



# PODCAST

## *Meet the Host: Stephanie Buxhoeveden*

Episode 123 – Podcast Transcript

[music]

[(0:15)] Roz Kalb: Welcome to the Can Do MS Podcast. This is episode 123. Hi, my name is Roz Kalb. I'm a psychologist and senior programs consultant with Can Do MS. I'm really pleased and excited to be here today with Stephanie Buxhoeveden, a friend and colleague of several years who's going to be hosting our Can Do podcasts in the future. She's the perfect person to fill this role because her own personal and professional experiences are going to bring out the best from all of our guests. Now welcome this opportunity to help all of you get to know Stephanie. So welcome, Steph. When I first met you 10 years ago, you were dealing with a brand new diagnosis of MS. Can you tell me and the rest of our listeners where you were in your life at that time?

[(1:23)] Stephanie Buxhoeveden: Absolutely. When I was 25 years old, I was a competitive weightlifter, a neurosurgical ICU nurse, and enrolled in an extremely competitive graduate program to administer anesthesia. So, I was going to become a, what's called a nurse anesthetist. I was pretty much the picture of a young, healthy, and ambitious person, until one day I noticed that my right foot was numb. Then over the next week, that numbness in my foot gradually crept up both of my legs, but I brushed it aside hoping that I just pinched a nerve while weightlifting and knowing that if it was anything more serious than that, I was not prepared to face it. The truth was, as a neurosurgical nurse, I saw the devastating effects of neurological disease every single day while I was at work, and I just refused to see myself as anything but young and invincible. But one day while I was in the operating room as an anesthesia student, my symptoms became so bad that I finally realized I needed help and I needed it fast.

At that point, I had lost all the feeling in my right arm. I wasn't able to move the muscles of my dominant hand, so I wasn't even able to push buttons, drop medications into a syringe, and my eyesight was so blurry that I wasn't really able even to see the monitors for my patients. So, I called my teacher, I went downstairs to the ER thinking again, they were just going to tell me it was a sports injury, no big deal. Uh, but little did I know when I walked into that hospital that morning as a healthcare provider, I wouldn't leave for over a week. And when I did, I left as a patient, and that admission was full of MRI scans, lab tests, spinal taps, you name it. Uh, and it took about a month to get the results back, but when they did, they came back as multiple sclerosis.

[(3:09)] Roz: That must have been an amazing disorienting day in your life. Uh, it's just hard to imagine what that impact was. So how did getting that news... um, you knew enough about multiple sclerosis as a person with a neuro background. How did that diagnosis impact the path that you had set out for yourself as an athlete and a nurse and just everything you had in mind?

[(3:42)] Stephanie: Yeah, and I think it was even harder because when I was diagnosed, uh, I was told that I had a particularly aggressive form of MS and it had already severely damaged my spinal cord, and they told me that because most of my disease was in my spinal cord, that my prognosis was pretty poor. They predicted I'd become too disabled to walk or continue going to school and advised me pretty much from the start to revise my career goals and start planning for the future. So, at the time, my way of coping with this news was- wasn't exactly denial, but just stubbornly resisting any sort of change. Like I was not about to let MS change the path that I had already laid out for myself. So, I continued school. I didn't even take a leave of absence, um, but my medical bills were also stacking up pretty quickly.

So in addition to school, I took a job as a nurse at the local MS center, uh, which was really a good fit because I already had a background in neurology, and that's how I became a nurse in the same MS center where I was a patient. But at that point, I wasn't really comfortable talking about my MS. It wasn't out of the closet, so to speak. Um, so only the people working there knew I had it.

Then there was a Friday afternoon, I was just about to leave for the weekend, and the mom of one of our younger patients called me in tears. Her daughter had stopped taking her disease-modifying medication and was deteriorating quickly, but she was 18 and legally allowed to make her own medical decisions, and the mom was distressed, didn't know what to do. So, I sort of whispered into the phone like, I have MS too. Like it was this big secret. Um, and I told her that I know being diagnosed at 25 is very different than being diagnosed at 18, but if her daughter wanted to talk, here's my cell phone number, tell her she can call me anytime.

Didn't really think she would. But that night, she actually did call me, and we spent three hours on the phone just talking about life, moms, and the future, not really even about MS, but by Monday she was back on her medication and we're still friends to this day. And that was the first time that I used my perspective as a provider and also as a patient to have an impact on somebody else living with MS. And that's when I realized like, this could be my purpose in life. Right?

So that week I chose to do something that scared me more than anything in the world. More than having MS. More than that is to leap into something with absolutely no plan. It is not in my nature. Um, much less something with a high risk of complete and total failure. But I went on to get my nurse practitioner degree and a few years later became the co-director of a comprehensive MS center in Virginia. And soon realized I had a strong desire to become more involved in MS research in order to advance the field. So, I decided to go back to school once again. I'm currently a PhD candidate and the first recipient of a NIH pre-doc fellowship in my school. And as a fellow, I'm researching how epigenetic changes which occur through exposure to different viral and environmental, and hormonal factors drive the onset and progression of MS.

[(7:00)] Roz: So something you said really, um, makes me want to ask another question.

[(7:06)] Stephanie: Yeah.

[(7:07)] Roz: So now you're a researcher and you're a clinician focusing on MS and MS research. So how do you think wearing those two hats has impacted the care that you give or the research you do for the good, but also in negative ways? Is there any- anything?

[(7:29)] Stephanie: Yeah. So, I think that's a great question. Uh, and people often think being a

clinician and a researcher gives me the advantage as a patient, but I would actually argue it's the other way around. Uh, I think being a patient has far and away made me a better clinician. It has taught me what's most important to my patients, which often is symptom management. We spend a lot of our time as clinicians and researchers focused on disease-modifying therapy, when in reality that's just a tiny, tiny piece of what gives the people living with MS quality of life. Um, and to me that's managed my symptoms effectively so I can keep going in doing the things that I love to do. And it has been a life lesson that there's no board exam or a textbook that will ever teach you what it's actually like to- to bring a disease home with you every single day. Um, and I have learned more from living with the disease than I ever could by studying.

[[8:33]] Roz: That's a- that's a great answer. And, uh, I think one of... that all of us in the field should- should take to heart, um, whether we're clinicians or patients. So, what about your personal life and all of this? You clearly proceeded on your professional path without letting anybody tell you that you couldn't or shouldn't. So how about the- the plans and dreams you had in relation to your personal life?

[[9:05]] Stephanie: I think my personal life, um, both has and has not changed for my original plans, definitely a yes and a no. I have lost some friendships from living with MS, including the loss of one of my best friends, who was actually the first person I called from the emergency room who just never called me back and completely vanished from my life once she found out what was going on. And while that was incredibly painful, uh, there were handfuls of people who actually stepped up, people I would've never expected. Coworkers, acquaintances who completely surrounded me with love and support at that time. And it's also deepened my relationships with my family, with my friends, and with my husband.

[[9:51]] Roz : Well, in terms of your personal life, are- are you at the place at this point where you pictured yourself? Or is anything different in your personal life than you had thought would be part of your life going forward?

[[10:07]] Stephanie: Uh, so I think that's a really great question. And honestly, before being diagnosed with MS, I wasn't sure that I wanted children. And since being diagnosed with MS, my husband and I haven't definitively decided we're never going to have children, but also we're not at the place where we want to have kids. That has nothing to do with my MS diagnosis. I know that women with MS do wonderfully throughout pregnancy. Uh, there are some considerations for afterwards. Um, but that has never been a major factor for me and my MS is having children. It's just something that we had already decided beforehand and maybe it's a little easier to not have kids and deal with MS, but that's certainly not the- not the driving force behind our decision.

[[10:59]] Roz : Awesome. So, you've mentioned your husband. Um, so when did he come into the picture, Steph?

[[11:06]] Stephanie: So, my husband and I actually met in college. We met as undergrads, and we had been dating for a few years and living together. When I was diagnosed, he was in New Jersey for medical school, and that's where I was getting my master's degree. And he just had a lot on his plate. So, I actually didn't really even tell him when I started having symptoms. I didn't want to distract him. He had a big test to study for. I didn't want to worry him and add this to his stress.

So, he was pretty surprised when I texted him that I was in the emergency room, but he was by my

side the entire week that I was hospitalized. And when I was diagnosed with MS, you know, I realized this was an incurable condition. They were telling me that my prognosis was poor, and I sat him down and I said it would be completely fine. No hard feelings if he did not want to stay. He was going to be a doctor. The world was at his feet, and I really could no longer say the same thing. But luckily, I chose well when I picked him as a partner and he proposed just a few days after I was diagnosed. And after hearing the hundreds of stories from other people living with MS and my patients, I realize how incredibly lucky I am to have a partner like him.

[[12:21]] Roz : So in addition to proposing to you and demonstrating that- that he's the most wonderful possible partner for you, what would you say is the most important thing he does on a day-to-day basis to support you and your busy active, uh, lifestyle?

[[12:40]] Stephanie: It's Michael, my husband. He's probably the most cool, calm, and collected human being you'll ever meet. I've seen him get angry maybe three times in our 13-year relationship. Uh, but one of those times he was incredibly mad at me and that grabbed my attention really, really quickly. I think I've mentioned this a few times, but I am stubborn. I don't want anyone to tell me what to do. I certainly did not ever admit- admit that I needed any help. And he sat and he watched me overexert myself, put myself in potentially dangerous situations, all while telling him I didn't need or want his help.

And I thought I was being brave, but now I can see I was actually being pretty cruel. Uh, he was going through this just like I was, and he wanted to do something to help, and I kept denying him that over and over and over. So finally, he snapped at me and that completely changed my perspective, and it took a long time to learn how to be open and honest about struggling and to tell him and the other people I love the most, that I wasn't okay, and that I do need help. Uh, but our relationship has improved as a result. Although he does frequently, almost daily need to remind me that I need to tell him when I need help and that I need to accept it.

[[14:01]] Roz : You know, I- I can really relate, um, to Michael on this one because hearing your story, one could be forgiven for thinking that you're one of those people who has outmaneuvered MS. You know that you have one-upped it many times over and if our listeners could see you, uh, they'd be even more convinced. So, what I see, uh, on my screen right now talking to you is a healthy-looking, absolutely beautiful, very talented young woman who's carved out this full, interesting, productive life. But we all know that's not the full story. So, when you admit to yourself that you need help or you need support, or you need to reach out to Michael for something, what's going on inside you that we can't see? If you're comfortable sharing that?

[[14:57]] Stephanie: Yeah, absolutely. And honestly, I used to, and sometimes depending on the setting and who I'm with, go through great lengths to cover up the fact that MS impacts my daily life. However, I've come to realize it's more important to be honest, not only because it makes me feel better, but it shows other people why it's so urgent and important to find a cure for this disease because it affects millions of people and by and large it's an invisible illness. So, I might have difficulty with my speech, I might need to sit down. I might suddenly need to run to the bathroom while I'm in the middle of a meeting or teaching a class. Um, but to me, bravery means being at peace with making those accommodations in order to accomplish big things. And I honestly can't even count the number of opportunities. Anything from hiking with friends to large public talks that I turned down because I was scared, I wouldn't be able to hide my MS.

So now I'm excited and proud to share the work that I've accomplished while making space and acknowledging my disability. And that's just one small way that I can help achieve a more equitable world for the other people who are living with disabilities. And obviously, as you know, very, very well, everyone with MS is different. And although I have used assistive devices in the past to walk, I'm doing quite well right now. My foot drop only comes on with extended walks or exhaustion or if I'm sick. Uh, and I'm a little limited in how far I can go and how long I can be on my feet for, but most of my symptoms, like you said, are invisible. So I have a lot of numbness and pain in my legs and in my face, a lot of muscle spasticity, uh, bowel and bladder issues, all of which I take medications for.

And over the last decade, I've really learned a lot about how rest, how diet, and how exercise truly do affect all of those symptoms. And that's been the key to my success. And it took a lot of trial and error. And at sometimes it feels like a moving target because my symptoms will change day to day based on sleep or stress or the weather outside. Um, and it's something I'm constantly and always working at, but I never give up because if I don't manage my symptoms effectively, I can't do any of the things that I enjoy.

[[17:21]] Roz : So you've mentioned how much your MS changes from day to day and how you've had to flex in your strategies of- of self-care. Um, and I'm sure our listeners can really relate to that because everybody worries about how unpredictable this disease is. So now you're a clinician and you're a researcher, you're managing your own MS as well as helping countless others, um, manage theirs. So, do you feel that you have a better handle on what the future is likely to be for you? They gave you a pretty dire prognosis at the beginning. So, what goes through your mind now after these years have gone by, uh, about what the future might hold for you?

[[18:09]] Stephanie: Yeah, I would say I definitely feel like I have an advantage because I am fluent in all this medical jargon. I do know how to interpret and implement research results, but I still struggle with a lot of the same things that most MS patients do. Like recently, I started getting the MS hug, which is that really intense squeezing around your torso and hurts. It's terrible. But I was sitting there wondering like, is this a new symptom? Have I had this before? Does this mean I'm having a relapse? What's going on with my body? I can't tell. And if I can't tell, I know other people must be struggling with the same type of questions, right? So, I also have come to realize I'm incredibly bad at taking care of myself. I'm great at managing other patients, but I will come up with a very scientifically sound reason why it's not a big deal and I don't need to bring it up to my doctor [laughter] and I don't need to go get tests done because obviously, I'm completely fine.

So for me, it's been really important to find a neurologist who knows that about me, uh, and is okay with telling me that I'm wrong and I completely deferred to them when it comes to my own care. And I don't know if this is just having lived with MS for over a decade now or having less... um, or having the opportunity to get to know so many other people with MS. But I would say I'm much less worried about my future than I used to be. You know, I've had to use a cane and I've had to use a wheelchair, which when I was first diagnosed seemed like the worst-case scenario and I thought life would be over if I ever needed those things.

But lo and behold, I was still the exact same person just from a seated position. I still had the same stubborn personality. I still accomplished everything I wanted to, even if it was different than the way I had planned it. And I've realized that parking in a handicap spot or using an assistive device or canceling plans on a bad MS day, even turning down potential opportunities in order to

prioritize my health are not life ending events. And sure, I've had times where I grieve what could have been, I get angry at my situation, but nobody's life turns out the way they planned. I've never met someone who's on plan A for their life, right? Change and unpredictability are part of our lives whether we know it or admit it.

And MS has shown me above all that I'm strong and that I'm capable of handling it. And I know that whatever uncertainty happens in my future, whether it be related to MS or not, that I have the tools to deal with it. And also, as a researcher, I have a lot of hope. There are advances coming that will mean a better future for people like me who currently live with MS. It means that the next generation who's going to be diagnosed will have hopefully an easier path than myself and those in the past. And maybe one day we'll even figure out how to prevent MS in most people.

[(21:13)] Roz : You know, a little aside here, but as you were- as you were describing, um, the MS hug, I- it occurred to me that you as a clinician and researcher should advocate to change the name of that since...

[(21:25)] Stephanie: Oh, it's the worst.

[(21:26)] Roz : Since it's- it feels so awful when a hug can feel so wonderful. So maybe you could work on that in your spare time, Steph, and- and come up with...

[(21:36)] Stephanie: Absolutely

[(21:37)] Roz: Better name for that. So...

[(21:39)] Stephanie: I'm so thinking the python grip would be appropriate.

[(21:42)] Roz : The python grip. The- the MS python grip would be just perfect.

[(21:47)] Stephanie: Yeah.

[(21:47)] Roz: Um, so before we- before we end here, I think there are one or two other things I want to ask you. One is, from your perspective today, if you could say anything to the young women and men, um, who are getting diagnosed with MS today, what would that be?

[(22:10)] Stephanie: I would say first and foremost, being diagnosed with MS today is not the same as it used to be. Even in the 10 years since I was diagnosed, we have so many more treatments, all of which are getting increasingly more effective, easier to tolerate, come with fewer side effects. Focus on not only just finding the right medicine for you, but your relationships. Learn from me and my mistakes that I made early on. Communicate with the people around you. Tell them what you're going through and what you need- and what you need and give yourself a lot of grace.

It feels like a rollercoaster at first. You never know what the day's going to bring or how you're going to feel, but everybody is lost at first. In time, you'll learn how to live in this new body of yours. You'll one day just be doing the things that you used to do and forget that you have MS, and you'll understand what makes your symptoms worse and what makes your symptoms better. And I think that's the key. Prioritizing your health, your wellness and one day MS will just be a small piece of who you are and your story and stop being this all-consuming monster that kind of like hovers over

your head. I promise, it just takes time.

[(23:30)] Roz: I heard a, uh, an interesting, um, bit of advice in there about, you know what makes your symptoms better and worse. And I- I think that listening to your body and paying attention when your body's talking to you is- is a really- a really good piece of advice for folks.

[(23:50)] Stephanie: Yeah, I think that's for me been the most important lesson. And I would say that we put a lot of emphasis on listening to our bodies and finding the right medicine and addressing our symptoms. But it's also really important to be in tune with your mood and your mindset because depression and anxiety are very common and also as treatable as any other symptom. You don't just have to live with it. So, I've learned that when I start dreading or avoiding something I typically love, it means that I have to make an adjustment. So, for instance, I went from working pretty much full-time from home. It was easier to ignore my MS because the bathroom's right there, food and drink are in the other room and I'm sitting most of the day. But when I started this fellowship, uh, I had to go back to being in person full-time and I was starting to dread it.

I mean, I went from being a person who hated quarantine because I needed to be around other people to a person who absolutely dreaded getting up and going to work in the morning and finally asked myself why. And then I realized, okay, well I work in a city, I park my car three-quarters of a mile away from the building I work in. I have to navigate multiple flights of stairs. I stay on my feet for about eight hours a day, then I have to walk the three-quarters of a mile back to my car and get home where I have to attend to my family's needs and cook dinner and take a shower. And it's just a lot.

Uh, and that's when I finally admitted that I needed to make some accommodations. So that was when I got my first handicap placard. I set up a stool at my lab station, so I didn't have to be standing the entire day. And I asked for a portable unit that does both heating and cooling. So my office is a comfortable temperature. And those three tiny changes took me from wanting to quit and dread going in every day to now I don't think about my MS and I'm having so much fun just being in the lab and working on my research and I'm back to focusing on the thing that I love doing.

[(25:59)] Roz: It's so good to hear. Um, I can just picture you bustling around in your lab, having a good time. So, it... you also reminded me about the 10 years ago when we met, because I met your mom at the same time. We were sitting in a table together at- at a meeting and I got to meet you both and- and talk to you both about what was going on and- and that makes me want to ask you this one last question. What would you say today to the parents of the kids or the teens or the young adults who are getting diagnosed with MS?

[(26:34)] Stephanie: I think it's incredibly tough to be a parent to a young adult who's just been diagnosed. And I often say that my MS is harder on my family than it is on me. I'm living with it every day. I've gained the confidence through the years to deal with it. But I think my parents live with a lot of guilt and fear and grief about losing their child's health, right? And I think their feelings often get ignored or overlooked completely. And there's such a razor's edge between respecting an adult child's autonomy and wanting to swoop in and take control as a parent. Your child might be away at college or like me living several states away and you're not seeing them every single day and they're not going to be willing to give up that newfound independence just because an MS diagnosis has come along.

And I know at 25, I felt like a full-fledged adult, and I did not really even let them come to my appointments with me. And I know that was very hard for them to be hands off because my diagnosis wasn't just one of the most difficult times in my life. It was one of the most difficult times in theirs as well. However, when you're a parent, you often feel like there's no room for your input or your feelings. Um, so I recommend finding someone outside of your child who can give you that emotional support or seek out a mental healthcare provider that lets you express your thoughts and your fears.

Uh, my mom and I actually started a support group on Facebook for parents living whose adults are, uh, living with MS. We have almost 300 members. So, if you're going through something similar, you can look us up. It's parents of Adults Living with MS. Um, and overall, I would just say prioritize communication. Create a family dynamic that creates rooms for everyone's feelings. Hopefully, they'll also find that it's not just a negative thing, that taking on MS as a family can bring you closer and push you all to lead more purposeful and meaningful lives.

[(28:41)] Roz: Well, clearly you are a dynamo and one, uh, who has bravely shared your whole story with us today and I can't tell you how much I appreciate it and how much I look forward to having you become our podcast host because you will do a fantastic job with all of our visitors in the future. Thanks, Steph, for being here.

[(29:11)] Stephanie: Thank you and thanks for this opportunity. I'm really excited about it.

[music]

[(29:33)] Roz: You've reached the end of another episode of the Can Do MS podcast. Thank you for listening. I'd also like to take a moment to thank Biogen and all our generous program sponsors for their support of the Can Do MS Podcast. If you like this episode, please be sure to give us a rating and a review. We look forward to having you join us next time. Be well.

[END]

*This podcast is made possible thanks to the generous support of the following sponsors:*

