

Why Bedside Manner Matters by Nancy Haug

"Get up, you're fine," said my husband. "It wasn't that bad of a fall. Get back up on your snowboard and let's go."

"But I'm not fine. I'm tingly all over. Something's wrong." Thus began my journey into the realm of Chiari malformation and syringomyelia. One airlift and two MRIs later I knew that I had experienced neurological symptoms after a relatively minor fall because a large syrinx left my spinal cord distended and ill-protected. I would need surgery and I would need it soon.

Arriving home, I faced the daunting task of learning about my disorder and choosing a surgeon to remedy it. As I learned about Chiari malformation, it became clear to me that there was quite an art to performing this decompression surgery. It appeared that all surgeons did a craniectomy, but how much bone was removed from the skull? Most did a laminectomy, but did they use C1 or both C1 and C2? Did they shrink the cerebellar tonsils through cauterization? And what about the patch; if they did a duraplasty was the tissue coming from a cadaver, a cow or me? One thing was for sure - this surgery was fraught with areas of judgment that could vary greatly from one neurosurgeon to the next. I had to search for the surgeon who could convey his expertise to me in a way that would make me feel confident and unafraid.

The vague symptoms I had ignored for years worsened somewhat after my fall, and I laid low as I searched for a surgeon. I bought groceries through the internet and taught my five children how to pitch in with cooking, cleaning and laundry. My mornings were spent on the computer and telephone, reading about neurosurgeons on the internet and placing calls to teaching hospitals. I was fortunate to live in Orange County, only an hour away from San Diego and Los Angeles. There were many renowned hospitals in my area, and I called all of them. I focused my efforts on finding a neurosurgeon who specialized in Chiari malformation and did frequent decompression surgeries. Since I had a large syrinx, I also wanted my surgeon to be experienced with syringomyelia. The icing on the cake would be a warm bedside manner.

During the ensuing weeks I chased down many leads. One San Diego neurosurgeon specialized in Chiari and had a warm personality, but her focus was more on pediatrics. A surgeon at USC did several decompression surgeries each month, but he used animal tissue for the patch on the dura, and I preferred that my own tissue be used for the graft. As I delved deeper into the internet, a neurosurgeon at UCLA caught my eye. My two disorders were his two specialties: Chiari malformation and syringomyelia. His list of publications was a mile long, and I decided that I was done searching for a surgeon. I called for an appointment first thing the next morning. It was hard to run a household of seven people when I felt dizzy and odd, and I was anxious to get this show on the road. My heart sank when the receptionist told me that the doctor was gone for a month and it would be two months before I could even get an appointment. How could I wait that long? What if I waited and then didn't connect with the doctor on an interpersonal level? I knew myself well enough to know that I needed that chemistry in order to trust this person with my life. In my muddled head, two months was an eternity. I had no choice but to explore other options.

A local neurosurgeon saw me right away and I was excited when the receptionist told me he could do my surgery within two weeks. Though he only did a handful of decompressions each year, he convinced me that the surgery was not technically difficult. As he proceeded to examine me, however, I felt no connection or chemistry with this doctor. The ambiance was cold and impersonal and it made me feel nervous and unhealthy. He checked my reflexes which were overly strong due to increased intracranial pressure. When I asked a question about them, he said only, "Your reflexes are pathological." As I left I felt scared of the surgery and discouraged about my health.

Back at home, I mulled over my options. This surgery was a big deal. My husband was very supportive, but the details and risks of the surgery were scary and his way of coping was to not hear any of the specifics. You don't want to bore friends with medical problems, and I certainly wasn't going to alarm my children by sharing any of the details. I needed to stay calm and handle this on my own. I decided that I would get my strength from God and my confidence from my surgeon. But what surgeon? Returning to the internet I again read the publications of the UCLA neurosurgeon (note: in keeping with the policies of this newsletter, I have omitted the surgeon's name). It looked to me as though he had written the textbook others might be using. It was clear from what I read that he had been a neurosurgeon for several decades and that he was one of the preeminent doctors in the Chiari field, one who did decompression surgeries each week. This was worth waiting for.

Not feeling like myself, I stayed home much of the time while I waited for my appointment at UCLA. I learned a lot about the surgery and made a list of questions. When the day finally arrived, I reflected back on my previous neurological exam and felt nervous. Would I again feel depressed, as if I had failed a test? The exam began with the doctor quietly perusing my medical records and asking an occasional question. He seemed to absorb every shred of information, and when he examined my MRIs, he appeared to see them more deeply and expertly than the other neurosurgeons. He found a tiny black line where my blocked cerebrospinal fluid had made a miniature escape route, and complimented me on my body's ability to attempt to solve a problem. When he examined my reflexes that the other doctor had termed "pathological," he expressed surprise that they were so close to normal given my MRI. Though he was looking for my deficits, his soothing demeanor made me feel healthy and relaxed. I had the odd sensation of having my fear dissipate entirely while listening to a description of my upcoming brain surgery. The doctor answered every one of my questions and seemed unhurried even though we had been there for two full hours. The surgery date was set for the next month and I left feeling immensely relieved.

I expected to feel a great deal of anxiety leading up to my surgery date, but instead I felt a very strong sense of serenity and contentment.

Each night I fell easily into a deep sleep. The confidence I had been seeking had been instilled in me by my surgeon. It had been well worth the research and the three month wait. When the morning of the surgery finally arrived, I was only slightly apprehensive and felt relaxed enough to joke around with my surgeon. A short time later, I was given a sedative and taken to the operating room.

My husband was updated periodically during the surgery, and five hours later it was complete. Everything went as planned and I was excited to have it behind me. Nausea and neck pain were my companions in the hospital, but both were fairly tolerable. My doctor visited daily and took the time to answer all of my questions. Three days later I was on the freeway, headed for home.

Choosing a neurosurgeon who was top-notch, yet approachable paid off during the recovery period. Since I chose an extremely accomplished surgeon, I never questioned or second-guessed his methods. Though he spoke with great authority, he had an attitude of humility, and as a result, I always felt comfortable calling him with a question. This came in handy because the days, weeks, and months following the surgery brought a varied array of new symptoms as my brain and spinal cord settled into place. Shortly after the surgery I found that if I bent my neck forward I experienced what felt like a jolt of electricity in my right foot. A call to my surgeon put my mind at ease as he explained that I would experience temporary nerve sensations as my syrinx closed in and my spinal cord readjusted. Once I knew that such sensations were part of the healing process, I was able to ignore them and focus on getting well. Most often, the issues were fleeting and they disappeared within a week or two. I learned greater patience as I recovered, because the process was very gradual. Though I seldom needed to contact my doctor, it was reassuring to know that I could call at anytime and he would personally return my call.

Before long, it was time for my three month post operative check. With MRIs in hand, I traveled back to UCLA. Though I was dying to look at my films, I kept the little string wrapped tightly around the red circle on the manila envelope to avoid misinterpreting them and fretting for no reason. It was enjoyable to see my surgeon again, and I could tell that he was anxious to see my MRIs. I wasn't sure what he saw, but I knew from his countenance that it was good. He wouldn't show me until he could find the same view before and after the surgery, and as he clipped the two films on the lit background, my husband and I were almost giddy with anticipation. I love "before and after," whether it be house remodeling or weight loss, but spinal cord "before and after" is truly the best. My doctor showed me how my large syrinx had collapsed to become little more than a slightly jagged line, healed by the corrected circulation of my cerebrospinal fluid. It was a joyful moment for all of us.

In a few months it will be time to get my 12 month MRI and go to my last appointment with my neurosurgeon. I am 90% better, and by that time I should be close to 100%. It has been an interesting year and I have learned a lot. I have gained an ability to live more in the moment and worry less about the future. I have learned to be more humble in accepting help from people and to be more patient when things come slowly. Though brain surgery can't help but be scary, much of my fear was obliterated by my doctor's expertise and bedside manner. Both of these aspects of your neurosurgeon matter because when you put your body in your surgeon's hands, you are putting your emotional state there as well. This is a serious surgery, so choose carefully. Do your research, be willing to wait for a top surgeon, and if you do not live near a metropolitan area, consider traveling. I hope that you will be successful in finding the neurosurgeon that gives you the best possible outcome.

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

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