Like Heartburn and a Hangover

How does chemo feel? Brain cancer blogger Adam Hayden offers an answer while contemplating time and five-day cycles.

April 11, 2024 By Adam Hayden

Day six is the toughest of the five day cycle. But I'm not convinced it won't be today. Today is day seven, and we aren't sure yet. My joints do ache.

This is all supposed to be a little funny because six and seven are more than the five days in the cycle, like turning up the volume to 11, we're counting outside the range.

If not clear, these days do not really belong. Seeing that for each chemo cycle during this phase of the protocol, you take the drug for five days, before a 23 day rest, it doesn't make a ton of sense to count a day as a six or anything after. It's five days on, 23 days off. There is no day six, is what I'm saying; unless that is "day one" of recovery. That makes sense.

Either way, day six was the toughest, and we're still waiting to see today after this cup of coffee.

No matter if we count it, don't count it, or call it something else, I've just felt shitty the past couple days. Terrible taste in my mouth like I ate something rotten, no matter how often I brush my teeth. And my teeth, they are sensitive to cold. I'm tired. Heavy. I'm constipated. My knees ache, which I guess could be chemo, or steroids, or I'm just living in an almost 42 year old body. By around 3:00 pm my brain wanders into a sauna and stares at me awkwardly with its towel barely covering its cerebellum.

I'm on chemo, and day six is the worst in the way that April is the worst month of winter in the Midwest because it still snows, and it's not even supposed to be freaking winter anymore.

I fielded a text the other morning from a solid rock in my life, maybe that was day three. "How do you feel?" "Like I woke up with heartburn and a hangover."

That's each morning on chemotherapy. At least, that's how it hits me. I'm sure individual results may vary. I was on this drug for a year between Sumer 2016 through Summer 2017, and now we're two months in for this year, with a total of twelve rounds showing on the physician's order. Another year?

If it works and you tolerate it, keep going.

For all we can say about the incredible advances in biomedicine, it often comes down to a little guess work, a little lab work, and the willingness to stay the course.

I'm a stay the course sort of dude.

Slow and steady.

One foot in front of the other.

I'm not in much of a hurry to get anywhere. I think this is really useful when a literal tumor is growing inside your brain because the default response is fight or flight. Taking a beat isn't a bad idea. I tend to be okay waiting; not having a plan. I do not exude indefinite patience like a fount of slow living, but I notice that I can have intention, I can have patience, and I can have trust.

That last one is key. When I say I'm not in a hurry, I mean this in a trusting way. I trust that I have the time that I need.

This is the wisdom of survivorship. I wrote a post a while ago about being a voice for the long term, and I think this post is one to tag with the same identifier.

I don't think I have all the time that I want. Obviously so. I do not want to consider that I may complete my life still wearing a ripped hoodie and Levi's 510s. Seems like a respectable age to die is with some Dockers in the closet. And those dress shoe sneaker things that guys wore after the facial scruff wasn't enough, and the clear-rimmed glasses thing peaked.

It's not lost on me that I'm at best only barely (barely) pulling off 510s.

When I was diagnosed, Gideon was 8 months old. Whitney and I had a conversation to discuss how we might build some memories so that he would have at least some imprint of his dad. Yeah.

We have a stack of National Brain Tumor Society, Head to the Hill, and Race for Hope shirts in our closet that Whit has a plan for when I'm dead. These are on my mind because we've been spring cleaning and this included our closet. The closet suggests your mortality. This is what is hard to understand on the outside. Cancer treatment isn't taking a ZPAC, even if it is five days. The mechanism of action includes the existential.

I have life insurance. I have a will, I have a Physician's Orders for Life Sustaining Treatment, a POLST form, for end of life decision making in the hospital. We've looked at states with death with dignity legislation. We've looked at sealing my dead body in a weird pod thing that gets planted, where I'll decay and grow a tree.

This is weighty shit, friends.

These are the sorts of things that, if you have been in our lives for eight years, you better know that these are conversations that we've had, because if you're here for me, for us, you need to

know the depths of concern that terminal illness will take you. You cannot know me divorced from these conversations. Sometimes it's good to just remind everyone that we're all living our lives, and we all have the sublime and the surreal, but my life really does include routine medical imaging for a deadly cancer, epilepsy, and now, chemo.

Sometimes the world suggests to us that we may be better off not saying the hard stuff, and so, I just wanted to say it. I'm good. But I'm not sure we're always serving ourselves best when we set our normative aim to the comfortable, quiet, and uncritically optimistic. Your boy has felt sub par, and it isn't easy to just figure it all out again after you've had eight years to figure out the first part. I know we talk about recurrence, and I've had trace imaging of disease on scans this entire time, but things feel a lot more like a new diagnosis than the continuation of something already going.

I'll say against all this, too, that I have continued to live! I've walked the boys to their bus stop every school morning, after Isaac started Elementary. I help with homework. We play outside, they tell me jokes, Isaac rolls his eyes at me, Gideon makes me scratch his back, all of this is a reason for joy.

See. This is what I mean by saying that I trust that I will have all the time that I need. I don't think that I have all the time to do everything that I want to do. There will be plenty left undone and unaddressed.

I trust that I have all the time that I need because I trust myself to make sense of whatever time I have. See it's like this. The time that I need is not for time to make room for all that I want to do, in five minutes or five years. It'd be nice if time bent to our schedules, but we know how ludicrous such an idea is. The time that I need is for me to fit into the time that is available, and the only time that is available is that which is unfolding in real time a t t h i s v e r y m o m e n t.

The time that I need is the time to be settled in this body, at this time, with this life, no matter how much time I have. I'm not really counting the time that's passing, at least not outside of this anniversary or whatever, and I'm not attempting to prognosticate any time remaining. It's plenty.

I mean only to say that day six is the toughest, and we'll see about day seven after this coffee, and these days don't even belong in the five day cycle. Life is bigger than the days we count. Even when the ones you count start with heartburn and a hangover.

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