Not Choosing Cancer; Choosing Family

A holiday guide for those with serious illness and their loved ones, by Adam Hayden, who lives with brain cancer.

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We have a saying in the brain tumor community, especially directed to people we meet who are recently diagnosed, “Welcome to the greatest family you never wanted to join.”

During the holidays you may be thinking about your own family, that you’re part of the worst family that you never wanted to join! But that’s not the point of this post! I’m not writing a guide to navigating the holidays with your family. Well, I sort of am writing this type of post, but more on that later!

What I am writing a post about is the family of patients–or survivors, or thrivers, or warriors, or pick the term that best describes your experience–and our care partners and loved ones, or “co-survivors.” In this post, I want to lift up our “family,” and emphasize why this really matters during the holidays.

Of course, “family” is not a monolith. So-called biological families are one model; fostered and/or adopted parents and children, is another. Single parents make families. Grandparents, aunts and uncles, or guardians are a model, too. Two dads or two moms are very clearly a model for a loving home, and it’s really too bad that this still must be argued for—I’m beyond arguing for that, by the way, while many things in life are complicated, two people who love each other is not one of those things.

The way I understand my family is not without its complications. My mom was adopted, and understanding what counts as family in that context and my connection to them is an issue that has dramatically shaped my life, as anyone who has read my writing about my wrestling with identity could tell you. But I’m not writing about biological and chosen models of family, not in this post, anyway.

We really are a family in the brain tumor community. I’ve shared before that when attending my first patient advocacy event I walked into the event and immediately recognized a room full of people with similar craniotomy scars on their heads, and I knew I was home. I was among my people; my family.

Cancer may not always be a death sentence, but it is a life sentence.

Cancer, at least brain cancer, is not “get it, treat it, cure it,” and move on. Sure, the effort when treating some cancers is to cure them, or at least reach a clinical evaluation of “NED,” or no evidence of disease, and that may be also described as remission, but brain cancer just aint’ it. Even those who complete treatment and have “clean scans” will continue to attend annual MRI scans for disease surveillance. Cancer may not always be a death sentence, but it is a life sentence, insofar as cancer is something that most people, when diagnosed, continue to either be monitored medically, or be mindful of, for their entire lives. And please don’t chalk up the latter to a psychological weakness or inability to confront and process trauma. It simply is the reality that cancer often recurs or metastasizes; in other words, comes back or spreads somewhere else.

If not the concern over “mets,” the protocols we use to treat cancer are themselves carcinogenic. For example, the chemotherapy that we use for brain cancer, temozolomide, increases the incidence of blood cancers. Radiation therapy, that I had for my brain cancer and is a component of the standard of care for many brain cancer types, can lead to the development of a brain tumor called meningioma, within the radiation field; while the process tumorigenesis, or beginning of the tumor, often takes decades to develop, the new growth that we spotted on my MRI scan a couple weeks ago could be either a recurrence of my brain cancer or could be this type of tumor, this is what we’re actively trying to figure out with my medical team.

Because widespread early-cancer detection is difficult for many reasons, including cost, accessibility, accuracy of result, and the risk of over-detection leading to over-treatment, many people are diagnosed as a result of a symptom presentation. In the wake of a diagnosis, people living with cancer become hyper aware of anything resembling a symptom as an early indication of cancer recurrence. Again, within the brain cancer setting, we may wonder about the severity or duration of our headaches–do I need Tylenol or an MRI? We may be concerned whether our disorientation and dizziness is because we stood up too quickly or experienced a partial seizure. Did we trip on the sidewalk like a normal person, or is a mass pressing on our motor strip above the parietal lobe? Given the cadence of active disease surveillance, the medical probability of recurrence, the known iatrogenic conditions, or conditions arising from prior medical treatment, and the sensitivity to symptom-like experiences, cancer affects your life far beyond the clinic or infusion suite.

More than concerns with our diseases, the social influence to be present for the holidays is a double-edged sword. We often feel the pressure to be present, to “make memories,” even at the expense of our comfort or wellbeing. The sense that you’re letting others down by not making an appearance at the family pitch-in is a reality, regardless of the “permission” to stay home that you may get from supportive loved ones. That you need to make the most of every special event because “it could be your last” is not an exaggeration. This is the lived reality of serious illness. To

quote one of my favorite authors, a philosopher of health and illness, Havi Carel, “Every social interaction becomes cast in the shadow of illness.” It’s tough to field questions all day from caring family members, even if couched in support. It’s difficult to be reminded of your own mortality, which is precisely what a family event filled with “memory making” becomes.

And listen, you may not be placing any of this pressure on your loved ones with serious illness. You may read this and think, Adam, man, I hear you, but we’re totally chill about your cancer. We don’t need to talk about it. Trust me, this isn’t, or isn’t always, a you thing. Like Taylor says, “It’s me. Hi. I’m the problem, it’s me.” Because we’re the ones living with this, we carry our cancer with us wherever we go. It’s likely frustrating to others that we cannot divorce ourselves from it, but trust me, no one is more frustrated than us patients that our lives are forever impacted by something we didn’t choose.

Few people who have not been impacted by cancer understand these experiences. Actually, that’s a big reason why I write, to bring others into our lived experience. Nothing affirms me more than when a fellow person living with a serious illness shares one of my posts, with the caption, “This.”

We didn’t choose cancer, but we can choose our cancer family; we’re the very best that you never wanted to join. If you’re a patient feeling frustrated this season or a loved one wanting to better understand what your family member with illness is going through, maybe I’ve helped just a little bit.

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