



## **Relapse and MS Series**

### **Balancing Relationship and Open Communication During a Relapse**

#### **Episode 10**

Rachel Lahti: Hello and welcome to the Can Do MS Podcast. My name is Rachel Lahti and I am the Programs Coordinator for Can Do Multiple Sclerosis. We are excited for today's podcast, which is the final episode in our three-part Relapse and MS Series where you'll learn how to manage potential relapse-related challenges at home, work, and in your relationships.

In this podcast, you'll hear from a couple living with MS as they share their experiences on how MS relapses have impacted their relationship as a couple as well as their relationships with family and friends.

With us today, we have psychologist Roz Kalb, and couple, Laura and Michael, to talk about how MS relapses have affected their relationships. So welcome to our speakers. I'd now like to turn the podcast over to Roz to kick off today's discussion.

Roz Kalb: Thanks very much, Rachel. I'm so excited to be here because I had the pleasure of meeting this lovely couple, Laura and Michael at a Can Do Program, a couple of years ago. And so this is our chance to get reacquainted again. So, thank you, Laura and Michael, for generously offering to do this. I am going to ask you some questions about your experiences with relapses. Relapses, in my experience, because they're so unpredictable and so variable from one time to the next, tend to cause people quite a bit of anxiety as they anticipate them but also put them into a bit of crisis mode when they happen and they have to make adjustments in their everyday lives. So I'm looking forward to talking to you about your experience but let's start first by getting some background on you. So how did the two of you meet?

Laura: Hi, I'm Laura. Michael and I met when we were undergraduates at Colorado State University, which is in the town we live in. He was the president of College Council and I was running a chemistry outreach program and he approached me to do some demonstrations for his group and so that's how we met when we were in college.

Michael: And I would say that the rest is kind of history. We dated from that point going forward and been together ever since.

Roz: So how long have you been together now?

Laura: Fourteen years.

Roz: Wow. And when in that wonderful fourteen-year history did MS join the family?

Laura: MS joined us about eight years into our relationship.

Roz: That must have been quite a shock for the two of you that right starting at that point, you must have started with a relapse that led to your diagnosis. So you had to deal with the challenges of MS all of a sudden when that happened?

Michael: Right. And to add to all that stress, we were actually long-distance at the time. I was at Georgia getting my PhD and she was still in Colorado working on her PhD and so it was really shocking to hear what was happening and trying to figure out what was going on and then on top of that, not being there to go through everything with her and it was quite a mess, to be honest.

Roz: Yes, and I think that the challenges of communication are always there but you two must be masters that it. So we will definitely talk more about that. Laura, can you describe for our listeners, what your initial relapse or maybe some of the subsequent relapses have been like for you? Are they all the same? Are they different?

Laura: Yeah, I sort of have two major classes, I guess, I will call them, of relapses. I have optic neuritis which happens to occur in my left eyeball and what that is and how I experience it is basically if you had looked at the sun without your sunglasses on and sort of have that blurred-out vision that's really washed out, that's what I experienced. Sometimes I experience it with pain as well and sometimes I haven't but I've had that particular relapse about five times. And then I've also had, sort of, my second class of issues in relapse land is what I would classify as sensory. I've had my hands and feet be numb or I've had a burning sensation in particular down my left leg. And so those are kind of the types of relapses that I've had and I've had each of those several times over the course of my diagnosis.

Roz: So the symptoms that you're describing more are primarily invisible. So when this first happened, you had to describe them to Michael over the phone, which I think is challenging. When this kind of thing happens in person now, first of all, how do you let Michael know? And, Michael, how can you tell what's going on with Laura?

Laura: I guess I would say in terms of trying to talk about it, I try to be as descriptive as possible. But you're totally correct, it is very invisible. The other thing that I've noticed just myself personally when I start to experience relapse is it's not always like optic neuritis, not optic neuritis, right? There sort of a continuum of new sensations for the patient, for myself. And so you kind of feel weird and I don't know that there's any other way to describe it. And so I basically try to tell him, "I don't quite know what's going on yet, but I feel weird. This is kind of what's happening."

Michael: And from my end, I think the first thing I learned and I learn this very early on is to make sure she knows that I don't think she's making anything up. I think there's nothing more frustrating than a patient than have somebody not believe that what they're saying is true and we have such a strong level of trust that I think that goes without saying but I've always made a point to make sure that whatever she says, I totally understand and work around and never second-guess what is occurring. But having said that, it is really challenging to understand what she's going through, and then how do you deal with that? I mean, it's one of those things where because it's invisible and I just have her words to go on, I kind of take shots in the dark on what we can do and what we can't do and how to proceed and it's challenging but she does a really good job of telling me what's going on.

Roz: Well, and it sounds like you do a really good job of listening. So, congratulations to both of you on that. So how do these relapses affect your day-to-day life?

Laura: It really varies a lot. Typically, with relapse, I also experience a much higher level of fatigue. And so I

have to pass on doing more activities and I try to save up my vacation and sick time if I'm not feeling well enough to go work. Of course, my relapses tend to be pretty long and you generally can't take months and months off work but besides that, I just try to communicate with people to some degree. At the same time, I also sort of isolate myself because I'm generally not feeling great. So you don't want to just be out and about in the world doing everything that you normally would do.

Roz: So from the time that I met you and got to know you a little bit at Can Do, I know that you're a very independent person. So, how do you communicate with Michael about how to manage those changes in everyday life? How do you let him know when you need help or when you don't need help so that he doesn't have to guess or read your mind?

Laura: It really is as simple as saying, "Hey, I can't see well enough to drive today and I have a doctor's appointment, can you take me?" Kinds of things and also making sure that he's not the only person who I'm relying on for that kind of help because he also has a full-time job and may or may not be able to take multiple days off in a row to go to every single doctor's appointment or every single steroid infusion or whatever it is.

Roz: How is that for you, Michael? I mean, it must be hard to miss out on some of those things that Laura needs to do like go to the doctor? But you also have a very busy life of your own. So how has it been for you to juggle that?

Michael: It's been very challenging. I think it's one of those things where I find myself walking a very fine line and unfortunately, to kind of just contradict Laura, it's not that simple. Because what I find myself doing is not wanting to make her feel like an invalid so I never asked her to help or do anything and not push her but at the same time make sure I don't push her too far and overextend her. And so a lot of that's an internal dialogue that I have with myself that I should be more forthcoming with but it's a balance that we play and it definitely has an impact on our careers and our separate lives, but it's something that you make a commitment to working through and then you just do that and that's not that simple but it's nice to say out loud anyway.

Roz: Does it get better with practice, you two?

Michael: For me, it does. The more we do it, the more refined I get at trying to help, and sometimes helping means not doing anything which is also okay, but at the same time, we've had so many variable experiences that it's hard to always predict and use the same skill set I just learned and apply it to a new situation.

Roz: Right. Because it's never quite the same, is it?

Laura: No. And I would say every relapse is different and something that I thought worked really great with the last one even if it's optic neuritis again is not working this time and so that leads to a level of frustration because you're like, "Well, this work last time why is it not working now?" Kind of thing and also the longer distance there is between relapses especially for me as the patient, I kind of forget those good communication skills, or I forget how I was doing this so well last time and so that's sort of a blessing and a curse in the sense that you don't want to be having a lot of relapses and be really good at communicating and doing that in a practice way. But at the same time, you also don't want to forget those skills if you haven't had a relapse for six months or a year.

Roz: Absolutely. So when there's a little bit of time between relapses or a long period of time, there must be concerns about the next one - when might it happen? What might it be like? So what kinds of fears or

concerns do you have? Laura first and then we'll talk to Michael about his.

Laura: I feel like over time as a patient that's really evolved for me. Initially, I was really worried about the next relapse like when is the next shoe going to fall? Am I going to get whatever back that whether it's vision or sensation after the relapse is over or is this the new reality? And it's really hard to know that. But I also stressed myself out a lot about that and within the last few years, I've just decided it's kind of not worth the stress and that I have to let some of that go. So, I would say that in many ways, I've sort of seen fear and worry as not being productive for me and, kind of, let that go because it hasn't served me.

Michael: I would say for myself that, yeah, the same sort of fear. I don't know how long each relapse is going to be? When they're going to happen? Is this going to be the relapse that sticks? I just don't know and so it's always worrying. Sometimes her relapses are really bad and to think she would be like that forever is really challenging, it just changes the way you look at everything but since, in the last couple years, she's kind of let go of some of that anxiety and fear has helped me let go some of that anxiety and fear. I've been trying my best to focus on the here and now and the day-to-day when it's good and that helps a lot. The hardest part is when you start seeing the big picture and start worrying about the future and how this is all going to play out.

Roz: So do you do that worrying about the future in your own heads, or do you find that you can talk about those fears to the future with one another without creating too much anxiety?

Michael: For me, I talked to Laura a lot about them. Maybe not as much as I should but I definitely talk a lot about them. It's good to have them out there. It's a lot better than them festering at least that's how it's been for me. I'm kind of a talker so that happens but, yeah, no, it's been good to talk about.

Laura: And for me, some of it is definitely still internal because I experience the physical sensations and so then you sort of have the internal debate with yourself, "Well, this feels weird today, should I tell everybody it feels weird because it's the beginning of something or not?" Or those kinds of things. And definitely, I worry about the future but at the same time that worry isn't always terribly productive and I tell Michael about those worries, but I found that channeling those worries into PT, OT, speech therapy, finding a new way to stress relief or something, doing something or getting more resources or whatever it is, like, actually doing something helps me a lot more than just worrying.

Roz: When you have had these conversations about the unpredictable future or what might happen if there were a bad relapse, are you also talking about some strategies or plans you would put into place now in case something like that happen? Do you have any plans in your back pocket? So to speak.

Laura: Kind of. But I feel like every relapse I've had has been so different, that planning is sometimes initially when I was diagnosed, I was so much a planner and I was ready for anything and I found that I didn't actually end up using any of those plans because they weren't useful to me. And so now instead of planning, I guess, I just try to find all the possible resources and kind of have an idea about what I would execute if I found that I needed it.

Michael: And for me, it's the same thing. Actually, letting go of planning for relapse because they've been so varied for us has actually helped a lot and not having to worry about, "Well, this is the plan so we stick to them." We are being more fluid and dynamic about what's happening and how we work together towards it makes it a lot easier because they are varied and it really helps me not worry about, "Am I doing something wrong?" Instead of being, "Okay. We're here now, let's just focus on this."

Roz: So you sound like a wonderful support team for each other, you talk a lot and you're very open with your feelings and your concerns, who else is in your support network?

Laura: Well, given that Michael was away at graduate school for six years during my initial MS diagnosis, I have some good friends in my area and a couple of, sort of, families in that way who helped me to navigate things, who went with me to the doctor's appointments and those kinds of things. So those people are part of my support network.

Michael: For myself, I don't really have a strong support network. I have sought out some counseling that hasn't been going as great as I thought. Some of it's probably me, I don't know. It's hard to judge if you're good in counseling, but that's neither here nor there. I'm going to keep working at it until I find something that really works for me but fighting something has become something of a mantra that I'm focused on trying to do.

Roz: Laura, you mentioned before that you do keep very careful track of your vacation days, then you try to make sure that you have time available when you need it, to manage a relapse, has that worked for you as well, Michael?

Michael: So far, yeah, we've not gone on a lot of vacations. We do take them but they're pretty rare and I've saved up about five weeks worth of vacation. So at the drop of a hat, we can do whatever we need to do, and actually my working place is pretty understanding of these things. So, that's not too big of an issue, but yeah, it's definitely something that we have it when we need it. We really focus on making sure that's available.

Roz: That's really, really good planning. When these relapse has happened, you're very very comfortable apparently talking to each other about what's happening, do you have extended family as well as these friends you mentioned who you need to communicate with about a relapse?

Laura: Yeah, absolutely. And I think that's kind of a very evolving thing in terms of communicating with others because I feel like you and your partner, kind of, learn like your tells and, I get tired and a little secluded when I'm relapsing but other people who might not be with you all the time don't necessarily know those things and their level of understanding about MS and about relapses can be very different. And I find it's hard to communicate with them about relapses especially when I'm having one only because I'm tired and kind of just want to go to bed and not tell you about all these things and answer all your questions and to reassure you that I'm okay. So that's a work in progress.

Roz: Do those friends and family call on you, Michael, for more information, and do you find yourself peppered with emails or phone calls about what's going on?

Michael: So my experience when I talk to the family is it's pretty fear-inducing when we talk about MS. It's pretty scary to them. They don't really fully understand and I've done my best to kind of walk them through it, but it's very overwhelming. I don't think they fully grasp what's going on. So that's more of a work in progress. I have to admit, as someone external, this can be extremely overwhelming to hear just all the different things that are associated with it, knowing that there's not really a cure out there and this is just a situation you have to live with and focus on. And I found that a lot of people who just aren't necessarily ready to hear that, they can struggle with it. So it becomes more of a hindrance to explain it to them than a benefit to have them involved in that immediate process.

Roz: So is the biggest challenge just to find a way to reassure them that you're getting good care and taking

good care of yourselves?

Michael: Yeah. Everyone has an opinion when it comes to medical stuff, I've noticed and not always is that opinion great. And so it's kind of hard to explain to them, "No, we've got it under control and this is what control looks like." And that's hard for a lot of people who are external to it too, to know that not everything is controllable and everything has a magic pill and we struggle with it, but we do our best and we're doing pretty well with it.

Roz: Well, you certainly are and it sounds like you're both kind of experts at dealing with things you have learned you can't control and certainly for some other people in your lives who haven't faced similar challenges, they're not as comfortable with the unpredictable or the uncontrollable. So trying to convey what you've learned and also conveying that you're taking care of each other, I think, is a great reassurance for the people who care about you both. So, that's great.

Michael: Thanks.

Roz: When a relapse happens, as I said at the beginning, it can feel like a little bit of a crisis in your life out of the blue that shakes your everyday lives up, so what does crisis mode look like for the two of you? What happens when you guys go into crisis mode?

Laura: Crisis mode - I was going to say I love that you said it's a little bit of a crisis mode. In reality, I would say that it's usually like the central thing that you spend all day every day thinking about when it's happening which is kind of unfortunate but it's true. So crisis mode is not just about relapse, at least for me, it's about my own internal dialogue as well, you know, "This is the new normal and I'm really worried about this. This is how it's always going to feel. How am I going to cope with that?" Those kinds of things and so I have previously gotten super stressed out and that in many ways for me makes the relapse worse. So then I'm not sleeping, I'm not doing a good job taking care of myself, I'm not seeking help, I'm just sort of spinning. And so that's what crisis mode looks like for me. And I don't know that I would encourage anyone to do that. I would try to do better coping-strategies and I think the only way to really get there was I learned that being stressed out wasn't helping.

Michael: I would have to say that there have been times when I have not helped that stress where I'm a natural fixer, it's what I like to do and when she's struggling and I'm like, "Let's do X. Let's do Y. Let's do Z." And I end up putting more stress in the situation than is necessary. And that has not been good. And it's taken me a while to learn that and back off and be like, "Okay, let's ride this out for a little bit and see what happens. Let's focus on some comforts," and just kind of take things slower that when I slowed down that seems to help everything else to take the stress or the urgency out of the situation and then just kind of focus on what we can do, what we can fix, and that has been helpful. I'm not the best at it, I'm still a work in progress, but we're getting there.

Laura: For me also, crisis mode involves being concerned about the health care provider and going to the doctor and going to the hospital and getting this infusion or all of those components and you can be super worried about those things. But those people are going to operate to some degree on the timeline they're going to operate on - they have an appointment on Friday or whatever it is. And, honestly, it doesn't hurt you really if you have to wait and it takes them a couple of days to set up whatever. It may not be comfortable for you as the patient but in many ways, doing whatever the medical thing is like maybe the IV steroids or something like that is also not comfortable. So just like being very here and now, this is where we're at, this is what we're doing, relapses generally speaking are very uncomfortable at least for me. They're not life-threatening. And so just knowing that kind of takes it down a notch.

Michael: And I'd like to interject that Laura has been an angel when it comes to dealing with the health care system. She is really taking the reins on dealing with insurance in a way that I think would stress me out beyond belief. So I really want to give her props for handling that because that is a skill set I just do not possess well to handle all that and maintain as stress-free about it as she does, considering.

Roz: That's a remarkable skill. I think maybe you should write a book about that, Laura.

Laura: I've considered that. Yeah. Well, but that's the other thing like you get on the phone with these people and they don't know your situation and they are just trying to do their job and so having a real reality check that even though you were experiencing something that is very, in your body, real to you doesn't mean that anyone else is experiencing that.

Roz: I just wanted to circle back to one thing you said before that I think is really helpful and important for our listeners, the reminder that although a relapse we may feel extremely uncomfortable and frightening, it is reassuring to know that it hardly ever involves any real medical emergency so that having to wait to see the doctor is frustrating and anxiety-provoking but it's not dangerous. It's not unhealthy for you. And I think the fact that you've been able to teach yourself that, learn it, and live with it really does help cut down on that stress a little bit.

Laura: Oh, yeah. Well, and many times it happens for myself at a time when it doesn't conveniently happen on Monday morning when I can call the doctor and get in that week. It happens on Friday night, right? And then your choices are Urgent Care and the ER and those kinds of places are very urgent, life-threatening, we got to treat you now, sort of situations and definitely, I have gone to the ER for relapses before but being able to take that environment and take their stress level down a little bit too, like, "Okay. I've done this before. This is what I would like us to do. You can run these tests--" Knowing that and talking about it with my doctor beforehand like now he knows he could get a call and he could talk to those people and tell them what's going on.

Michael: And that's one area where maybe and the fixers help because I can be in that situation and I don't have any fear about the doctors or the medical profession so I can be calm and help them focus and say, "Look, we've done this before. Let's just work the situation that we have and just see if there's anything we can talk about or do," and really take the stress and have the emotion out of it and be Laura's calming voice, but you can't always be.

Roz: So it sounds, Michael, as though you have gotten to know Laura's health care providers. So I guess by going to doctor's visits or being part of these relapse events, has that helped you to feel more comfortable that you also know the team who's working with Laura.

Michael: Absolutely. I've also talked to her neurologist at a couple of different points including he does the occasional like open forum talk at a restaurant and talking to him there and really understanding where he's coming from and the treatment that Laura is on. It does help quench a lot of my anxiety and fears to know that we have a good neurologist who is really thinking about Laura and that helps me a lot knowing that the care she's getting is in the best light and really focused on her, that helps me a lot.

Roz: So we all have coping strategies. Some better than others, some more effective than others, but we all develop them. Could you, Laura, tell me a little bit about the coping strategies that you have used in stressful events. Some of the ones that have turned out to be not so good coping strategies and then maybe some ones that you found that are better?

Laura: Yeah. So, initially, when I was diagnosed a lot of my coping strategies were and I actually learned this when I ended up going to speak with a counselor, but I was practicing being scared in my own head and being worried. So I was like, "Okay, my doctor's appointment is two days from now," and like I just practiced that and get myself worked up and stressed out about it and my counselor was like, "Okay, well, what if we don't do that?" And I was like, "Well, I don't know how to not do that." Like doesn't make sense to me. Like I should be worried about it and she really challenged me to just try not to have that internal dialogue, to replace it with something else or for example, I had bad reactions sometimes to medications and things and a lot of that was just my own stress and working myself up. And so we found ways to relax. I listened to meditations now and things like that and sometimes it just helps to like talk about it or write it down or things like that. Since my diagnosis, I've been pretty good about keeping notes, whether that's just for myself or to talk to my doctor about. So things like that.

I also tried consuming alcohol and drugs and those kinds of things, that's not really a good coping strategy that generally makes you feel a whole lot worse. But asking for help and seeking resources and not practicing being stressed, is really probably my best coping strategy.

Roz: How about you, Michael?

Michael: So I do a variety of things. I think the thing that helps out the most is I talk to Laura about all this. Just sometimes getting it out there helps a lot so it's not just all in my head. That's very useful. Not always, sometimes getting it out there then puts the ugly thing that we all have to deal with in front of us and that's not great. But in the long run, it's better just not necessarily the short term. Also, this is a hangover from grad school, I meditate before I go to bed. I just take ten minutes and I just focus on an activity like walking backward through the door helps calm me down so I can sleep and I appreciate that. And then I would definitely say that once or twice a month, I will just blow off everything, go out with friends and try a couple of drinks on and have a good time and forget all about everything and that might not be the healthiest thing, but, man, every now and then, that feels great to just be outside of the situation for a little bit is really, really helpful. It's taken me a while to not feel guilty about that, but once I didn't feel guilty about it, it felt great. And I think it's actually helped us both out by doing that.

Roz: So we all know that relapses happen unpredictably, but what strategies do you use, if any, to try to plan for potential relapses or even to try to prevent them from happening?

Laura: I was going to say, I think, that in many ways planning for relapse is difficult, but to some degree, preventing relapse is a little bit of a lifestyle choice to some degree not to say that if you have a relapse that's because you've messed up something in your lifestyle, but the healthier I can be, the better food choices I can do, the more I can exercise, the more I can reduce my stress are all good prevention and planning situations because if you're just always running around and always super stressed out, that, in my case, tends to lead to relapses. The other, sort of, prevention strategy, I guess, I would say is that I am on a disease-modifying therapy and I feel like that and continuing to be on it has helped decrease my relapses.

Roz: The two of you have done such a remarkable job managing this intrusion in your life over quite a few years now, do you have any advice for others that you would like to share about how to handle this kind of challenge?

Laura: Yeah, absolutely. MS relapses and MS, in general, is a major life stress and so you really have to connect with yourself and figure out how you practice being stressed, how you get stressed out, what you do when you're stressed out if that's helpful to you and serving you or not. And I found that a lot of the way



that I previously dealt with stress was not helpful to me and so then you have to be okay with changing it. Like, "This isn't serving me and I have to do something radically different." So, in some ways, I'm actually grateful to have MS because it's made me be very real and honest with myself and figuring out what I can and can't do as a person and not promising everything to everyone. I was going to say the other component that I feel like MS has really taught me is to, sort of, get over all the hang-ups you have personally about, "Oh, I should or shouldn't say this to somebody," or, "This is or isn't okay," and I'm not saying throw all social norms out the window, but a lot of them I found don't actually serve people and if you just are honest and can tell people, "You know, I'm having a bad day," or, "This is what's going on," or, "I don't really know yet and I feel kind of weird about it," that that sort of level of honesty helps a lot.

Michael: I would say that the thing I would tell other people is - this is really really hard. Don't think that it's not and it's okay to fail at it, it's okay to be bad at it. You are going to be bad at it for a while. I think I'm still bad at it. I'm still learning a lot. And it's one of those things where I think if I approach it from like, I want to be there and be supportive and be helpful that as long as I focus on that and try to get better and learn from my mistakes or are even just try something new that that's really helpful. But I don't want people to feel like we have all the answers, we sure do not and it is a very hard thing to go through and it's one of those things where you just have to focus on what you have and be happy with what you have when you can and you're not always going to be great at it and that's okay. It's a long road and it's a hard road, but you can get through it, everyone can.

Roz: Is there anything as a couple that you think has grown for you as a result of sharing this experience together then you would like other couples to know?

Michael: I would say that it's really amped up our honesty with each other. Like there is no such thing as a secret between us. I mean, I think, we're at the point now where she knows my feelings as fast as I do which is actually great and horrible at the same time but overall it's a very good thing. And that as a couple it is made us really focus on us. It takes a lot of the other stress out of a lot of other things and we really need to focus on what we're doing and how we're doing things and that can be really empowering to know that we're really focused on this and us and how we together as a team get through it. It took a while to get there, but it has been building and building our relationship stronger because of it.

Laura: I completely agree and just say that the other thing that it has really done for us is if one or the other of us is messing up, whatever that means like not communicating well or something like that, you can honestly say to the other person like, "This is not working, we have to do this differently." And undergoing that change process is just faster and easier the more we do it.

Roz: I'm glad to hear that this experience has helped you to make such a wonderful relationship out of something that was wonderful apparently, to begin with, but has clearly grown in wonderful ways.

Rachel: All right, everybody, that's all the time we had today. Thank you to Laura and Michael for sharing your experiences. And, of course, I want to say thank you to Roz for guiding today's discussion.

Roz: Oh, well, it was my pleasure. I was so glad to reconnect with Laura and Michael and as always, I learned every time I talk to people living with MS, from their experiences. So thank you so much for sharing so openly and beautifully what your experience has been.

Rachel: This podcast is part of the Relapse and MS Series, a collaborative initiative led by Can Do MS and Mallinckrodt to better understand how MS relapses can impact your home, work, and relationships. Please remember to listen to all three podcasts in the Relapse and MS Series which are available on our website

and apple podcasts. We also encourage you to view our Relapse and MS Webinar, which is available on our website [cando-ms.org/relapse](http://cando-ms.org/relapse). Thank you for joining us.

[end]