



Embracing Carers Series

Supporting a Spouse

Episode 28

Krista Sipf: Hello and welcome to the CanDo MS podcast. My name is Krista Sipf. I am a Program Manager here at CanDo MS. We are excited for today's podcast which is part of our Embracing Carers series. Joining us today, we have two support partners, Matt and Warren along with Psychologist Roz Kalb. Thank you guys so much for joining us today and of course, thank you for sharing your perspectives as support partners as you navigate life with MS. Without further ado, I will hand the conversation over to Roz.

Roz Kalb: Hi everyone, I am very pleased to be here with Warren and Matt who are going to share some of their experiences as support partners for their wives with MS. My name is Roz Kalb, I am a clinical psychologist and I have been working at CanDo MS for twenty years now, and I have had the opportunity to work with both Matt and Warren in the past at programs and I am thrilled to have them here today. Matt, could you go ahead and introduce yourself, please?

Matt: Sure. Hi, my name is Matt. My spouse's name is Kelly. She was diagnosed with Multiple Sclerosis in 2018 and my role as a caregiver to her is largely mental and emotional support with occasional physical support on a particularly bad day.

Roz: Great. How about you Warren?

Warren: Yeah, hi. My name is Warren. My wife's name is Loretta. She was diagnosed with MS in 2012 and it has progressed to the point now where she is in a power chair and requires my daily emotional and physical support.

Roz: So Warren, can you describe how your role as a support partner evolved over time, from the diagnosis to where you are today?

Warren: Sure. When she was first diagnosed and they said she had MS, we shrugged our shoulders and looked at each other because she really had very, very minor symptoms so it was really more about just supporting a wife, you know, husband supporting a wife with an MS diagnosis and it has evolved now to providing a lot of physical and emotional support on a daily basis.

Roz: Is she able to do anything on her own? Some things on her own?

Warren: I would say for the most part she can eat on her own, she can pretty much just about eat. Both her legs are very weak, one of her arms. So, for the most part, anything else with, let us say the activities of daily living like dressing, toileting, bathing, I have to assist her with.

Roz: So what would you say were the major milestones along the way that impacted your life personally and your relationship as a couple?

Warren: I will probably say that the first part was this diagnosis and it was, "Okay she has MS and we do not know what it means, and life kind of goes on as normal." So we thought. And then there was this progression stage where instead of it being this very slow or like relapsing-remitting, it was this sudden progression of the symptoms where all of a sudden it became very difficult for her to walk and to support herself. She was still independent but losing her balance. Partial loss of function. And then I think there was this kind of emotional stage where she went into depression lost a lot of weight for a while the doctors helped us to get ahold of, to recognize that issue and to be able to address it and now I would call it, this strong dependence stage where she is no longer able as I mentioned earlier, to care for herself and so, my assistance to her is throughout the day.

Roz: And you work from home and that is how you are able to do all of this?

Warren: Yeah. I am very blessed in that. It happened at a time when both our children were grown and independent, that I had retired from the Navy Reserves, that I started a business on my own, at a time when she was in need but not as much need and I can run my business from the house essentially. I do not have to travel extensively anymore either.

Roz: So Matt, you have told us that your assistance at this point is really a lot of emotional support and just being there for Kelly when she needs that support. How has Kelly's MS impacted you personally?

Matt: I would say it has impacted me in a number of ways. Some of the ways are more subtle and just not easily observed. There has been an increased mental and emotional stress and anxiety largely relating to fear of the unknown, fear of the future, particularly concerns over future finances and even concerns over how should hard we push her to continue to work? Does she continue to work because she feels good enough to do it? Or does she step back a little and maybe work part-time or not work at all? Because she does have days where she struggles more. That is still something we are trying to work through. I would say also loss of sleep just largely related to anxiety and then changes in our plans, we even one time canceled a trip to the Grand Canyon because she just did not think she could do it. She did not feel up to it that week.

Roz: You also moved in part because of the MS. Could you describe that a little bit? That was a pretty major move for you and your lifestyle.

Matt: Absolutely. We moved to Hawaii because of a dream of mine. Many people dream of many things some people, it is a corner office and a large building in a fancy job wearing a nice suit, some people it is a big fancy house, some people would say an exotic sports car, me it was living on a tropical island. That was my goal in life largely and we got there and we did it and we did it for a couple of years and then after navigating the healthcare system in Hawaii for a little while, we ultimately determined it was not going to work. At one point, she even went without medication for six weeks because they just could not get it to her. There were too many roadblocks, too many obstacles for her there to feel comfortable.

Roz: That must have been a huge loss for you personally, a loss of a dream and a goal. How did it impact you as a couple beginning with the diagnosis? How would you say your partnership has evolved from the beginning?

Matt: Well, we historically have had a very strong, very close-knit, cohesive type of relationship even to the point of not necessarily having to communicate things verbally because we just knew what the other person would expect or think or anticipate and communication was always very strong, nothing was off the table. The anxiety that came on both our parts with the diagnosis certainly impacted communication and problem solving in general and just making everyday decisions and then over time, some of the continued anxieties, particularly, probably for me, have probably caused me to be a little overly protective of her and even to the point of it being unnecessary.

Roz: How does Kelly react when you do that?

Matt: Actually, usually pretty positively. For the most part, she recognizes that I am just looking out for her. Occasionally, I think it comes across as overbearing.

Roz: Would Loretta ever say that you were overbearing, Warren? Just checking.

Warren: Yeah. Because I have to do so much to help her these days and her independence is gone and the funny thing is I am like, I would be very happy for you to do it on your own, thank you. It is not like I have to or want to do this, but I feel like I need to and it is hard to put yourself in someone else's place that normally would do certain things and try to do it the way they would expect you to do it. That is a constant challenge.

Roz: So as Loretta's MS has progressed and it sounds like it has progressed quite significantly in a relatively short number of years. What would you say have been your biggest challenges as that evolution has happened?

Warren: I think in the beginning the challenges were not as great as they are now, but certainly along the way they were learning to be patient, simple things like as it became harder for her to walk but she could still walk and use a cane. I would have to extend my arm and let her walk at her pace which would be far slower than my a-type personality would

normally allow for. I think accepting the limitations of what we could not do anymore and just saying it is okay. All right, so we cannot travel, we were very fortunate to live in Spain for two years and I think that took care of the travel bug that I was thinking I would have to do or want to do when I retired so we realized travel is not what it used to be and will not be. Learning to be more of a stronger emotional support partner, being able to try to put myself in her shoes, which is difficult at times, especially when we are both frustrated. Finding the right resources to help us as things evolved, that was a bit of a challenge. Learning to balance my needs with her needs, that is a tough one too. What you have to give up as a result because you cannot do everything anymore. Adapting the house for handicap accessibility was some big changes there and then trying to plan for a future financially and for physical care. I would say those are the major challenges.

Roz: Together, the two of you have brought up two really important topics that I want to try to meld together. We are going to [inaudible] some about communication, but I want to go back, Matt, what you said about your own feelings of anxiety and then Warren, you talked about your worries and trying to plan for the future. When you, as support partners and loving husbands feel your own anxiety building and your own worries, do you find yourselves being able to share that with your partner? Or do you feel like you have to kind of hold it in so you do not upset your partner? How do you sort that out? Matt, why don't you go first?

Matt: Sure. Depending on the circumstance, I would answer that question in one way versus another. There are times where I feel perfectly at ease sharing anxieties, worries, frustrations, etcetera with her, in bringing her in on that conversation that is going on in my head already and getting her input on it or just having her be the person to listen to me. There are many times, however, and I find them to be somewhat increasingly frequent where I choose what I am going to bring up. The effort is to protect her or to shield her from some of the realities of life that maybe would add to her anxieties that I am experiencing. Sometimes that probably is helpful, and sometimes it is probably not, and sometimes it is just hard to tell when it is helpful and when it is not. The goal I know is good but the result, I think, goes both ways.

Roz: So, you are juggling her needs, and your needs, and sometimes you think you are right on target in your decisions and sometimes you are not sure?

Matt: Absolutely.

Roz: How about you Warren? In your communications with Loretta, where do you think you fall on that continuum at this point in your relationship?

Warren: I think we try to be a little guarded. She is feeling pain that day, she does not always express it to me. She does not want to throw out all of her issues and add to my concerns if you will. I do not have a lot of day-to-day anxieties. It is more future concerns and the eight hundred-pound gorilla in the room that we have not talked about and yet need to and we are working rapidly towards that. On a day-to-day basis, I try to share a little things about my work and what is going on and keep her involved with that and she seems interested enough

to hear so I think we try to communicate but certainly the big thing is the long-term issue. The one piece of the puzzle we have not quite answered yet that we need to really sit down and we are planning to meet with a, I think they call it an elder care attorney so we can do wills, power of attorneys, talk about future of long-term care, have someone position to help us if we need that, so we are rapidly approaching the time we are going to have that meeting and then we will probably talk more about it at that time.

Roz: And that is the eight hundred-pound gorilla you are talking about?

Warren: Yeah.

Roz: All the what-ifs about the future and how you would plan for them.

Warren: Correct. We are a little more along the road than of course Matt is, in that we have taken care of the physical needs aspect for today. The power chair, the stairlift, the day-to-day things, support groups, all of that is working at this point. It is more the future.

Roz: At CanDo MS, you have both heard us talk about the importance of communication as a linchpin and relationships as a path to greater intimacy to balanced effective partnerships and keeping the ship afloat. Are there topics for each of you that you find particularly difficult to talk about for one reason or another many that are still challenges for the two of you?

Warren, you can go first. Besides the eight hundred-pound gorilla, we got that one, that is a toughy.

Warren: All right. I think it is a delicate balance or dance between being a care person and a care partner or spouse, that at times you could wallow in your own sorrows and the husband-wife relationship turns off and it just becomes 'I am a caretaker' and I try to guard against it. I am not always successful. But that is a bit of a challenge. Also with Loretta's spasticity and physical ailments and disabilities, the topic of intimacy is rarely discussed and that is a challenge and we joke about it at times and we recognize it is a limitation at this stage and I guess like other things, we accept that as something that is not ever-present or more present in our relationship.

Roz: But it sounds as though you have done a lovely job of maintaining connection and closeness and a feeling of partnership in spite of that huge loss and you must have had to work hard to make that happen.

Warren: Yeah, I think a little bit of it is we have invested in the bank for a lot of years now, so to speak. We have been married for, what is it, thirty-five years. The joke is that, if you are married, you need to keep putting money into the bank, you need to keep making deposits in terms of adding to the marriage and never let it be where the money starts coming out of the bank, but we have got so much in the bank that I think despite the bumps in the road that we have got so much invested in each other, so much deeper love that we may argue more, but we get over those arguments more quickly because I think there is bigger fish to fry at the

end of the day. It is not because Loretta feels like, 'Oh my God, she has to depend on me.' I think it is just there is this deeper connection that is overcoming the day-to-day head-butting that we- I mean our kids might find it amusing at times, we are old couples and we are nagging and yapping at each other, but we realize there is more to it.

Roz: Matt, you have talked about the communication that you and Kelly have always had. Being very in tune with one another. It must have been something you could really count on and love in one another. Has MS challenge some of that, bringing up some topics that are just harder to talk about or for example, so many of Kelly's symptoms are invisible to other people. Probably not as invisible to you as to some people around her but has that been a challenge in terms of how you to communicate with one another?

Matt: I think it has. There are not particular topics that I would say either are off-limits or otherwise never get discussed. However, I think that both of us are somewhat selective about what we talk about and when more so than we ever were in the past. I know for sure that I am because it is intentional on my part to shield her like I said, from additional concerns and worries. Particularly for things that I can just handle on my own, I do not need assistance with. If I do not need to worry her over it, I do not but I think she does the same for me and I could see the potential for, at some point, that causing disconnect between us but I would say so far, it has not. To comment on the visibility of her symptoms, I would say, actually sometimes, our communication has been most hindered with respect to other people because they just do not understand, which is part of the reason I think we connect so well with CanDo and we have such a great appreciation for the programs offered.

Roz: Kelly is pretty independent right? And she is working full-time and you both go on about your business, but some days as you mentioned she has bad days or days where she does not feel so good. You ever feel that you get mixed signals from Kelly about what she needs or does not need from you in the way of assistance? Or is she able to be pretty direct when she needs help or when she does not need help?

Matt: I would say that is an evolving situation. When you and I first met and interacted at a CanDo event, I remember a topic coming up about offering assistance to your partner, and initially, she was pretty resistant to the offer for assistance. More so, even than she was prior to being diagnosed with MS. In the past, in our marriage, if she needed assistance, it was not an issue. After she was diagnosed, there was some issue in her thinking about my offer for assisting her physically if it appeared that she needed it. Over the past, probably year, she has started to, I think, recognize more when she would benefit from assistance. Whether that is just a physical helping hand being reached out to give her a balance or bringing her walking sticks with us when we are going out as opposed to her being resistant to that as she initially was. I think we are at that point in time where that is just changing a bit right now and I see her being a little more willing to accept assistance when she recognizes that she needs it than she used to be.

Roz: I think you have both alluded to a really important topic that we will spend a lot of time

on at CanDo MS and that is the role of assistive devices or equipment and we talked about them at CanDo MS as a tool for the whole family and I wonder whether that has been your experience. And we will start with Warren when Loretta transitioned from one type of mobility aid to another, did you also feel the benefit of that? Or when she first accepted the use of a mobility aid?

Warren: Oh, definitely. I think Loretta had a little resistance but not strong resistance. She would walk around and start initially lose a little bit of her balance and fall and it was almost like a notch in the belt, like, "Oh, yeah. I had another fall." And joke about it, but there got to be enough falls that it became dangerous and concerning so she transitioned to walker and I think she accepted it and worked with it well. And then for movement outside the home, over time, there was a need for a wheelchair and like everything new in the beginning, she maybe did not like it, did not like how comfortable she was not or this or that and then eventually came to accept it so the wheelchair became the mode of transportation outside the home and I became the person that pushed. When we go in a shepherd center and there would be all these people flying down the hall albeit most of them were younger and they had spinal cord injuries so they learn to operate independently, but here I am pushing her and I do not know that I was feeling, I do not know what the word is, like I am in the limelight, but I am pushing her but almost like I wanted her to do it herself, but that never came to be. And then, I think CanDo helped us to see that we needed to move forward with more mobility and that was the power chair. Now it is up to her. I pull it out of the vehicle for outside the home, a more portable version, she pops in it and she is like in a go-kart and can race down the street if she wanted to and I feel good about it both for her and for me. For in a store, I no longer have to be there pushing her. I can say, "I am going to the stereo department.", "I am going to the men's clothing, I will meet you later." And I think it gives her a little more sense of Independence. The access to more mobility is a positive for her and me.

Roz: Matt, you mentioned the walking poles when you are out walking and we understand that walking poles helped Kelly feel steadier, may help her be safer, and enjoy her walk more but what does it do for you?

Matt: The majority of the time she does not want them with her, part of the time, well, a lot of the time that she has them with her, she is not using them. Either because she does not want to or does not feel like she needs it. When she has them with her, even if she is not using them, there is a sense of comfort for me knowing that she has something that can benefit her if she chooses to utilize it. There is also a sense of freedom that it gives me that I know that she does not have to depend on me if she chooses to use those. What ends up happening more often since we do as many things together as we possibly can, is if she feels unsteady she will grab my hand or grab my arm. That does not bother me in the slightest because I want to take care of her but it is nice to know that we have another option, especially when she does have it with her so that if we wanted to do something at a slightly different pace, it is not a problem.

Roz: So when your partners, wives are using the appropriate mobility device for whatever

activity, do you feel like you can be a little less vigilant? A little less primed to jump in and catch or support? I mean in that sense, does it relieve you of some anxiety? Or not?

Warren: I would say definitely. I mean, when Loretta had falls, she had sometimes some bad falls that resulted in stitches, I do not have to worry about that anymore. Of course, she is beyond that ability to walk but I know she is safe, I know also that if need be, she can go to the fridge and get something. If she is out of water at her table or move about a little bit do some things on her own so yeah, a lot more comforting to me to know that she has got this ability and has lowered her risk of injury.

Roz: One of the things we have talked about at CanDo, how a support partner [inaudible] out time in a day, right? There is time for work, there is time for your wife and the things you like to do together or time to help her if she happens to need help, and both of those things can take up a pretty good majority of the time in a day or a week. What has it been like for you to try and take care of yourself or attend to your needs?

Matt: I would say that has evolved as well just as many things have. In retrospect, whenever she was diagnosed, I fell off of my own priority list immediately. In fact, I remember a conversation with a friend in which he asked me how I was doing and I started to talk about Kelly and he said, "No, I want to know how you are doing." And I remember telling him, I honestly do not know because right now, that is not even on my radar. All that matters to me is how she is doing, are we getting what she needs, if she have the resources she needs and I remember telling him that I will worry about myself when I get time. Well months later I still had not made time for that and then somewhere around that point is when I met you guys. Started having those conversations about me needing to take care of myself, too, and I remember vividly those early conversations with you and the CanDo team about that topic and then probably for several months, I went on making a pretty weak effort to do anything for myself and then really only more recently have I actually made it more intentional. It is still a smaller amount of time than probably what is most beneficial but I love photography so I try to make an effort to get out and shoot wildlife pictures or landscape pictures. I even invested in a professional camera a few months ago, which shocked me how much that cost but I did that for the purpose of getting out and enjoying it and really making something beautiful. I do not always do the best at getting out and getting exercise like I would like to but I have over time, recognize the need for taking care of myself as a part of taking care of her. And so I have started to make conscious decisions to do something I want to do even just for a few minutes. Sometimes it is just taking a short walk, getting outside for a minute, sometimes I just go sit on my back porch. Anything that gives me just a little bit of time for myself and sometimes for me that is just silence.

Roz: Given your busy work life, silence must sometimes [inaudible] really good. How about you Warren? How did you overtime, balance Loretta's needs and your own in a way that worked for you?

Warren: I have always been good about taking care of myself. Sports is always been a huge

thing for me, exercise. Even when I traveled, I would find a way to go to a gym or run. Some people say when they travel they just cannot do what I have always been in the mindset. It has to be done. Even with the progression of Loretta's illness, I am able to do it. So I still play hockey in a league. Albeit it is at night and if it is late at night, I will put Loretta to bed first. If it is medium time a night, when I come home tired, I have to put her to bed. It is not easy, but I make it happen. I get to the gym. It is Loretta's schedule first in terms of the daily routine, in terms of appointments. And then the trick I think is to really just schedule for yourself things to do. So, I know, usually, Friday is my free day where I am going to either go to the lake and boat or I am going to go play pick-up hockey or I know I am going to go to the gym at four in the afternoon and by scheduling it, outside of Loretta's needs, you can get enough. The one thing I am missing a little bit of is that peace and solitude or just laying my head down a little bit because to me, it is always, "I have got to get my exercise in to charge the batteries." But I do miss that quiet peaceful time and I do fight for that a little bit.

Roz: Fight with yourself or fight with Loretta for it?

Warren: Oh fight with myself. I mean, that is not her burden, that is mine and I have to find a way to make that happen at times.

Roz: I really value the time that the two of you have taken to share your experiences. You are both so open and clear. I am wondering if each of you could share some thoughts for other support partners from your perspective. Let me start with Matt, you are newer at this and in a slightly different place and if you were talking to a lot of support partners in your realm, what would you want them to know?

Matt: The first thing that comes to mind, especially if I am talking to somebody who is maybe facing a fresh diagnosis so to speak, would be to have a blank slate for your expectations because you do not know how this is going to impact the person with MS. You do not know how fast it is going to impact them. Day-to-day, things look differently than you think they should, and sometimes your partner might have the appearance of greater disability and you think she is getting worse and then the next day, things are fine, and it is a little confusing. I would not say set your expectations low, I would just leave them blank. That way you are going into this so open-minded that whatever happens, it is like, "Hey, that is fine, I did not have any expectations for the day so this is okay with me." Just very open-minded in terms of your expectations and then as time goes on, if I were talking to somebody that is as far along into this as I am but not nearly so far as people like Warren, I might say do not be neglectful of everything else in your life just because MS is now a part of it. Because that was where I found myself for quite a while, was basically just dropping everything else just to think about this and then letting it occupy your mind far too many hours of the day. Life does go on. This just becomes a part of your life. And that was a difficult lesson for me to learn and I think I am still learning it.

Roz: Okay. Thank you, Matt. And Warren?

Warren: I think Matt has touched on a lot of it. My comment to the blank slate is that, that is great. I wrote a note to myself, be open, and accepting of change because you do not know what is going to happen. You just have to be prepared that things more than likely will change and you just got to be ready for it. Certainly, take care of yourself equally as much as you want to take care of your spouse who has MS and this is something I think a theme throughout the years, I have learned is you are not alone, that there are many resources out there that can help you like CanDo, MS Foundation Society, other people that have experience in this. You just have to tap into these resources. Do not ever go it alone. It is not a battle we want to face alone and you do not have to.

Roz: Great. Thank you both so much. As always I enjoy working with the two of you and I hope that there will be more opportunities to do that in the future. Take care of yourself. Stay healthy. Keep your families healthy.

Speaker: This podcast is part of our Embracing Carers series. An initiative led by EMD Serono in collaboration with leading caregiver organizations around the world. Their goal is to increase awareness and action about the often-overlooked needs of caregivers. Be sure to check out the Embracing Carers page on our website <http://www.cando-ms.org/ec> Thank you for joining us.

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