The Next Chapter: Cancer Recurrence

It’s surreal to consider the Adam of diagnosis in 2016 and the Adam of diagnosis in 2024, writes the brain cancer blogger and advocate.

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“Based on all the testing that we’ve done, we can conclude that this new growth is likely recurrence of your glioma.”

The same doctor told me seven and half years ago that, “It is extremely unlikely that you will not have a recurrence.”

Guess he was right!

These conversations bookend my first chapter of survivorship, from newly diagnosed through the standard of care protocol, rehabilitative therapy, my return to work, mental health care, maybe 50 or so scans, and now this recurrence. Candidly, the seven and half years that we’ve lived with cancer (truly a “we,” a cancer diagnosis impacts the entire family) is a lot longer than we imagined that we’d have. Each morning that I walk the boys to the bus stop is a reminder that our youngest was less than a year old when I was diagnosed. We weren’t sure whether he’d have well formed memories of his dad. Today, I get to scratch his back for bed nearly every night. Our oldest is a sixth grader. I played Mario Kart 8 Deluxe with our middle guy a couple hours ago. He won. In my defense, my diagnosis date coincides with my permanent pedestrian status. Ongoing problems with partial seizures keeps me out of the driver’s seat. I call shotgun.

Hope is hard to come by these days. I mean generally. Have you seen it out there? The world, I mean. Boy, it’s a shit show! In the brain cancer world, we have hopeful stories, hopeful trials, hopeful clinical outcomes, hopeful research in the pipeline, but hope is an exercise, and sometimes you’re too worn out to get in the reps.

In the past few weeks, I’ve had three CTs, two PETs, four MRIs, an echo, lab work, and the emotional turbulence of a few uncertain diagnoses before arriving at this one. When you turn 40 years old in life, everything feels like it happened “a few years ago,” and when you turn seven brain tumor years old, life is measured in scans more than anything else, and my scans have suggested to clinicians everything from stroke to meningioma to venous malformation, to glioma.

I gripped my Walkman on the bus where I faced some bullying with Green Day’s Dookie as my soundtrack for facing some jerk kids. Of course, I know better now that being a jerk is often a mask for fear or uncertainty. Dookie, the album, turned 30 this year, so my world feels like it’s becoming

obsolete. Though, Green Day's newest album just dropped a month or so ago, and it slays. Growing older puts me, oddly, out of touch with myself because I consider myself, well, I don't know, younger. Sometimes I'll meet another dad and they'll be in like khakis, a collar shirt, and some wingtips, and I'll think, "Dude, he's grown up. Oh shit, he's gonna shake my hand. Straighten up your back"

A brain tumor diagnosis jolts you out of the normal flow of life, I mean, the status quo life. Living longer with a brain tumor can place you out of step with the brain tumor community because we can lose a lot of friends the longer we live. What a strange case of double jeopardy: aging in your life and aging with a brain tumor. You're sort of a pariah in both settings. Don't get me wrong, I feel supported everywhere I am, but being in your early 40s with a terminal cancer is sub-optimal.

Back in the newly diagnosed times after my awake craniotomy (brain surgery) and a month-long stay in a brain trauma unit, I found something I didn't know I had: grit.

This go 'round I'm observing something else, and while I am not shamelessly cross-promoting blogs (see, I'm not even linking to it), I've been on a year-long expedition through an important identity marker in my life, writing two-bit commentary and stumbling through academic literature on a part of my life that has become increasingly important to me. This has proved useful, even if only accidentally so.

I'm not a big "the universe has a plan" type of guy. In fact, I've always eschewed notions of a plan governing our lives from the outside. Divine intervention or everything happening for a reason … these frames have rarely been helpful to me. If that greater plan includes me getting brain cancer, that's a bad plan from where I sit.

Wolf Parade, one of my favorite bands, sings, "I would say, it's in G-d's hands, but G-d doesn't always have the best goddamn plans, does he?" Just to have it on record, about that "does he," I would not assign gender to G-d, but that's another discussion entirely!

Exploring this important part of my identity in a more focused and dedicated way through this mysterious other blog was an outlet to get away from patient advocacy for some time, an indefinite amount of let-me-stop-talking-about-freaking-brain-cancer time. I intentionally served only my most important responsibilities in the brain tumor community: service to a board of directors and service to a wonderful virtual community, but I was taking a step back. In the space created, I took up this other topic.

The bad scan in November came and now in February the official word that this isn't a mere anomaly, or a late effect from radiation therapy, or a more manageable type of non-malignant tumor called a meningioma. No, this is recurrence. Strangely, it's this recurrence that reminded me of the obligation of advocacy, for myself, with others, and on behalf of the next generation of patients. A deep exploration of my personal identity collided with news of recurrence. It was then that pieces fell into place.

My time getting clear on who I am, or who I am at this stage in my life, ran head-first into brain

cancer, when that was what I was trying to avoid. It's the identity marker that imposes itself onto me. This time, I have spent the past year trying to figure out who I really am. This reminds me of another song, "You want to know who I really am? Yeah, so do I."

Getting clear on who I am, or at least taking some meaningful steps in that direction, has prepared me to encounter tumor treatment. Again, resist the urge to explain this by appeal to a greater plan. For me, life is happening, and it's our part to make meaning in real time by bringing our experiences, goals, values, and relationships to bear on life. I definitely see how that can feel like a bigger plan when it clicks. I tend to think more in stories than in providence. Candidly, I'm not sure how different those two things are.

It's surreal to consider the Adam of diagnosis in 2016 and the Adam of diagnosis in 2024. Now I'm harvesting the benefits of some true self work, which may be far from finished, but further enough along to take comfort in it. I'm ready for the next round of treatment, so we close the chapter on the first part of survivorship, and we open the to the next. Recurrence.

Hope may be hard to come by these days, but I've got enough of it, and I'm settling in for chapter two.

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