

National Multiple Sclerosis Society

MS Learn Online Feature Presentation Getting There: Staying Mobile with MS: Part 3

Tom

Welcome to MS Learn Online I'm Tom Kimball

Tracey

And I'm Tracey Kimball and we're glad to have you back for the third and final part of ""Getting There: Staying Mobile with MS."

Tom

That's right, so far we've spent some time on the impact of mobility, specific symptoms that play a role in mobility and ways to manage mobility.

Tracey

So in this web-cast we'll hear about ways to adapt our cars, our homes and take a look into the future of mobility options.

Chapter Five: Mobility Behind the Wheel

>> **Theresa Marchetta:** Doing everything you can to keep your body as mobile as possible is only one part of the puzzle. What about your environment? It's important for everyone to be able to navigate, manipulate and appreciate our world. The number of accessible buildings, modified vehicles and assistive devices continues to grow every day. It is now easier than ever to get around your home and in your community, maintaining your independence and getting there, wherever "there" may be.

>> Having an adaptable van has made a world of difference in my life, from how I take care of things for my own household and my family, to how I work within the community.

>> The most important things to me is being able to be there for my son that's 9 years old, taking him to school, taking him to extracurricular activities. Just being able to go when I want to go.

>> It's very important to stay active and to stay driving and get out there in the community. And it doesn't just involve the standard car with the foot pedals. You can do all kinds of things. You can drive from a power chair, you can drive with hardly any arm strength now. There are so many adaptions out there.

>> When we start looking at mobility in terms of adapting vehicles, some of the manufacturers, and GM is one, they have done a lot of work building mobility equipment to fit into their vehicles, and are usually very helpful.

>> Through GM Mobility, we believe there's a tremendous opportunity to serve a need. People are looking for solutions that allow them to come out of the house and become active members of society, and be able to participate in family activities. For people with MS who would like to continue to have the opportunity to drive, you really need to be evaluated by a certified driving rehabilitation specialist. You really do need to be instructed on whatever equipment might be prescribed for you, and you have to be tested and certified before your license will be granted by the state.

>> "Oh, look at this! How cool is this!" "Once you get used to it, it's pretty good." "I love this."

>> Part of what I do is help people to be able to learn how to drive with adaptive devices so that they can drive with hand controls, for instance.

>> When I first started using hand controls, again, I was very petrified and I was nervous, but I knew that I was a good driver and that I could do it. And it took me about a month of practicing in the neighborhood, driving around before I finally got out. And I'd say it was about a year so that it is second nature. I don't even think about it.

>> Once an individual has their license to drive with equipment, the next step is to find a mobility equipment dealer in their market. These mobility dealers most often are certified by the National Mobility Equipment Dealers Association. You can find these members either in your local phone book or on the Web at www.nmeda.org. In terms of funding the purchase of the vehicle, there are a lot of sources that might be available given your particular situation and your state. Some sources you may want to check with include the Veterans Administration, state and vocational rehab facilities, your local insurance company. You can also even speak to often community agencies that are interested in supporting people and getting them back on the road.

>> It has given me the independence that I could never imagine. I can get out and I can do the things that I want to do, especially with my son, and being able to go shopping with my husband or going to dinner.

>> I've only had a van for a few months, but it has opened so many things for me. It's just made a world of difference.

Chapter Six: Design with MS in Mind

>> The thumbnail definition of universal design is the design of the built

environment in products in ways that allow use by the widest range of people possible without regard to age, ability or size. So, it's integrated design that works well for a wide range of people. If you do it right, it also looks good. There are a lot of things you can do in your house

>> We made it so there was no thresholds between each room.

>> Flooring and stairs are two areas to look at.

>> My husband designed this little hallway so that it -- I didn't have to worry about the step.

>> Thick pile carpet is a problem.

>> We went with the hardwoods because, again, it be a smoother surface.

>> Having something like an extension cord which crosses the route of travel can be a real hazard for everybody, but can be a special hazard for folks who may have trouble walking.

>> Mobility has always been a big part of our business, being able to get up and down and to get around. If you get the right products to help you at the right stage of your life, that helps you to live more independently and to live well.

>> This is a mod rail that's designed to help you get in and out of bed. >> These are transfer benches. You sit down outside the tub, pick your feet up, put them across, and the you have to slide your body into the tub.

>> This is an alternative to remodeling a bathroom.

>> As you can see, I have a rol

>> By taking barriers out of the home, we can enjoy our home, make the most of our lifestyle in it. This is a stair lift, a low-cost way to have an elevator in your home, and it glides up the stairs, allows you to enjoy the levels in your home.

>> Steps are a big thing, and these ramps are portable and allow you to carry them with you. Use the scooter, walker, anything to get to a friend's home, your family, overcoming a barrier, and they're easy to carry, and easy for a caregiver to put into a vehicle. As you can see, they've designed it so they're about 10 to 15 pounds in weight.

>> One of the good things we've noticed in the past 20 years is increasing attention and increasing acceptance of all the issues that we're talking about. You'll even see mention of accessibility modifications in one of these reality home rebuilding shows that they have on TV. So, clearly, people are beginning to get the message that they don't have to put up with the status quo. They don't have to put up with the house that doesn't work for them.

Chapter Seven: Future Trends in Mobility

>>Theresa Marchetta: Since its inception in 1946, the National Multiple Sclerosis Society has spent more than \$500 million on research in the relentless search for a cure. The future looks bright for people with MS as advances in treatment, management and rehabilitation continue to develop.

>> Neuro rehabilitation is a very rapidly growing area of research in multiple sclerosis and other neurologic diseases. The Locomat is a device that has been shown to improve the ability to stand or walk in patients who have weakness in their legs due to stroke and spinal cord injury. We were able to demonstrate improved mobility in patients with MS. The National MS Society has given us a larger grant to look at a three-year trial using the Locomat to help retrain people how to walk or stand with greater ease. The Locomat right now is not widely available. There are several centers that are testing it. We're hoping that the results of the trial will indeed show that it is a practical, effective, and cost efficient modality for people with multiple sclerosis and other neurologic diseases.

>>Theresa Marchetta: Thank you for joining us on this journey towards better mobility for people with MS. There are a variety of tools out there to help you stay active and mobile. Put them in your toolbox and use them. They are an investment in your lifestyle and yourself. For the National MS Society, I'm Theresa Marchetta. Thank you, and let's all keep moving.

>> My 4-year-old, he will come tearing around the corner and he'll say, "Daddy! Daddy! Daddy!" And he gives me this big hug. That's what keeps moving me forward. I'm still his dad. I can't play, but you know what? That's okay.

>> I think that it has impacted my life and me as a person in a way that I never thought that it would. I would not have been as understanding as I am.

>> I think he's learned a lot, too, from having a mother in a wheelchair. If he sees that I might be a little bit down, he'll come up and give me a hug or a kiss. I'm just blessed in so many ways.

>> I just hope the kids learn that dealing with adversity is okay, that we can handle things that happen to us. Yeah!

Tracey

We've certainly learned a lot over the past three segments of "Getting There: Staying Mobile with MS."

Tom

Yes, we have and we hope you have found it useful as well.

Thank you for joining us for MS Learn Online.