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*Introducing Lisa Deck 00:56*

One of my first gigs in my nursing career was working at the Detroit Rehabilitation Institute. I was working with a 30-year-old man with quadriplegia from a gunshot wound to the neck, practicing driving his motorized wheelchair with a mouth stick. Coming down the hall towards us was a 40-year-old man recovering from a severe stroke learning to maneuver his wheelchair with his right hand and right foot. He was tilting dramatically to his right and drooling quite a bit. His very young wife, quite dressed up, was following behind him, looking bored and a bit disgusted. Out of the corner of his mouth, the man with quadriplegia said, “Glad I’m not him.”

Everyone with a chronic illness has a different story. You really can’t compare. I have my challenges. You have yours. It’s what we know. You’ve heard my rap: we manage or don’t at any given moment with our constellations of genetics, conditions, circumstances, environment, and behaviors. It’s special to meet someone in a gathering of 300+ people with a motley assortment of chronic conditions. Lisa Deck and I met at the Healthe Voices Conference in Dallas this year. We found ourselves across the table at a Society of Participatory Medicine meetup. When we found ourselves at last month’s PCORI Annual meeting, we took the opportunity to chat. Here’s that conversation.

**Health Hats:** Hi, Lisa. Thanks for joining me.

**Lisa Deck:** Thanks for having me.

**Health Hats:** A week ago, we had a virtual picnic. I love the sound of that.

**Lisa Deck:** It sounds very exciting.

**Health Hats:** Really, we plan to meet for lunch, and your son wasn't feeling well. So, we decided instead of canceling we would have a virtual picnic. We chatted. Lisa, how do you introduce yourself at a social gathering?

**Lisa Deck:** Isn't that a million-dollar question? I will say, "I am Lisa Deck, a four-time stroke survivor, and a rare disease patient. I was misdiagnosed for many years, but I've survived two brain surgeries to correct [Moyamoya Disease](#). I am disabled since my early 20s; however, I've become a passionate patient advocate for a variety of organizations. I run a nonprofit called Sisters at Heart. I also volunteer at The American Heart Association. I have been a volunteer advocate and patient for the [American Heart](#) and [American Stroke Association](#) for almost two decades. Now I'm involved in the rare disease space with [Rare New England](#) and speaking and sharing my story in a variety of different opportunities. I tried to take advantage of sharing my story because I think it provides hope. I'm learning even here at PCORI and different events that make me recognize that as a patient I have a wealth of experience I can share. I'm learning that I have value, and I can bring that value to a bunch of different situations.

**Health Hats:** Where were you when you first realized that health was fragile?

**Lisa Deck:** I had a random sledding accident when I was a junior in college. It was New Year's Eve day. I was visiting a friend up in Burlington, Vermont. I went sledding, and unbeknownst to me going down a hill there was a ramp built in the hill. I went off and came down in the sitting up position. Picture somebody sitting on a sled going up and landing straight down, and I broke my back. That was the first major injury I had in my life. Besides the pain and the recovery, which was about three months, I had to wear a brace that made me sit up straight and correct the problem in my back. It was a T12 compression fracture.

**Health Hats:** A low fracture.

**Lisa Deck:** Yes, it was pretty low, right at the bottom of my spinal column with all the health challenges. It was my first realization that my plans for life might not be what I wanted them to be. That accident took away my ability to study abroad in Spain. I was supposed to leave five days later to study abroad. It had been a big decision for me to make that decision to go because I was not adventurous. I was leaving what I knew. So, I made the decision, and it was taken away from me. And that was my first mental exploration at overcoming a challenge.

Four strokes between 21 and 39 06:11

**Health Hats:** Tell us about four strokes. You're a young person.

**Lisa Deck:** I was, but I still am.

**Health Hats:** You still are.

**Lisa Deck:** A year after my sledding accident, I suffered my first stroke, and that's when I say my health journey started. I do think my broken back helped prepare me for what was to come.

**Health Hats:** Because you were in your 20s?

**Lisa Deck:** I was 21 years old. I was about to graduate from college. It was a week before college graduation. I had all the typical signs and symptoms of a stroke but didn't recognize that stroke could

happen to young women who seemed healthy. The first hospital sent me home. The second hospital diagnosed me with the stroke. That's only because I was proactive and went back. The first one sent me home, and I decided I was in too much pain. I had all the symptoms. I didn't know what it was. It was shocking to find out it was a stroke. I did lose some movement in my hand at that point. I eventually gained it back six months later with OT.

**Health Hats:** Occupational therapy?

**Lisa Deck:** Correct. Six months later, I suffered a second stroke. I was on my first day at a client, and the same symptoms happen. The doctors admitted me for about three weeks to find out what was going on. At the time they diagnosed me with [central nervous system vasculitis](#).

Central nervous system (CNS) vasculitis is among a family of rare disorders characterized by inflammation of the blood vessels, which restricts blood flow and damages vital organs and tissues. A serious condition, CNS vasculitis can block the vessels that supply the brain and spinal cord, causing potentially life-threatening complications such as loss of brain function or stroke.

The treatment was intense. It was a full-court press. So, I was 22 years old and was undergoing chemotherapy, prednisone, and blood thinners, all to stop the strokes over those years. The side effects were plentiful. I had a third stroke, and the doctors took me out of work, and that was a huge disappointment for somebody who always had a plan. Yeah, my plans were gone.

**Health Hats:** What kind of work were you doing?

**Lisa Deck:** I was in IT consulting. I didn't necessarily know what I wanted to do, but I had always worked hard at being a good student and achieving and having the hopes of making a difference. Accidentally, I found a way to make a difference. But it wasn't the plan that I had in mind. After my third stroke, eventually, I was in declared remission of that disease. My life went on. I became a volunteer with the Heart Association. I looked for other patients, other people to help me figure out what was going on. That is what I did with the Heart and Stroke Associations. I eventually married. We grew to a family of four and eventually moved out of the DC area back up to New England. At this point I had a wonderful opportunity with the American Heart Association. I was selected to be a national spokeswoman, and that was an opportunity to take my story and share it nationally. It was changing the perception of stroke. If you look at me, I look like a young woman, and you don't see a deficit. There isn't a physical deficit. I now can use the term invisible illness. It was a way to show people that stroke can happen to anybody, not just the elderly. I was excited about this opportunity. I started a website, and I was going.

Not yet a superhero 09:59

Then I had a fourth stroke. Now this was a different opportunity or different situation because I had two young children at this time and was 39 years old. I was a mom, and while it was about me, it wasn't as much about me as it was my children. After the fourth stroke the doctors diagnosed me correctly with Moyamoya Disease. All those years it had been an incorrect diagnosis. And Moyamoya is a rare cerebrovascular disease that causes narrowing of the middle cerebral artery and causes strokes and seizures. All this time that's what was happening to me. We didn't know that, and I was very happy to have the correct diagnosis. But then I heard the bad news: there is no cure, and there is treatment. I

soon learned that I would need not one but two brain surgeries. In doing the research, I had become more of an engaged educated patient. I decided if I was going to have brain surgery, I wanted to go to the best neurosurgeon for Moyamoya Disease. My research took me across the country. I had to leave my family and my children for about a month to have these brain surgeries. Fortunately, I have supportive family and supportive community. Looking back, it went as well as it could. But as you can imagine, brain surgery is challenging and painful. I lost my speech for a while. I had nausea, pain, fatigue, bruising - typical stroke pieces. I'm happy to say the surgeries were successful. They increased my blood flow seven times to what it was. My husband thought I might become a superhero. I have not yet, but I did go home. For probably about two years I had a lot of mental and emotional healing to do. It all happened so fast. I was focused on my children, not on me. How do we make this okay for them? We did, but there was a lot of PTSD and soul searching. Now it's been four years since my surgery. I'm happy that I am doing much better. Now I'm more fully committed to giving back and helping others because I can.

[Becoming an engaged patient 12:27](#)

**Health Hats:** Let's talk a little bit more about being an engaged patient. That's such a big term, and there seems like there are so many pieces to that. When you were talking about researching to find the right surgeon and the right treatment, that was one part of engagement. How else do you think about that both as a patient and as an advocate?

**Lisa Deck:** I want to take you back to the beginning of my story when I was a 21-year-old who's left side went numb. I had a terrible headache, and I'm in the basement of my apartment, calling my parents asking, "what do I do?" They told me to go to the hospital. That hospital sent me home. For context, this doesn't matter, except I was graduating. I had a job set up for that September. I was graduating magna cum laude. There was no stress left. I had one or two exams, but they didn't matter. I was a very good kid going to this doctor. They looked at me as a college kid partying, convinced that I was doing drugs. I told him I wasn't. I could have said - this occurred to me years later - do a drug test. Test me, but I wasn't thinking. I was a kid. I had no idea to do that — fast forward 20 years, where I have been working with doctors and working with hospitals and insurance. As you know, as a patient you become an expert. I now had this new stroke and new possibility of how to treat it. I knew what to do. I knew the questions to ask. I also knew that I couldn't just decide. I had to talk to my insurance. So not only did I have the technical skills to go through and talk to insurance. I knew what it was to get second opinions. I had known as a patient what I needed to do. I now was able to accept help. In my early 20s, I thought, "I can do this." I was very pig-headed. You don't know until you learn. I think now I can help other patients. I tell people. "accept the help or write down what you want or have somebody come with you and take notes." It's not only the technical piece. It's how you navigate your emotional experience as a patient to make it the best for you. Somebody was telling me the other day; the minute you hear the diagnosis, you don't remember anything. Bring somebody with you. It's the big things, and it's the little things. I guess that's what you learn in time, and I don't wish for anybody to be a patient. But as you go you learn a lot more, and that can help others.

**Health Hats:** So, there's the engaged of the research. There's the engaged of speaking up for yourself. There's the engaged of asking for help. In my advocacy now, my frame is being the CEO of your health,

being the CEO of your health team. A good CEO doesn't do everything. The good CEO has a team and knows when to delegate.

My multiple sclerosis is progressing very slowly, but it's progressing. My neurologist prescribed an infusion twice a year that costs \$100,000 a dose. I asked my neurologist if I needed to get it. I understood every word he said. But my brain couldn't put all the words together. Thankfully, I had my Abridge recording app turned on. I had pushed the big pink button. I went home. My wife and I listened to the transcription several times. We decided it was worth it. I'm grateful that we could take time to make an informed decision. Thank you Abridge. Abridge was created by patients, doctors, and caregivers. Check out the app at [abridge.com](https://abridge.com) or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Introducing kids to health and wellness, illness 17:13

So, you're a mom. You have two kids. How have you introduced them to health and wellness, health, and illness?

**Lisa Deck:** It's interesting because my story began before them. I held on to and became a stroke survivor. I was proud of that title because I didn't have a job in the typical sense. But I was a very active volunteer. That is who I always was. I was open with my story because it provides hope to people. That's a way for me to connect to people, to other patients. It never was a secret to my children that I was a volunteer and a survivor with the Heart and Stroke Association. Both my children have been to many events. They always knew that mommy had had strokes. They didn't know what strokes meant. When I went into the hospital for the fourth stroke, I debated should they come in? Should they see me because my side was numb? I still looked fine, but I was concerned. They came in, and I said, "I've had these before. They're very serious. But I'm okay, and we're going to figure this out." It was a whole new perspective because they were six and eight. When I look back, that's little. They're little. They don't understand. My husband and I figured out what they could know and what they couldn't know. I look back, and we did hold some things from them. But we didn't hold most of it. The primary thing we had to tell them was, "I'm going to California for a month, and you're not going to see Mommy and Daddy for one month." That is hard to tell little kids. That was all that concerned us. That's not getting to your point. Even when I speak, I talk about that. I don't even talk about the surgeries. The surgeries were terrible and hard, but the piece that was the most difficult was leaving and hoping they were okay. But in talking about that since then, wellness and illness have become a huge part. They know that now it's so critical. And it's always been critical, but I need to be well. They know sometimes mommy has to rest. I noticed earlier you had a pin that says, "I love naps."

**Health Hats:** "I'm good at naps."

**Lisa Deck:** I'm very good at naps, as well. And I think my kids and I joke about it. But they know sometimes mommy needs to rest. They know that I'm always telling them, "we should exercise, we should walk. We should do things to be healthy." My kids are involved in many things. They have not

found one activity that is their huge passion. But throughout the year, they need to do something to move. They know that is all part of health and wellness. It's not just going to the doctor and making sure you're okay. It's living that lifestyle. I also think they are aware of how much work it can take to manage my health care. They see that I'll be on the phone with insurance and then I come in with "oh my goodness. I can't figure this out." So, they're aware of that. I think they do recognize how many pieces there are to be the CEO of your health care. I try to teach them a lot is empowerment and confidence.

**Health Hats:** How do you do that?

Learning to fail well 20:42

**Lisa Deck:** I give them the ability to make decisions and to learn that they can do things. I'm not great at it.

**Health Hats:** Does that mean that when something needs to happen, you could choose this, or you could choose that. They have choices, and they're making choices about themselves, or is it like pumping up their confidence that you can do it?

**Lisa Deck:** I'm going to say yes to the first piece. I think it's giving them choices and then saying you live with that choice, and you have the power to make that choice. Then that's what you do. Also, I know that I have put my kids in situations where they weren't going to succeed, and I think learning to fail is okay. I don't love it because I like to win. I was an athlete back in my day, and I am competitive. But sometimes you have to learn how to fail. That's what I've learned in life by my health problems. For my kids, there are certain things I say, "it's okay; you don't have to win." But doing it provides confidence even if they're not going to win or succeed. You still try. That's what I try to teach them.

Healthy equals balance 22:05

**Health Hats:** Now that you've been through all this - what a story. What does healthy look like to you?

**Lisa Deck:** I'm finally finding healthy. My emotional stability was challenging for a couple of years. I remember someone saying after surgery, another fellow Moyamoya patient, give yourself at least a year, and I did. Even after the second year, I was still challenged. I found most was my ability to manage stress was lower. I was very overwhelmed certain times. I would have these little breakdowns and turn into a puddle, and I think now I am doing well. I've taken charge of my physical health with the things I can control, which are my eating well and exercising and self-care. I know self-care is all the rage. I do think taking care of myself, and I apparently like you like to do many things, and I like to learn so I'm often saying yes to opportunities because I want to keep learning and I want to keep helping but I'm finding there are times I have to say no and I have to set my boundaries. Yes, so healthy to me is maintaining that lifestyle where physically I'm able to be in good health, but emotionally having the connections with my family and friends and having the things that excite me like travel and reading and journaling but also that downtime I need to take naps or to rest. So, it's trying to kind of find that balance. I think that's what healthy means to me.

**Health Hats:** Okay; balance. Yeah, that's good. I find that for me, one of the most important things I think I've learned is to manage the manageable stress.

**Lisa Deck:** Absolutely. Right

Please bother me with your problems 23:50

**Lisa Deck:** I think it's true. It goes back to breaking my back. It's still, to this day, probably one of my biggest disappointments. That situation could not be recreated. I did go travel through Europe. But it's not the same. My strokes took away a profession. But I was able to find what I'm doing, and that is satisfactory. Having that perspective is great, but you still day-by-day and minute-by-minute need to figure out how to remember that. As much as we have these huge things hanging over our heads that are chronic long-term illnesses. You still can't fight with your children or still have to parent. You still have to figure out how to pay the bills. I found that when I was sick at the time, people didn't want to bother me with menial, silly things. I was like, "please tell me about the latest problem because I am sick of thinking about my problems. I'd rather talk." That's another piece of advice I gave to somebody in my town just recently who was diagnosed with an illness. I reached out to her and said, "I have a couple pieces of advice, and you don't have to listen, but they're things I've learned. One of them is don't shut yourself in and don't let your friends not talk to you about their stuff because that's important because that's what life is so challenging.

Life's absurdities 25:36

**Health Hats:** Dealing with the chronic illness with your strokes - having all this experience with the health care system is often an infuriating and crazy-making shit show. The best part of the Health Voices conference was the talent night where people were making light of their many disasters. We/I was in stitches.

**Lisa Deck:** Absolutely, me too.

**Health Hats:** Not only was I in stitches, laughing so hard is so cleansing. Clearly, when you're in the middle of stuff, you want to kill somebody, but you can't enjoy it until afterward. What kind of experience have you had that was so absurd that at the time was infuriating, but since has been one of those absurdities?

**Lisa Deck:** I will tell you this story. One comes to mind. I look back. I was so naive. Back in 1997, at the second hospital where they were trying to diagnose me with the stroke, I was in pain with a severe headache, and my whole side was numb. The lights were too bright; the sound was too loud. I had gone for a CAT scan and maybe an MRI. It's a little blurry. I remember they wanted to do a spinal tap. I didn't know what that was. But I said, okay, because, again, I just did whatever they said. Mind you; I was 21. "We have a resident who is going to perform the spinal tap. Is that okay?" Again, I don't know what a resident is, and I thought I was educated. I said, "sure no problem." If you don't know what a spinal tap is, it's where they take a long needle and put it into the bottom of your spine to extract fluid. I think the idea was to determine if it was a stroke or not. In my head, I didn't understand. So, I am lying there. My friend was there with me, a college friend. Picture this: we're in this little room, and we have to turn toward them in a gown. They have to expose my entire back side so they can get to the bottom of my spine. They say to my friend, "you might want to hold her hand." So, I'm holding my friend's hand and the resident proceeds to miss three times. They hit my spine, just not the right spot in my spine. This pain was as much pain as I've probably felt. A huge needle going into your bone and missing, and they say, "oops wrong place." Come to find out this resident had never done a spinal tap. So, my bum is exposed, and there's a very handsome doctor there. I become like a trucker. The things that were coming out of my mouth were terrible. I'm swearing and screaming, yelling, and I'm saying terrible things because the



pain is so horrible. Of course, this good-looking man is right there, and I don't care. He's looking at my butt. I look back, and it was terrible. It was crazy. Finally, I said "okay, enough. This isn't working." They eventually have a doctor do it who had experience. It didn't hurt at all - one shot in, no problem. I look back on this silly time where I was swearing, and my bum was showing, and I'm very embarrassed. But I look back at the absurdity and say how did I not say no to that? How did I not say no after the first miss? There are so many lessons learned. I'm embarrassed by the whole situation, and I never saw those doctors or any of those people again. Thank goodness, I wonder if someday they'll ever appear and say, "I was that one." I might punch them in the face. That's the absurdity. So terrible at the time and it wasn't until years later, I can look at it and laugh and say wow. Things I've learned it's terrible, but it was funny.

**Health Hats:** What should I be asking you that I'm not?

You are an expert now 30:42

**Lisa Deck:** One thing that I ask myself is, "what's next?" Coming to conferences like this and talking to you and talking to people, there's so much to be done. I want to tell other patients, "You have power." I heard somebody say today, "finally after 40 years, I was able to take and recognize that I had experiences that other people needed." That is something all patients don't recognize. You might not even realize it as you're going through it, but you have an inner strength, and you're gaining knowledge and power that you can share. Healthcare today is changing. We have a voice. We need to share our voices whether it be a personal story or whether it be with the healthcare system or through patient engagement. You can be the CEO of your health care and take care of yourself and those around you. You can help make a difference. The collective power is there. That's what we're doing. I'm not sure exactly how I'm going to do that, but I'm open and willing to be a part of it. It's very exciting.

**Health Hats:** Anything you'd like to ask me?

**Lisa Deck:** What do you enjoy sharing most with your podcasting audience?

**Health Hats:** That's a good question.

Legal to be nosy 32:09

**Health Hats:** I like discovering and sharing stories of hope and help. I've been a nurse for 45 years and a direct care nurse for 20 to 25 years. And the part about being a nurse that I enjoyed the most was that it was legal for me to be nosy. I was an intimate part of people's lives for a few minutes. I enjoyed that. I felt like I was a guest in their life. I was a translator and a connector. I enjoyed that. Then with the MS I really can't do that stuff anymore. One of the things I like about podcasting is that I have license to be nosy again. I'm a guest in your life for a minute. There's something about sharing these stories. What can we learn from each other? In the next five minutes or your next experience, there's a seed that you can plant. "Did you guys listen to that podcast with Lisa Deck? She said, blah blah, and it clicked in my mind." If it gives somebody a moment of strength. My audience is not only people who are see themselves as patients. Some are also professionals. Can they realize that we are the CEO of our health? They are the guests in our lives. Maybe have that moment of realizing some of that.

**Lisa Deck:** I think the potential of collaboration and teamwork is huge, and it's exciting. A podcast like this does that. Not only are you asking for a story but what have you learned? What are some of the



things that work? What does that look like? And I think by having that conversation opens it up to other people so. Thank you for having me. It's really exciting to be chatting. Thank you.

**Health Hats:** Yes, thanks for joining me. This has been great.

**Lisa Deck:** Wonderful. Yes. No problem.

Reflections 35:18

Wow, four strokes by age 39. Quite a record for a sportswoman. I hear a story about trust. First, no benefit of the doubt by the first diagnosing person thinking that Lisa was a drugged-out college student. Then Lisa's trust in herself as a patient expert. Experience and engagement reinforce each other and builds confidence. No mystery that I appreciate I'm "good at naps." My grandkids knew from day 1: "Opa, you need to rest, don't you?" "Yup, I'm just closing my eyes for a few minutes." So far, I don't know how else to introduce young people to choices about health, wellness, or illness other than including them when someone in their lives is actively making such choices. Lead by example. Also, no mystery that I appreciate Lisa's emphasis on telling her story. I'm delighted to be a channel.