Can Do MS Podcast

Growing Together

Episode 11

Krista: Hello, and welcome to the Can Do MS podcast. My name is Krista and I am the Programs Coordinator for Can Do MS. We are excited about today's podcast, which is part of our Embracing Carers series. Embracing Carers started in 2018 with podcast episodes Four, Five, and Six. If you have not listened to those, please make sure to check them out. Today, we will be releasing two podcasts in the Embracing Carers series. We will be joining Physical Therapist, Mandy Rohrig and couple Caroline and Tim, as they discuss the challenges of navigating life with MS. So, now I will go ahead and hand the conversation over to Mandy who will take it away from here.

Mandy Rohrig: Thank you. Hi everyone and welcome to the Embracing Carers podcast series. My name is Mandy Rohrig and I am a Physical Therapist with Can Do Multiple Sclerosis. I would like to introduce our two podcast participants, Caroline and Tim. Caroline and Tim have been living with MS for a couple of years now. I am going to let you let Caroline and Tim go ahead and briefly talk about themselves. Tell their stories of how they met and how that looks. So, Caroline, do you mind starting us off about your life with MS?

Caroline: No, that would be great. Hi, and thank you. It is great to be here. In 2001, I lost the ability to see or walk unassisted. We did not know what it was at the time. I was traveling in Guatemala with a bunch of friends. By the time I got to the doctors and they were able to run some tests, they told me I had MS. Multiple sclerosis. I did not know anything about it. So it was a big learning curve. My life changed a lot, but I have been able to adapt a bit, quite a bit over the years.

So, before my MS, I was quite active. I was a whitewater kayaker, I trained horses, I was a cowgirl, mountain biker. I did all that stuff. After MS, my life changed. My corporate life was no longer, I redefined myself. And I am still active. But I do things more like fly fishing and gentle activities. And that is my quick, brief story about me with MS. And I was very fortunate, a couple of years ago, to meet Tim.

Mandy: Can you describe how you and Tim met?

Caroline: You bet. A couple of years ago, a friend of ours, we have a mutual friend. And he had known her for a long time, since elementary school, and I have known her for a couple of years, but she has been a family friend. I have known them for a long time. And I say that because it is very important, I think, the trust and being able to meet people that come highly recommended. And I met Tim and just greatly enjoyed him the first time I met him. And it is just been wonderful ever since.

Mandy: So Tim, can you share the characteristics that drew you to Caroline when you guys first met that day?

Tim: We had, we are, about two years ago, we had met, we have gone out as a group, with a group of people. We have gone out a few times, and I met Caroline and my friend, that told me about Caroline. And then one night, we had, we have gone to a mixer and then we all went out to get a bite to eat afterward, my friend, Caroline and I. And Caroline and I can talk for two hours. We just found out that we had a lot of things in common. A lot of, just a lot of shared interest. And yes, the conversation has slowed real easy and she was just a breath of fresh air. We just connected on so many levels on that first meeting and it just went on from there.

Mandy: Tim, can you describe what you did or what you thought when Caroline shared with you that she had MS?

Tim: Well, I had found out that she had MS through my friend, and I, actually, I knew nothing about MS at that point, other than, multiple sclerosis. I did not really know what the disease [inaudible]. So, I did a little bit of research and found out what it was. And when I met Caroline, she did not seem any different than anybody else. There were no outward manifestations of her disease. She was just another person at the table. So, I did my research and it did not seem like I was biting off more than I could chew at that point, but it did, I did have some concerns about it at the beginning. But after, like I said, after talking to her that first night, it kind of went away real quick.

Mandy: So, it sounds like you are getting to know her as a person and as an individual, kind of calmed any fear or hesitation that you had about the disease. Once you got to [inaudible] the person. Okay. Caroline, were you fearful at all when you and Tim met? And when feeling that connection, were you concerned that he would be concerned about your MS?

Caroline: Yes, that is interesting. I was concerned as to what sort of person he was and how he would respond to the MS. When you are out dating and you have a chronic illness and stuff, sometimes people do not understand, often they do not understand. And that had been my experience in the past. But that quickly changed when I got to know Tim. Completely different than other people and just so attentive to my MS and concerned and I know he had done a little research and that alone meant a lot. Yes, it was just his support, I thought I felt like I could feel it from the beginning, and his understanding and that to me was very important. And that is part of why were, a big part of the connection and what we have together.

Mandy: Caroline, you touched a little bit when we first started visiting about your symptoms when you were first diagnosed and how they impacted your life personally and professionally. Can you describe now what symptoms you are living with and how they impact you in your personal and professional life?

Caroline: Yes. Most of the symptoms that I deal with on a regular basis, I still have visual problems, pain, fatigue. Fatigue was a big one for me and all of these I have to say, have subsided quite a bit. But if I do not take care of myself, they will rear their ugly head in a matter of minutes. So this muscle spasms, tremors, the bladder. I am trying to think of some of the other issues, but those are the ones that come to mind right away. Sometimes, I get a little off-kilter, my balance is off, things like that. Like I said, if I find myself not taking care of myself, then all of those symptoms come back hard.

Mandy: What are some of those things that you do to take care of yourself, to manage your symptoms optimally?

Caroline: Some of the best things I do to take care of myself, to keep those symptoms at bay. One of them is to eat well and keep very close attention to my diet. Also, to remind myself to slow down. We get in such a rush, rush, rush in this world, and that is just increasing, and the ability to slow down and let your mind rest. And basically, let yourself recharge your battery. It is like a phone battery that is got too many apps running and you just get worn out. So, a lot of what I do is to learn to slow down and rest and take care of myself. Some other things I have had to do is just set some boundaries that I was not used to setting before. Just to make sure that I would, I am able to take care of myself. So, those are some of the top things. Also, a lot of nerve-calming type of exercises like yoga and gentle walking and things like that, that just are gentle to the body.

Mandy: So, Tim, since a lot of Caroline's challenges, it sounds like are invisible symptoms. How do you know when she is having a good day or a bad day? How do you and how do the two of you communicate her MS challenges and manage her MS challenges?

Tim: Well, I mean you said it, the communication. And I can sense a lot of times that she is off a little bit and I will just ask her, "Are you doing okay?" And whatever the response is, I will react to that. We need to slow down, we need to stop, we need to take a rest. Whatever we are doing, if we need to leave where we are at because she is not up to it anymore, that’s fine with me. It is more, for me, it is all about her comfort level and what she can do. She is really active. She is a go-getter and she pushes me to be better and to go harder. So, sometimes I am happy when she says, "I got to slow down." "Okay, good. I am right there with you." And I have learned so much over the last year about the disease, and about how it affects her and other people with the disease I have seen. I have met a lot of people with MS in varying degrees. And you see a lot of the commonality between them, of the fatigue, of the, just "I am off. I am off-kilter a little bit here." And it is all easily workable, just as long as we communicate openly and honestly about what is actually going on. Things always seem to work out.

Mandy: Caroline, can you offer an example of how Tim specifically helps you manage one of your MS challenges?

Caroline: Let us see. One of them. Well, I think I have a bunch of them. I really want to go back to communication and its ability to help me. Sometimes, this is interesting, like we will be at an event or something, and all of a sudden he just, I will kind of get a wave of, like I am not too stable, kind of a dizzying wave that goes through me. Or I will be at an event and all of a sudden I will sort of gently grabbed his elbow and he usually knows that I need a big strong cane at that point. And there have been times where I have had to use a cane. Tim has not seen me use one in the last couple of years. I have done much better. But I think also it is because I have been able to rely on him a lot and knowing he is there, like when we are traveling and knowing he can be there to help me with the bag. He gives me a certain confidence that I do not have without him there. And he also calls me on my BS, too. I mean, just honest, the baloney of, if I am trying to do too much or something like that. I mean, he is honest and he makes sure I am taking care of myself and that is wonderful. I love it.

Mandy: So Tim, what are some of the phrases, for our listeners out there, what are some of the phrases that you say to Caroline to help encourage her, to realize when she is maybe cross that invisible line of doing too much? Because I am sure our audience members can relate to loved ones with MS who have trouble doing that.

Tim: My go-to was always "Are you doing okay?" And sometimes I feel like I asked that way too much but it is, like I said, I can sense something but I got to, I just got to check in, "Are you doing okay?" And she will say, "Yes, I am," or "No, I am not." "Okay. So what do we, where do we go from here?" It is, like I said, my go-to is, "Hey. Are you doing okay?" Because I can sense it and a lot of times it is, "Okay. Well then, let us, what, where do we go from here?" It is not, I mean for us, it is not, I do not want to say not a big deal because it is a big deal. But I mean, because of the relationship we have, with the openness and the honesty, and the love we have for each other, we are blessed in so many ways. And so that is just part of the day-to-day routine. So, for me, it is just "Okay. This is what we got to do. Let us do it." So it works out really well.

Mandy: Tim, how does Caroline help you manage any feelings and challenges that you have as a result of the MS? It sounds like you are good at communicating with her and she is good at communicating with you and kind of reading each other's nonverbal cues. But what about when you are starting to have some feelings and anxiety about the disease?

Tim: About her MS?

Mandy: Yes.

Tim: You know, I really do not, I do not think I have got that point where I realized that what she is doing and what she is going through, it is out of her control. She has no control over it, and as I have no control over it either. So, I have never gotten to the point where I am like frustrated or you know, how do, you know, why is this going this way or lost my temper because of it. I am there for as much as I can, be in whatever way I can be. So, yes. I have learned so much in the last few years. We have done a lot of traveling and done a lot of stuff MS-wise.

Mandy: So, it sounds like a lot of flexibility and communication is how the two of you have worked together to manage this disease.

Tim: Yes. Completely.

Mandy: You both mentioned traveling, right?

Tim: Yes.

Mandy: So, let us talk a little bit about some of the leisure activities that you guys like to do together and how that makes both of you feel? For example, your traveling experiences, maybe dancing, just interacting with friends, to share a little bit about those day-to-day activities.

Tim: Like Caroline said she is, before she got MS, she was extremely active, a lot more active than I was. And so, since I met her, I learned how to ride a horse. I learned how to fly fish. We do go dancing, we love to go dancing. There is just a ton of stuff, but traveling, we have done a lot of traveling together and we travel really well together. The stress that a lot of people experience and traveling, we do not have that. We have never had that when we travel. It is always as if we are off on our next adventure or like "Oh, wow. This is it[?]. Whatever happens, happens." So, it is always been great.

Mandy: Caroline, how do you guys made traveling successful? Are there certain, it sounds like you plan. So, are there certain strategies that you could recommend to help people find greater success with traveling?

Caroline: Traveling. Well, if you have someone as compatible as Tim, it does make it easier. Like he says, it is kind of amazing. We do plan and probably the most important thing is that we always know, and this goes with just life with MS, we are going to have a plan A, but we also are going to have a plan B and plan C in our pocket. Just because of the way the illness works, I may not be up for something. We may have to change. I may need extra help. Again, I think a lot of this goes to just Tim who he is as a person and also his caregiving experience of just being very caring and attentive. Talking while you are traveling, knowing what each other needs, knowing what you want that has been really big, and asking for help. He is pretty good at spotting when I need help. But sometimes you might be with somebody that does not spot that easily and you need to ask someone, you know, "Can you help me carry this bag?" The other thing too is, do not be shy to go up to the airline agent and tell them I have MS. But you do not even have to say that but you have a medical excuse to get on the plane early, to board early. Because just standing in line and that long line waiting and then walking down what often can be a warm terminal, and all of that, that alone could knock at least a digit or two off your battery power, like a bar. It just can sap a person's energy really fast. So, even if it is an invisible disease, just know that you have a reason to board early or do what you need to take care of yourself. And I think that is really important for people to understand, and then if you can have someone like Tim there that does make it much easier.

Mandy: Caroline, I am assuming asking, accepting, and communicating help has not always been as easy as you because you have worked at it. You have really worked to try to make that more helpful for you and your life managing MS. And asking, accepting, and communicating help is difficult for a lot of people who live with MS. Can you just describe, kind of just your evolution. How you came to that realization that asking for help, receiving help is okay, and is okay in certain circumstances?

Caroline: Yes, you bet. Asking for help is probably one of the biggest benefits I have gained from my journeys with MS. Just to give you a little, and I do not, you may be too young to remember Murphy Brown the TV show. But when I used to work in the corporate world that was sort of my nickname, I did not ask for help. I did it all myself. I was Wonder Woman. I could do it. And then interestingly, through the course of my disease, I had not noticed but a good friend of mine had noticed and she said, "You know what, you have learned to ask for help since you have gotten sick." And bringing that awareness to mind just almost snowballed the effect that "Okay. Well, let us really think. What can I ask for help? How can I get more people involved? Delegate more, and make more of an impact with my energy because I do not have as much energy. So how can I extend the least amount of energy and get the most done? And it is almost like going from maybe up to a power player to a finesse player because you start learning you do not have that energy. You do not have that strength and you have to learn how to work with what you have. And asking for help, it has been a big challenge, I think a lot of it. But some of it I learned on a tea bag, which sounds so funny, but it was one of those Yogi teas that said, "When ego is lost, self is limitless." And it was just one of those things that we have got to remember to always let our ego go. If we can let that go, there is so much more we can do out there.

And that is a big part of asking for help is just saying, "No, need to be prideful," or just, "Not your ego." It is okay to ask for help.

Mandy: Now, Tim, I would ask you in return though. Do you ever need help yourself? Are there times when you find yourself asking for help of Caroline? How does that look? Can you describe it?

Tim: Oh, definitely. Definitely. It is funny to bring up the word 'help' because it is the shortest prayer in the world, help. And a lot of people perceive our look at help as a kind of weakness and I learned a long time ago that it is not. I cannot do everything and I do not want to have to do everything. And I do need help on a daily basis. So, for me, to ask for Caroline for help, if I am not, if I am struggling or if I am tired. I get tired too and not because I am dealing with Caroline all the time. I have a job and I was taking care of my dad before he passed away. So, sometimes when I, you know, it is like "Hey, you know what? I got to slow down. I need some time." Like Caroline said the ego, just, you check it before you wreck it. It is, you got to leave it at the door and just say, "You know what, I am not, it does not make me a lesser person just because I am asking for help." I am more than happy to accept that, I am more than happy to give it.

Mandy: So Tim, you alluded to your experience as a care partner for your father, and having a conversation with you prior to this, you have also shared that you are a care partner for your mother. Can you just describe to our audience your extensive support partner, care partner experience?

Tim: Well, my mom passed away in 2006 from ALS. And that was horrible to watch and it was difficult to watch and I was not in the greatest place in my life at that point when she was dying. And I would go down and visit her, she was trapped in a bed with a body that does not work, but the mind, they still did. And it was very difficult to see her in that condition because she is such a strong, vibrant woman up till that point. So, I went through it but I do not feel like I was the greatest caregiver at that point and I learned from that experience. So, when my dad got, started getting older and started getting more frail, we are going to do assisted living. Anyhow, we go down and see him, might have him up for dinner. I am more than happy to do that because he has done so much for me, it was my turn to return it. And then, back in February, we found out he had liver cancer. So, I basically had to watch him, the disease eat him away. He was always happy to see me and always greet me with a smile. And so, I looked at those experiences. I was blessed that I got to spend those time with him, the last few months of his wife, and just be there for him. And for me, it was a very positive experience. I never looked at it like a chore. I never looked at it as like, "Oh, you know, I got to deal with that again." Sometimes, it gets frustrating how fast he has asked the same question over and over again. But still, it was like, this is a guy that I owe my life to and I was more than happy to be there for him. And I am glad I did.

Mandy: So are there, it is, I am sorry about your tremendous losses, Tim. You clearly have endured a lot of sadness and hardship. Are there any tools or strategies or lessons that you learned that you could share that helped you prioritize that caregiving role while still prioritizing your own health and your own wellness and your relationship with others?

Tim: Well, I think the empathy that I have. I am not the one who had cancer. He is the one who had cancer. I am not the one that looks slowly, you know, my memory was going, either one. And so I am sure, I looked at it like he is got to be frustrated, too. He is got to be very frustrated. So, anything I can do to relieve that frustration or ease away for him, I was glad to do it, because I would hope somebody would do it for me later on. And that is, I mean, that is not why I did it, like "Oh, I need to get paid back at some point." But that giving, that being of service and that giving back really is important to me. We go through life and, like Caroline said, we are so busy all the time, and to stop and say, I can help here, I can do something here and give it back as a very rewarding feeling.

Mandy: So, Caroline. How did you support Tim when he was serving as such a significant role in his, as a care partner for his parents?

Caroline: I did not get to meet his mother, but I did get to meet his father and it was just so special. I actually loved going down there with Tim and Tim's son and spend time with their dad. It was really sweet. He was just a neat man. I have always heard so many wonderful things about him. We grew up in the same community, knows a lot of mutual friends. I think just being there, I mean, that is what I wanted to do was just be there for him and be by his side and be there as much as I could. And spend as much time as I could with his dad because he was pretty good when I met him, but you could see then when the decline hit, it was starting to get pretty quick. So, we did as much as we could and that was really special to me.

Tim: Excuse me, I got to have-- Having Caroline there with me and those last few months really helped me a lot because I had somebody I could talk to, I had somebody to express my feelings with and get them out into the open, rather than keep them all bottled up. It was sad to watch this man that I love and who I considered my hero slowly waste away. But thank God, Caroline was there to walk through it with me.

Mandy: So, the importance of partnerships and being together and that time together is monumental, it sounds like, for the both of you.

Tim: Right. Yes.

Caroline: Very much so.

Mandy: Are there any other ways that you support one another? Because we like to talk about care partners, not just for the person living with MS, but the person living with MS supporting the person not living with MS. So, it is really a partnership between the couple. Do you guys have any additional advice or strategies or anything else that you would like to share that you have learned along the way?

Caroline: I am going to jump in here first. I think some of the most important things to remember is to be patient. Be patient with yourself and be patient with others. We do not know what other people are going through. I have learned that so much with Tim and just what he was just stating about, how frustrated his father must be to be the one who is experiencing that. And to remove us from, to really think about what the other people are going through. And smile at yourself and smile at others. It is just one of those things as positive as we can say, I think, is great and one of the cheapest forms of flattery. Just smile at somebody and let them pass it on, and I just think that is good. I just like that. It is the last thing out there.

Tim: I agree with Caroline and all that. I think one of the keys to our relationship is openness, honesty, and communication. We are not afraid to talk about anything and we express our feelings very well with each other. And sometimes we disagree and we realized that it is okay to disagree on some issues. That is life. I think we have been very good at communicating what is going on and where we are on a daily basis.

Mandy: Wonderful. Well, clearly, you guys, have a very loving, balanced partnership with a lot of empathy that you share with one another and you clearly value what the other person brings to the partnership. Any final thoughts or any other comments you would like to add.

Tim: I love you, Caroline.

Caroline: I love you, too, Tim. You know, one thing I think what is important to know is that, for me, I know that Tim is good for me. And I knew that when I met that connection, there was just something there, as we have said. And I know he is good for me and as part of my self-care challenge for self-care with MS is doing things that are good for me. And I know that sounds interesting, but when you find healthy, happy people that you connect with, include them in your circle. And, like any friendship, it takes work to keep a friendship, but it is all worth it. It is all happy work and it is just good. So I just tell you guys, embrace those good people in your life and bring them close to you and tell them how much they mean to you.

Tim: I agree. Caroline makes me want to be a better person and she brings so much to the table. And I am blessed to have her in my life and I thank God every day for that. We push each other and we are there for each other and it is been an amazing two years. I look forward to the next two and the two after that.

Caroline: Me too. One day at a time.

Mandy: Wonderful. Well, thank you, Tim. Thank you, Caroline, for your time and for your, sharing your experience and your expertise.

Tim: Thank you, Mandy.

Caroline: Thank you. Thanks for having us.

Krista: Wow, thank you to both Tim and Caroline for joining us. We really appreciate you sharing your experiences to help others. And of course, thank you to Mandy Rohrig, as well, for facilitating. This podcast is part of the Embracing Carers series, an initiative led by EMD Serono, in collaboration with leading caregiver organizations around the world, to increase awareness and action about the often-overlooked needs of caregivers. Be sure to check out the Embracing Carers page on our website, cando-ms.org. Also, please tune in for our second podcast in the 2019 Embracing Carers series, which is available now on our website, as well as on Apple podcasts or wherever you get your podcasts. Thank you so much for joining us.

[END]