Cancer Health™

On Being a Mascot

What I have learned this year is that personal identity is not static and unchanging. We are adaptable.

May 26, 2017 By Adam Hayden

“I do not want to be the cancer mascot,” I naively said a few days after awake brain surgery (craniotomy and tumor resection/debulking). Cards, balloons, social media posts, and visits from friends and family weighed heavily on my badly bruised, traumatized, and swelling brain. In this post I reflect on my journey, one year on.

The trauma of brain surgery is so significant that now, one year later, my MRI scans continue to show post-surgical changes. The brain tissue that is my parietal lobe is shifting posteriorly toward the occipital horn. The worst news we could receive following an MRI is tumor progression (growth), and so far there are no signs of this progression. The scans are “stable.” Stable is terrific! And stable can also be misleading. Regardless of stable tumor/disease status, each scan reveals new swelling, shifting tissues, blood flow abnormalities, developing and decreasing fluid pockets. These are occurring with my brain tissue all the time. The brain is the organ that is most easy to damage and most difficult to heal.

I often forget, and this lesson is lost on many, that I have brain damage. It is with deep, deep breaths of relief that I am yet to experience any outward-facing language or higher-level cognitive deficits, but when I am critical of myself, when I am frustrated with my inability to effortlessly walk, feel, sense, or shift weight or pivot toward my left side; when I am depressed to wake up with yet another headache, when I have to cancel dinner with friends because of fatigue, I remind myself that, after all, I do have brain damage.

My surgery was one year ago, to the day, May 26, 2016, prior to me sitting down to pen this blog post today, on May 26, 2017. One year ago in May, 2016, I hesitated sharing too much of my story for fear that I would alienate friends, drive people away who lack the desire, emotional wherewithal, or open-mindedness to join hands with their friend Adam, a former grad student, a recent bartender, a new dad to young children, who now lay in a hospital bed, his head bandaged, his left arm and leg weak and flaccid; someone who requires a visitor badge to spend time with. A 35-year-old young, bearded, indie rock dad who was diagnosed with an incurable brain cancer, which typically affects people, mostly men, in their 50s and 60s, not their 30s.

“I do not want to be the cancer mascot.”

I had over 40 staples in my head, I was stuck in a hospital bed or a wheelchair, and nurses popped in and out of my room every twenty minutes to take vitals, or administer meds, change the IV drip, or measure the amount of urine I was evacuating. I exemplified a hospital patient. There was no choice but to be a mascot because I was dressed in it, bathed in it, immersed in it.

I was a cancer mascot. What would I represent?

I saw your head tilts, your furrowed brows, your smiles, turned down at the corners. I watched donations pour in to sustain our family and keep our financial heads above water while swallowing the pride, informed by societal norms, that a husband and father should provide for his family. Please know that our community of friends near and far, loved ones and strangers, classmates and coworkers, we could not be emotionally, financially, or physically stable as we are without your support!

May, 2016, I stared out the window to look onto the busy world, sobbing with my wife. May, 2017, still staring out the window, and still sobbing with my wife, but not as often. I embrace my role. I am a mascot! I am fortunate to have the strength, the cognitive processing power, an articulate nature, and above all, a supportive network of family and friends to embrace my role.

Proudly, even.

A fundraiser was organized for our family, with permission, but we had no involvement in scheduling, planning, advertising, or organizing for the event. When we were informed a couple weeks ago of the planned date for this fundraiser, and that it would take place, tonight, May 26, 2017, Whitney and I looked at each other, smiled, and released our wet eyes. What more can be done on the first anniversary recognizing your life forever there after would never ever be the same again? We said “great, it will be an anniversary party.” We have chosen to embrace our new life, to try our very best to share with the world, led by honesty, vulnerability, and speaking in unison with the voices of other survivors, accompanying them, another voice in the choir.

I didn’t want to be the cancer mascot because I feared it would strip me of my identity. What I have learned this year is that personal identity is not static and unchanging. We are adaptable. We learn, grow, evolve, fail, sob, rally, and push on. Somewhere in there we locate our values, and finding bedrock in what is most important frees us of fear that we will become something we do not want to be, and instead helps to be who we are, regardless of circumstance.

I didn’t want to be the cancer mascot because I didn’t know what I was representing, what values would shine through, what a symbolic exemplar of cancer would portray to the world, and today I have a little more insight into the symbolic representation of a terrible disease that touches, through direct diagnosis or diagnosis of a friend or loved one, one in every two Americans. What we need is honesty, vulnerability, passion, and a willingness to embrace our challenges.

Each day is not easy. I am an ass sometimes. My curated life through this blog and social media is not designed to disguise my bad days and hard times, but instead, I seek to demonstrate the power one person has in representing something bigger than they are. We are all cheering each other on, and embracing our shared encouragement is the role of a mascot.

What mascot can you be for the people in your life? What do you seek to represent?

Happy anniversary, and cheers!

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