

A PATIENT'S JOURNEY IN CURATING HER MEDICAL TEAM FOR WHOLE PERSON CARE

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Twenty-nine years ago I was born with Short Bowel Syndrome, which required me, from birth, to depend on feedings through a gastrostomy tube and central line. To this day, I require IV nutrition daily. I am not yet thirty years old, and I have had 65 surgeries, including a small intestine organ transplant, and bilateral hip replacements. I understand how the medical system works—and where it fails. I now have an incomparable level of knowledge and first-hand experience with our healthcare system that I hope to use to enlighten and educate.

My care for the last three decades has not been whole-body. Instead, it has been fragmented highly subspecialized care, leaving me doing well in the short term, but with no cohesive long-term plan. I had discussions with my current medical care providers, I left teams that were inadequate, I inquired opinions of new doctors from around the country and curated my own team of professionals from three states in order to LIVE, not survive in a hospital. The result: Whole person care with me as the driver and coordinator.

I will impart pieces of my experience to understand what it takes to create the “pit crew,” the healthcare system was not providing me, and how you as a medical provider can be the best advocate for your patient on their “pit crew.” Hear real examples of patient-provider interactions, the vital importance of shared decision making, and the details behind true compassion that inspire whole person care. ■