

The Day the Brain Tumor Returned

A Personal Essay

By Michele Alishahi

We got the terrible news on a Monday.

It was February 4th, one month after our move to North Carolina. We had barely settled into our apartment when it was time for my husband's MRI.

Even though he was in remission, Jim had one every four months. It was a precautionary measure, to catch the cancer early, if it came back — a possibility that haunted me every time he had an appointment.

Jim had remained cancer-free for over four years, much longer than the doctors had expected, given his brain tumor: a glioblastoma, the most common and most aggressive of primary malignant brain tumors. The five-year survival rate for Jim's age group was less than 20 percent.*

January had marked the seven-year anniversary of Jim's original diagnosis.

So far, he had beaten the odds.

On February 4th, our luck ran out.

“Unfortunately, the scans show sign of tumor recurrence,” the neuro-oncologist said.

For years, I had hoped and prayed I would never hear those frightening words again. Although, deep down, I knew the truth: one day I would. It was a matter of time.

After a four-year hiatus, our old enemy, glioblastoma, was back.

I was stunned when we got the MRI results. I stared at the doctor in disbelief. Did I hear him right? The cancer is back? There must be a mistake. How does a tumor come back after *four* years?

“We caught it at a good time,” the neuro-oncologist said. The cancer had not spread to other areas of Jim's brain; it was still in the early stages.

I nodded, but could not formulate a response — me, the one who was on top of everything related to Jim's cancer and overall health.

I looked at my sweet husband. He had a serious expression, which was a rarity; Jim was born smiling. He appeared to take the news in stride. I did not. My mind struggled to comprehend this new reality.

Yet, as difficult as it was to hear the terrible news, I should not have been so shocked.

The preceding October, Jim began experiencing tingling sensations on the right side of his body. They usually lasted several seconds, but did not prevent him from doing anything.

The doctor said they were likely mini-seizures and increased Jim's anti-seizure medication, which nearly eliminated the sensations.

But, within weeks, other symptoms showed up: Jim's mild language impairment, known as aphasia, grew worse. It became more difficult for him to speak, although I could tell he knew what he wanted to say. He just could not get the words out. And he often drooled without realizing it.

Was the increase in medication affecting Jim? It was not unusual for him to experience side effects. At least, I hoped it was that. I planned to talk to the neuro-oncologist about it on February 4th.

Jim's parents and a close friend had noticed the changes in him, and wondered: was the glioblastoma back? They told me later that they suspected what I did not want to see.

And that was the crux of it: I lived with Jim. I shared my life with him. I loved him and took care of him for seven years. I knew better than anyone that something was wrong. I simply did not want to face it.

Because I knew what it meant.

Seven years earlier, on another Monday, this time in late January, Jim and I had received the shock of our lives.

"You have a mass the size of a golf ball pressing up against your left eye. That's what's causing the migraines and the double vision, Jim," the doctor said. "You're lucky you came in when you did. You have a brain tumor."

With those words, Jim and I were thrust into a scary, unfamiliar world we knew nothing about.

I was terrified of what the cancer diagnosis meant: I could lose Jim. He was my first love. I was determined to do everything in my power to help him beat the cancer, no matter what the cost. I was not going to let him go without a fight.

In all the years I cared for Jim, I never regretted my decision. I did it for love.

But when I look back on the twenty-five-year-old me, I see a frightened young woman who had no idea what she was getting into — not for the long term.

I was focused on one thing: helping the person I love get into remission. That was all that mattered; it was the finish line.

I believed once Jim was cancer-free, he and I would go on living our life together, like any normal, healthy couple. I realized there would be side effects, but I did not grasp the implications of what that meant.

The young me did not think about the sacrifices that would have to be made in the years to come. Or the toll the cancer-fighting journey would take on Jim or me.

It took Jim nearly three years to beat the brain tumor. Together, we lived through two brain surgeries, radiation, years of chemotherapy, and dozens of MRIs.

The day finally came when Jim went into remission. The glioblastoma was gone. But the brain tumor and the treatments had left behind many side effects, including: hearing loss, minor short-term memory loss, mild aphasia, weakened bladder control, unsteadiness, and muscle weakness on his right side.

Jim and I created a life together that was as normal as possible, given his limitations. We lived in a limbo world, between full-blown cancer and a life with no terminal illness. I accepted this new reality. I was grateful for every day I had with Jim.

For four years, we lived a quiet life. Jim and I settled in Kansas, close to his extended family; we bought a small townhome; and I got a job working for the state legislature.

This was the ideal environment for Jim. He had a comfortable home, family and friends nearby, and a spouse who loved him, took care of his health needs, and provided for him financially. Jim was able to focus on getting better, after years of cancer treatments.

The possibility the glioblastoma could return was always there, though, hovering in the background. Every four months, I was reminded how fragile our life together was. It could change in an instant, depending upon an MRI result.

Jim and I dealt with this uncertainty by living year-to-year; we did not plan for the future. While our family and friends moved forward with their lives, we stayed static.

As time went on and Jim remained cancer-free, I struggled balancing his need for an unchanging life with my need for a life that offered more.

I felt stuck in a life I had willingly chosen, and actively participated in creating. Since his diagnosis, I had put Jim's needs ahead of my own, wanting to do what was best for the person I loved.

In the process, I had stopped living for me.

It was my idea to relocate to North Carolina. I needed to feel like I was moving forward in life. I thought a new state and a new job would satisfy my desire for a change.

It was not an easy decision to make.

I grappled with it for months: Was it in Jim's best interest? Was it worth it to disrupt our lives and move to another state because of my need for more?

Or was it better to play it safe and stay put, like we had for the last four years?

But then, I wondered: what if Jim remained cancer-free for another five years? Was this how we wanted to continue living our lives?

There was no right or wrong answer. Finally, Jim said, "Let's just go for it." He knew how important it was to me, and supported my decision.

The move was an opportunity for a fresh start.

But was it really?

We made surface changes: a new environment and new people in our lives. However, our circumstances stayed the same; we still lived in a limbo world defined by the glioblastoma.

I took a chance with the move to North Carolina. I bet on the likelihood Jim would remain in remission for years to come. I gambled against the odds.

I wanted to believe he was the exception to the rule. He would be the one who actually beat the glioblastoma — for good.

For seven years, I had dedicated my life to Jim, the cancer-fighting journey, and the life we had built together. I needed something to hold on to; hope for the future to counter the uncertainty and the powerlessness that came from sharing Jim with a brain tumor.

When I noticed the changes in him, I struggled with admitting to myself that the cancer was back. I did not want to face the possibility because it meant the end of everything he and I had fought for all those years.

I was no longer the naïve, inexperienced twenty-five-year-old woman who had no idea what she was getting into, or who believed that if you fought hard enough, remission was achievable.

I was a veteran of the brain tumor world. I understood the devastating impact of a glioblastoma; I had witnessed it firsthand. I knew that if it came back, it would be the end for Jim. His body had taken a beating in the years before remission. He did not have the physical strength to fight the brain tumor again.

The MRI results on February 4th forced me to confront the reality that the cancer had returned. The tumor was there on the scan: a tiny white area in an otherwise dark image of the brain.

I could no longer deny its existence.

A year later, Jim and I were back at the doctor's office to get the most recent MRI results. This time it was on a Wednesday, February 18th.

I was prepared for the news; I expected it to be bad.

Two weeks earlier, Jim began experiencing pain on his right side. I suspected it was because of the glioblastoma.

My initial reaction when he told me? A deep sense of foreboding. I knew in my soul: the end was near.

My fear was confirmed when the neuro-oncologist put Jim on steroids to reduce the brain swelling caused by a growing tumor. Days later, when I informed him the pain had not gone away, he doubled the steroid dosage.

It was worse than I had imagined.

The latest chemotherapy drug combination had not been able to slow down the glioblastoma. It was the fourth time in less than a year that the brain tumor had grown resistant to the cancer treatments.

February 18th was the turning point that I needed to finally let go.

The MRI results, once again, forced me to acknowledge a reality I had struggled to accept. My worst nightmare was about to come true. I was going to lose my first love. There was nothing I could do to stop it.

After eight years of battle, the glioblastoma was going to win.

I surrendered to the inevitable.

It was a painful, but liberating experience. I felt a heavy weight lifted off my chest for the first time in months. I could breathe again. I knew no matter how difficult it was for Jim to die, in the long run, I would be okay.

Once I owned up to the truth, the fighting no longer mattered. It was pointless, a waste of precious time and energy.

For the next three months, I made the most of the time I had left with Jim. It was a privilege to be by his side, to share the last days of his life with him, and to help him die — with love and peace.

It was the most meaningful experience of my life.

The End

* Ostrom QT, Gittleman H, Farah P, Ondracek A, Chen Y, Wolinsky Y, Kruchko C, Barnholtz-Sloan JS, CBTRUS Statistical Report: Primary Brain and Central Nervous System Tumors Diagnosed in the United States 2006-2010. *Neuro-Oncol* 2013 Nov; 15(sup 2): ii51.

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Michele Alishahi