



PODCAST

Mental Health and MS: Understanding Resilience

Episode 171 – Podcast Transcript

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 in MS research. This is episode number 171. Today, we're excited to welcome our very own Roz Kalb. Roz is the psychologist in senior programs consultant with Can Do MS. You've heard her here before on this podcast, but today we're welcoming her back to talk about resilience. This is a timely topic since May is Mental Health Awareness Month. Thanks for being here, Roz.

Roz Kalb: Well, I appreciate the invitation. You and I have had some wonderful conversations over the years and so the chance to do it for a podcast is very special to me, so thanks.

Stephanie: Yeah, absolutely and I'm really excited about today's topic, you and I are both passionate about this about resilience and the- uh, the opportunity to be emotionally agile. So what exactly is resilience and what does it mean to be resilient?

Roz: Okay, so, you know, there are a lot of written definitions, very academic, very psychological, but I heard a wonderful definition that I think really clarifies it. And that's to think about whether you as an individual are more of a tennis ball or an egg. And of course, what that means is that when you bounce a tennis ball, it comes right back up, right? It comes back to life ready to go. And when you drop an egg, well, it splats. So all of us, I think have [(2:00)] moments when we're more tennis ball than an egg and some moments when we are more egg than tennis ball. But I think that's a good starting way to think about resilience as bouncing back from challenge, from adversity, from any negative experience kind of ready to put your best foot forward.

Stephanie: I love the tennis ball and the egg because it's such an accurate representation of sort of what it feels like, right? Everybody's life is unpredictable. We all face challenges. Those challenges are definitely augmented by MS. So how does unpredictability challenge our feelings of being resilient or can it offer us an opportunity to grow?

Roz: So I think I want to back up a little bit and just remind people that this is not an either-or. It is not as though somebody is always resilient or always able to bounce back. I think we vary a lot depending on the circumstances, our emotional state, our cognitive state, and life experience. What unpredictability does is really force us... force us to think about what it means to be resilient and bounce back when there's so much going on that you can't control. And I think the key to that is not to spend your emotional and physical energy trying to organize the raindrops, as one of my patients used to say. We cannot control a lot of variables or things in our lives and so we need to

focus on those things that we do have an impact on. Those things we- we can control. And I think the most resilient people have an easier time [(4:00)] sorting those out where to put their attention. And of course, MS offers so many opportunities to test one's ability, uh, to flex with what's going on. Um, you and your life have had to flex a lot of times depending on- on what was going on. So, I think that's what in- unpredictability adds to this.

Stephanie: For sure, I think it also gives me an opportunity to experiment and see what works and what doesn't. You know, I... This week, I've been trying to step up my exercise and the last few times, it was all good, I felt energized. Yesterday, I think I went a little too far and I spent the rest of the day kind of laid out and fatigued and I said, okay, lesson learned. I will pivot, I will adjust and that's life. That's MS, right? The goalposts kind of always feel like it's changing at times and sometimes you succeed in reacting to a challenge and sometimes you have a failure but always you learn something about yourself and your response and can apply that in the future when you're trying to face the next challenge.

Roz: You know, I think that brings up a whole other aspect of resilience and-and that is what Susan David has called emotional agility. And I love that term because it asks us to look at how we respond emotionally to the things around us. If-If we can experience our feelings, face our feelings with curiosity, and then accept those feelings rather than being hard on ourselves or saying, oh, we shouldn't feel that way or that's not a nice feeling, we accept our feelings, learn from them and then step away. [(6:00)] Just far enough from our feelings to be able to ask ourselves, what's important? What are my values and how do my values direct me to take steps forward?

So with your example, which is a great one of wanting to exercise more when you have a not-so-good day or any of us has a not-so-good day. We have to acknowledge the feelings that we have about that. Oh, I didn't try hard enough. Oh, I failed today. Oh, I'm not living up to my own expectations and- and feel those feelings. Look at them with curiosity, accept what they are and then say, okay. But where do I want to go from here? What do I want to learn from what's happened so that I can take the next steps?

For- So for you, you did it automatically, you reflected on it and you said, maybe I pushed it too much, tried too hard now, I'm paying a little bit in fatigue and so I have to step back but my value, my desire is still to increase my exercise. So now I'm going to put one foot forward, start again, and try to remind myself this time, I'm not going to push too hard. And that's true whether it's exercise, whether it's any experience in life. We want to do it with moderation and that can be because of MS symptoms. It can be a normal aging where we want to keep doing more and more but maybe aging makes it impossible. So dealing with the feelings of loss about that and then moving forward.

Stephanie: Absolutely, and I think there's a big difference in [(8:00)] how I handled that situation 11 years into my diagnosis versus when I was first diagnosed. And I was a serious athlete and that would have devastated me being so fatigued by a simple workout that I probably would have avoided going back to the gym ever. I was- I was a lot more rigid at first. I think what MS has given me is that ability to be more flexible. So is that resilience?

Roz: I think it absolutely is resilience and I think it goes also with Susan's David- Susan David's definition of emotional agility. You... If we're too rigid with our feelings and our thoughts, it kind of freezes us in place, right? We're hamstrung by the way we look at things through a single lens that has been, oh this is the way I always did it, right? But when you can be flexible with your thoughts

and feelings, um, then you can see things from a few different perspectives. And you're now able to say, with experience in time, some days with MS are good, some days with MS aren't so good. I'm going to do better on some days and others so that you congratulate yourself on your good days and on the days that aren't so good, you give yourself grace and you say I'm going to rest up a little and try again tomorrow. And that's what allows you... That flexibility of feeling and thinking is what allows your own values to lead you towards whatever you want to try to do next.

Stephanie: Yes, 100%, giving myself grace was something that did not come easily. That is something I had to work at and for. [(10:00)] And what took me by surprise is when I was able to be resilient when I am able to adapt to a challenge and do something, not despite it, but just because it's part of me and now I have to adapt to it and it is what it is. Things that maybe I would not have been so proud about like accomplishing a 30-minute workout, I'm using a lot of workout analogies today, but... [laughs] But I'm more proud of myself in a way for doing that with adaptations than I would have been when I was more able-bodied and I didn't face challenges. I think a lot of confidence and self-esteem comes from the ability to adapt to a challenge and overcome it and face it.

Roz: I think you're absolutely correct. And I think although people are frightened by the idea of having to shift gears or do things differently or try different tools or strategies, what in fact happens is that that problem-solving approach or that solution-oriented perspective actually, um, loosens us up, right? To be more experimental, to be more daring, to think more creatively, um, and that's growth, right? So it makes perfect sense that you're prouder of these, um, current successes which have tested your creativity and your problem-solving and your determination in ways that just being a natural athlete and pumping out all this exercise just came automatically. You didn't have to do anything except be the natural athlete you were. This is much more challenging. And I think we all face that with aging, with chronic illness, with growth that [(12:00)] life...

Stephanie: With being a new parent, it's cool.

Roz: Being a new parent. Being a new spouse.

Stephanie: Yeah, all of these...

Roz: Like a new job.

Stephanie: Yeah. Absolutely. We're all constantly taking on new roles and incorporating new things into our identity throughout our lifetime. And so I think those are all important things to keep in mind.

Roz: So I have a question for you, you mentioned a minute or so ago that you had to learn to give yourself grace, and I wonder if you could... maybe we could both, but if you could share how you did that because I think that's such a key part of building one's resilience and you've had to do a lot of changing and adapting in your life. So how did that come to you giving yourself grace?

Stephanie: Very slowly, um, because it's funny the things that you take pride in not only when you're young and healthy, um, but with life comes, comes new perspectives on what's important, right? So I think when I was young, I placed a lot of emphasis on my physical strength, my

capabilities, the way I appeared outwardly to others. And I spent a lot of the first five years with MS going through extremely... uh, like [chuckle] extreme I would say, like cartwheels trying to hide the fact that this affected me in any way, right? Because, um, showing that I was in pain or I was having trouble walking or I was having trouble with my speech, to me, those were embarrassing, right? I didn't want people to see me differently. And then I realized, you know, I was just looking at my MRI with my doctor and I have, you know, a dozen spinal cord lesions and I can still walk, that's pretty amazing.

I took a moment to really appreciate [(14:00)] everything that my body was doing right despite all of the damage and all of the challenges it's been facing. And sure it-, you know, my speech might be a little slurred at times or I might have trouble walking but, like, I can still do it. And so I started focusing on what I, not what I no longer had but how successful I had been in overcoming the things that MS has thrown at me. And instead of coming from a place of, oh my gosh, I have all these divots all over my body from giving myself injections and people are going to think I'm so weird for having to go to the bathroom every 30 minutes, to being like, look at me go. If it takes having to take frequent bathroom breaks or look a little funny in a bathing suit, whatever. I've overcome this big, huge, challenging thing and to me that became more of a point of pride than a point of shame. And it was really just reframing that emotion.

Roz: I think there's another aspect of reframing that's really important to this conversation and that's also related to youth and-and- and growing older. But we- we- we're more rigid in our youth. We think there's only one right way to do everything. We've been taught this is the way you do it and this is how you'd be successful and this is what you look like when you're successful. And with MS, people may be called upon to think about doing activities very differently than they did before, or even, um, trying new activities that they would never even consider. And I think, um, this problem-solving approach to life means being willing to look at a problem from different perspectives and come up with a solution that works [(16:00)] even if it means doing it differently than you did it before or using a mobility aid to assist you to do it, um, or trying something new all together because that's what keeps your life busy, full, and active as opposed to a world that's getting smaller and smaller because you're stuck in this rigid way of thinking.

So for me, resilience over the lifetime means looking again with curiosity at the changes that are happening and saying, "Hmmph, what can I do to keep doing the things that align with my values, that give me pleasure, um, that are adaptive and that keep me moving forward? Resilience.

Stephanie: Yeah, absolutely. Absolutely and I think it also is incredibly helpful to make friends with people who get sort of what you're going through. So I didn't know a single person with MS when I was diagnosed and now I have hundreds of MS friends. And it has really helped me problem-solve and think creatively to talk to my peers and see how they've navigated similar issues and see firsthand how successful they've been and how full their lives are. So that is something I would recommend to anyone who's struggling to be resilient to face these challenges is to find your people. Find your support system who maybe has navigated something similar, and help them help you.

Roz: So I've another question because we're talking up until this last comment you made about people being resilient within themselves, how they as individuals approach their feelings, their thoughts, and the situations that they're confronted with. But most [(18:00)] people are in

relationships of some kind. They may have partners or spouses. They have extended family. They have kids. And in order for a family to be, um, emotionally agile and to be resilient, they have to do some of this together. And it's hard enough for one person to work on their resilience and build their resilience but sometimes people have to do it, um, in unison. And do you have any thoughts about how people manage that?

Stephanie: Yeah, I think MS is unpredictable and disruptive to everyone not just the person with MS but the loved ones, their cares- their care partners, their kids just like you mentioned. Everybody is affected even though it's just the one person technically living with it. And it does impact how your family does things, right? So maybe you like to go on weekend-long camping hiking trips and now that's off the table. What do you do now together that is still meaningful?

So I have found that all of this resilience and-and life strategies and creative thinking and problem-solving applies equally as much to my family as it does to me and we've all had to navigate that with each other. But what I have found is that if you do something that's incredibly uncomfortable, right? You're worried that your symptoms are going to get in the way you're worried that it's going to be a total disaster, uh, doing those scary things with your support system and communicating very openly about the anxieties and fears you all have regarding it, takes a lot of the pressure off. And if you do things like the first time I went on a hike, I did it with the people who I felt most comfortable with in the world. Because if I'm going to be in an uncomfortable [(20:01)] situation, I at least want the safety and security of those I love around me.

And we always have a back-up plan, right? So if it gets too overwhelming for any one individual person, we have a plan. We say, "Okay. This is the code word and we can get out when- whenever we need to." But I do think that while we spend a lot of time talking about the person who is directly affected by MS, all of this is applicable to everyone in their circle.

Roz: You know, I talked to a lot of people with MS who are so worried about the impact that their MS is having on their family members, particularly spouses, partners, young children. And I think families learning to be resilient together is one of the greatest gifts that we can give people we love. Teaching our children to face unpredictability, to deal with adversity, to problem-solve, to flex, um, and to be creative are gifts that they will take with them their whole lives. So I think that's something to feel positive about.

I do think that that process that family learning to be resilient together starts back at the beginning where you and I started which is being open and-and curious about your feelings and your thoughts. And I think in many families, that's hard. Children may have worries about asking questions or upsetting a parent or not thinking they're going to like the answers they're going to hear about how their parent is doing or what's going to happen. But being able to talk openly about grief, about anxiety, about the unpredictability, [(22:01)], even about frustration or anger that having a plan B is always necessary, um, to get those feelings out there, then everybody can breathe kind of a sigh of relief and start working on the solutions. But maybe it's just because I'm a psychologist but I think it all starts with owning a- owning our feelings, respecting our feelings, and having self-compassion, um, or giving ourselves grace, whatever you want to call it for those feelings that we have.

Stephanie: Yeah, and I- I will say my husband in particular has made the worst of days so much better just by being who he is. And I can think of so many examples, but I think the most poignant

one is the day that I finally had to use a mobility aid. We had to go to CVS and buy me a cane, I think I was 25 at the time. We weren't married yet. We were engaged. We were planning our wedding. And, you know, I never thought at 25 and a bride-to-be, I'd be in CVS picking out a cane. It should have been one of the worst days of my life.

But I have this ridiculous picture of him because he bought a top hat and a sash and he put that on and had my cane and wouldn't give it to me because he's running around the house like Mr. Peanut. Um, so he's helped me approach like so many of these... you know, on the surface setbacks with humor, uh, and help me just sort of make light of the day-to-day crap that comes with MS. And I think as a- families who approach things with humor, we've interviewed a lot of people on this podcast who have very similar stories where days that should be just god-awful setbacks. When you tackle it together as a unit and you find the humor and you find the grace, uh, I think that's the biggest gift that MS can give us sometimes [(24:00)].

Roz: You know, I see that, um, a lot in our coaching programs at Can Do. And, um, in any of the small breakout rooms where people are getting together, now, these are not loved ones. These are not people they know well, but they- they are a group of people with whom they feel comfortable, you know, that others in the room will get it. And we're talking about things like a bladder and bowel challenges or, um, changes in their sex lives or changes in their relationships. And they find themselves laughing, sometimes laughing and crying at the same time. But in that room, they are able to laugh and find humor in some of the most painful things. And I think that that's one of the reasons that those small group coaching sessions are so impactful for people, um, because it's safe, right? And then sometimes because they feel safe there and they laugh and they share, then they're able to go back to their families with a slightly different perspective about some of those things and bring some of the laughter home. So I-I think that community whether it's surrounded by people you know well and love or just people with whom you feel safe, that community feeling helps build resilience as well.

Stephanie: Definitely, for everyone. So one more question before I have to let you go. Something I struggle with and I know a lot of people struggle with are these sort of conflicting ideas of MS throws a lot of challenges at you, but you can adapt and you can overcome and you can still do all the things that are important to you. But then also this conflicting message sometimes seemingly, [(26:00)] which is "Put your health first and prioritize self-care and mental health and- and take it easy and listen to your body." Um, so sometimes it's confusing, right, to know when to push your limits and when you can be resilient and overcome the odds and when you should accept that there's been a loss and that maybe I can't walk in heels anymore, and maybe I should just grieve and let go. How d- How do you begin to approach that? [chuckle]

Roz: Well, I don't think that it's an either-or, Stephanie. I think that it's, um, again, you know, we talked at the beginning about looking at your feelings and your thoughts with openness and curiosity, it's also looking at your body and how your body feels with openness and curiosity. And whatever we're doing, we need to listen to our bodies, right? So, I think you want to try things, you want to have adventures, you want to go about your business doing the things that you want to do, but you want to do them in ways that don't overwhelm or exhaust you, right? So if you're having a good day and you have 17 things that you are determined to get done in tu-, including that workout, you're then going to pay for the next several days, right? Y-You may accomplish those things on a good day, but the rest of your week will be, you know what?

So it's always about, um, the five Ps that we talked about that the OTs teaching- teach us. You know, you want to plan how you use your time and that's determined by your values, by your priorities, by your commitments, [(28:00)] right? Those are your priorities. Then you have to piece yourself and you have to be honest when you talk to yourself about, "What can I realistically do in a day and still be okay at the end of the day?" Then you want to use the tools and the strategies to do all those things in the most energy-conserving way. Right? So that's positioning. And I always have trouble remembering the fourth P but you really want to prioritize plan, pace yourself, and then do things in a position that gives you the most comfort and is least fatiguing.

And I think that's how you find that balance. You're not going to be able to do- none of us can do everything we want to be able to do all the time. Some things we can continue to do with adaptations whether it's MS or aging. Some things we may need to say goodbye to and feel sad about, but the world is full of new opportunities. And so, we adventure out and try new things. Give ourselves a pat on the back when that works, give ourselves grace when it doesn't, and keep the adventure going.

Stephanie: I love those last three sentences you said. I think capture resilience perfectly and helps us realize why it's so important to incorporate it into our everyday lives. So I want to thank you so much for being here and for sharing your thoughts and your wisdom with us, and I hope our audience gets a little something out of this talk we had.

Roz: I hope so. I did. I always learn a lot talking to you, Stephanie. So, thanks.

Stephanie: Thank you so much, Roz.

In the description of this podcast, you can find resources, [(30:00)] programs, and more information on what we've talked about today. Thank you for listening to this episode. And if you like it, please leave us a rating and review on Apple podcasts or Spotify. We appreciate your feedback. Lastly, we'd like to thank all of our generous sponsors for their support of this episode. We couldn't do it without them. Until next time, be well and have a great day.

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