



**National
Multiple Sclerosis
Society**

MS Learn Online Feature Presentation Getting There: Staying Mobile with MS: Part 1

Tom

Welcome to
MS Learn Online. I'm Tom Kimball

Tracey

and I'm Tracey Kimball. The possibility of losing one's mobility can be a scary thought for anyone with MS. In this web-cast we begin an important three-part series titled "Getting There: Staying Mobile with MS"

Tom

Yes, in this segment we'll specifically explore how MS affects mobility and living healthfully.

Tracey

and the devices we can use to help maintain our mobility.

Chapter One: Activities that Keep You Moving

>> Movement is a part of who we are. Our ability to be mobile gives us the freedom to go where we want to go. For some people with MS, mobility can be a challenge. For others, there may just be a few bumps in the road. But challenges can be overcome, and bumps in the road can soon disappear in the rearview mirror.

Hello, I'm Theresa Marchetta. And in this video we're going to be looking at the different ways that you can help yourself to move forward, to stay active, and to be more mobile. How does multiple sclerosis affect mobility? What's going on inside your body when your muscles tire out, or when your legs feel tight and constricted? MS is thought to be an autoimmune disease. The body's own defense system attacks myelin, the fatty material that insulates nerves, allowing the nerves to transmit impulses rapidly. The loss of myelin slows those impulses resulting in many symptoms of MS, though symptoms can interfere with your ability to get around.

But there are many things that you can do to reduce the impact of those symptoms, from exercise and healthy living, to medications and assistive devices. There are options that

can help you stay more active, be more independent, and continue to do the things you value and enjoy.

>> With MS, healthy lifestyle is very important. Well, it's important for all of us. The problem is that you also have a disease on top of that. And I don't care if it's MS, it's diabetes or whatever, it's almost more important for you to be better at maintaining your lifestyle, because you don't have a lot of reserve. You don't have some extra things that the rest of us can sort of sometimes skim by with.

>> Our clients with MS, the most important thing for them to do is to maintain their activity level. We don't want them not doing and not participating in the activities that they love so much.

>> It's really no different for me because I have MS than it is for my husband who doesn't. We still have to motivate each other to get up and moving to be healthy.

>> Activity is so important to keep our muscles moving and to keep our legs and muscles in shape, and to be able to continue on with the simple tasks during the day.

>> The Heuga Center was founded in 1984 on the premise of Jimmy Heuga's philosophy of exercise was beneficial for people with MS. We've expanded our programs over the years based on participant feedback to incorporate many, many more aspects of health promotion and wellness.

Our fitness evaluation serves a couple of purposes: giving them the opportunity to exercise, figure out a level of intensity, a level of duration. What we try to do is find what people enjoy doing, what they will be successful with. The therapy balls, or the Swiss balls, it's very good for people with MS because, one, it's something that they can do in their home; two it has the versatility to incorporate a number of different activities, like stretching.

>> You're doing great! Great! Go only as far as you feel comfortable.

>> It can help with something, it can help with some balance activities.

>> It's nice to be able to not only strengthen your muscles, but also strengthen your balance. You've just mastered going from a wider base of support balance to a more narrow base of support balance. You've just improved. "Ta-da!"

>> A lot of communities have programs that people with MS can join. Yoga is very good because it does help with stretching, it helps with spasticity, it helps maintain range. Tai Chi is good because it helps with balance as well as some strengthening and some coordination.

>> Things like yoga are a great way for us to really connect our mind and our body, but most people with MS, including myself, have thought there is no way I can stand there and balance on one foot, or get into those weird contortions and be comfortable and okay. But that's not true. Many yoga classes are meant and adapted for people with MS.

>> One of the types of exercise that we use frequently in people with MS is aquatic therapy. You have to be a bit careful with the temperature of the pool, and you should, if at all possible, be able to get into the pool initially with a therapist.

>> I guess I lost the ability to get in and out of bed as my MS progressed, and I got into a wheelchair. But in the last year and a half that I have been consistently exercising and in the pool, I am now able to get myself in bed and out of bed every morning.

>> Thank you. If I could live in the water, I would. And that, again, brings so much joy. That helps a lot with the attitude and keeping a smile on your face, and just the way it makes you feel. You're just so free to move and walk around. You can actually stand and talk to somebody, where usually I'm sitting and looking up. It is a true freedom to be in that water.

>> There's one lady, she's been in the program the whole entire year. She was in a wheelchair, and now she is actually up walking. She does have a walker and she does get fatigued, but she can actually walk on her own. And exercise has helped her actually be able to become independent and do her own things.

>> It's interesting when you look at a person's overall mobility. Simply by strengthening a person, you can tremendously increase their ability to walk. For example, if you can walk a hundred feet, you can walk a thousand feet.

>> I wanted to walk a mile and I couldn't even walk six feet without falling down. But I worked up to being able to walk a half mile by doing it incrementally. Until the day of the race, walking. And I kept walking, and you know what? I made it all the way to the end. And that was the greatest joy in teaching me that I can do anything that I allow my mind to have a vision for.

Chapter Two

Moving Ahead with Assistance

>> One of the hardest roles I have as a physical therapist is when you get to that point where the client who has MS to say to them, "We probably need to use something. Your balance is getting worse; you're having difficulty. We need to go to an assistive device." And that's very difficult, because now all of a sudden -- you know, MS can be a very hidden disease. And the minute you have a cane in your hand or a walker, it changes it.

>> The very first time that physical therapy said that I was not safe enough with a cane, I had to have a walker, I was furious.

>> My typical day, I can get up and be pretty mobile, but as the day goes on, fatigue sets in and symptoms become a little more prominent, and I realize I need that stick to lean on.

>> It's better to reinforce what you think of as a normal pattern than to stagger, because even when people regain the ability to walk well, just because they might have that ability, if they've been constantly reinforcing a poor pattern, they won't automatically go back to a normal pattern. Try this for now. Be safer now. Don't assume you're going to use it for the rest of your life. Let's make you safe now. Let's make you walk well.

>> I think it is very easy, whether it's around energy conservation or mobility or around assistive devices, for families get into power struggles. What I ask people to do I take a respectful stance, and to discuss concerns. "I know you want to walk by yourself and are walking walls, but when I saw you fall it broke my heart." That's a far, far different stance than, "You fell, you're going to get hurt; you now have to use a walker." That's not respectful.

>> You get through that mad thing and you've got to remember you've got to keep yourself healthy. And just because you're on a cane or a walker maybe right now, doesn't necessarily mean you're always going to be.

>> It was a very, very difficult decision to purchase the cane, but it was also important to me that I be able to make this trip and to continue to do all the things that I love to do. And so I set aside the other emotions and bought the prettiest cane I could find.

>> A physical therapist can help select the assistive device. Part of that selection process is what's going to give you the most stability, to help you get where you want to get and use the least amount of energy.

>> My role as a medical supplier is to help educate people about what their options are, and help them to become independent and mobile, not only in their home, but in the community. Go to somebody that is knowledgeable, has experience to take specific measurements, to understand the person's disability, and to make recommendations based on the unique needs of that individual.

>> I've used my scooter for three and a half years and the mobility that it's given me and how it makes me feel so much more independent has been a godsend. I was really worried about my family. I thought, "They're no going to want to go anywhere with me on the scooter." And to be honest, they like it better, because now I don't hang on them anymore.

>> I think there are some new things on the market that have come out. They weren't developed for people with disabilities; they actually were developed for the general public. And one of those was called a Segway. People with milder balance problems and mobility, this might be the thing to use.

>> I got the Segway because it will help me get outside and it keeps me standing up, and I do much better standing up. And it's good for my legs and good for my exercise pattern, to be standing rather than sitting.

>> It doesn't have that stigma of being an assistive device. On the other hand, there is a problem, it's not paid for by insurance. But I do see that as something do particularly for people with fatigue.

Tracey

It's easy to feel powerless when we have MS. But we need to remember we have choices. Choices to live in a healthy manner and choices with assistive devices if mobility is impacted.

Tom

Thanks for joining us for MS Learn Online. We encourage you to join us for the next two segments, where we'll learn about the effects of spasticity and fatigue on mobility, adapting our cars and homes to improve mobility and we'll look at the future of mobility options.