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HEALTH SENSE

Motion sickness

Restless legs syndrome keeps you going (even if you want to stop)

By Judy Foreman | May 17, 2010

The symptoms of restless legs syndrome sound so bizarre — creepy-crawly feelings and an uncontrollable urge to move the legs, especially at bedtime — that until recently, many people who experienced it simply weren't believed when they described it to others.

Betsy Dunn, an 85-year-old Cambridge businesswoman who has had restless legs for nearly 30 years, remembers a doctor saying she must be depressed. "I walked out and never went back," she says. "All I needed him to say was, 'I don't know what this is, but together we will find out.'"

In severe cases, like that of Donald Loveland, 75, a retired Duke University computer scientist now living in Dennis, the urge to move the legs overwhelms everything else, including pain. Right after back surgery, he recalls, "it was actually painful to be up but I had to get up anyway."

Ron Blum, 38, a Jamaica Plain e-mail marketer who first noticed his symptoms as a 7-year-old, recalls that the minute he lay down and tried to sleep, "my left leg felt like it had to go for a walk." Though he never told his parents, he'd get up and walk for hours in circles. It wasn't until years later that a friend heard about RLS. "He called me up and said, 'Ron, I know what you have. It has a name.'"

It also has growing recognition. RLS may affect some 12 million Americans, according to the National Institute of Neurological Disorders and Stroke, as reported on the National Institutes of Health website (www.ninds.nih.gov/disorders). The NIH supports research into the condition at major medical institutions across the country, as well as within its own labs.

The NIH report notes that the number of RLS sufferers may be even higher than estimated. Some people with the condition don't seek medical attention, believing that they will not be taken seriously, that their symptoms are too mild, or that their condition is not treatable. Some physicians wrongly attribute the symptoms to nervousness, insomnia, stress, arthritis, muscle cramps, or aging.

"You can think of RLS today as where sleep apnea was 10 to 15 years ago," says Dr. John Winkelman, a psychiatrist, RLS expert, and medical director of Sleep Health Centers, which is affiliated with Brigham and Women's Hospital.

"We used to think of sleep apnea as a bunch of fat guys snoring," says Winkelman, who consults for drug companies that make RLS medications. "We are also just beginning to recognize the potential negative medical consequences of RLS." A number of studies have hinted that the syndrome might be associated with more serious conditions.

Not to mention the toll RLS takes on the quality of life.

"There were many, many nights when I would sleep for only two and a half or three hours," recalls Roberta Kittredge, a 65-year-old retired teacher in Hampton, N.H., who first got RLS when she was pregnant. (Some studies suggest a link between RLS and high estrogen levels.) "Every night I went to bed positive I would sleep, and two or three minutes later, I was out of bed and walking the floor for hours and hours."

There is currently no single diagnostic test for RLS.

“We know what’s wrong,” says Richard Allen, an associate professor of neurology at Johns Hopkins University. “The neurobiology of RLS is definitely clear.”

Levels of iron fall too low in parts of the brain, resulting in reduced availability of dopamine, a neurotransmitter that carries information between the body’s cells involved with movement that is also deficient in such disorders as Parkinson’s disease. In addition, four genes have been linked to RLS, which often appears in families.

The dopamine connection helps explain why RLS has such a distinct circadian rhythm, says Allen, who also consults for companies that make RLS drugs. Dopamine levels follow a clear 24-hour pattern, with levels lowest in the evening. Moreover, presumably because both RLS and Parkinson’s involve low dopamine, some of the dopamine-enhancing drugs used to treat Parkinson’s — like Mirapex and Requip — also can reduce or eliminate RLS symptoms in some patients. Side effects may include nausea and headache. Taking iron supplements has been helpful in decreasing or halting RLS symptoms for some patients.

“I would probably be dead by now because of exhaustion,” says retired Newton architect Paul Dudek, 70, whose life improved dramatically when he was finally diagnosed and treated with medication.

Dopamine also plays an important role in erectile function, and epidemiologist Xiang Gao of the Harvard School of Public Health has shown that men with relatively severe RLS have nearly double the normal risk of erectile dysfunction. (Xiang Gao has no ties to RLS drug companies.)

But dopamine isn’t the only neurotransmitter that plays into the RLS picture. Histamine, for one, is a powerful brain stimulant, so drugs that block histamine — antihistamines such as Benadryl — can significantly exacerbate RLS symptoms.

One of the frustrations with RLS is that symptoms are usually triggered just when a person needs to sit or lie still, such as on long plane trips or when sitting in the audience at concerts and other presentations. Symptoms tend to be most severe at night.

Once asleep, 80 percent of people with RLS also exhibit another condition: periodic limb movement during sleep (PLMS), in which the legs jerk as often as every 20 or 30 seconds. Researchers from the University of Montreal and elsewhere have shown that each involuntary PLMS leg movement is associated with a dramatic increase in blood pressure.

Studies suggest RLS might be associated with more serious medical problems, such as increased risk of heart disease and stroke.

If a link between RLS and high blood pressure is confirmed, the impact would be dramatic. “Hypertension is a powerful predictor of premature death,” says Dr. David Rye, a neurologist at Emory University who studies the genetics of RLS and PLMS and has the conditions himself. Rye also consults with companies that make RLS drugs.

So far, though a number of researchers have noted associations between RLS and other diseases, no one has established causality between RLS and the other conditions. RLS is not an established risk factor for cardiovascular disease in the way that cholesterol is, for example.

While understanding the condition is a complicated task, RLS patient Kittredge can offer some hard-won advice to people who might be suffering in silence and shame: “Find an educated doctor . . . who understands RLS,” she says. “There is hope out there. I am living proof.”

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