Cancer Health™

Surviving to Bear Witness

After living with this disease for two years, I extend my deepest gratitude to those who follow my journey. We mark this milestone together.

June 10, 2018 By Adam Hayden

Sunday, June 10, 2018 marks two years after Whitney and I were transported in a wheelchair accessible van from an inpatient acute rehab facility to the IU Health neuroscience center. We sat in my neuro oncologist's office and received news of my glioblastoma diagnosis. A kind, compassionate nurse who would become more than a member of our care team, but also a dear friend, held each of our hands.

I am unsure of what to say on the day of this important milestone, but I am compelled to offer a few words–really, the task of this blog.

I published my first post to this blog in October 2016. The staff physiatrist discharged me from inpatient rehab four months prior, and I received the GBM diagnosis only weeks before that discharge. In October 2016, I recently completed a six-week daily chemo and radiotherapy protocol, and I began the 'maintenance' chemotherapy cycle: five days, high-dose chemo, followed by 23 days off, and repeat.

I struggled to settle into a rhythm and direction for this blog.

Early posts revealed a thinking-out-loud style of scientific explanation, connections with philosophy, and personal narrative about a young man, husband, dad, brother, and son, internalizing a devastating cancer diagnosis. I wrote many posts with an aim in mind that never fully materialized. Posts proved too scientific for casual readers, too flimsy for academics, and too personal for many friends. I continued to write, striking a chord with some here and there. Often the reader thanked me for keeping everyone up to date, among other encouraging remarks, noting my positive attitude, vulnerability, and bravery. On the latter, I call up Abraham Verghese writing the forward to Paul Kalanithi's When Breath Becomes Air. Verghese (roughly) remarks, "how brave it is to reveal yourself in this way."

If there is bravery to recognize, it is rooted in my vulnerability.

In July 2017, nearly one year after our trip to the neuroscience center, news broke of Senator John McCain's diagnosis. I was first notified in a tweet (a "mention") by an academic colleague. I wept. I wept for the Senator and his family, for me, and for my family. I wrote an open letter to McCain to be published in medical journalism outlet, STAT News. The letter received an overwhelming response from people affected in one way or another by GBM, including newly diagnosed patients, others living with the disease, care partners of those with the disease, and relatives of people with GBM who died.

Article comments, increased blog traffic, and a full inbox signaled that my commitment to continued writing and posting found an audience. That audience, my audience, includes those closely impacted by this disease. Comments and emails expressed an important and instructive theme: people seek to tell their stories and impetus to do so may be triggered when people share a common suffering. GBM is diagnosed in three people per 100,000. This qualifies GBM as rare. Compare GBM incidence to breast cancer, which is diagnosed in one person per every eight. Nearly 300,000 people are diagnosed annually with breast cancer, contrasted with 14,000 cases of glioblastoma.

Consider the disparity in incidence rate.

I note these statistics only to emphasize the reality that if you’re looking for a resource to discuss your illness experience, the peer population is disproportionately small contrasted with the horror of the disease, for those with rare diseases such as GBM.

It is an honor to receive and reply to emails from people impacted by GBM. Many of these patients and care partners are now friends. Sadly, I have heard from loved ones about the death of people I emailed with frequently. It is a sample size of a population dying in the thousands each year; nonetheless, these are deeply personal losses. I am humbled to consider that in the final weeks, maybe days, before death, I was in active dialogue with a (now) late friend. I thank the loved ones who exhibited vulnerability, hence bravery, to open an inbox, to read email conversation threads, and to inform an unknown person on the other end of an optical fiber cable their loved one is now gone.

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To the patients and care partners who look to me for next steps in their own journey, or to reflect in the rear view mirror to recall and process their own experiences, I mention the broad range of experiences shared across a rare disease population, but notice each is unique to the individual.

Telling our stories to each other, to our social circles of influence, and to our clinicians is an effective way to locate our agency, that is, to discover those outcomes for which we may exercise control, amidst a disease and circumstance for which an abundance of variables exist outside of our control. Expressing our experiences through storytelling is an effective means of establishing a supportive network who endure the journey alongside us, and yes, to celebrate our milestones.

It is a fitting conclusion to say a few things about where I am today. The reality is when given a life-limiting diagnosis like GBM, everything changes, yet, surprisingly maybe, nothing changes. I am still uncertain of which alternative is favored: for all to be different or a return to the familiar.

Frustratingly, maybe, but not uncommon in spaces between such tension, the answer lies in the middle.

Many think—mistakenly, by my judgment—that a life-limiting diagnosis affords an opportunity to sort out priorities and pursue “what matters most.” For many, physical impairment, cognitive deficit, decreased life expectancy, and financial toxicity limit the pursuit of new or revised priorities and mythologized bucket lists.

What is different is the perspective that must be adopted. You still must do the laundry, but you fold the shirts with acute knowledge of your own mortality.

Two years following my diagnosis, the Adam that existed pre-diagnosis is dissimilar from the Adam now, two years on. Though, these historically competing personal identities are far from strangers. I continue to enjoy coffee with former faculty and friends, I recently submitted with a friend and colleague a co-authored chapter to an academic press, I try, and often fall short, to balance my responsibilities to my wife and family with my own aims and personal projects. I returned to work. I maintain responsibility for house chores that I am capable of completing. These activities are familiar and routine.

After an especially busy travel season, where I was in Chicago, D.C. twice, and San Francisco within a six- or seven-week period, my wife reminded me that while I aim to leave a legacy in the world, my greatest contribution to the future is a commitment to be present with the family; with our boys. This tension exposes the dual nature of illness: to serve ourselves before we cannot, or to serve others while we can.

There is little success to be found in chronic and advanced illness. There is no victory, fighting, nor conquering. I find these frameworks for illness harmful. So also, there is no succumbing to disease nor losing the battle. There is life. There is death. What there is, is enduring. Enduring is another name for survivorship. We survive to bear witness. Bearing witness is vulnerability, and it is vulnerability we recognize as bravery. Survivors are constrained to record their experiences. To leave behind something permanent from the ephemeral.

If there is something Whitney and I have sought to teach others, lessons we learned ourselves, it is we live to bear witness to endure each day. Our endurance is strengthened when we commit ourselves to being on the journey with others. Thank you for hearing our story and for telling us yours.

Enduring. With vulnerability. With bravery. Together.

June 10, 2016; June 10, 2018.

xoxo.

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