



MS Path 2 Care Mood, Cognition, and Spirituality Episode 16

Host: Hi and welcome to the first episode in our three-part MS Path 2 Care Wellness Podcast Series brought to you by Can Do MS and Sanofi Genzyme. MS Path 2 Care Resources encourage those living with MS to work with their support partners and care teams to address all aspects of MS Care and Wellness. Each of these podcasts will focus on different dimensions of wellness through the eyes of a couple who has lived with MS for over thirty years, Myra and Steve Lazonick [?] of Elkhorn, Nebraska. In tonight's episode, Myra and Steve will discuss their experiences with mood, cognition, and spirituality with psychologists Roz Kalb.

Dr. Roz Kalb: I am very happy to be here with Myra and Steve Lazonick [?] to talk about some of the cognitive, emotional, and spiritual issues around living with MS. So, I am going to start with you Myra. How long ago were you diagnosed with MS?

Myra: Well, it is been thirty-seven years now.

Roz Kalb: Thirty-seven years and do you remember back then how you felt when you were diagnosed? We have got those words.

Myra: Well, I was really scared because the only person that I had ever known to have it was a next-door neighbor who died very young. Having him as a nineteen year old who died of it or at that time that it is what they kind of said. But I think now they do not really say it that way, but yeah, maybe scared.

Roz Kalb: A student, very frightening. And Steve, how about you? Remember what you were feeling when you heard that virus diagnosis?

Steve: Myra and I were scared also, having never been through anything like this before. It was a real slap in the face. We are just starting a life. We had just celebrated our first anniversary. We are taking a trip to Alaska and coming back from that she is developing some weird symptoms. In one sense we are passing them off as just stiffness from the travelling at that time. And as we dug into it deeper, Frank Adams' MS. Yeah, it was really scary because we did not have the internet back then. We did not have a lot of knowledge in our hands that we could just say, "Oh, read about this and learn and go from there:". We were kind of left hanging, and that is where the fear comes in.

Roz Kalb: Absolutely. So, Myra at that time, did your doctor asked you anything about how you were doing emotionally with the diagnosis?

Myra: No, I do not really remember him asking that. In fact, I have never really had a neurologist, or a doctor asked me that. To tell you the truth, he offered a support group and at that time I did not think that was something that I needed. I really did not want to acknowledge that I had it.

Roz Kalb: So, nobody was asking you how you are feeling? Did you ask yourself how you were feeling emotionally? Or did you just kind of put one foot in front of the other?

Myra: Well, you know, I think what happened was that we live in a town where they put in the newspaper that I have been in the hospital. And that is when I had the spinal tap and all that and found out I had MS. So, the next-door neighbor asked me why I have been in the hospital? And she was holding her small child, and I said "Well, I found out I have MS.". She took three steps away from me as if I was contagious, and I think it was at that point that I just made this conscious decision. I am not talking about this to anyone. I do not look like I have MS. I do not have any symptoms that given me some medicine by this time and I felt better. And so, I rarely talked about it.

Roz Kalb: So, it sounds as though you did not really focus on your emotional wellness until pretty far after the MS diagnosis. So, I am going to ask you both. What does emotional well-being mean to you have thirty-seven years later?

Myra: Well, I think probably holding my emotions or at least keeping my emotions in check because I think a lot of times when the fatigue of MS, it tends to bubble up the emotions. Like I can get angry easily or they are like all over the chart. And so, I think trying to do things to help that fatigue, be it taking a rest, or exercising, or eating right. But anything that will try to alleviate having that fatigue ends up making it being emotional.

Roz Kalb: And so, when you are more fatigued, you will feel you have less control over the emotional ups and downs?

Myra: Yes. Absolutely.

Roz Kalb: So, stay rested helps you feel more. How about you, Steve? What does emotional well-being mean for you personally at this point in your life?

Steve: It really was keeping her calmness and even float everything. I kind of relate it to a graph of a sine curve where you start at zero, you go to a positive peak number less than one, you come back to zero go to a negative one, come back up to zero that repeats over and over again. Emotional well-being for me would be to keep the positive number as high as it can be. Keep the neck and for as long as it can be. And keep the negative number as small as it can be. For short, it is can be how I do it? I am still learning. It is a journey that is never ending because as progression occurs different situations arise that I need to learn how to manage, how to react to it, how to comfort and support. We have patience throughout the whole process.

Roz Kalb: It is very interesting because that is sort of an engineers of the way of describing the same ups and downs that Myra is describing. But my retribute some of those ups and downs to the MS itself because we know that emotional liability or ups and downs are symptoms of MS. But for you it is dealing with your own feelings about all of this at the same time that you are trying to be sensitive to Myra's emotional ups and downs, which is pretty tricky.

Steve: It is tricky. Sometimes I bury my emotions in trying to be supportive of the ebbs and flows of her emotions. I carry a lot of things internally to where frustration sets in and learning how to deal with that. Finding releases for my own emotions, especially back then where the two of us did not talk a lot about it. I buried myself in my work. I was managing lots of people in a production environment. You are dealing with their issues and I could easily transition those feelings over to them while avoiding having to address the issues that she was going through or how they were affecting their reactions [?].

Roz Kalb: And so, was there a point, because it sounds like you have come to a very different place now, in your relationship in dealing with the emotions of MS. Was there a point at which you, Steve, discovered that you could communicate with Myra in a way that allowed you to own your own feelings? Even while Myra was coming first?

Myra: I think the Can Do Program. We went to initially locus[?] up to being able to communicate in a better way and I think he realized how I was feeling and vice versa.

Steve: And the Can Do Program, the four-day program, being around other people or going through on the same journey we are going on. In to this day, when we go to jump starts or other MS activities, I kind of feel like I am with friends even though I do not know about them.

Myra: You can be yourself.

Steve: And I can be myself. We have developed a good friendship with one couple from that we met at Can Do and that continues throughout for six, seven years. And to be able to talk with them, which we just did this summer. And you do not necessarily even have to talk about the issues at hand. Just the fact that you are talking and having a conversation and you walk away from that with a load off your chest and you feel good.

Roz Kalb: And that is very wonderful because I think that load in your chest, you must overtime start to feel really overwhelming, like you are going to explode.

Steve: At times, yeah. I kind of laughingly say that [inaudible] signs that go swim and on swimming, I can yell a lot and nobody is going to hear. And it is kind of primal saying that I am getting it out of my system.

Roz Kalb: But it works, right?

Steve: It works. I used to have to drive 45 minutes to work each day and spent a long time in the car allowing me to sort through some emotions. Understand what is affecting me and how my life is going.

Roz Kalb: So, if I can just recap a little of what you are saying, you guys were at the Can Do Program?

Steve: That is right.

Roz Kalb: Okay, and you were diagnosed 37 years ago. So, what you are telling me is that there were a whole lot of years where you were both keeping a lot of feelings inside.

Myra: Well, I think a lot of it was that for twenty of those years, I really did not have a lot of symptoms. And so, it was very manageable. No one knew I had it. I could go get some medicine, feel better, and everything was great. And in my mind, I did not have it. I just thought I was going to live like that forever. And then eventually, about twelve years ago, I started having some little small symptoms that were progression. So, I think that was at the point when I started realizing that this was real. I do have a MS. I have to acknowledge that it happens. And the Can Do Program helped me do that. And I think that it opened up that communication for us both to realize that. I did not know that I am learning things as we do these podcasts to from about Steve. We continually, every time we listen to a webinar or go to a jump start or go to learn any kind of information about MS. We are learning about each other in the meantime, and that is I think the beauty of all of this. We can ask any more of your programs than that.

Steve: Could I just add to that, when she was talking about, you know, for twenty years by having some of those. When she had symptoms for me here was the mindset to look really awkward and I feel it. And then the problems are solved. That is not necessarily so...

Roz Kalb: Tough learning curve, isn't it?

Myra: Yeah. I never really told him that I was having these symptoms, really. I would just sometimes call the doctor and just hope it is the medicine. I mean, I might say, "Oh, I am having some dimliness [?]", but I never made a big deal about it. And so, he never really knew for sure what was going on with me. Even though I really did know, I was not admitting it either.

Roz Kalb: Well, sounds like you were busy protecting yourselves and each other from the realities of MS. So, we know that MS causes changes in mood and emotions for both people, for you Myra diagnosed with MS and for you Steve being a support partner. What aspects of your relationship do you think these changes impacted the most? It sounds from what you have said so far that it affected at least your communication.

Myra: Yes. Absolutely. Yeah, that was probably the big thing. I cannot think of another thing that it was affecting, other than, you know, once I started progressing then of course everything changed. Because then, there was the issue of how far do I have to walk? I had foot drop and I am counting my steps. Then our lives are changing dramatically. But up to that point, not so much.

Roz Kalb: Well, this is kind of a tough question, but can we talk about how communication is kind of the foundation for closeness, for trust, for intimacy, for feeling like a partnership. So, would you say that until you got more comfortable communicating with each other about your feelings, did that created a bit of a wall between you?

Steve: Yes. As you have been talking, I have been thinking about it and we came from two different worlds. Not grossly different or anything like that, but her family was more verbal about health, family issues and things like that and my family was not as formal. Myra was diagnosed, and we told my mom about it and she said, "Well, we cannot tell your dad because he was dealing with Parkinson's.". So, I came from a family that did not talk about the emotions. Did not express them heartily where she came from, what they did, and it was a learning curve for the two of us. She was expecting me to react and learn to express issues the way she was growing up. And I am sitting there going, "What am I doing a different thing?". Because is the way I was raised, and this is my comfort zone.

Roz Kalb: So, I have known you for many years now. So, I was not there for those early years. But it does mean now that you are connected in a very wonderful and intimate way for your partnership. So, it sounds as though your ability to communicate about all those feelings you were each having is actually brought you much closer together.

Myra: As you know, I would say that that is true and I think the one thing that I have learned through this whole entire process is that I have to express what I need. I cannot sit here and think that he is going to read my mind, and that is exactly what I did for twenty years. I thought he was just supposed to look at me and know that my fingers were tingling. Now what there is just this feeling did he think that, but that is the kind of the way I was. And so then finally, when I am progressing, occasionally, I would mention, "Oh my gosh. I am so tired. My foot's dragging.". You know, I do not know, I was going on, "Why is my foot dragging?". But then he would still thought asked me, maybe a couple of days later, "How is it now?", but I would think he should. And so, this is what we have learned through going through listening and going to Can Do is that I

have to say what I want, and what I need, and how I am feeling. It will not going to be able to read my mind.

Roz Kalb: So, one of our goals for this podcast is to help other people go through this process faster than twenty years. Okay. So, if you look back over the last many years, what other symptoms of MS besides these emotional issues that contributed to some of the communication barriers? For example, when you talked about some of the physical changes and physical symptoms. Have you experienced any cognitive changes that have been interfered with your communication?

Steve: We are on that stage now. It has been slowly progressing where I may have mentioned something to her or even our daughters told me or something, and she does not remember it. Or did you remember we have a conversation, but it is weighed heavily on us.

Myra: Well, I mean it is kind of at the forefront. We now realize that this is kind of an issue, that I have some memory issues. I have a hard time making a decision and sometimes like particularly when I am fatigued. For example, we were in with some friends. Well, this is when we took a trip and we met a bunch of people at the restaurant. I was very tired, but I have been up since like five o'clock in the morning or something and they said, "Well, what restaurant do you want to eat? What kind of food do you want?". I could not tell them to save my soul. I said, "Somebody just pick it and I will be there. I just cannot make that decision right now.". And those are the kind of things that we notice or we are with friends. We have friends at like cards and we are not real big game people. But I go along with it and they are explaining the directions of the game and it is kind of going quickly. And it was like if you talk too quickly and give me too much information at once, I cannot grasp it all, it just won't process. And so, those are the kinds of things that were noticing in our relationship that he has to be aware of.

Roz Kalb: So, knowing that Myra was a very successful teacher for many years. Very smart. Very quick. Very creative. What is it been like for you to watch this gradual change in how Myra processes information or learn things, how is that for you?

Steve: It makes you very sad. You want to have empathy for the person. Watching it occur and I am thinking about her mission being at the restaurant and try to make decisions for me. Watching what she went through was painful. It was like watching a wave come over and check her out to sea, and unless I stepped in, I could not keep her on ground. And it was a learning experience because this was the first true, I would call it hard case of seeing her cognitive issue occurring. And I did step in and started saying, "Okay, wait a minute, let's just do this.", in this kind of refocus the attention. Well, I heard her for a long time, pretty much screwed dinner that night. I told to look at her face that it was another uncomfortable situation for her to be in and I couldn't fix it. That is the issue. I cannot fix it.

Roz Kalb: And for you that must have been like an in-your-face kind of [inaudible], where this is something different about me?

Myra: Yeah, it really was because it was with people that I did know very well. It was my family, but I had not seen them for a long, long time. And so, they did not know me to be this way. And so, it was embarrassing, really. It is how it was and I had to just say to them, "I am sorry. I am really tired. I cannot make a decision right now.". That is what I told.

Roz Kalb: So, now I am seeing you both in a very, very different place. You seem more relaxed with all of this. You are very open with each other, with me. You talked about all these changes. You have just seemed much more grounded than the way you have described your experience in the past. So, this brings me to a question about the spiritual aspect of wellness. And now for me spirituality means really feeling grounded in

the world around you, connected in whatever way is meaningful to you. Has this been a part of your lives of dealing with MS? How would you talk about your own spiritual wellness issues? Think about it.

Myra: Well, I think that we have always been churchgoers for one thing and we have always attended church together. Our daughter did too. And so, that has been a big part of my life. But for me now a lot of my spirituality comes from gratefulness, and I practiced that every day before I go to bed. I think about at least three things, sometimes much more, that I am grateful for it. Sometimes it can be as silly as I am glad I have a toothbrush or I have electricity that makes me cool so that I do not have to sit in the heat that bothers me and what bothers my MS. So those are things that I do to help me stay grounded.

Roz Kalb: Steve, is there anything you feel about being grounded yourself because you clearly are in a different way now?

Steve: Like see, what is grounded me is understanding that all that we have talked about, her talking about being grateful. I could say, you know, being able to sit on the porch and watch the sunset or drive through the mountains and see the trees children colors and all those things all play together. Through all the years we spend together, we have a transmission that is moving us down. Or her line, as long as we are communicating and supporting each other. We provide the energy to those gears to that transmission. MS is breaking the cure or breaking a tooth out of here where transmission does not work smoothly. So, we need to find workarounds and on that journey, now I have understood what the cognitive things. I have to make more decisions or do more planning and then bring that to her. And that moves the vehicle through the transmission down the road. In the past, when we took vacations or when we are on trips, we just say we are going to go do this. Now, I will look, is the place handicapped accessible? Can we do this? Can we do that? We could go here, go there. Then I take that information to her weight all out. And then we pick and choose through the menu that I have created and put a travel plan together.

Roz Kalb: So, when I am here, is that part of your grounding that is in the integration in your partnership? That you have sure grown together, work together, and found this way whether it is from a teacher's perspective or an engineer's perspective. You found a way to work together in a very powerful way. So, thank you for sharing all of that.

Host: Thank you, Roz, Steve, and Myra for the engaging discussion. And thanks to our listeners for tuning in to this episode of the MS Path 2 Care Wellness Podcast Series, a partnership with Can Do MS and Sanofi Genzyme. Be sure to check out the other episodes in the Path 2 Care Series, diet, exercise, and healthy behaviors and home, work and relationships. For additional resources, please visit www.mspath2care.com.

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