Cancer Health™

We Wait. We Wonder.

If you are facing your own experience of illness or are affected by those who are, this post may shine a light on these challenges.

August 13, 2019 By Adam Hayden

Many have reached out to our family recently with help or requests to offer help. For that we are grateful. Many have said, “what can we do?” We invite your support. I want to address what is so challenging about living life with advanced cancer. If you are interested, I encourage you to read on, to learn more about the difficulties of “survivorship.” If you would like to help, you can find information near the end of the post. If you are facing your own experience of illness or are affected by those who are, this post may shine a light on these challenges, so that you may be supportive to your loved ones. We truly are in this together.

When facing a serious illness, in our case, a terminal cancer, the diagnosis—receiving it, I mean, sitting beside your spouse or loved one, across from your oncologist, while their nurse reaches to grasp your hand—is a watershed moment of devastation and uncertainty, but before planting your feet on the ground, you are undergoing more scans, preparing for surgery, coordinating daily rides to the radiation therapy treatment center, and learning how to mitigate the side effects of chemotherapy. This is “active treatment,” and for all of its complications, interruptions, and social costs, at least you are “doing something.”

After active treatment, after the diagnosis is accepted, after life with brain cancer shifts from the center of your life toward the background and casts a shadow to shade every experience, this is when we feel most helpless; frustrated.

This is survivorship.

I’ve talked about this before to describe the uncertain period of time after active treatment, but before “disease progression,” the clinical language for the growth of cancer.

Brain cancer, even after near-total surgical removal, can, and often does, “recur” because microscopic cancer cells are difficult to distinguish from healthy tissue in the brain, and these hidden cells grow quickly to form new tumors. In the words of my neuro-oncologist, “it is extremely unlikely that you will not have a recurrence.” It is so unlikely, in fact, that we wring our hands nervously every eight to twelve weeks, waiting for the MRI results, for “disease monitoring.”

Scanxiety.

But regular episodes of brain scans, or “imaging,” and the 24 to 48 hour lag time to meet with our oncologist to hear the results, does not adequately capture the full experience of living each day with this ambiguity. Imagine that regrowth of cancer is imminent, but when the recurrence may occur is totally uncertain. There are no preventative measures to be taken; no clear actions to mitigate the risk factors; the risk factors, themselves, are unknown.

People often say, “I could get hit by a bus tomorrow.” Yes, you could, and yes, that’s a good reason to put your heart and head into something that matters to you every day, but waiting for disease progression is different. See, I know the bus is coming, I just do not know its route; whether it’s running on time. I do know that as my disease progresses I may be subject to a second (or third, fourth) surgery, or more radiation therapy, likely to cause cognitive impairment after the first round beamed a lifetime dose into my brain as part of the standard treatment protocol. With progression, I may expect language impairment, loss of memory, personality changes, inability to read or write… these are all possible symptoms to present if (when) the bus shows up.

So we wait.

We wonder.

We dress our children and stir the oatmeal. We sign homework folders and take out the dog. We manage the logistics of three children and a single driver. We swim against the current of cancer to create a childhood for our kids that resembles normalcy.

But it isn’t.

It isn’t normal.

We sign up our kids for soccer, and another in art class, and we move money from one credit card to another with a lower interest rate, and we scribble back of the envelope calculations every month to make sure we’ve earned enough to pay the bills, always mindful that if my income exceeds the Social Security Administration earnings cap, which is federal poverty level, my disability disbursements will be cut back or suspended, disincentivizing work, even the little I can tolerate on a restricted hours, work-from-home status.

We wake up some days and speak to 130 first year medical students (like I did recently), and we take the main stage of conferences to motivate change in healthcare (like I will next month), and we organize local fundraisers to raise thousands of dollars for brain tumor nonprofit organizations (like a team of us have done for two years), and we put on scrubs and help care for people after strokes, trauma, amputation, while our loved one struggles with their own health at home (like Whitney does each day).

We wake up other days, nauseated, lightheaded, and we wonder if these are early signs of recurrence. Or maybe just a headache.

We wait.

We wonder.

It isn’t normal.

You affirm every day that it is good to be alive. And it is good to have the opportunities to take a terrible circumstance and channel that energy toward good works. You are grateful for supportive employers who let us get away with far too much, and appreciate our work all the same. You acknowledge a terrific community of friends and family–and strangers–who send gift cards in the mail to buy groceries, or cut generous checks that cover a month’s worth of rent, or discreetly hand over folded bills to purchase nutritional supplements for your oldest child who’s at risk for developmental delays, if he doesn’t gain weight and increase calorie consumption, so they tell us.

But you recognize that community support has a limit. And asking for help is humbling, if not humiliating, and you think maybe you should bite the bullet, find a way to return to work full time, lose the benefit status, but make up the earnings in income. But you reflect that people with “normal” life expectancy end up wishing they pursued something more aspirational with their lives, and you do not have normal life expectancy–”it is extremely unlikely”–so why fight symptoms and fatigue in a modified or adaptive work setting, when your time can be filled reminding healthcare that it’s a human practice more than it is a scientific one (as I have tried to do speaking and writing). With all of these thoughts circling your mind, you are grateful you’ve lived for three years with something that kills some people in ten months, but you ask, how can we live three more years this way?

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I was diagnosed with glioblastoma 38 months ago. Our community has carried us these three years. You gave generously to our family in the fall of 2016, immediately after diagnosis.

Now we invite you to support our family again.

Whitney and I have lived in the open with blogging, speaking, and often, wearing our hearts on our sleeves. It is in this spirt that I tell you, we have deliberated the publishing of this post for the past several weeks. The problem we face after three years of survivorship is summed up in this article review of a recent National Cancer Institute (NCI) report: “patients with malignant brain tumors accrued health care costs that were 20-times greater than demographically matched control subjects without cancer.”

Despite Whitney’s tireless work with four (yes, four!) jobs (1. inpatient occupational therapist; 2. sub-acute care for the elderly occupational therapist; 3. developmental preschool occupational therapist for children; and 4. part-time yoga instructor), and my part-time work and occasional honoraria for public speaking, plus my disability benefits, we close the monthly budget gap with credit cards. Copay expenses go toward my medications, specialists, and our share, after insurance, of the $115,000 brain surgery that gave me the best chance at longer-term survival.

We must ponder the following questions:

Medications or kids sports?

Copays for the best doctors and mental health professionals for our kids or trips to the zoo and new clothes for school?

The freedom for me to speak at medical conferences, publish articles, and continue work on my book manuscript or exhaust all of my energy reserves working as much as my income cap allows?

Maximize each day of my limited life that remains, whether that is three months, three years, or thirty, or sit at the dining room table with Whitney for another month worrying about bills?

The choices we make are choices of personal goals and values. Whether your values align with ours, influences your decision to help in the way we are asking. If we are not so aligned, that is OK, too, we are still in community.

For those who have helped us: friends, family, siblings, parents, cousins, faith community, former professors, we thank you.

For those curious how you may do more, we have launched a GoFundMe to help our family close the monthly budget gap. If nothing, we have tried our best to be transparent through illness. We thank you for donating toward meeting a $8,000 goal to give our family a little breathing room this Fall.

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This post originally appeared on Glioblastology on August 12, 2019. It is republished with permission.
