

Your Experience Is Your Commodity

Patients who speak often about brain tumor clinical care or research must revisit some heavy shit on a regular basis, writes Adam Hayden.

July 25, 2024 By [Adam Hayden](#)

Here's the damn thing about being a useful patient: The shittiest thing that's happened to you, assuming nothing worse has happened—chas v'shalom!—your life-altering, very serious, super frightening diagnosis, cytotoxic therapies, and actual brain surgery is put in service of, "setting the tone for the meeting."

Imagine walking into the office tomorrow morning, and Tim from accounting is like, "Hey, tell us about your divorce again."

What I want to say is that patients who speak often about brain tumor clinical care or research, from their perspectives and lived experience, must revisit some pretty heavy shit on a regular basis.

This is not to say that we don't want to do this. The artist has a brush, the poet, their journal, and for communicators, our tool is speech; speech in all forms, verbal and nonverbal, written, quick looks shared with a partner, sign language and touch, and all in between. Sometimes I express my speech in a hoodie at a non-hoodie event or with a pair of pink half-cabs while I pace the stage. Salmon, actually. (easter egg #1)

Ok, break.

My brother has a degree in something creative writing maybe. I don't really know. I'm just short-cutting a longer description to establish his credibility. He's good. He was managing editor of this and published in this book and that. He marks up my writing in helpful ways.

That was the credibility bit.

He's a good writer and says smart things.

We both can turn a phrase.

Remember, Mr. Potter? (easter egg #2)

So my smart brother with the good stories, he's the one that got me to think about Adam. The

Adam on the page. The narrative Adam. It's me who is curating ideas and images about myself and selected material from my life, as I perceive it, then delivering it through that other guy, public-Adam. Narrative identity Adam. You may be more used to him than to me. He's sometimes the one you're reading. Not me back here, doing the writing.

It's taken me, I mean actual-me, it's taken me maybe three years to understand the thing my brother said. Wisdom from the younger brother. Like when Jacob got the blessing.

Adam on the page is Adam in the world. As for me, I'm anxiously taking notes on the back of the agenda during the research meeting so that when he's called on,

because he most definitely will be called on

"We haven't heard the patient perspective on this topic yet."

He looks less like an idiot. Or we do.

The truth is, I gotta have public-Adam.

Friends, I don't have it in me to give you me as often as that communicator shows out. Me, who really did have that awake brain surgery, and me who may not live to see my kids do more really cool shit. Me, with my uncertainty, my insecurity, my anxiety, my inclination toward packing profanity into conversation so full that we ratchet-clamp the sound waves and save the intimacy and privacy of conversation only for us in a bubble that once formed is only for those inside and so fragile that after the membrane is ruptured, the contents are never replaced.

Public-Adam is for the world. The you who is you and the me who is me are only for each other.

John Perry [called](#) it the essential indexical. He tells a great story about a shopper whose shopping cart carries a bag of sugar that's sprung a leak. The shopper pursues the sugar trail to let the other shopper know. "That's when I realized it was me who was the making the mess." Great paper if you ever take an upper level undergrad course in the philosophy of language.

Here's the point. When you're a useful patient, your experience is your commodity. The product. And the thing on the shelf is not the idea in research and development. I'm a work in progress, but public-Adam, he sells. In advocacy, we're selling everyday.

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