Moving On With Life

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.*

I'm a 51-year old Texas educator. Until I was diagnosed with Syringomyelia in January 2005, I'd never heard of it. In early 2005, I had gone to my neurologist with strong pain ("dysesthesia") in my left arm and hand (my only "serious" symptom of SM), which had started in 1999 but had flared up again over the 2004 Christmas break.

I knew something unexpected was up during an MRI my doctor had ordered when the tech informed me that my doctor had ordered up an extra set of back images (originally he had ordered just images of the cervical area). Within an hour after my MRIs, my doctor called me up and discussed the "serious cavitation" he saw on my images. He introduced me to the terms "syringomyelia," "Arnold-Chiari Malformation" and "syrinx." He invited me to get online and to find out all that I could.

A couple of weeks later, at his advice, I saw a neurosurgeon (an old classmate of my wife's, it turned out). My syrinx ran from C2-T8, and I had what he described as a "classic" Arnold-Chiari Malformation. The surgeon said the syrinx wasn't the worst one he'd ever seen, but certainly big enough to warrant surgery. I was astounded to look at the syrinx on the plates and to realize that it had developed over the course of thirty years (when my earliest symptoms began to occur) without causing me any more problem than some mild occasional headaches and arm pain over the years. Now I was looking at the prospect of future paralysis, or other serious potential problems.

I spent three months researching the disorder, discussing it with people on phone and online, and learning as much as I could both about the disorder and about possible surgeons who could perform the operation. I wanted to know everything I could about the procedure, and went so far even as to look up articles on the surgical instruments used in such operations.

Anyone facing decompression surgery faces, first, the whole phalanx of decisions about what to do. The internet is a marvelous source of information, but I encountered numerous differences in the way surgical teams performed the surgery. Some plugged the obex; some used electrocautery in reducing the herniation of the brain; some used segments of the patients' own tissue as dural patching, while others used synthetic patching. Some didn't patch the dura at all. With such an array of techniques, a person facing surgery must plow even deeper and consider what was truly best for him or her.

By early-April 2005, I'd done a lot of homework, and I sought a second opinion from a colleague of my neurosurgeon. Relaxed, down-to-earth and pleasant, this doctor went through a long set of my questions with me. During the conversation, he mentioned that he had performed approximately 250 decompressions -- a good number, I thought. I asked him what, on a scale of one to ten (with ten being the riskiest), he would rank decompression surgery. He thought a moment, then said, "I'd give it a two, maybe three. It's pretty straightforward, as surgery goes." He characterized it as "pretty routine." I was comforted by this -- the number gave me a good mental picture. Because of this doctor's specialization in skull-base neurosurgery, I began to consider him for the operation instead of the first surgeon -- a decision I made firm after I got glowing reviews about him from several of his previous decompression surgery patients.

I underwent foramen-magnum surgery on May 16th. The operation went relatively fast -- two hours at most -- and before I knew it, I was being wheeled out again. I spent seven not terribly uncomfortable hours in Recovery, then was moved to ICU. I quickly came to hate morphine -- my face itched intensely, and the morphine made me very nauseous -- but there were other ways of dealing with the pain. Though the doctor had warned me that the surgery was often one of the more painful ones he performed, I went into the surgery not knowing what to expect (especially when one of his ex-patients described the aftermath as "pleasant."). As it turned out, my doctor was correct: the pain was excruciating. The first couple of weeks, virtually every bone in my skull hurt. Some days I felt like the back of my skull had been crushed like an egg, and in email to friends not long after I got home and was able to sit up, I described the pain periodically as "ghastly" and "grisly." Fortunately, the worst pain lasted only two weeks, then receded quickly.

Going into surgery, my biggest concern had not been the operation itself, but the aftermath, and the possible complications. I especially feared infection, dural leakage, and meningitis, all of which were possible, I'd been told. My doctor had removed a portion of my top cervical bone, a small portion of my suboccipital bone in my skull, and had patched in a small section of Duragen (a synthetic collagen patch made, I was told, from "pounded cow tendons"). Making his rounds the first few days, when I was in the hospital, my surgeon expressed great satisfaction with the way the incision looked. But complications did set in.

Two weeks after surgery, I had to return to the Emergency Room with a 101 fever (the magical number, the nurses had advised me), and strong shooting pains in my head that made my whole body flinch. After a day of tests, the staff told me I had aseptic meningitis -- not terribly serious, and quite treatable. I went on a round of cortico-steroid medication, which made me feel remarkably better (and gave me a roaring appetite). When I came off the medication, however, the meningitis returned. My surgeon (who was always reassuring) told me that the steroids had a 100% cure rate, but that some cases were more nagging. Mine ended up lasting three months -- three rounds of medication. But eventually the medication worked, and my body returned gradually to normal.

In November, I had my six-month post-op MRI. Though the syrinx was still there, it had diminished in size and thickness, and the doctor said my spinal system looked ("exactly the way I wanted it to look at this point"). I have returned to work, am lifting things (including my children), working outside, and I have regained my old life pretty much as it was. Though my syrinx will probably never go away completely, I no longer worry about the complications that might have ensued had I not had the surgery done.

A year ago, I sat at a computer reading all I could to prepare myself for what I faced. Had I been able to travel back in time from 2006, I would have told myself to do it exactly as I did:

1) to read all I could about the condition and the surgery;
2) to read about the surgical procedure itself;
3) to decide which of the procedures I wanted done (my doctor sealed it when he told me, "I'll never perform anything on a patient that I wouldn't want done on myself");
4) to ask many questions of surgeons, including the risk factor, the number of surgeries they had performed, and how previous patients had fared;
5) to get phone numbers of past patients and ask them how their procedures had gone with a specific surgeon;
6) to call my insurance company and discuss the surgery with them;
7) to consort with everyone -- including informed people online -- about the surgery and condition; and
8) to be methodic and not to rush into a surgery.

Syringomyelia is a potentially life-changing disorder, and surgery doesn't necessarily "cure" it. But normal life can and does continue after surgery. One day before my operation, when I was discussing, on the phone, my upcoming surgery with an official of one of the nation's SM-ACM groups, she said to me, "most people who have the surgery have it done, then get on with their lives." More than anything, I wanted to know that this could happen: that after surgery, my life could go on and get back to normal.

Happily, it did.

-- Roger Jones