Four Months, Four Years, Four Lessons: Notes on Survivorship

Recently, we met (virtually) with my neuro-oncologist to hear the results of my recent MRI scan.

June 4, 2020 By Adam Hayden

"My surgeons' skills have added time to my life, more time with my wife, more time with my kids. Thank you to my entire medical team."

Adam, October 13, 2016

I published my first blog post to this site in early October, 2016. That post came right around four months after hospital discharge (the "Four Months" in the title of this post). I checked into the surgery floor at IU Health Methodist Hospital with Whitney early in the morning, May 26, 2016. Four years ago, to this day, May 26, 2020 ("Four Years" in the title).

In my first personal blog post, I wrote the words you see quoted above. I include those words here to signal my continued gratitude for my team. These thanks are well placed, as our family recognizes this significant day in our calendar.

Today marks four years after my craniotomy and surgical removal of a seven centimeter primary brain tumor from my right parietal lobe, an area of the brain responsible for five major functions, including sensation, motor control, and spatial reasoning.

Today we met (virtually) with my neuro-oncologist to hear the results of my recent MRI scan completed Saturday (May 23, 2020). This is a scan we will not soon forget. Masked, we entered the hospital Emergency Department because the general radiology entrance is closed on the weekends. (Radiology shares a back hallway with the ED for trauma-related imaging.) The security checkpoint includes a metal detector that reminds us of the complex social conditions that surround the lives of some people cared for at the county hospital. We also wondered what further precautions would shape the encounter during a time of COVID-19 related restrictions.

Whitney and Adam pre-MRI, May 23, 2020Courtesy Adam Hayden

Worth mentioning, also, after an area of slight concern appeared on our prior MRI in February, our oncologist recommended adding an imaging technique called perfusion to this recent scan. The perfusion technique lengthens the duration of the procedure by several minutes and includes placement of an IV and additional injection (beyond the routine contrast dye) to study blood flow.

Here we were, then: After four years, something like 25-30 scans, despite our typical anxiety (scanxiety) that accompanies each routine MRI, we faced new circumstances, if only slight disruptions: Whitney's recent course of illness after testing covid positive, the masks we donned, the secure entrance, distancing from others in the registration line, the new imaging technique, the empty hospital absent of visitors, and the pervading concern that maybe we were catching new tumor growth in its nascency.

Adam’s MRI thumbs-up, May 2016Courtesy Adam Hayden

Our visit this morning revealed news of a positive outcome: The scan shows no new growth, and our doc chalked up the concerning area to late-effect radiation damage. We might relax our

concern for the near-term, and we look to August for our next routine MRI.

I do not want to let this day pass without offering something constructive after 48 months living with a disease that kills many in half that time ("Four Lessons"). These are not definitive, action-guiding principles for life. They are simpler. They are variations on a theme that I shared during a talk at Stanford Medicine X in 2019, refined and updated for my presentation at the End Well Symposium at the end of last year, and shaped by the contours of my personal manuscript that hopefully finds its way to print over the next year. These are lessons from living, while dying.

Consider your quality of life today. When faced with a decision in the operating room to pursue aggressive surgery at the risk of left-sided paralysis or take a conservative approach that would protect my motor function but leave tumor remaining in the margins of the surgical area in my brain, my surgeon instructed that I, "Make a decision based on your quality of life today, not what you think it may be in the future." This turns out to be good advice for living in general, not only in the operating room. Each of us has an uncertain future. It is good to plan for the future, mitigate against harms and obstacles, and yet all any of us have for sure is the present moment. Arrange your life so that it aligns with your desired quality of life today, not an imagined future.

Face fear with familiarity. Focusing on the present and allowing the future to unfold is frightening because it asks first that we allow the uncertain and unknown into our lives. I suggest that we face fear with familiarity. What information is available to us *today*? What is within our control *today*? What is the *immediate* source of our negative emotions and intrusive thoughts? Becoming familiar with those things we may attend to in the present helps us acknowledge our fears, not to escape or dismiss them, but to become familiar with the inner workings of our brains that are wired to alert us to danger, even when that threat isn't right in front of us. Familiarity is the antidote to fear, and I am reticent even to express this sentiment because fear is not intrinsically bad. Allow yourself to fully experience that breadth of human emotion, but center yourself with the focus on what is present and at-hand.

Consider what to say to a cancer patient. When I instruct others to consider quality of life today and leave the future uncertain and unknown, I am flirting with everyone's favorite thing to say to cancer patients, "I could get hit by a bus tomorrow." This phrase and the war metaphors that are prevalent in disease rhetoric are two facets of the illness experience that I've objected to in blog posts, tweets, and op-eds. They are more than unhelpful; they are harmful. Taking the latter first, the problem with framing cancer as a fight or battle minimizes the potential for wholeness and wellbeing that are available when an illness is embraced into our life narratives. A war leaves casualties, winners, and losers. Surviving is not a victory and death is not a failure to fight. Instead, maturity and growth through illness are possible, whether treatment leaves us with no evidence of disease or end-stage progression. Wars and battles leave little room for growth and acceptance, what scholars call *existential maturity*.

This advice specifically, and the next, are sensitive to the context of the patient and their preferences. I know many patients who frame their own experience as a fight, and that is their metaphor to claim. For me, in my most insightful moments, I've felt more the *sage* than the

soldier. Illness leaves us with wisdom, not war.

Rethinking thoughts and prayers. This is a tricky one. We each are licensed to our beliefs, and all of us should extend as much charitable interpretation as possible to the words that others speak to us. I remind myself often that others express their very best intentions, and those intentions supersede the literal words they use. Though I'll say this, it is very common for folks to cope with another's serious illness by fitting that person's illness into a Divine plan. I cannot get on board with this. It does not fit my conception of The Divine to imagine that I was singled out, given a potentially life-limiting disease, and by those circumstances, forced our kids to face the loss of a parent, so that God could teach a lesson through my experience. For God, whatever God is, surely there is a better way to teach lessons than clamp me to a table and open my skull. When encouraging someone facing illness, center your religious beliefs in what brings you comfort as the friend and observer, but be careful not to thrust your beliefs onto the person experiencing the illness. I recognize that your show of support for me is expressed through your carefully considered prayer and meditation for my healing, but healing may not be a cure. The healing may be my acceptance that no cure is available.

As you move forward, navigating these uncertain times of public health crisis, you may consider these lessons that I've practiced these four years: Align your decisions to your desired quality of life today. Live presently and familiarize yourself with those things that you fear. Consider healing, well-being, wholeness, and personal growth that may come through experiencing illness. And extend charity to others while respecting their beliefs.

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