Tumors in My Brain and Words Off the Leash

Brain cancer blogger Adam Hayden strays from the expected path: “It has been tough to write recently.”

March 25, 2024 By Adam Hayden

I asked you in an Instagram Story which topic to blog about next: “Work, Rest, and Meaning” or “Getting Ready for Treatment.”

In that very unscientific, by no means statistically significant poll, “Work, Rest, and Meaning” won out roughly 60/40. Good enough for me.

And I agree anyway.

That’s a topic that I want to address.

I’ll even draw back the curtain, I already have that post 90% completed, and did so before I suggested the topic in the poll. Work smarter, amiright? That post still sits nearly complete in my drafts folder.

To give the whole game away, before these posts hit your inbox they’ve already been tested on TikTok or Instagram Reels, or outlined in a Google doc, or developed from my favorite Notes app folder, “Pseudo Twitter,” that I started after leaving Twitter/X and needed a place to brain dump 280 characters at a time. Sometimes Pseudo Twitter ends up on real life Threads, but I’ll save the commentary for the paperback release.

Despite it being a fan favorite and more or less complete, we’re not going to worry about that work/rest topic tonight.

Tonight, I’m exercising my creative license to follow my words off leash, down the worn path, sniffing at flowers and bugs, barking at squirrels, tilting my head at whatever is scurrying beneath the ground cover.

It’s been tough to write recently.

I had really hit a stride around the time of the first bad scan back in November. I was producing multiple posts each week, some about new diagnostic tests, some about treatment options, one

about a new imaging study I had enrolled in, and I heard recently, after my (really, our, with Whitney) inside jokes post that “bring towels” has now made its way into one of our favorite couples’ lexicon. I couldn’t be happier about that. May it be my legacy!

I mean it when I say it: It has been difficult to write recently.

I think one reason is owing simply to the fact that my brain has been swollen with inflammation, causing pretty debilitating symptoms, and now I’m medicated with yet even more antiepileptic med and steroids on top of that. Oh, and in the liminal recovery space post-chemo cycle, before the next starts in ten days. I didn’t say that I would write about work, but at work, I run our communications, so a lot of the creativity that I have in the tank drains dry by the afternoon.

On top of all this, I do have growing tumors in my brain, which may have deserved mention before anti-epileptic meds and steroids! Whitney and I had drinks with one of my uncles years ago after he returned from a running trip in Colorado. I asked him if it was the altitude and thin air that made running more difficult. “No. It’s the fucking mountain you’re running up,” he said with signature dry delivery.

Vimpat and Decadron? No. It’s the fucking brain cancer!

What I do want to say tonight is that:

People are kind.

We are loved.

I am frightened.

And I am reaching in the dark to know what next step to take.

I’ve addressed the theme in this blog for years that in health care, information is currency, and patients are impoverished. In theory, we may call this epistemic injustice. This manifests as physicians withholding information from patients, for fear we “can’t take it,” or failing to take our symptom reports seriously, owing to our failure to articulate them in clinically relevant language. My anchor for this discussion has been the physician and narrative medicine innovator, Arthur Kleinman, who discussed the process of doctor’s taking “illness problems,” family, finances, work, etc., and translating them into a narrow set of technical issues: disease problems. But friends, it’s more accurate for me to say, “I’m sick,” and not, “I’m experiencing disease.” Like, I don’t feel well. I wouldn’t say, “Boy, I’m really feeling the deletion of the glucose-proton symporter SLC45A1 and truncal alteration.”

Epistemic injustice may also refer to the general condition of patients to not have access to the information and clinical judgment that a physician does, and so, we often second guess what we’re experiencing. When I couldn’t get out of bed last week because of a terrible headache, it was actually Whitney who phoned into the doc. “I’ll be fine, just leave me in bed with the lights off.”

Several hours later, only twenty five minutes after my first steroid dose, I was already sitting up! Whitney knew to call. I didn't want to "be a bother," whatever that means.

"What trial would you do if you had a recurrence?" This question is one I hear often, and have heard often, as a somewhat known patient advocate in the brain tumor community. I have always had a grip on the latest funded research, who was opening trials, what investigators were getting big NIH grants, what institutions were recruiting top docs to build out their new neuro-oncology practices, and so on.

Then we had a bad scan. And ruled out things. Then ruled things in. Then it was like, shit, this isn't localized disease. This is actually quite serious. Then people started saying things in months. Like a newborn, at some point it's six weeks, then three months, then under a year, then 18 months, the way we talk about time changes, and those divisions of time change us, but time grows in new life and shrinks towards its completion. I was told the same stuff on June 10, 2016, and I launched into the most disciplined nutrition, chemo, and supplement regimen I could. Hearing these things now, beginning in February, I'm like, "Somebody get me a beer."

I've signaled this for a while: Long term survivorship is endurance, and you just get tired. Sometimes you need to lie down on the trail and let the settled dirt cushion your belly and snack on a peanut butter chew.

Don't worry, friends, despite the more tired admission, this post isn't my white flag. We haven't even had the first scan post-first chemo cycle. Plenty of living left to do! But while most of us haven't needed to think much about brain cancer for eight years, I never really stopped, and now it's yelling at me to pay attention, and I'd rather ignore it.

I want to spend more time with my illness problems, without the distraction of my disease problems. I never understood why physicians so often relinquish control over their care when they are diagnosed with serious illness. As a patient, speaker, organizer, board member, and pretty fucking knowledgeable non-specialist, that decision has become more clear. There can be something better about not knowing what something means than knowing exactly what it does. Who wants to be impoverished now?

This blog post was published by Glioblastology on March 19, 2024. It is republished with permission.
