



Embracing Carers Series Praising Partnerships Episode 12

[music]

Krista: Hello and welcome to the Can Do MS Podcast. My name is Krista. I am a Programs Coordinator for Can Do MS. Today we are really excited for this 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 are releasing two podcasts in the 2019 Embracing Carers series. This is the second of those podcasts, podcast number twelve. If you have not listened to podcast eleven yet, please make sure to go back and listen to that. For today's discussion, we will be joining physical therapist Mandy Rohrig, and couple, Dave and Laura, as they talk about how Dave's diagnosis has changed the dynamic of their relationship over time. So with that, Mandy, please take it away.

Mandy: Hello, everyone. My name is Mandy Rohrig. I am a physical therapist and Senior Programs Consultant with Can Do Multiple Sclerosis. Welcome to our podcast for the Embracing Carers podcast series. I want to introduce to you all this lovely couple that we have with us today. Their names are Dave and Laura. Dave and Laura, I am going to just dive right in and have you two tell us a little bit about yourself, how and when you both met.

Dave: Well, I guess I will start this off. We met back in 1988 at a little gift store, a little card store in Alexandria, Virginia. It is a cool story. I walked into this store and I saw this woman--and granted I had just turned 20. I saw this woman-slash-girl, I did not know, and I knew right away, I am not kidding, I knew right away that I was going to marry that woman. The biggest issue however was, well, two things. One, I had to ask her out and two, she was not going to be my wife if she was married. So I walked around this shoebox of a store for an hour trying to figure out the courage and in the meantime, I asked her, "Hey, are you married?" and she said, "No, I just turned seventeen. I am going to be a senior in high school." It was a little bit weird but it worked out really well because I found a card that said "Hey you" and on the inside, it said, "What is happening?" So I wrote a quick little note, "What would you say if I asked you out on a date?" and I gave it to her. She rang it up and I bought it, and I gave it right back to her and said, "This is for you," and we have been together ever since.

Mandy: Dave, that is a great story. Laura, now did you feel similarly when you first saw and met Dave?

Laura: Well, I definitely knew right away that this was somebody that I could really fall for. So certainly, after talking with him for a few minutes, I was hoping that he would do more than just simply introduce himself. So certainly when he brought up the card and gave that to me and I rang it up and gave it back to him, I was wondering what might happen next. So it was definitely a nice thing to have him hand it right back and say, "No, this is for you." That was definitely what I was hoping for and yeah, we set a date for that very weekend, and we have been together ever since. That was, what, thirty-one years ago so it has been a little while that we have been together.

Dave: Thirty-one years ago yesterday.

Laura: Yes, true.

Mandy: Ah. Happy anniversary, one day late. Laura, I will let you start. Tell us a little bit about your life together before your journey with MS began.

Laura: Okay, well, of course when we first got together, we were really pretty young. Really, once we got through the college years and got settled out here in Albuquerque together in our marriage, really a lot of our experiences together were going out and doing very active things together. We have always loved doing sports, everything from snowboarding to mountain biking to hiking. We have also been definitely very excited to travel together. We actually went on a semester at sea together during my last semester of college, and that really gave us the travel bug. So that is something that pretty much every year we try to scrape together money to go on some adventure somewhere around the world. We definitely were a very active couple in terms of getting out, doing things, and being very physical.

Mandy: So Dave, when you were diagnosed with MS, can you tell us a little bit about the symptoms you experienced and how that felt for you as an individual and as a couple?

Dave: Well, my first sort of MS wonkiness, I noticed some things were a little bit weird when we were in Vietnam and Cambodia on some travels. Then a little bit after that, I noticed some lightning flashes in my eyes and I dismissed it as, "Okay, that is just weird." I went to the optometrist and he said, "Oh yeah, you are fine." Then I was watching ESPN one fall night in 2005 and my right side just went totally numb. Gradually, in the course of about a half-hour. That kind of freaked me out so I went to the mirror, I smiled, and my right lip did not come all the way up. So I figured, "This might be a time for me to go to the ER." I went into the bedroom. Laura had gone to bed a little bit earlier and I just told her, "Hey, you know, I am just going to run up to ER. I will be back in a little bit." So that worked out fine. The folks at the ER said, "We do not think it is a stroke but it could be MS." That definitely wiggled me out. I was in rough, rough shape because, yeah, it made a lot of sense. It took six months to get diagnosed but in that time, those first few months, I cried a lot, I lost ten pounds--not a weight loss solution I would recommend to anyone. It was hard. It was harder mentally than it was physically. I still did not have too much disability. The numbness had gradually faded away and I was, called, "back to normal" but I knew I was never ever really going to be normal again. And funny, when I got diagnosed officially in the spring of 2006, I had already started Active MSers, which is a blog to help people stay active physically, intellectually, and socially with this disease. It happened maybe a week before I got my official diagnosis. But I knew that train was coming and I was as prepared as I could be to handle this disease.

Mandy: So Dave, you did start to touch on a little bit about how your MS diagnosis impacted your life, so tell us a little bit more about how it did change your world personally and professionally.

Dave: Well, at the time, I was just launching a car magazine and that was pretty unfortunate because this was right before the big economic downturn. So that lasted maybe six, seven, eight years. But I had always worked from home since even the mid-90s shortly after I got out of college. I have not had a regular, called, "full-time job" in decades. Initially, the disease did not, I guess floor us, because everything kind of clicked along as usual. I was taking daily shots, we had to make some modifications to our travel plans, but nothing too significant. It was not until pretty much the spring of '09 when things got a little more aggressive and my MS got gnarly. I started to use a cane, and then things got pretty bad. Then I was using a walker and I was struggling. Laura was there the whole way trying to help me through all this stuff. There was one time when I was so frustrated, I went out of my way to change my hairstyle because I thought, I do not know--

perhaps stupidly--that if I shaved my head, it might give me some good luck. The only thing it did is make my poor wife just look at me and say, "Okay, now you are really looking sick." But it was a big challenge for me at that point.

Mandy: So Laura, other than Dave's haircut, how did his symptoms impact you? How did they make you feel? I am sure that diagnosis really rocked your world also.

Laura: Yeah, certainly. Right when he got the diagnosis, I can still picture the doctor's office and her telling us that yes, in fact, it was MS. I just remember feeling like I was going to pass out. Just really having no idea what that was going to mean for our future. So certainly at first, it was a very scary diagnosis. Soon after that, I mean in the first few months, again as Dave had mentioned that really his symptoms were not redefining our life too much in the first several months to a couple of years. So we just had to make some accommodations in terms of exactly what physical activities we might do, or he would need a little assistance with this or that, but nothing too serious. That really was fairly easy to work around for a little while, not too scary. But then eventually, once he started having to walk with a cane, then with crutches, and then with the walker, clearly it got more frightening. We had to make a lot more adjustments in terms of what we did as a couple for our daily activities and in terms of how we split our duties at home and housework, and also of course what we went out to do together for fun. We had to really adapt our physical activities and say, "We could still figure out how to do some of them, such as biking," but we had to change exactly how we did things together. Certainly, as his disease has progressed, unfortunately, we have had to make more changes and so of course I had taken over more of the physical duties that he used to do around the house. But we just figure it out. We see what needs to be done and as things change, we figure out how we can adapt things and make it work and move forward.

Dave: I would like to add that before things got more aggressive, we definitely got more aggressive on the travel side of things. So we just accelerated some of our more aggressive travels. We ended up going to New Zealand and to Bhutan and to Thailand, and to places that we really wanted to go to before things got too, too hard for me. We just put the accelerator down and just went for it. We also went to Morocco. Well, all over the world really. We figured, let us take advantage of our opportunities while we have them.

Mandy: So now that your MS is more involved, it sounds like, can you tell us, Dave, a little bit more about those symptoms and how the day to day life has kind of changed for you guys?

Dave: Sure. I think. Nowadays I use a wheelchair pretty much full-time. I still gimp around on a walker, some at home, but for the most part it is in a wheelchair. I ride my hand bike or my arm bike pretty much two to three times a week. Last year, I rode it a hundred and fifty-something days out of the year. That has kept me really physically fit. I also work out on other days that I do not ride at home or at the gym, and so that part of me has kind of remained the same. I have always been really active. Our travels also have remained, "the same" but as far as day-in, day-out, Laura now helps me a lot with probably all of my regular duties have been shifted. That really came to a head a number of years ago when I was killing a spider and I was successful and I was so proud of myself and I bent down to clean it up, and then I flipped on the floor, spilled over backward, cracked my head on a wall, and ended up with staples in my skull. So that did not go how I planned it to go, and now Laura is the spider killer and spider cleaner-upper. And she is not thrilled.

Laura: Yeah, I think it was kind of the [inuadible] way to make sure that I took over that particular bug-killing duty. I thought that was a little over the top.

Dave: But it was effective.

Laura: It was very effective.

Mandy: [laughter] So what are some other examples for day to day life? Maybe some other examples of shifting roles. Maybe with cooking or other household duties.

Dave: Well, the kitchen is probably our biggest transformation because I used to be the chef of the house. I would cook all the meals, breakfast, lunch, dinner. She would occasionally boil an egg on the weekends. But...

Laura: Maybe a bit more than that but go ahead.

Dave: Ultimately, yeah. So I would take out the trash and I would do all the little things. Empty the dishwasher, put everything away. And now, yeah, we share our kitchen duties. I prepare some food but she will get all the food out. She is a better caretaker of fish than I am, and she does all the grocery shopping. I used to do all the grocery shopping. I still do some chopping, I am still a decent chopper, at least if my arm is not too tired from cycling. It works out well but it is still really frustrating because I was a super chef. I was going to be a little "top chef Dave" and instead I am kind of like "mediocre chef Dave." But I am dealing with it okay. But one thing I do still do is I definitely load the dishwasher because Laura cannot load that thing worth a dang.

Laura: Yeah, we still try to divide duties that play to his strengths and the things that he can still do so that we make sure that it is not just me kicking him out of the kitchen saying, "Okay, you cannot do this anymore." We do try and make sure that he still does the things that he can do and that includes, like you said, the chopping. And he is very good at supervising, so he is very good at telling me exactly how I should cook and exactly how I should flip this and boil that. Those kinds of things. And then yeah, as far as the dishwasher, for example, he will put everything in the dishwasher because he does not particularly like the way that I do it, which I am fine with that. Then often he will actually take things out of the dishwasher when they are done and put them on the counter, and then I am the one that will go around and actually put everything back where it belongs. Up in the cabinets and down below, and in places that he cannot easily reach. Or if he just cannot carry something very easily across the kitchen or if it is heavy, then that is my duty to take care of that sort of thing.

Mandy: It sounds like you guys have developed quite a team, though. Like you have identified each other's strengths and weaknesses, and you help each other out with getting the job done, if you will. But for some people [crosstalk]

Dave: Yeah, we are like the wonder twins activate.

Mandy: Go ahead, Laura.

Laura: Oh, I was just going to say I think it is good for him physically and mentally to help still contribute in any way that he can. And it is good for me, too, not to have to try and do everything when I know there are still some things that he is perfectly capable of doing. So he still gets to contribute to the household and I get a little bit of a break on this and that. We just have to make sure that it is those things that will not cause him to injure himself, like falling over picking up a spider. You just got to find the right duties and the right distribution of things.

Mandy: Setting up for success, that is right. But it is easy to look back now, I suspect, and realize that you have made these shifts and these changes. But for some people with MS, it is really hard to ask for help. And

Dave, do you mind just sharing that evolution that you have had, maybe learning to ask for help, learning to ask Laura to do things for you that you were perfectly capable of doing in the past. If you mind sharing a little bit about that?

Dave: It was really hard at first. When I was cycling on a regular bike and I had a bout of optic neuritis, it made it really hard to see, so I could not cycle on my own. But I could see well enough so I could see my wife's back and her bike if I was right behind her, but if she got out of my sight then I could not see her. So I needed someone with me to bike and so she would bike ahead of me, just a little bit, and I would follow her. If we needed to pass other people on the trail or avoid an obstacle, she would holler back and say, "Hey, we have got a stick," or "We have got some cyclists. Let us pass and then cut back in." I mean literally, I would not see someone riding toward me until they were right on top of me. It would have been an accident waiting to happen. Thankfully, she was able to help me through this stuff. That was kind of the start of me starting to rely more and more on her for assistance. Now, yeah. I really honestly could not do it without her because she has been the ideal care partner for me. I will say, probably the most extreme example of caregiving was when I was taking part in an NIH clinical trial and got a stem cell transplant. This was back in 2010 to kind of hopefully slow down some of this MS progression, which it did. But during that time when I was in the hospital for three weeks, every minute she was with me except for bathroom breaks. She slept with me, she took care of every single thing. And when I passed out sitting up in a chair, she was the one that screamed and got the nurses to come in and help me right myself. It was a really trying time and she saved my life.

Laura: And if I might add kind of going back to your original question about these changes in roles and asking for help, people should realize that a lot of these things do not happen overnight. So it does take a little bit of time to recognize that maybe this is not going so well anymore in terms of performing this task, and maybe there is a need to adapt here and it might, in some cases, mean not doing that task anymore and handing it out to somebody else. Or it just might mean thinking about a different way to approach it. As an example--it is not exactly an example of asking me to help--but one example is that obviously at some point, David felt that he had to stop driving a regular car. But that did not really happen overnight. You gradually realize that "Hmm, I am not really as good at this as I used to be." So for a while, he did not drive at all, but then we came to the realization that, hey, if we put hand controls in the car, then that really is something that he can do. He can drive with the hand controls and that gives him a lot of independence back on something that he had relied on me completely to take him around town. And I was happy to do that but at the same time, we were able to come up with a solution that allowed for him to do more for himself and take a little bit of the pressure off me. And again, that was not something that happened overnight. That was something that we realized over time, that "Oh, you know, this is a way that we can adapt this. It will really improve the way that things are going for him and for me in terms of getting some things done."

Mandy: It is difficult at times though I would suspect to balance that ability to allow Dave to have this independence but at the same time keeping him safe, right? In insisting on helping him when it is necessary, do you guys have any other examples about when you kind of struggle with that help, asking for help balance in your partnership?

Laura: Well, that is something that definitely you have to develop over time. So it might be that I am the one to realize watching him try to do something, that he is struggling with it and he is doing his best but perhaps it is something that it will be easier for both of us if I was to take that particular thing over. Obviously, when it is a matter of safety, that is definitely something that I should take over. And you know, sometimes it is just as simple as, for example, he mentioned earlier that now he does pretty much all the chopping in the kitchen, but there are a lot of other things that he does not do. But there are times when I will see him struggling with the chopping because he just came back from a bike ride. He might still want to

help but I will go, "Okay, honey. It looks like you are a little tired today. Let me go ahead and take over that duty right now. Tomorrow, you can go back to being my sous chef but for right now, let us go ahead and hand this off." Sometimes, it is the other way around and he is the one to realize, "You know, I am just really not feeling it today, honey. Can you do this one thing that normally I would do but it would be better if you could take it over for the moment?" So we just work as a team like that and realize that people have good days and bad days and you just adjust as need be.

Dave: Again, I am stubborn and I try to do things on my own as much as I can. We were at a concert together at a winery and there was a little step, and when I say "little step" it was maybe at most a couple of inches. But it was a drop-off and I had to use the bathroom, which happens when you have MS, the urgency thing. So I figured, "You know what, I am a big boy. I can do this on my own. I do not need my care partner for this one thing. I will give her a break." So I went over backward and then everyone gasped when I flunked over. Laura was not very pleased because she was in line for the bathroom and she heard the noise, and there was her husband on the floor.

Laura: Of course, I knew right away. I heard the ka-thunk and all the commotion. I am like, "Oh, what did my husband do? I left him alone for two minutes." But these things happen so he learned and we both learned from that experience. I make absolutely sure he does not have to go to the bathroom if I am going to leave him alone and go to the bathroom myself. And if there is any chance he might need to go, I will just take him with me especially if there is any sort of obstacle that he might need to clear on his own. And he tries not to do those sorts of things by himself if there is a possibility that he could get hurt. Hopefully, he will ask me or even ask somebody else to give him a little bit of assistance rather than just saying, "Ah, I am sure it will be fine," when it might not be so fine.

Dave: And yeah, the three big issues for me are my walking, my spasticity, and the bathroom department. I mean on a scale of one to five, my bathroom issues are low but they are always there, and it drives me bonkers. But she has learned to be very very patient with me and my fifteen minutes it usually takes me to use the bathroom. It does change how we do things just because I do not usually leave the house early in the morning. Let us go a little bit later and if I do need to use the bathroom, if there is an available bathroom I never pass it up. Laura is smart enough and patient enough to wait for me and encourage me to go use the bathroom before we need to drive anywhere because she knows we are going to be late if I do not get my butt in gear. She is good at keeping me on task, at least in that department.

Laura: I try.

Mandy: You guys do a great job of helping each other and keeping each other in check. So you have talked a lot about your relationship with one another and how the roles have shifted and how you really developed this teamwork to help you guys manage the challenges of MS. Do you mind sharing a little now about how MS has impacted your relationship as a couple and the relationship that you have with your friends?

Laura: Sure. So as far as our relationship as a couple, as things have progressed, we have definitely just, again, adapted to what we do together. I mean we have fortunately always enjoyed a wide variety of activities together from all the outdoor activities that we used to do a little bit more of to just simply going out for a nice meal or watching a movie together. So we might do a little bit more of the indoor activities than we used to. We still find a way to get out and, say, do our bike riding together. David also has a special wheelchair he can use on off-road types of trails, so we can go on hikes together and, of course, just strolls around the neighborhood. So we can find ways to get out and do those kinds of things together, but then we do more of the easy kind of date nights. Indoors, maybe a little more of that than we used to. As far as our friends go, we have been very very lucky with our friends who a lot of them have been friends with us

for a really long time. They have seen things change over time and they completely understand what Dave is going through and what both of us are going through as a couple in terms of the things that we can still do with them that we might do before, and some of the things that we really cannot do with them anymore. Like some of the folks that we used to go, say, snowboarding with a lot either, for example, we will go to a cabin up in the mountains together and David is willing to just kind of hang out in the cabin and enjoy a little time to read and maybe do some of his website work while I go off and go for a few hours of snowboarding with our friends. Then we will all come back and have dinner together and enjoy the evening together. Our friends will even, if we go over to their house and they have steps to get in the house, they are willing to come out and help me carry him over the steps into the house. We also have friends that are willing to bring food over to our house and cook at our house because they know it is just easier for us to stay here. David has really nice access to all the rooms and the bathroom in our house and the kitchen. So they will bring over food and we will just make food together over at our house and enjoy an evening here instead of going out to another place that maybe we would have gone in the past.

Mandy: Dave, how does that make you feel?

Dave: How does it make me feel? It makes me feel really fortunate that I have got such great friends who will go out of their way to help us out. I mean, it is frustrating but I got my head wrapped around living with a disability a while back. And when things get bad, I try to remind myself that I have done this before and I can keep on doing this. I just need to keep making changes. And I do not like to make changes but it is necessary. Like with our recent travel tendencies are more now to go on ships because they tend to be pretty darn accessible. If a certain port is not accessible or has limited accessible bathroom access--the bathrooms in Russia really are not very accessible, even the handicap ones. But some are. But you just never know and so it is nice to have a floating dock or a floating station that you can go to where you know you are going to be able to take a shower every night. It is frustrating but at the same time, I try not to let it bother me too much because I know I have got a lot of friends with this disease and we are all working in different ways that we can keep on doing what we love to do. Yeah, we have to change but working together with Laura, we can still do a lot of what we have loved to do ever since we got together thirty-one years ago.

Laura: Yeah so we try and focus on those things that we can do, and try not to focus on the things that we cannot do. Again, cases like going on a cruise with friends or family, that means that everybody can do what they want to do to their level of ability. There are times when you might go your separate ways to do certain things, but then you can always get together on the ship to have a meal or you can go off on certain travels together onshore, but maybe not other ones. But again, there are ways to adapt and make sure that everybody gets to do things that they like to do and get to do plenty of things together still.

Mandy: So in closing, I will start with you first, Dave. What specific advice would you have for other couples who are trying to maintain a balanced and loving partnership in the face of this disease?

Dave: I guess I would start with "communicate". Communicate with each other because if you need help and you do not say that, you are going to look really stupid when you hurt yourself. I have done that too many times. At the same time, I need Laura to communicate with me when I am fluffing off. I do, I think we all do. I sometimes take her for granted and while I am sitting watching baseball and dinner is getting made, I am like, "Well, this is a pretty nice life. I think I will have a beer." That does not usually go over that well. I need to assist. I need to do my part so she just needs to sometimes remind me. I am usually decent but not always.

Mandy: Laura, what are your final thoughts?

Laura: Yeah, I think it is definitely good for both people to always have a little bit of patience. There are times when you are going to have to step back and say, "Okay, maybe one of us needs to adjust things today or moving forward, and just take a step back and adapt however is necessary." And again just have patience with it. Not everything has to adapt overnight and you can, again, communicate with each other and talk about the things that you are feeling and the things that you need. In some cases, it might be that he needs more help from me, and in other cases, it might be that I need a little more support from him in some kind of way. Whether it is doing a few of the things that I know that he is capable of doing or if it is just providing some emotional support that day, or if it is both of us saying, "Eh, we are not going to do this one thing today. We will put that off until a day when we are both feeling a little more up for it." Of course, it is always important to just go ahead and be open to the idea that things are going to change and you are going to have to make some adaptations. Just go with it and talk about how you can move forward and do that together.

Dave: I also think you need to remember to say "please" and "thank you". I mean those are the little things and you might be with your caregiver or care partner, and you might know each other really really really well, that does not matter. Still, remember to say "thank you" and "please" because that water glass, that pint of beer is not going to refill itself, and when it does and your partner helps you, acknowledge that.

Laura: That is love right there.

Dave: [laughter] "Thank you for a beer, honey." That is a sign of love. And some Cheetos. I had to get my Cheetos thing in there because yeah, I like beer and I like Cheetos. But I do not overindulge in either one. Moderation is the key, that is what I say.

Mandy: [laughter] So patience, communication, love, and hydration. Those are the key to a successful, loving partnership. You guys have been absolutely fabulous. Thank you for sharing your stories and speaking so authentically and honestly with our audience. Thank you so much, Dave and Laura.

Dave: No, thank you.

Laura: Yeah, thank you.

Kristy: Thank you to both Dave and Laura for joining us today. We really appreciate you being open to sharing your experiences together as you navigate life with MS. And of course, thank you to Mandy, as well. 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. Thank you for joining us.

[music]

[END]