

## Saying No To Surgery... By Louise Whitaker

**Ed. Note:** *The opinions expressed below 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.*

When I first heard the words Chiari Brain Malformation I about had a heart attack. Since I was a kid I had all these different symptoms that couldn't be explained, when I was in my early twenties they grew worse. As a child I would go outside and pace with hands clenched for hours; this was something I had to do, now I am sure the neighbors thought I was the family idiot and maybe they were right. I hated school, could not concentrate, had headaches and poor posture. I would look down most of the time, apparently this was a big problem for one of my teachers, since she used to make me walk with a book on my head to learn posture.

When I was about 26 years old I started going numb on the right side. If I bent over it felt like my head would explode and heaven forbid if I sneezed or coughed, I thought I would pass out and the pain in back of my head and shoulders was and still is unbelievable, so started my long affair with chiropractors, which did not help much but I was clutching at straws. I took so much ibuprofen I had ulcers in my stomach, but if you didn't have anything in black and white that doctors could see they didn't give much pain medicine.

I once had vertigo for thirty one days straight. I thought I would go out of my mind, I used to argue the point with my brother that you could not know you were spinning out when you were laying down. Well, I was wrong, now what does help is open only one eye, then slowly open the other eye. I don't know which is worse, vertigo or to be standing at a store and feeling as though you are falling backwards. I had to tell myself it is not really happening. I didn't fall and I really don't have butterflies in my stomach.

Then there is walking into walls and getting out of a car and being off balance. I did that once and was holding on to the car to keep from falling. At the same time I tried to convince this young truck driver at the convenience store that the old girl was not drunk. He was bent over laughing, I gave up my explanation. I made his day.

I seem to be antisocial. I like the thought of people but find myself avoiding contact when possible. I am a female and I don't even like to shop. I even shy away from my kids. I love them. They are great kids, its just that I am afraid for them to see what different problems I have like dizziness, panic attacks and I lose my train of thought. Its easier for me to cover up on the phone or PC.

My husband of thirty three years informed me a while back that I have split personalities. I told him thanks a lot. I needed to hear that. I told him I have learned what different people want from me and it is easier for me to try and talk or act the way they expect me to, instead of telling them I don't want to talk to you because the back of my brain is shaking like a bowl of jello.

My first visit to the neurologist was a disaster, when I left home that morning I felt fine, better than usual. All of a sudden after about 50 miles down the road it was like a switch turned on in back of my head. Then it starts the shaking like jello. I thought when I got to the doctor I would tell him and maybe he would do an ECG or whatever they are called and see what it was doing when it felt like this. But all he wanted to know about was neck and head pain. Well I have that all the time. I was interested as to what my brain was doing. All he was interested in was where I saw stars and holes outside or inside the house. Well it has always been outside. I eventually just walked out. I wanted answers and he wanted text book symptoms.

Then I went to a neurosurgeon and he wanted me to have surgery but I declined. I go to him yearly, one year surgery is the thing to do and the next it won't help anything but the sleep apnea. Now he would like to ditch all his Chiari patients, well the sleep apnea was easy to fix without "sleep clinic". I just ordered a CPAP machine online and they are expensive without a prescription. Learning to use it on my own has been an experience. After a year I have finally gotten used to it and I do feel a little less tired the next day.

I do have problems swallowing sometimes. Although not as often lately, it is a strange feeling, especially if eating out.

There are some things I do to try and help the pain, for instance I have this table that you stand on and strap your ankles to it. Then you lean back and eventually you are hanging upside down, it does help my back but the main reason I do it is I think it shifts my brain off my spinal cord. I don't know if it actually does, it just seems possible to me. After all every little centimeter helps, also I do some stomach crunches while in this position and let my arms hang down for a minute.

But you must realize this is coming from a person that ordered "Mind Aerobics for the Brain". They are cassette tapes I listen to every day, I must confess I don't think they are helping my mind any but my purse is lighter. In all fairness I've only had them a month so we will see what happens.

There are a lot of good medicines out there and I hope most people can take them. I have tried "Neurontin" and anti-depressants. I can tell they would do me a lot of good, only thing is I have food and drug allergies and break out in hives. I still have hope for new antidepressant drugs that I can take. On the plus side I can take vicodin for pain and zanax for panic attacks. Its just I take the least of these I can get by with because of all the hype about addiction.

I was born into a very violent family. I was the youngest and only girl. I have taken care of my mom for the last 20 years. She died in May

2003. I was also the guardian of my brother after his stroke at 57. I also held a full-time job most of this time. MY husband has had 2 heart surgeries and now has CHF so it seems I have been a caregiver a long time. I say this because I think stress plays a large role in Chiari pain and depression, but in all honesty I think I would have depression anyway. It has always been a part of my life.

I have read a lot about Chiari surgery and have even watched it on the PC. I still don't see or hear anything that changes my mind about having surgery myself. What I perceive of the people that have had it is they trade symptoms of one kind for something else. My self at least feel familiar with my problems even though I don't like them.

In this town of about 8,000 there are two other people who have Chiari's, one female and one male. They are in their mid-thirties. Both had surgery and both had problems. The female got an infection and her head would soak her pillow through. The pain was something fierce. She had surgery in July 2003. She is just working herself off steroids. I don't know if it is the mis-handling of hospital staff or a physical therapist or if these problems occur everywhere. Right now I would have to be hog-tied to have the surgery. But here is hope for the future. A lot of people are doing good things to help us, but funding is short and progress is slow.

My short-term memory is the pits of course. It has its plus side. I have the best timer they make when cooking - the smoke alarm screams and I know lunch is well done. Now it really gets tricky when I can't remember whether I took my medicine or not. I am taking blood pressure, thyroid, nexium, I usually don't take any vicodin or zanax in the day time, unless pain is unbearable or I am under a lot of stress.

Actually I feel that daily pain is stressful in itself. I feel that I could have been a better wife, mother, and daughter than I was. Pain and pressure in your head and spine can make one fly off the handle faster. I am sorry to say it didn't and doesn't help my caregiver attitude and this I deeply regret.

My last MRI was not much fun. It took about thirty minutes and this time they had decided not to use the pillow for your head and neck. It made the machine to close to my face. I didn't say anything but when they rolled me out I had rears rolling down my face. Needless to say, next time I will use the pillow.

In all fairness I realize doctors did not learn much about Chiari in medical school. They are allowed about 15 whole minutes for each patient. It takes me that long to remember why I am there in the first place. Then they have to explain to insurance companies and drug companies and lets not forget codes. I wonder if they have a code for Chiari Malformations, I really feel they are also under a lot of pressure from all sides. I continue to hope and pray that our medical policies change, and eventually I think they will have to .

It would be wonderful if anyone could go to a doctor and hear she could just have the absolute best care or medicine, without that doctor having to weigh pros and cons about any decision he makes, and who knows? All things are possible although in this case the chances are probably slim and none.

I feel the best help we can get is from each other. I had wrote a letter to a group about using cervical traction everyday, and not long after it came out I got a phone call and this guy told me it was one of the worst things for most people to do, so I stopped it and have not had the feeling of falling backward very much. I am eternally grateful to him, even though I can't remember his name. People that have somewhat rare conditions need to stick together. We are our own best help.

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

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