

This Time, the Situation Is Serious

I usually act as if it's all okay, writes brain cancer blogger Adam Hayden, but that's a disservice to me medically and to my family.

February 27, 2024 By [Adam Hayden](#)

But I don't wanna give you too much/ Or let you know it's shaking me up/ I only really wanna tell you enough so you know/ It's nothing serious/ I know there's love in every word that you said/ Telling me how I had some miles up ahead/ But when I look out, my feet are on the same ledge

—“[Nothing Serious](#),” Ages and Ages, 2019

I received a signed record, t shirt, and maybe some other swag from the songwriter, singer, and front man of Ages and Ages, quoted above. I listened to their song “[Divisionary](#)” throughout treatment when I was first diagnosed years ago. Actually, I started listening to Ages during opening duties at the bar I worked at during grad school shortly before my diagnosis, then their music joined me in my ears at the hospital.

While there, I had really significant left-sided impairment; in fact, temporary paralysis! I would lie in the hospital bed and air guitar to that song to try and get my left arm and left hand moving again. “Do the right thing, do the right thing. Don't you know you're not the only one suffering?”

Whitney reached out to the band to let them know how meaningful their music was (is) to me, and they sent along a care package. Thanks, Whit. Thanks, Tim. ????. Also, please don't have the label sue me for my liberal use of the song to frame this post.

“Divisionary” came out about a year before my diagnosis. “Nothing Serious,” was released in 2019 for their album [Me, You, They, We](#). Ages has set the soundtrack to my life with brain cancer, well, part of it. I'll always have Bay Area punk rock and Midwest emo on the mix. I should say that I'm not sure whether it sounds complimentary to say an album is the soundtrack to brain cancer, but seeing that brain cancer is the impetus for just about all of my speaking, writing, and organizing, I do intend this to be high praise.

This song, “Nothing Serious”: “I only wanted to tell you enough to let you know it's nothing serious,” is me exactly. I am both the guy at home living with brain cancer, and I'm the persona speaking and blogging about it on the internet. Often, after I've published a post or uploaded a video, I've processed the ideas that motivated the media, and I'm on to the next emotion. This

does not mean that I'm inauthentic, but it does mean that I've already processed what many of you are reading for the first time. All of my posts begin with a few thoughts tapped out in my Notes app, usually at least a couple of days before I publish the post. The Adam at home is much more volatile, more emotional, less refined as what greets you on the page.

"I only wanted to tell you enough to let you know it's nothing serious."

It is Serious

It is serious, though, this time, for me; for us. And it's been a little tough this time around to let myself know how serious it is. My knee jerk is to under-report symptoms and play it off as all okay. This may serve me at times, as far as attitude goes, but it's a total disservice to me medically and to my private life with a family that deserves me at my best, whatever that best can be, and not being honest with myself about the difficulty we're facing is not the best way to achieve that goal.

I now have small satellite tumors around a central mass. At least one of these satellites has crossed the midline of my brain to show up in the other hemisphere. This is usually a sub-optimal prognostic indicator. I had a pretty tough seizure Saturday mid-day, including some muscle spasms, and strange sight and sound phenomena. And by "pretty tough," I mean it was the worse since the one that put me in the hospital a few years ago. It was scary and debilitating. Then I had another, smaller seizure this morning. So in short, things are serious.

Multi Channel Communication

I don't know what's next. Part of being public is bringing everyone into the story and trying to communicate enough to give honest reports, but you're reading real time updates, not settled plans. I also break a lot of communication rules when my online messaging gets ahead of more formal or professional messaging with "key stakeholders." This includes friends, family, and employers. I don't know what that big seizure this weekend indicates. I had some right arm involvement, which suggests that the new area on the left hemisphere could be impacting me; my tumor has been on the right side of my brain, affecting the left side of my body, so this is new.

Caveat: I have no idea if any of that is clinically sound because I'm just a dude. All in all, it doesn't do any good to ignore the warning signs, and I'll inform my neuro oncologist tomorrow morning to take whatever action may be advised.

Tension and Priorities

Whitney rearranged her entire weekend to serve as full time caregiver. She is this for me all of the time, but for the past couple of years, my care needs at home have been lessening. That was not the case this weekend. We snapped back to significant care needs over the past 28 hours. We'll need to negotiate all of this care and independence again. As for me, I'll need to engage work

about what is realistic, and I know that everyone at work prioritizes people as a top consideration, and so, I'm less concerned, as I am mindful of my commitments. Strangely, maybe naively, at the time of my first ever MRI in late-May 2016, I handed off everything that afternoon and went on leave. This time, I'm struggling to know how to handle all of this.

There are commitments at home and to our family, too. I need my spouse, kids, and extended family, and they need me. I guess it's time to admit that this is, in fact, not nothing, but something, something serious. When it's serious, we have to act like it is, and I'm trying to tell myself this.

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