

## *Awakening to Life After Battling Brain Tumor*

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“How old will I be when I die?” That is the question I wanted to ask God. My religion teacher squinted her eyes and my fellow classmates wondered aloud about such a bizarre inquiry. We were only eight. My peers were asking questions like, “When will I get married?” or “What will I be when I grow up?”

Last March, I began to experience significant dizziness. I went to a general practitioner, and then to an ear specialist, who ordered a precautionary MRI scan. I was annoyed with the inconvenience. On March 19, the day of the scan, I was planning to leave D.C. in four days to work on a political campaign. But after the test, I heard the words that would change my life. I had a brain tumor. Those are shocking words when you are twenty-four years old and feeling invincible.

As I struggled to comprehend this new predicament, I continued my routine. I went to work, to my karate class and socialized with my friends. These days were sometimes awkward. People did not know what to say or do. To sustain myself, I created distance from my fear. It was my way of dealing.

The process of obtaining doctor’s opinions and making a decision moved very quickly. Fortunately, most of the doctors offered similar opinions and courses of treatment. My friends went with me to visit doctors and helped me clarify my options. In Ringwood, New Jersey, my parents conducted research into the best medical treatment. Discussing the medical details with my mom and dad removed every ounce of energy from my body. After conversing with several specialists, I decided to have brain surgery at the National Institutes of Health (NIH). The NIH is one of the world’s leading biomedical research facilities that accepts patients for clinical trials. The location of my tumor made me a candidate for treatment. My date was set for April 22.

Time became this intangible entity. Support from my family and friends kept me going. My friends from the DC Self-Defense Karate Association had a party for me a few days before the operation. Over twenty people crowded into Sharron and Will’s kitchen late in the evening for a head-shaving ceremony. Those close enough touched my shoulder and grabbed my hands. There was a lot of love in that room. I could feel it.

My parents, John and Barbara, arrived a few days before the surgery. They brought me cards and gifts from Ringwood. My friend Christine made me “Jeannine’s Hospital Comfort/Anti-Boredom Kit” filled with items like crossword puzzles and nail polish. The care and concern often became unbearable. The conversations with my parents were stiff and restrained. They were as scared as I was.

My only sibling, John, then joined us from Ithaca College. I sometimes call him my angel of mercy. The two days before my surgery were a blur of conversations, tests and meetings. The doctors and nurses answered all of my questions, but I could not process it all. When one of my neurosurgeons outlined the potentially debilitating risks of the surgery, I told him not to scare my family. He insisted that we all needed to know.

Less than twenty hours before my surgery, I had my last MRI scan. Lying in the machine, peering out through my caged head, two emotions passed through my mind: intense fear and an indefatigable trust—trust in my doctors, trust in a higher power, and trust in the process.

A few hours before my surgery, I sat in my hospital room window, in the dark, looking at the sky. I was too numb to pray. When my parents and brother arrived, I battled to keep myself composed. It was only after the morphine shot into my leg that I began to cry. On the gurney to the operating room, my spirit seemed elsewhere. It was not the medication that overcame my body, but fear. My mom, dad and John were then told they could go no further. They kissed me and I was wheeled to the operating room reception. I returned to myself when I noticed parents holding their baby in his little hospital gown. I looked at them, and I knew it could have been much worse.

After a drug-induced sleep, I woke in the operating room for language mapping testing. My tumor was located in my temporal lobe, the speech and memory center, and brain mapping was necessary to reduce the possibility of cognitive impairment. My doctors were also investigating the effectiveness of an infrared camera to differentiate between my tumor and healthy brain tissue.

A blue sheet was draped over me. I could not feel my head. I watched a red television screen that provided the visual images for both verbal and memory testing. My role was to identify each object on the screen and also to recall the previous image. I struggled to stay awake. I remember looking at the images, but offering the verbal identification with my eyes closed.

During my surgery, I tried to recite a poem that I wrote entitled, "The Abyss". I began, "Stagnant on the surface, electrifying echoes of a dead calm." After completing the first few lines, I lost the words. I was not in pain, and I told that to my neurosurgeons while my brain was exposed to the air. At one point I did feel a sharp sensation in my head where the doctors were working up against a large vein. As I cried out, I heard the doctors say they were finished. I quickly fell asleep.

The doctors had removed my tumor, which was the size of a thumbnail, along with one centimeter of surrounding microscopic brain tissue. It took twelve hours. As they wheeled my bed out of the room, one of my doctors stood at the door. I remember looking up and grabbing his hand. I don't remember if I said anything. I hope he could see the gratitude in my eyes. It was over.

In the Intensive Care Unit (ICU), I struggled for consciousness as the doctors and nurses plugged me into a wall of machines. My mental and physical exhaustion only permitted a brief visit with my family. Alone, I lay in my hospital bed, my thoughts meandering. I only wanted to sleep, but my body would not allow it. I felt my shallow breathing and a clicking sound in my head. My entire right leg was numb.

After two nights in the ICU, I returned to my hospital room that had accumulated over fifteen flower arrangements. Over the next week, I had a stream of visitors. I had never before so appreciated the people in my life. I also let my family take care of me for the first time since I was a young child.

I was sent home after almost one week in the hospital. I was afraid to leave the twenty-four hour hospital care. Fortunately, my mom stayed in the area for two weeks to take care of me. After less than one month, there were no obvious signs of what I had endured, other than the scarf on my head. I returned to work, and from the outside I looked fully recovered. But I did not feel whole. I tired easily and my brain was still in the process of re-routing. My universe had evolved with such intensity that I struggled to define the changes. I still do.

The pathology analysis labeled my tumor a low-grade glioma. I learned that the study and treatment of brain tumors is not an exact science. The diagnosis of tumor types is subjective

and there is no cure for most malignant brain tumors. Each year, approximately 100,000 people are diagnosed with a primary or metastatic brain tumor. Brain tumors are the second leading cause of cancer for children and young adults up to age 34. Many brain tumors, both benign and malignant, cannot be removed due to their location. There are over 100 different types of brain tumors. Because brain tissue is required for vital cognitive and motor skills, it is virtually impossible to remove each and every tumor cell from the brain. Unlike other parts of the body, standard radiation can only be used once on the brain, and chemotherapy has not been proven effective for most brain tumors. These treatments can also have serious and permanent side effects.

Four months after my surgery, I had a conversation with a neuro-pathologist. She reiterated what other doctors had told me: that statistics indicate my tumor will probably return someday. But then this doctor said, "They removed your tumor and surrounding tissue. There is no evidence of further growth. To me, that means you are cured." This was the first time I had heard such hope and optimism from a doctor. Her reassurance helped me to develop the belief that my body is healthy. I remain determined to be an exception to the statistics.

In my frailness, I discovered how to accept my vulnerabilities. To save myself, I summoned my strength to fight. To embrace the support of my family and friends, I acquired the ability to reach out. To heal, I also learned how to support myself. My brain tumor precipitated an awakening. It gave me new life.