

My MVD

Background:

I am 47 years old and have had trigeminal neuralgia for 8 years. The first five years were non-eventful, with low doses of Topomax and Trileptal controlling the pain. Until they just didn't anymore. I have since been taking increasingly higher doses of Gabapentin, Carbamazepine and Amnriptaline, finally reaching the point that I just couldn't function. The pain had worsened along the way and I knew it was time to bite the bullet and have an MVD.

My MVD fear was not so much the surgery itself, but the risks of going into a hospital... MRSA, staff infection, etc. When the pain escalated to 45-minute taser-like attacks, the decision was a "no-brainer," and I was practically running to the operating room!

After doing significant research, I decided to go to Dr. Raymond Sekula at University of Pittsburgh Medical Center. Here's why: 1) UPMC is where MVD-inventor, Dr. Peter Janetta, practiced. He has been quoted as saying that the reason some MVDs fail is usually because the surgeon doesn't find all of the compressions. I figured he trained the up-and-comers to be thorough, increasing the odds for success. 2) Even though I live in Virginia, my insurance, Humana, would cover everything in-network. 3) I had family nearby that my family and I could stay with before, during and after.

Considering that I am almost 2 weeks post-op with no pain and doing well, I am very pleased with the choice. That's an understatement. I am overwhelmingly grateful to everyone who has helped me get my life back. The experience was not without incident, however, and I'd like to share some things that were surprising to me, many simply a result of it being my first surgery.

Pre-Op Prep:

- I read just about everything I could find on Living with TN and in the Stricking Back book on MVDs. I like being informed.
- I packed way too much stuff. I bought a neck pillow, but never used it. I left the hospital in the same clothes I wore in. I didn't even touch my toiletries while in the hospital. I can honestly say that for the first time ever, I didn't care one bit what I looked like!
- The MRI (3 days pre-op) – The technician didn't make sure all of my hair was inside the cradle and when he sent me "in," it got caught. Ouch! Fortunately, it wasn't a chunk. I pulled free before he got me back out and then he made sure everything was contained. He went into the booth and from that point on, he didn't say another word. The MRI started before I was totally settled, so I spent the next 30 minutes afraid to move. It was rather uncomfortable.
- Tests and appointment with Dr. Sekula (2 days pre-op) – I spent a lengthy, tiring day at UPMC getting a lot of tests (hearing, EKG, brain stem evoked response, blood work, xray). Dr. Sekula said the MRI showed only one small blood vessel compressing the nerve. He would rather have seen a large compression and wasn't sure if the MVD would stop the pain. He said the MRI was 3D and would show everything. Needless to say, my heart sunk. An MVD was the last resort and everything had fallen in place so well to allow it to happen. I prayed and couldn't shake the feeling that this was the right thing to do. I just decided to have faith and move forward. I am so glad I did!!
- I had a free day before the surgery, so we visited family. I had been avoiding public places in the couple weeks leading up to the surgery to keep from getting sick and I certainly didn't want to take any chances now. I had a light dinner, showered again using the medicated soap they gave me to help prevent infection and went to bed early.

Day of Surgery (Weds. 10/15/14)

We had to get up at 3 am to get to UPMC by 5:30 am. I couldn't eat or drink anything after midnight, except for a sip of water to take meds. We got checked in and I wasn't really nervous until the nurse called me (and a few others) to go back for prep. I wanted to run... home! As we were walking the long, winding corridor, I fought the urge to ask "What are y'all in for?" or engage some other such nervous babble.

Once out of my clothes and in my gown, they let my fiance and parents join me. And the fun began. The anesthesiology assistant had trouble finding a vein for the IV. Apparently, when we get nervous or cold, our veins shrink back into our bodies. He tried twice with no luck and called another guy over. He flicked the back of my hand really hard a few times and a tiny little vein popped up. It must not have worked very well once in surgery, because I counted 7 more needle pricks on my hands and arms afterwards, a couple of which bruised badly.

Both Dr. Sekula and the anesthesiologist came by briefly to see if we had any questions. I was blank. Either I was really well-prepared or just not thinking clearly. I just wanted it over already!

About 5 mins before the scheduled surgery time (7:55 am), they took me back to the OR and I had to get slide onto another bed. It wasn't as easy as I thought. I guess the pre-meds were kicking in. But I was still awake and could look around the room as people were getting ready. Then the oxygen mask went on and that's about all I remember... until I woke up, three hours later.

The first thing that came to me was that I had been dreaming about a little boy and I had the impression that we had been playing with a red ball. He was sitting on a grassy hill, or more like perched on it like an angel on a cloud. Bright sunshine illuminated the sky behind him. He was waving good-bye, smiling... so precious. I was happy, but it was bittersweet as if I had mixed feelings about leaving. He was nothing but pure joy and I felt like I would see him again someday. I tried to tell them (whoever was wheeling me out) about the dream, but all I could say was "I was dreaming." It was hard to talk.

Then all of a sudden... brace yourself... this part is bad. It was days before I could even talk about it. Right after coming to, I had the most severe, horrendous face pain – 10 times what I had ever felt before. I was screaming, writhing like I was trying to get away from it. A nurse asked me what kind of pain I was having. I could only point to my face. She said, "like before the surgery?" I nodded and managed to say "worse."

By this time, I was in my bay in the recovery room and they started giving me some kind of pain killer via the IV. It was Dilaudid. SLOWLY, it started to work. And then, my arm started hurting like hell! It was killing me. I was a wreck, not understanding the face pain and now wondering if they were poisoning me. The nurse, Sandy, said I had small veins and sometimes it's painful when they are trying to put so much in so fast. She gave me an ice compress.

At some point Dr. Sekula came in and told me that the surgery went well and they decompressed the nerves without incident. What... nerves? Plural? But I could only think of my arm hurting and told him about it. He told Sandy to turn it down. I could hear her mumble under her breath that it would only prolong the agony, but it did ease the pain some.

Not long after that, the anesthesiologist came in wearing scrubs. Though my vision was blurry, I could see he was not happy with the nurse and she seemed surprised by what he was saying. I was getting

really concerned that she had made a mistake and I was going to suffer permanent nerve damage in my arm. (Not the case, more on this later).

They let my fiance and Mom come back to see me briefly. Only 2 people were allowed. My Dad couldn't come. They were smiling, clearly happy that I was alive and could talk. It was awful seeing their faces fall when I told them about the face pain and how bad my arm was hurting. We were all just devastated and confused.

It seemed like I laid there forever, and I found later that my entire time in recovery was about 2 hours. Sandy told me it was time to go, but I heard her tell others she was having trouble with the records transfer system. It kept going down and she didn't know if the orders were being sent. While she was working on this and getting very agitated, I think I lost the room I was supposed to go to. And then, no one from transport was available to take me. So Sandy decided to wheel me herself.... to an overflow room since all the other rooms were full. There were about 6-8 other people in there, with curtains dividing each area. That was a bit of a bummer, but they said that each nurse had only 2-3 patients to care for, so I would get more attention. I was okay with that until I found out they wouldn't let anyone stay with me overnight.

My first nurse, Linda, was great! She told me that the post-op face pain was not uncommon and reminded me that the nerve was compressed for a very long time. She also reassured me that my arm wasn't permanently damaged. She cleaned me up and got chairs for my family. Now this is where the real fun began! I thought I would be drowsy and sleep most of the day. But I was totally wired! Linda said that is not uncommon either. Anesthesia usually makes people sleep, but sometimes, it can have the opposite effect. So, for the next few hours, I sat there in bed and laughed my butt off at everything! In my mind, we were all having a good time, laughing and joking. I was informed later that they were just laughing at me!

After a couple hours, I was getting up to walk to the bathroom with the Linda's help. Apparently, that was a really good thing. All I knew is it felt good to stretch and move, even though my legs were heavy.

My parents left around 5 pm and Bill, my fiance stayed with me until visiting hours were over. I started getting tired, but was still not sleepy. I was looking forward to dinner until it came. The smell made me queasy and I could only take a couple bites. Oddly enough, they served pork roast with gravy and the pepperiest sweet potatoes ever. Not bland at all and way too rich. They also served fresh fruit. I ate some of that and the pudding, of course!

As the evening went on, I was getting more and more tired, and achy. When Bill left at 9 pm, I felt pretty sure I would be going to sleep. But that didn't happen – for 33 hours after surgery!! It was a miserable night. Nothing seemed to control the pain enough for me to get comfortable, and I simply could NOT sleep!! By the morning, I was a mess.

I had a melt down when they told me I couldn't be discharged until I went for a post-op hearing test. They were going to wheel me there at 9 am. I felt so horrible. My head hurt, my neck hurt, my arm still hurt and all I wanted was to sleep! I was not being very nice. I finally relented to the test if they would agree that I could go home. They said it was up to me. I dreaded the hour drive back to my fiance's parents house, but I knew that I had to get out of there to get some sleep.

So, I they gave me a Valium and something for nausea and I was wheeled over to Audiology for the stupid test. I came out of that and was so happy to see Bill there in the waiting room. I almost cried.

Then they wheeled me back to my “room” and I changed clothes. Bill went to get the prescriptions and my Dad and Mom wheeled me down to the lobby. At first the smell of Starbucks made me want to puke, then I realized I was REALLY hungry. Dad got me a scone and a green tea and I had a little bit of both. I couldn't really take all of the commotion in the lobby, but when the fresh air hit my face, it felt so good!

Backing up a little... the night of my surgery and the following morning, members of Dr. Sekula's medical team came to check on me. I didn't realize that they were now considered my doctor and I would not be seeing Dr. Sekula again. They didn't seem to have read my chart and it was really annoying for the morning doc to ask me about what meds I had taken overnight. As if I knew! Well, I knew at the time... we tried several things, but by then I wasn't tracking on anything. Sleep deprivation was taking its toll big time. And I didn't think to ask them all my questions because I kept thinking Dr. Sekula would be coming to see me before I left. So, that was confusing.

All kinds of other people came to check on me too... a patient representative, case worker and finally, someone from anesthesiology! I told her about what happened, shared my concern and that I just wanted to understand what happened. She was happy to help and went off to investigate. Soon, she came back to report... the nurse had given me the exact dosages at the exact times the anesthesiologist ordered. I guess when he found out she had turned it down, he came in and fussed because he is very particular about the way things are done. My arm would be fine. It has been really sore, but now almost two weeks later, the pain is just about gone.

So I have just passed the 2 week mark following surgery and I'm doing really well. I have been weaning off meds and have had some brief, somewhat muted shocking pain. I'm not going to worry about that now and within a week, my plan is to be totally off the meds. It is awesome to have a clear head again! My energy is coming back gradually. I am still moving slow (or slow for me), but have been going for short walks in the last couple days. I will keep increasing my activity level until I get my energy back.

I'm sorry that this is so long, but there were so many things that came as surprises to me, I thought it might be helpful to others. In hindsight, I would not have waited so long to do this, despite how horrible the first 33 hours were and no matter what the final outcome is going to be. I am grateful there were no complications and optimistic that my prognosis is good. Sekula's nurse said there's a 92% chance it will work for 7 years or a lifetime. Those are great odds!

And one final note... there were actually multiple compressions, small ones, but more than the one that appeared on the MRI!! Sekula found that one right away, and went deeper to the root of the nerve where there were more. So, UPMC was a good choice. And I will be eternally grateful to God and everyone who helped me through it all.

Please feel free to let me know if you have any questions!