The Brain Tumor Hot Take That Nobody Asked For

It takes a long time to truly accept a diagnosis like brain cancer. Our bodies and brains remain convinced that we can recover and get back to life as usual, but rarely is this the case.

October 23, 2023 By Adam Hayden

“The a brain tumor hot take that nobody asked for,” I tapped out on my phone one day recently. I’m not a fan of appealing to dictionaries to frame up an essay, but Google returned a decent one for hot take:

> A piece of commentary, typically produced quickly in response to a recent event, whose primary purpose is to attract attention.

I guess that gets it pretty right. I continued tapping, “The general brain tumor emotional landscape splits into extremes: fearful, uncertain, and grieving or overcompensatingly energetic and ready to fight.”

A friend replied to the Thread after posting, “Why not both?” And that’s a good point. Things are rarely so discreet or dichotomous, we often hold conflicting emotions at one time. My spouse and I have an inside joke that we call “The shovel protocol.” This came up after a talk that I gave to the palliative care department at a local hospital. Following the talk, Whitney and I hung around and chatted with a couple of the physicians. We were only 18 months or so, maybe two years, after my diagnosis, and by the population statistics for my disease, my days were numbered. We asked about so-called “death with dignity” legislation, specifically raising that in Indiana, our home state, this type of law isn’t on the books, and so, did the physicians have suggestions about residency requirements for other states.

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must continuously improve transparency and dialogue in patient-provider communication.

“Take it easy,” was the reply, or something like that. Whitney works with these doctors, so we could be a little friendly. I had just delivered a talk after all, on my feet, energetic, stitching together ideas from philosophy and my lived experience with illness. In other words, I wasn’t near death! This was five years ago, so clearly we didn’t need to be calling for last rites! And jokes aside, Whitney and I are proponents of this type of legislation that recognizes the patient’s autonomy—though we didn’t need to be having that conversation then. The fact that our minds were preoccupied with plans for the completion of my life long before we needed to be is a reminder that prognosis shapes decision making, which is not a call to withhold prognosis; rather, we must continuously improve transparency and dialogue in patient-provider communication. That’s the lesson! More information is always preferred. It’s our lives on the line, and I encourage clinicians not to make the decision for patients whether they’d want to hear the information.

Leaving the hospital following the talk, Whitney and I were discussing death with dignity, and she said, “Well, I guess when it’s time, I’ll just have to take you out back and hit you upside the head with the shovel, then bury you with it.” We both laughed and laughed.

Hence, the shovel protocol!

Here’s a great story, when Andrew Joseph from STAT News visited our family to write up a story about this pretty young dad with brain cancer who was giving talks all around the country and blogging about it, Drew was interviewing us in our kitchen while we cooked dinner. I had been speaking with Drew on the phone weekly in the several weeks leading up to his visit, and I felt really comfortable with him. We’re still in touch, and I call him a friend. During that interview in the kitchen, Whitney mentioned the shovel protocol, and I remember exclaiming, “Boonnggg” to mimic the sound of a shovel banging me on the head! That made it in the STAT News piece, so now Whitney is implicated if I ever go missing for an extended period!

Anyway, the point of all this is to say that the shovel protocol is the perfect example for holding two, conflicting emotional states at once. When we’re crying, we may say, “Get the shovel!” We laugh through our tears. So yeah, things are never quite so discreet or dichotomous!

Back to that social media post, I continued to compose my thoughts:

> There isn’t a recognized space for long term survivors to process their emotions, which are not grieving, but neither are they up for a fight
>
> Us long termers only very recently came to terms with our diagnosis, and tragically, not many came before to guide us

That was the thrust of the post: Most brain tumor survivors are either newly diagnosed and ready to fight or completing their lives, filled with anticipatory grief. Us (really) long term survivors don't neatly fit in either category. Even at a couple years out, the setting for this story with the palliative care team, we were inquiring about death with dignity. At 18 months post-diagnosis, my radiation oncologist told me, "Congrats on becoming a long term survivor!" He didn't know that half of it.

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Long term survivors fail to fit in clean categories. It takes a long time to truly accept a serious diagnosis like brain cancer. Maybe, though I'm speculating here, we're encountering a phenomenon that is nearly tautologous, meaning that to accept a diagnosis means also that someone is a long term survivor! In other words, acceptance neither comes quick nor easy—we can't hack our way to acceptance.

Our bodies and brains remain convinced that we can recover and get back to life as usual, but rarely is this the case. If not physical fatigue or impairment, it's aphasia, or difficulty with speech; if not speech, it's seizures; not seizures, it's mood disorders. You get the picture. We have to live into a new way of being before we can come to terms and accept that way of being. Long term survivorship isn't counted by months or years only, but instead, maybe we should count long term survivorship not as relative to total life expectancy or by an arbitrary point after diagnosis. Maybe it is best to count long term survivorship by long term stability, in one phase of the disease trajectory.

The days of strict diets, active regimens, and consuming any and all information that I can find are past. I'm 20 pounds heavier, quicker to crack a beer, and I chalk up survivorship to biological dumb luck, not Rick Simpson Oil. Admittedly, this isn't a normative ideal. Maybe I'm just a grouch (NSFW, lots of expletives in the link).

The really complicated thing about this, especially in cancers with a grim prognosis, is that the longer we survive, the more friends we say goodby to along the way. This steady-state of loss is especially concentrated for those who have chosen to become active volunteers or advocates in the community, which you should totally do, by the way! Don't let my rather dour post stop you. Volunteering as a brain tumor advocate is a great reward that I am privileged to enjoy. Leading a monthly virtual support group, lending my lived experience to a smartphone companion for people living with GBM, traveling to DC, and organizing our local community to raise $80k for brain cancer research through the Tumor Takedown Tailgate are incredible gifts to me and my family.

And, not but, always an and. And, the ironic thing about this disease is that when you reach a

handful of years of survivorship, the mentors to guide you are few and far between. We assume that the need is most at the beginning (diagnosis) and at the end (death), but the middle could use some help! Wait. What's this, another and? And herein lies the way forward. I'm here, and it can be lonely, but maybe me and some of my 5+ year out buddies can be the ones to stick around for the next generation of long term survivors—maybe you're getting here and seeing this post. I'll be around for you. At least until my wife comes running with the shovel.

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