



Embracing Carers Series

Prioritizing Your Emotional and Physical Well-Being

Episode 5

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 second episode in our three-part Embracing Carers series; focusing on those supporting a loved one with MS. Today, we have three guests joining us: psychologist Meghan Beier, physical therapist Mandy Rohrig, and support partner Malcolm Newton, whose wife, Mary, is living with MS. Meghan, Mandy, and Malcolm are going to discuss how support partners often neglect their emotional and physical well-being to care for their partner with MS.

Rachel: Malcolm will share some real-life stories, barriers to prioritizing his health, and how he maintains his own individuality while caring for his wife. And once again, I would like to introduce Meghan to kick off our discussion. Meghan, please take it away.

Meghan Beier, PhD: Thanks, Rachel. It is great to be back today to discuss the challenges support partners face when it comes to prioritizing their own health and maintaining their own sense of individuality. This is a really important topic because forty to seventy percent of family members report clinically significant symptoms of depression and up to thirty-five percent of support partners report that their health has declined as a result of care-providing responsibilities. Additionally, we know that support partners are more likely to report a decline in their own overall health if the person they care for has an emotional or a mental health problem.

Meghan: More positively, though, there has been a great expansion to research on effective interventions for support partners and loved ones. There are now a number of empirically supported and validated resources that can help support partners from things like online support groups to online educational courses and even interventions developed for working with an individual or family therapist. We also have physical therapist Mandy with us today to talk about prioritizing physical well-being. Welcome, Mandy.

Mandy Rohrig, PT, DPT, MSCS: Thank you, Meghan. I am really, really excited to be here today to make sure that support partners are physically taking care of themselves, just as much as their loved ones with MS. I am a physical therapist from Omaha, Nebraska, where I work in an outpatient physical therapy setting, where I specialize in working with people with MS and

their loved ones as well as individuals who have balance or vestibular disorders. So, since Can Do MS emphasizes care for the person with MS, we also emphasize a lot of self-care and self-prioritization for the individual who is supporting them as well. As an organization, we believe that both people are living with MS, just in distinctly different ways.

Mandy: So, physical health and physical wellness for the support partner may include primary care visits. It may include smoking cessation interventions. It might include weight management or preventive care such as mammograms or immunizations; making sure your blood pressure or your cholesterol is being monitored closely. And of course, my favorite, exercise. But more specific to MS, the support partner physical health may also include simply learning proper transfer techniques to help prevent injury or maybe encouraging the loved one who has MS to use an assistive device, so as to ease the burden of the caregiver. So, support partners, caregivers, loved ones-- whichever label you prefer; they are often selfless. They are people who prioritize their partner's physical health often over their own, making certain that they get to their doctor's visits and their physical therapy appointments, or their exercise classes, but rarely carve out that time for their own physical health, and that is why all of us are talking here today. So, Meghan, would you please tell us about our guest who is joining us on this podcast?

Meghan: Absolutely. So, today we are going to be speaking with Malcolm Newton. We are going to hear about him and his wife, Mary's story and the challenges he has faced in taking care of himself. Welcome, Malcolm. Will you please tell us a little bit about yourself and how you met your wife, Mary?

Malcolm Newton: Sure. We are both from Atlanta, Georgia. I work in the healthcare industry. I am a salesman, but also run a couple of little healthcare companies that I have started with different partners. My wife, Mary, and I actually met in carpool when we were five years old in kindergarten and we went to elementary, junior high, and high school, altogether for all 13 years, and we have been married for twenty-seven years together. Actually, dating before that about six years.

Meghan: What activities do you and Mary do now that keep you connected?

Malcolm: A lot of things that we do now are not too physically demanding. We have started to watch different shows on Netflix and Amazon. We also do some fair amount of card playing, which is a feat in itself because I was not a good card player when I started off and I did not really like playing cards, but it has got to be something that we do together. We do a small bit of traveling although that has gotten a lot more difficult in the past five years as she has got some vestibular issues as well. And we keep up with our daughter who is twenty-two and living in New York and trying to be a professional dancer.

Meghan: Do you remember your reaction when Mary was first diagnosed with MS?

Malcolm: It was December 26th at eight o'clock in the morning. My wife's primary care doctor

called us, woke us up and said, "Hey, you know what? After some of these tests we have run, I think I want you to see a specialist. Worst case scenario, it could be MS," which led to a great, you know, rest of our Christmas vacation. And then, a very good, trusted friend of mine who was in Harvard Medical School at the time; he and I were talking, and Mary was there, and I was describing the symptoms that she was going through and without knowing what was going on he said, "Gosh, that sounds like MS to me." On our way home from that lunch, my reaction was not the greatest. I remember that to this day. But again, that was a long time ago. Then there is another doctor's visit two or three weeks later. The guy said, "Oh, no. It is not MS," which was a huge relief and then she had another relapse, I guess, three, four months later. And so, it kind of became more and more obvious to us that it obviously was MS, and then later that summer, we finally got into a very good doctor in Atlanta.

Malcolm: He told us, "Yep, it's MS." But, I had a couple of not-too brave reactions back in the day. We had only been married for two years. I think I was twenty-eight, and the prospect of having a wife that had MS, or a partner that had MS, was very scary. So, I was not, I did put on the bravest face.

Meghan: I am sure many people can relate to those feelings of fear. How long has Mary been living with MS at this point?

Malcolm: Twenty-five years.

Meghan: Twenty-five years. Okay, and what are the things that you support her with at this point, either emotionally, physically, cognitively?

Malcolm: On one hand, it does not seem like a lot but I think I think if I describe it, it would sound like a lot because I do the cooking and the cleaning, and the shopping, although we have gotten some folks to help us a little bit with the shopping and bring groceries over. We are not to the point where I have got to physically, totally help her get dressed. She can still drive. She can get in the car and go see her parents who are in assisted living place. But, I try to help her with getting to the car because she needs her scooter and that is kind of heavy to get in the car. So, I take it down and put it in the car and sometimes I will take her over there. But the list is long. Trying to keep the house or the apartment straight, walk the dog. Help her in-and-out of the shower so she does not fall. She is trying a new MS exercise program and she needs spotting, so I am making sure I am doing that. But obviously, this has built up over the last twenty-five years to where-- I am really just adding one more thing. And so, now, it does seem to take up quite a bit of time but that is what I am here for.

Meghan: Yeah, absolutely. I am going to turn it over to Mandy to see what question she has for you in terms of a physical therapy perspective.

Mandy: Malcolm, I am just curious. It sounds like you provide a lot of loving assistance to your wife, and I suspect right now it is somewhat instinctive, given that she has had MS for twenty-five years. Can you just tell us a little bit about some of the struggles and successes as you

transition to this greater need for her to have assistance?

Malcolm: Well, she is a very determined individual. Always has been. I am, I guess, I would say actually naturally kind of a caregiver for my fifty-three years of existence. That is kind of what I do, I guess. And so, I have probably overstepped my bounds too soon. She has probably tried to hold me off for too long. So, we had some troubles there where I did not let her "fall", I guess. You can put the fall in quotes sometimes, or sometimes it is literally fall. Well, I am not going to sit there and watch her fall but I did not let her sometimes try when she could have still tried and she would have to tell me, "Hey, I can still do this. Back off." And I would do it but I would back off and I would still try to be within arm's length, or I would just try to be there in case she did fall. But those were some of the struggles that we had through the first, you know, fifteen years, in particular the last five years. It has gotten to a point where some of her resistance to me helping is just going away because there have been some serious falls that have hurt, and it scared her and so she has gone. Really, five years ago, it was kind of cane, possibly walking, and then kind of cane, walking, cane, maybe to where it is either cane walker or scooter now, almost all the time.

Mandy: So, was it challenging to learn each other's cues or just kind of define those boundaries that were certainly always changing, right? Like, one day she needs help with one task and then the next day she may or may not need help with that task. How did you two work through that communication?

Malcolm: We saw her parents have an issue where they were trying to take a casserole to a friend who was sick and her parents are obviously older, and the last thing they needed to be doing was to be taking a casserole to a friend. Mary's mom fell and grabbed Mary's dad, pulled him down. There were injuries and all kind of things happened, and that escalated. Everybody in the family is trying to help them, and so, Mary and I had a discussion and I had to talk and said, "We do not need to get there because of pride or determination. We need to make sure that we are careful so that we do not make things harder on ourselves than they already are."

Mandy: Malcolm, I feel like you very lovely illustrated how it is often important for couples to consider use of assistive devices and tools, and ways to help themselves physically to keep them safer, and how sometimes using those types of tools are not just benefiting the person living with MS, right? They are benefiting both of you. So, shifting gears a little bit, Malcolm. Do you feel your medical health is a priority? Do you participate in regular doctor's visits and checkup?

Malcolm: No. I am just being honest. I am not a big-- I just do not do that at the moment. I know I should. I know it does not make any sense, whatsoever, for me not to, but it is not a priority. My day is focused on work and trying to make money; taking care of her, and doing whatever little exercises I can for myself.

Mandy: So, it sounds like the barriers for you to participate in regular preventative healthcare,

regular doctor's visits are time and care-giving responsibilities.

Malcolm: If I went and I found out, "Hey, I have got something going on," you know, that might be the straw that breaks the camel's back. There is just a reluctance to go do that. Number one and number two, there is also a little thought in my mind. Well, I am pretty healthy.

Mandy: So, you mentioned that you exercised. Can you tell us a little bit about what exercise you do?

Malcolm: You got a group of good friends and we do, we play as much basketball as we can but your old man basketball. And we do a lot of it on the weekends, Saturday and Sunday, and then during the week, I try to do some weight training at night once I get kind of married to that after-dinner and that kind of stuff, and if I can go down to the weight room at our apartment, I will go down there. It is not hit-or-miss. There are times when it is good and easy, and I make sure that I go do it, but then there are other times where I just get too busy. Currently, right now, I am doing a good job of all of that. There is weight training and then I am playing basketball as much as I can. As much as my old knees will let me.

Mandy: How do you manage to find that time to exercise when you have listed all the things that you have to do in a regular day? Do you just say, "Hey, Mary, I am going to go and I am going to exercise. This is my time." Does she know that? Do you communicate that to her? How do you manage that?

Malcolm: She is on board with that, as well. I did my basketball for about ten or fifteen years. No, actually, fifteen years at least. And it got to the point where, if there was nothing important that had to be done on Sunday afternoon, but for some reason, "Hey, I do not want you to go," or, "Hey, let us go shopping," she would notice and I would notice, too, that I would get very, very grumpy towards the end of the afternoon saying, you know, my mind would be racing, "Hey, I need to go get this exercise. This release." Although, I would not say it sometimes. But we did come to an agreement that, you know, Sunday afternoon if it is not life-threatening, we are carving that out for me to go play basketball. She understands that I need to get out from time to time and just let off some steam, or get the positive energy flowing, or whatever that happens when people exercise.

Mandy: That is great. So, it sounds like you and Mary have developed a routine over the years that has allowed you to carve out that time, and you need communicated that together and made it very clear that, that is something that is important to you. So, Meghan, in addition to physical health, can you tell us a little bit about why emotional health is a priority, and the opportunity for Malcolm to give us some of his insights as well.

Meghan: So, I just wanted to follow-up a little bit on what you were just saying, Malcolm, is that exercise to you seems at least one way that you are managing your emotional health. Is emotional health a priority? And in what ways do you cope with the frustrations that come

along with, just all the day-to-day things that you have to do, and then also having MS as part of your life as well?

Malcolm: It is not a priority. This kind, like my physical health. I will be honest. And I have noticed there are times when things get more difficult or darker, I guess is the word, or you know, if she has to be going through a relapse. I tend to be more angry at things. Yeah, driving around the city. If people cut me off or they are not fast enough off the red light, I am a little or a lot more impatient. Again, by doing just a little bit of exercise during the days really does help with that. And then I have got a friend or two that, things get kind of rough, I can call them up and we can go to lunch and just kind of have a session where we download everything and say, "Hey, here is why things are kind of crappy right now." There are folks that will listen and then if things get really crappy, there are folks that will step up and step in, and try to help out. It is a struggle. There is no question about it.

Meghan: Sounds like you are managing those symptoms in some ways through your exercise and then you have a friend who is a really good support system. If you were making it a priority, not saying that you have to, but if you were making it a priority, what would look different?

Malcolm: Get involved in a group session. I am actually, physically, pretty close to some places that have some support groups. I could probably do that once a month, but I have not done that. I could possibly go talk to somebody, you know, once a week, twice-a-month kind of deal. We have done this kind of thing before. I have done those kind of things before and they have proven to be a little bit helpful. Somebody wrote in here in one of these things that, "Hey. MS is not cheap." Neither are those things. So, trying to juggle it all, that is just something that I think, "Okay. Well, maybe I could do that later," and then it just never happens.

Meghan: It is also hard to fit those things in when you have so many other things going on. Making a priority list and figuring out, you know, prioritizing all of the things that are going on and all the things you could be doing, and figure out what is most important now and maybe what are things you could do in the future. Do you have a support system outside of that one friend that you described?

Malcolm: He is involved in my basketball group and we got about eight guys. They are all pretty supportive. Very supportive. I could put out a call, "Hey, I need X, Y & Z," and it would show up. It is not just limited to that basketball group, actually. Once a year, we go off on a weekend with a group of folks, about ten couples. We put out the call before, "Hey, need somebody to help us bring in groceries over," or, "Need somebody to help get married to her therapy at Shepherd Center," and some of the folks have really stepped up. We have had a good support system.

Meghan: And what kind of hobbies do you have, individually, outside of your basketball group?

Malcolm: Work and take care of Mary, and basketball. The things that I do in basketball are the things I look forward to. My daughter laughs at me, she says, within the first two minutes of introducing myself to somebody new, she says, "Hey, I am Malcolm Newton. My wife has a MS."

Meghan: Thank you so much for answering all of our questions and answering them honestly and openly, and describing both the positive aspects and the things that maybe you would like to continue working on. But I would like to kind of turn it over to Mandy to see if she has any final questions for you.

Mandy: Malcolm, you sound like a wonderful support partner and an amazing person. We appreciate your time and your honesty with this conversation. We just want to ask you any advice or final thoughts you would have or that you would offer to others in this role of a support partner that may help them improve or optimize their own physical health?

Malcolm: You got to get out and make time for yourself because that, sometimes, is the only time that it is not front and center in your brain. For instance, I do not know why I do this, if I go to the grocery store and get something, something in me makes me feel like I need to hustle and get back. Although we are not there. We are not at that point, but there is just some kind of little bit of anxiety in me that, "Hey, I have to go get all this stuff and I got to find it, and I got to get home." Tomorrow, I am supposed to go on a business trip to South Georgia. I am going to be thinking about getting back home and what is going on at home most of the time. Once I am done with my meeting, I am going to be hustling home. When I get home, everything will be fine, but there will be that anxiety. But when I am out doing my basketball or my weight training or something athletic or physical, I always, it is remarkable that, when I am done and I start walking to my car, I remember, "Oh, okay. Well, now what I need to do for Mary?" But I am also reminded, hey. Wow. For that hour and a half, I was not thinking about, "I need to go to the grocery store. What are we doing this afternoon? What do I need to do? Do I need to watch clothes or whatever," again, the activity gives my brain the hour and a half where it is not front and center, and it is needed and refreshing, I will say.

Mandy: Wonderful. Thank you. Meghan, do you have any final questions for Malcolm?

Meghan: What final thoughts do you have for others who are new support partners, or somebody who just found out their partners was diagnosed with MS?

Malcolm: We were in the Can Do MS program again in March. A lot of folks were newly diagnosed and they were talking, "Hey, it is not all that bad. My wife can still work. My husband can do this. My partner can do that. Things are going good." Hell, back, because we had been starting in to, you know, this last five year period where things started to kind of go from relapsing, re-admitting to secondary progressive, where it is really-- gosh, it is such a slow decline and there is no real proven, total way to stop it or slow it, even though we are trying with medication. Number one, I want to say get with your doctor and make sure you

are taking all the steps you can.

Meghan: Let me follow up with one follow-up question to that. What do you wish you had known as a support partner? What would have made this journey easier for you, if you had known it at the beginning?

Malcolm: There will be good times still, and there will be relapses and there will be times when things are still kind of okay. Take advantage of those times that are still okay. Maybe just take it one day at a time, but also plan for the future and doing as much as you can.

Meghan: Thank you again for sharing your story and thank you, Mandy, for joining us today, as well.

Rachel: Thank you to Malcolm, Mandy, and Meghan for joining us. And Malcolm, we really appreciate you sharing your personal experience as being a support partner to help others understand the challenges and benefits of prioritizing their well-being. 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 our Embracing Carers page on our website <http://www.cando-ms.org/ec>. Please tune in to our third podcast in the Embracing Carers series covering the topic 'relationships and planning for the future' which will be available on our website and apple podcasts on October 31st. Thank you for joining us.

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