



Fatigue Take Control Part 5

>>Speaker: We spend our days in a variety of different environments: our homes, our communities, our places of employment. These environments at times can pose challenges for someone living with MS. Uneven surfaces, sidewalks without curb cuts, stairs, long hallways, and warm temperatures can contribute to a person's fatigue level.

>>Speaker: Frequently, not changing the environment, not changing the way things are set up are the things that lead to narrowing of life experiences. So, thinking about change rather than giving up the activity you love is a way to start managing fatigue and getting back into life.

>>Speaker: I was looking at the world the way I had always looked at the world in the past. Even though I knew I was fatigued, I wasn't really changing my way of operating in the world. And I think Jane had the same approach and expectations, that we were just going to continue to do things the way that we had always done them, and that doesn't really work.

>>Speaker: We tend to live with what we have. We tend to think this is the way something is and we don't look at the environment and say, huh, I could change that. So, one of the things we want you to do is to look at everything in your environment and think about whether it could be changed.

>>Speaker: I bought this lot and decided this was where I was going to park myself. I hired an architect, and he and I talked in detail, along with the builder that I hired, about the things that I needed in this home to make it as comfortable and as accessible as possible given where I was at with my MS challenge.

And so initially the architect and I and my builder talked at great lengths about making sure the elevation of this home was such that I could come in the front door, no steps. And also make sure that on the interior of the home the kitchen area I could get around very easily in, and with the island that I have here in the kitchen, it was placed where I could zip around it and get to the refrigerator and get to the pantry. I can have things set up in the bath area specifically that were designed by the architect and my builder to assist me, grab handles, wide doors. I have all 3-foot doors on the interior. It makes it easy for me to swing in and out of places and I don't hit things and wrack my knuckles or anything. So, they're small things but very important in making it a comfortable home for me to operate in.

>>Speaker: Being a mechanic and mechanically minded, if there's anything that's not too hard, like changing light bulbs and that type of stuff, I do do that. But I also take a chair along with me so that as I do tire, I sit down, rest, get back up and work a little more, and then sit back down and rest again.

>>Speaker: One of the things I did, I'm short. So, when every -- when the whole family was here in the house with me, everybody seemed to put things on the top shelf. Well, I could never reach them. And then after I was diagnosed, it was very hard for me and I was very afraid to get up on ladders to get stuff. So, I moved everything down to the lower levels and to the lower shelves that I needed to get my hands on. And whatever is in the top cabinet, I don't care, because I can't get it and I'm not going to try. So, I put things at a level that I can use them and they are readily available to me.

>>Speaker: When my office recently moved, I worked with a person who was designing the layout of my desk, my computer and my file cabinets so that it would -- when I would have to get up and move around in the office, it would be the most efficient, so I didn't have to do a lot of walking around the desk. But I could get into the desk from both sides to either get to file cabinets or get to my recliner. And the computer is just right behind me in this great chair. I just kind of swivel around.

>>Speaker: Initially, when I was diagnosed with MS, my symptoms were very, very minimal, and I was a full-time outside sales rep. So, I was on the sidewalk talking to customers eight hours a day. And wanting to be proactive with my employer, I took him aside and said, "I'm noticing that my fatigue factor is starting to become an issue." He was very, very supportive and was able to move me into a telemarketing/sales position, which took me off the street completely right away. And we are right now in the process of getting me set up so that I can work from home.

Working at home is -- it gives you a couple different options. Number one, for me, when I need that 10- or 15-minute break, where I need to elevate my leg, or I need to just get away for 5 or 10 minutes, it's a lot easier to do that at home than it is in the office workplace, because obviously there is a lot of pressure within the office to kind of stay at your desk and stay focused. And it's a little hard to take your leg and plop it in top of a desk and elevate it. So, the home scenario is a lot different.

The other thing in working at home is it gives me a lot more flexibility. I don't have to worry about getting up at 5:00 so I can be at work at 8:00, do my makeup, to put my wardrobe together. I can jump in the shower, put on my sweats, get in front of the computer and I'm at work, and I'm at work a lot faster, and there's a lot less work or fatigue involved in getting ready and prepped to get to work.

>>Speaker: In addition to modifying your home and work environments, addressing walking difficulties, using mobility equipment, and changing your mode of transportation will help you to get where you want to go.

>>Speaker: Long-distance walking and standing are both very fatiguing for my legs. I wouldn't consider walking a long distance, because I know I wouldn't be able to walk back. I really have to know where I'm going in advance before I go there, so I can size up whether I can walk that far.

>>Speaker: Many people report that they do a technique called wall walking. They'll walk along and hold onto pieces of furniture or, if there is no furniture available, they'll hold onto the walls as they're walking along. This may be an indication that you're not getting good information about the ground you're

walking on from your feet. Not knowing where your feet are makes walking difficult even if you do not have weakness. A cane gives information on what the ground is like. Other problems should also be addressed. These can include tight muscles, dizziness, spasticity or lack of coordination.

What we call foot drop is often an early change in walking that some people experience. When the muscles of the ankle are weak, they may not be able to hold the foot up when you lift your leg to take a step. Toes dragging or catching can potentially cause you to trip.

>>Speaker: I will trip more often if I'm tired. And tripping to me is like stepping on a garden hose and falling all the way to the ground in a split second and not having any idea that I did it. And my foot drop occurs more -- it's more pronounced when I'm extremely fatigued.

>>Speaker: A second common walking problem is weakness in the muscles around the knee. This can result in the locking of the knee as you go to put weight on that leg. Again, this is very inefficient. It can also be painful and can contribute to deterioration of the knee joint.

>>Speaker: An ineffective compensation for foot drop and knee hypertension is circumduction, or swinging the leg out to the side when taking a step. These walking problems can all be very inefficient and can easily and nearly invisibly be compensated for by using an ankle/foot orthosis, or AFO.

>>Speaker: Without my braces, I mean, I think every step I would take I'd probably be falling down, so I really -- I depend a lot on braces.

>>Speaker: I've been wearing AFOs, leg braces, for 10 years now, and I wear them all the time. And I use crutches. The truth is, when I picked out the fabric to make my AFOs, I didn't really think in terms of how perfectly they matched my crutches, but they do. It's just -- if you have to use things like that, it's like having a wheelchair that is colorful or kind of racy looking. It just -- it's another way of decorating, I guess.

>>Speaker: Finally, weakness may be present at the hip muscles. When the muscles at the side and back of the hip are weak, people will shift their weight over that leg as they're taking a step with the other leg. Using an assistive device, like a cane or a forearm crutch or a walker may compensate for this and make your walking more efficient.

>>Speaker: The scooter has been very, very beneficial for me. You know, I own a lumber company and I've got 13 acres of lumber out there and big warehouses that I like to go out and be involved with. This is my wheels, and I go all over the place.

>>Speaker: Having a scooter has really enlarged my world in terms of it was getting harder and harder to walk, and so it's just traveling less. And with the scooter I can whiz a mile or more through Portland to (inaudible) restaurant and whiz back, you know, probably at a risk to myself and others, but I enjoy it. I've got a van with a ramp and a sliding door, so if I have to go out to an event, I get in my van. I mean, I use my van and the scooter and I come back to the paper and I'm just much sharper.

>>Speaker: My van has a lift. It's kind of like a crane that picks it up and just puts it into the back of the van so I can operate it myself. It doesn't require any strength and I can easily operate it. So, it's really a relief. If I'm going to be outdoors camping, I use the scooter, put that in and take it with us.

>>Speaker: Just like there are a lot of different environments that we need to function in, there are a lot of different choices of vehicles that we can choose to get us from place to place. If someone with MS is using a scooter and is putting that scooter into the back of a van, then they have to get from the back of that van around to the driver's seat and into the driver's seat before they can take off.

If they have a modified van, where they can just drive that scooter right into the van and then transfer into that seat, it saves a lot of walking and a lot of steps. Some people can even go a further step and have a vehicle that they can actually drive from. They may actually be able to drive into that vehicle in a wheelchair right into the driving compartment and not have to do any transfers or take any steps at all, and have saved a lot of energy.

It's important to not narrow your life too much, and if using a piece of equipment will help you participate in the activities that are important for you, that is the right choice.

>>Speaker: I figure if I want to be with the family while they're walking through the zoo or walking through the mall, I would have to use the scooter, and I figured if people stare or if people look at you because you're riding on that, it doesn't really matter as long as you're spending that time with the family.

>>Speaker: Before you decide to give up something that you enjoy doing, look for ways to change the environment. Many times a simple change at home or at work will allow you to continue to do what is important. As you look around your environment for things to change, you may find that the easiest thing to change is the way that you are getting around.

Walking problems can cause you to use a lot of energy getting from one place to another. Getting the correct equipment for your walking problem is a very important step in managing fatigue. A physical therapist is the best person to help you identify and treat all of your walking problems, explain the various equipment options available, and help you decide what solutions work for you. You may find the best choice is to minimize long-distance walking and use mobility equipment instead.