

Dream on: Managing sleep disorders



At least half of people with MS have sleep disorders. Here's how to catch more Z's if you're one of them.

by Matt Alderton

Multiple sclerosis can be exhausting. Literally. In fact, fatigue is the most common symptom of MS, according to the Cleveland Clinic, which says fatigue occurs in as many as 95% of people with MS.

It's a frustrating irony that another common MS symptom is sleeplessness, which can be both a cause and a consequence of MS-related fatigue, according to Abbey Hughes, PhD, a rehabilitation psychologist at Johns Hopkins University School of Medicine.

"If you are experiencing moderate to severe fatigue, poor sleep quality could be one factor that's contributing to it," says Hughes, whose specialties include MS and sleep disturbances. "At the same time, you might be increasing your caffeine use to help with fatigue management during the day. But if you're drinking coffee too late, the caffeine can stay in your system and make it difficult to initiate sleep later."

It's a vicious cycle in which almost anyone can find themselves trapped. But it's especially common in people with MS, over half of whom are known to have sleep disorders, according to researchers.

"There's a two- to three-times higher prevalence of sleep disorders in people with MS," says Hughes.

She says the most common sleep disorder in both the general population and in people with MS is insomnia, which is defined as having trouble falling or staying asleep at least three nights a week for a period of three months or longer.

Other sleep disorders that are common in people with MS include sleep apnea, a condition in which breathing repeatedly stops and starts during sleep; restless leg syndrome, which is marked by an irresistible urge to move one's legs at night; periodic limb movement disorder, which causes repetitive cramping or jerking of the legs during sleep; and narcolepsy, which causes sudden onsets of sleep during the day.

Having any of these conditions alongside MS can have serious consequences, according to Catherine Siengsukon, PhD, associate professor of physical therapy and rehabilitation science at the University of Kansas Medical Center.

"Sleep is strongly associated with health-related outcomes," Siengsukon says. "It's one thing to have a bad night of sleep every once in a while, which most of us can deal with from time to time. It's another thing to have insomnia or another sleep disorder — especially if you have MS, because the body needs sleep to function and cope with MS-related symptoms. If you're not sleeping well, that can contribute to the worsening of those symptoms."

If you're experiencing chronic sleeplessness, rest might seem hopelessly elusive. However, by understanding what causes sleep disorders — and what can cure them — you can finally graduate from counting sheep to catching Z's.

MS and sleep disorders

The first step to getting more sleep is to understand why you're getting less, according to Hughes, who says there are several common causes of sleep disorders in people with MS.

- **Multiple sclerosis.** "MS is a demyelinating condition. It causes nerve damage to the neurons in the brain and the spinal cord, which make up the central nervous system. And the central nervous system plays a pivotal role in regulating our sleep-wake cycle," Hughes says. "If you have nerve or neuronal damage in areas of the brain that are responsible for regulating the sleep-wake cycle, that can be a direct cause of sleep disturbance."
- **Sleep apnea.** MS might also affect areas of the brain that regulate breathing and muscle control in the throat or lungs, which could lead to sleep apnea.
- **MS symptoms.** Symptoms like pain, bladder dysfunction, temperature dysregulation, spasticity, numbness and tingling can all interfere with sleep.
- **MS medications.** For example, many doctors prescribe steroids for patients who are experiencing MS exacerbations, and steroids can cause insomnia, Hughes says.
- **Disease-related behavior.** "When people are coping with MS symptoms, they sometimes develop unhelpful behaviors to manage those symptoms, which in turn disrupts sleep," explains Hughes, who says people with MS might nap during the day, for example, to cope with fatigue. "While short naps can be helpful for fatigue

management, naps longer than 20 minutes can start to get into deep sleep, which then takes away from your ability to fall asleep at night.”

- **Anxiety.** “Often, people with MS worry about having a chronic condition, or they worry about things like income and finances,” Siengsukon says. “Understandably, that can contribute to sleeplessness.”

6 strategies to improve your sleep

Once you know the source of your sleeplessness, you can take action to address it, according to Siengsukon, who says your first course of action should be talking to your healthcare professional.

“Often, people with MS do not mention their difficulty sleeping to their healthcare provider because they have so many other things to talk about,” Siengsukon says. “But if you bring it up, often there are things that can be done.”

Siengsukon prefers cognitive behavioral therapy, or CBT-I, for insomnia. In 2020, she and four coauthors published the first study demonstrating the efficacy of CBT-I for people with MS.

The cognitive part of CBT-I teaches you to manage or eliminate negative thoughts and worries that keep you awake, while the behavioral part teaches you to develop good sleep habits. Therapy typically lasts for six weeks, during which time patients meet weekly with a sleep medicine specialist and keep a detailed sleep journal to help them identify positive and negative sleep habits.

“It’s about increasing thoughts and behaviors that can make sleep better and reducing thoughts and behaviors that are maladaptive to sleep,” Siengsukon says.

Whether you do them independently, under the care of your healthcare provider or with supervision from a behavioral sleep medicine specialist, here are six strategies you can borrow from CBT-I to improve your sleep quantity and quality:



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1. Avoid nighttime stimulation

Caffeine and other stimulants can help you fight daytime fatigue, but consuming them in the late afternoon or evening is a bad idea if you struggle to sleep, according to Hughes, who

suggests avoiding stimulants after 3 p.m. to keep them out of your system at bedtime.

You should be equally mindful of the clock with regard to alcohol and exercise. Alcohol might help you fall asleep but can make it hard for you to stay asleep. Exercise, meanwhile, can elevate your heart rate and body temperature, which can keep you awake if you exercise vigorously too close to bedtime, Siengsukon says.

Even television can have a stimulating effect, according to Hughes, who says to avoid action, thrillers and cable news programs before bed in favor of programs that are more soothing.

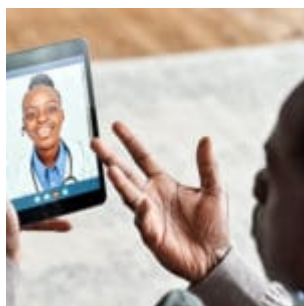


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2. Re-evaluate your medications

It's important to review your medications with your healthcare professional, Hughes says. You might want to talk to your healthcare professional about getting off existing medications if their side effects are keeping you awake. Likewise, you might want to add new medications — for example, bladder control medication to assist with nighttime urination — if they'll help you sleep better. Or perhaps you can change your schedule to take a disruptive medication in the morning instead of in the evening.

3. Get out of bed if you can't sleep

If you're having trouble falling asleep because of restlessness or MS symptoms, don't continue to lie in bed. Instead, get out of bed and do something else, then try again later, suggests Hughes, who says you shouldn't stay in bed longer than 10 minutes if you're tossing and turning.

If you have mobility issues that make it difficult to get out of bed, do something that's "relaxing and distracting," Siengsukon says. For example, listen to an audiobook.



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4. Proceed (to the bathroom) with caution

It's normal to get up in the middle of the night to use the bathroom, especially if you have MS. When you get up, however, avoid overstimulation, Hughes advises. Go to the toilet nearest your bed, for example, and keep the lights low. If you're concerned about mobility or fall risks, installing dimmer switches and grab rails can help you move around safely without waking yourself up too much.

5. Optimize your sleep environment

Sleep might come easier if you keep your bedroom cool, dark and quiet, according to Hughes. Blackout curtains can help block light, and multilayer bedding, with sheets and blankets that you can add or remove as needed, can help keep you cool. You can even purchase cooling mattress toppers that draw heat away from the body, and electric cooling pads that regulate the temperature in your bed.



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6. Use technology — sparingly

If you watch your tablet or play with your phone in bed, stop, advises Hughes, who says doing anything in bed other than sleeping trains your brain that it's OK to be awake in bed.

And yet, technology can be a useful sleep aid. There are evidence-based mobile apps that can help you induce or monitor your sleep. Popular apps, for example, include Calm and Slumber, both of which use guided meditations, soothing stories, relaxing music and calming nature sounds to help you fall asleep. Hughes, meanwhile, recommends the Cleveland Clinic's Go! to Sleep app and the U.S. Department of Veteran Affairs' CBT-i Coach app, both

of which offer tips to help you improve your sleep and sleep diaries to help you track it.

Speaking of sleep tracking: If you use a fitness tracker to monitor your sleep, be mindful of your relationship to your device, Hughes and Siengsukon caution. Although fitness trackers can be helpful for recognizing positive and negative sleep trends, it's easy to become obsessed with sleep scores, which can actually harm your sleep quality by making you overly attentive to it.

Destination: sleep

At the end of the day, sleep is as much a destination as it is an activity. For people who have sleep disorders alongside MS, it might take a little bit longer to get there. But eventually, you can still arrive.

"It doesn't have to be hopeless, and it doesn't have to take two years of treatment," Hughes concludes. "Setting just one or two small goals to change your sleep habits — whether that's going to bed at a different time or reducing TV watching and phone use in bed — can make a big difference."

Matt Alderton is a writer and editor in Chicago.

Learn more about [sleep and MS](#).