



## **MS Path 2 Care Home, Work, and Relationships Episode 18**

Host: Hi and welcome to the third and final episode in our three-part MS Path to Care Wellness podcast series, brought to you by Can do MS and Sanofi Genzyme. If you missed the first two parts of this series, please go back and check out the last two episodes. MS Path to 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. In this episode, Myra and Steve will discuss their experiences with home, work, and relationships with Psychologist Roz Kalb.

[Music]

Roz Kalb, PhD: We are back with Myra and Steve and we are going to talk about work, home, and relationships together. So Myra, can you start by telling us a little bit about your career and how MS started to impact it?

Myra: Yeah. Well, I retired from elementary school teaching thirty--oh gosh, I taught thirty-seven years or thirty-six years, and I retired nine years ago. Right before I started to retire--or I was thinking about retiring, I was having trouble with fatigue and getting through the day. And then I was eligible for retirement anyway, and so we decided by talking to our financial planner that it was okay to do that because I was not taking early retirement. I was eligible. And so it just made sense to do it.

Roz: Okay. And did you work for a long time with a lot of physical discomforts of MS?

Myra: No. Over the years, I think that I had some small exacerbations. One with the MS hug which is where you feel like you have a compression vest on, and you just can not breathe. And that was sort of the precursor to that I started progressing. And so then, that was when I did get a neurologist, and I knew that it was time to address the MS issues that I had been kind of pushing to the background. After I had taken some medicine it went away, but then towards the end before I retired, I was just having a lot of fatigue. It was hard to get through the day because I just wanted to lie down or take a nap about three o'clock every day. So I knew that it was probably time, even though I probably would have took maybe two or three years if I had I not been having that.

Roz: And prior to that time, had you talked about your illness with your supervisor or your colleagues?

Myra: I had never talked about it with anybody really until I had the MS hug and I missed a week of school because of that, and so then I had to tell people.

Roz: And how did they respond?

Myra: They were very empathetic actually. My principals and teachers that I work with, they were all very caring and, "what can we do to help you?" They wanted to know more about the disease at that time, and they had no idea I had it. And so I guess in hindsight, I should have probably told them that I did, but I did not need to because I was not having a whole lot of trouble.

Roz: So in addition to the pressures of regular work life and teaching young kids, which I know you did, you were also keeping to yourself this whole inner life that was going on in your body. So that must have been pretty stressful.

Myra: I did and I will never recommend that. I mean, obviously one of the things that we have learned from going to Can-do programs is that, communicating with people about the disease itself, and how it is affecting me is important. Not only our friends and my our daughter, but Steve--I did not tell anybody how I was feeling. I mean it was happening so rarely that sometimes I could forget that I even had it. It was just not that big of a deal until later on it started progressing.

Roz: And Steve, how has this impacted your work life at that time?

Steve: Early on, it did not pack my work life that much. She mentioned taking a day off here and there when fatigue set in, and I would not know about it. I always left earlier for work than she did, and got home after she returned home. And I would find out about it when I came home and she would mention, "Oh I decided to stay home. I was tired. I was fatigued." And for me it was, "Oh how you feeling now?" "Oh better" or "I might take another day," she would say, or whatever she chose to do. So it did not impact my work. Overtime though, I think emotionally it did affect my work. I try not to let it show it work as she progressed. I do not think I could ever say I made bad decisions at work, worrying about her condition or what she was going through. So I just carried on and buried myself in my work.

Roz: So when you started to talk about retirement, did you talk to anybody else or get opinions from anybody about how to go through that process, or did you just decide yourselves?

Myra: Well, the school district that I worked for had seminars for retirement. And then we also talked to our financial planner. And so, it just seemed like it was the right thing to do because I was eligible, and so we knew we had enough money for a retirement. And so it makes sense to.

Steve: And I attended meetings with the school program.

Myra: Yeah, we both did.

Steve: Yeah we both did, so I understood what was going on. I could share that information with our financial planner, and they looked at the numbers and made sure that we were in a position to do that. And that I set a goal that I would retire so many years farther out. And when they looked at everything, it made sense to them, and it made sense to us, too. And her retirement really was just a natural. It is time.

Roz: Sounds like you did it very carefully and thoughtfully.

Myra: We did.

Roz: So I know you love teaching, and I know that that was really central to your sense of who you were as a professional. So then you retire, what was it like for you to then? How did you find a new Myra, so to speak,

who is no longer the teacher of elementary school children, but a new part of your life?

Myra: That very, very first year, I did go back and I helped out, because I was teaching English as second language in the last bit. And so, I did go back and help out there a little bit. So I kind of kept my foot in the door, but then after that, I think what happened was I realised that because of the fatigue, now I could pace myself and I would not have to do everything on a weekend. I would not have to do all the grocery shopping, all the cleaning, and all that, all on the weekend. I could just spread it out throughout the week, and feel very comfortable then, and not have that fatigue so much.

Roz: So you are able to focus on other activities.

Myra: Yeah.

Roz: ...And on your household chores and things. Steve, what was that like for you? What changes did you notice in your role in the household as Mira's MS progress, but also as she was home focused on the home? What happened?

Steve: When she was working, a lot of times Saturdays were the day to get everything done--Saturdays and Sundays. When she was working, a lot of times I did the grocery shopping on Saturdays, while she did laundry. After she retired, a lot of that work--grocery shopping moved to the midweek, and laundry was done midweek. So it opened up our weekends to, where after I came home from work on Friday, we had a Saturday and Sunday. We had a weekend that we really did not have before. We had no time for ourselves. After she retired, we had time for ourselves.

Myra: And I think we took made it a conscious effort then to plan things that we could do together, like outdoor concerts during the summer time going to a venue to a concert, or just see a speaker or whatever, but actually searching for things to do together because we had now had the time, and did not have to spend so much time on the household chores.

Roz: So I have heard you say something in the past, Steve, that really had an impact on me. And it was, you are talking about how Myra is a pace-setter. So now, you are retired Myra. You are at home. You are balancing activities in the household, and also trying to do all these things together that you have never had a chance to do. What does it mean to you, Steve, to say Myra is a pace-setter?

Steve: It means that I need to be aware of her physical well-being and emotional well-being. And being the pace-setter, if she has an energy to do things, we do them. She might have an idea to do something, we go do it. I might have an idea to do something, we go do it. If the energy is not there, I have to understand that, and thing I wanted to do or she want to do, we put it on the back burner. I can not force her to do something that is going to take away her energy. Energy management for her as key. Energy conservation is key, and if we do not conserve and manage that energy, she is exhausted and we get nothing done.

Roz: So we have talked a lot about communication, and it sounds like you must have had to do some really good communicating to arrive at that understanding of how you were going to manage your life after retirement.

Myra: I think that what happens is that he does a lot of planning on his own to where he will say do you want to go to a movie or out to eat tonight, and sometimes I say, reclusively yes; and sometimes I say, that is not going to happen tonight. Maybe you go get takeout and bring it home instead, or maybe we have been cleaning together, and I just do not feel like cooking that night. And so he will go get that. And so we

communicate about that, but I think that that is the key now is that he has to ask me, "Do you feel like doing that?" And I will say, "Well maybe not today" or "Yeah, let us try it." For more long-term things, let us say we are going to go on a trip or something, or it is going to be visiting our daughter in Minneapolis, we plan ahead for that and we try to conserve my energy in such a way so that we can manage it. So it is always a juggle though. You never quite know for sure what is going to be happening.

Roz: But you can't juggle without that communication?

Myra: And flexibility. And patience.

Roz: Patience, flexibility. So one other issue, I know you take great pride in your home, and how you take care of it, and how you have always been taking care of it in the past. And now, you have some limitations. So how does it feel for you when Steve has to step in and do some things that you would have preferred to be able to do yourself around the house perhaps?

Myra: Well, I hate it because I can not do it. And a lot of times I try, but I just do not have the energy, or the balance, or the ability to do it. And so, like last year, I broke my ankle and that was sort of the catalyst to Steve to kind of taking over the grocery shopping, the vacuuming, and as sort of has continued on even though the ankle is okay now. The shift has gone more to him than it is to me for the household duties.

Roz: Is it hard to watch somebody doing things differently than you might do them yourself if you were able?

Myra: Yeah it is sometimes, but we laugh about this now. But there are things like, for example, you have a drawer for your utensils in the kitchen. When I am cooking, I do not want to have to go searching for the spoon that I wanted to be in this slot, rather than that slot over there. And so sometimes he laughs at me because he was like, "Who cares where that spoon is?" And I said, "For me to have to stand there for five minutes looking for that, that is using up what little energy I have to cook. So those are the kind of things that we laugh about sometimes, and sometimes they probably it is like pulling his hair round about.

Roz: But humour helps?

Myra: It does, it does.

Roz: Fair to say. So we have talked a lot about a lot of different areas of well-being together: at home, at work, in your relationships. What do you think is the biggest thing that you have each learned about caring for these different aspects of your wellness? How do you how do you pull it together for yourselves and with each other?

Steve: It took a while for me to understand that I can not continually do everything for her bit her beck and call, so to speak. Not that I do not want to be, but I need me-time as well. When I have time for myself, I re-energize my batteries. So I am more supportive of her. And also, what she just talked about, having a place for everything and having those things in that place. I talked earlier about managing and conserving energy. It has taken me quite a while to understand that that is key for her survival. If I am not doing those things, and other things as well, that starts building the wall between us. So I need to knock that wall down, or we both need to knock the wall down, through communication and understanding of why she needs something that way, or something done for her. But also for her, she understands and she has actually pushed me to go have that me-time, because she knows I will come back and be more supportive when we have our time together. And it strengthens the team. And that is what we are, we are a team.

Roz: Anything you want to add to that?

Myra: I could not ask for a better support partner or spouse.

Roz: You guys do an amazing job.

Myra: Yeah.

Roz: Amazing. Thank you for sharing.

Host: Thank you so much, Roz, Steve, and Myra for the engaging discussion. And thanks to our listeners for tuning in to this episode of the MS Path to 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: Mood, Cognition, and Spirituality; and Diet, exercise and healthy behaviors. For additional resources, please visit [www.MSpath2care.com](http://www.MSpath2care.com).