

National Multiple Sclerosis Society

MS Learn Online Feature Presentation Getting There: Staying Mobile with MS: Part 2

Tracey

Hi I'm Tracey Kimball and welcome to MS Learn Online.

It's good to have you join us for our second segment of "Getting There Staying Mobile."

Tom

Thanks Tracey. I'm Tom Kimball and I'm looking forward to viewing this web-cast where we'll spend the next 10 minutes learning more about the impact of spasticity and fatigue on mobility.

>> There are times, you know, that I have difficulty in a meeting or difficulty throwing balls with the kids. Or, they want to go on a bike ride and I can't because I'm too tired or it's hot outside. Do what you can. Keep going forward. You're not a part of the MS; the MS is part of you, and you need to separate the two.

>> Fatigue is the single most common and the single most disabling symptom that we see in multiple sclerosis, the single most common.

>> One of the things that occupational therapists work on with people with multiple sclerosis is the symptom of fatigue. So, you just have to be very selfaware.

>> I prefer to keep things in the lower cabinets, and mainly that's just a way of pacing yourself and not fatiguing yourself out.

>>> We really work on energy conservation. Put a stool in the kitchen, because today you may be able to function just fine, but tomorrow standing may be a little too much. When you go into a grocery store, look around and make sure. Occasionally, there will be a bench somewhere within the store. Know where those resting spots are. Or, if you feel that you're going to get halfway through the grocery store and not be able to make it the rest of the way, maybe that's the time to plan, "Well, I'll grab the scooter." So, you really do have to think more in advance than you did before. And that's why it's very good to write a log and to be able to say these are the activities that I do during the day. And look

at where those fatigue times are so that you can have maybe a 30-minute break or an hour break, to be able to rest and to get your body back and moving.

>> Often a reason why people are unable to continue working because of fatigue.

>> Fatigue was really very debilitating for me, and I just was not able to do my job. I took a part-time disability so that I could only work three days a week.

>> But this, too, has many treatments that are very helpful. In fact, I think probably the medicine that my patients with MS appreciate the most is Provigil. And basically it's a stimulant, but it tends to work exceptionally well for people with MS, especially those people with MS who have fatigue late in the afternoon.

>> I tried a number of different medications and the one that has worked the best for me is Provigil, and that enables me to have enough energy to last the entire workday. And that enabled me to be able to return to work on a full-time basis.

>> Another medicine that works very well for fatigue in MS is amantadine, and that is usually taken two or three times a day. Fatigue and depression often go together, and certainly depression is going to make fatigue worse. It's very important to recognize this and to talk about it with your physician, because, again, it's something that's easily treatable. We have medications today for depression that have minimal side effects. If a person's fatigue is partly due to depression, then the antidepressant medicine may be very helpful in terms of dealing with the fatigue.

>> I want to add the importance of maintaining your emotional health, because that's how you maintain your activity in the world and your relationships. And those two things are the most important of all.

Chapter Four: Managing Spasticity for Mobility

>> Spasticity usually means stiffness, stiffness. But it's a peculiar kind of stiffness. It's stiffness in an arm or leg, that's what we call velocity-dependent. That is the faster you move that arm or leg, the stiffer it gets. "Push out to me. Push." This comes from a lack of regulation of the nervous impulses in the spinal cord. So, spasticity is the symptom that we need to manage, but not all spasticity is bad. Sometimes we need spasticity to stand on, to transfer with, to walk.

>> We do have a lot of people that use their spasticity as a way of mobilizing themselves, being able to stand. Without the spasticity, they're just not able to function. But you also have to look at how is the spasticity affecting you in regards to pain? I mean, we don't want you hurting and we don't want it throwing you out of a chair, either.

>> After we've determined that pain is not a problem, then we begin a graded exercises program designed to try to decrease the spasticity. This is heavy on range of motion exercises, heavy on stretching exercises, aerobic exercises, exercises that will move the joints to allow the muscles to loosen up.

>> The majority of the spasticity that patients can initially be treated with a simple stretching exercise program that can be developed by the physical therapist.

>> And most people are tighter on their non-dominant leg.

>> The time-honored medicine that's been commonly used for spasticity is baclofen, and that's a pill that will decrease your spasms and help improve the stiffness that a person can experience with multiple sclerosis. The problem with the baclofen, people sometimes notice, is some sedation. And the problem also is that you seem to have to take the baclofen all day long. They have fabricated an intrathecal baclofen pump. I have several patients with intrathecal pumps now. And you're able to give onethousandth of a dose of the medicine than what you might take if you were taking the pill by mouth.

>> This pump constantly puts out a tiny, tiny dose of this medicine, and it's going right to where it needs to be. It helps the spasticity or the tightness, and you don't feel the dizziness.

>> It's not for everyone. You've got to make sure you go to the doctor to have the medicine titrated. There are complications associated with it.

>> There are times when I feel like I'm too loose, like my legs are so heavy that I can't pick them up. And I'll go in and I'll say let's turn the thing down a little bit, and so they'll do that. And if I need it turned up, they turn it up. "How about just 2%?" "Two percent, okay, we can do that." It has really improved my mobility.

>> Another medicine patients use is tizanidine, or Zaniflex. Zaniflex works in the brain to decrease the level of spasticity. It seems to have a very good control of spasms. Patients with MS seem to respond nicely to it. Another medicine that patients use is Dantrium. Now, Dantrium works right there at the muscle to decrease the level of spasms. It's not used as commonly in multiple sclerosis because not only does it decrease the spasms, but it may decrease the strength of the normal muscles. Another procedure that people use for spasticity is botulinum toxin injections. People talk about Botox and its cosmetic use, but we're using botulinum toxin here specifically on spastic muscles to decrease the tone and spasm that the patient may have.

>> The other thing that Dr. O'Brien has been doing for me is the Botox. Now, this isn't for wrinkles in my face. He puts that medicine right into the muscles that are really tight, that are causing that foot to turn in. And then in between three and five days, that muscle relaxes and that foot straightens out. And at that point, then I can be real aggressive about trying to stretch that muscle out.

>> I've been treating patients with MS for 25 years now, and the beauty of this that I've seen is just all the progress we've made and how people are improving.

Tracey

Fatigue and spasticity are big culprits in mobility so it was nice to focus our attention there

Tom

Yes, and learn there are ways to help manage these common symptoms.

There's one more segment of "Getting There: Staying Mobile with MS" correct, Tracey?

Tracey

That's right Tom.

In the final web-cast we'll learn about adapting our cars, our homes, and about future concepts in mobility.

Tom

That sounds great. To our MS Learn Online audience, thank you for joining us. We look forward to having you back again soon.