The Lesson of the Rose Tree

A cure seems lofty and intangible, while daily management of disease feels like an achievable goal, writes brain cancer blogger Adam Hayden.

July 2, 2024 By Adam Hayden

We have a Rose of Sharon, a type of flowering shrub, just off our back patio. Ours stands about seven or eight feet tall and has beautiful pink and white blossoms. I love this plant. The location places this shrub in view when I write in the mornings from our small table in our kitchen, and the flowers are high traffic areas for bees who visit the blossoms in their grand act of pollinating. The whole thing reminds me that life carries on, whether we're mindful that it does, or not. The plant doesn't need much from me for its survival and the bees show up whether we're grilling out back or away for a long weekend. When I'm anxious about anything going on, and I'm anxious a lot, I think of the Rose of Sharon that quietly thrives out of sight and out of mind, until one of the flowers catches my eye in a ray of morning sunlight.

The shrub wasn't blooming this year when the other flowering trees in our yard were waking up from winter, and I worried something was wrong with my favorite plant. A week or two ago, supporting what I've said here, I wandered out for my morning coffee to see the pink flowers opened. I let out a sigh of relief and spent time gently smiling as the branches swayed in the heavy Indiana June air. With this smile, my eyes became wet, releasing tears, then staccato breaths while I sat and sobbed.

I suppose I'm just tired. Or overwhelmed.

I am coming off another chemo week, and I'm experiencing such fatigue and frustration. Stable scans, especially disease response and signs of slight tumor shrinkage, used to be moments for celebration, and we did take time to celebrate recent good news that the chemotherapy seems to be having a positive effect, but anymore, stability is less of a motivator to continue the course and is becoming a mile marker on the trail that I'm tired of hiking.

I'm immediately aware that what I've just said may sound callous to some who are hanging on the results of a recent scan and would do anything to hear that it is stable. I'm reminded of a post not long ago where I discouraged people from framing cancer like a battle, and I received blowback from other patients, "Who are you to tell me how to frame my experience?!" I guess this is why many diverse voices in patient advocacy are needed. Anyway, irrational as it may be, sometimes I'm secretly desiring a drop in blood counts or another anomalous scan so I can get off this fucking ride. And again, I'm saying this with eyes wide open that I know people in my life this very week who have needed to suspend therapy for one of the reasons mentioned, and that, objectively, is

not a good thing. I'm only voicing my experience, in this moment, in this body.

During a research meeting I was invited to attend this week with 50 or so participants, a real who's who in the brain cancer research world, a doc who's practically a founder of the modern clinical management of brain tumors, opined openly that they feel the devastation of this disease after more than 30 years of clinical practice, "I've lost so many patients," they lamented. I'm telling you, this disease just grinds on you. Another diagnosis, another round of chemo, another grant cycle to fund your lab and research program, another enrollee in hospice or empty Zoom window from the support group.

People throughout the research community are beginning to temper their aspirations—and their mission statements—to manage the realistic expectations of brain tumor outcomes. Less and less do I hear calls to cure brain tumors, and more often I hear the call to improve our therapies enough to treat brain cancer as a manageable, chronic condition. This is my position, too. Cure seems lofty and intangible, while daily management of disease feels a goal that is achievable, even within my lifetime. I'd say that I'm a model for this chronic disease management, having recognized eight years post-diagnosis, earlier this month. But with chronic disease management we should recognize that developing therapeutics to achieve this state is one thing, and putting it in practice is something else. The science may be there, but the supportive care is not. Like the doc's three decades of loss from their clinical reality, the almost one decade of mine testifies to this same reality: brain tumors are devastating diseases.

Instead of trust, maybe there is a dose of envy I feel for this plant that is content with its own lifecycle to lie dormant then vibrant, sleeping through winter and opening for summer, trusting the bees will do their part. It's envy I feel for a lot of living things that walk through their lives without the uncertainty that haunts mine. But of course, envy isn't productive; trust is. If I turn that trust inward, I must trust that my life matters; my partnership with my spouse and my parenting to our kids matters; my participation in research matters; this blog matters. Trust makes space for the blossoms to surprise us, when we try not to preoccupy ourselves with anxiety about their absence. Trust means just that: truly trusting and letting go. Showing up another day, doing our part.

Maybe that's the lesson of the rose tree.

This blog post was published by Glioblastology on June 29, 2024. It is republished with permission.
