Control the Messaging About Your Illness

Patients enjoy faster and better access to their digital health data, including test results—but they retain control over framing and sharing it. Here's an example regarding my recent scan.

February 9, 2024 By Adam Hayden

I have some info about my scan results from Thursday. You'll hear that update in another post early this upcoming week. I know things that I am not telling you in this post. I'm controlling the messaging. Messaging is something that I can control, and I'm not ready to share that control just yet.

Each person living with a serious and complex illness knows this experience well: Serving as the communication hub for the dissemination of medical information. We provide updates at the intersection of consuming information, processing information, and packaging information. Each step in the communication flow requires a level of effort, whether that is developing the conversational competence to digest jargon-laden medical reports or the emotional intelligence to cultivate emotional regulation and management.

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>
> —Glioblastology

Navigating illness; indeed, navigating life, requires scientific literacy, critical thinking, and social emotional learning. I have come to understand serious illness not as the aberration of normal life; rather, serious illness is life in its most intense presentation. Few things are more intense than being told news of a life-altering medical condition, and then being called on as the spokesperson for that illness to your community.

I think these things that I've said are borne out by the anecdotal evidence. When I complain of confusion, memory impairment, or mild disorientation, people often reply, "Oh, I'm forgetful, too,

you’re probably just getting older!” When I lament about dreams that I likely won’t achieve, I’ll hear, “It sounds like you’re having a mid-life crisis!” In both circumstances I want to say, “No, I have brain cancer. These are part of the impairments and conditions of living with a life-limiting disease.” In fact, reducing my lived experience to “just getting older” may help you frame the illness in a way that does not seem so scary, but it does (unintentionally, I trust) belittle my lived experience. There is a fine line between encouraging and gaslighting.

Still, there is something instructive here. That my reports of serious illness remind people of “normal” things in their lives, like aging or questioning your purpose and goals, does add weight to my claim that serious illness is life, amplified.

Courtesy of Adam Hayden/glioblastology.com

Leaving our neuro oncologist’s office after hearing my diagnosis, Whitney rolled me back to the medical transport van to leave the treating hospital and return us to the rehab hospital, where she’d settle me in my room and take off to return to our kids. Spending a month inpatient is tough no matter what your circumstances may be, and for us, part of the difficulty included managing our three young kids while I was in a hospital 45 minutes north of where we lived.

I think of that medical transport driver often, they were in for more than they may have bargained for, giving us a lift to and from the treating hospital that afternoon. As soon as we loaded me into the back and ratchet strapped my wheelchair to the bolted on metal rails I pulled out my phone, and we started making calls.

Representative of how we’ve handled my brain cancer from go, we openly shared about my illness in front of that driver who was privy to our intimate conversations with beloved friends and family, slowly describing the terms of my brain cancer and its grim realities. The Adam and Whitney in that medical transport van could never imagine that my future self would be describing this

experience seven years later in a blog that documented many of the major moments to occur in the intermediate years.

Controlling the messaging has long been a burden left to clinicians. Breaking bad news, showing empathy, facilitating sensitive conversations about a patient's wishes when advanced directives are absent or families fail to reach consensus. Clinicians now face a new consideration when communicating with patients, new federal policies and guidelines implemented a punitive approach to prohibiting information blocking.

Information blocking is a practice by an "actor" that is likely to interfere with the access, exchange, or use of electronic health information (EHI), except as required by law or specified in an information blocking exception.

Office of the National Coordinator for Health Information Technology

Policies to limit information blocking are welcome! For too long patients have had their "access, exchange, or use of electronic health information" "interfered with." I am not interested in a policy debate in this post, but I'll say that as a general rule: I am entitled to data about my body. It's my body. It's my data.

For clinicians, these new provisions usher in an age of transparency previously unknown in clinical care. I can now read the clinical notes that my physicians write to document my care, and everything from lab results to, you guessed it, radiology reports are pushed directly to my smartphone, so long as I've enrolled in the patient portal. This means that I'll see many of my medical findings before my physician does. As an aside, I was very recently invited to join an investigative research team to examine immediate access to test results and patient preferences I'll keep you updated!

The push notification came last night around 6:30 pm. My folks happened to have the kids for a regular grandparent hangout, so Whitney and I sat together to read the report. I meet with the oncologist Monday morning to discuss. Whether you all know this, our practice for years has been to quietly digest test results together, then update our community following the after-scan visit with my doc. We do this for two reasons: First, while radiologists are experts in reading images, my doctor is the expert in my clinical management, so we look to him for a more decisive word. Second, if there were to be any changes in my treatment, my doc would be running point on that, so rather than trickle out information incrementally, we usually wait to update everyone after we have the complete picture.

In short, we control the messaging.

I'll post again soon. Following the visit Monday morning we'll have a more full picture to share before we reset for the next round of whatever is next. Scans? Other tests, like the echo and CT angiogram I had recently. Blood work? Something else? We've found that we need to have our arms wrapped around a thing before we share the messaging. Illness is life amplified, and in life, we are always balancing our human needs for social support with our private needs to protect a

space that is just for us.

Agency, your sense that you're in some control of things that happen, is often the first thing you lose when getting a bad diagnosis. Exercising some control over how we frame and share news is one of the few places where we have agency left to express. I can't wait for you to read the update in a couple of days. Then we'll share the messaging, but for now, there is something edifying about holding on to information that is ours to negotiate. We're consuming, processing, and packaging.

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