Nova Lee Lives With Chiari, It Doesn't Live With Her

My experience with Chiari started in May, 2003. It came without any warning or delay. Suddenly I was dizzy, losing my balance, having vision problems, nauseous, felt as if my ears were going to explode, trouble with speech (slurring & not saying the right word), foot dragging, difficulty swallowing and heart palpitations. I remember telling my husband, one night going to bed, "I'm dizzy and I don't know why, and if anything happens to me overnight, you will know." I finally collapsed one day at work, and was taken straight to my doctor's office by a colleague

In the beginning, all sorts of minor ailments were ruled out, viruses, pregnancy (please not that!) . I was given Gravol for the dizziness and told to rest a few days. Inner-ear infection, viral or otherwise was the first theory, and after blood work and some tests, perhaps Meinere's Disease. Thus began a very slow process to find out what was going on. More tests would be needed. At this point everything goes through your mind, did I have a stroke, tumor, growth, lesions, Parkinson's, ALS or MS.

I am married with three children under the age of 11, work full-time and did not want to be slowed down by any illness. However, I needed to find out what was going on.

After being referred to an ENT specialist, I underwent ENG tests, hearing and visual tests to only have them all come back normal. By this time my speech was slurred, my thoughts and words did not always jive, I had left-sided face numbness that lasted approx 3 weeks (this was scary) and more vision problems, all left-sided. I had become very clumsy and my perception of objects was bad, dropping dishes, reaching for objects only to miss and sometimes injure myself (ie knife or doorknob). I was not sleeping, my head felt like it was bouncing back and forth like a ping-pong ball all the time and I felt exhausted and miserable most of the time. My doctor prescribed a sleep aid and this at least allowed me to get adequate sleep at night.

It was one of my ENT visits that the specialist first started mentioning that this could be MS. My heart dropped and felt as if my world was closing down. MS was certainly not what I was expecting (although I don't know what I was expecting) and all I could think of was there is no cure, there is no cure for this. Diagnosis for MS was only through a MRI, which in my case could take up to 6 months. Also a CT scan had to be done first to rule out life-threatening tumors, growths or lesions. Hearing all this was very devastating and upsetting. This meant there could be something really SERIOUS wrong with me.

During all of this I managed to work, fairly productively, however there were certain activities, work and leisure I could not participate in. My children began to get used to having a Mother who could not drive them places (I stopped driving for almost 9 months) and join in their school outings, games and activities. My husband was a Godsend and most evening after working I would come home to supper ready or started. Some physical tasks, vacuuming, carrying items (groceries or baskets of clothes) became more challenging - I didn't know when I would trip, or suddenly "veer" to on side.

Family, friends and co-workers were very supportive to me during this time and would have to put up with many "dizzy" moments and incidents, some of which are joked about now. I did however, encounter "the you don't look sick" syndrome and "it must be all in my head" (now that IS funny!). The best way to handle that is to understand most do not understand the condition and perhaps some ignorance. I do not go around and try to explain why I'm like this only that it happened.

My CT scan came and went with no life-threatening issues. This was a tremendous relief and all I could keep thinking was I need the MRI. In one way the not knowing was harder on me than the knowing at that point. Tell me if it is MS, so I could move on with my life and deal with it.

Five months after the first onset of my symptoms I had my MRI. My follow-up appointment wasn't for two weeks after. Every thought went through my head at that time. If it was MS, since most everything else had been ruled out, it was going to be very upsetting to me and my family, but I knew somehow I would manage. I actually wished it to be MS so I could at least put a name to this. My husband and I went to the specialist together for the results, who by now I was quite comfortable with and relaxed. His words were "Well, it's good news, bad news". It's not MS, but we did find something. This relieved me but also scared me. That was my first introduction to Arnold Chiari.

Afterwards followed the classic list of events, see a neurosurgeon who said yes, we can do surgery, when do you want it. Yes, I can give you back 80% and yes this is not life-threatening, just life-altering.

I had the surgery February, 2004, a craniotomy for decompression & duraplasty. I had part of the top cervical vertebrae removed to make more room. Waiting for surgery in hospital that morning (I was first case - good to get it over with) I almost walked out and said No I don't want this done. I'm glad I didn't. Two days later, I really wished I hadn't had it done. The time spent in ICU was the worst time of my life (I am unable to take conservative drugs for pain due to drug allergies) and this caused some unsettling moments for me and my doctors. My surgery was on a Tuesday and by Thursday evening I was resting fairly comfortably at home. Two weeks later I felt fine from the neck down. After the first month I was completely normal, mobile and looking forward to returning to normal life.

Looking back over the last several years I do remember having a few of the symptoms that I thought everybody had. Like coughing too much gave me a headache; laughing too much also would bring on a headache. Sometimes I would have difficulty swallowing and would wonder why. I guess these are a part of me now, and have always been.

I still have some deficits but the main ones with my balance, head-bouncing (my surgeon said my eyes are as focused & still as can be), some numbness and occasional speech mistakes have all been taken care of by surgery. For me the idea that this was fixable, that it meant very little intrusion to my life, and allowed me to get back to my normal self (within reason) again gives me the outlook and thought that having Chiari, although not fun, is still not as devastating as it could have been.

I live with Chiari, it doesn't live with me.

-- *Nova Lee Horne*
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