



Fatigue Take Control Part 1

>>**Speaker:** My MS symptoms are sneaky. They're numbness in my left foot, my left arm, my left hand, and, of course, fatigue big time. I get very, very, very tired. Fatigue sometimes takes over to the point that I need to have at least two days that I call my pajama days.

>>**Speaker:** The biggest physical problem is the fatigue, which I'm calling it fatigue, that's a bad word. Because everybody gets fatigued, everybody experiences fatigue, people who don't have MS experience it. So, when I or you mention MS fatigue, they equate it to their own experience of fatigue. And it's a whole different ballpark. It's like a firecracker and atomic bomb. They're both explosions, but the atomic bomb is quantitatively -- qualitatively different than the firecracker. And that's what this fatigue is.

>>**Speaker:** Fatigue in MS is the most often misunderstood symptom. A lot of times people who don't have MS think they understand it because, after all, everyone's been fatigued at some point in time. So, when a person with MS says they're fatigued, somebody without MS says, "Well, sure, haven't we all been fatigued?" But it's not the same thing.

>>**Speaker:** Fatigue affects most people with MS. Understanding the underlying medical causes and potential treatments are the first steps to learning to take control of fatigue.

>>**Speaker:** We have an official definition of fatigue. It's a subjective lack of physical or mental energy that is perceived by the individual or their caregiver to interfere with usual and desired activities. What that means for a person with MS is that they just don't have the energy to do the things they want to do. Fatigue is the most common symptom that people with MS complain of. It significantly impacts people's lives and affects 80 to 90

percent of people with MS. It's one of the most common causes for people with MS to have to stop working. So, it is an incredibly important symptom for physicians to recognize and for patients to learn how to live with.

People with MS who have fatigue interfering with their lives should not just accept it. There are many, many things that can be done to help people lead fuller and more energized lives, and they should work with their physicians and other healthcare providers to learn ways to manage their fatigue.

>>Speaker: Many people, when they're diagnosed with MS decide that they are going to beat this disease. They're not going to let it make them disabled, they're not going to change their lives, they're not going to change how they do the things; they're going to forge ahead and do the things that they would normally do anyway. Unfortunately, with a disease like MS that can affect so many parts of their life, this is not a proactive way to manage the problems.

>>Speaker: We want people to learn that they can manage their fatigue, and to do that you first have to understand what fatigue is.

>>Speaker: The major difference between the fatigue people with multiple sclerosis experience and the fatigue that otherwise healthy people have is the impact that the fatigue has on activities of daily living. For example, someone with multiple sclerosis may work during the day and come home and not be able to prepare dinner or not be able to go out for a recreational activity, like going to the movies with their spouse, simply because of their fatigue. Even if these are things that they see as their responsibilities.

In contrast, an individual without MS who has transient fatigue, may feel tired but can overcome that problem to meet the task at hand. About 60 percent of people with MS will say they will not complete their responsibilities because of fatigue. In contrast, almost none of people without MS who were queried about this reported that they will be unable to meet their responsibilities because of fatigue.

>>Speaker: Primary fatigue of MS, or what some people refer to as lassitude of MS, or MS fatigue, is fatigue that is caused by the illness itself. It is not secondary either to the problems that the MS cause or the medications. What people commonly describe that have this is that they awaken in the morning feeling good and energized, but particularly in the early and late afternoon they run out of energy. They feel excessively tired and don't have

the energy that they did in the morning. The energy often improves, actually, in the evening, so it's very common for primary fatigue of MS to be at its worst point in the afternoon.

>>**Speaker:** Generally, what we do is we look at a person complaining of fatigue and try to rule out any treatable causes of fatigue, and what is left is considered MS primary fatigue.

>>**Speaker:** Right now, most of my symptoms involve my legs and dizziness and balance. My legs are quite weak, and particularly if I walk or exercise, they get extremely weak. Fatigue, I think, has a major impact on my life, and I think there are two different types of fatigue. Fatigue of my legs from exercising and moving around versus fatigue where I just feel tired and drained and I just need to sit.

>>**Speaker:** First of all, there is a type of fatigue referred to as nerve fiber fatigue. What this is, is a person will notice that they can walk a ways, and then after walking a block or two blocks or half a mile they'll develop difficulties moving one of their legs. This is a special type of fatigue that's a direct consequence of there being loss of the insulating material, or myelin sheath, around nerve fibers so that increased energy is required for those nerves to fire. After a period of time they just simply tire out.

Another type of fatigue that patients with difficulties walking and moving have is that of the fatigue of disability. It takes much more energy for somebody with leg weakness caused by MS to walk about than somebody who has normal strength. This increased energy expenditure required for walking, whether it's due to weakness or balance difficulties, can contribute to fatigue.

An approach to managing this particular type of problem, the fatigue of disability, is to use appropriate walking aids or other devices to help people move about, to help them conserve their energy.

It was around 1998, and I had started seeing a physical therapist, and she timed my walk and she watched my walk and could see that my right leg was really dragging and just not as strong, which, of course, I could feel, and I just didn't know what could be done about that. And she suggested a brace, which I didn't know anything about braces or how it would work, but I thought, well, I'll give this a try. And so I got the brace, and I'm wearing both

of them now, and I really notice that I could walk much farther and more efficiently with the brace on my right leg.

>>Speaker: The weakness that people experience with walking is usually a result of damage from the disease. It's often something that needs to be compensated for and will not be fixed with exercise. Using the right equipment will not only make you more efficient but will you safer. And it's interesting that the people around you, your family and your co-workers, they will notice these changes that you've made at first. But once they realize that you're taking care of your problems, they're more relaxed and they're more comfortable with you.

>>Speaker: People with MS develop a weakness and then as a consequence of that they decrease their activities. Most people with MS are actually deconditioned. Their muscles are deconditioned, their cardiovascular system are deconditioned because of this reduction in physical activity. A regular exercise program can reverse that process and thereby improve energy.

>>Speaker: Traditionally, people with MS have been told not to get hot and to not overdo it. Unfortunately, many people with MS will translate that not overdo it with don't exercise. They may increase their body temperature, may notice other symptoms increasing with exercise, and that's frightening to people with MS. They feel like if their symptoms are increasing, the disease is worsening. What research has shown is that people with MS can exercise regularly and can actually improve their fitness level without deteriorating their neurological condition. Regular exercise is a way for people to take control of their lives and is one of the important ways to help manage fatigue.

>>Speaker: I'll go to sleep right away. It's just like that's not a problem, you know. But then I'll wake up at night to go to the ladies' room, the bathroom or something, and I'll stay awake.

>>Speaker: When I first go to bed, I have trouble going to sleep. I have the sensations of tingling in my legs, which at times causes me not to be able to drift off to sleep like I used to.

>>Speaker: Many people with MS don't sleep well. Insomnia affects at least a quarter of people with MS. The causes of insomnia are quite variable, however. Some people have problems with spasticity or involuntary movements, and some people have significant problems with bladder

control. Other people suffer from various pain problems that interfere with their sleep. Some people have a condition called restless leg syndrome, where they have a sensation that their legs need to move that will awaken them. Regardless of the cause of poor sleep, like all of us, during the day they're going to be fatigued. And that situation is very important to identify the cause of the difficulty sleeping and to treat that cause.

>>**Speaker:** Being able to take the proper medication so that I can sleep through the night has just made a really, really big difference.

>>**Speaker:** Depression has been a constant for me over many years, and I didn't know that it was an MS symptom until I was diagnosed with MS and started researching on the Internet.

>>**Speaker:** You know, it's just really hard to live with this thing that changes -- has changed the way I live my life, and that's real distressing. And MS has caused great loss in my life. I used to hike, I used to be very, very physically active, and so those changes have been emotionally pretty wrenching, and I've had to over periods of time, of course, it's not just a one moment, oh, gosh, now I understand what's happening; it's very sad and now I'll go on. It just keeps on going, having to accept the changes.

>>**Speaker:** Depression is a major problem for people with multiple sclerosis, as well as other conditions, and while there are many examples where someone is tired but not depressed, it's almost impossible if you're depressed not to be tired. So, when you're dealing with somebody who is depressed, you have to deal with the depression, treat the depression, manage the depression before getting into fatigue. Because if you keep focusing on fatigue and not dealing with depression when it's present, the fatigue will never get better.

>>**Speaker:** I used to think, where is this flaw in my character that's making me depressed? But, yeah, I've been on depression medication as long as I've been diagnosed with MS, which is 10 years, and it keeps me operable.

>>**Speaker:** I think the antidepressants help me with that stay positive and realize that I can live with this disease. I just have to accept it and modify how I live.

>>Speaker: You know, fatigue is a common complication of a whole variety of medical problems. Let me give you some examples. Anemia can cause fatigue. Heart disease, lung disease, cancer can cause fatigue as a symptom. Fatigue can be a manifestation of an infection. Bladder infections are quite common amongst people with MS, and this is commonly an overlooked cause of increase in fatigue. It is therefore important in assessing a person with MS who has fatigue as a major problem, to make sure that they don't have another medical condition that may be actually the cause of the fatigue.

>>Speaker: There was such a large number of medications that have fatigue as a side effect, including medications that people take for their MS, as well as medications they may be taking for other conditions. For instance, medications that are used to treat spasticity, such as tizanidine and baclofen, can cause fatigue as a side effect. Some of the medications the patients take to help control their MS can cause fatigue as a side effect. This is a particular problem with the beta-interferons. After being on a beta-interferon for a period of time, most people will eventually stop having these side effects, but there is a group of people that have persistent fatigue as a side effect of the beta-interferon that can interfere with their day-to-day activities. So, it's important for people with MS who are experiencing fatigue to discuss with their doctors whether one or more of the medications they're on could be contributing to their fatigue.

>>Speaker: The only comparison I can give is heat does to me what kryptonite does to Superman. It just renders me powerless.

>>Speaker: Heat can temporarily make the symptoms that a person with MS has worse. And one of the symptoms that can worsen temporarily is fatigue. This is a direct consequence of there being nerve fibers that have lost their insulating material. These demyelinating nerve fibers become very sensitive to changes in body heat. So, anything that raises a person's body temperature, such as exercise, being in a hot room or being outdoors on a hot day, or getting into a hot tub can result in a temporary increase in MS symptoms.

>>Speaker: Managing heat sensitivity means a number of different things that you have to think about. Is it hot outside? Is it hot in that room? Am I too warmly dressed? Is there an alternative to going into that hot environment? Another thing that you can do to control heat sensitivity is to use active cooling techniques. This could be using a cooling vest. Some

people use cooling scarves. Taking a really cool shower might help you feel less fatigued.

>>Speaker: While there isn't a special diet that can help manage fatigue, there can certainly be an interrelationship between fatigue and how a person eats. And fatigue can actually be a contributor to a person's poor nutritional status.

If you think about it, if a person is tired or they don't have the energy, then the consequences that they may lose their appetite, they may not want to cook dinner, that may be the last thing they want to do. So, as a result, they may be grabbing for the things in their cupboards to snack on or become more reliant on fast foods or takeout foods, which oftentimes don't offer the healthiest food choices. Or they might just skip meals altogether. And the problem there is that then they're not getting the energy or the nutrients that help metabolize energy in the body, for their body to function effectively. So, it's sort of a vicious circle. On one hand we have fatigue contributing to poor eating habits, and that poor nutritional status contributing to fatigue.

>>Speaker: The treatment of primary fatigue of MS requires a multitude of approaches. As we've already mentioned, it's first and foremost important to make sure that the person is not suffering from fatigue related to another cause that is treatable. Some things that people can do for themselves that are useful include being on a regular exercise program, because this will definitely improve the person's energy. Many people find that if they can take a short nap in the early afternoon, that this helps to re-energize them in the afternoon.

Dealing with heat issues is also important. There are also some medications that can help with primary fatigue of MS. Energy conservation is also important in managing primary MS fatigue. This basically means finding the most efficient ways to do things in one's day-to-day activities.

I think it's pretty clear that everything we've said about fatigue and MS indicates that it's quite complicated. It really takes a team of healthcare professionals and also the cooperation of the person with MS and their loved ones to come up with a program that allows them to manage their fatigue.

>>Speaker: The first important thing that a person needs to realize is that fatigue is real, it's not because you're lazy, it's not because you're dimwitted; it's

a real disease symptom and it can be coped with and dealt with and successfully managed.

>>Speaker: Talk to your physician or healthcare provider about the possible secondary causes of fatigue. Look at weakness, for instance, foot-drop, de-conditioning due to lack of exercise, difficulty sleeping, depression, other medical issues; fatigue as a side effect of medication, heat sensitivity and nutrition. In addition to exploring possible secondary causes of fatigue, talk to your healthcare provider about available medications to treat fatigue. Many people with MS have found them to be very helpful in fatigue management.

Participating in a scheduled exercise program is another thing you can do to add to your energy reserves. Talk to your healthcare provider before you start or change an exercise program, and request a referral to a physical therapist to help you find a program that will work for you. Taking control of your fatigue does not mean making it go away; it means making choices and using all of the medical options available to you to manage your fatigue so you can remain independent and accomplish what is important to you.

>>Speaker: Your level of independence changes when you have something like MS. I'm continually trying to remain independent, but the fact is, you're having to ask for help. There's a lot of areas that you can't be as independent as you would like to. So, I think it's just a constant effort to do what I can and what I'm comfortable doing and what I can safely do. And I feel as long as I'm doing that, that's a step towards independence.

>>Speaker: Fatigue left unmanaged can have a major impact on a person's life. However, with appropriate medical evaluation, treatment and support, you can learn to take control of fatigue and continue to do what is important to you.