



MS Path 2 Care Diet, Exercise, and Healthy Behaviors Episode 17

Narrator: Hi, and welcome to the second episode in our three-part MS Path 2 Care Wellness Podcast Series brought to you by Can Do MS and Sanofi Genzyme. If you have not listened to the first part of this series yet, please go back and check out the last episode. 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. In this episode, Myra and Steve will discuss their experiences with diet, exercise, and healthy behaviors with a physical therapist, Mandy Rohrig.

Mandy Rohrig: Welcome everyone. We are glad you are joining us for the podcast about diet, exercise, and healthy behaviors. I am so pleased that Myra and Steve are with us today to talk about these topics. So Myra and Steve, when you think about healthy behaviors, what does that mean to you? Myra, let us go ahead and have you start.

Myra : Well, of course, diet exercise keeping mentally healthy is probably the biggest part of it because that helps you have a positive attitude and a little bit more resiliency. Everything is kind of tied together to that mental attitude that you have, but obviously, diet and exercise too, are very important.

Mandy: Great. What about you, Steve?

Steve : Well, I have to agree active physically, mentally, and socially being active with friends and neighbors, going out, doing things, having people around that you can visit with. So your world is not closed in on you, but also I was thinking about this healthy behavior for us is ensuring you have your cane, your AFL, Walker, scooter, anything we need, plus the medications that are used for the MS.

Mandy: Sure, That is a good point to make sure you have all of the tools that you need...

Steve: Right.

Mandy: ...to set you up for success. So for you, it certainly sounds like being healthy comes with a very holistic perspective, Steve, have your priorities with diet and exercise changed over the years? You guys have lived with MS for a long time.

Steve: Yeah. We have lived with it for a long time prior to being married, I was a typical single guy grabbing a meal where you can get it. Were not too concerned about what I was eating and how much I was eating. I was active playing softball, doing other activities, bowling, swimming, going out on [inaudible] trips with friends then as you get married actually has your working and your work world starts to become more important or takes more time. You let things go, you are inconsistent on how you can exercise. You are not maybe getting meals in a timely manner and have good quality food. Then after retirement things changed

being around the house and doing things here with Myra, I realized how much things have changed, how important it is that I maintain a good lifestyle in order to support her. So what I have done is taken up swimming. I swim three to four times a week. I play pickleball when I can, and we have also looked at our diet, try not to eat too much food, make sure we are getting a balance of vegetables, fruits, and whole grains and things like that.

Mandy: So, you mentioned that getting married was a catalyst for changing some of your priorities and health habits. Were there other shifts in your life that made you look at diet and exercise differently?

Steve: Yeah, with age, the body starts slowing down and it is easier to put on weight, you get those aches and pains throughout our married life. We have done a lot of things together, we do a lot of gardening and things like that. And there are always those aches and pains that night, the next day after spending a day in the yard. But again, as I age, as people age, you realize it is a finite timeframe for the body, and if you want to go all out, do everything you can possibly do. You possibly could use up that body before it is time and so I guess for me, I looked at it that this is a partnership I need to be here and support Myra and that if I do not take care of the physical being, I will not be here long enough to do the things that I needed to do to help ensure she has a good life.

Mandy: Myra, have your priorities changed over the years?

Myra: Well, again, as I mentioned before, I think with age, you do need to have a healthier lifestyle, but I never really liked prepackaged meals and things like that, and I like to cook and so we ate together almost every night, really when our daughter was young and when she was at home. And so we go out to eat sometimes now, but I still try not to buy prepackaged food. But I think with MS too, it requires a little bit more planning for the meals, at least. So we try to make out a meal plan for the week and then Steve will go buy the groceries for those plans. And then we work on it together because well, for me gross shopping now is really fatiguing and so we just try to go once a week after I had made that plan out for him, but we still try to eat together at home quite a bit. And I think that that helps, but there are nights when in fact, a couple of days ago, I was right in the middle of making dinner and the fatigue just was overwhelming. And I said, "I have got to go sit down, you need to finish this meal." And so I think that those are the considerations now with the meal planning, it is not even so much the food, although we try to eat a balanced meal, but it is working around how I am feeling when we are making meals.

Mandy: So it sounds like you guys have a plan. You always have a plan in place for your meals, but you also have to remain flexible, right?

Myra: Right.

Mandy: Because at any moment, symptoms can arise and you have to figure out a way to manage it. And over the years you have developed strategies to make that work. Myra, has your perspective on exercise changed over the years?

Myra: I was not super, super active, but I did play tennis when I was younger and was on the league and those kinds of things, but I would not call it an everyday go to the gym kind of exercise. I really did not have time, I was a teacher and I had come home and I was just too tired and had other things to do. So I did not tend to exercise so much, so I feel like it has changed a lot. Now that I am retired, I have more time to go work out and I found a gym that is for people with MS. I have been going there for seven years, and so it is great because the workout is tailored toward what I can do that day. And it is not like everybody has to do the same thing and so I think that I do realize now how important exercise is for the health of my MS, really

because if I do not go or if we are on vacation and I do not work out, I can really tell a difference. And so now where I go pretty consistently with three times a week, it is an hour class, there are four sets in each of the eight stations that we do, and it just makes a big difference. I had hated to think about what I would be like if I did not go, and so I think that exercise has become a lot more important to my lifestyle.

Mandy: So it sounds like you both have shifted over the years to reprioritize exercise for yourselves, but also for each other, right? You respect that time and make certain that that time is reserved. So, how did you go about that? How did you go about making diet and exercise a priority in your busy, busy lives?

Myra: Well, for me personally, I have always been a list maker. And so, if I have something on a list, I really feel compelled to do it that day. And so, I have added exercise onto that list and I make sure that I go, I make sure that I have that time carved out of my day to do that. And even so much as going on a walk. Sometimes Steve will say, "Well, do you want to go on a walk?" Well, he is throwing it at me at the last minute? And I might not want to go. But if I think about it earlier in the day, "Oh, this is going to be a really nice day. Let us go for a walk this evening." I tend to have, I need to have that like schedule a little bit. I like to have things kind of scheduled out. I have always liked that a little bit, but it is really like that now. I mean, because if this morning I think, oh, well I think I will go on a walk and then at seven o'clock when we think we are going, it is 95 degrees out. I was like, "I am not going to go then."

Mandy: And it allows you to kind of organize your day around that, right?

Myra: My day and my thoughts. Yeah. I kind of like to know what is going to happen.

Mandy: Yeah. What about you, Steve? How do you make diet and exercise a priority and how do you support each other with that?

Steve: Well, again, I am unfortunate that she has a schedule and I can just tag onto that schedule and do my thing. I do not go to her gym. I go to the Y and other pools to swim when she is at the gym. But as Myra said, the schedule is important for her to have her day organized and for me, just to pop in and say, "Let us go for a walk," does not necessarily work. So I have realized that I can not twist arms and make her do what might not be the best thing to do that day or at that moment. So I keep an open schedule. I will make a suggestion that we think about doing this as her day goes on and she realizes she can do it, we do it. The thing with MS is that her condition sets the pace of what we are going to do. Be it cleaning, be it gardening, exercising, going to a movie, going out to dinner. If things are not working correctly that day, we will just have a backup plan and do things that would fit in with what she can get it accomplished. It does not do us any good to plan to work in the garden let us say all day long and physically drain her, where she can not function for the next two days. So having an alternate plan, being able to adjust our plan or cut it short and get done what we can do is more important.

Myra: I think, to do it at the beginning of the day, for me, like especially gardening or anything, kind of more physical like that. And it is cooler in that part of the day. And so, if I am going to go do that, it will probably be at the beginning part of the day versus later in the day like if we were going to go to, let us say a concert, an outdoor concert in the summertime, I am going to take my scooter along. And so, then I am not expending a lot of energy to do that activity.

Mandy: It sounds like you always have a plan, but you have flexibility in your plan. So you are never limiting yourself to doing things you want to do. You just have a menu of options and when you do them might vary slightly.

Myra: Sure, yeah.

Steve: Exactly.

Mandy: Yeah, that is good. So for people who are struggling to get motivated to exercise, which is certainly common among people living with MS and support partners, what kind of advice would you give? Myra, let us start with you. What would you advise for those folks who are struggling?

Myra: Well, I think for one thing, if you do not decide yourself that you want to do this, then it is just not going to happen. And so, if you can find a group that you can work out with or even a friend that you can come have, come over to your home and maybe do it with you, do a tele-fitness, kind of a thing, they have tons of those on the line. That would be a way to help you get staying motivated. But for me personally, when I go to the gym, there are all the other people that are like me. And so, we share ideas. Sometimes it is just a recipe, but a lot of times it is, "What did your doctor say when you went there this year?" Or, "What kind of medicine are you taking? How is it working for you?" So again, as I said before, I put it in my daily plan, but I do wake up some mornings and I do not want to go, but I think, "Well, what am I going to feel like if I do not go?" And so, I make myself go and but I like it too for the socialization of it. And I think that is probably really the key is that if you can find someone to work out with, or a group of people to work out with, that helps a lot.

Mandy: Yeah. So Myra is motivated it sounds like, by that social environment. Steve, what about you when it comes to exercise?

Steve: I think people have to be realistic, be comfortable with what I can do, what you can do, and give it your best effort. I know for me, swimming came naturally. So that was what I picked to do. And that is my go do that three to four times a week. And I know for me, when I am not doing something well, I can get down on myself and want to stay away from it. And it helps to have Myra encourage me to continue to try and do things. And I will use the example, is pickleball. When I first started playing that and she encouraged me to keep going and keep trying and you will get better. And she is correct.

Myra: I think too for him, I was encouraging him to play too for the socialization of it. Because when you are retired, your world comes in just a little bit. You do not have as many social contacts. And so, I thought, well, I certainly do not want him sitting at home with me all day long. And so, well, I mean, that is a two-way street. I mean, not only because, it is nice to have some time to yourself, but also, so he does not have to sit around looking at me all day. So, I have encouraged him to do that, because pickleball is more social than swimming for sure.

Steve: Swimming, you can not talk to too many people. It is kind of difficult. But the biggest challenge is taking that first footstep out the door and going and doing. Once you are over that first hurdle then things get better.

Mandy: Trying something that maybe is a little out of your comfort zone.

Steve: Sure.

Mandy: Yeah. Myra, Steve gave us some examples of his exercise. I know you touched on briefly about what you did for exercise. Can you just elaborate a little bit more?

Myra: At the gym, it is all geared towards agility, balance, strength, your ability for motion, stamina, all of

those. And so, the exercises that we do are almost the same as what you would find at any gym really, but what is nice about it is that you just, at any gym, you would be doing weight training. So, you might have free weights or a rowing machine, a back machine. There is a machine that is called a wave. You can actually just stand on it and it exercises your muscles without you actually even moving, a lot of balance actually. We do that too and, oh, I forgot aerobics, because getting your heart rate up is very, very important. So, all of those exercises are things that you do at a regular gym, but why I do not go to a regular gym is that I do not like to watch all the able-bodied people that can do it so much better than I do, where the gym where I go, we are all in the same boat. And so, you do not feel like you need to compare yourself to anyone. Which I have to say, that is some advice I would give, is if you are going to go to a regular gym and maybe your MS is not so bad, just do not compare yourself to anyone. Just do your own thing, and be happy with whatever you are doing.

Mandy: It goes back to what Steve mentioned, having confidence in yourself, feeling comfortable in the environment that you are exercising in.

Myra: Even if you are a person that is in a wheelchair, I mean, you have to say that there are, again, a lot of teleconferences where they will show you how to exercise in your chair. Or, even if you are not in a chair, but you just can not walk well, there are still many things you can do in a seated position. Can Do is a great resource because they have a video of people exercising that you can watch and follow along.

Mandy: Yeah. Truly anyone of any ability level can exercise.

Myra: Absolutely.

Mandy: They really can exercise. Do you guys have some activities that you do together, that you enjoy doing together?

Steve: I will start out with traveling. We like to explore the country, go places we have never been to before. Back before Myra was so much affected by the MS, our travel plans were pretty much, we did it together. Let us go here. Let us go to Disney World, let us say, or let us go to the West Coast, or let us go to New England and do things. Now that MS has been a bigger part of life. What has happened with our traveling is I will do a lot of pre-planning of it. I will find areas that are handicap accessible, find hotels that will support us in other activities to do, and then bring that to the table and discuss it and let her think about it and see if that makes sense to her. It becomes more of a two-phase operation where I will do the legwork upfront, figure out where we might want to go, what would we might want to see, do the timeline of where we will go, when we will be there and how long we will stay, and then let her look it over and say, "Yeah, this looks like a doable thing," and put that into our schedule.

Myra: Another thing that we have realized is that long trips for me are hard, and so we try to do... About a five-day trip is about just right for me. Even if we are flying somewhere, two of those days are going to be flying. Then we do three days of fast and hard and do a lot of stuff in those three days. Then I am wiped when I come home. But it seems like those short trips are more doable for me. We also have a dinner group that we belong to. We go out once a month and then we go over to each other's houses and have something to eat afterward. I started a Bunco group in our neighborhood, and so that helps me be more social. We do not do that together, of course, but the activity... Well, like in the summertime, I guess we go to a lot of concerts, outdoor concerts and things like that. I mentioned my scooter that I can take. I just sit in it while we listen to the concert. I think we go out of our way to try to plan things almost once a month. It might be like going to the Omaha Community Playhouse and watching a play, but something special that gets us out of the house. Maybe we are going with friends, maybe not, but at least it gets you out of the

house. You are doing something.

Mandy: So, avoiding isolation and trying to stay active, even when the weather maybe is not as ideal, which we are... We all are living in Nebraska and we are approaching the winter months. Do you guys have any ideas about how to manage inadequate weather?

Steve: That is the hard part. When I was working, I had the... I will call it a luxury, of leaving home every day and getting out and about, so I did not feel the isolation that she might have been feeling. It has become a... I do not want to say a challenge. It is a task may be, that we have to work through, and right now we are in the planning stage of what we might be doing this coming winter. We have already planned a trip to see our daughter in Minneapolis, and nothing [crosstalk]...

Myra: We are going to the beach in February.

Steve: Oh, that is right. Yeah.

Myra: Yeah, to Turk's and Caicos, but those are the kinds of things that you have to make a conscious effort. I mean, even in the wintertime you can go to the movies. You can still go to see shows at your event center in the city, so I think that it does not necessarily mean that you are going to be outdoors anyway.

Mandy: Let us talk a little bit more about exercise. Myra, can you tell us a little bit about how you have adapted your exercise, and have you used any tools or accommodations or changes to how you approach exercise? Can you tell us a little bit about that?

Myra: Well, just to give you a little background, I was diagnosed in 1982. I went for almost twenty years with very, very few problems. I mean, I had some exacerbations every now and again that we were... They would give me some medicine, I would get better, and I would go on about my business. But about ten years ago, I started noticing that my foot was dragging when I had to get warm. I had been on a mission trip with my daughter's youth group and started noticing that. Of course, at the time I thought it might be arthritis or something else. I did not really recognize it as being something with MS. But then as time went along, I did start to see more problems and then I had what is called the MS hug. For those of you that do not know what that means, it feels like a compression vest on your body and you can not breathe and you can not think about anything else. It just was really, really painful. Then I was recommended to see a PT. I think I saw one or two before I met Mandy. Mandy has this uncanny ability to read my mind and understand what MS is doing to me and give me the right kinds of tools for stretching and exercises, so that was where I started. Then I kept regressing and we got to the point where... Well, I was using a cane at this time now. I had purchased a cane on my own and was using that. But then Mandy recommended that I see an orthotist that made an AFO, which is a leg brace for the foot drop, or drop foot. As awful as it is to think about wearing it, it did open up my world because I was able to walk better because of having the AFO on. Having a cane, too... I know I was so hesitant to ever use a cane, but once I started using it, people all of a sudden realized I had something going on and they would open doors for me, where before it was like I was just walking with my foot-dragging. Once I got the cane, I felt like that kind of opened up a world in itself. Then the AFO, that helped a ton. But then as time went along, then walking long distances was so, so hard. We had been to five days Can Do program. There was a guy there that had a scooter, and so we asked him questions. I think that that is another very important component, is that you have to be inquisitive about different kinds of adaptive equipment that you can have. There are so many things out there now. I mean, I saw a thing on Facebook yesterday about a guy that stood up for the first time in fourteen years with a wheelchair that makes him stand. I am thinking, "How wonderful it is that we now have all of this wonderful adaptive equipment." You have to get over this stigma of what will people think because it is all about your own

safety and how self-preservation. You have to use adaptive equipment to stay alive so you do not have falls. And that was what was happening to me is that I was falling frequently, but eventually, then we got a scooter, we got a lift for the car, so it was easy to put in and out. So it is not so hard on Steve to put in and out of the car. But all of those adaptations that I have made have now opened our world up because before the scooter too, I would not go anywhere that required lots of walking. I did not want to go to Target. I did not want to go to a store that was a big store. I did not want to go anywhere. Once I got that scooter though, I was in control of it, and that is one of the things I still enjoy about that is that I am in control of that scooter, and then we go and we do whatever we want to. Sometimes it requires some investigation on Steve's part to figure out if I can take it or do we need when we go to a concert, do I need handicap seating, which of course I do, but they just roll it in there and they take a chair away, and that there we go. It is always the best seat in the house. So there are ways to get around this and you just have to get over the stigma of using them.

Mandy: Excellent advice. Steve, how has it felt knowing that Myra is safer and she is able to do, you do what both of you want to do together and what she wants to do on her own?

Steve: It takes a load off you. It really does emotionally. You do not have to worry, but the key is, do not accept what you have today as being the end-all of everything. There is always something new coming out there. Your condition might be changing requiring a different cane or different AFO or whatever it might be, and you just do whatever it is you need to do to make things work for you. The possibilities are endless. You can get everything you would need if you just look for it and adapt it to what you need or the conditions you are in.

Myra: I feel kind of lucky because Steve is pretty handy, and so he was noticing that on my scooter, if I want, sometimes if I take the scooter, I still want to use my cane and walk once I get to wherever I am going. And he noticed that I had trouble with, there was a cane holder on the back of the scooter that was made for that scooter, but it was behind me. And so I would get off of the scooter and it would not be right there where I needed it. So he made me a little cane holder to put on the basket that is on the front of the scooter, but it made a world of difference because what did you see that made you think that I needed that?

Steve: Well, when you stepped off the scooter and stood up, you are not stable. And then to turn to your left or right to retrieve the cane from the back of the scooter, you were not stable, the risk of falling increased. So I got to thinking about that adaptation that I can make the scooter, and we put a cane holder on the front basket and it is right there, handy.

Myra: But that is what is nice about him. He is always thinking about a way to make my life easier.

Mandy: But I think what the two of you illustrate so well is this willingness to use adaptive equipment, knowing that it is the key or the gateway to doing things that you want to do. You guys give some beautiful examples of that, so I think that is really awesome.

Steve: Thanks.

Mandy: So let us touch on a little bit more when you do find yourself unmotivated or unable to exercise, it is time or if it is symptoms or just maybe you are just getting simply in a rut. How do you get through that? Steve, why do not you start by telling us how you work through those ruts?

Steve: Again, I am fortunate that she has a plan and a schedule that helps her manage her day, and I can just lock into that. And again, as I said, she goes to the gym, I go to the Y and swim. Do I always want to go? No,

especially when it is cold out and there are 6 inches of snow on the ground, but I force myself through talking myself into, I need to do this. It is good for me. It is good for her. So the big thing for me is just, again, I said it earlier, taking that first step. What is that old saying? The longest journey begins with a single step and that is where it is for me. Just you are going to do it, go do it.

Mandy: So, Myra, what about you, when you are feeling unmotivated or unable to exercise because of symptoms. Explain to us how you work through that. How do you get past that kind of rut or that obstacle?

Myra: Well, I said before that I realized what I feel like if I do not go. And so that helps a lot, but I have to be honest with you, there are times, especially after I have been away from it for a little bit like I broke my arm. And so then it was a long process to get back into it. I broke my ankle. That was also a long process to get back into it. You have to just take it slow. And so if you say, "Okay, well I think I will just go once a week or I am going to go twice a week" and then you can bump it up if you can, I try to go three. So I think that just remembering to take it slowly and do what you can do, be happy with whatever it is you do, even if it is. Well, Steve and I were talking about this last night, that on the days that I do not go work out, I need to try to go up and down steps more because it is still quite difficult, and so that would be a great exercise for me to do that a couple of times a day on the days that I do not work out. So it does not have to be a huge thing, but keeping your body moving in some way is probably, it makes you feel better, and so that is a motivator in itself.

Mandy: So you two have clearly prioritized diet and exercise over the years. It sounds like it is been a work in progress though, right? So how or where, or from whom did you learn how to make these things a priority in your lives? I know it was not easy.

Myra: Well, for me, my parents were fairly young and so they were very active. They loved boating all things and all sorts of things. And so I was always looking at parents that had a healthy lifestyle and my mother was a great cook. She always made balanced meals, and so I think that because I grew up that way, that is kind of the way we ended up having our marriage and our relationship with our daughter that way.

Mandy: Steve, do you have any comments?

Steve: Your support team can be a contributing factor to it via PT, your doctors, nurses, other care providers, can provide you guidance on what to do or what you might think about doing and get involved with that. Again, setting a goal for yourself, and you might not always achieve what that goal is you set, but understand and accept that you did something, you tried something and you made a difference in your life. And hopefully, that difference will help support somebody that you are helping take care of.

Myra: And I have to reiterate the health care team too, because once you find somebody that you trust and that is making you feel better, then that also helps you keep moving and keep doing what you should do, be it a nutritionist or your neurologist or anybody like that, that maybe specializes in MS in particular, that will help solidify what you are trying to do.

Mandy: So that is great, find members of your healthcare team who can help serve as that nudge if you will, to keep you on target. But then also it sounds like continuing to support each other you can help.

Myra: Yes.

Mandy: So you have offered lots of tidbits of wisdom during our conversation, but if you were to look back and say, "What do I wish I knew, thirty years ago, that I know now," what would you say? What have you

learned about diet and exercise that you wish you would have known?

Steve: Well, for me, a person thirty years younger would have said needed to do a better job of taking care of the physical being, that you are going to live quite a long time, many years, hopefully in retirement and that other people are going to need your support to live their lives. And I would have been more active in taking care of my physical body by exercising, by eating better, by doing more social things, and being more active, rather than just focused on family and work. There is nothing wrong with being focused on working, but it should be a balance, but maybe second or third in the list of priorities, being more concerned about family and your personal wellbeing.

Mandy: Myra, what about you? What do you wish you would have known?

Myra: Well, not to hold me up against other people. Be comfortable with what you are doing and how you are living your life and not compare yourself to other people's standards, I think is what I would do. I would compare myself, when I was younger, to others that were maybe more successful, athletically or even educationally, a lot of different things. So just do not compare yourself. But just keep trying and try things out. If it is an exercise program or a diet program, try it, see if it works for you. If it does, and you feel better, then keep doing it.

Mandy: It is good advice. Any final thoughts, Myra and Steve?

Steve: Well, I would just add not to accept the status quo. What you are doing today might be working for you, now, but maybe in a year, five years, ten years down the road, it is not working so well. So adjust, adapt, and adjust to what the situation is, at the time, and still push yourself.

Myra: Be flexible.

Steve: Yeah, be flexible, but push yourself to try to do the best you can do. Be comfortable with what you are doing and do the best you can.

Mandy: Great. Well, thank you both...

Myra: You are welcome.

Mandy: ...for your time. Thank you, listeners, for joining us for this conversation with Myra and Steve. Have a wonderful day.

Narrator: Thank you, Mandy, 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, Mood, Cognition, and Spirituality and Home, Work, and Relationships. For additional resources, please visit www.mspath2care.com.

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