



PODCAST

Figure It Out: Adaptations and Staying Active

Episode 150 – Podcast Transcript

[music]

[(0:22)] Stephanie Buxhoeveden: Welcome to the Can Do MS podcast. I'm your host Stephanie Buxhoeveden. I live with MS and I'm also a clinician and MS researcher. In this episode we'll be celebrating Can Do month in honor of our founder Jimmy Heuga. Jimmy was all about discovering what you can do to be able to enjoy the things you love. Today we welcome our guest, Danica King, who's thriving with MS, thanks to her amazing ability to adapt to the unexpected. I see a lot of Jimmy's Can Do spirit in Danica and I'm very excited to have her join us today to share her story. Welcome Danica.

[(0:58)] Danica: Thank you so much for having me.

[(1:01)] Stephanie; Let's start with, uh, you telling me a little bit about how you were diagnosed and how long you've been living with MS.

[(1:07)] Danica: Okay. Well, the first thing that I noticed is I couldn't really walk straight, and my girlfriend also noticed I couldn't walk straight and she said, "If I didn't know you, I'd think you were drinking." And I don't drink and she knows that, so she told me to go to the doctor. Um, also I was having light sensitivity issues, so I went to the doctor and without the doctor examining me with them just hearing what I was going through, talking about me being clumsy, they said, "I think you either have MS or Lupus." And I was like not thinking I had either of those, but I was like, "Okay, I'll play along."

I went to both doctors and after having an MRI and a lumbar puncture, it was confirmed that I had MS and that was 13 years ago.

[(2:07)] Stephanie: Wow, sounds like it was a big surprise.

[(2:10)] Danica: Yeah. Um, actually I have an aunt on my mom's side of the family that has it, and that was the only other person I had ever heard of in my family having it, so it was a big surprise to me. Yes.

[(2:26)] Stephanie: Yeah, same with me. I didn't really know anybody who had had it before, especially nobody young and it kind of came out of left field. Now, what MS symptoms have impacted you the most over the last 13 years?

[(2:41)] Danica: Okay. I would say my cognitive issues, that's why I can't work anymore, so that probably was the biggest change because all I ever wanted to do was go to work and make

money, but, um, as far as since that happened, it's been my walking, the fact that I have issues walking. I can't walk unassisted, either I'm using my rollator or my manual wheelchair. Um, that's been the biggest thing, just not being able to walk unassisted.

[(3:19)] Stephanie: Absolutely, and now you wrote a book called Figure It Out. What does figure it out mean to you?

[(3:26)] Danica: Okay. Figure it out for me means realizing you can't do everything the same way you used to do it, so what you have to do is figure it out, find another way to do things. Um, many times people think that I just have it all figured out, which I wish I did. I do not, but I know who to go to. I have a lot of resources, um, who to go to help me figure it out, so it's just all about that process, knowing who to go to, who can assist you to help you figure it out.

[(4:05)] Stephanie: What you said really resonated with me that in order to do things, even though they might be different than how you pictured them, you have to figure it out because the alternative is not doing it. Correct?

[(4:16)] Danica: Right, absolutely. Yeah.

[(4:19)] Stephanie: And as a result, you have probably one of the busiest and most adventure filled lives of anyone I know, so tell me, were you an athlete before you were diagnosed with MS?

[(4:33)] Danica: I absolutely was not an athlete before. I was diagnosed with MS. Um, when I was a little kid, I used to swim. Um, in high school I went skiing, but that probably was more about the ski bus and being in the ski lodge than the actual athletics of skiing, but, um, so no, I was not an athlete. This is all new.

[(5:02)] Stephanie: You actually figured it out because you have ms and are now doing things that you would've never pictured yourself doing.

[(5:09)] Danica: Absolutely.

[(5:11)] Stephanie: Tell us a just a little small snippet of some of the things you enjoy doing the most.

[(5:16)] Danica: I wish I could give you a-a small snippet, but there's a lot of things, but some of my, um, favorite things are cycling. Um, that's something I do with Sportable, which is my disabled, not mine, but I'm a member of a Disabled Sports League here in Richmond, Virginia. Um, my favorite activity with them is cycling. Um, but I do... also do kayaking, swimming, archery, wheelchair pickleball, wheelchair lacrosse and wheelchair tennis.

Um, also I'm a member of road racing, which is training for both the 8K and the 10K in my racing wheelchair, so not only am I an athlete, but I'm a competitive athlete. I'm not fast, but I'm on the race track. Um, through Sportable. They also do some activities that are not the, um, regular list of their sports. They do like one-off days, and with that I've done axe throwing, rafting, wheelchair, softball, something called swing car, which is a hand-controlled ATV, and I drove it and it was the dirtiest I've ever been in my whole life.

That was like my favorite one-off activity, and I had swamp butt, and it was so fun. Like I never thought you could have so much fun being so dirty.

[(6:56)] Stephanie: That's awesome.

[(6:57)] Danica: Um, outside of Sportable, I'm also very active. I've flown an airplane, gone surfing, skiing, rode horses, wheelchair bowling, and been in a fishing tournament. Somehow, I was in a tournament and I never been fishing before, but that's the beauty of all these adaptive activities. You can do stuff you never did before and be in a tournament, so that was fun. Um, I've done aerial sling classes and most recently I went hang gliding and that was my favorite.

[(7:37)] Stephanie: That sounds awesome. I've certainly never done most of those things.

[(7:43)] Danica: Yeah, so your question about was an... was I an athlete before? No, but I consider myself an athlete now.

[(7:51)] Stephanie: Now. Why? What drove you to start this journey of adaptive sports?

[(7:59)] Danica: Well, I'm pretty active in the MS community, so I saw other MSers doing stuff. I'd see it on Facebook or hear them tell me about things they did and I was like, "I want to do that." So I signed up. It wasn't... it was just, I'm not working so I want to do something, so why not do this.

[(8:28)] Stephanie: Let's go figure it out.

[(8:30)] Danica: Absolutely.

[(8:32)] Stephanie: Now I really admire the fact that you've achieved such amazing things. You've published a book, you rock climb, and you do all of those things because you have MS not despite it. Now I sometimes get incredibly anxious about whether my symptoms like bowel and bladder or fatigue or going to interfere with my plans, and sometimes it's just really tempting to give up before even trying. Are you ever scared of doing things because of your MS symptoms? And if so, how do you conquer those fears?

[(9:03)] Danica: Um, I don't really have fears like that. Um, I do... another one of my major symptoms is the fatigue. The fatigue is really bad. Over the years it's gotten a lot worse, so most days I take naps. Many times, I, um, often have to plan my day around the nap, but as you know, life doesn't work out great, so you can't plan every single day, but I plan the days that I can the most. Um, you talked about bladder. I'm on some medicine to help with my bladder issues. Um, as far as bowel, which is also a problem I have.

Now I have 2 bowel situations that I wish never happened, but I will say everyone that I'm hanging around with, they all know that I have MS, so whatever happens, I'm not doing anything on purpose, but it does happen and the way I look at it, as long as the good days far outweigh the bad days, I'm okay. If, you know, 2 bad things have happened, like I'm-I'm not... it hasn't deterred me from going out or-or anything. You know, I may have been sad that day, but then I just kept going after that.

[[10:33]] Stephanie: Absolutely, and I sort of live by the same philosophy. Have I at times been discouraged or had a bad day? Yes, absolutely, but I work with my husband, he gets me back on track for the day. 1 bad moment doesn't mean an entire day is ruined, and we sort of have a phrase of nothing ventured, nothing gained. Yes, it might, it might feel easier to stay home and let the fear win, but if you don't get out there and try, you might not do half of the amazing things that you've done. Right?

[[11:09]] Danica: Absolutely. Absolutely.

[[11:13]] Stephanie: To me you're just the best example of what's possible when you make space for your disability, and you allow adaptations to help you thrive, and I think those 2 things are really key for everyone living with MS is we have MS, it's undeniable. We have to adapt to whatever symptoms we deal with. Do you have any advice for someone who may not want to use an assistive device or ask other people for help?

[[11:40]] Danica: Yes. Um, I would say don't be embarrassed or ashamed to use your assistive devices, or to get some assistive devices because the alternative is missing out on life, and like myself, I do a lot of things. I don't want to miss out on all those things. Um, I don't want to just... granted I like TV, but I don't want to just sit home and watch TV, so yes, I would say if there's something that exists that can make life easier, then use that. Um, I personally wear AFOs on both legs. Um, I have a hip flexion assist device. I usually use my rollator, but sometimes I have a manual wheelchair.

Um, I have hand controls for my SUV ramped outside of my house to help me get to my car safely, and a stair lift so I can get to the second floor of my house, so there's so many assistive devices that exist. I mean, I have trouble writing, so I have pens that are fatter or utensils that have a fatter handle, so whatever you need to make life easier, I suggest who's ever listening to this that you get those things because it really does help, and as far as asking for help, I used to not ask for help.

I've always been very independent, which I still think I'm pretty independent, but now everyone that comes to my house know they have a project to do. Like it's almost a running joke with all my friends and family. They walk in, they say, "Okay, what's my project?" And it may be something like carry something upstairs or take something to the car or whatever, but I have no problem asking for help now.

[[13:51]] Stephanie: That was something that I found to be the hardest thing especially in the beginning, because I wanted to clinging onto my independence, and that was some of the best advice I ever got, which is instead of putting the pressure in the moment that you need help, trying to think up things people could do for you, have a list ready to go, so I had a relapse list and this person was going to drive me to my MRIs and that person was going to get groceries for me and this person was going to do X, Y, and Z, and having that list ready to trigger when I needed it, that really helped get me past the... in the moment wanting to reject the help.

Also made the people in my life feel really good because they were doing something and they're contributing and they were helping.

[[14:33]] Right. They were helping you out.

[(14:37)] Stephanie: That makes them feel good. Right. Everybody wins. It's a win-win.

[(14:40)] Danica: Right. Um, that reminds me, you said something about um, going for the groceries. Like I get my groceries delivered so they put 'em on the porch. Um, things like that. Like I never would've thought of that. I would do something like that because I actually enjoyed going to the grocery store, but I can save that energy and used it to go rock climbing yesterday. Like you don't want to use all your energy for something that there's another way that you can do it, so you can save all the energy for all the fun stuff.

[(15:19)] Stephanie: Absolutely. That is my new motto, especially since COVID now, with most of the stores offering curbside or delivery, it's just so much easier to have those types of things come to you, so then you can spend your valuable time and energy out there doing the things you enjoy the most and living with. Right.

[(15:37)] Danica: Right, yes.

[(15:38)] Stephanie: I want to back up to some of the assistive devices you listed now. I think you are wonderful at plugging in and learning what's out there, but that's a real challenge for a lot of people with MS to A, even know what assistive device they need and B, figure out how to get ahold of it. Can you tell me a little bit about your healthcare team? How they help you find those devices? Is it your neurologist, is your-your physical therapist? Who do you go to for those things?

[(16:09)] Danica: I would say, um, it's actually a combination. Like if I'm struggling with any particular thing, like, um, I was struggling with being able to write, I went to OT for a number of different things, but one of the things I told them... occupational therapy, um, one of the things that I told them is I was having trouble writing, so they had me order these large pens. I didn't even... I knew large pens existed, but I thought it was like a gag.

Like I've seen little kids with like fat pencils. I didn't know there was actually a real use, medical use for something like that, so my OT has helped me with that. Um, when I went from my rollator to needing a wheelchair, I went to my MS specialist and he sent me to, um, the company that does an examination to find out what type of next level device you need, so he was the one to help me with that. Some of the other things, because I'm very active in the MS community, I'm hanging out with a lot of people, so they tell me about things that they have.

They make suggestions to me, so it's-it's everyone. A lot of it is what's your need? I'm like, "I need to cut things." I've never seen special scissors, but I was like, "I know they have to exist." So I went to Amazon and typed in like adaptive scissors and I ordered those scissors and they work great, so it's a combination of people, you know, Mr. Google, everything.

[(18:17)] Stephanie: Yeah. I-I think I get the best insider information from people with MS, but it's all about like you said, narrowing down what task you struggle with. Is it chopping food, is it walking, is it writing? And realizing that you can start with your MS specialist. Occupational therapists are angels from heaven. They will take whatever symptom or whatever task you're struggling with, whether it's fatigue and running out of energy, difficulty writing, and they probably like you said, have a tool to help you with that.

[(18:55)] Danica: Yes.

[[18:57]] Stephanie: Um, physical therapists to help you maximize the use and benefit you're getting out of those assistive devices. There's so many things out there. Um, and it's important to have a well-rounded care team to help match those things to you.

[[19:15]] Danica: You just said physical therapists and that reminded me of another affordable activity. Sorry to keep talking about it, but I just love them so much. Um, they started a walking team. Now, I talked about I can't walk unassisted, but they're like changing the term of walking, however you get from point A to point B, so I'm walking with my rollators, some people have canes, scooters, and my physical therapist was helping me with activities so that I can make it around the lake.

We're doing it at a lake and I made it around the lake last Friday, so yes, tell people your need and they can usually help you figure it out.

[[20:10]] Stephanie: Absolutely. There it is again, figuring it out. Now the other issue I have heard and seen firsthand is that adaptive equipment can be expensive, so I know in Virginia here we have stores that sell secondhand or exchanges where people can donate and then others can pick it up for free, but they're also nonprofit organizations such as the MSAA who will provide free adaptive equipment including cooling equipment, so there are organizations out there to help connect people with MS, um, with free or reduced price adaptive equipment.

Danica, have you ever had to use a organization or resource?

[[20:58]] Danica: I use all of them. I use all of them. Um, yes, I have used the, um, MSAA, I've used their... gotten cooling items from them. I've used the MS Foundation. Um, I actually used their computer program. Um, I got a computer, actually my book that I wrote was with the computer that I got from the MS Foundation. Also the National MS Society, their navigators are so helpful, and the one thing about the navigators is if they can't help you, they have no problem referring you to someone else that can help you, so a lot of times I'll start there and they may send me to one of those other places.

[[21:55]] Stephanie: That's great, and in your experience, was it pretty easy to use those resources?

[[22:00]] Danica: Yes. Yes. It's-it's, um, very user friendly I would say. Sometimes you have to fill out an application or something like that, but I have nothing but time, so I have no problem filling out. Some people don't want to be bothered with filling out an application, but if it's going to get me what I need that I can't afford because I'm on disability with a fixed income, I have no problem taking time to fill out the application.

[[22:35]] Stephanie: That's really great advice and we'll include some of those resources in the description of this podcast for sure. Are there any last parting thoughts you have for everybody listening today?

[[22:46]] Danica: Um, yes. I just want to let everyone know that life doesn't end with MS. Um, I do way more as an MS person than I did before I was diagnosed.

[(22:59)] Stephanie: Thank you so much for being here and sharing your experience and your wisdom with everyone. I'm really happy that we could bring your story to our audience.

[(23:10)] Danica: Thank you so much for having me and everyone, check out sportable.org if you're near the Richmond, Virginia area and you want to join our league, um, we'd love to have you. Thanks again.

[music]

[(23:29)] Stephanie: Thank you for tuning into this episode of the Can Do MS Podcast. We will have a link to those financial resources and Danica's book, *Figure It Out* in the episode description. We'd like to thank Biogen, Viatrix, and our generous sponsors for their support of Can Do Month and this podcast episode. Until next time, be well and have a great day.

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

