

It's Been "0" Days Since Last Incident

Hi, my name is Adam, I have brain cancer, and I overthink everything. What's the significance of diagnosis day versus a cran-iversary?

April 2, 2024 By [Adam Hayden](#)

The diagnosis anniversary is one of the more arbitrary dates that we cling to in patient communities. What if the most important date that we should all invest in, is today?

Hi, my name is Adam, I have brain cancer, and I overthink everything.

What is the diagnosis date? I mean, sure, the date we were diagnosed, acknowledged annually, but not only annually. My diagnosis date was June 10, 2016, so all June 10th's feel some sort of way, and so do other 10th's and other June's, and other people's diagnosis dates remind me of my June 10th. Or my surgery date, May 26, or my first ever MRI scan, May 13, a Friday the 13th, for whatever that's worth, but I only ever include the Friday the 13th connection because superstition masks random chance, and nothing is more frightening than random chance, even Friday the 13th.

I guess what I'm saying is that this entire stretch from Stat MRI order on Friday the 13th, 2016, to neurosurgical consult the following Monday, May 16th, the functional MRI scan for brain mapping of my eloquent areas on May 24th, then the awake craniotomy (brain surgery) on May 26th, transfer from the surgical hospital to admission in an intensive rehab hospital on May 31st, and discharge on June 24th, the diagnosis date on June 10 is less a punctuated timepoint and more a season of grief.

In this, the diagnosis date is probably the date that matters the least to me. The date of diagnosis is a date that information is shared, and so, from the perspective of shared decision making, patient autonomy, medical ethics, and quality of life, there are few days more significant than the diagnosis date. Though, if we're weighing significance through the lens of receiving life altering medical news, the diagnosis date is it.

But for all that happens on diagnosis day, the only change before diagnosis and after is the information with which you are now burdened. Nothing actually happens on the date of diagnosis.

Now, I only sort of half mean this, if that. Our bodies keep the score, and whether it's physiology or psychology, we're all wired up in these bodies, both powered by them and restricted to them, and to receive life altering news is to physiologically change our circuitry. Stress hormones and signaling pathways, heart rates and blood pressure, sweaty palms and anxious breath, the

information shared and received on a date of diagnosis is not exactly how I've said it, that "nothing happens." To wit, a lot happens.

I just used "to wit." Hot damn if I'm not a good writer.

The diagnosis date is this day that changes everything, and yet, functionally, it's a day Whitney rolled my very weak and impaired self into an exam room at the IU Neuroscience Center to hear some information, and when presented in these ways, you can see that this day pales in comparison to the several days before it: undergoing my first ever MRI, undergoing a neurological exam administered by a neurosurgeon, undergoing my first every functional MRI, oh, um, undergoing fucking awake brain surgery. Those are days where something happened. On the scale of "sit in a wheelchair and listen" to "have your skull opened with a saw and your brain cut into while you're awake," you can see why I am taking pains to unpack the distinction I'm driving towards with respect to the diagnosis day. Namely, maybe you see why I say the diagnosis day is the more arbitrary day to which we apply significance. A day when nothing, well, "happened."

But I've just lied.

The diagnosis date is a day we cling to because, arbitrary or not, that date marks the start. It's a total fabrication to say that someone's illness starts on this date. My brain tumor was likely a slow growing tumor that, at some point during its disease trajectory, underwent a malignant transformation, began growing aggressively, and caused the worsening symptoms that ultimately brought us to that first Stat MRI order, which is all to say that I was unwittingly living with some sort of brain tumor for at least several months, if not longer, before the actual clinical presentation showed up. So to say, "Hey, I was diagnosed on June 10," is exactly right; it says so right there in my clinical history, but nothing "started" on June 10 is I guess what I'm saying. My brain tumor could possibly have been diagnosed in a range of dates, within which includes the summer of 2016.

Does this make sense now? My general skepticism with respect to the significance of the diagnosis day? Maybe it's why I prefer to recognize the anniversary of my surgery, a craniotomy, as in, our cran-iversary. We eat a brain cake as a family, we have Facebook memories and cell phone pics from the day. I remember signing over power of attorney to Whitney in pre-op before getting rolled back for surgery. I remember sights, smells, and so on. I regularly rehearse these events in my mind's eye for fear of losing them or to remind myself it really did all happen.

See, even that rehearsal is assigning meaning.

If we took a few cleansing breaths together, scanned our bodies from head to toes, engaged in diaphragmatic breathing, cleared our minds, and sat with our thoughts, we could recall yesterday's walk to the mailbox, but if it were to fetch bills, who cares, and why would we ever do that? Rather, if that rip to the mailbox were to retrieve a letter of safety from a partner stationed overseas, we may find great value in recalling that stroll to the mailbox on that random day. But see this, that letter started its transit days ago, and so, to assign the meaning to the day you received it is not to tell the facts of the matter, but it is to incorporate the significance of the event

into our life story; the time that something marked a new status. Maybe not the genesis of the thing in the world, but the genesis of the thing in your lifeworld. Our lebenswelt, as the old Germans phenomenologists called it.

The diagnosis day is the day that life was flipped on its head, but it's not a day that anything happened. Right? Do you see the machinery I'm trying to bring to bear on this? Our lives were changed on diagnosis, but the world was not.

Life happens at the intersection of events and the meanings we make from them.

I'm driving myself into the ground again.

I

'm doing a lot of really cool things, too. I had a sort of "return" to giving an in-person talk this past weekend, and I immediately felt the affirming waves restore my soul to balance as I took a few labored steps onto the auditorium stage. I feel so at home there. So free. So willing to own that space and welcome others into what I have to share. I've been giving plenty of virtual remarks, and I am one of the most vocal pro-virtual assembly advocates you'll find. From accessibility, to cost, to convenience, to environmental impact, I'm so far on the side of virtual organizing that I'll pick that all day long.

And.

Fielding a live Q&A, in the hall, with in person participants in front of me, where I can tiptoe to the edge of the stage, manipulate my body, lean into a pensive question, or puff up my chest when I field one that is more pointed, I was reminded how at home I feel "lecturing."

But my vain efforts to bolster my confidence notwithstanding, I'm by and large driving myself into the ground. I'm rebelling against myself. I stay up too late, eat too much crap, pour a glass of wine when I could brew a cup of chamomile, and let myself off the hook for physical activity because I'm feeling fatigued or whatever.

I don't share this for my absolution.

And don't get all caught up in your feels about all this or try to tell me, oh it's okay, give yourself a break, it's all about balance and moderation. We all know this. I would guess that at least half of you could say exactly what I've just said: Not taking care of ourselves in the ways we know to be most beneficial for our wellbeing.

I hear you, friends. I read your comments. I love you all so much. I know your idiosyncrasies, and your backgrounds, and your tools for meaning making that you project onto me. We all do it, it's how we operate. Us human animals are prosocial great apes who evolved to live cooperatively for the common good, and that means all sorts of things socially, and so, while some messages sent to me of "bigger plans" and "everything has a reason" are anathema to the way I characterize my own experience, I acknowledge that when you tell me this, it's sincere, and I value sincerity.

So don't let me off the hook. Or tell me it's ok. I don't need you to. We're learning together here, friends, and sometimes it's ok to just say, "Adam, I liked that, it made me think, thank you." That's all I'm really after, to help us all think carefully about things.

But I am driving myself into the ground.

For me, it's vengeance.

My body betrayed me.

Who gets a brain tumor, seriously?

A doc told me years ago, "Just go home and have some ice cream," and I thought, "why don't you go home and stub your toe." I was so angry that in the face of terminal illness I chose to become strict, and that this doc saw that as a net-negative had me fired up.

As I've matured in illness, I understand the pervasive nature of these reward mechanisms that we manufacture to palliate our existential distress, and I understand the value of weighing quality of life that accounts not only for how to sensitize the body to chemo and radiation through complementary strategies, I also understand that often we do just need a big fucking bowl of ice cream.

Back in November, after the first bad scan, I committed to returning to a more diligent health routine. We have a couple of magnetic weekly menus, whiteboard, things like this, on the fridge door. On one of those I wrote "11/21/23." That was the date I returned to a health-focused regimen. Before we even concluded the recurrence of glioma, I already knew what it was, and I knew to best weather the coming treatment, I needed to restore my body's physical health, at least cut out some of the nonsense. And through the major winter holidays I maintained that discipline, until I didn't, and that's fine. Really. Part of maturing is understanding that our natures are not fixed, and for every time we choose one thing, we can always choose otherwise at the next opportunity.

Yesterday, last night really, just before bed, on my last lap through the house to check door locks and auto program the coffee maker, I stopped at the fridge, un-capped the dry erase marker, and scribbled "3/24/24."

On March 24, nothing happened. I mean, we actually hung out with Whitney's family at her parents' place, and it was a great day, but speaking casually, nothing, like, happened yesterday. But neither does anything happen, on the day of greatest significance in a patient's life, the day of first diagnosis; see how we're gathering the loose ends?

Nothing need happen in the world for us to allow something to happen in our lifeworlds. Maybe that's March 24? With my next scan in a few days on March 27, blood work, then contingent on that scan not showing explosive tumor growth or something else, we'll begin the second chemo cycle next week. Another five days on toxicity at a super high dose. It is not easy.

Getting ready for chemo is like training for the half-marathon you signed up for as a new year's resolution that finally catches up to you in May. Why are we doing this? No matter now, the bib is in your mailbox and the race is next weekend. It's time to activate resiliency and get myself right.

"3/24/24"

I chuckled to myself thinking of sitcoms and internet memes. When I broke my covenant with myself after that 11/21/23 date, I had erased the digits, leaving the slashes to plug new dates into the formula. I set dry erase pen to the whiteboard that said "__ / __ / 24"; plotting in yesterday's dates I smiled, "It's been 0 Days Since Last Incident."

Maybe today is another "day one." Yours could be, too, by the way, if you need it to be for some meaning that needs to be made from the raw materials of the events in your life.

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