

The GI Jane Story - *One Woman's Journey through a Lumpectomy and a Craniotomy*

TOO YOUNG FOR A LUMPECTOMY

My mom was diagnosed with breast cancer in 2001 at the age of 57. It came as a shock to our family because we didn't have a history of cancer in our family. The doctors attempted several lumpectomies. Finally, my mom opted for a mastectomy. My mom was fortunate enough to catch the cancer early. This, along with her decision to remove the entire affected area, meant she did not have to suffer through chemotherapy or radiation.

The doctors turned to me, her only daughter, and advised me to have an early mammogram at age 35. No way! I didn't think it was necessary and didn't want to waste my time. Besides, I had just been married. Even though I didn't think I needed to have a mammogram because I wasn't yet 40, my mom worked in the same office with me at the time and she nagged me day in and day out. I knew that my mom would never stop with the mammogram talk until I acquiesced. That's what mom's are for.

Wouldn't you know that when I finally went in for my first mammogram at age 35, the lab technician did indeed find something "suspicious." I didn't quite understand what was happening and I didn't want anyone to worry, so the only person I told about the biopsy was my husband, Carlos. They asked me to return for a stereotactic biopsy, which I did - alone. I don't think I fully understood the ramifications of what was happening.

At the lab, the doctors couldn't reach the "suspicious" tissue to get a good sample because it was so near the muscle wall. This meant they had to order an "open biopsy". When I asked what that meant, the radiologist said that I would have to be scheduled for surgery. "When would be a convenient time?" On the way home from the lab, I called my husband and then drove home in tears. We were incredulous. I was just too young for all of this to be happening. I really didn't want to have surgery.

During a second series of mammograms and an ultrasound a few weeks later, the doctors found a second suspicious tumor in my milk duct. At this point, the doctors told me that there were no other options; I had to undergo surgery to remove the tissue. I was young, a newlywed, and did not want to have my breast cut open. So what did I do? I tried to put it off; I tried to avoid it. In short, I was in denial. Carlos told me that he would love me no matter what and the doctors promised that the scar would be just a couple of centimeters and that I would barely notice the scar. Unfortunately, things turned out a bit differently. Well, Carlos still loves me, of course, but the scar ended up being much longer than a few centimeters.

In June 2003, the surgeon removed the tumor along with all of the tissue along the chest wall of my left breast. All of the suspicious tissue removed was benign or pre-cancer. To be on the safe side, I had asked the surgeon to remove anything and everything that was suspect. My life was indeed more important than a breast. I will never regret that decision.

After the surgery, my left breast was 2 cup sizes smaller than the right side. The insurance company refused to pay for reconstruction because I didn't actually have cancer. At one point my mom and I were both on the phone with the claims agent and my mom said, "Do you think my daughter had the lumpectomy for fun? If she had cancer in the right breast would you pay for that one to be reconstructed but not the left one?" That didn't change the claims rep's mind, so I had to write letters over and over and send photos showing my scarred and mangled breast. Cancer or no cancer, I had gone through that surgery to save my life. The insurance did end up paying for the reconstructive surgery, but it took time, several long letters, and those horrible photos.

ASPIRATIONS OF GROWTH

After the lumpectomy, nothing else really fazed me too terribly much. Except the other small hiccup in my life.

On Friday, January 18, 2008, I had a grand mal seizure while on the phone with Carlos. He called me from work at our regular “call-in” time before heading home. I explained that I wasn’t feeling well, the phone went dead, he called back, he heard some muffled noises, then the phone went dead again. He had no idea what was happening and was growing more and more worried so he called our neighbors, the Hogans, and asked them to walk over and check on me. Dilmus and his daughter rushed over to our house and saw that I was out cold on the floor. They called 911. Carlos dropped everything, sped home from work, and called my sister-in-law, Karyn, to ask her to drive over too. By the time the ambulance arrived, I had revived, but I was still very woozy. The EMTs took me to the ER, where they gave me a CT scan. The scan showed a 1½” mass or growth called a tentorial meningioma (which is usually benign) about 2” behind my right ear. The ER doctor told me that I had to stay in the hospital overnight.

The next day, the on-call neurosurgeon told us that the tumor would need to be removed right away because it had grown so large by this stage that it was actually cutting off the blood supply to my brain stem. That was what had caused the grand mal seizure. They scheduled my surgery for 2 days later. The morning of the surgery, my head was shaved. Shortly before I was to be sedated, the neurosurgeon, scheduled to perform the surgery, called Carlos and me into a room. The neurosurgeon told us that the tumor was being fed by 2 major arteries, which made the surgery very difficult. He wanted to run some more tests to be certain, but he indicated that he did not feel comfortable doing the surgery where I lived in Fort Myers. Wow! As I was being wheeled off for more conclusive tests, my brother, Richard, squeezed my hand with such intensity and looked at me with such sadness in his eyes. My family had never been more afraid. We hadn’t really cried until that point. We cried then. We realized now that this was more serious than we had previously thought. The neurosurgeon made a tough, selfless decision that morning. We were thankful that he did. He’s a good doctor. I will always appreciate what he did for me that morning.

I was discharged from the hospital and sent home. The next day, I went back to work, bald. The office girls wore scarves to show their support and my brother, Richard, who works with me at the office, cut his hair really, really short in solidarity! At this point, I had no staples in my head. Just a bald head. I felt very loved by my co-workers. It’s good to have a support team.

We had to find another neurosurgeon and another hospital that could perform this specific, more complicated brain surgery. It seemed that tentorial meningiomas aren’t that common and a bit tricky to remove because their location in the brain. I needed a team of neurosurgeons in a university setting.

So off to Tampa I went a few weeks later. It turned out that the tumor had been growing very slowly in my head since I was around 16 years old. I had the brain surgery on February 11, 2008. The majority of the tumor was removed in a 7½ hour procedure. They had to leave a small portion of the tumor behind for fear of damaging the arteries and surrounding veins in which case I might not walk or talk again...best to just leave a bit of it there. I was only in the hospital for 2½ days...yes, count’em ...2½. Back to work in 2 weeks. Just had to wait for the staples to come out. (Not sure why but it was definitely easier on the eyes once they came out.) I was doing laundry 3 days after brain surgery. (Some things never change!)

So I’m never alone...it’s me and Quaid. That’s what Carlos named the tumor when we first found out about the tumor in the hospital in Fort Myers. Some people think that it’s strange that we named my tumor but it makes me laugh and that’s what kept me going...laughter. He named the tumor “Quaid” because of that Arnold Schwarzenegger film, “Total Recall,” where the little mutant guy pops out of Arnold’s body. (You get the picture.) When I got the MRI of my tumor, it was so big (almost 2”) that

we would draw smiley faces on the images! It was kind of a cute tumor once it had a smiley face, completely round.

It was sort of nice having a name for my tumor especially since I have to live with it now. I know that this is not how a lot of people deal with tumors and believe me, it is NOT fun having grand mal seizures and falling down on my face. It is not fun when Carlos comes home and I have blood on my face and my jaw might be broken. It is not fun when we have to rush to the ER. But this is my life now. I live with Quaid. I don't have a choice about that. But I can laugh. That is my choice. I choose to be friends with Quaid and we laugh together. My life is different now than before.

I choose to be happy. Life is all about choices. My tumor is benign so I have less to worry about than someone with a malignant tumor. My sky is a little bluer. Leaves are a little greener. Something about waking up after a major surgery does that to you. I thought it would wear off. It hasn't yet. Maybe it will.

Another life-changing experience was being bald. Of course, I was bald because my head was shaved, not bald from chemo. The two are very different. I only know what I know. You learn so much about yourself when you are stripped down and bald. I didn't cry when they shaved me because I wanted to donate my hair to Locks of Love and I thought about how happy some little child would be to get a wig of my hair. Up until then, I had very long blonde hair, which I thought was very pretty. I will admit however that I was scared I was to look in a mirror and I didn't like touching my head at first. But Carlos loved my bald head! He rubbed it all the time! He rubbed it to help me to fall asleep at night. He thought I looked beautiful bald. I had dark circles under my eyes because I was so sick and on so much medication. To hide the dark circles, I just wore extra makeup. I think you do that when you're bald to compensate for the lack of hair.

I had a wig but I never wore it. I did wear little cotton hats because of the cold A/C they always have running in Florida. My poor bald head would get cold! And getting ready? I could get ready in 10 minutes flat. Being bald had its perks.

I kind of thought I looked like Demi Moore in "GI Jane". One day, I asked my nephew, Andrew, who was 10 at the time, what he thought.

Andrew said, "You look like a boy." I showed him the cover of my "GI Jane" DVD. He said, "Yeah, you look like Demi Moore." I got a bit excited at the thought of my nephew agreeing with me and then he added, "But she looks like a boy, too."

It's all perception, I thought. If having a brain tumor could finally make me feel as beautiful as Demi Moore when I'd never had much self esteem before, this bald thing might not be so bad. It took being bald to see myself as beautiful for the first time in my life.

I believe that this brain tumor could be one of the best things that ever happened to me. Before I was only half awake but this experience opened my eyes to what is important in life. Someone said to me, you know, your life is really going to change and I thought, you know, my life wasn't all that great anyway...good...I needed a change.

I wasn't scared to die. I'm just not that type of person. But I was scared to live. I needed to be shaken up a little. I was so adventurous in my twenties but I wasn't dedicated to anything. Now in my forties, it was nice to see my life flash before me so I could take stock of what's really valuable.

I do have some brain damage although it's not cognitive damage. My life is not easy. Life is not easy for my family. I can't drive yet. I have to set up a lot of "systems" to make it through my day now. I have migraines. I will probably have to contend with seizures the rest of my life. I am hopeful that my anti-seizure medication, or maybe some alternative method like yoga, will someday help me. I don't define myself by my "disease" or my "disabilities" but I do feel that I have used these as tools to learn

and grow and become a better person. It's true what Friedrich Nietzsche said..."that which does not kill us makes us stronger." I am stronger because of this experience and so is my family and so are my friends.

I started reading "Eat, Pray, Love" by Elizabeth Gilbert just before I was having the brain surgery. I decided to wait to finish the last chapter until after the surgery. This gave me another reason to wake up. "Don't go into the light, Jane...you have to finish that book!" Upon reading the last chapter, I identified with the statement that I am strong like an oak tree. And I realized that I was always strong. I am the oak tree. I was always the oak tree. I just didn't know it. It took the tumor for me to figure it out. It took being bald to figure it out. It took being stripped down and bare to come to the awareness that I am indeed a strong woman and to appreciate how strong I am.

Now I'm concentrating on the stuff that really means something to me.

Advice: Surround yourself with all of the positive people that you can and get rid of the negative. Period. Life is too short to waste on people who try to sap your energy. Don't be afraid to do anything if it's important and worthy. You can do it! People will help you achieve your dreams! Be positive and thank people and give people credit who help you get there. Don't be an island. You need people and community...especially if you have a tumor. Make a decision to make a difference in this world and then do it.

Thank you Cindy Papale for encouraging me to tell my story!