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One Day, I Will Die

To be an informed and empowered patient, I must not only confront my prognosis, but in fact, I must become comfortable with it.

December 12, 2016 By Adam Hayden

Sitting on the couch at my parents’ house, my older two boys bounce on the cushions beside me, I flick my thumb upwards against the cracked glass screen of my iPhone to scroll the mobile-optimized pages of Vice to read the article “The First Time I Let Someone Die” (December 10, 2016).

Tears well in each eye. The corners of my lips turn downward like the taught angles of a freshly laundered pillowcase, pregnant with a newly fluffed pillow. My index finger and thumb form a right-angle and rest above my chin, below my lower lip, squeezing my cheeks on either side, the webbing between my thumb and finger in the formed L is scratched by the coarse hair of my beard. My bent elbow rests on the soft fat of my belly and my posture is convex or crescent moon, as I fold in on myself, barely sobbing, beside my children playing.

Dr. Rahul Jandial’s piece is a personal anecdote borrowed from his neuro-ICU residency. The article recalls a patient Dr. Jandial was unable to save, her family, and the circumstances of her car accident and brain swelling, leading to her inevitable death. Dr. Jandial draws us into his narrative and offers a glimpse of his patient’s physical scars traded for the emotional scars he continues to carry.

Please follow the provided link to read Dr. Jandial’s article. It is important. (Of course, first, I hope you finish mine.)

I sob often, and I am not ashamed to admit this is not a post-diagnosis development. The proper conditions regularly result in my tears. These conditions include, but are not limited to, the following: romantic comedies, deep, meditative breathing, Neutral Milk Hotel live recordings, powerful personal anecdotes, and lying beside Whitney in bed, holding hands, wondering how long or short our lives together will be cut.

Dr. Jandial’s contribution to my Sunday afternoon reflection meets the previous criteria. You see, we humans are deeply empathetic, and when we read an account like Dr. Jandial’s, we imagine ourselves as the young resident, or the patient, or the patient’s family, or, many of us need not imagine at all because we are the patient; we are the family; we are the resident.

I sob this afternoon because each contemplation of my own mortality introduces a new lens through which I view the future inevitability: my own death. My empathetic connection to Dr. Jandial is that one day my physician will let me die. I am the patient whose pathology revealed the inevitable march of disease toward patient death. I empathize with my doctor, and I sob for her. I sob for myself.

This will strike many of you as uncomfortable, as if I am admitting defeat too early in the battle. To signal a white flag of surrender is not why I write this post, at least not any more than I think Dr. Jandial published his narrative only to remind us that often medical intervention fails. The motives are much deeper, and the lessons available for us to learn, if we take the opportunity. Dr. Jandial reports, “To take care of the dying you have to become comfortable with death.”

So it is with glioblastoma.

To properly care for myself. To be an informed and empowered patient, I must not only confront my prognosis, but in fact, I must become comfortable with it.

Before surgery I wondered if my heavy eyelids would gently shut and never again open. In the days leading up to my surgery the closing of my eyes became ceremonious, ritualized, rehearsed, and well practiced. I closed my eyes to usher in death. What would this be like? I wondered if I would be aware of death, if my body would sense my slowing pulse, my labored breathing, or only the heavy eyelids would signal death.

These thoughts were somewhere close to the surface when I gripped the back of my hospital gown to pull it closed and shuffled to the bathroom in the pre-op wing of the hospital to be prepped for surgery. I passed by other rooms where other patients were prepped by other nurses. I received an IV line, my clothes and possessions were bagged like I was spending a night in the drunk tank, and surgeons, OR nurses, residents, family members, and the chaplain marched in and out, drawing the curtain open and closed with dramatic theatrics. Maybe this was a dress rehearsal. The actors entering and exiting the stage. The curtain opens and draws close. When it was time for my performance, I squeezed my wife’s hand.

Exit stage left.

Curtain opens.

Break a leg.

The fluorescent lights passed overhead as my gurney wheeled down the OR corridor. Hypnotically these lights clicked by like street lamps through the window of a speeding car. I was surprised that doors to other operating rooms opened and closed. I wondered if those same patients I hid my modesty from earlier were now laid bare on the OR tables as I sped by. The white lights washed out the details. Soon would be my room. My eyes squint from the white fluorescence of the operating room. My eyes gently close. I feel my pulse. I feel my breathing. I am alive. I am prepared. I am comfortable with the craniotomy we must now perform.

The surgical resection of my 71mm primary brain tumor was a complete success: a gross total resection. Nearly 95% of the tumor removed. A gross total resection is a strongly positive prognostic indicator. My ability to remain awake, calm, and responsive during surgery accomplished two things: first, my my left-sided sensory and motor function was protected, preventing left-sided paralysis, and second, my patient-surgeon-partnership facilitated aggressive tumor removal, adding months or more to my expected survival.

My memories are vivid of the procedure, and I recall one of my surgeons telling me, “Dr. Kenner will make you a little drowsy for us to close.” I recall the three-point, 30-PSI fixation device unscrew. Then my head cradled and wrapped in bandages by the competent hands of my surgeon. Soon those fluorescent lights click by again, this time back tracking our earlier route, now heading out of the OR and toward recovery.

It turns out (surprisingly) the (awake) brain surgery proves to be least challenging obstacle to overcome. In the months since I have received PT, OT, neuropsych evals, chemo, radiation, seizures, and a wearable electric cap to treat my tumor with electric fields. Nearly each day I scour the internet for new case studies, clinical trials, research papers, and genomic information to inform the care, treatment, and new frontiers for dealing with my malignant brain cancer.

I am often irritable, short-tempered, quick to scold my kids for throwing food or refusing to dress for school. I am on long-term disability. I cannot drive. I am stir-crazy. I am praised publicly for inspiring others with my positive attitude, but I often hurt the feelings of those closest to me.

I am seeking comfort in the face of difficulty. Dr. Jandial reminds us that our efforts may fail, and failure leaves a scar. The lessons are in the healing, and I learn more each day.

This post originally appeared on Glioblastology. It is republished with permission.
