

MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



SLEEP MATTERS

*How Multiple Sclerosis
Can Affect Sleep*



An educational series for people with multiple sclerosis (MS) developed in conjunction with the International Organization of MS Nurses (IOMSN).

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Hello, and welcome!

Sleep problems can affect anyone, with or without MS. You may be surprised at how addressing sleep dysfunction can help to improve many other parts of your life. Proper treatment requires getting to the root of the problem. This is why it is important to discuss sleep problems with your MS healthcare provider.



The MS Empowerment Series was developed for the International Organization of MS Nurses (IOMSN) to provide information and resources for people with MS. As a neurology nurse working in MS care and research for over 30 years, it's my privilege to be part of this program.

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SLEEP MATTERS

Whether it's tossing and turning during the night, staring awake at the bedroom ceiling, or multiple nighttime visits to the bathroom, sleep can become yet another challenge for people living with multiple sclerosis (MS) instead of a restful release. Failure to get a good night's sleep spills over into daytime issues, compounding existing problems like focus and energy.

A good night's sleep is so important, but why is it so elusive? Having MS can make a person feel tired often, so why is sleep so difficult? Tiffany Braley, MD, MS, Associate Professor of Neurology at The University of Michigan's Multiple Sclerosis Fatigue and Sleep Center, explains that sleep problems are extremely common in people who have MS (see Infographic, page 4), but they don't always receive the attention they deserve. "Sleep problems should be given

"Sleep problems should be given higher priority because they impact overall health and many aspects of MS, such as fatigue, mental health, and cognitive function."

— TIFFANY BRALEY, MD, MS

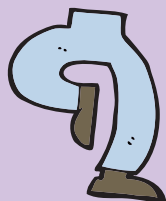
SLEEP DYSFUNCTION IN MS

Up to 70% of people with MS have at least 1 sleep disorder, but few have sleep dysfunction diagnosed by a physician.*

INSOMNIA

- sleep onset
- sleep maintenance

Affects 42% to 58% of people with MS



RESTLESS LEGS SYNDROME

One study found RLS in 19% of people with MS vs. 4% of those without MS

OBSTRUCTIVE SLEEP APNEA (OSA)

38% of people with MS screened positive for OSA, but only 4% had a diagnosis



EXCESSIVE DAYTIME SLEEPINESS

About 30% of people with MS report daytime sleepiness, but 62% report fatigue

*Brass SD, et al. Sleep disorders in patients with multiple sclerosis. *Sleep Medicine Reviews*. 2010;14(2):121-129.

higher priority,” she comments, “because they impact overall health and many aspects of MS, such as fatigue, mental health, and cognitive function. Often, discussions about sleep problems are eclipsed by other issues that seem more pressing when patients see their MS care provider,” Dr. Braley says. Her research at Michigan Medicine focuses on the crucial connections between sleep, the immune system, and neurologic disorders like MS.

How Are Sleep Disorders Identified?

It’s important to get to the root of sleep problems, Dr. Braley says. This usually starts with an in-depth discussion with an MS nurse or other health professional about sleep habits, sleep quality, and symptoms that might be disturbing your sleep. The provider may ask questions about your sleep history, such as those listed in **Table 1**. It might help to have a spouse or sleep partner provide additional input.

The next step may be to consult a sleep specialist. Depending on what issues are identified, an overnight sleep study (called a *polysomnogram*) may be recommended to evaluate sleep patterns and breathing during sleep. (See box on page 9, **What Happens During a Sleep Study?**)

Effect of MS Symptoms on Sleep

Sleep problems may be due, in whole or in part, to MS symptoms. These symptoms can make it more difficult to fall asleep and stay

Table 1. What You Might Be Asked About Your Sleep Habits

1. What is your main difficulty or complaint? These might include:

- Trouble going to sleep, staying asleep, or waking up earlier than desired
- Abnormal movements during sleep
- MS symptoms such as spasticity or bladder problems disturbing your sleep
- Snoring, choking, gasping for air

2. Sleep habits:

- What time do you go to bed? Get up in the morning?
- How long does it take you to fall asleep?
- How often do you awaken during the night? How long do these typically last?
- Has anyone observed or mentioned sleep problems you might have?
- How does your sleep pattern change on the weekend?
- What are you usually doing in the hours before going to bed?
- What wakes you up?
- Do you have any food and drink habits that might influence your sleep?
- Do you take any medications (prescription or over-the-counter) or other substances to help you sleep?

asleep. “This highlights the importance of a comprehensive approach to the sleep assessment,” Dr. Braley explains. “An MS care provider can help you to identify and address potential complicating factors among MS symptoms.”

Spasticity or Pain

Spasticity often contributes to sleep disturbance in people with MS. Spasticity is like a painful muscle spasm or feeling of tightness. It is caused by abnormal muscle firing and impaired voluntary control of skeletal muscle. Spasticity affects as many as 85% of people with MS and can occur at all stages (not just in advanced MS). Treating spasticity with medications such as baclofen can help to alleviate sleep disturbance.

Bladder Dysfunction

Bladder dysfunction, especially the need to urinate during the night (nocturia), is one of the most common MS symptoms that disrupt sleep. Women with MS experience bladder



problems about twice as often as men. Nerve damage from MS may affect bladder function in several ways, including:

- reduced sensation that the bladder is full
- impaired reflexes that signal when urine is released
- less ability for the bladder to contract

For some people with MS, addressing bladder issues can be the key to improving sleep quality. This involves an individualized approach that the MS nurse or other provider can discuss.

Mood Disturbances

Anxiety or depression can be a cause of sleep problems—and they can also be made worse by sleep problems. People with MS who have depression have been shown to have higher risk of insomnia than those who are not depressed. Even when clinical depression is not present, worry and rumination about the stresses of life often disrupt sleep, especially when a person is trying to return to sleep after waking up. While it may seem impossible to shut off that “nagging voice,” self-hypnosis and guided meditation can be effective.

Sleep Apnea and MS

Obstructive sleep apnea (OSA) is a condition in which the upper airway collapses during sleep. According to Kathy Bennett, RN, a nurse practitioner at the University of Michigan, another form that may occur in people with MS is “central sleep apnea,” in which the brain fails

What Happens During a Sleep Study?

A sleep study usually involves an overnight stay at a hospital or sleep center. Contrary to what many people think, you’re not lying on a big lab table under bright lights. The room is similar to a hotel room, with its own bathroom. You will not share the room, and it will be dark and quiet during the test.

Before you go to sleep, sensors will be placed on your scalp, temples, chest, and legs using a mild adhesive. The sensor wires are long enough to allow you to move around in bed. During the sleep study, sensors are used to record your brain waves, oxygen levels in your blood, heart rate, breathing, and eye and leg movements during sleep. A technologist will monitor your movements via a low-light video camera. An audio system will allow you to communicate with the technologist. Although you

probably will not fall asleep as easily or sleep as well as you do



at home, this usually doesn’t affect the test results. A full night’s sleep isn’t required to obtain accurate polysomnography results.

to send the proper signals to the muscles that control breathing. During an apnea episode, breathing may be partially or totally blocked for a few seconds or longer. The person may cough, choke, gasp, or snort loudly to reinitiate breathing. Signs of OSA include daytime sleepiness or fatigue, multiple nighttime awakenings, snoring, and choking or coughing episodes observed by a sleep partner. Frequent urination (which may be a sign of increased urine production during sleep) may also be a sign. Your health-care provider might use an instrument such as the “STOP-BANG questionnaire” (Table 2) to screen for possible sleep apnea. A “yes” to 3 or more answers might indicate that you should be referred for a sleep study.

The treatment of choice for OSA is positive airway pressure (PAP), which involves sleeping with a mask that delivers airflow at a certain pressure to prevent the airway from collapsing. The air pressure may be continuous (CPAP), or may vary by inspiration or expiration (BiPAP). PAP has been shown to be an effective treatment for OSA and will often greatly improve sleep quality, fatigue, sleepiness, and overall quality of life. Some people might be put off by the idea of CPAP, explains Kathy Bennet. “I reassure patients that CPAP has a high benefit-to-risk ratio with few side effects. Many people with MS report improved functioning, more energy, less cognitive dysfunction, less fatigue, and fewer headaches following treatment.”

Table 2. STOP-BANG Questionnaire for Sleep Apnea

1. **S**noring: Do you snore loudly (louder than talking, or loud enough to be heard through closed doors)?
2. **T**iredness: Do you often feel tired, fatigued, or sleepy during the daytime, even after a “good” night’s sleep?
3. **O**bserved apnea: Has anyone ever observed you stop breathing during your sleep?
4. **P**ressure: Do you have, or are you being treated for, high blood pressure?
5. **B**ody mass index (BMI) greater than 35
6. **A**ge: older than 50 years
7. **N**eck circumference: men, shirt collar 17 inches or larger; women, shirt collar 16 inches or larger
8. **G**ender: Male gender

Dr. Braley’s research team has shown a connection between OSA and cognitive impairment in people with MS. “This raises the possibility that treating sleep apnea could help to improve cognitive function in people with MS. A trial at the University of Michigan is now enrolling patients to explore this possibility,” says Dr. Braley. (For more information, go to UMHealthResearch.org and search for CPAP to Treat Cognitive Dysfunction in MS.) Treating

sleep problems could potentially help with MS symptoms such as pain and depression as well, she notes.

Restless Legs Syndrome: How Does It Affect People with MS?

A person with RLS experiences an uncomfortable or “crawling” sensation that is usually alleviated by voluntarily moving the legs. These

symptoms often get worse at night or when the person is lying down. RLS should be distinguished from spasticity, which is more often described as sharp pains, cramps, or a “charley horse.” It is possible for a person with MS to experience both spasticity and RLS. A questionnaire called URGE may be used to screen for RLS (Table 3). RLS can be treated with medications, or sometimes iron supplementation if RLS is due to low iron levels.

What Steps Can You Take On Your Own To Improve Sleep?

What about basic measures to improve “sleep hygiene”? Can these make a real difference for people with MS? Some of the simple steps recommended to improve bedtime habits include:

- Reduce or eliminate “screen time” an hour or two before bedtime.

Table 3. URGE Questionnaire for RLS

Urge	Do you have an urge to move your legs?
Rest	Do the symptoms get worse with rest?
Get up	Do symptoms improve when you get up and walk around?
Evening	Are symptoms mainly present, or worse, in the evening?



- Sleep in a darkened room. Even small sources of light, such as LED lights on appliances or your phone, can potentially disrupt circadian rhythms (the body's natural sleep clock).
- Reduce noise. If the bedroom environment is noisy, try a sound machine with soothing sounds like ocean waves or soft rainfall.
- Manage stress. Self-hypnosis or guided meditation may be used to help calm the nagging "inner voice" that keeps many of us awake at night or prevents us from falling back asleep.
- Avoid caffeinated beverages or stimulants in the afternoon and evening.

Self-help approaches are always a good place to start, says Dr. Braley, and may be sufficient for some people whose insomnia is linked to poor bedtime habits. Other people with MS require a more comprehensive approach to treating sleep disorders.

An added benefit to treating sleep problems may be reducing fatigue, Dr. Braley suggests. "Prior research has shown that effective treatment of sleep problems, including sleep apnea, in people with MS can lead to improvements in MS fatigue," she says. "As fatigue is one of the most common and debilitating symptoms in MS, improvement of this symptom is one of the most meaningful outcomes we can potentially accomplish when treating sleep problems."



Medications That Can Cause or Worsen Insomnia

Some of the medications used to treat multiple sclerosis (MS) can interfere with sleep. For example, dalfampridine (Ampyra) is a therapy used to help improve walking speed in people with MS. Insomnia is one of the commonly reported side effects with this medication. Since dalfampridine is taken in two daily doses, 12 hours apart, a possible solution is to take the first dose very early in the morning (say, 6:00 am if one rises to use the bathroom at that hour), and then take the second dose 12 hours later (6:00 pm) as directed. The idea is to avoid taking the drug right before bedtime. This may help to minimize the side effect of insomnia.

In addition, some drugs used to treat depression have insomnia as a possible side effect. These include fluoxetine (Prozac), sertraline (Zoloft), and paroxetine (Paxil). "When you're looking into the causes of sleep problems, don't forget to consider the medications you may be taking," suggests Dorothea Pfohl. "Be sure to provide your MS nurse or other healthcare provider with a list of all the medications you are taking, so medication side effects can be ruled out or addressed."



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