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Proem

In May 2019 my wife, a couple of friends, and I went to Spain to hike the Camino de Santiago pilgrimage. Full disclosure, they hiked I road in taxis, in my electric wheelchair, and with canes. Now the same crew and two others are planning a trip in April 2022 to hike the Portugal Camino, God willing, and the creek don’t rise. I thought I’d reprise the three episodes associated with the Spain adventure over the next couple of months to get myself back in the groove. Although the six of us have known each other for more than 55 years, have traveled together in various assortments and conditions including hitchhiking, foreign and domestic, we are all close to or over 70 with various aches, pains, and disabilities. Two years after the Spain Camino I am less mobile and less cocky, but all still rarin’ to go. Plus, if not now, when? This episode, #19, was first aired May 3rd, 2019, six months into my now three-year podcasting journey. No sponsor yet. Less music. Again, still risk taking and curious. Let’s drop in on this flash from the past.

Taking stock 02:41

Hey there, glad you could join me. I'd like to pause and take stock of the past six months and look a bit to the future. We're in the middle of a series with Young Adults with Complex Conditions Transitioning from Pediatric to Adult Medical Care. I've published 7 episodes in this series. I'm taking a brief break on the series and traveling to Spain. While we're here together I'll look back at the series, talk about Spain, and reflect on my patient/caregiver activism journey.

A guest in other people’s lives 03:20

First, I cherish the opportunity to be part of intimate moments in people's lives. In my career as a practicing nurse I thought I had license to be nosey. I was a guest in other people's lives. People are often amazing. They face complicated and frustrating challenges, jump hurdles, find help, and relieve



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boredom with humor. This inspires me. It fuels my fire. It gives me perspective. I've got it good. No, I've got it great. I'll tell you a quick story here.

Glad I'm not him 03:59

When I was an aide at the Detroit Rehabilitation Institute, I was working the evening shift with a man in his 30's who had had a gun shot injury to the neck. He was quadriplegic (no abilities below the neck). He was headed down the hall learning to navigate his motorized wheelchair with his mouth stick. He couldn't swivel his neck. Coming toward us was a man in his late 40's who had had a severe stroke. He was hemiplegic (no function on his left side). He was learning to mobilize in his wheelchair using his right arm and leg. He was listing heavily to the side and visibly drooling. His 20 something wife dressed as for a dinner date was trailing behind looking thoroughly disgusted. My guy glanced over as he took his mouth from the joystick and said, "Glad I'm not him." Gotta love perspective and appreciate what you do have.

Anyway, is this series we've heard from a young adult in high school and in college and a parent. I have 2 interviews completed with people in their 30's, already through their transition, as well as other people in professional support roles for those young adults.

Mobility enhancers rule! 05:25

OMG, I'm going to Spain for two weeks. I first went to Europe when I was 17. I hitchhiked from London to the Lake District, to Amsterdam, Paris, then Scandinavia. I went with my sister's boyfriend who ditched me. It was my first experience I was alone for 2.5 months. I had a great time. I only spoke English and met lots of people - native and fellow travelers. People took me into their groups, their homes, their lives. I mostly slept outdoors or in hostels. My wife and friends are veteran hikers who annually hike for a week or two - the Grand Canyon, Brice Canyon, and more. This year it's the Camino de Santiago pilgrimage in Spain. I don't hike. I've always stayed behind. But Spain? Forget it. I'm going. Ed, a colleague at the Agency for Healthcare Research and Quality, introduced me to a travel agent in Madrid that he and his disabled father used for the hike a couple of years ago. This agent took my wife's hiking itinerary and booked us wheelchair accessible rooms and a driver for me. I'm ecstatic. Mobility enhancers rule!! I will be recording the trip and will share here in future episodes. Stay tuned.

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Gazing past our navels 08:04

Next, what am I doing with my life? My mission is to empower people as they journey toward best health. Best health = peak capacity. Getting the most out of your genetics, your circumstances, and your abilities. Such wide-open possibilities and opportunities. My primary vehicle is my presence: my varied experience, my words, and my heart. As an extroverted person of privilege, I seek and share what works for people and what doesn't. I find tables of healthcare governance, design, operations, and learning to sit at and I give voice while working to open doors for others to join or replace me. Others with different experiences and skills. These past couple of years I've focused on informed decision-making along the health journey, communication and dissemination of research and learning, pain management and reducing opioid use, and transitions of care for people with complex and chronic conditions. I'll continue these efforts as I am able. Recently, I've been inspired to home in on health equity and building the capacity to learn and grow (inspired by my new podcasting friends and colleagues, Ame Saunders of State of Inclusion fame and Maria Xenidou of Impact Learning fame. You can find links to their podcasts and work in the show notes). Neither of these inspirations are health care focused. There's a lot, we in healthcare can learn from gazing past our navels.

Differentiating sound and noise 10:02

This leads me, finally, to the experience of podcasting and learning the craft of podcasting. Learning podcasting from Seth Godin and Alex DiPalma's Podcasting Fellowship has supported me as I fine tune contributions to you. I have entered and enriched a world-wide nurturing, challenging, informative network of citizen experts. I'm already full of myself. This community appreciates me, cheerleads for me, seeks my wisdom, and gently points out where I can grow and improve. As some of my abilities diminish, my senses and voice expand. I can better differentiate sound and noise. I can use sound to listen more deeply. Just as two canes and an electric wheelchair maximize my mobility, the podcasting journey strengthens my voice and my presence. Hang on!

Reflection 11:17

Well, this 2019 episode holds up pretty well in spite of some setbacks and bumps in the road. The charge I felt from completing our part of the Spanish Camino continues to this day. Elation that I could do it! I am not my disability. My disability gives a tint to my spectacles (both definitions of spectacles: drama and vision). I better take my electric chair into the shop and make sure the nuts and bolts are tight. I no longer use canes, rather cane crutches. They take more space. I can't walk as far and I can carry less. Adapting, adapting, adapting. Onward!

