

It's Brain Tumor Awareness Month; This One Is for Those Who Mourn

It is a great privilege and often a great difficulty to bear witness, writes brain cancer blogger Adam Hayden.

May 2, 2024 By [Adam Hayden](#)

One of my greatest, most rewarding, and privileged opportunities in this world is also one of the most difficult. May is Brain Tumor Awareness Month, and this one goes out to those who grieve. I see you. I hear you. I hold space for you. And I try to learn from your wisdom. This paragraph is a gentle content warning for those who fall into this category of those who are bereaved members of the brain tumor community xx. ♥ -a.

The greatest and most rewarding opportunity is to be with my peers, and who are my peers? When I think of friends, colleagues, mentors, and innovators, my dear connections in the clinical, research, and nonprofit communities come to mind. But my peers, these are others living with a brain tumor. Regardless of the type, grade, neuroanatomical location (I included that one mostly to use the word 'neuroanatomical'), whether malignant or nonmalignant, treated and requiring only annual surveillance, or in active recurrence, recently diagnosed, a long term survivor like me, or adjusting your goals of care to wrap you in comfort as you near the completion of your life; my peers are others living with a brain tumor. All of us. We are connected in ways that people without a brain tumor will never fully experience or understand.

As a peer, I have the absolute privilege to receive emails, direct messages, texts, calls, and messages passed through mutual friends to support those recently diagnosed. I also have the privilege to co-facilitate a virtual brain tumor support space called the [Brain Tumor Support Conversations](#). This monthly group has convened for several years, and in the space we share together, we are given the gift to bear witness to the brain tumor experience that others so vulnerably share, and many of us are given the gift of a space to share about our own experiences. I also have the privilege of knowing many of those in our local community who are living with a brain tumor.

The privilege is to be a trusted member of the community and to have my life immeasurably enhanced by sharing space and learning from hundreds (thousands?!) of brain tumor peers during my eight years of survivorship. The challenge is bearing witness to the stories of suffering that this

disease causes. These stories include the deaths of community members or to hear about their death from their surviving care partners. It is a great privilege and often, a great difficulty, to bear witness.

In May, you'll hear stories of inspiring accomplishments, breakthrough therapies, and new diagnostic techniques. You'll be asked for money to benefit nonprofits in the space, and you may be attending a signature event like the Race 4 Hope DC or Head to the Hill. These last two are coupled events that have signaled the start of Brain Tumor Awareness Month for Whitney and me for the last eight years. We are not attending this year because the dates coincide with taking chemotherapy for my recurrence. This year would've been our ninth year on the Hill with the National Brain Tumor Society (two were virtual during the pandemic). We are already missing the days spent in community, even though they are still a few days away.

The tone of Brain Tumor Awareness Month is often a tone of hope, mobilizing, and inspiration, and speaking as someone who works to be a person in this world who gives hope, mobilizes, and inspires, I embrace these messages.

I embrace them, however, mindful of the voices we no longer hear with our ears, but must listen for in our heads and hearts.

Something you may not hear much about during Brain Tumor Awareness Month are stories of those who are the surviving partners, families, friends, loved ones, and clinicians of people who have died because of a brain tumor.

First birthdays, first anniversaries of a loved one's death, first meals at the restaurant they loved, first smell of the perfume they wore, first time to the playoffs for their favorite team, first words from the child you welcomed into this world together, these all may be experiences that you have had this year, and now it the first Brain Tumor Awareness Month without them.

For those who are not marking their firsts this year, but many more, I imagine the grief is something like the worst of my brain cancer symptoms, they never really go away, I just have learned to live with them. Impairment is a part of me, even though it is an absence, of a kind. Maybe grief is this way.

It's Brain Tumor Awareness Month and this one goes out to those who mourn. For those whose voices we will not hear this year, may their memories be for a blessing.

Holly Gainsboro is a dear friend of mine, and she facilitates the [Grief Support Conversations](#). This is an exclusive virtual space for bereaved members of the brain tumor community.

If you are experiencing emotional distress or crisis, the [988 helpline](#) is available to you 24/7, across the US.

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