



Embracing Carers Series

Managing Mood & Cognitive Changes in Your Loved One

Episode 4

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 MS. We are excited for today's podcast, which is the first episode in our three-part Embracing Carers series focusing on those supporting a loved one with MS. Today, we have two guests joining us. Psychologist Meghan Beier and support partner Karen Peterson whose partner Anne is living with MS. Meghan and Karen are going to discuss how the different moods and cognitive changes can impact those supporting a loved one with MS. They will also share some real-life stories and strategies for responding to these mood and cognitive changes. Now I would like to introduce Meghan Beier to kick off our discussion. Welcome, Meghan. Would you please tell us a little bit about your experience working with people with MS?

Meghan Beier, PhD: Thanks, Rachel. I am really excited to be here today. I am a rehab neuropsychologist from Johns Hopkins, and basically, that is a big word for working with people with MS who have mood and cognition changes. As a psychologist, I work with people to help modify these symptoms so they and their families can live more functionally or live their best life. To get this started, I would like to share a little bit of some information about the prevalence of mood and cognitive changes. Approximately 50% of people with MS experience mood changes including anxiety and depression and up to 65% of people with MS experience changes in their cognition or their thinking skills. These, as well as the more well-known symptoms of MS, like physical changes, can have a major impact on loved ones. Support partners of people with MS can experience increased stress, more psychological symptoms, and changes in their quality of life. In a study that was conducted by the National Caregiving Alliance, 77% of support partners report feeling compassion but also fear anxiety, anger, confusion, and isolation when their loved one is diagnosed with MS. Over time, if we look at how people transition, a study conducted in Canada found that support partners remain empathetic but about one-third of those support partners show signs of mental health conditions like depression. 42% report significant fatigue and 20% report feelings of anger and frustration. All of this tells me or tells us that it is really important to recognize these symptoms in people living with MS but also their partners or their loved ones around them and try to develop strategies to navigate through these challenging waters. So today, we are going to talk with Karen Peterson and hear her and her partner's story, and the way they took on these challenges. Welcome, Karen. Would you please tell us a little bit about yourself and how you met your partner Anne?

Karen Peterson: So, thanks, Meghan. I am from New York. Both Anne and I live about 45 minutes north of the city out of Manhattan. When Anne and I first met, I was a college athletic director and now I work as a middle school high school athletic director. I met Anne through mutual friends. I was living in New Hampshire at the time and she was living in New York. And I had family living in New York, my sister lived here so I ended up moving down to New York. And we have been together for 30 years.

Meghan: A long time. So can you tell us a little bit about your relationship now? What activities do you and Anne do together to stay connected?

Karen: Yeah. So we are very fortunate. Anne is doing pretty well physically, she has her moments and her struggles but we play golf together when we can, we spend time with our pets, we like to travel. We have a house in Maine, that is our happy place to kayak, and sit on decks, and eat lobsters, and visit with friends whenever we can. We also like to just hang out at home when possible. I work a lot of hours and work a lot of weekends so anytime we can get it home for some quiet time together is pretty precious to us.

Meghan: So work and spending time together takes up a lot of your time. How do you maintain your own well-being?

Karen: Sometimes I am not very good at that part. I do try to work in the garden whenever I can, dirt seems to be a relaxer for me. I have a great support of a group of friends and people that I also work with. So we depend on our friends a lot for support and fun and they are always there for me to talk to. So even though work takes up a lot of time, I should be doing things like exercising more but hopefully, when I retire I will be doing more that.

Meghan: Support partners can have a lot of different reactions to a loved one being diagnosed with MS. Do you remember your reaction when you learned that Anne was diagnosed with Ms?

Karen: Yeah. I remember my reaction pretty clearly. I remember exactly where I was. Her diagnosis was a struggle. They said she had MS. I said she did not have MS. So, MRIs were not very big back then. So, I do remember getting the final news. I was at work and I just remember being pretty devastated. And sort of knew at the time that would be a reaction I should not show to Anne, that I was going to have to be strong for her because she was very devastated. And my first thought that our lives would never be the same, that she would probably be in a wheelchair, and my heart really broke for her at the time.

Meghan: What were some of the first mood and cognitive symptoms that you noticed in Anne? So, you said she was pretty devastated. How did that first present when she was diagnosed and maybe as time went on?

Karen: Yeah. So, I noticed mood changes before any cognitive changes. So, she was in the

hospital at the time and came home and was struggling with optic neuritis and balance issues but she pretty much checked out. She did not want to engage with me, with our friends. She put on a strong face in front of her family because she did not want them to see that she was struggling but when it came to me, she was not very engaged, she did not want to talk. She was on steroids at the time. It was really hard for us to figure out what was going on. Well, I thought it was a combination of the steroid treatment and the fact that she had received this devastating news so she probably was not going to be in a good mood. But Anne is a planner, was always a planner. And she stopped planning, she stopped planning meals, she stopped doing anything that she could even do around the house. And she was devastated that she was out of work. This had happened at the end of the year so we were in the summertime, and she was a teacher so we had a little time to get ourselves together. But I know in the forefront of her mind was how was she going to get through a lesson? How was she going to get to school? How was she going to work? Her work was very important to her. And I did start to notice that she was having trouble. When she did talk to me, word retrieval was an issue for her and so I know she was really struggling with how was she going to continue her life as a teacher. But she pretty much checked out on all of us.

Meghan: So, there was a lot of uncertainty for her and uncertainty for you about what was going on as well. So at first, you thought maybe this was about the steroids or maybe just the initial diagnosis.

Karen: I never even thought of depression at the time. Anne has never exhibited any depressive behavior at all and during our relationship. So, I figured at least she just had a rock dropped on her pretty much and if she was not feeling well and she was on steroids. So I figured we were just going to have to try and get through this but she would not sort of snap out of it. It was like, I bring friends over, she was not attentive to them, she would watch some TV, she would go upstairs. We had a greyhound at the time and the greyhound was one to take care of her. So she and the greyhound would go upstairs and I would find myself sitting downstairs by myself. And then, she would even take the remote with her. So looking back on it, I know now that she felt like she was losing control but she was really obstinate. She tried to get in the car and try to drive when she could not see. I tried to work deals with her. We live in a two-story house and the bedrooms are upstairs, and I said, "If you come down, you need to let me know or have somebody else come and help you." And so, she comes down the stairs halfway by herself and then goes back up just to irritate us. But that was behavior - that was she had never exhibited that kind of behavior before.

Meghan: So, she did not want to lose her independence but it was worrisome for you as well.

Karen: I was worried to leave her alone. At that time, her mom was alive and I would ask her mom to come over but she was again, pretty brave in front of her family. It was hard for me to figure out how to go to work and make sure that she was safe so that was very worrisome. And sometimes I would call and she would not pick the phone up so I did not know what was going on at home. So that was pretty stressful.

Meghan: So, when did you learn that mood symptoms could be a part of the MS diagnosis?

Karen: Well, we were lucky that we live near an MS Comprehensive Care Center and did a lot of research and changed her doctor there. And started to see a psychologist and who mentioned that some of this may be associated with MS. We really did not pinpoint that. I would have to say until about six or seven years ago when more research was done and that is when we really found out that the depression was a symptom of - could be a symptom of MS just like her numbness on her right side was in her optic neuritis. And we said, "I am not crazy. I do not need to go see somebody." And we are like, "No, you are not crazy. But something is going on." And she said loudly, "The only reason I would go is that I am crazy." We did not really know that for a while about the symptomatic nature of the depression.

Meghan: So, jumping forward in time a little bit. You said about six years ago, you learned that depression and these kinds of mood symptoms could really be a part of the MS diagnosis. Tell me how that changed your thoughts or what you felt about these kinds of symptoms that change your perspective on them.

Karen: Yeah. I think it did. I know for Anne, it was sort of a big hurdle. She finally looked at me and said, "I have not been crazy all these years." It did make a big difference for her and she thought at the time that would make a huge difference for people who were newly diagnosed. She has often said, "If I had known it was part of the MS progression or if I had known it was just a symptom of MS, I would have reached out for help sooner." Just like you do when she was on medication for this numbness and tingling that she feels and spasms that this would - she would have just been more willing to sort of taking that first step and trying to get help for it.

Meghan: So that must have been really difficult for you to hear. You are noticing her mood changes but having those conversations for her suggesting maybe going to see somebody but then hearing, "I would not go in unless I am crazy." What was that like for you as her support partner?

Karen: It was very frustrating. I had a couple of friends who lived close to us at the time and they were wonderful. They would come over for dinner a few times a week despite Anne being cranky and not really wanting them there and we were all trying to encourage her to go see someone. We had gone to some newly diagnosed meetings and I had picked up some cards and people for reference. Anne came home and threw them all away and I would go through the garbage and keep them in hopes that we could get help. But it was very, very frustrating for me thinking that you really need to talk to somebody and knowing that I think she did not really want to talk to me because she was scared and did not want to let me know that, and I was scared and did not want to let her know that so that was a difficult time.

Meghan: So, what was the tipping point? What brought Anne into the MS Center to start seeing the psychologist?

Karen: I had sort of gone into protection mode. And I always tried to be upbeat at home and try and look at the light side of things and none of that was working, none of that changed her mood. And then like I said, it was getting pretty lonely. She was not engaging with me, she was not talking to me, she would either watch TV or go to bed. And so, one night I just sort of, I had reached my breaking point and I just said to her, "We can get through the physical stuff but you have to be present with me. I can push around a wheelchair if I have to. We can do anything we need to do to get through this but I cannot do it by myself." I probably did not say it that kindly. I think that she will tell you that she kind of woke up and said, "We really all I have been thinking about who is just self-absorbed with me and did not realize that this was affecting anybody else. And so it was at that point that she started considering going to see somebody at the MS Center.

Meghan: How did you find the professional help you needed?

Karen: I actually got the psychologist card at a newly diagnosed meeting that was being run by our local MS Chapter. And that person happened to work at the MS Center where we had relocated with Anne's new doctor. So, we found this Comprehensive MS Center and got her a read on this psychologist. And I knew it would probably be important for us to go to somebody that knew something about MS if possible, work with MS patients. We thought that might be more beneficial.

Meghan: And what was your role in all of this? Did you go to any therapy sessions with Anne or how did you transition with her?

Karen: Actually the first time we went, my two friends and I went with her. They did not come in with her to see the psychologist but there was a new brewery, this was when microbrewery started to happen. And there was a new one that opened right near the office and so we bribed her and said if she would go see the psychologist once, we would take her out for a beer and a burger. And so she reluctantly said that she would go so it took three of us and a beer bribe together there. And then I went - probably the first two or three sessions, I went in with her and started to work with the psychologist. Then I stopped going because I knew that she probably needed to be able to express herself without me being around. So she went on her own from then on.

Meghan: And like Anne, did you at any point have any feelings of depression or anxiety or things that you thought you could seek help for?

Karen: Yeah. I think in retrospect, I certainly do now at the time when I was in the middle of it all I just had to keep going I had to keep my job, I had to keep the house going, we had pets we had to take care of, I had to figure out how to take care of her and keep her safe. So, in retrospect, yes. I have had my days of depression and certainly my difficult days. I felt it was more - I guess I describe it more as loneliness despite my good friends around me. I felt like I had lost my best friend and partner like she was sort of gone and missing at that point. It was almost like a grieving process when I look back on it. I wish that I had gone and as Anne

started to see her psychologist, I wish I had done the same thing on my own because I think it would have been helpful to help me and let me understand better what I was going through, and also maybe strategize about how I could best help Anne.

Meghan: Were you able ever to connect with other support partners of people living with MS?

Karen: When we went to the newly diagnosed meeting, there is somebody usually brought somebody so there were - I am sure, there were support partners in the room and we talked a little bit but I do not think there was as much of a heightened-awareness of the support partner at that point. I have certainly seen that change in the last few years, with the work that the MS Society has been doing and Can Do MS and lots of groups. There was not like, we all got together and chatted about it. I think I do remember talking to a couple of people and everybody's story is a little different because everybody is dealing with different symptoms. So, I remember there were some care partners that were dealing with more physical stuff and at the time I thought, "Oh that has got to be difficult." I am not sure the physical stuff any more challenging than the depression and cognition but I do see a lot more of that happening now which I think is great.

Meghan: So, circling a little bit back to the beginning of your story with Anne and getting into working with the psychologist, I would like to hear a little bit more about how that was helpful to her? What changes did you see? And if she got any other kinds of mental health treatment at the time.

Karen: I guess a couple of things happened. She started to enjoy going to talk with the psychologist although she did not really, she would never say that out loud. But what I saw starting to happen was, she would come home and I would say, "How did things go?" And so, she was working on some coping strategies about how to get back into teaching. If you talk to Anne, she will say that one of her biggest struggles was this loss of control. She thought that she could not control anything that was going on. There was not a cure. She was not sure, the future was so unpredictable, what something else going to happen in another month. But she really started to work with her psychologist on just small things at first like how to regain control and deal with some coping skills in the classroom so that we could get her back to work. And she was fortunate enough that she was able to go back to work through her psychologist and then her doctor. She did finally get on an anti-depression pill which Anne calls her happy pill. And after a few months of being on that, we saw a big change in her. She started to feel better. So it was sort of a combination of that. That is pretty much how her total mental health package worked for her. So these coping skills, getting back into the classroom, and then getting on some medication that helped her.

Meghan: So, you were lucky enough to be near a Comprehensive MS Center that had a psychologist who knew about MS. But for those listening to the podcast who might not have such a resource. I just wanted to take a quick break and comment on other ways that they might be able to find similar resources. The National MS Society has a program called The Navigator program which can direct individuals to resources in their specific area and you can

access that by the National MS Society's website. There is a phone number for the MS Navigator Program and there is also a chatbox on the website that people can log into. There is also a website called www.helppro.com which has a drop-down option for mental health professionals with experience in MS. And many neurologists and Primary Care Providers also have access to mental health providers in their specific community. So, those are a few ways that maybe other people might be able to access similar resources that you both did. Anything else that you can think of that I have not mentioned?

Karen: Look. We are lucky. We live in the New York City area. So, we were fortunate that we could find the healthcare that we needed here and we had insurance so that was very helpful. But I know a lot of people are going more to websites and all the good people that do these programs. I know that that has been very helpful.

Meghan: So, how did you manage overtime to cope with the emotions that you had throughout this entire period?

Karen: It has not always been easy and we still have days. It is really our friends, our support group of friends and family have been extremely important to me. That is kind of what gets me through the day. My work, too, keeps me busy. But really, it has been our network of friends that have been most helpful to me and we feel fortunate that we have great friends.

Meghan: What is it about those friendships that help you see their support? Or what is it about them that shows you that they are in your corner?

Karen: Well, they kind of went on the journey with us, many of our friends. And I have some friends that are in the health care profession and everybody sort of pitched into. One thing I did when Anne was first diagnosed was, let us try and find out as much information as we can about MS because we knew very little. And so they kind of went on that journey with me and if they thought they found a resource that we could tap into that would be helpful, they would call. They also check in with me to this day to make sure I will get the question, "How are you doing?" Like, "I am fine." "No, but how are you really doing?" And they check in with Anne a lot, do not tell her but they do. They check in with her and if they detect something that might not be quite right, they give me a ring and just to check in with us and make sure that we are okay. And they make sure that we have fun.

Meghan: How do you balance being a support partner in the MS perspective and your relationship? So, not kind of leaning too much to being a care provider but maintaining that partnership, that relationship that you both have.

Karen: I would lie if I said that her diagnosis and us going through this journey did not change our relationship. I think it did. And we still struggle with that. I am kind of a protective nudge, to begin with by nature. And so, all of this that we were going through and particularly when Anne was being a little like a curmudgeon really did affect how we reacted to each other. And we have spent a lot of time and a lot of years trying to regain our relationship though, I guess

the way it was which probably it has not and nobody is. All relationships evolve over time. But I have had to take a step back and there has been some points where - particularly when it looks like she is not feeling well or something is up, I can be sort of constant like, "What is going on?" "Are you okay? You should talk to me." And so, we finally at one point she said, "You are like a pain. I got a mother I do not need another mother." I said, but I have to be - because at the beginning of this when mood issues were a real problem, she would not confide to me. She would not tell me anything. And so, we finally came to an agreement. I said look, "I will stop asking you how you are and do you need anything. If you will promise me that you will tell me when something is wrong." So we kind of came to that agreement over the years. So, I try to back off as much as I can. But I am way overprotective and that drives her crazy. So we have had to work on those kinds of things and we have had to change a little bit of how we do stuff. So, Anne has a lot more energy in the morning and she gets more tired as the day goes on and at night. And I tend to work late so what was happening is I would get home from work and she would sort of being out. And so, she was out early in the morning when she was teaching. And so, we really did not get to spend much time together. So, I took a look at my schedule and I trade to stay home a few mornings a week because Anne is retired now so I try to come in a little later to work because I tend to work nights, weekends, and afternoons more. So that we have some time a few days a week in the morning just to reconnect. So, we have tried to make those kinds of adjustments around when she is feeling best when we have the energy to do stuff. So there have been those kinds of accommodations that we have tried to make in our relationship as well.

Meghan: So that sounds like a lot of communication over time and making adjustments as you noticed things that needed to be changed.

Karen: Yeah. Unfortunately, it takes a little while to figure that out. So, there is always like a rough spot before that. But yeah, you kind of figure it out and try to be reflective and then, try to communicate with each other, what is going on and then come to some sort of a solution. But I do not think it is - I think that happens in every relationship, the diagnosis that is always there and then uncertainty sort of ramp some of that up. And also how she is feeling and how I am feeling. I mean, there is I think I am very susceptible to sort of stress-related health issues. So, I have to be careful about making sure I am taking care of myself and not under too much stress. And I have had to learn to allow and to take care of me. That has been hard to do but in retrospect, I realized that has been very helpful to her because that is the control that she wants and she wants to play that role so that took a while for me to figure out as well.

Meghan: That is a really good point that a lot of times I have heard - I hear from people that if you are caring for somebody who has a diagnosis of MS, they almost let their own health go or do not focus on their own health as much and that is a lesson that you have learned and you have had to focus on overtime.

Karen: Yeah. And I think that no matter what folks are dealing with in terms of their MS symptoms, I have learned to ask Anne to do stuff for me. It took me a while to do that. I felt like I had to do it all and I should not ask her and she is dealing with enough. But what I found

was even if I could find one small thing that she could do that was helpful for us or as a family, that made her feel better, that made her feel useful, that made her gain some control back and gave her some energy so I have tried to focus on asking her to do some stuff and not hesitate doing that and we just have to be honest with each other. She has to tell me if she has something - she does not think she can do, then we figure out something else. I think the ask is important.

Meghan: What other advice or whatever other thoughts do you have for people who are newly diagnosed? Not just people with MS but their support partners as well.

Karen: Well, I think reaching out for help is the most important thing. There is a lot of resources as you mentioned. If you are not even in an area with a lot of resources, you can get online and try to find some help. I encourage, even if the person with MS does not want to get help at first, I would encourage those in a support position to get reach out and get help for themselves. Even if it is just information or someone to talk to about what they are going through. I think that is really important. I think that this is a life-long journey and you may have to seek support at various ways of through that journey. We have had our ups and downs, you go along for a while and everything is great and then something else happens or there is a blip in the road. I think you have to have it in the back of your mind that you may have to ask for help at various stages. I think it is great to laugh and to cry together and continue to be honest with each other. Those are things that we have found helpful.

Meghan: Extremely well said. Are there any other thoughts that you have that you think somebody listening might need to hear? Or any questions that I did not ask that you think would be helpful for anyone listening to here.

Karen: Yeah. I just hope folks that have might find that our journey and some things that we went through would be helpful for them. And I think it is important to realize you are not alone. When Anne was diagnosed with MS, she goes, "I think I am the only person with MS." I am like, "Well, I do not think that is true. There is probably a couple of other people out there. So we just have to go find them." So, that initial shock of the diagnosis is tough to get through and it does feel lonely at first but the more you can surround yourself with resources and like people, I think the better off you are. And just try not to be isolated. For sure, you are not the only people going through this and what you might think other people have an experience. I am sure that there are people out there that have experienced the same thing. So it is just a matter of trying to reach out and find them.

Meghan: Karen, thank you so much for sharing your story and Anne's story as well and helping other support partners who might be going through something similar.

Karen: Yep, I am happy to do it and hopefully folks find this program helpful for them.

Rachel: Thank you to both Karen and Meghan for joining us. And Karen, we really appreciate you sharing your experiences to help others understand the impact mood and cognitive

changes can have on those supporting a loved one with MS. 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 cando-MS.org. Please tune in to our second podcast in the Embracing Carers series on the topic of taking care of yourself, which will be available on our website and apple podcasts on October 17. Thanks again for joining us today.

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