

Life With Cancer: Between the Inevitable and the Abstract

Blogger Adam Hayden knew his brain cancer was 99.9% coming on back at some point. And now the bad scan is here.

February 7, 2024 By [Adam Hayden](#)

“It is extremely unlikely that you will not have a recurrence.”

One of my grandads died around 90 odd years old. We should be so lucky! A mild mannered man from Terre Haute, Indiana, he spent his career working for the railroad, a good union job that afforded him a house, kids, and a retirement nearly as long as his career!

I guess multiple myeloma was the thing that did him in, and this is the right result if you ask me. Now hold on! Listen to what I mean when I say that.

I loved that man, his love of hats, his index cards that he'd keep in his front shirt pocket with jokes, funny stories, or interesting facts that he'd been accumulating and wanted to be sure he shared with us when he'd visit. In the last several years of his life, after grandma had passed, he became quite the Seinfeld fan; although, he did call it “Steinfeld,” and he thought Elaine was “Ellen.” No matter, he and I could recall our favorite episodes with each other when he'd make the schlep from Terre Haute to Indianapolis about every other week.

As a kid, when we'd visit from Arizona and stay at grandma and grandpa's 1950's Terre Town bungalow, grandad would pull down big train atlases. He'd explain which engine was what, where the tracks lead coming out of this station, and how he'd have to pull these big levers to avoid a railroad collision. He was in the Civilian Conservation Corps before all this, turned away from the draft for medical reasons that showed up on his physical. He didn't like not serving, so it'd have to be the CCC. And before that, his own dad had died when grandad was young, and he left school to work hard and care for his mom and sister.

He used to hitch from Indianapolis to Chicago to Cincinnati. “If you were in a uniform, people would give you a ride,” I remember him telling me.

Courtesy of Adam Hayden/glioblastology.com

Before family consensus found it safer for everyone involved that he no longer drive, he had been pulled over ... for going too slow.

"Sir, I pulled you over for driving too slowly. Can you tell me why you're going so slow?

"I just don't have anywhere to be at the moment," he replied. May his memory be for a blessing.

Oh yeah, so multiple myeloma. It's a blood cancer, and right around the time grandad was dying with it a new drug had just entered trial, with promising preclinical data. The care team had offered this to extend grandad's life by maybe another few months. In family consultation, the decision was made not to put a 90 year old man with a failing body on a brand spankin' new

clinical trial. The man was in his 90s, for Gd's sakes! He lived a long, productive life, had a good family to show for it, and by all accounts he had made peace with things.

Anyway, multiple myeloma got him, and that was the right result. See what I mean?

Seven goddamn years with this son of a bitch in my brain is getting old. Some days it's a slog, and some days you'd have to pinch me to remind me that I have cancer. Before you get too pollyannaish about all that, there isn't a single day that goes by without my left leg, weak with atrophy and out of range with the cell tower in my brain on account of a big hole being there, doesn't topple me over, slam itself into a door frame when entering a room, or hyperextend my knee and lock itself up. "If I catch myself on the wall, does it still count as a fall?" I asked Whitney a day or two ago.

All is good.

I'm just saying, seven years with a thing; that thing hasn't gotten any better. I've just gotten better at handling it.

Whitney and I have been handling it. I mention this pretty often, but we've been married longer with brain cancer than without. It splits our marriage just about 50/50. Pre-BC/Post-BC. Like BC and AD, right? Pre Brain Cancer and In the Year of Our Tumor.

We've surely had the occasional anomalous scan. We've had the big worries and extra scans to track down a troublesome area on an MRI, but as quickly as we circle the wagons, necrosis, blood artifacts, late-effect radiation damage; it works out. No doubt that we're always super grateful for good news! But live in that space with me for a minute. This cancer is 99.9% coming on back at some point, so when we get a bad scan it's never like, "What could this be?" It's always, "OK, here's the one we've been waiting for." This is not negative, glass half empty thinking. This is simply the reality of the disease, borne out in doctor's offices, research papers, and the deaths of those as powerful as a sitting [Senator](#) or the (then Vice) President's [son](#). This disease even got the greatest ever prog [drummer](#).

This is all to say: [Strikes and gutters, ups and downs](#) with brain cancer, man. Here we are again with another bad scan. But this time, pretty definitely something's going on. Like, I'm getting way more tests than I'm used to. It's circle the wagons time, and I don't think we'll luck out with, oh your brain has chronic microhemorrhages, no worries. (Truthfully, I'm not sure chronic microhemorrhage is a no worries situation, but I'm also embellishing on the radiologist's exact words.) This time we've got tumor boards and second opinions and treatment ideas and surgeon consults, and so on. In short, we're dealing with the actual bad scan that we always expected would come. It's here.

I'm living through the thing that felt both inevitable and abstract. Mortality is climbing the charts for inner monologue again. It's surreal, or I'm overreacting, or both. I always thought things would get frantic, and let me tell you, friends, there are plenty of opportunities for frantic on the horizon. Everyone's got a plan until you get punched in the mouth. Tyson said that, so let's feel

comfortable cherry picking. Anyway, it's not been frantic, it's been a chore. This test, that test, another IV, more gowns, remember the one about my pants [dropping](#)! LOL

I really expected something to happen when a doctor told me a mass was growing in my brain. Like we'd shift into some sort of memory making marathon of existential proportions. Instead, it sort of feels like I just don't have anywhere to be at the moment. I mean, we left the hospital the other night, grabbed carryout, and made sure the kids did their homework. That's a very normal crisis.

After all, "It is extremely unlikely that you will not have a recurrence." I like likely and unlikely, and if this then that, and probabilities, and statistics, and updating your priors like a good Bayesian. Granddad pulled those big levers and avoided catastrophe, but it was always only a job. You don't think about the wreck when you're punching the clock. I guess we're on the clock, and I'll report for more scans on February 1st. Pull some more levers; avoid some collisions; grab carryout on the way home. Either way, the worst scan or not, have you tried the new falafel place? It's good, y'all. This is living between the inevitable and the abstract.

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