Cancer Health™

A Curious Place: Cancer After a Milestone

This post is dedicated to my dear friend Jessica Morris. Rest in power, Jess. XX

December 17, 2021 By Adam Hayden

I came into brain cancer in a very curious place: Young, otherwise healthy, finally getting my shit together, and seeing on the horizon an opening onto new vistas of possibility. The enthusiasm for that moment in time—life suspended above the turbulent waters that cancer churned—held acceptance of the diagnosis at arm's length. Like the musical notation on the bass clef that anchored a song while the melody wormed its way into your ears and animated the feet beneath your beating heart, my confidence in the rhythm of fresh and new opportunities rooted my life in an optimism that the gasp of a cancer diagnosis could not quiet.

The melody of daily life crescendoed to frantic staccato notes while my body moved from scan to scan exposed to needle sticks, scalpel, and blood, but the bass hit on the quarter notes and kept me marching forward. I was of two songs; two lives. A stable life where I was a spouse, a young dad, a grad student. Another life was born in an exam room: "I regret to inform you that you have a brain tumor." The optimism of the former life proved recalcitrant in the face of the latter. Neither story would be subsumed under the other.

Our songs, our stories, they are ourselves, our narrative identities, and for now, my life told these two stories. One story sang of hope and the other lamented hope's loss. In the in-between space, a vacuum of meaning and a dearth of certainty; there was fear, but the antidote to fear is information, and the pursuit of information in inquiry.

The devastation of a brain tumor could not overcome the earnestness with which I pursued the science of the damn thing; the inquiry; the curiosity. And so here I was in a very curious place: Still hopeful. Still optimistic. But dying (so they said). But rather than let the virtue of curiosity dissolve into a fool's errand, I dove into my disease, armed with inquiry, in pursuit of information, the antidote to fear.

All areas of life were fresh: only a few years married, young kids, a new job, the end of grad school, and even brain cancer was fresh. It was new territory, a rare disease, strange seizures, side effects, and cytotoxicity. For a hungry mind, I feasted on the fresh information.

Part of surviving a disease, part of being a patient, is becoming the expert in the lived experience of your illness. The mechanisms of action sit in the petri dishes and textbooks but the experience can’t be recapitulated in the lab.

Over time, the new experiences become old experiences, and the monotony of a life under medical management becomes routine. It’s no longer hopeful, nor optimistic, nor fresh, nor whatever else, but instead, life is a long, protracted chore that must be endured. There are no more surprises, only symptom burden, and without surprise, there is suffering.

Five years is my landmark.

I’ve lost the rhythm and life has been writing the melody. It is common in our community to hear of internet friends, friends of friends, and distant friends die, but this year I’ve lost three personal friends; brain cancer friends. What if what was fresh has rotted? And the devastating disease is putrid flesh decomposing on the skeleton of reality where hope once lived. Could the once unimaginable achievement five years ago of celebrating this half-decade milestone with a cold beer and a few tacos be the song’s end? Would life be devoid of surprise from here on out, and only suffering remain?

But what if things may be made new all over again?

In just twelve months time I will be six years post GBM diagnosis. If only 5% of us make it this far, what good does it do to the 95% if I don’t continue to report from the front lines of illness? I am a journalist deployed to a new world that tragically few know.

I am a voice who now embarks on their sixth year of survivorship.

I come into the realm of survivorship in a curious place: An expert in the lived experience of my illness, but not yet an expert in the geography of long term survivorship. You and me readers, we figured out the first five years together, and now we are cartographers on a more grave mission, to chart the course from years six through ten.

Do you hear it? It’s that rhythm; song, dance, and story. I see on the horizon new vistas of possibility.

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