Can Do MS Podcast
My Motto: Adapt and Overcome
Episode 33

Krista: Hello and welcome back to the Can Do MS Podcast. This is episode 33 titled My Motto: Adapt and Overcome. With us today, we have psychologist Lucy Carriere and program participant Jessica Hinton. We are going to hear a bit about Jessica today and how she stays motivated and moving forward. Thank you both for being here.

Lucy Carriere: Thank you for that introduction, Krista. My name is Lucy Carriere and I am a clinical health psychologist based out of Las Vegas, Nevada. I have been working with individuals diagnosed with MS and their families since 2014 and I have been with Can Do since 2015. I am also joined here with Jessica. Jessica, I would love for you to introduce yourself to our audience and tell us a little bit about you.

Jessica Hinton: Sure. Thank you for having me. My name is Jessica Hinton. I am 40 years old. I was diagnosed with MS when I was 23, so I have been living with it for about 17 years. I live in Nashville, Tennessee. I am a geologist working with the Army Corps of Engineers. I am also an army veteran. I served for four years in the Army and left there to go to school for Geology. I have made my way here to Nashville over the last several years working in construction. I am also just recently, well not recently, about a year ago engaged to my support partner who has been wonderful throughout this whole journey.

Lucy: So tell me, having lived with MS for as long as you have you have, you have certainly experienced many trials and tribulations in managing this disease and living as a young adult, and pursuing a career and family. Tell me about that journey. What that has been like for you as you have navigated all of these things simultaneously?

Jessica: It has definitely been a challenge. It had its ups and downs. I have had what I would call three major episodes over the last 17 years which caused new disability. Every time that happens, of course, you have to overcome something new. You have to find a new normal and I would say emotionally that has been a huge challenge but there is always a way to overcome it. When I was 23, I went blind and fortunately that came back. I was an undergrad, I had just gotten out of the military and I was an undergraduate studying geology and I had no idea what was going on. It was terrifying. I thought I was going to have to drop out of school and fortunately the day I started to initiate dropping out of college was the day I started to have a little bit of vision come back. So that gave me hope that whatever was happening to me would eventually resolved and fortunately over the next month it did come back almost completely and I was able to carry on with my studies. Yeah, and then it was pretty stable for the next five years. I had some symptoms like fatigue that everybody seems to have and for the most part, it did not play a huge role in my life except for the uncertainty of what does it mean to have MS. I would have loved to have had access to a program like Can Do MS back then just to be in touch with other people within MS and kind of understand it better and just to have that support.

Lucy: It sounds like you were really feeling potentially that isolation. Like "Are there others like me?"

Jessica: Yeah, absolutely. Absolutely. Then as things progressed it started to get a little bit more challenging. I definitely felt that. When I had my second major episode is when things really started to go downhill, if you will. I had an episode on attack on my spine at the shoulder level. I became almost completely immobile and thank goodness I had an MS specialist doctor at the time who recognized it quickly enough that we were able to treat it with IVIG, and I regained my mobility. I still have a lot of chronic pain from that and weakness and things but I just considered myself so, so incredibly lucky that I was able to regain all of that. That is really when I think my true MS journey began. I was working full-time for mining company at that time and fortunately, my boss and my co-workers were incredibly supportive. I remember my 28th birthday, all that I wanted to do, all that I wanted for my 28th birthday was to be able to go back to work because I had been partially paralyzed for a couple weeks prior to that and going to work requires me to walk upstairs and to be able to sit for long periods and to use my hands. I remember it took me like 10 minutes just to get up the stairs, but I did it and then my boss insisted that we buy a cot and put it in one of the empty offices so that whenever I needed it I could go getting emotional.

Lucy: That is so incredible.

Jessica: Whenever I needed it.

Lucy: Yeah. How they are supportive to your needs.

Jessica: Yes, it was amazing because I never expected that. So whenever I needed it, I can go rest and I did and it was okay. They were happy I was back, happy that I was trying I guess. Then a couple of years later I ended up going to grad school in Illinois, and that was a challenge with the fatigue side of things and the physical side of things. I had not found a medication that really serves me well at that point, so I was trying different things but nothing really seemed like it was helping the symptoms, though I just remember I felt like such a dork. I had one of those rolling suitcases that I would carry all my books in and I remember people looking at me like "what is wrong with you?" Like "Are you lazy? Are you a weirdo?" I am like "Whatever. I am here. I am doing it."

Lucy: Yeah, you were fighting through it. I mean, what tenacity and just [inaudible] and making the most of your situation.

Jessica: Right. Exactly. I think that was the first time that I really felt what it meant to have an invisible disease because people make judgments about you based on your actions. Years later, I had a professor, when I was going through another graduate program, who made fun of people who did that and I got so mad at him in the class. He is like, he just thought he was being funny like these people are being lazy and I said, "Excuse me, you do not know what this person is going through. You do not know why they are doing that. They might have a back issue or they might have an invisible disability. You just do not know."

Lucy: It was too heavy.

Jessica: Yeah, so then I think he was embarrassed because he realized he knew that I had MS and I think he realized that he put his foot in his mouth. But that was, I think, one of my first experiences having an invisible disability where it can be a challenge just to know to react and to how that makes you feel about yourself, that people are making these judgments about you. When you view yourself in a certain way, like I was a soldier, I will overcome all of these things and you are viewing me like I am weak. That was always a hard one for me. I think actually the Can Do MS program that I attended last year really helped me to come to terms with things like that.

Lucy: In what ways, Jessica? Could you tell me a little bit about that?

Jessica: It made me feel okay with it. Like I am not alone. It does not make me weak. It is okay to own it, almost like granting myself permission to be a disabled person. To have limitations and to not judge myself or hate myself or think less of myself because of that. Does that makes sense?

Lucy: Yeah, it sounds like you really have been working really hard at integrating in that aspect that "I have MS and it is a part of my identity, but it does not define me."

Jessica: Yeah, right. Exactly. Exactly. Yeah.

Lucy: I am just so struck listening to you. During these series, some points in your life where you had quite an extended and prolonged experience of disability and how at earlier, I was just still attempting to go to work and I see you as doing far more than that. I mean you were actively fighting through those periods of incredible uncertainty. What do you think was driving you through those weeks of not realizing "Will my vision come back? Will I be able to walk again?"

Jessica: Refusal to give up or to give into it, I think. I had to be a resilient person from a very young age. I think it came naturally to me. I think my military training probably contributed to that. They tear you down to your base level and then they build you back up. I remember that feeling of "I will never be the same type of person that I was before" when I was going through basic training. I just remember having this conversation with the other female soldiers in our barracks. I could not go back to being that person because I feel like I have done so much after this. So I think that both of those things really taught me resilience and MS itself has taught me resilience just because I do not want to give up. I do not want it to take over my life. And that is been a blessing and a curse. It has been a positive and a negative because it is also one thing that I have continued to struggle with, is acceptance of my limitations. Again, I think the Can Do MS program really just kind of hit home with me, the acceptance aspect of it because for example, I am a geologist and when I was going through grad school, I had the opportunity to go in two different directions that I was very interested in. The first one was construction like engineering which would require a lot more physical activity. The other avenue was working in the laboratory and I am certain I would have enjoyed both. I would have been stimulated intellectually in both realm, but I could not accept that I had these physical limitation. I continuously told myself "No, you will make it better. You will make it better. You will be able to do these things. You just have to get there and you will be able to work in the field. You will be able to stay long weeks in a hotel away from your heating pad and your Tempur-Pedic mattress." All of these things that I honestly have taken for granted. I won't need those things then, for some magical reason I won't need them and here I am. I did not really fully accept my true limitation and I would not say it has caused a lot of conflict because thankfully, my boss here as well is very understanding. So we have carved out that kind of a new path for me that I do not have to go into the field and do a lot of the physical activities that I normally would. So I am so incredibly blessed that I have had that opportunity here, but it would not have been an issue if I had just accepted that I do not have the same abilities that I had when I was a 28-year-old army soldier. Here I am 40, too, so there is that factor as well.

Lucy: It sounds like though it was really important for you to be able to make that decision like you wanted to push yourself in ways that sounds like in retrospect, maybe you pushed yourself a little too hard.

Jessica: Yeah.

Lucy: But it certainly was a lot of lessons, I think, that you took away from that and recognizing "Where are my strengths?"

Jessica: Absolutely.

Lucy: Where are some of my areas that physically are just a little too challenging for me or push me to a point where I am just not enjoying my quality of life, right?

Jessica: Right. Absolutely. Absolutely. I am the kind of person that likes to push my own limitation because sometimes you find that you have a new limitation like you pushed it. You pushed it back a little bit or you move forward a little bit, you can do a little bit more than you originally thought you could. And then eventually, you find where that boundary actually is and you cannot go over that boundary, but then I like to push a little bit later. Give us some time. Push it a little bit more and maybe, I guess, that is kind of the way that I have always done things. But now I would say that I am older and wiser, I can now accept where that actual boundary is, where that limitation truly is and not punish myself because of it.

Lucy: That is a huge part. I mean what [inaudible] and just to have reflection and being okay.

Jessica: Being okay with not being okay, I think. That is huge and it just given me such peace of mind. I remember after attending the Can Do MS seminar last year, coming back to work and feeling so empowered because I felt okay. Finally being truly open with my employer about what my limitations are and where I need to draw the line in the sand. I cannot do these two-mile hikes in the middle of the June summer with limited access to water and things like that. I just cannot and it is that horrible for everybody. No one wants to do that but especially as a person with MS where it could push me to being in the hospital or could trigger some sort of relapse that I am permanently disabled, have a new permanent disability as a result. No, I cannot accept that. Can Do helped me to accept that I think, except that I need to accept the limitation, if that makes sense.

Lucy: Sounds like it really gave you that experience with the program just so it gave you that permission to be open, to be vulnerable.

Jessica: Right. Yes.

Lucy: Or reflect on yourself. Okay, where is my quality of life in this? I can push, push, push, but to what end?

Jessica: Right. Exactly. Exactly to what end? Just to show myself that I am not weak or that I am still that 20-year-old soldier, but I am truly not any more mentally or physically. Yeah.

Lucy: Jessica, what advice or tips strategies might you share with those listening and trying to really recognize that inner resiliency that you have really beautifully laid out for us today? How many others find that or recognize it?

Jessica: I think gratitude is one way. My fiancé actually got me a gratitude journal earlier this year and it has been beautiful because it has helped me appreciate what I do have, either physically or just in life. And then also pinpoint some sticking areas where I have room for improvement and journaling that helped me to identify some areas that I would kind of harp on but I did not realize I was harping on. And I would just review my notes and be like, "Okay, I have mentioned this thing for two weeks straight not really realizing it." So, recognizing that I was actually able to actively and intentionally work on that particular thing. I will tell you what this particular example was. I was working with a woman who was just not a nice person and I felt that I was intimidated by her and it was plaguing me like it was making me feel physically ill. I did not recognized that it was causing such conflict in my own mind. So I actively worked on being not more assertive-- well, kind of more assertive but more standing my ground, I guess you could say, with this person. Ultimately, over the following weeks I gained this woman's respect and she actually work much more pleasant to me now. But I guess the point in that is, reflection on what your challenges are and baby steps. Like not giving up... I do not feel like I am explaining this very well.

Lucy: No, I think you have done a great job. I think what I am really hearing and I imagine others to is just that that decision to start journaling as a means of practicing gratitude, which we talk a lot about as a positive way to cope was just an incredible exercise in self-exploration, and recognize some of those strings, some of those areas for continued growth.

Jessica: Right

Lucy: [crosstalk] MS related on that. There are still with that spirit with your tenacity and that inner strength that has really shown through.

Jessica: Thank you. That is a nice way to put it. Yeah, I would say overall, the resilient factor just comes from not letting it defeat me in a way... How to verbalize it, I guess.

Lucy: And I think too that resiliency is an active process, right?

Jessica: It is.

Lucy: Either they have it or do not, I mean you really had to work at it and continue to what we call this psychological muscle. You have physical muscle, right?

Jessica: Right. Yeah. Yeah.

Lucy: And you really have been practicing that psychological muscle as you have been living with this invisible disease and navigating these challenges.

Jessica: Yeah. I think one of the things that have helped me is to acknowledge that "Okay, my limitations now might be different. But what do I do instead?" So instead of, I guess, accepting that there is a new way of doing things and those new ways are good. They can still be good. They can still be... I do not have to be in this strictly, clearly defined box that I have set for myself at this one time. I can actually change the shape of the box. For example, with ongoing disability and new limitations, I have had to change the types of physical activities and exercises that I do, and that has just been a continuous thing. Like, "Okay, well, I cannot ride bikes anymore." I love riding bikes. Do I keep riding bikes? Well, no, I cannot. So what do I do instead? Okay. I am going to try swimming. Okay. I will do swimming for a while. Well, now, I have vertigo so I cannot do swimming. Okay, no more swimming, no more biking, what can I do next? Rock climbing. Well, with limitations I can still do rock climbing so I do rock climbing. Things like that and it is actually kind of fun but it opens up a new world of possibilities that you would not normally have thought you could do.

Lucy: You have learned to regroup and adapt.

Jessica: Yeah. Adapt and overcome, I guess, would be my motto.

Lucy: Absolutely. I think that is a wonderful way to just capture the 17 years you have been living, navigating and learning to thrive with this invisible disease. As we wrap up Jessica, any lessons, strategies, tips that you would like to impart on our audience and those living with MS?

Jessica: I would say embrace MS. Love yourself. That sounds silly but it is true. You deserve happiness. You deserve respect. You deserve to treat yourself with love and care and you deserve happiness. So, explore gratitude and explore, owning your gratitude and owning what you need as a person. Yeah, own your needs and just keep trying. Do not live in that hole of you what you have lost. Just keep trying. Adapt and overcome, if you will.

Krista: Words to live by: Adapt and overcome. Thank you to Jessica and Lucy for the extra motivation as we move into the New Year. Also, thank you to our listeners for tuning in. Do not forget to give us a review wherever you listen to your podcast. Additionally, thank you to our 2020 online program sponsors for making this podcast possible. Thank you to Bristol-Myers Squibb, Biogen, EMD Serono, Sanofi Genzyme, Genentech, Novartis and Mallinckrodt Pharmaceuticals. Be sure to check out our other podcast episodes. We also now offer transcripts for all of our podcasts. If you would also like to have a text version of this audio podcast, you can access those on the website cando-ms.org. Again, thanks for tuning in and have a great day.

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