A Voice for the Long-Term Cancer Survivor

I've lived with brain cancer for several years. How can we better serve long-term survivors, not just the newly diagnosed?

September 19, 2023 By Adam Hayden

Burning Hot Takes

In the past couple months, I've posted two brain cancer hot takes. The first was a reminder that we're not "battling cancer," and I don't think that is a useful metaphor. This hot take earned me some criticism from within the community. Whereas I see our effort to endure the disease and grow along the way, replies to my post reminded me that framing cancer as a fight is a rally cry for many of my peers. Fair, and I've tried to maintain that whatever framing is useful to us, it's our patient right to employ it—even if not the preferred point of view for others.

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The second hot take is the basis for this post: Long term survivorship is lonely. The community would be good to begin thinking about serving long term survivors, not only those newly diagnosed, newly recurrent, or the loved ones of those deceased. For long term'ers like me, living with a brain tumor for several years, you are who I have in mind when writing this post. Everyone is welcome here, but it's my long term peer group who I seek to be in dialogue with. My years of survivorship have not included recurrence, and so, for those who have lived several years with a brain tumor and have experienced recurrence, I'm not sure whether you'll relate to all of what I say. Mileage will vary I guess.

Excess Distress

I was diagnosed at 34 years old. Symptoms started when I was 32. That's young. I had a gut feeling that something was wrong, but it would take 15 months to finally get a scan and a diagnosis. At our first meeting when treatment began, a radiation oncologist looked right at me and said, "You do know you're going to die from this, don't you?"

This is not to elicit your sympathy or to admonish a doctor. That's irrelevant to this post. I'm just explaining to you that in otherwise good health at 34 years old with a job, spouse, a condo, and three kids, a surgeon took a bone saw to my skull and shortly after, a doctor told me that I would die.

That will fuck you up.

I'm four months into my 42nd year, and so, from symptom onset through today, I've lived with a psychological state of uneasiness for ten years—a state of persistent distress.

Excess distress, I'll call it.

Bathroom selfie on one of those reflective nights of excess distressAdam Hayden

I think about the “excess death” measure used over the past few years to gauge the true impact of covid. Yes, people die, but these are the excess deaths that didn’t have to happen—the excess deaths beyond the projected baseline count of deaths for a given period.

Life confronts us—each of us; all of us—with times of fear, loss, distress, anger, grief, emotional dysregulation, and anxiety. I hear that ‘trauma’—the word—is overused these days. I don’t know about that, but I’d say that trauma from many sources, or I should say, no matter the source, trauma manifests in the physical. The body keeps the score. “Your issues are in your tissues,” my spouse told me that her yoga coach often says.

And I think for us sick people, we can measure the impact of our condition in my rather unscientific excess distress heuristic. Someone told me that some of my anxiety reminded them of a mid-life crisis. No, a mid-life crisis is a projected baseline anxiety for a given period. Life limiting illness is excess distress.

Long Term Loneliness

The brain tumor community splits into extremes: grieving, loss, and uncertainty or overcompensatingly energetic and ready to fight. We either privately hold our grief to shield the newly diagnosed, or we’re a “brain cancer warrior” ready to “kick cancer’s ass!” There are those who must walk away from the community to process their grief; to get a little space. And there are those with nervous energy who dive head first into the community with walk/runs, swimming, cycling, and posting inspirational quotes.

As for me, I’m just tired.

I’m a long term survivor. And neither am I grieving, nor am I up for a fight. It’s lonely out here. I think the deal is that I’ve actually managed to more or less come to terms with my diagnosis—yes it takes this long. Learning to live with brain cancer makes one a witness to others. An empathetic witness. One who can sit and be present with one who is suffering to give value to the experience and help others make sense of what is happening. But here’s the deal, the tools to move in the direction of acceptance include mental health care, supportive community, access to top notch oncology care, and, the one thing that you can’t shortcut, time. I’ve had seven and a half years.

Because time is a finite resource for those living with brain cancer, the more of it you have, the fewer fellow witnesses are with you along the way.

We’re back to the extremes: Someone always recently died, and someone is always newly diagnosed: the loss and the nervous energy; the grief groups and the kick-cancer’s-ass crowd. But for those who limped along, long enough to get some perspective and wisdom, our needs are different.

Independence and Isolation

Several years ago I wrote a blog post titled “Independence and Isolation” that described the paradox of desiring independence but discovering that with independence—toileting without assistance, managing seizures with medication, using an assistive device to avoid falls—comes isolation—fewer visitors, you’re trusted to stay safely at home while others are away.

You’re thrilled to shower without a nurse or aid holding you up, but now you’re left at home for hours at a time because the world actually goes on. Independence and isolation. I’ve learned how prescient that post was so early after my diagnosis.

I guess I’m totally independent now, or something. I travel alone when the flight is within a couple hours from Indy and/or my stay away is only a night or two. I work a pretty typical (remote) schedule. I prepare most of our meals at home, and because of Whitney’s work schedule, I get the kids up and off to school every weekday. And this is all very good! But when I tune into what patients are up to, it’s often treatment-related. OT/PT, going for radiation, just finishing or just starting a chemo cycle, maybe recovering from surgery. When all of these things are years behind you, you begin to feel out of sync with the community that you know and knows you best.

Most of my (non-brain cancer) friends haven’t had a bone saw to the head.

Insider-Outsider

Living so long with brain cancer is hard to explain. I can be more precise, living this long stable with brain cancer is hard to explain. Two major issues shape the experience. First, being a long term survivor sets you apart from the community. “What’s your secret?” is a constant question that I’m fielding. More personally, it’s hard to write posts like this one you’re reading. The easy label to apply is “survivor’s guilt,” and this is right, as far as it goes, but we should be careful not to assume we know what our labels imply.

Each month I’m introduced as a co-facilitator for our monthly brain tumor support group: “After being diagnosed with glioblastoma in 2016, Adam used his background in philosophy to find new purpose for his life.” While true, that 2016 date hangs over my head during that call. While others share news of their recurrence, their diminishing options for available therapies, or announce the “heavenly birthday” of a late spouse, here I am month after month, year after year. Sure, intellectually, everyone on that call wants to see me remain stable and continue to show up; exactly how I feel about our call attendees who recognize years of survivorship. But telling yourself this and freeing your body from holding this guilt are different projects.

Your issues are in your tissues.

It’s another independence-isolation paradox. What makes me good on those calls is the time and experience I’ve had to see other people living with a brain tumor or caring for someone who is,

and to learn how to view the illness through their eyes, so far as my empathy and moral imagination allow me to. Depersonalizing my experience makes me a better facilitator, but this means compartmentalizing my experience and trying not to let it seep into my co-leadership on those calls. Where I can be useful ("Yes, I had an awake craniotomy, and here is what I'd suggest…"), it's good to draw from the well of personal experience, but when my emotions detract from others or competes for the attention or support that a group attendee seeks, that's moderator's privilege and should be held in check through self awareness and, more importantly, knowing where to seek support and not pursue it in the wrong places.

Like the long term survivor that stands outside of the community norms, my facilitation role necessarily places me outside of the experience I seek to facilitate for the attendees. I facilitate support for others in those meetings, and I do experience reward and meaning-making; though, it would be inappropriate for me to seek support in that setting.

Death by 1,000 Papercuts

There's no such thing as a good brain tumor, and everyone's brain tumor experience is unique. These are the two lines that maybe I say most often. These, and, "Well, that's just like, your opinion, man," but that last one doesn't have anything to do with brain tumors!

What's frustrating about my brain tumor experience is how manageable it is—but not all the way manageable. I'm not that sick, but I'm sick enough. I'm suffering death by 1,000 paper cuts.

My motor impairment means I'm frequently off balance and hyperextend my knee every few steps, my proprioceptive deficit means I stub the toes on my left foot at least daily on a door frame or peice of furniture, I'm off balance in public, leaning into my cane, and I become transiently dizzy or disoriented every so often. I don't drive because of seizures, so anything outside the house requires a ride from friends or family or an Uber, and if attending something outside the house, I'm less able to just leave when I want. I may escape my isolation, only to confront dependence. I am a proponent of recognizing our deep social needs and interdependence, but those are counter cultural views in tension with the shared setting of individualistic, neoliberal meritocracy.

We are a product of our lived experience and our lived experience is necessarily shaped by social factors.

The issue here is that my impairments are not in any way significant on their own. And yet, taken together, day after day, in tension with America's bent on individualism, we don't have a mechanism to validate the daily lived experience of someone who struggles to find ready-made community. In the community of a rare disease, the long term survivor is in a yet even more rare subset. Where is the voice of the long term survivor.

A Voice for the Long Term

I said something earlier about my perspective on survivorship: endure and try to grow along the way. Facing the frustration of the moment, maybe the next step is to cultivate a voice for the long term survivor. It’s lonely out here, but we have wisdom to share.

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