



Hitting the Mattress

Getting a good night's sleep is hard enough.
Don't let multiple sclerosis turn your bed into the enemy.



GLENN SCOTT:
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with MS

BY AMY PATUREL, M.S., M.P.H.

PHOTOGRAPHS BY JOEL SALCIDO

Even before Glenn Scott was diagnosed with multiple sclerosis (MS), he was pounding his mattress in frustration. “I was waking up at 2 a.m. and was lucky if I could sleep until 4 a.m.,” he says. “I was living on four to five hours of sleep a night.” And with a career in information technology in Austin, TX, and a huge software implementation project in Europe, Scott couldn’t afford to keep losing sleep.

Research suggests that most adults need eight hours of sleep to function well. Sleep is critical for learning, memory, and problem solving, to say nothing of its effects on the body’s internal systems (especially the heart, lungs, and hormones). And yet, in today’s time-crunched society, up to 47 million Americans don’t get enough ZZZZs. Toss a disease like MS into the mix and restful slumber can seem like a pipe dream—especially after you’ve taken a five-day course of steroids.

DOES MS CAUSE SLEEP PROBLEMS?

Every night MS patients like Glenn lie awake, suffering in silence. Beyond the stress of battling a potentially crippling disease, MS involves physical symptoms such as numbness, muscle spasms, and debilitating pain that can make sleep nearly impossible. Beyond the physical symptoms of the disease, six percent of MS patients have a diagnosable sleep disorder. Some suffer from involuntary twitches and kicking, called sleep-related movement disorder. Others require frequent trips to the bathroom (nocturia) or have ongoing ringing in the ear (tinnitus).

“It’s like an alarm clock that you can’t turn off,” Glenn says of his tinnitus. “You can disregard it during the day with the ambient noise and distractions. But at night, when you try to lie quiet and still, it’s impossible to ignore. Along with the numbness and pain, the constant ringing makes sleep really difficult.” Glenn uses a white noise machine at night to distract him from the tinnitus, but a full night of rest is still rare.

“Among veterans treated in the VA health system, sleep disorders are twice as [common] among MS patients than they are among the general population—5.9 percent vs. 2.7 percent,” says Christopher Bever, M.D., professor of neurology, pharmacology, and physical therapy in the department of neurology at the University of Maryland.

In Dr. Bever’s study of 206 MS patients, presented at the American Neurological Association’s annual meeting in 2008, 75 patients had a sleep-related movement disorder, meaning that they had involuntary movements interfering with sleep. The remaining 131 patients suffered from other sleep disorders, including obstructive sleep apnea (in which the tissues of

the throat interfere with breathing during sleep); central sleep apnea (in which the parts of the brain that regulate breathing slow down); rapid eye movement (REM) sleep behavioral disorder (where patients act out their dreams); and narcolepsy (which often causes patients to fall asleep unexpectedly and at inappropriate times during the day).

As to whether MS is the cause of these sleep disorders or simply a co-existing condition, Dr. Bever says it's likely a mix. Either way, they should be discussed with your doctor. "Some of these sleep disorders, like sleep-related movement disorder and central sleep apnea, may be caused by the location of MS lesions, which are areas of damage within the brain." In his study, 65 percent of patients with sleep-related movement disorders had lesions in the primary and supplementary motor cortex areas. Other sleep disorders, such as obstructive sleep apnea, are caused by upper airway obstruction and are less likely to be caused by the MS.

Unfortunately, many neurologists aren't aware of the association between MS and sleep disorders. As a result, patients like 45-year-old Veronica Pittaluga of Winter Haven, FL, subsist on little or no sleep for years before their physicians suggest a formal sleep evaluation.

"I told my doctors that I'd had trouble sleeping and had been taking sleeping pills on and off for years," she says. "I always chalked it up to stress, perimenopause, or pain in my legs from spasticity." Pittaluga was diagnosed with MS in 1996, but she wasn't diagnosed with sleep apnea until 2008.

The consequences of delaying diagnosis can be serious. "While the most immediate problem associated with sleep disorders can be daytime fatigue—which is a bad thing—sleep disorders can also have important medical consequences like high blood pressure and heart problems," says Dr. Bever. "It's important for MS patients with daytime drowsiness to ask their physicians about sleep disorders and determine whether referral to a sleep center would be appropriate."

DRUG TREATMENTS

Depending on the type of sleep disorder you have, a variety of medical treatments are available to help you return to restful slumber. For sleep-related movement disorders, medications are usually the first line of defense. Traditionally used for Parkinson's disease, dopaminergic agents like ropinirole (Requip) and pramipexole (Mirapex) increase dopamine, a neurotransmitter that regulates muscle movements. Benzodiazepines and



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narcotics may also be helpful for sleep-related movement disorders. Patients with narcolepsy also respond well to medication—usually stimulant and antidepressant drugs.

In addition to pain meds (especially narcotics) and anti-convulsant drugs such as gabapentin (Neurontin), many MS patients

take sleep medications like zolpidem (Ambien, Ambien CR), eszopiclone (Lunesta), and even anti-anxiety medications such as alprazolam (Xanax). Patients like Glenn often can't function without them. "My neurologist prescribed Ambien CR, which was good at knocking me out. I was still waking up at 2 a.m., but without the medication, I wouldn't get any sleep at all."

Still, experts advise against relying on sleep medications. Beyond the addictive nature of these drugs and their impact on sleep patterns—often for days after patients take them—such medications may also interact with other prescriptions. What's more, the meds wear off within six hours for most people. After that, their legs hurt, their feet burn, they have pins and needles everywhere, and they can't fall back asleep.

"Every time I turn over in my sleep, I wake up," says 35-year-old Beki Rhein of Springfield, MO. "My hips or my legs hurt and then I can't fall back to sleep." To prevent awakening in the wee hours, many patients try to stave off slumber for as long as possible. But that launches them into a vicious cycle of lying awake at night and then trying to stay awake during the day.

As to whether MS is the cause of these sleep disorders or simply a **co-existing condition**, Dr. Bever says it's likely a mix.

"I had a month where the fatigue was so debilitating that I couldn't get off of the couch," says Rhein. "That's when I started taking Provigil." Modafinil (Provigil) promotes wakefulness and is approved for narcolepsy. Some patients with MS find it helps them battle fatigue too. However, at \$12 a pill, Provigil isn't an option for the average American, especially since most patients need about 2 pills a day—\$8,760 over the course of a year.

"The drug company tripled the cost of the medication as it became more widely prescribed," says Mark Mahowald, M.D., director of the Minnesota Regional Sleep Disorders Center in Hennepin County, MN, and professor of neurology at the University of Minnesota Medical School. "I don't recommend the medication for two reasons. First, scientific studies show it isn't effective for fatigue caused by MS. Second, the price is unconscionable."

Some patients who have MS may also have narcolepsy; modafinil may work for them. Nevertheless, Dr. Mahowald recommends seeing your doctor for an appropriate prescription since the drug is so expensive.

OTHER MEDICAL TREATMENTS

The most widely recommended treatment for moderate to severe obstructive sleep apnea is continuous positive airway pressure (CPAP), which provides patients with pressurized air to prevent the airway from collapsing. Even though most CPAP units are the size of a tissue box and many are available with a built-in humidifier for comfort, many patients still have trouble wearing the mask while they sleep.

In some cases, your doctor may prescribe BPAP instead of CPAP for obstructive sleep apnea. BPAP or BiPAP is short for bilevel positive airway pressure. It functions the same way as a CPAP, but provides two different levels of pressure. The machine mimics normal breathing by providing a higher pressure when you're breathing in and a lower pressure when you're breathing out.

Even so, many patients have a hard time using the machine. "It's not natural to lay down with a mask and have air blowing up your nose," Pittaluga says. And for people like Glenn Scott who tend to feel claustrophobic in confined spaces, the mask may not be an option. That's where surgery comes in.

Uvulopalatopharyngoplasty (also known by the abbreviations UPPP and UP3) is a surgical procedure used to remove tissue in the throat and widen the airway. The procedure allows air to move through the throat more easily when you breathe, which helps reduce snoring. Trouble is, the results of the surgery are somewhat disappointing. Breathing may improve immediately following the surgery, but improve-

ments tend to deteriorate after about two years. Studies suggest that UPPP, as a stand-alone procedure, is effective in less than 40 percent of patients.

"My surgeon was very good about setting expectations and explained that the surgery didn't have a very high success rate—and that some patients may come out worse off than they were before," says Scott, whose surgery was ineffective.

Another procedure called the Stanford Protocol is essentially a "cocktail" of surgeries aimed at addressing the entire airway. The Protocol operation involves two phases: a soft tissue surgery including UPPP; and maxillomandibular advancement, a surgery that anchors the tongue muscle to the chin and pulls the tongue forward as well. If the procedure is effective, the tongue will no longer block the airway when the patient sleeps.

SLEEP: IMAGINE THAT!

Instead of letting sleepless nights wreak havoc on her life—or relying on sleeping and waking medications to function—Pittaluga incorporates lifestyle strategies that promote restful slumber. She

Sleep Disorder or MS Symptom?

With up to 87 percent of MS patients reporting fatigue, it can be difficult to determine whether sleep problems are a symptom of MS or whether the patient has a diagnosable sleep disorder.

"Fatigue is ubiquitous with MS patients. It's almost intrinsic to the disease," says Mark Mahowald, M.D., director of the Minnesota Regional Sleep Disorders Center in Hennepin County, MN, and professor of neurology at the University of Minnesota Medical School. "Unfortunately, the medical profession doesn't understand fatigue very well. We don't know what causes it, we can't measure it, and we can't treat it."

In some cases the exhaustion is so overwhelming that patients can't get off the couch. "I feel like a noodle and I just have to relax," says Rhein. "It's tempting to blame everything on the MS, but not every sleep issue is related to MS. That's one of the most frustrating things about the disease."

If you're fatigued during the day and can't seem to get a full night of sleep, ask your partner or spouse whether you twitch, jerk, and move during your sleep or whether you snore loudly—two indications of a diagnosable sleep disorder. "If there's some suggestion that you have a sleep disorder in addition to the MS, ask your doctor for a formal sleep evaluation," says Dr. Mahowald.

Beyond fatigue, sleep disorders are associated with **high blood pressure and heart problems.**

turns off the TV and the computer at a reasonable time, stops eating several hours before bed, and avoids caffeine. When it's time for bed, she tries to get as comfortable as possible.

"I have a pillow that supports my neck. It helps with the BPAP mask when I'm lying on my side," she says. "I also place a pillow in between my legs to alleviate pain in my hips and legs."

Experts also recommend aerobic exercise, both for day-time fatigue and sleeplessness. "It's a paradox," says Jeffrey Cohen, M.D., staff neurologist and director of the experimental therapeutics program at the Cleveland Clinic's Mellen Center in Cleveland, OH. "People are completely exhausted and we're telling them to exercise. But it really does boost their energy level."

In fact, several studies show that regular aerobic exercise helps combat daytime fatigue, which can make it easier to sleep at night. And don't forget "alternative" remedies like hypnosis, guided imagery, and progressive relaxation.

"Your typical waking and sleeping times are programmed in your mind. Instead of counting sheep, try re-setting the program," suggests Donna Fremon-Powell, certified guided-imagery therapist and hypnotherapist in La Habra, CA. "Both guided imagery and hypnosis bring your brain into a deeply relaxed state. Plus, during this time, the mind may be more willing to accept suggestions such as 'I will sleep soundly through the night and wake fully refreshed and alert in the morning.'"

Experiencing hypnosis or guided imagery—or listening to a relaxation CD as you fall asleep—can help you change negative sleeping patterns and invoke more restful slumber. Many patients find they can be lulled into sleep after visualizing themselves in a tranquil environment, such as with a babbling brook or peaceful palm trees swaying in the breeze.

"If you awake in the middle of the night and put the CD back on, you'll usually fall asleep again without any trouble," says Fremon-Powell. She suggests selecting a CD that's approximately 45 minutes so it coincides with your natural sleep patterns (hers is available at gladheartproject.com).

Another useful tool is repetition. "Repeating phrases like 'toes go to sleep, feet go to sleep, heels go to sleep,' and working your way all the way up to the top of your head, often works well for people with severe sleep issues," says Fremon-Powell. When you mentally put each part of your body to sleep, you're more likely to relax and release anxious thoughts—including whether or not you'll fall asleep tonight. NN

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A DOZZZEN TIPS

1 Wake up and go to bed at the same time every day, even on weekends. If you sleep in, you might not be able to fall asleep the next night. The reason? You have to be awake for a certain amount of time before you'll be sleepy enough to fall asleep again.

2 Create and stick to a nightly bedtime ritual. Instead of balancing your check book, turn to soothing activities like taking a warm bath, meditating, or reading.

3 If you can view a clock from your bed, move it. If you've just woken up and you look to see what time it is, you have to take yourself from transitional sleep to full awakening, and you've made it harder to fall back asleep.

4 Create a safe haven where you sleep. Sleeping soundly requires the right environment: dark, quiet, comfortable, and cool. While some potential sleep saboteurs are beyond your control, blackout shades, earplugs, humidifiers, and fans can help.

5 Watch what and when you drink. Tea, soda, chocolate—they all contain caffeine and stay in the body for three to five hours. Eliminate caffeine after noon, and try not to drink liquids before bed, especially if you have nocturia.

6 Get moving, just don't do it right before bedtime. Study after study shows that people who are more physically active get better sleep.

7 Use your bedroom for sleep and sex only. Reserving the bedroom for only sleep and sex actually helps strengthen the association between bed and sleep. Reading in bed is fine IF it helps you fall asleep.

8 Use your mind. Visualization and imagery can help calm both the mind and the body, which allows sleep to set in more naturally.

9 Time your meds carefully. Ingesting medication—just like ingesting food—kick starts your metabolism. Take medications, herbal supplements, or other remedies early in the day.

10 Don't drink to fall asleep. Alcohol may make you feel sleepy initially, but it actually makes it harder for you to stay asleep.

11 Immerse yourself in daylight. Getting sufficient exposure to light during the day can help you stay awake and alert during the day, and prepare you for a good night's sleep.

12 Write it down. Instead of ruminating over the day's dramas right before bed, set aside a "worry time" earlier in the day. If your sleep problems persist, keep a sleep diary, noting the type of problems you're experiencing and when they occur. It's a useful tool to have when you talk to your doctor.