From Sandie's Desk

Restless Leg Syndrome

For most people, night is a time of rest and renewal; however, for many people with Parkinson's, night all too often brings anything but. The reasons for nighttime difficulties are multiple and complex. While some difficulties are related to Parkinson's, we can't blame Parkinson's for everything. Today, my topic is Restless Leg Syndrome (RLS)—the most common disorder you've never heard of.

RLS is very common for people with Parkinson's (although it also affects people who don't have Parkinson's), and is seen in approximately 10 percent of the population. My experience in speaking to people with Parkinson's is that they are not aware that they have RLS. Like Parkinson's, RLS is a neurologic disorder that involves movement of the legs, so folks think what they are experiencing is yet another Parkinson's symptom; therefore, they don't mention it to their doctor.

The symptoms of RLS:

- 1. Include a strong urge to move your legs, or to walk, which you may not be able to resist
- 2. May be accompanied by uncomfortable sensations that I have heard described as creeping, itching, pulling, creepy-crawly, tugging, or gnawing
- 3. May be associated with numbness, aches, and cramps
- 4. Start or become worse when you are resting
- Are worse in the evening, especially when you are lying down, so you may have difficulty getting to sleep, or you may wake up multiple times during the night
- 6. Can be serious enough to disrupt sleep, resulting in sleep deficiency and daytime drowsiness. This may cause major problems in the home, as well as in your social and work life.
- 7. May get better when you move your legs. Relief starts very soon after starting an activity (like walking), lasting as long as the motor activity continues and beyond ending the activity, allowing you to relax and get back to sleep.

Some people who have RLS also experience periodic limb movements during sleep. These are jerks or jumping movements that occur every 20-30 seconds on and off during the night. (These jerks/jumping movements should not be confused with the sudden, usually single jerk that sometimes happens as our muscles are relaxing just prior to falling asleep.) These movements are not harmful but can be frightening—especially to your bed partner.



Sandie Jones

Sandie Jones trained as a registered nurse, specializing in psychiatry. In 1998, she joined Parkinson Canada. and is now an integral part of the Information & Referral team. In this role she has provided information on support, education, medical aspects, coping strategies, community services, and other information about Parkinson's disease and it's management, not only to people living with Parkinson's disease and their families, but to professionals working with these people as well. This role has given her a comprehensive insight into the problems of people living with Parkinson's disease, as well as their carepartners.



Just like Parkinson's, research into the cause of RLS is occurring worldwide, but so far no one single unifying cause has been identified. There are no lab tests available to confirm or deny the presence of RLS. Diagnosis is based on your medical history and a thorough physical examination.

Anemia (a low red blood-cell count) and/or low levels of iron in the blood frequently contribute to a worsening of RLS, so anyone with this diagnosis needs to have his or her blood checked, as these problems can be easily reversed.

There are over-the-counter and prescription pharmaceutical therapies available to ease the symptoms of RLS, so it is important to talk to your doctor about your symptoms.

How to live with RLS:

- 1. DON'T FIGHT IT! Don't suppress the urge to move. Get out of bed and find an activity to get your mind off your restless legs.
- 2. Find physical activities that help you deal with the symptoms and create an exercise schedule.
- 3. Eat a healthy, balanced diet.
- 4. Start a sleep diary. Keep track of your sleep/wake cycle to help the doctor determine what is causing your sleep disturbance. Dictate into an audio recorder if writing is illegible.
- 5. Sometimes a hot, soothing bath helps.
- 6. The dopamine agonists Mirapex and Requip are effective in the treatment for some individuals with Parkinson's and RLS, which is why it is important to talk about your symptoms with your doctor.

Sleep is an essential part of life that most people can take for granted, and any condition that causes sleep disturbances can greatly reduce your ability to function. Being well rested means you will be better able to manage your symptoms.

The first step to treatment of sleep disturbances is recognition of the problem. Help your doctor by keeping a record of your nighttime activities (well, maybe not ALL of them!) so you can give accurate information during your appointment.

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