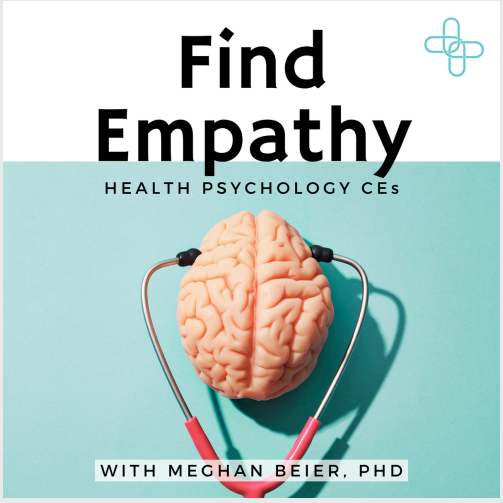
Find Empathy

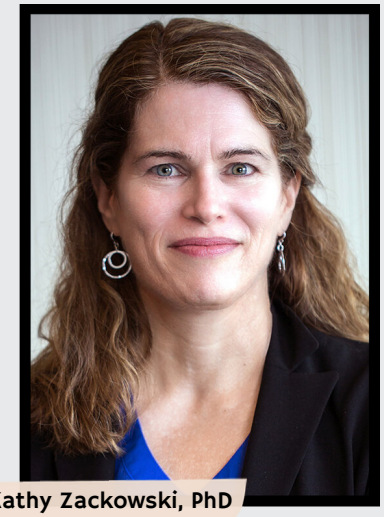
Multiple Sclerosis & Exercise

EPISODE 6



Meghan Beier, PhD

Daryl Kuchera



Kathy Zackowski, PhD

Peiting Lien, DPT

Course Objectives

Summarize the mental health benefits of physical activity and exercise in individuals with MS.

Identify at least two common barriers to exercise for individuals with MS, and strategies to help your patients overcome these barriers.

Identify at least one exercise strategy that can be used by individuals with Advanced MS.

Multiple Sclerosis & Exercise

[00:00:00]

[00:00:00] **Daryl Kucera:** I think the best experience, not only the education was having the MS itself, you know.

I am so blessed to have been diagnosed with MS, because I had the advantage of, like I said in 2001 to have the illness, but really didn't affect me too much. So when we started our program, I was still doing a lot of things, still walking, still jogging, still running. So I was able to work with individuals that are still able to do that today, but as the illness progressed and I went to a cane and went to a walker, and now we're into a power chair. It's great to identify with not only those individuals that are, in quotes, "high-performers" to also those that are in a power chair. Having that experience, not only knowledge from school, but also the knowledge of having the illness itself has made it very easy to adapt any type of MS that comes into our gym.

Introduction

[00:00:56] **Meghan Beier, PhD:** Welcome to the Find Empathy Podcast, where we discuss the interaction between health and emotions.

My name is Dr. Meghan Beier, and I'm a clinical psychologist with training in Health Psychology, Rehabilitation Psychology, and Neuropsychology. In this first series, we're going to focus on a population that I work with very closely, individuals and families living with multiple sclerosis.

If you would like continuing education credits for listening to this episode, please head over to findempathy.com/learn.

If you're a mental health provider that specializes in health populations, like multiple sclerosis, please, also head over to findempathy.com and click on, "Get Listed."

We would love to list your practice in our directory and being listed is free. We're trying to help families and people living with chronic or acute medical conditions find the providers that can help them most.

[00:01:59] **Meghan Beier, PhD:** Not long ago, people with MS were told to go home, rest, and not overexert themselves. Through the work of both patient advocates and exercise researchers, we now know this advice to go home and rest is not only wrong, but potentially harmful. Current data demonstrates that exercise and movement in people with MS is associated with improved cognition, mood, fatigue, and improved progression outcomes.

In this episode, you're going to hear from three wonderful experts: Daryl Kucera who runs an in-person and virtual gym called MS Forward, but also lives with MS. A physical therapist at Johns Hopkins named Peiting Lien, and the Associate Vice President for Research at the National MS Society Dr. Kathy Zackowski.

Each of the experts that you hear will share a unique perspective on the importance of exercise for people with multiple sclerosis, including: how to keep moving when living with MS, the benefits of physical therapy, and an overview of the latest and most important research.

One thing that I think is really unique about this episode is hearing about how to exercise in advanced MS.

We're going to start with Daryl Kuchera who runs an in-person and virtual gym called MS Forward.

Daryl Kucera

[00:03:17] **Meghan Beier, PhD:** Can you share a little bit about yourself, your name and your journey with MS?

[00:03:22] **Daryl Kucera:** You bet. Thank you, Meghan again for this opportunity. This is, this is sensational. My name is Daryl Kucera. K U C E R A is how you spell the last name and I'm actually located in Omaha. Nice, bright, sunny Omaha, Nebraska. It's about 60 degrees today. So it's great to be in the Midwest for sure.

So, my journey with MS started in 2001 is when I was diagnosed. Optic neuritis was my very first symptom. It was just, I think it's amazing how people remember the important things in their life, right? Their birthday and anniversary, if you're married you know, those types of things, but you also remember the day that your life changed and for me it was September 18th, 2001 at 10:10 in the morning. I think people that are listening to this, remember and identify with the very same thing.

[00:04:09] **Meghan Beier, PhD:** And at the time, you had started a gym or were planning to start a gym. Is that right?

[00:04:15] **Daryl Kucera:** Correct. It was really a calling. We felt and for the entire year for about a year up to that time we really wanted to train athletes. I had been an athlete through high school, through college. I've coached all the way through after the playing days were over and it was really to start a program to educate young adults the proper strength, training, plyometrics, stretching, speed training. And that's exactly how we started. So ironically, it was August 18th of 2001 was our first class that we had.

[00:04:45] **Meghan Beier, PhD:** How did that mission with your gym change after you were diagnosed with MS?

[00:04:52] **Daryl Kucera:** Exactly. And again, I think everybody here that's listening to this will identify with this, you know, you really have a choice, right? And it was a month to the [00:05:00] date that we opened the gym is when the optic neuritis started. So you have a choice, you can give in or you can pick the ball and run and we made the choice of continuing to go.

Once you're diagnosed, maybe right after that, it's pretty normal. The sight came back and things were kind of normal for a period of time. So we made the decision to continue going with the gym.

[00:05:21] **Meghan Beier, PhD:** But now you've shifted gears. You're still doing some of those first things that you described, but you're also working with people that have MS and chronic medical conditions too. Is that right?

[00:05:32] **Daryl Kucera:** That's exactly right. I had a pretty severe exacerbation in 2002, and, went through physical therapy, occupational therapy. And as I met with more of the therapists, it's their point was, why don't you think about doing this with your gym? And so we met with the MS Society, a group of neurologists here in Omaha, some physical therapists that knew about us. And we've modified our programs and started the programs with MS and chronic illness in May of 2003.

[00:06:04] **Meghan Beier, PhD:** And even before COVID you were offering classes that were virtual.

[00:06:09] **Daryl Kucera:** That's exactly right. And kind of the funny story with this, I was doing presentation in upper Wisconsin. It was an MS presentation, and there were probably 40 dairy farmers in this presentation. And we talked about the importance of movement and exercise and not only for the physical, but also for the emotional, mental. And, you know, their point was, Well, this is all great, but I live a hundred miles from Green Bay. I live a hundred miles from another place. Well, how do I get to a gym to do this? And so that really spurred on the idea of maybe we should start doing teleclasses and, and really draw in those individuals that are in upper Wisconsin, for instance to learn more about MS and have a exercise program. That's how it started.

[00:06:55] **Meghan Beier, PhD:** I can relate to that. My dad is a large animal veterinarian and he travels around to all different horse farms and cattle farms. People work long hours. They're getting up early, they're working all day. It's very difficult, for them to take the time to go to a gym. So this, seems like it would be very convenient.

[00:07:13] **Daryl Kucera:** You know, and that's really true, Meghan, I'm sure these guys are getting a lot of exercise managing cattle and what they're doing on their, on their acreage or their farms, but it's still different. It's so important to keep your shoulders strong, your back strong and your heart strong. And maybe you don't always get that in the day to day. So it's a nice compliment to your daily activities.

[00:07:33] **Meghan Beier, PhD:** I'm curious to learn how did you get the experience or the expertise to adapt exercises for people that have MS and other chronic illness?

[00:07:43] **Daryl Kucera:** Wonderful. So it's a combination of two things I believe. So first off, I am my thesis away from my masters in fitness, which is exactly like exercise science, but more of the focus is on program development. But the specialization is on that bridge between the hospital and life. So, the goal is once you leave the hospital, what can life-skills, lifestyle, what can exercise, nutrition possibly take away from some medicines that you're on. I got, got the bachelor's degree before we even started the program for that individuals with MS.

But I think the best experience, not only the education was having the MS itself, you know.

I am so blessed to have been diagnosed with MS, because I had the advantage of, like I said in 2001 to have the illness, but really didn't affect me too much. So when we started our program, I was still doing a lot of things, still walking, still jogging, still running. So I was able to work with individuals that are still able to do that today, but as the illness progressed and I went to a cane and went to a walker, and now we're into a power chair. It's great to identify with not only those individuals that are, in quotes, "high-performers" to also those that are in a power chair. Having that experience, not only knowledge from school, but also the knowledge of having the illness itself has made it very easy to adapt any type of MS that comes into our gym.

[00:09:16] **Meghan Beier, PhD:** Many times I'm working with people who may be using a power chair or may be using a walker. And some of the comments that I hear are things like, " I don't think I can do an exercise program." Have you heard similar comments and how do you respond?

[00:09:31] **Daryl Kucera:** Yeah, absolutely. Our motto is, you know, your body better than I ever will. So for some individuals, we have a structured program that we do. It's always trainer led, it's always structured. With some individuals respond great with the 20-minute workout, right. 20 minutes and they can sense the fatigue starting and so great. That's their workout. Some can go an hour. And it's interesting for those who are on disease modifying therapies. You know, maybe that next day you don't feel that great. So the next day you're still at the [00:10:00] gym, but you only work out for 20 minutes, but then another day of the week, you don't have those symptoms. So you work out for an hour. Every day is different so every workout is different. So you know, there may be five, six, seven, eight people in a class, but you're going to have your own unique workout based on how you feel that particular hour of that particular day.

[00:10:19] **Meghan Beier, PhD:** And what are some of the benefits that you see? Both physically and mentally when people are exercising regularly?

[00:10:27] **Daryl Kucera:** You bet, and certainly the physical, right? Cause we're going to work everything, we're going to work, like we always say, from toes to nose. I think a proper program isn't just repetitions and sets and stations, there's a lot of laughter in between. In between the sets individuals come early and they just laugh and talk to individuals, then they stay late, and I think so much of that, just that normalization again, impulse, normalization, just being able to do everything you used to do before.

So even though our program is designed around the physical component of exercise, you know, we will do a lot of things to, to work the mental. So for instance, if you are on a balance board, you're safe, there's a cage all around you, we will have you do multiplication or addition or subtraction, while you are balancing let's work the mind as well. So it works really well that way.

[00:11:22] **Meghan Beier, PhD:** That's wonderful. There's a few research studies that are coming to mind where they did that, where they had people exercise while also doing cognitive tasks. And it helped both their cognition and their physical functioning.

[00:11:35] **Daryl Kucera:** You are right on Meghan and I really believe that it does.

And, you know, you're balancing you go, okay, I'm working on balance, but it's amazing how you were working on your core, right. You're working on. Cause you have to stay on that balance apparatus, and your core gets engaged the entire time you're on there. You don't think about that. You think about balancing.

[00:11:52] **Meghan Beier, PhD:** And with your virtual classes, do you have that same sense of community where people are talking after the class?

[00:11:59] **Daryl Kucera:** Very much. So, you know, if the classes for instance, nine o'clock in the morning, people will log on at 8:45 and just talk. So when we get ready to start the class, the first thing we usually to have to do is, "okay, it's nine o'clock let's stop laughing."

We have multiple accounts so we can use them one account for nine o'clock. Then they can stay on and talk. And then and laugh and then we start the next class or the next account. So works really well. But I think that is, you know, if it's, if it's just a class. You know, and when I was in my twenties and things were great and asked you that works not wonderfully, but, you know, stop those, stop, go next station, that kind of thing.

But, you know, I think as you know, we, we get this till almost with MS and they, maybe you brought this up earlier before, you know, the pandemic has been going on for 13, 14 months now, just that laughter with people is so important, even if there's a screen in between you. I think it's so, so important. And so exercise is the driver, but the the joy and laughter and camaraderie is just as important, I think.

[00:12:58] **Meghan Beier, PhD:** Yeah, I can imagine. That's what keeps people coming back because sometimes it's hard to motivate yourself to exercise, but if you're going to be laughing and there's friends that are going to be looking out for you or asking, where you were, if you didn't come, those things are the things that keep people coming back.

[00:13:14] **Daryl Kucera:** You said it perfectly, Meghan is exactly right. And it holds people accountable. And that's exactly right. Why isn't Meghan from Baltimore on with us this morning and you will get a voice message or you look at a text and say, Meghan, you, okay? Things okay today? You kind of become part of a family that way. So you're exactly right.

[00:13:33] **Meghan Beier, PhD:** What are some of the biggest barriers that you see that stopped people from exercising or getting in the way of exercise?

[00:13:40] **Daryl Kucera:** Yeah, I think the biggest is just that, and I think it's true for everything in life. Meghan, if you lead with MS. It's always going to be difficult.

Right? Well, I have MS, so I can't if I have MS, so I can't. And I think that's the biggest barrier. It's amazing what you're going to be able to accomplish. And I think people think, well, I didn't really work out or exercise before I had MS, now you're adding MS to the plate. I'm never going to be able to do it.

So it's just that doubt that that self-doubt that you have, and maybe a little bit of fear, I think as well. And, and that's one thing we want to do is make them feel really comfortable. So, and I think a lot of people like me, for instance, I'm in a chair, so they go, well I can't work my heart. I can't get the cardio part of it.

And Oh my gosh, we can take it through, you can stay in your chair. We can box for five minutes. First of all, it's fun, but really your heart rate going or we'll do, people are familiar with the battle ropes. You see a lot at different shows now, and it's amazing how battle ropes will really get your heart going and work your core and work your shoulders and chest and back, and never have to leave your chair.

So I think it's. There's so many options that we can have that I don't think people know about to really get that benefit the physical, as [00:15:00] well as the like we said, the emotional, the mental, but part benefits, the cardio benefits out of everything that you do.

[00:15:05] **Meghan Beier, PhD:** I'm curious, we've talked about people with MS at the gym, but are other people coming to your gym as well? People without MS or chronic conditions? Support partners? Family members?

[00:15:13] **Daryl Kucera:** Great question. And yes, it started just with MS. And now we have many individuals that have Parkinson's and are sight impaired and have spinal cord injury.

So it's, it's really a facility now. We never want to say that we are a therapy facility. We are not, I am not a physical therapist by, by degree, by licensed, nor are trainers that we have. So it's really a post therapy program. So once they're done with physical occupational therapy, or sometimes when insurance says you're done, then they can come and continue a wellness program. And it's amazing how, you know, we, when you have individuals in the same class that have Parkinson's, or maybe some sight impairment or dementia or spinal cord injury, like we said, it's amazing how that bond comes together. It's about the individual, not about the illness and it's amazing how they learn from each other and how much they apply their lifestyles to somebody maybe with another illness.

So I think that's the great thing. We don't just want to say just because you have MS you can be here, but otherwise you can't.

[00:16:21] **Meghan Beier, PhD:** When you have bad days, your symptoms are flaring up or when you're feeling extra fatigued or maybe even if you have days where you don't feel as motivated, how, how have you worked through that for yourself?

[00:16:32] **Daryl Kucera:** Yeah. And it's very simple I always do is maybe. 15 minutes stretching program. That's all I use. What's not taxing, but it's stretch. It's it's, you know, you're stretching. So you're getting the oxygen and the blood flowing through your body and it just will make you feel better. It just automatically does.

So, you know, I'd really don't lift weights, those kinds of things, I just have a breathing and a stretching program and it really makes you feel better.

[00:16:59] **Meghan Beier, PhD:** And if I'm remembering correctly, you worked with the University of Nebraska on a few research studies?

[00:17:05] **Daryl Kucera:** Well, you have a great memory and did studies with the University of Nebraska medical center. The first was really just to prove that

individuals with multiple sclerosis can have the strength, same strength curves as those that don't. And we proved it. It was through a six-month study with 63 individuals.

And yeah, we proved that people can make the same gains. On a structured program, I guess those that do not have multiple sclerosis, one area that wasn't, that was, we didn't have the same gains with your core. And I think that may be it, maybe the illness, it maybe because we're aging one day at a time. You don't have that core strength that you did maybe when you're in your twenties. So that was the first study that we did. So we proved that and the second was Another study that proved that an exercise program can help the mental cognition as much as the physical.

So we proved again, six month study, we had 47 individuals and people made between a 40 and 60% gain on cognition through an exercise program. So that was really, really an encouraging, encouraging program.

[00:18:17] **Meghan Beier, PhD:** That's wonderful. I looked at your website, before we talked and you also have not only exercise classes, but you have some cognitive rehab classes going at your gym as well. Can you talk about that?

[00:18:30] **Daryl Kucera:** Thank you. And we have, it's another individual. It's not myself, but it's another individual first name's Amy, that worked with individuals with Parkinson's for probably 27 years, cognition classes and speech classes is what she really works on. We have an individual here at the gym that when she started our gym, she didn't say a word. She did not talk. And some of it was just fear and just, she had done for a long time. And then she went, her next stage was kind of looking at her husband. To make sure that, you know, it's okay. When she said her husband kind of answered the question and now, I mean this in a nice way, when I say this, we can't keep her quiet, it's just, it's wonderful to see. If you, if you put the time in the results are wonderful, regardless of where you are. I mean, we, we have an individual here that is an amputee. We have an individual, that's a quadriplegic.

And, you know, so really the movement is really probably chest and up. That's all he can do, but it's amazing how people can improve their lives with the program, with people that care. And everybody that comes to our gym, whether it's tele teleprogram or the in-person program. We absolutely love you guys because you're putting in the effort to make yourselves better. So let's work let's work through this together.

[00:19:48] **Meghan Beier, PhD:** It sounds like you've seen some really amazing transformations in the people who come to your gym.

[00:19:53] **Daryl Kucera:** Yes. We talked about the young lady that she's talking all the time, that's wonderful. But you know, individuals that [00:20:00] came in with being pushed in a chair are now walking and doing different movements. Like a sit to stand type movement or, or doing ropes where they started out 30 seconds, but the battle ropes, 30 seconds and they were exhausted and now they're doing 8 minutes without stopping.

Even for me, I have one really good appendage, which is my left arm, but it's amazing just with that one hour, I can really get my heart rate going and I can really feel great about what I'm doing and I can accomplish a lot. And so even if we always say let's strengthen what remains right.

As strength remains, if it's a wrist and a hand, we're going to work that to make it also work your limbs in your heart as well. We started talking about the pandemic. Unfortunately in this world that we live in, there's always going to be the next virus. There's always going to be bacteria germs, there's flus, there's colds. So, if we can keep our lungs and our heart and our muscles strong, we have a great chance of fighting, fighting that off. If the next one comes around again.

And that's the big thing that this is, this is a lifestyle decision.

[00:21:03] **Meghan Beier, PhD:** I'm curious if you have any new programs that you're working on or anything that's underway that you wanted to share or talk about.

[00:21:11] **Daryl Kucera:** Thank you. Yeah, we we've entered a partnership with the University of Nebraska Lincoln, Go Big Red! If you guys are anybody in Nebraska, out there on the East coast, but the final year medical engineers are, for part of their capstone project, are building four pieces of therapy equipment for us. So the first is a, a leg press leg, press machine. It is all pneumatically driven, which means there's no pins that you change, the no plates that you put on. It's all driven by hydraulics. All you do is set a dial and that's what the spring resistance is going to be. That's number one. And the nice thing is you don't have to transfer to a chair, you just take your chair, drive it up to it, and you're ready to go.

And the second is a cardiovascular machine, similar to a new step. If you guys are familiar with new steps again, it does not require a transfer. If you're in your

own power chair, you come right into it, your legs go into an elliptical apparatus or otherwise it's more of ergometer apparatus. Number three has a hip rotation where, you know, again, we don't get a chance to. You know, kick and kick out and kick forward and kick back. Like we used to do, maybe when we were younger, this apparatus allows you to do that. So again, you drive your chair right up to it. You don't have to transfer your legs, go onto a plate, and depending on the direction you want, you can go as far around the world each way as you want it forward back. So again, it's really work, work in the hip flexors and areas that we don't get to do if we're not walking that much anymore. And the last is just a stretching machine. So it's a elevated stretching platform with at the end, there's a hip abductor and adduction machine. So abduction, you're moving your legs out. Adduction. You're moving your legs in.

So it's really allows us to get more into the therapy portion of the strength training.

[00:23:07] **Meghan Beier, PhD:** There's tons of resources in your gym, but what kind of resources do you like to share with others?

[00:23:15] **Daryl Kucera:** Yeah, you know, there is, you know, again, the MS society has a wealth of resources. But we have a program called an open gym. We have an hour during the day where we just talk, answer questions, talk if people have specific questions, we could just talk about it. We just want to be that resource. If we can't provide the program, at least we know exactly where to send you to get the information.

[00:23:38] **Meghan Beier, PhD:** If people want to find your gym follow the work that you're doing, what's your website, where can people find you on social media?

[00:23:45] **Daryl Kucera:** Wonderful. M S forward that's the name of our gym, www.msforward.org, is our website. And there's a lot of information on that. I'll show my age when I say this, but, you know, there's things with blogs and the things with social media that I'm not smart enough yet to really all understand it, but that's all available through our new website.

And one of the greatest resources is our members. They have lived with MS for a long period of time. They have had the disappointments, but they've also had the victories. And I think by being in contact with each other that gives everybody a purpose. You know, I think if every day, you can do something to make somebody's life better, that's a great MS treatment, in my mind.

You know, John Wooden used to coach UCLA basketball was a 10 time NCAA basketball champion in the sixties and seventies and he had a quote that said, "You cannot live a perfect day without doing something for someone who will never be able to repay you." And that's, I think that's so sums things up.

You brought up the question, what if you're not feeling that great, what if it's just an off day and your fatigue and those types of things, what really works for me personally is just sending a word of [00:25:00] encouragement to a friend.

It may be there's so many social media it's now there's texting there's emails. Just sent a note of, "Hey, just thinking about you today" and that will just mentally and cognitively and psychologically make your day better. Making somebody else's day better will make your day better as well.

[00:25:20] **Meghan Beier, PhD:** Thank you so much for all your words of wisdom for sharing this information and for taking the time to talk with me.

[00:25:26] **Daryl Kucera:** Meghan. I'm very humbled that you asked me to do this, so I appreciate that time and God bless everybody.

Peiting Lien

[00:25:32] **Meghan Beier, PhD:** Now that you've heard from Daryl and his experience, both as a person, living with multiple sclerosis, as well as someone involved in motivating others to stay active, we will turn to hearing from Peiting Lien, a physical therapist at Johns Hopkins.

Peiting discusses when to think about referring your client to a physical therapist, why she advocates for addressing mental health concerns, as well as steps for goal setting.

[00:25:57] **Peiting Lien:** Well, thank you so much for inviting me and having me on. My name is Peiting Lien. I'm a clinical specialist. I'm a board certified, neuro clinical specialist here at Hopkins.

I think my special interest working with persons with MS started all the way back in college days, that feels forever ago, but I can still very vividly remember my very first patient with MS.

It was during my clinical rotation. I just remember going in there every day thinking, am I really helping this gentleman here? And. Yet he taught me a very

important lesson that today I'm forever grateful for is that it was very humbling, but yeah, it was very powerful that even though it may seem like nothing, all I did every day was going in there and stretching him before that nursing staff could help him get out of bed.

He let me know that those stretches made a big difference in how he felt and how he was able to move and get on with his day. And so it really wasn't until I moved to start working here at Hopkins, about 11 years ago, I started to get to work more with patients with MS. And I'm located in the outpatient setting.

So I get the privilege of working with those that are within the community that are still ambulatory. They can come see me. But that's really run the gamut of those that are so young and working and busy with families all the way through to those that are retired. But are actually really just having to deal with the effects of aging. Like all of us.

[00:27:28] **Meghan Beier, PhD:** What are some of the most common reasons that people with MS come to see you or would come to see a physical therapist?

[00:27:37] **Peiting Lien:** I would say the most common reason that I specifically get is a main challenge or complaint of having difficulty walking and specifically of dealing with foot drops and tripping.

And a lot of times that they also have noticed that they're having more frequent falls or near falls and are losing their balance a lot quicker than they used to be. or they just in general have a harder time getting around. And they may note this as in, they can't keep up with their family or kids or just doing their day-to-day activities.

[00:28:16] **Meghan Beier, PhD:** And are there other reasons that people with MS come to see physical therapy and some of the things that I'm thinking of off the top of my head are maybe vestibular issues or sometimes I'm hearing from patients that they're seeing physical therapy for pelvic floor exercises.

[00:28:35] **Peiting Lien:** A lot of times the vestibular issues are really triggering well, yeah. Basically more due to balance and feeling dizzy or off. A lot of times bowel and bladder issues are very common with people with MS. So a lot of times they do seek out pelvic floor therapy to help them with those symptoms.

So yes, I also get some. Patients come through and say I've been working out, but I'm much, much more fatigued after I work out. And so they actually are

seeking out for better ways of how to handle and manage their overall day to day physical activities as well.

[00:29:17] **Meghan Beier, PhD:** Okay. That's very helpful. And in what ways do physical therapists help with symptoms like fatigue or like even chronic pain?

[00:29:25] **Peiting Lien:** I think fatigue is a very big topic for patients with MS. And it impacts each, every one of them in a very specific or different way.

So a lot of times we dive in a little bit to try to tease out what is the cause of this fatigue. If this fatigue is really because from. The physical activity standpoint, the physical component of things, then that is totally up our alley of trying to teach. Is it from stiffness? Is it from difficulty moving around?

And so then if that's the case, then we really [00:30:00] try to tease out what exactly is causing such difficulty and challenge in moving and getting around which that might be stretches that might be strengthening exercises. But if the fatigue is, could go the opposite direction too, like some people are very gung-ho about getting everything done in a day.

And so sometimes I end up having to really talk through like, how do you manage a day and what are some strategies that we may have to incorporate? So that the battery remains at a decent level instead of crashing and burning. And then basically they're laid up for the rest of the week after a big day of doing all the activities without pacing.

So you also mentioned about chronic pain and Chronic pain can be in two categories. One is more based upon the pathology of MS, which is impacting on the brain side of things. And that definitely, we work closely with the other health providers their neurologist, their primary care, but really for PT standpoint, we're really trying to address that the chronic pain that may be contributed or caused by more of the musculoskeletal aspects of it. And again, it could very well be spasticity increase in tone, which causes increase in stiffness and then joint pain. So then we can definitely help and manage that.

It could also be from weakness where basically that changing the way we're walking. So we're doing all these compensatory strategies, which then causes more of discomfort, whether it's hip pain, knee pain, or back pain, and for all of those physical therapy can definitely help and address.

[00:31:45] **Meghan Beier, PhD:** That's really helpful. I'm actually working with somebody right now. Who I think saw physical therapy because she was having knee pain and she was doing, you probably know the term for it. I don't as a mental health provider, but her legs swings out to the side rather than a typical walk, which was giving her a lot of hip pain.

[00:32:06] **Peiting Lien:** Yes, absolutely. I think our bodies are amazing and we're designed to move in a very efficient way, but we also know Oh, if this isn't going to clear my foot and because I have weakness, I can't clear my foot. I'm going to slip, stub my toe, our bodies, it's like amazing, to figure another way out to get the tasks done.

Now, whether that's the best optimal way of moving or not is yet to be said, and which then can cause that pain that you're referring to Meghan about that hip pain and a lot of times even back pain.

[00:32:39] **Meghan Beier, PhD:** Interesting. I have another question here. I typically work with people who have concerns about using assistive devices. They're either very embarrassed to use them or , they feel like they're not quite ready, or they feel like they're giving into MS if they're using an assistive device. And I've heard from other physical therapists that sometimes that can actually help with fatigue or can help reduce pain or have actually increase mobility. So I'm just wondering your perspective, or if you have any thoughts about use of mobility aids for people who are having those difficulties with walking or foot drop or any other reason?

[00:33:17] **Peiting Lien:** Yes, absolutely. A lot of times I really do think that it is someone's choice of what they want to use.

We can make the recommendations earlier days. That will be much stronger, but now I've learned that that they probably choose or. A patient with MS. Choose to move a certain way for a certain reason. And just for the reason that you've explained that whether it's the cumbersomeness of it or that how other people perceive or giving into MS.

Those are all really valid. And w what I try to present to the patients is that. At the end of the day, what is the goal we're trying to achieve? And let them decide that's for them to decide if the goal is to be able to participate with the activity with the family without feeling so tired, even though you walk from here to there without any assistive device, but you're so tired and you can't even participate, is it really well worth it?

Or. Could we try something so that you get to use it. And so that you get to participate with the activities with the family, which is probably the ultimate thing that you set out to do anyway. So when I presented that way to my patients, they're a little bit more willing and open to that. The thought of maybe, Hey.

Yeah. Yeah. What is the end result I'm trying to achieve? Am I trying to prove that I can walk without any it just the device and then not able to participate or is it truly that I want to participate and that's more important to me. So I think trying to like dialogue with the patient of what is it that's really meaningful to them makes a big difference as to what they [00:35:00] would like to use. And sometimes it just, for them, they're just not ready. And it is okay. However, if it is a safety component or safety concern, then the dialogue might be a little bit more firm. I always say that one too many falls is one too many falls, and there's a switch that you wouldn't know, whether you start losing your confidence. And then things starts to go downhill from there. Or you fell and you broke something and that really lays you back and ties you, pulled you back. Presenting it in that frame, like they're more willing to also to see the bigger picture. And then again, they decide.

[00:35:40] **Meghan Beier, PhD:** I love that because you validate what people's concerns are or you really hear where they are and then meet them where they are and you make a decision together in terms of whether that's the right fit for them. And also whether it matches their goals, right? Because so some people, their goal might be to be as independent without any assistive device. And so then meeting them at that goal is very different than meeting somebody whose goal who wants to have as much energy as possible so they can participate in an activity.

And in terms of that, I think there are a lot of overlaps, or I guess there's a lot of complimentary things that happen between physical therapy and mental health providers. So what you just described to me sounds very much like you're meeting the person where they're at, you're trying to understand what motivates them.

And then figure out a shared goal to work on. And many times I think mental health providers do similar things not necessarily always with physical symptoms, but in what ways have you found it helpful to collaborate with a mental health provider? In terms of working with people that have MS.

[00:36:51] **Peiting Lien:** Over the years, I have found it extremely helpful to have a mental health provider on the team. And I keep referring to this almost

like it's teamwork. I only get a sliver of this, that I focus on the physical component, but I tell my patients all the time you have an Olympian, who's going to compete in the Olympics they have a whole team behind them. So why shouldn't you? So essentially I think a lot of times it is really difficult for someone to process what's going on with their life after receiving a diagnosis with MS. And then also just as life comes on, and then there's a lot of challenges and I always tell them it's really much nicer to have more tools in your toolbox to be able to deal with life.

Some of my patients have challenges with significant depression, anxiety and then difficulty in managing their stress, which all of those will then exacerbate their MS symptoms.

So having a mental health provider on the team basically can help address those and provide specific strategies. And that, that will allow the patient to have some more capacity to then participate in the physical sense. And so a lot of times we might dialogue, like what are some of the things that they've provided you as a strategy and how can we then integrate it into your physical activities? We can't separate the brain and the body. So in a lot of ways it's such a team approach to treat the whole person.

[00:38:20] **Meghan Beier, PhD:** Yeah. Yeah, absolutely. I know many times for me, it's so helpful to have a physical therapist on the team because if somebody is describing to me, concerns about falling or fears about falling or how to get back into exercise. I can address maybe the anxiety part of it, but I also want to know that they're safe before I'm telling them to go and try something.

Having somebody be evaluated by physical therapy or give safe exercises or teach somebody how to do something safely can be really effective and helpful.

Are there other reasons that you think a mental health provider should refer somebody to physical therapy?

[00:39:01] **Peiting Lien:** If your client comes to you and is sharing with you about their frequent falls or they're tripping, and they're really kind of just brushing it off and not really paying attention to that, and just thought, thinks that's just part of my day to day that shouldn't be the new norm.

And that will be a nice sort of a hint to say, Hey, maybe you want to consult a physical therapist to see if we can make that a little bit better. So that safety aspect of things I think will be very helpful. If someone also maybe verbalizing

that there. they're working really hard. And yet that's really impacting the rest of their day in terms of getting things done or just super fatigued.

And that makes them more tired at the end of the day. I think that's also a nice time point and be like, Hey, would you like to consult with a PT and see if there's a better way of managing your day-to-day fatigue? Because a lot of times I think that can [00:40:00] very well be because a physical tightness or stiffness or barrier basically contributing to the fatigue or that that there's maybe a better way of managing that.

[00:40:11] **Meghan Beier, PhD:** And I know, I think we all know that with insurance , there's a limited number of physical therapy sessions. So even when people really benefit from physical therapy, it's not indefinite. So do you have any suggestions for how How someone can maintain their gains, or even if they're working with a mental health provider ongoing how that mental health provider can sort of support the motivation to maintain physical therapy gains?

[00:40:38] **Peiting Lien:** Yeah, that's a wonderful question because we're always concerned about insurance coverage and this is an ongoing process. Not one of those done and done type of a deal. And so I have a lot of patients that I get to see throughout the years. And what we do is we just do touch points. And so every year they need, as they call it, tune-ups they might reach out and then come and see me for an evaluation to see if we need to update their plan of care or new exercises or any new things that's bothering them.

But also that then The ownership is on them to continue on with it. And just like you said, about the consistency of continuing on with the activities after physical therapy.

So one thing I think is really helpful to collaborate with a mental health provider is basically setting goals to see how, what is that patient's specific goal. And I always find that even As an athlete, I hate going to work out without like actual goal in mind as in if there is like a trip coming up or something and I always tell my patients. I'm like, nobody really likes to exercise for the sake of exercise. They tell you it's so good for you. I get it.

We need to have a frame around, like, why would we do this? So what is the real why? And I think exploring that with a mental health provider also is very helpful and just keeping it very real, did make them feel better, did make a big difference. I think that makes them want to do the exercises. There's like thousands and thousands of exercises.

And they're basically saying I'm spending forever. That's my full-time job. I think that's also not. And so I'm coming. Together and formulating a workable realistic activity plan is invaluable. So I think the mental health provider can also come in at that point to set some specific goals too, with them will be very helpful.

[00:42:40] **Meghan Beier, PhD:** It's interesting that you said a trip because I, I literally was just talking to somebody the other day, who is planning a trip to Europe with her significant other, and had talked about worrying about the increased amount of walking that she was going to do and how that would affect her.

And one of the things we talked about was going to physical therapy, or maybe getting an evaluation with physical therapy so that they could give her sort of a pre-trip ramp up, or how to get ready for that trip so that she would have either ways to manage her spasticity while walking or even increasing her stamina.

What are your thoughts about that?

[00:43:19] **Peiting Lien:** Yeah, absolutely. I think that's a wonderful way of getting some one increasing their physical activity, but with a wonderful goal in mind. But I also have to remind, remind a lot of my patients like. You don't really just go from the couch and start running a marathon and expect yourself to survive a marathon.

So in a lot of ways, this is very similar. It could also be very simplistic as in you don't expect yourself for not being sore, doing all weekend of yard work when you haven't done yard work in forever. So it's, it's very similar. So I'm having basically a physical therapist come in before your trip and really guide you through that progression will be very invaluable.

And a lot of times it really helps you to then enjoy the trip and having gotten ready for that versus just be like, Oh, I'm on this trip. And all these things came up and it really wasn't, you weren't able to enjoy their trip because we didn't really plan for that physically. And that sometimes then robs the joy of the actual trip.

[00:44:28] **Meghan Beier, PhD:** I wanted to ask a little bit more about exercise outside of physical therapy. Your physical therapy office is housed within a gym.

[00:44:37] **Peiting Lien:** That's correct. Yeah.

[00:44:38] **Meghan Beier, PhD:** Is there a transition for your patients from physical therapy into working with trainers at the gym, or just getting them used to using the gym equipment so that they can have that seamless transition out of physical therapy?

[00:44:53] **Peiting Lien:** Yes. So right here at this facility, they have a very specific and special program [00:45:00] called a prep program, which is short for physician referred exercise program.

So they have staff on site who's a PT assistant / nurse. And who would take someone through the exercise equipment, but a lot of times, if we know like a patient is interested in continuing on the physical activity in the gym, we try to like link them up with a personal trainer that they then have a familiar face and then can actually then transition into that.

For those that don't live nearby as I have a lot of patients that don't live near this community. I really try to encourage them to seek out whether it's a support group, whether it's like an exercise program yoga, Tai Chi classes, or if they have the means and the finances definitely set them up with a personal trainer.

So I really think again, back to that team approach it really takes that team to come together and really help and allow this person with MS to live life, to its fullest. And whether that means that meeting with a personal trainer one-on-one, a nutritionist or whoever. You want to get that team together to provide that support is invaluable.

[00:46:13] **Meghan Beier, PhD:** I really appreciate the time and energy you put into having this conversation with me. Any final thoughts or anything that I didn't ask you that you think would be helpful for mental health providers to know?

[00:46:25] **Peiting Lien:** I think for any mental health provider that is seeking for a physical therapy practice that actually specializes in neurological practice. One website that's really helpful is the APTA, which is the American physical therapy association website, which has a link that says, "find a PT" and you would actually then also click on a neuro specialist in, in the filter, so that the patient is able to see someone who specializes in neurological conditions and not just. Someone else that maybe seeing other specialties. Similarly, if someone is complaining about bowel and bladder issues, there's also a radio button in there that says pelvic health specialist.

Kathy Zackowski, PhD, OTR

[00:47:11] **Meghan Beier, PhD:** Finally we hear from Dr. Kathy Zackowski. She is the Associate Vice President for Research at the National MS Society. And she was previously a research faculty member at Johns Hopkins. She will talk about some of the literature and research that supports physical activity and people living with MS as well as ways to incorporate movement, even for people with advanced MS or significant physical disabilities. Finally, she also share some resources for physical activity and movement.

[00:47:43] **Meghan Beier, PhD (2):** Kathy begins by describing her background.

[00:47:45] **Kathy Zackowski, PhD, OTR:** I have, kind of a, varied background. So I also am an occupational therapist and, treated people with MS for about 15 years. I also, had a laboratory and was on faculty at Johns Hopkins School of Medicine, which is why I met you, Meghan.

And there, um, my work was really focused on trying to better understand, walking and balance, and difficulties with that due to chronic conditions like MS. I also have a master's degree in exercise physiology. Through this sort of those three kind of areas, neuroscience, OT, and exercise physiology, I've always had kind of a special place in my heart for the importance of exercise.

And so I've, I've read a lot of material around this and in my new role at the National MS Society, I'm really, we have a wellness working group of individuals that are specifically interested in exercise and physical activity. And these are researchers. And the idea is what do we, you know, what do we need to be studying to better understand the importance of this very specific kind of activity? So, you know, I think there's lots of new information out there that I haven't been shared.

[00:48:57] **Meghan Beier, PhD:** That's great. And because of your background in so many different areas, I was really excited that you were part of this. A while ago, a few years ago, when we were both at Johns Hopkins, when you were at Johns Hopkins, you gave a talk and I think you started that talk with a quote from maybe it was a researcher from NIH, and it said something to the effect of if there ever was a magic pill, that exercise would be that, and I'm probably getting that quote wrong, but I wondered if you could expand on that, on that quote? What makes exercise so important? What makes it that kind of magic pill?

[00:49:31] **Kathy Zackowski, PhD, OTR:** Yeah. I remember I do use that a lot and I don't remember who I stole that from, but it wasn't, it wasn't from me, but I really liked the analogy. Because, I think one thing that each of us can do to manage our health is to exercise and, and with MS this becomes even more important, right? Because people with MS have symptoms that vary and the symptoms that disrupts what they want to be doing with their life.

And so anything that people can do for themselves [00:50:00] outside of pharmacologic interventions is really empowering to them. Right. So I'm not saying don't take your disease modifying therapies, but I'm saying exercise, in combination, has a lot of benefits for people. So even if you just think, you know, it's physiologically, it increases circulation brings oxygen to the brain strengthens muscles.

So there's that avenue, the importance of exercise, but it also impacts people mentally right. Improves depression. It's shown to improve anxiety. It improves fatigue, balance, quality of life. It really just affects so many different facets of our lives, but it just seems, like a really important, piece to not forget.

And unfortunately, people with MS aren't active enough. So it's a really important thing to emphasize to people, but there's a lot to gain by exercising and, and there's definitely more to lose by being more sedentary. So my new, my new quote that I've been using, you know, maybe a pill, isn't the right analogy because it's more work. Exercise is more work than taking a pill and our society pushes this idea of, we want something to fix it. And exercise definitely takes effort and planning. But the new quote that I use is that sitting is the new smoking.

[00:51:17] **Meghan Beier, PhD:** Mm.

[00:51:17] **Kathy Zackowski, PhD, OTR:** So the same idea, like we need to be up and stay active because just as we know how bad smoking is for us, we know now that smoking in particular is really bad for MS, but also it, this idea that we're staying sedentary, is way, way too much is sort of gaining more and more traction.

[00:51:37] **Meghan Beier, PhD:** Well, and I know, as a mental health provider, I've seen some data looking at that connection between exercise and mood. But as you mentioned, exercise can impact a lot of different MS outcomes, or at least there's a correlation between exercise and a lot of different MS outcomes. So can you, broad strokes, talk a little bit about what does research tell us about

exercise and some of these things that people might be thinking about when they come into a mental health providers office?

[00:52:08] **Kathy Zackowski, PhD, OTR:** Sure. There's pretty convincing evidence that exercise can improve symptoms of MS. And so if, walking is often a really important goal for people with MS. And, walking is so important to everyone's independence. Um, so there have been quite a few studies that have really looked at the importance of exercise and physical activity.

And so one thing to keep in mind is that exercise is something you do, has repetition and you have a goal with it.

Physical activity is something that you do every day around the house, with your job, anything that raises your heart rate. And so the research is really saying that you need to have, participate in 150 minutes per week or more of exercise and, or 150 minutes per week or more of lifestyle physical activity.

So the important thing I would, I guess I would emphasize is that. This is exercise or physical activity can improve other symptoms that are really bothering people, whether they're physical symptoms like walking and balance, or whether are symptoms like, related to cognition, like memory or depression or anxiety.

But a critical element that I get a lot in the clinic, is that, you know, I don't really know where to start. So I want to exercise. I don't really know what to do. So as a mental health provider, one thing you could encourage people to do is just start slowly and gradually progress. So really use your own common sense.

Just you want to be active. And so what feels comfortable and interesting to you? That's the kind of exercise or physical activities you should be doing. It needs to be based on, you know, what your ability is, what your preferences are and how you can do it.

[00:53:48] **Meghan Beier, PhD:** I have a follow-up question that wasn't on the questions I sent you earlier, but I want to ask your opinion as both a clinician and a researcher. One thing that I come across a lot with people is that they either want to: dive into exercise to quote unquote, make themselves better, or keep themselves strong or keep themselves from progressing or, they want to use a tool, or they see using a tool to help them be more functional as, "giving up."

So if I, I will only use that tool if I do 10 weeks of exercise and don't see any benefits. I know I didn't ask you to think about this ahead of time, but do you have any thoughts about balancing that, using tools like, using a wheelchair, or using a walker as a functional tool to keep somebody more active and also engaging in exercise?

[00:54:44] **Kathy Zackowski, PhD, OTR:** Yeah, it's a really important point that I think, unfortunately, our society, again, really makes people feel like using a tool is a crutch. And that's really very it's. I don't think that's very true. If you think about [00:55:00] someone who wants to, who doesn't have MS and wants to go running, they have the choice to go outside or they can use the treadmill.

That's a tool that allows them to exercise. So what I emphasize to my patients a lot is, you, you can use these tools to give you the independence and freedom to exercise. So maybe use your walker when you're walking outside for exercise, because that way you can probably go a little further. Safely. Right.

And you don't have to worry about falling because really the last thing you want to be worried about when you're exercising is the safety hazards, right? And so tripping or falling, or just feeling too tired and not knowing where you're going to sit down is stressful. And so that way you're not really able to push yourself to get the benefits of exercise.

Whereas for example, if you can walk with your walker, and your walker has that little seat attached to it. Now you're carrying your seats so you can push yourself to make, you can make a goal for your exercise. Stop, put the brakes on and sit down and, and, and rejuvenate so that you can get your, so that you can turn around and come back, but you might be able to actually exercise more.

And, and, and so, you know, when you exercise more, you, you can gain strength and endurance, and this can allow you to be more functional. So I would just encourage people that the tools you use, everybody uses tools to exercise. It just might look different for someone with MS. Instead of using the treadmill, they are going to use their walker, or even, even if they can't exercise, they can't walk very much, even if they can move their wheelchair by manually using their arms for a certain distance. That's a great way to get some benefits. So you want to raise your heart rate. You want to use your arms so that you can get stronger, and this allows you to do it safely. So even if you don't always use your wa your wheelchair, maybe just use your wheelchair for exercise, because again, it gives you that freedom to push yourself a little bit more. Is that kind of what you were getting at?

[00:56:58] **Meghan Beier, PhD:** Absolutely. Yeah, I love, I love those examples and, and that is something that I also talked to people about is, that these tools are here to benefit you. They're not here to hold you back and they don't mean that you're giving up and that if we can. These tools to widen our world then, that means that you maybe could be more engaged even after a bout of exercise where you feel a little bit more fatigued. Maybe you can use the tool afterwards so that you can put your energy into exercise, something like that.

[00:57:26] **Kathy Zackowski, PhD, OTR:** Yeah, exactly. And I also use this analogy of the amount of energy that each of us. And I've noticed it more that even as I age that I have a certain amount of energy and I am a morning person, so I have a lot more energy in the morning. But as the day is I go through my day, I have less energy. So figuring it out for yourself. When do you have the most energy? And can I exercise during those times? So that I can get my, I have, motivation to push myself.

And then, I, as you exercise over a weeks, you will notice that your endurance changes so that you will have more energy for longer. So initially when you start exercising, I think you will feel more fatigued, but, but that isn't, you know, if you can persevere and get through a few weeks of exercise, you can see the benefits of that.

[00:58:13] **Meghan Beier, PhD:** Right. Well, I think you've highlighted a couple of different things that might be barriers that get in the way of exercise. So fatigue might be one of them, maybe even physical functioning might get in the way. Are there other barriers that you commonly hear of that get in the way of exercise?

[00:58:30] **Kathy Zackowski, PhD, OTR:** Yeah. You know, I mean with COVID right. A big barrier is that, I can't go to the gym now I have to do something at home. So your physical environment is a, a really important, thing that considering is often considered a barrier. And you know, there are ways to, instead of trying to get to the gym, you could try to, um, use equipment at your home.

There are, there are always solutions. I guess that might be the first thing I mentioned is that if you see a barrier. Think about what a solution could be. And if you can't think of anything, talk to people around you. Cause I think support, you, as a mental health provider might be able to offer some help and just problem solving, or you know, someone in their family could, or, you know, there, there are different ways to, there are different solutions for the many barriers that exist, outside of, just, where you're going to exercise, it could

be, you know, that socially you have barriers. So you have limited support from family members. This might be something for sure a health care provider would, could hear about. So are there, other, peer support coaches or programs that you could be involved in that would, that would ma you know, build up that social environment so that you, could, could, get yourself to be more active in, in different ways?

Are there other barriers that I find a lot is fear? You know, I have an exercise in a long time. I used to be really active in high school, but now, you know, it's 20 years later and I don't even know if I, if I feel like I can do that. So that apprehension that [01:00:00] comes with, you know, having a condition that, you know, makes moving difficult and also just with age, but, it's really important to you start small and set really small goals so that you can feel accomplished. And that, you know, that helps people, have those choices helps them feel empowered to do more. And then when they're successful, then people often are like, wow. I, I, I, I think I can do a little bit more. Right. And so it gives you a little bit more, energy to, to try.

Other things that I've found that works is to keep a diary of how you feel after you exercise even just a little bit, just to, because you won't remember that a week ago, you felt terrible when you exercise and now it's not quite as bad, but you forget some of those subtleties. If you don't write things down.

[01:00:46] **Meghan Beier, PhD:** Yeah. I love that. You brought up the small goals and there's a researcher out at Stanford named BJ Fogg who talks about doing tiny habits, so very small goals. So I love that you brought that up. It's something, I talk about a lot with my patients. And also sort of tracking how it's going, because that can be a huge motivator for people.

[01:01:05] **Kathy Zackowski, PhD, OTR:** I think also people tend to think, you know, we don't, I don't have time to exercise and. not saying everyone has a lot of time. And, I know we all struggle with it, but this perceived lack of time is really a big barrier. So laying out your schedule and trying to think about where do I have some flexibility?

Because again, you don't, I'm, you know, I'm recommending, the society and know. Or the researchers are recommending 150 minutes per week. And some people are like, oh my God, that is way too much. There's no way I have time to do that. But you could break it up into little pieces, like you're saying, I mean, even like five minutes, a five minute pause to exercise.

I can tell you personally, I use this myself because I have a really busy schedule, but, I, I know I need to get up and move and I don't have a lot of time for it. So I do these little snippets of small. I know. Can Do MS uses the term snacks, exercise snacks. And I like that idea. Just little, little bits that you can, you can actually do quickly.

[01:02:06] **Meghan Beier, PhD:** Yeah. And they have them on Instagram and other things like that. These like little five minute videos that you can follow along with to do exercises in small chunks. I like that.

[01:02:16] **Kathy Zackowski, PhD, OTR:** Yeah.

[01:02:17] **Meghan Beier, PhD:** Are there other resources? I know you brought up Can Do, and you've mentioned the MS Society, but are there resources that are available to help get people back into exercise or, to maintain exercise once they get started?

[01:02:29] **Kathy Zackowski, PhD, OTR:** So one thing I thought of that I know won't be, accessible to everybody. If you're any of your clients are still working. There are often employers that will offer benefits to, to keep their employees healthy. And so it might be really good to explore that and see if they can help with a gym membership or, what do they offer? I know one group gives everyone a Fitbit to wear because they want, and this decreases their health insurance cost. So it's, that's the benefit to the employees that if I buy actually move more, I get some benefit. So don't be afraid to ask your employee about that or your employer about that. The society has this, this, this area called pathways to wellness in MS, that is a really specific, program. That, offers educational videos for you to follow, that, that touch on a lot of different topics, but exercises is, is in there in a couple of different ways. Uh, the other thought I had was, you know, YouTube is an amazing resource for exercise. I use it all the time.

There's free videos. You don't always want to do the same kind of exercise every day. You know, using those free resources is, is really important. Things to keep in mind when you're just kind of going rogue like that and just going on YouTube or Google to search for things, make sure that the exercise that you're, you know, the video that you're watching kind of makes sense to you.

And it, it, it, isn't too hard, um, because you don't want, again, you don't want to fall or hurt yourself and you can hurt yourself. Like part of the issue with exercises. It's really not. Like everyone can do everything. You have to kind of figure out where you're at. What's a good level for you to work at to raise your

heart rate and still be able to get through the rest of your day and complete all the things that you know you need to do. But I, I definitely think YouTube is a great resource. There's also a woman named Emily Riley that I would, that I would encourage people to look up. She is a, she works for this National MS Society, but she's also a physical trainer.

And she is doing a project with the University of Pennsylvania where they do wellness group exercise. And can sign up to do this for free. You just, I would look up her name or, under wellness group at the University of Pennsylvania, but there, I think there are, you know, I would look around locally at your other universities that are nearby and see if they offer any kind of exercise program.

You don't necessarily have to go to an exercise program that is for [01:05:00] MS. Right? You can. That's what I meant by kind of using YouTube and kind of thinking practically about what it is you can do. Um, there are sitting aerobic classes. There are, there are Pilates classes that are all on the ground, so you don't necessarily have to be able to, you know, be jumping around, to do aerobics.

Anything that raises your heart rate, anything that makes you move your body is, is fair game. And so don't be afraid to make, problem solve on your own and think about what it is that you have fun doing. I mean, maybe it's just dancing. There's plenty of, of research actually now. That dance is a great form of exercise.

And so just put music on and dance around with your kids. That's another way to like, get some exercise.

[01:05:44] **Meghan Beier, PhD:** I love that. Yeah, absolutely. Yeah. And, and maybe this kind of your last answer plays into the next question that I had is, you know, sometimes people come and see me and we talk about exercise. Activation for improving mood or addressing cognition. And if people have more advanced MS, or they have more physical disability, sometimes they feel like they can't get into exercise.

[01:06:09] **Meghan Beier, PhD (2):** And, I think you and I both both know that's not true. But can you talk about that a little bit more? I mean, are there ways that people with advanced MS can still exercise?

[01:06:19] **Kathy Zackowski, PhD, OTR:** Yeah, there, it's a really important, points that you want to, yeah, I would definitely encourage. The listeners too, to realize that anybody can exercise with any amounts, as long as you can move

your body. Even just one body part, you can do exercise. So, there are, you know, we wrote this paper, earlier this year that's published that provides a really specific examples of exercise for people at different ability levels.

Just to give you a few examples, I think breathing is really underrated. So we have to breathe, right. And oxygen is critical for our brain, but when you, and you take for granted that, you know, you get out of breath when you go up and down stairs, for example. And now when you're in a wheelchair or you use a walker, you probably try to limit how many times you have to ever use your stairs and you limit how much you walk, just because you don't want to fall.

So in MS that becomes a really big problem because now you're never raising your heart rate. And now your lungs never get that experience of really being, pushed to, to, take in more air. And so I encourage people to use this really cheap thing. You can get it at like a drug store called a spirometer that, you blow into it. And there's a little ball that floats up and you can essentially use it as an exercise tool to, to keep your lungs in better fitness shape. So, I, and anyone could do that, right? You don't have to be able to walk. You don't have to be able to use your arms, even, you just need to be able to keep breathing, but it's really important, especially as we go into winter, because that can stave off sometimes some types of pneumonia, you know, you need to be able to breathe and your lungs need to have, that experience of expanding and contracting. And we don't, you just don't do it as much if you're not getting out of breath for anything which happens so much when, movement becomes difficult.

The other really important, thing that I, well, there's a couple, another important thing to keep in mind is that stretching is really important. So as you sit for longer periods of time, You know, your muscles are soft tissue.

And so they end up contracting or getting smaller, like shorter. Um, so just to use one example, um, I'll just use my biceps. So if I always keep my arm bent, then my bicep, which is that muscle on the top of your arm, that gets shorter. And so if I stay that way and never extend my arm, those muscles will stay shortened.

And so that sounds like, well, not that big a deal, but, but if you imagine that now I want to reach for something. Now that muscle doesn't know that it can stretch anymore because you've let it stay shortened for so long. So that's that sort of describes the importance for stretching. And that you have to give your muscles that, that, that motor memory, that they can stretch really long and they can get shortened, but you don't want to let them stay in one position too long.

And when we sit for long periods of time, our legs, for example, get, get really stuck in that position of sitting. And so it's really important to stretch those legs out. I mean, every hour you should do some kind of stretch. If you're sitting at your sitting all the time.

[01:09:29] **Meghan Beier, PhD:** Hm.

[01:09:30] **Kathy Zackowski, PhD, OTR:** And so another, a third thing I wanted to bring up that I think shouldn't be, that should be considered, but would require going to a physical therapist, at least initially would be to use electrical stimulation.

So the way this works, it's not really as fancy as it sounds essentially. You just put a little electrode, which is like a little pad on top of your skin. And that, and it's attached to a little wire that can, provide a little impulse of electricity, just a little tiny one [01:10:00] enough to help you drive your muscles.

So the way we make our muscles move now, again is just by you decide you're going to move, but this electrical stimulation device can be used to try to help move muscle or help get muscles to contract when they can't, when you can't do it voluntarily. And I've seen. There are lots of different ways this can be used.

There are electronic devices that can be, that can stay on your leg and can help you as you walk. And there's also devices that you can just use, when you want to exercise, but, and they're not all expensive. So I would definitely encourage, you know, encourage someone who is really struggling to find a way to exercise because they can't move enough voluntarily.

To explore this idea of, of functional electrical stimulation. Again, I, you would need to go through a physical therapist or someone trained to use this. So you don't hurt yourself. The biggest harm is really that you could burn your skin because you are using electricity. But it really, there there's no other negative side effects.

So it's, it's perfectly safe when it's done by someone who is changed to. And then, uh, one last thing I'll mention, because I really do believe in this, like there are people studying, you know, how do we get people who are unable to move very well? How do we get them exercise? And because we know exercise is so important.

And so the last thing is just this idea of bed mobility. So if you may, if you're laying in bed, even just the act of rolling one direction and then rolling the other

direction, trying to lift your knees. Moving your arms over your head. All those things are called bed mobility from a kind of an occupational therapy perspective, but all of those things are so important because you're using your muscles to move and you want to keep that independence of being able to move in bed.

It's also a really safe environment. You can't fall, you're already laying down, right? So as long as you don't roll off the bed, which would be not good, you'd want it. Otherwise, it's a perfectly safe way to exercise. And, and I think, again, something we kind of forget is exercise, but it really can be for a good form of exercise, especially for people who have trouble moving against gravity, in a seated or standing.

[01:12:10] **Meghan Beier, PhD:** That's great. Thank you. These are such good examples of ways that people with advanced MS can exercise. I love it. And I know some of my patients also work with places like Kennedy Krieger, and other rehab centers who can, who have advanced equipment to help them move, even if they aren't voluntarily able to.

[01:12:27] **Kathy Zackowski, PhD, OTR:** Yeah. Actually in one last thing and would just jump in before we, other thing is to look for centers, they don't have to even specialize in MS. So, for example, the Kennedy Krieger Institute really specializes in spinal cord injury, but they, but MS kind of fits into that. Cause your spinal cord is and is involved with MS um, especially when there's physical disability. So being open to other institutes or centers in your local area that might have a facilities is important.

[01:12:54] **Meghan Beier, PhD:** That's great. So one final question, and then we're going to end is just, if people want to find out more or they want to follow either the work that you're doing or other exercise researchers, do you have any suggestions for where they can learn more?

[01:13:08] **Kathy Zackowski, PhD, OTR:** So I would, I would definitely, look at the National MS Society. You know, I worked there, which is, which is great, but I know that they're very careful about what they put on their website. So I, it's a good sound source for finding information about wellness, about exercise and physical activity. Um, and you can trust that I would also really encourage you to go to Can Do MS. I think they are also very careful about what they put online. I you know, I would encourage you to read critically. So when you read things online, don't just agree with what they're saying. I would really, make sure it comes from a, a source. An academic source would be my, my, my first, my first opinion.

But I, but I encourage you to read and stay informed, but, but people that. Published in journals that are peer reviewed, then you know, that there's more credibility to what they're saying versus always just reading magazine articles, which might not have as much of that critical piece is really important.

So we, so that you can share with your clients, the best information, and not be providing, you know, even inadvertently kind of misinformed.

[01:14:20] **Meghan Beier, PhD:** Great. Well, thank you so much, Kathy. I really appreciate your time and expertise.

[01:14:24] **Kathy Zackowski, PhD, OTR:** Thanks for having me. I really appreciate talking about this topic. I hope it was helpful.

Conclusion

[01:14:28] **Meghan Beier, PhD:** Thank you for listening to the Find Empathy podcast!

If you would like continuing education credits for listening to this episode, go to: findempathy.com/learn.

Our goal is to help people living with challenging medical conditions find the mental health providers who understand their diagnosis.

Our education, and this podcast, is focused on increasing the number of [01:15:00] mental health providers who can help.

If you are a psychologist or a mental health provider that specializes in health populations, please consider signing up on the free Find Empathy directory. Go to findempathy.com and select "Get Listed."

We would love to connect with you on social media. Look for us on Facebook, LinkedIn, Twitter, and Instagram.

If you have suggestions for topics you would like covered by this podcast, let us know. Our email is info@findempathy.com.

Finally, please know that the opinions expressed by the experts today are their own. We are not financially supported by any of the businesses or resources described in today's podcast.

Also remember that the content provided today is for educational purposes only. Please seek the guidance of your doctor or mental health provider for any questions you might have regarding your own health or medical condition.

Thank you so much for listening and we look forward to you joining us in the next episode.

GET YOUR CONTINUING EDUCATION CREDIT

To get your continuing education (CE) credits for reading, listening, or watching this podcast course please visit https://learn.findempathy.com/courses/mood. You will be required to officially enroll and complete a post-test assessment as well as a course evaluation.

This course is $30 and awards 1.5 CE credits.

If you have questions, require a downloadable print version of the test, or need the test to be provided in audio format please email us at info@findempathy.com.

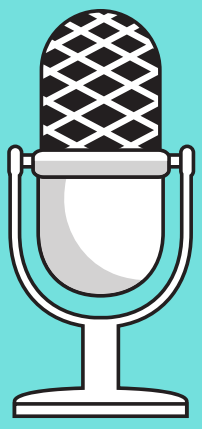
MORE COURSES

To find more podcast courses like this visit: https://findempathy.com/learn, or subscribe to our podcast on your favorite podcast platform.

JOIN OUR FREE DIRECTORY

Our mission is to help connect people living with challenging medical conditions find mental health providers who understand their diagnosis. If you are a psychologist or a mental health provider that specializes in working with chronic medical conditions or health populations, list your practice in our free Find Empathy directory. Go to https://findempathy.com/get-listed/.

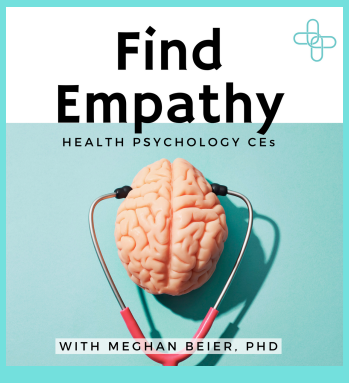
Thank you for participating in this course!



SUBSCRIBE TO

FIND EMPATHY

Look for **Find Empathy** on Apple Podcasts, Google Podcasts, Spotify, CastBox, Stitcher, and more!



Find Empathy, operated by Empathie, LLC, is approved by the American Psychological Association to sponsor continuing education for psychologists. Empathie, LLC maintains responsibility for this program and its content.