Living With Cancer: Insidious and Destabilizing

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January 17, 2019 By Adam Hayden

"Don't think, daddy! You can't think right! You have a brain boo boo. Just ask me next time."

Isaac, our confident, insightful seven-year-old, the oldest of our three boys, said these words to me this morning, when I shoved his lunch box into his backpack while rushing out the door to catch his school bus. The prompt for his cutting remarks was my explanation of the contents I packed for his daily lunch. "I thought you liked that stuff!" I muttered dishearteningly, with a mixture of confusion and exasperation.

My crime: thinking, or rather, as we may say as adults, assuming, and on that charge, I am surely guilty. I assumed a handful of snacks, protein, a juice box, and a square of chocolate would be a fine lunch for our oldest guy who is limited in his food options, after Whitney and I discovered, with the help of a functional medicine practitioner and blood, urine, and saliva testing, that Isaac suffers from several food allergies.

I've raised before the issue of talking to kids about cancer, but what we face, the daily grind of parenting three young boys, my spouse who must work outside the home to serve as our primary earner and carry our medical benefits, and the primary at-home guardian, me, suffering from brain cancer and the host of accompanying neurological disorders—namely, headaches, seizures, and motor impairment—is a combination of factors that affects our kids in untold ways. It affects me, too, in a deeply fracturing sense. A fracturing of my will from my ability; my plans for the future and my practical responsibilities.

Surely we all squabble with our kids, and for this reason, motivated by a desire to connect, or to comfort by striking chords of relatability, or for fear of peering too closely at a situation that is all too frighteningly real, friends say to me, "Yeah, we get lip from our kids, too," or, "We also have a picky eater." But the burgeoning independence and personality of an oldest child, or picky eating habits or allergies, and even the stressors of an at-home guardian fail to address the insidiousness of serious illness.

"You can't think right! You have a brain boo boo."

The 17th c. philosopher Thomas Hobbes, in his important work The Leviathan, envisions conditions for people absent of government oversight: a “state of nature,” he called it. Important to note is that Hobbes is writing in a time when Europe is ravaged by a bloody civil war and political crisis. At any rate, Hobbes considers life to be “solitary, poor, nasty, brutish, and short,” in this state: “a war of all, against all.” Hobbes did not consider this a historically accurate description of pre-political humanity; rather a thought experiment to motivate his political theory.

During my first semester as a philosophy undergraduate we read excerpts from Leviathan. My professor pointed out the “insidiousness” of the imagined “natural state.” The point, my professor emphasized, is not that everyone is locked in combat. Instead, the threat of instability looms large, and this unsettling psychological state is a hindrance on people’s desire to live well.

Living with cancer is insidious and destabilizing. A psychologically unsettling state. After active treatment has ended, at least for brain malignancies like glioblastoma, patients enter a period of disease monitoring: MRI (brain) “scans” every eight to twelve weeks. The return (recurrence; regrowth) of glioblastoma is near certain, regardless of surgical success or response to chemotherapy. After recurrence the disease is near-universally fatal, and the five-year survival rate is a dismal 5.5%.

My working life, that is, “work” in all forms, including: my paid part-time work, and also writing (blog posts like this that you are now reading), speaking, interviewing, advocating, and so on, is taking its toll on me both physically and emotionally. My days end in fatigue, and continuing to tell my story, though with innumerable positive implications for myself and others, is also like retuning to the scene of the crime. I am surely threatened by this destabilizing psychological state. Do I continue to work? Do I retire to a life focused on family and permit myself to let go of self-governed responsibilities, or, like Hobbes, are these self-governing practices the only things separating me from a natural state?

Following my son’s ill-delivered but insightful advice: it would be better not for me to assume, but to ask all of those closest to me and to myself, how might I best seek a life well-lived?

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