

Learning Lessons This Holiday With Cancer

This is why I show up, because each moment with my family is a sacred moment.

December 22, 2016 By [Adam Hayden](#)

Defcon: Seizure

Light-headedness, bordering on dizziness, headaches, worsened by fluorescent lights, anxiety, and uneasiness, especially in large crowds, weakness through my left leg, a three-pound battery backpack and electrodes taped to my head. It is time for our preschoolers' (the older two boys) Holiday program. I am a six-foot-two, awkwardly gaited, cane-hobbling attention-grabber as I shuffle through the chaos of hundreds of young families to find seats and keep a hand (or at best an eye) on our youngest. Grandparents are there to help us, and there is an unspoken young family code that if an 18-month old is running by, drooling and smiling, you are licensed to scoop up and restrain this child-on-the-loose until a parent or guardian arrives to relieve you.

Whitney and I volunteer at our kids' school regularly: field trips and "special days" celebrated around birthdays, distributed across our two boys we have enrolled, and the three years we have had at least one child attending, we've volunteered at Crabapple Creek often. Lately these events have totally drained me. The fatigue and other physical challenges put me in defcon five for seizure risk. My body has taken to rather sudden, mild seizures when I place too much stress on it. Like an overheating engine, after a long day, a stressful event, or over stimulation from bright lights, patterned and textured floors, or colorful walls, my brain short-circuits. I experience the familiar twitchy, dizzy, motor function loss characteristic of seizures. I usually feel it coming a few seconds before seizure strikes, and I must sit down. Immediately.

A War of All Against All

Thomas Hobbes wrote about the state of nature, a competitive, every person for herself, war of all against all. I have read Hobbes a handful of times, as I suspect many with at least a BA in Philosophy have done. My closest reading of the Leviathan, where Hobbes articulates his theory, happened in a History of Philosophy course, Society and State in the Modern World, or something like this, a seminar-style discussion course.

Hobbes imagined a violent natural state, red in tooth and claw. Each person has a natural right to survival, and in the face of limited resources, our competitive drive and natural rights lead to a life that is "solitary, poor, nasty, brutish and short." Hobbes proposed our only path toward peace is to

acknowledge that our right to survival is better protected by cooperation, and so we contract together and appoint a government to enforce our pact. This is one theory of social contract: Rousseau articulates an alternative view, but that will have to wait for another time.

My lesson from that seminar, and a close reading of Hobbes, is this: the really frightening thing about the natural state is not the literal violence of a war against all, but it is the insidious, psychological threat of the potential for war, losing one's natural right to survival. The war is psychological; fear-driven.

Navigating big events, especially those with young families, hundreds of quickly moving children, and overstimulation of being in the center of these things, reminds me of this Hobbesian view because I feel the strain of this psychological war. I am fearful of seizure. Where could I sit? How could I avoid a scene? What if I lose consciousness? How close am I to Whitney, who will know what to do?

I am consumed by my fear, and I fail to engage meaningfully in the event.

Hobbes instructs us to, whenever possible, pursue peace. Create a contract for cooperation. I apply these lessons to my own psychological war, defcon: seizure. I seek the cooperation of spouse, friends, family, and remind myself to be honest, to trust others, to acknowledge my right to self-preservation is better protected by setting my individual rights aside and contracting with those in my community. Hobbes imagines this will be a challenge because we are competitive by nature. For those of you who have had to rely on others, given medical, financial, or other personal hardship, recognize the difficulty in sacrificing your own rights, but also notice the value in cooperative living. It is difficult to admit you need help. But to be fully present, we must give up our selfish, first-person view, and rely on others.

Dealing With Ambiguity

The Holiday program includes a dramatization of the nativity. Our middle child was the "blue king," signaled by his blue construction paper crown. Our oldest was Mary's donkey. Before the nativity the kids show off their "circle time," a daily school activity. Each child is assigned a different "job" ("Continents," "Solar System" "Weather Watcher" "Line Leader," etc.) to perform and learn by doing. In the comfort of the classroom the children happily perform their "jobs" without much goading from the teacher, but under the proud gazes of grandparents, flashing camera bulbs, and strange surroundings of a new environment, the children are less cooperative. I am impressed by how well the teacher and aid handle the kids' uncertainty and anxiety.

I once held a position, senior training specialist, and one of the responsibilities included coaching leaders on creating and executing personal development plans with their direct reports. These "PDPs" were competency-driven, meaning we coach behaviors rather than specific tasks. A competency that many struggle to get right is dealing with ambiguity. No surprise: most of us hate change, we fear uncertainty, and we like our routines: we are creatures of habit, we like to say. To successfully deal with ambiguity, the behaviors include being present in the moment, knowing your resources, communicating openly, and making decisions with limited information, not waiting

to see the whole picture.

Few deal with ambiguity better than preschool teachers. Our CEOs should shadow teachers as required “onboarding.” Better yet, more teachers should be made CEOs, or at least paid like it! Teachers live in the moment with their kids, looking for opportunities to turn every day experiences into lessons, going with the flow, embracing change, helping their kids be part of a process rather than only gears in the machine. We all want to be part of something, and working in cooperation helps us achieve a common goal.

Showing Up for the Holidays

Cancer is filled with uncertainty. The rhythm of my life is monthly chemo, bi-monthly brain scans, repeat until the tumor grows back. In the words of my neuro oncologist, “the probability that this tumor will not recur is highly unlikely.” My life is waiting and uncertainty. If brain scans are stable, that is, show no tumor growth, what therapy is working and should continue? If we see tumor growth on the next scan, what treatment failed?

My therapies include (or have included) radiation, chemo, Optune Tumor Treating Fields, ketogenic diet, diffusing essential oils, and nutritional supplements. I monitor these therapies closely to narrow variables so success or failure can be attributed to a therapy, but all this is dealing with ambiguity, attempting to make decisions based on limited information.

Of course the biggest uncertainty that my wife whispers in my ear as we share a bedroom with our sleeping baby in the crib beside our bed, usually the older two boys have found their way in to snuggle, and the five of us are tightly packed in these close quarters, reminded that we’ve given up our own space to move in with my parents, and they have given up their space to welcome us, is that each Holiday, this Holiday, could be my last Holiday, or the last Holiday that I feel well enough to be out of bed, attending Holiday programs.

This is why I go to see my kids dramatize the nativity, even though I attract strange looks, accidentally step on people’s feet, and risk seizure. This is why I show up, because each moment with my family is a sacred moment.

Learning Lessons

We can draw lessons from my experiences because they are not only my experiences: they are our experiences. We all face uncertainty. We all face difficult decisions. We all have individual goals and have to balance our desires with those of our community. What I am learning through writing this blog is that dealing with a grade IV glioma, a primary brain tumor, a disease without a cure, is that my life experiences are distilled, different in degree, maybe, but not different in kind or type from the challenges we all face. We walk a similar journey. I give voice to our shared struggle like tasting a concentrated ingredient on its own makes it easier to pick out in a dish.

Here are some more of the lessons I am learning this Holiday season:

- Put your individual hang-ups aside and recognize we all need help from family and friends. Focusing only on yourself leads to a Hobbesian state of nature: psychologically damaging and fear-driven. Ask for help! Cooperative living is peaceful living.
- Do what our teachers do: deal with ambiguity. Do not fear uncertainty and change; embrace it. Become comfortable with limited information and closely monitor when your attempts at solutions work and when they don't. Adjust next time accordingly.
- Most importantly, show up! We may have a hundred reasons not to attend an event, family gathering, party, dinner, or whatever, but taking on a challenge today and making it through is better than putting it off until tomorrow and never getting the chance.

Happy Holidays, friends! I'll see you next year.

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