To Handle Distress: Do As Much You As Possible

I write this post to address one fundamental question: How do we feel normal, when so much around us is changing?

March 27, 2020 By Adam Hayden

"Today you are you, that is truer than true. There is no one alive who is youer than you."—Dr. Seuss

I've read many great articles about homeschooling, setting up the optimal space for working from home, and activities to engage kids during long stretches indoors. Online fitness classes are easy to find. Bands are streaming sets online, and Netflix rolled out the very cool movie night watch party feature to connect with friends virtually. Many employers are scheduling recurring "coffee meetings" to bring their remote employees together. Universities have shifted in-person instruction to online lectures.

These are all incredible changes that happened within a matter of days! We should be encouraged by these moves to act in a unified way to protect the health of our communities. Still, we have plenty of work to do to reinforce adherence to CDC guidelines, and it would serve each of us well to heed the advice of epidemiologists and healthcare workers–like my wife–who are sharing their experiences from the frontlines.

This post is not to reiterate those cautionary tales, and I do not want to repeat the terrific resources that so many have made available.

Instead, I write this post to address one fundamental question: How do we feel normal, when so much around us is changing?

Over three months, beginning in May 2016, Whitney and I reacted to the news that I was diagnosed with the aggressive brain cancer, glioblastoma. With this diagnosis we were confronted with my mortality: the dismal five-year survival rate for GBM is less than 10%. Yet this existential threat to my survival, Whitney's husband, the dad to our kids, was only the tip of the iceberg. Just beneath the rolling waves of serious illness was a greater threat: the complete disruption and reorientation of our lives.

In short order, I stepped away from my full-time career working in learning and organizational change management, Whitney stepped away from her full-time position at the hospital to care for

me and our boys, and she shifted to a variable schedule, with enough hours to maintain benefits eligibility, requiring that she commit to working every weekend; we sold my car because my persistent seizures made driving a risk to myself and others, and we sold our condo both because the second-floor walk-up was incompatible with my limited mobility following surgery and the mortgage seemed impossible to maintain after losing my salary.

By Fall 2016 our lives were barely recognizable to what they had been only months before.

I share this because the disruption and the reorientation of daily life may feel a lot like what you're facing now in response to social distancing and other mitigation or suppression efforts to slow the spread of the novel corona virus or covid-19.

I want to offer the advice that I give to newly diagnosed patients and their loved ones who reach out to me through this blog or through Twitter.

I am frequently asked this question by newly diagnosed folks who must reorient their lives in light of serious illness–usually for those reaching out to me, the diagnosis is brain cancer, but I think the advice generalizes.

Imagine that you walk into an office visit with an oncologist, and you walk out with the information that your life expectancy is now measured by reference to "median overall survival."

This is not unlike the news all of us are reading today, in light of covid-19. Our communities, the number of presumptive cases, the exponential logarithms that predict "points of no return" to exceed hospital capacity, and the predicted mortality rates, both mortality for covid-19 but also mortality rates for other life-threatening events like heart attack that are increased because hospitals reach capacity and clinicians and beds are unavailable, this news is a difference in degree, not a difference in kind, from the one-on-one giving of diagnosis between a doctor and those within their care.

"Adam," I am asked by folks facing cancer, "What now?"

In simple terms, this is my response: Get back to doing something that feels like "you," just as quickly as you can!

In the hospital after brain surgery, and then in an inpatient rehabilitation hospital where I re-learned to walk, bathe, feed, and dress myself, very little of my life looked like the guy who dribbled a soccer ball outside with the kids or littered the countertop with books and journal articles to write papers for grad school.

I was on a locked brain trauma unit. I was using a wheelchair. My family could only visit on limited hours. Even the clothes that I was used to wearing didn't fit because my body had swelled because of high-dose steroids to control brain swelling.

But I could read, and I could write, and I could continue working out the details of the philosophy of

science literature I had studied in grad school.

Clearly this is a niche market! What feels like you may look nothing like this! But what's important is that feeling like my life was totally disrupted, I could reclaim some of the activities that felt normal; that felt like me.

So as you scroll past the alarmist articles, please for your health and the health of our communities, be informed and take action! But if you're feeling overwhelmed and distressed; if you're feeling like nothing is normal. If you stare at yourself in the mirror and wonder, "What now?"

Try doing as much you as possible, and you may find that when the world is disrupted and you must reorient your life, you can trust that your values, goals, and purpose will carry you through.

This post originally appeared on Glioblastology on March 23, 2020. It is republished with permission.

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