

# Sick People Are Sick Sometimes; That's Ok

I finished the fourth monthly cycle of chemo, writes brain cancer blogger Adam Hayden, and I really have not been feeling well.

June 6, 2024 By [Adam Hayden](#)

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This post goes out to a dear friend: RK. This post would not have made its way onto the page without a recent conversation that helped me to tease out the discomfort I was feeling and put language to it. While thank yous are often inadequate: Thank you for that and for all the conversations we've had.

Let me give it to you straight: I really have not been feeling well.

I finished the fourth monthly cycle of chemo Thursday, with five days taking the drug and 23 days off to recover. It's been taking a little longer, and a little longer, and a little longer to feel recovered, and the chemo has me feeling pretty lousy during the five days and the subsequent several after that. My episodes of focal seizures are still around, and a couple nights ago I experienced a brief period of confusion following a small seizure, which isn't typical. Then this morning, I woke up and immediately hurried to the bathroom, where I became sick to my stomach.

It's hard for others to hear this.

Or at least, it's a little uncomfortable.

It's uncomfortable for me to write this. I'm a chronic underreporter of my symptoms. I worry constantly that I'm overreacting or medicalizing otherwise typical physiological events that occur in anyone who is aging and isn't getting into the gym very often. I've become so good at managing my symptoms, I no longer take them as impairments; no longer appreciate the stress of living in this body. Of course, I do live with impairments, and living with this body is stressful. I'm reminded of a meme I saw recently:

I'm built different.

Incorrectly, I think.

Sometimes I have to remind myself that I have literal fucking brain cancer. And this isn't like, "Oh,

I'm happy you feel well enough that you forget about your cancer." Instead, it's the I just tripped and fell down in front of everyone, "I guess I do have brain cancer" sort of reminder. Feeling a little unwell shouldn't be a big surprise, this is a very serious, very lethal, rare disease, but rare as it is, it's all I know, and I lose the reference point with "feeling well," if 'well' means typical biomarkers and functional health.

There is another reason that I don't like talking about my symptoms, and it's because who the hell really wants to hear it, anyway? I've been blogging here since October 2016. And the talks, the Reels, the TikToks, the fundraisers, the MRI Day Selfies (™). Honestly, who the hell wants to hear it anymore, amiright? I'm probably only projecting, but I question this more often than you'd think. I'd bet that other patients, care partners, advocates, loved ones who have endured cancer this long feel similarly.

I admit that I don't make it easy to gauge how I feel. I present with a very positive attitude most of the time. I genuinely experience a happy enough demeanor day-to-day. I've reached a feeling of wellbeing within illness. And when I'm not at my best, I know how to force myself to shower, comb my beard, open my eyes wide in the mirror, and join meetings or events with enthusiasm. I sort of mean this jokingly, but I'm a professional. At this point, I'm a pretty seasoned public speaker, and part of being good at public speaking is the ability to turn, whatever it is, on. At least for some predetermined time.

Anyway, enough about me, let's talk about you.

Gentle critique here, but there is another reason to not disclose the downer side of living with brain cancer, and it is this. Y'all say some wild shit!

I'm not out here policing language, but I've picked up the double edged sword of this honesty thing. On the one hand, I always strive to tell you the truth about living with illness, and I also try to educate everyone about the disease itself. I love this. My objectives are honesty and explanation. But sometimes I hear things like, "Wow, well I didn't think it was this hard last chemo cycle," or, "I thought you'd be bouncing back now that you finished this recent cycle."

Those things are not necessarily wrong to say, but when saying these things, you are making two mistakes that are all in how a sick person hears it.

See, first, saying this sort of confuses the particulars for the generalities. Because I usually feel some way on some day, that doesn't eliminate the possibility that I'll feel some other way today! My body is far from a well oiled machine, and this '95 Buick Skylark may not always fire up when you need it to. Whether it's the treatment fatigue or tumor effect, there's quite a lot of volatility from one day to the next.

But worse, and here's the second thing, if I say I don't feel well, and you tell me that you thought I was feeling well around this time last chemo cycle, you've now undermined my experience. You've heard my report then compared it with another time like a fact check. You've made me feel like I'm not trusted. I think what you mean to be saying is that this is a bummer that I don't feel well at

this time, because at this time, last time, I was feeling better, but what I am hearing is that how I feel right now isn't good enough without giving it some comparator; some sort of verification.

Man, all I know is that I can't really trust my body. For god's sake, my left foot was swollen huge for a few weeks, then subsided in the course of like three days, and apparently that was that? One fat foot for a few weeks. Cool. Totally normal.

As far as me not feeling great, it turns out that sick people are sick sometimes, and that's OK.

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