>>Kate Milliken: Hi. I’m Kate Milliken, and welcome to MS Learn Online. Feeling tremendous fatigue is pretty typical for many people with MS. However, there may be another reason for the extreme tiredness, outside of the common fatigue symptom. Many people with MS have trouble falling asleep or staying asleep. Dr. Rock Heyman, Chief of the Division of Neuroimmunology and Director of the MS Center, the University of Pittsburgh, is here to talk with us about sleep disorders. Welcome to MS Learn Online, Dr. Heyman.

>>Rock Heyman: Happy to be here.

>>Kate Milliken: So, just to start this dialogue, what are some of the reasons that people with MS have sleeping disorders?

>>Rock Heyman: Well, they have all of the same things everyone else gets. Unfortunately, MS doesn’t protect you from any other condition or problem, and then our MS therapies, MS itself, dealing with the complications of MS, and so many factors interplay.

>>Kate Milliken: And certainly there are other factors even people without MS experience dealing with things like apnea, caffeine, stuff like that.

>>Rock Heyman: Certainly. And some of the biggest factors on trouble falling asleep, or insomnia, relate to mood, often, and MS is a huge challenge on mood. Mood comes from the brain, not the heart. So, we see people who have
depression, which frequently can cause unexplained waking up earlier than somebody wants, where they wake up dead tired, but not refreshed. Just the opposite, insomnia or anxiety, and certainly, I think, the first day people have MS, hardly anyone would sleep well. And the same after any-- family stressors, changing concerns about your health, your kids’ health, you name it.

>>Kate Milliken:  Fear of an episode?

>>Rock Heyman:  Yes, and so, particularly in the first few years, dealing with anxiety and depression can be important factors, and not getting into the bad habits of, you know, drinking coffee late because you were tired and couldn’t get everything else done, or not exercising until the very last thing right before bed.

>>Kate Milliken:  Dr. Heyman, are people with MS more prone to sleep disorders?

>>Rock Heyman:  It appears that they are. The common sleep disorders most people may be familiar with, obstructive sleep apnea, heavy snoring, but also stopping breathing at night, where oxygen levels may drop, or even simply the work of having to wake up to take every breath can make people more tired during the day, and that may need a sleep study to sort out.

But the other, more common disorder I believe in sleep in MS is the restless leg movement associated with what’s called “periodic limb movements.” The restless legs, uncomfortable feelings or sensations in the limbs where you have to move them to get comfortable, so people may get up and out of bed and walk around the bed three times, feel great, jump back into bed and hope they fall asleep before the legs get uncomfortable again.

But there’s also a disorder that, while people are sleeping, their leg will stiffen repetitively, and it could be every ten seconds, it could be every twenty-five seconds, and even if it doesn’t wake somebody, it’s like your mom coming into the room and grabbing your foot and saying “Wake up, there,” and you get into lighter sleep, and we don’t get that good, refreshing deep sleep that helps us all feel better in the morning. That’s something the bed partner may notice, and it can be hard for people with MS to sort those repetitive movements that occur every so many seconds from true spasticity or spasms, which can bother a lot of people with MS, too.
>>Kate Milliken: So, from your perspective, what are some things that can be done to help people with MS sleep? What are some tips that you give?

>>Rock Heyman: Well, I think certainly trying to understand, sleep is not just the absence of being wake, so you would like them to pay attention to their schedule. If a medicine causes you to have more energy, chances are, it will cause you to have insomnia, and it’s great to get out for once in a while, you know, see a movie, have a dinner, get away from the house, but if you’re taking your anti-fatigue medicine late in the day, it’s certainly likely to aggravate your mood, or-- your mood, your sleep, which-- anyone who’s got trouble with sleep is going to get moody eventually anyways.

But schedule-wise, exercise right before bedtime. Exercise is important in MS, but exercise right before bed kind of ups the metabolism and makes it less likely to get good sleep. Some gentle stretching before bedtime can also prevent the nighttime cramps and stiffness that wake people up, and MS throws in all those variables like an overactive bladder can wake people up every hour, all night. That’s certainly not conducive to sleep, and there are different things your doctor can do to help out with that. Fluid restriction before bedtime can be helpful, but if someone’s already fluid restricted all day because they’re teaching school and don’t get bathroom breaks, or just don’t have the opportunity to get their fluids in, it’s not going to help their constipation and all the other things that can happen with MS.

So, it’s a delicate balancing act, and I think it’s important that people with MS pay attention to understanding sleep, and looking at programs like this may be helpful.

>>Kate Milliken: The-- as someone with MS, I’m certainly aware of, you know, the big looming MS fatigue, it’s something I’ve experienced, and the majority of people that I know with MS always talk about this fatigue, and it’s interesting to have the concept of fatigue versus the concept of sleep. Could you tell me about, kind of, the distinction?

>>Rock Heyman: It sometimes is clear-cut, and sometimes it is not. I think for typical MS fatigue, it is usual minimal, or almost absent when people wake up. So, if somebody wakes up and they have great energy, but by the time they’re dressed, showered, off to work, they’re exhausted, or sometimes not even that much, that could be, indeed, MS fatigue, whereas if somebody wakes up and they’re dead tired before they’re out of bed, they’re just exhausted, chances are that they may have some other disturbance, and it could be a general medical problem, like
thyroid or diabetes, it could be a medication affect from their anti-spasticity medicines they took before bedtime, or an antidepressant that was taken and caused drowsiness, but it could also be a sign of poor sleep or a sleep disturbance, like sleep apnea, like periodic limb movements, restless legs, some of the things that people with MS may be actually more prone to, rather than protected from.

Kate Milliken: The other thing that I found my from my experience is-- you know, when I-- pre-MS, I think that part of me thought, you know, taking a nap or sleeping late was something that was kind of indulgent or lazy, but, you know, as I kind of have progressed in my own MS journey, the whole concept of sleep has turned into something a little bit more therapeutic, that it’s something that your body really needs, and it can be restorative. Do you feel the same way for your patients?

Rock Heyman: Sleep is something that is necessary for the body. It’s not a great sign of good health to say, “I’m just going to skip sleep or push through,” and sometimes that’s the best medicine. Instead of taking another chemical or pill into your body, sometimes scheduling a break, sometimes it’s just rest, even not sleep. MS fatigue often responds quite well when people have cooler temperatures, the cooling vest, cold beverages. Sleep-disturbance related fatigue tends not to respond much to colder temperatures.

Kate Milliken: These are obviously some great tips for people to kind of change their lifestyle to try to help with the sleeping issue, but what if these strategies don’t work?

Rock Heyman: Well, there are many different options. Mood can be a significant component, and many people are reluctant to see someone for their anxiety or depression, but it can be much better than throwing medications at the problem, or, worse yet, using alcohol to try to fall asleep, which can get people to sleep, but it ruins the sleep structure at night, and can lead to other problems.

Kate Milliken: Doesn’t help in the morning, either.

Rock Heyman: No, it doesn’t. The other issues, people may want to see a Board-certified sleep specialist to consider a polysomnogram, which is a sleep study, and that is where we actually monitor the brain waves, we look at how breathing and movement is going, are people getting deep enough sleep, going through the normal structures of sleep, but there’s a whole community of both
neurologists, pulmonologists, mental health professionals, a variety of people who can help with sleep disturbance, but it’s good to start off with talking with your neurologist and possibly even your family physician.

>>Kate Milliken: Dr. Heyman, thank you so much for giving us an insight about sleep. For MS Learn Online, this is Kate Milliken. Thank you for joining us.