as occasional nightmares regarding my surgeries. And as I'm sure it is with all Chiari patients, I live with constant fear that someday I will need additional surgeries.

In regards to physical symptoms, I no longer get the same headaches that I did, but I do deal with daily back pain and frequent neck pain. However, I am incredibly grateful for the progress and improvement made.

In 2007, I became pregnant with my daughter. By this time, my surgeon had already given my case to a local neurologist so I no longer had to travel an hour to Philadelphia. He had warned me that I might need a C-Section, a decision my Ob-Gyn and current Neurologist concurred with. Unfortunately I did not learn until the day of her birth that due to the spinal shunt, I would need to have general anesthesia rather than local anesthesia. Having been four years since my last surgery, I hoped that I would be ok with the general anesthesia although I was not planning on it and was not happy about it. I couldn't have been more wrong. The experience triggered a relapse in all of the progress I had made and my husband worried about the possibility of Post-Partum Depression. Fortunately, with the support of my family and friends, as well as the love of my beautiful baby girl, I was able to once again get back to myself.

Being a Chiari patient has changed my life in more ways than I knew possible. It has strengthened me, humbled me, made me question the medical profession and my faith, and has caused more stress, fear and anxiety than any other aspect of my life. I decided a long time ago I would not let my Chiari define me, but it has absolutely become a part of my past, present and future.

-- Kristen C. Grim

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

[Home](#) | [About Us](#) | [Email](#) | [Donate](#) | [Get Involved](#) | [Privacy Policy](#)

Disclaimer: This publication is intended for informational purposes only and may or may not apply to you. The editor and publisher are not doctors and are not engaged in providing medical advice. Always consult a qualified professional for medical care. This publication does not endorse any doctors, procedures, or products.

© 2003-2020 C&S Patient Education Foundation