

## Community Conversations The Role of a Physical Therapist and Occupational Therapist Episode 19

Host: Welcome back to the Can Do MS Podcast. We are so happy you could join us for this episode in our community conversation series. Today, we will hear from physical therapist Mandy Rohrig, and occupational therapist Stephanie Nolan, as they discuss the differences between PT and OT, when you may want to consult which discipline, and their passion for working with people living with MS.

Mandy Rohrig, PT, DPT, MSCS: Welcome, everyone. My name is Mandy Rohrig. I am a physical therapist from Nebraska. I have been working with people who have MS in their families for nearly fourteen years now, and I am joined today with Stephanie Nolan. I am really glad that she and I get to have a conversation today about the complementary roles of PT, physical therapy, and OT, occupational therapy throughout the disease course of MS. So Stephanie, would you like to introduce yourself to our audience?

Stephanie Nolan, OTR/L: Hi, everybody. I am Stephanie Nolan. I am an occupational therapist. I have been working with people with MS for probably about six years now and I have loved this journey. I have learned so much and I have had such a great time becoming part of Can Do. I have learned so much more even being with Can Do so I am excited to share some information with you guys today about occupational therapy, physical therapy, and how we work together.

Mandy: Great. So, Stephanie, let us start with the role of the occupational therapist. How would you describe how an OT contributes to the overall MS Healthcare Team?

Stephanie: One word really comes to mind for me and it is independence. My primary goal with every person I see is independence if possible, as much as possible. We might address independence by working on energy conservation or working on modifications or adaptations to make the environment more accessible and also making sure people are safe. I think the more safe that people are, the more independent they can be. But independence and especially being able to take care of themselves.

Mandy: I love that because PT shares a similar focus, right? We want people to do as much as

they can independently and enjoy their lives.

Stephanie: Absolutely.

Mandy: Why do you enjoy your work? Why did you become an occupational therapist? What do you like about it most?

Stephanie: I get this question a lot, especially for my clients and it is really funny because I do not think there is one exact way to answer that. But it is those moments when I just see somebody do something that they have not been able to do or did not think they could do and they do it. It is the light up in their face, it is the ability to be independent again or have that autonomy of being able to use the bathroom by themselves, simple as that. The excitement on someone's face when you say, "Somebody does not have to help me in the bathroom anymore." That is huge and being able to feel that privacy even again is great. It is really just seeing that light in someone's eyes when they are able to do something on their own.

Mandy: I love the light too, that is magical, is not it?

Stephanie: It is.

Mandy: Stephanie, what would you say are the primary areas of focus for an occupational therapist in MS Care?

Stephanie: So this I would say depends on what stage in life somebody is in. If somebody is young and in college, the focus might be on getting around the school, accessing the environment, being able to cope and manage different techniques for learning and using equipment if they need to for typing or writing. But if it is somebody who is maybe a parent, focus maybe more on how to take care of their child, how to manage changing diapers if there is a fine motor deficit, something like that. And then, there is work and how can you keep up at work and how can you modify your environment there to be able to type or use the computer systems or pass this amount? And then, there are the retired couples who like to go and enjoy traveling and I am not retired but I enjoy traveling too for sure. Being able to travel or enjoy leisure activities and maybe certain events that are really important to them. Other things would include driving or home management, which I think all of us have to do and none of us really want to, taking care of the house and how to clean and how to cook and keep your life going.

Mandy: That is great. So, there is a strong theme of independence. It sounds like and a strong theme of trying to make sure that you can do the daily tasks that you need to do and that you want to do.

Stephanie: Absolutely. I know that people sometimes confuse our roles. So how do you explain the role of PT in MS Care? What are your particular areas of focus?

Mandy: Yeah. I think Stephanie, we have a very similar overall goal. We want people to be independent. We want people to be able to do what they can do as often as they can do it, right? I think physical therapists in the role of MS Care specifically, we can help people both early in their disease as you alluded to and even as their disease progresses. Earlier in the disease that might be more looking at baseline ability levels and establishing what are the strengths and what are the existing challenges that may be present early in the disease. Actually later in the disease, it is not too much different but the interventions that we try to employ may be different. Later in the disease, we might use more tools, mobility aids, bracing, and other types of adaptations that can allow people to still achieve that goal of independence or optimizing their mobility. I also think that it is good for people to think of occupational therapy and physical therapy as complementary. But occupational therapist you guys, you are the experts on fatigue management, more fine motor, more use of the upper extremities. It is a good way to think of that for clients. Whereas PTs work a little bit more on gross mobility. For example, walking and balance retraining in the context of movement, in gross movement. We also help with spasticity management as you guys do too, I suspect. Working with the other members of the healthcare team to make sure that spasticity is not interfering with mobility. And then, I would also comment that we work on strength training, aerobic training in addition to both balance training and flexibility training. Overall, again moving what you can as often as you can is the goal of physical therapy as well.

Stephanie: So to follow-up on that, I know that some PTs offer pelvic floor therapy. Can you explain a little bit about that?

Mandy: Yeah. Pelvic floor physical therapy is that it is a pretty specialized area of PT, and what pelvic floor physical therapists are is they have our folks who have additional training beyond our general physical therapy training. They work on strengthening the muscles and different via different strategies to help the pelvic floor muscles, there is a bunch of them down there, as well as our lower abdominal muscles to be stronger. It is especially helpful for those folks who have bladder issues, may not be helpful for all folks who have bladder issues because different bladder issues can be addressed with different strategies. But certainly, worth having a conversation with an urologist or your neurologist to determine if the type of bladder that you have may benefit from pelvic floor physical therapy. And if so, and you find yourself on the hunt for a pelvic floor PT, the APTA which is the American Physical Therapy Association, apta.org. You can search for a women's health physical therapist to help you with this particular issue. That is a great question, Stephanie because it is something that we do not often talk about.

Stephanie: Yeah. It is a really interesting subcategory of PT and it is so specific but it is really important. I think a lot of people find it very helpful for them. Our roles are very different in some ways but we also overlap. How would a person with MS or a family member decides which one of us to see?

Mandy: This is a really great question because it is often confusing for people with MS and

their families to know any of us on the health care team who should they pursue, who should they call and contact. But when we are talking specifically about physical therapy or occupational therapy, I think you are safe. The short answer is you are safe to reach out to either one, right?

Stephanie: Yeah. I feel like we often will ask to say, "Hey, maybe actually OT would have been better." We bounce back and forth.

Mandy: Exactly. Because of that, there is that mutual respect that understanding of what the other discipline does and the realization that it might be okay if you see me one visit but you really need to visit with an occupational therapist. In short, the short answer would be either one of us is fine. But the slightly lengthier answer would be, again, if you are having more issues with gross mobility, walking balance, big muscles involved in your body, the strength and the endurance of those muscles maybe talk with a physical therapist. If you are having more challenges related to specific activities of daily living related to activities in your home or work and you may need the expertise of someone like Stephanie, an occupational therapist who can really dive into the nitty-gritty of those movements then, you may need an occupational therapist. I would also add and I would like your opinion on this too, Stephanie. We both work on fatigue management, right?

Stephanie: We do.

Mandy: Fatigue is a big issue for people living with MS so, from the perspective of a PT, we work on fatigue management when it comes to cooling movement efficiency so that you are not wasting valuable energy. Moving in a way that is inefficient and that uses too much energy, but we also look at it from the approach of conditioning as well. Someone who is deconditioned may need a little bit of exercise from a physical therapist in order to kind of optimize their fatigue as well. How do you guys approach fatigue management?

Stephanie: From the OT side of things, we do a little bit of kind of the same things that you said, but our focus mostly is on adaptive equipment a lot of the times. What could you use to make that task easier? How do we save some of that energy pulling up your pants so you can enjoy that energy later on at your son's soccer game, right? Finding different pieces of equipment to help maybe you need, something like a shower chair to conserve energy in the shower. That is a huge one and gets hot and showered. Again, we are hardcore and focusing on that heat, managing the heat, and in the showers, knowing to cool your showers. They should not be so hot, it may be sitting down. Also modifying your routines. How can you pace your day? We call them the four Ps; pacing, planning, prioritizing and positioning. Those four Ps are really important in saving energy throughout the day so you can use that energy other things you love is going to be using it on vacuuming the house. I think that is more of the way the OT focuses on that energy conservation where that is why we make such a great team because there are so many areas of energy conservation that one therapist cannot do it all in one day so it is great to have both disciplines kind of take each a little section in work on how we can improve energy consumption and have a better function really.

Mandy: Absolutely. I mean, for as big of an issue as fatigue for people living with MS, it is great to have more than one set of eyes trying to tackle the challenges. Because of the ways, we have chatted about already how our roles can overlap. We obviously have very many opportunities to work together to improve safety and to improve independence and overall comfort. Can you just describe a situation that would illustrate how you work with a PT to help someone with MS?

Stephanie: Absolutely. I love working with PTs because like you said having extra eyes. We also see different things that one of us could miss in another conceit especially when I was working inpatient, I love having code treats and one example, even though it was always a little tough that I love code treats was toileting. Getting three people in the bathroom might be a little bit weird but sometimes we had to do it to figure out why was it hard to get up and down from the toilet? Why was it hard to manage to clothe? What do we need to do? How are we going to approach that? The OTs, I would generally take over, "Okay, here is the adaptive equipment. Here is how you can manage your clothes. Here is the proper chair to use over your commode." Sometimes, I would recommend off a day just something simple like that because it can save you a little bit of energy for cleaning yourself after. Educating all the energy conservation if necessary, the OTs would address vision also, sometimes they seem could be a challenge and cause some balance issues. We talk about energy conservation and the routines of, when do you use the bathroom? How do you plan to use the bathroom? The PT had this whole other perspective which is awesome. They would work on like, "Okay, we can tell there is a weakness in this part of your leg during this part of the transition. This is where we need to focus on." So they would do strengthening or the spasticity like you mentioned it earlier, or even just a loss of range of motion and how to modify or workaround that range of motion or stretch maybe, maybe that is all they needed to be able to get that transitioning from the toilet up. Orthotics are another thing that the PTs do and OTs are not so huge to the lower body Orthotics, but maybe there is a special orthotic that they need to help with that transfers in general. Mobility devices, you already mentioned from the PTs' perspective. What device is correct? We do not want people just grabbing whatever they saw at the local drugstore and throwing it in front of them because it can actually be dangerous if you have the wrong thing. A PT is a person who is going to help us in that situation in the back. What do we use? What is proper for them? Again, the balance and the endurance and strengthening, and then as far as toileting we can also even throw a pelvic floor in there. Some people have trouble releasing their bladder to go to the bathroom and it held the fourth PT might be the right person who addresses that goal.

Mandy: I think what you just described so beautifully was this teamwork. These multiple people looking at the same situation but through a slightly different lens and with everything in MS Care, it is so important to have that team of people really strategizing and collaborating and working together to help you do what you can do. In the ideal world, when would you like to begin to see a person living with MS? I do not think we always get to see them when we want to see them. If you could pick and choose when you get to start seeing someone living with MS, when would you like to see them?

Stephanie: I wish I could see everyone before they even knew they had MS. How about that? Educate more people about MS before they ever even know about it in personal experience but it is hard to say because it depends on the level that everyone's at. I would love it if everyone who was diagnosed with MS could instantly have an OT consultation and it does not need to be full treatment even if it is just consultation because we know what to ask and the doctors have so much to do with so much to take care of it that in the medications and dealing with asbestos and all those things that sometimes they do not get to ask, "How was your sleep last night?" Or, "Did you use the toilet?" "Okay, this morning." Those are the things that we jump into. It would be nice if I would say within the first month if we could say, "Hey, let us do a quick consult. Let us just talk about what you are experiencing." Sometimes people do not even know they are having a problem until an OT asks, "Well, what about this or that?" So it would be nice to do a console as far as treatment as soon as you start to see you are losing function or independence, especially in self-care. If you are asking for help for things now that you did not need help for two weeks ago, I would say, "Ask your doctor for a consult. See if there is something an OT can do." Because a lot of times, I feel like people do not get that referral until it is really a struggle until they are completely dependent on someone else for a shower or they are about to lose their job because they cannot figure out how to modify the environment or how to keep up with everybody else. I guess that is a lot of different answers. Yeah, and I just wish I could see everybody with MS as soon as possible. I would like to ask you the same question though. I am sure you share my frustration that people are often referred much later in the game and you would like them to be seen sooner. How do you feel about that?

Mandy: Quite similar to you actually. I think often people sense and you see this too. People with MS are very intuitive with their bodies, they are the experts on their bodies. They often sense when something's changing and when something is becoming more challenging even before their neurologist or their MS Provider recognizes that. So yes, I would encourage people to advocate for themselves, trust your discretion, and when your body feels different or when you find something more challenging, speak up and do not hesitate to ask for those referrals. I, too, would like to see people at diagnosis if possible or shortly after diagnosis. I think it is really valuable at diagnosis for the opportunity to have rehab provide education in addition to the education that they are receiving from their neurologist because to your point, Stephanie, they are looking at medication management. Their role is to really focus on halting that disease or slowing that disease whereas we are going to look at it differently, right? We are going to look at trying to keep them moving in the best way that they can and helping them to set themselves up for success in the future not just with their MS but their overall physical health and wellness. At diagnosis is ideal but that is not always the case, right? I think seeing people any time during the course of their disease is fine. Some folks we just see after relapse, some people we see we have prep of pre-scheduled opportunities just like you would with your neurologist or with a dental check-up even where you just come in for periodic tune-ups, the PT looks and evaluates how your movement in was with a couple of key outcome measures and we determine if there is been a significant change or if there are any challenges. Sometimes that leads to subsequent therapy, sometimes that leads to, "Hey,

you are doing a great job. Keep it up. We will see you in another six months to a year." It circles back to that theme of advocacy being your own advocate, making sure that you are getting the help that you need when you need it. So, yeah. I think it is important to make sure you just speak up. Speak up for your needs, and when you need help ask for that. I think we should talk a little bit about the ways that occupational therapy and physical therapy also support the support partner. I think in Can Do MS, we talked a lot about that the fact that MS affects everyone in the family and the closest loved ones. We actually had a participant at a recent program say that MS is not a me-disease, it is a we-disease. I think that that participant very succinctly described how we approach MS as an organization. Can you tell us a little bit about how OT supports the support partner?

Stephanie: Absolutely. The first thing that generally comes to mind, I think that most people would think of is if the support partner is helping physically with transfers or mobility and things like that. Educating the support partner on how to do those transfers or help with that mobility in the safest way possible to prevent injury to themselves. That is the first thing that usually comes to mind and a lot of times support partners did not have the training and they just slowly grew into this role of helping lift the wheelchair into the trunk and slowly their back is starting to hurt over time. That is definitely a huge area of focus when we work with support partners as well. But the other things to know is that our support partners are kind of our detectives. They are in there, they are the private eye kind of. They are in there and they are paying attention to the things that are changing. They often will notice things before the person with MS does and they can point out those small changes that they are seeing. Maybe the spasticity and one leg have gotten a little bit worse lately and they are noticing it during that car transfer. It is really important for us to be communicating with our support partners also so that we can find out the little things that are happening when we are not there. We only see them maybe an hour week if that. But the so the support partners are every day to see those little things that are happening that we do not see. Also, some support partners and this is not all, really love to help their loved ones, they really want to do everything for them and dote on them and let me help you with this, let me help with that. They are afraid that they are going to get hurt so we want to do everything for them which is a loving thing and it is usually, totally out of a good nature but sometimes it can take away a little bit of independence for that person with MS which can be frustrating. Educating that support partner on they are safe if they use adaptive equipment and letting them see therapy happen, letting them watch. They did this transfer with a sideboard and they did great in therapy. They can do it by themselves. Let them work on it because we also do not want that person to lose that strength or lose that skill. I think though there is this hope to be kind and good and helpful, sometimes it can be a little bit hindering so it is just important to educate them that this person can still be independent with these activities. Let them do it. Give them that autonomy and that feeling of, "I can do these things for myself still." I also find that a lot of times when I am trying to problem-solve something. There is a situation, for example, I had a client one time that had this bizarre shower, it was the weirdest shower I have ever seen. There was this glass wall of this built-in cherry, all kinds of funny stuff and I could not get tub transfer bench or a shower chair or anything in there but the support partner and I talked about it with the person with MS and we were able to gather as a team problem solved. How

could we modify it? What could we do? The support partner said. "Well, we can just take that glass wall down like that does come down. I do not mind doing that." They are also not just the detective but they are also finding out these ideas and these solutions to things with us. The more involved they are, I think the support partner can be able to almost do some of the things that we are doing but not have to see us. They might learn that natural problemsolving skills of, "Oh we can just modify this. We did not therapy a couple of weeks ago without having to call for help for this." So those are the areas I would say I focus the most on with my support partners.

Mandy: That is great. I feel similarly, actually. I know in Can Do programs, we do a lot as physical therapists to help support the support partners as well. I loved what you said about the kind of teaching communication on how to help, when to help more importantly because at the end of the day, the support partner, the rehab team PT, OT we all want the same thing, right? We all want the person living with MS to have the optimal independence safely and as often as they can. PT has a similar priority. We often will help with transfers, we will also teach them how to help properly with walking so that they are not jeopardizing their own safety so very similar to you. I would also add that early on in the disease when perhaps maybe there are not as many physical challenges and I bet you do this too, Stephanie. We do a lot of education.

Stephanie: Absolutely.

Mandy: The support partner being at those sessions with PT or OT is really important because we can educate on those invisible symptoms and give people a better understanding of what that might feel like because it is hard to explain, it is hard to convey to people that we love, challenges that they cannot see. So I think often having that collaboration with the rehab team and kind of that third-party if you will is really just helpful. At the end of the day, if someone listens to this and they are like, "Hey, I need Stephanie, but I do not live by her." What is the best way for someone to find an occupational therapist who understands MS?

Stephanie: Usually what I tell most people to do is to go to the National MS Society website and find the Navigator Program there. So, the MS Navigator,

you can call them and you can ask for help finding any resource you can imagine through them. They have great resources but you could say, "I need an OT who understands MS. Can find one in my area for me," and they will help you. Their website also has that same thing so if you go to their website, the National MS Society website, and then you go to the menu and click down into resources and support and there is a section called find doctors and resources. You can literally type in your zip code and it will pull up whatever practice you are looking for whatever type of therapy looking for, it will pull it up a huge list of who is in your area. So that is a great way to do it. There is also the American Occupational Therapy Association website as a search engine and there is also to be able to find an OT in your area. I know it matters what type of PT you get also. Can you explain its importance for someone to see a PT with experience with MS?

Mandy: Yeah. I agree it is challenging sometimes because no two people with MS presents exactly the same so having someone who understands that spectrum is really important. I would say it is important to make sure that you find that PT who understands MS for a couple of reasons. Because fatigue is one of those symptoms that is pretty widespread among folks living with MS, so someone say for example who does more Orthopedic faith-based physical therapy or sports physical therapy may not understand how that fatigue can present, how that fatigue can fluctuate between sessions and they may be more tempted to push and progress based on a protocol that is more traditional in Orthopedic type of care. I think that is one key difference when searching for a PT, make sure you have someone who understands that fatigue as well as that heat sensitivity. That is something else that is really unique to MS, how that can bring on symptoms present those pseudo exacerbations bring on symptoms. A PT without that understanding or OT without that understanding might be hesitant or may not know when to scale back or when to push so I think that is really important. But I also would argue and you maybe feel similarly, PTs with an understanding of MS, occupational therapists with understanding of MS were not everywhere. If you have a rehab professional that you are comfortable with, that you trust, that is interested in your care and is teachable and trainable and willing to have that dialogue, that is okay too. That is just as important because they can grow and learn with you about how to optimize your overall movement. So finding someone you trust is just as important I would argue.

Stephanie: Yeah, I would agree. I think actually that is where I was when I first started with MS. I remember my first client with MS came and I thought, "Oh my gosh. I do not have extensive training. I do not know all of the detail things." But I knew the basics and when you just think of the person as a whole and it helps you get through it. I would say now my treatment would be way more different than they were then but also the things that we did back then, we make huge changes in his life. So, yes. I think still finding an OT or a PT that is teachable that likes to learn exactly what it is, I think is they are willing to take in that information and learn it with you and help problem solve it with you because that Foundation of OT and PT the same is to understand the body figure out how to help that body and how to work in that environment with it. So, I agree.

Mandy: I think that summarizes why we like working in MS, right? We love the problem-solving spirit that our clients with MS have. We love the changing, the individuality of these folks but most of all I suspect you share this to that resilience and that determination is so respectful and amazing and it never gets old so it is such a privilege to work with this population.

Do you have any closing comments, Stephanie?

Stephanie: No, I think this is a great topic. I am so glad we get to share this information. It is a question I get very often so hopefully, it will clarify for a lot of people. But though we work separately, we work together. We do different things and work together so great. So, I love it. Thanks, Mandy for having me today and chatting with me. It was great.

Mandy: Thanks, Stephanie. It was a pleasure.

Host: Thank you so much, Mandy and Stephanie, for your incredible insight and thanks to our listeners for tuning in to this episode of the community conversations podcast series. We would also like to thank our sponsors Biogen, EMD Serono, Sanofi Genzyme, Celgene, Genentech, and Mallinckrodt Pharmaceuticals for making this series possible. Be sure to check out the other episodes in the community conversation series featuring more discussions between health care professionals. For additional resources, please visit www.cando-ms.org.

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