Telling You for the Last Time

Adam Hayden, 39, is a writer and speaker living with brain cancer. He lives with his wife and three sons in Indianapolis.

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I grew up on Seinfeld, so his 1998 Broadway show–turned—album, I'm Telling You for the Last Time, meant something to me. Jerry Seinfeld buried the rich onstage material that formed his stand-up career and the "show about nothing."

He vowed never again to use that material.

The best comedians convince you they're funny before delivering the first punch line. Similarly, when I deliver my material, audiences see buzzwords like patient-centered and patient advocacy, and they decide what to expect before your sick body takes the stage.

A good bit holds a mirror to our lives with candor, courage and comedy. I once started a medical ethics talk with a projected image of my brain under MRI that showed a 7-centimeter surgical cavity in the right parietal lobe. "I needed this diagnosis like a hole in the head," I quipped.

Now, it's time to let go. I've honed my material for five years, and I've had a good run with it. Five years of my life drafting, crafting, revising, delivering—it's exhausted, and so am I. A film crew spent two days with me and my spouse recently, and at the end of filming, I knew my best material was no longer mine. I'd handed it over.

I'm telling you for the last time.

It's not the doctors; it's the system. And when we see each other, doctors and patients, the admins are in trouble.

In fleeting moments of restorative justice amid toning alarms and proning patients, a healer catches your eyes in theirs and you are seen. But mostly, it's wristbands and gowns, murmurs outside your inpatient door and rounding physicians so busy they carry their sealed Tupperware lunches into the room to look at your incision.

We can learn so much about an individual's cancer without even meeting that person. But to know a disease is not to know the person who has it. We're rich on data but short on humanity.I'm telling you for the last time.

I don’t care about clinical language. I only learned the jargon so that the doctors would hear me. Maybe it’s time to use ours: We speak in experience and emotion.

I’ll dismiss your suggestion that I wait for our visit to hear the results. I’ll read the test report when it’s posted because it’s my data, my body. I don’t need your paternalism; I need your partnership.

I don’t care what you think about Dr. Google. I read everything I can. It’s my life, and I won’t let your distrust or skepticism of my capacity to absorb medical information stand in the way of pursuing my care as an equal member of the team.

You sequenced my disease 30 years ago, the one I share with thousands of others to revolutionize medicine, but genomic sequencing is a luxury, not a standard of care, and all my friends are dying.

Five years of brain cancer, from diagnosis to major milestones—I’ve told that for the last time. It’s a new show, a new set, new bits to work out. I don’t know where this will lead. But you can’t live with brain cancer and stay safe, and you can’t keep a comedian off the stage.

To read more of Adam Hayden’s blog posts, go to: cancerhealth.com/hayden.

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