

Both Sides: Coming Back to Work as a Healthcare Insider after a Patient's Journey

Helping my husband navigate his diagnoses, treatment, and ultimate death from pancreatic cancer has been the most humbling and shattering experience of my life. I'm back at my desk after this odyssey, and though still with grief as my companion, I find that my approach to my work is informed and refueled with purpose and perspective.

Navigating Healthcare as a Patient

I've spent most of my career dedicated to the healthcare industry. Like many of my colleagues, my personal mission has been to help make healthcare better – that is, more patient-centered, affordable, and accessible. My husband was a patent attorney working in the biotech field. He had a PhD in biology, was astute in deciphering medical research, and could understand treatment pathways at the molecular level. He was also an expert in the business fundamentals of the pharmaceutical sector of healthcare.

If there was any duo equipped to deal with a healthcare challenge, it was us. And indeed, we did fine most of the time. We were empowered and informed navigators who directed treatment and connected with providers. Bart was a scientist and problem solver



who didn't just skim, but read in depth medical literature related to his disease and treatment options. He enjoyed conversing with his providers as a sophisticated partner, not just as a patient.

And yet, we were regularly surprised by what we could not control and how many gaps we

still faced. There were the absurdities of incomprehensible benefit design, the stream of nonsensical paperwork for services we didn't even know

we had received, dangerous misjudgements from new residents-in-training, misfired handoffs, and ultimately, insufficient support at end-of-life.

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human. I learned about the kindness in bearing witness to pain without flinching, how actions speak more than words, and what an honor it is to care for those you love. For these reasons, I am forever changed.

Professional Takeaways from a Personal Journey

Still, as I am making the surreal re-entry from full-time caregiver to full-time work, I know we can—and must—do better. While it will take years to unpack all the lessons I learned about our industry, here are some of my most

immediate takeaways:

1. Most People Are Good

Everywhere we turned – whether dealing with insurance issues, providers, facilities, food service, and so on – we met kind-hearted people who were there to help consumers and patients. Various sectors of the industry routinely point fingers at others as being the root of ‘the problem,’ but in truth, most people in healthcare just want to do the right thing.

We saw this with the enrollment specialist who brought humor and optimism to the onboarding process at a new

treatment facility; the oncology nurse who advocated for a bed instead of infusion chair; a surgeon who spent five hours in an emergency procedure at the end of his long day to reduce Bart’s pain after recovery; and countless smiles

Lessons from the Maze

I became adept at navigating the healthcare system from a patient’s perspective just as I navigated the maze of tunnels connecting the web of buildings in the Longwood Medical Area. First I walked these tunnels with my strong and vibrant husband as he started treatment; later I knew them too well with a wheelchair or to get food during my visits.

Having a patient’s-eye perspective of this journey was illuminating from a healthcare system perspective, and about life itself. For me, the day-to-day frustrations paled next to changes in my overall world view from this experience. I learned how simple it could be to find meaning in life, how little we really need, and how few words sometimes need to be said. I learned what it felt like to be wholly and unequivocally on the same team with another

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from food service workers when paying for meals in hospital cafeterias. I still am moved when remembering a new practitioner who gave me a hug after a particularly hard day and said, "I see what this is for you."

2. Everyone Is Frustrated

No matter what challenge we were facing, each person along the treatment and administrative trajectory was frustrated by their inability to fix or even improve upon the limitations. The challenges are ubiquitous and monumental. Many of our nurses and doctors took it upon themselves to shield us from the burdens of extra paperwork, to ease the frustration of a 1:00 am trip to imaging because of a misfire from in-facility transportation, or to lighten the logjam in procedure prep. And when they couldn't shield us, they apologized for it. When mistakes did inevitably occur, those involved wanted to explain what had gone wrong and why, and make clear that it wasn't for lack of caring or trying. I have empathy and admiration for those who shoulder this tension every day, trying to make a difference on the front lines.

3. Tools Are Inadequate

We still do not have information technology

solutions to enable collaboration across multiple treatment disciplines. The industry has invested billions of dollars trying to crack this nut over the past few decades, and we still lack fundamental capabilities. Often, physicians making rounds in

the hospital collected information from visits by the previous specialists by asking Bart to fill them in. Bart began to take pictures on his iPhone of procedure results, so he could show the next providers to

visit. At one point, we worked with a series of doctors who were coordinating Bart's treatment through email strings on their mobile phones. There were several email threads that included the same subject line, but contained different participants. No one could keep track of who had what information, leading us to be told many different versions of Bart's treatment course all in the same day. This seeming chaos can be

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4. Oncology Heroes

Physicians and nurses working in Oncology (and other specialties) are heroes. They deal with dire, devastating, and tragic news every day. These professionals meet with people at their most vulnerable moments of suffering and mortality. On days when there was bad news, somehow our oncologist could magically find 60 minutes on his schedule to walk through results, implications, and options. Such talks require technical acumen, emotional connection, and objective distance all at once. So few among us possess this capability and face such high stakes on a regular basis.

5. Stepping Back: We Can Do Better

We can do better as an industry to treat people more humanely and improve their care,

quality of life, and ability to navigate the system. As insiders, we know too well the challenges, incentives, and complexities that keep prices high and services inconsistent. And yet, often, we are so busy in operational basics and urgent demands that we are unable to address the

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With all of this goodness, and all of

the profound gaps in the system, surely we can make a difference. I have been asked by many whether I would want to return to work after this journey.

The answer is unequivocal. Yes. I have experienced just how deeply healthcare touches peoples' lives, and I have never been more committed to roll up my sleeves and do what I can to make it better.



"Let's not stay too busy to accomplish great things."

Nancy Wise, Managing Partner, Spring Street Exchange

Nancy founded Spring Street Exchange because she wanted to work with like-minded individuals in striving to make healthcare how it should be, rather than the way it has always been. Her work in the industry has ranged from tiny, community-based nonprofit service organizations to billion-dollar insurers, and most things in between. She specializes in the intersection between big ideas and practical planning, which she believes can only be accomplished through radical collaboration and using a new set of tools. Her secret sauce is in leading strategic planning and visioning initiatives.

Nancy has a master's degree in Public Health and an MBA from the University of California at Berkeley and a BA in American Civilization from Brown University. She is from both Pittsburgh and Alameda, CA, but now lives in Lexington, MA, where the shot was fired that was heard around the world.