



2017

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Recommended Citation

Ross, Janell M. (2017) "From darkness to hope: A journey through patient experience," *Patient Experience Journal*: Vol. 4 : Iss. 3 , Article 4.

Available at: <http://pxjournal.org/journal/vol4/iss3/4>

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From darkness to hope: A journey through patient experience

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Abstract

After beating Hodgkin's Lymphoma, we believed our interaction with the healthcare community would be through routine check-ups. Little did we realize radiation scaring would lead to a complex diagnosis with no viable treatment options locally. The journey took us to the Cleveland Clinic where we tapped into something bigger than the latest in medical breakthroughs; we lived the patient experience. This is a true, personal story of tragedy, comfort and resilience followed by a realization of a heart's desire to make a difference for others in the patient experience field.

Keywords

Patient and family centered care, physician engagement, patient experience

Framing the Journey

Each of you have come to this space of being a leader in patient experience from varied pathways. When you consider your role and the people you lead, consider the impact of the seemingly unrelated events and the resilience of the human spirit. Whether you notice it or not, the work you do makes a difference. This is a personal story of perseverance and of hope; to inspire you, or maybe cause you to ponder a little more about what comes next for you, or a gentle nudge bringing you back to your purpose.

A Journey from Darkness to Hope

As a child, my thoughts were filled with dreams of what life had to offer; of treasures that were measured by their value to the heart. Health issues were real in the world yet they seemed to occur in a faraway place or with people who were well advanced in years. Engaging with clinical teams was the furthest thing from my thoughts as I put in place carefully prepared plans for my adult life. Each phase of life was carefully orchestrated; college, then marriage followed by a meaningful career just as I had dreamed. Life had other plans and threw a curve ball that took me down a path never anticipated. Please join me as I share a life changing experience, a journey from darkness to hope.

You Have, At Best – 18 Months to Live

My dear husband Rob conquered Hodgkin's Lymphoma twice. The full mantel radiation he received in 1984 was the latest in cancer treatment. With cancer in the rear view mirror, we thought the worst was behind us. Fast forward to Memorial Day 2012, as we walked the dock at our marina, he had to stop and catch his breath several times. We boarded a friend's boat for a trip to our favorite lunch spot on a nearby island where Rob had an ischemic attack

that left us both scared and uncertain of what was happening. Later in the week, he was admitted to a regional medical center after a middle of the night trip to the emergency department. A fellow walked into Rob's hospital room and casually stated, 'You have pulmonary hypertension, pulmonary fibrosis and a severely stenosed aortic valve with at best, 18 months to live.' He then turned and walked out leaving us speechless and shell shocked. The attending came in later, deeply apologized for his fellow, pulled a chair next the hospital bed, put his hand on Rob's forearm, walked us through what was happening within Rob's body and helped us gain a better understanding of the actions being taken.

Finding Hope

After several local appointments, there were no viable treatment options. We realized the complexity of his case and of our situation. Our journey took us to the Cleveland Clinic where we not only found options, we found hope. Over the course of the next 3 years, he received a beautiful gift of a double lung transplant with simultaneous aortic valve replacement, a kidney transplant in which I was his living donor, then commando heart surgery - 2 valves replaced, 1 valve repaired and the left ventricular chamber reconstructed. He was the only lung transplant patient in the world to live through such a surgery.

Forever & Always, No Matter What

I marveled at the strength of the man I married; such a passion for life, determination and resilience. He wasn't a perfect patient however, he was real with his expressions of his thoughts and needs. He often reminded me of a quote we had at home, "Forever & Always, No Matter What." We believed that together we could get through whatever came our way.

The lung transplant team led by Dr. Marie Budev joined us on the journey and rallied by our side fully engaging and exceeding all expectations. I witnessed how all other priorities were set aside and true caring for the human spirit transpired as she stayed near Rob's bedside for over 16 hours when pneumonia settled into the new lungs. The team served as the wheelhouse that gathered all needed specialties together. While he was the patient, there were expectations for which we were accountable. The care plan rested on every member of our team. Little did I realize at that time I was watching clinical partnerships play out in real time. While Rob fought valiantly, his condition worsened and the battle was too great. When it came time to let go, the team moved the mountain of protocols and processes to carry out his final wish; to pass on from this life not in the medical ICU but in the peace and tranquility of the heart/lung transplant floor - our home away from home for many months at a time with nurses, techs and staff he loved as family.

It's true that when someone so close to you passes, a part of you dies as well. I didn't think I could be whole again. I sat down with Marie a couple weeks after Rob's passing and she shared, 'the heart never fully heals the hole caused by loss; over time, it just finds a way to work around the hole and Janell, you aren't alone as you learn to work around the pain. We will continue to be here for you.'

I am the Patient Experience; Being Part of Something Bigger

There was something I experienced at The Cleveland Clinic - it was the Patient Experience. What did that mean now? How could I use what I've lived to make a difference now for patients, families and clinicians. I am the Patient Experience. I have lived physician engagement. I have been a sounding board for leadership rounding and watched servant leadership in action. I have coached fellows on communication strategies with patients and their families and have reassured nurses of the reason they chose their field when their emotions hit the wall. What does this mean going forward? I had always taken pride in my skills in operations management and organizational efficiency but my job wasn't fulfilling after being part of something so much bigger.

I started volunteering as an advisor for the Patient Family Staff Advisory Council in the Frankel Cardiovascular Center at Michigan Medicine. From the moment I interviewed with the Program Manager, I felt a sense of belonging. What would it take to work in a Patient Experience role? Was it education or exposure to more influencers in healthcare? I concluded that both would be helpful so I began working on the PX Leadership Certificate program through the Beryl Institute.

As I participated in the virtual classes exploring concepts in metrics, healthcare leadership and employee engagement, I wondered what it would be like to be a PX leader at a recognized health system; reviewing HCAPHS scores from the ED; wondering which subject matter experts to gather to create meaningful and sustainable solutions; or to somehow find a way to help that one particular team see through the lens of the patient and realize the impact of their words. With the certificate in hand, I decided to step into another unknown space and sit for the Certified Patient Experience Professional exam. I studied countless hours and engaged in weekly study sessions with seasoned PX leaders. We banded together like Navy Seals on a mission. When I received notification of passing the exam, I experienced a level of elation that was known to my heart but not felt since the days of being with Rob.

I am the Patient Experience now and soon I will be leading the Patient Experience addressing issues with systems, processes and bringing staff back to the purpose of their work. There is a difference. While others have invested in various clinical training enabling them to treat and heal disease, I have invested in understanding the care of human beings, caring for their inner heart. This is learned and experienced when you're the primary caregiver in a complex case; sitting on the side of the bed when you learn all the intricacies of a complicated diagnosis, or your presence and embrace are the only solution when anxiety strikes with full vengeance.

Moved to Create Meaningful Experiences

It is beautiful when the mind is able to fully comprehend the depth of what the human heart feels. This has been a remarkable journey. Losing Rob was not the outcome I expected or wanted. Reality doesn't always harbor a sense of calm yet now is the time to move on down this new path. The journey began with looking for options, to find hope in the midst of turmoil. It developed into something much larger than the medical struggles we faced. Rob's passion to push through adversity was an inspiration to many. The realization came that even with the latest in medical advances, health care is human beings caring for other human beings. A few months ago as I strategized my aspirations with a trusted advisor, I was challenged to write the story of my journey. "It will bring clarity to your thoughts," she said. I realized the journey brought clarity to what is meaningful. It revealed my purpose. It provided grounding in what is needed to be accomplished.....I need to leverage the experience within my heart to inspire others. With that, I hope to create life changing experiences for patients, families and others along the way.

The Heart of It All

Creating that type of life changing experience involves a challenge to break toward new thoughts. I'd like to charge you with thinking about this field a little differently.

There's so much more than data analysis and implementing communication strategies which script out phrases for encounters. Isn't the patient experience about what is meaningful to the heart; the heart of the patient, the heart of the physicians, the heart of all staff? When was the last time you took a moment to appreciate how impactful your staff and physicians can be to the patient experience? I challenge you to share this with them, to think about a family or a service team that you encountered where nothing compared to what you knew; where N=1. Draw upon the greatness within you and with your teams. When each of us do just that, we will truly make a remarkable difference not only in patient experience, but in the lives of all with whom we interact.