

Caregiver Unaware

Category: Not Knowing

written by Mark VanderKlipp | April 1, 2019

My Dad is eighty-nine years old and has a glioblastoma, the same as former Sen. John McCain. He's doing well despite his condition, and my siblings and I are surrounding him with support. Someone lives with him full-time, and we have a weekly check-in meeting so we're all apprised of his current condition and contributing to his health. Based in our home town, my brother and sister are his primary care team; I live two-and-a-half hours away.

In February I traveled there to work from his home for a week. First thing Monday, I took him to a progress appointment with his neurology team. Coming in from the outside, I had almost no current knowledge of his condition or medications. Because of that, I was unprepared when the staff person at reception handed me a sheaf of paper on a clipboard to fill out by hand. I asked her whether it was necessary since my Dad's entire medical record is with this one large health system; she confirmed that it was.

Now I'm thinking that the information I provide, minimal as it might be, will somehow impact the care he's about to receive, or the information he's already got in his medical record. And my Dad, in his current condition, is unable to help. I started with his name and birth date, and almost immediately his nurse came through the door to call us back.

I asked her whether it was necessary to fill out the forms, and she said "No, of course not. Give those to me." We were both relieved. But why did this have to happen?

Reflecting on this six-minute interaction, I've mostly thought about that staff person behind the desk. She was as much "at the mercy of the institution" as we were. She's directed to tell everyone to fill out paper forms as they enter and presumably do something with them when they're brought back. We would have been much better served with a welcome, check-in, a cup of coffee and a short wait.

The rest of the story: Later, I set up a meeting with the VP of Patient Experience. I brought this to her attention as a service design problem, describing the stress that this created for me and my dad. She said, "You want to know the biggest sin? Even if you'd filled it out completely, we have no means of actually recording that information."

The lesson I learned is that a healthcare experience is as much about what you *don't* do, as what you do. Designing the experience around the needs of the patient and family would be the starting point to solving this problem. It's a culture, training and communication design problem that can be solved using participatory design.

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