PATIENT EDUCATION | INFORMATION SERIES

Restless Legs Syndrome

Restless Legs Syndrome (RLS), also known as Willis-Ekbom Disease (WED), is a common sleep-related movement disorder. About 1 in 10 adults in the U.S. have problems from restless leg syndrome. It also can be seen in about 2% of children. Women are twice as likely as men to have RLS. People with RLS will have symptoms most often during times when they are less active, especially at bedtime. RLS most often causes an overwhelming urge to move your legs and sometimes other parts of your body.



This urge is often associated with unpleasant sensations in different parts of the body. The symptoms can be mild to severe and can affect your ability to go to sleep and stay asleep. People with RLS often sleep less at night and feel more tired during the day.

What causes RLS?

The exact cause of RLS is uncertain. Studies have shown that low iron levels in the brain may be the cause or may be associated with RLS. Genetics likely also play a role, so if you have a family member with RLS, you are more likely to have it.

Some medical conditions may trigger or be associated with RLS. These conditions include iron deficiency, kidney failure, Parkinson's disease, diabetes, rheumatoid arthritis, varicose veins, and peripheral neuropathy. Pregnancy, usually in the last trimester, can also cause RLS. RLS due to pregnancy often resolves on its own within a month after delivery.

Some medications, such as those to treat depression, other psychiatric conditions, nausea, colds/allergies, heart problems, and high blood pressure may also cause or worsen RLS. Environmental and lifestyle factors like alcohol, smoking, caffeine, diet and stress may also play a role in RLS.

How do I know if I have RLS?

There are 5 key features that you *must have* to diagnose RLS. One way to remember the first four is to think of the first letters of the word—**URGE**:

- Urge to move: With RLS, you have an overwhelming urge to move your legs (or other affected body parts). Usually both legs are affected, but some people may have symptoms initially in one leg that may later occur in the other leg or in other parts of the body, such as the arms or torso. You may also have unpleasant feelings or sensations such as a creeping, crawling, itching, aching, or pulling.
- Rest induced: The symptoms occur or become worse when you are sitting or lying still and resting.
- Gets better with activity: Movement, such as walking, temporarily relieves or improves the symptoms.

Evening and night accentuation: The symptoms occur or are worse in the evening and night, usually when you get into bed to rest. Symptoms from RLS may cause difficulty falling asleep or staying asleep, which may lead to feeling tired the next day. People with mild RLS may only notice symptoms after a long period of being still and may not have disrupted sleep. People with very severe RLS may have symptoms after a short period of rest and have major problems going to sleep and staying asleep. Many people with RLS also have periodic limb movement movements (PLM) in sleep, which are leg twitches or jerks that occur repeatedly throughout the night and that may disrupt sleep.

The **fifth key feature** is that symptoms should not be due to another medical or behavioral condition such as leg cramping, arthritis or habitual foot tapping. Other conditions may have similar symptoms but do not meet all of the 5 features above. These conditions include peripheral artery disease or arthritis that can cause discomfort in the legs but movement often makes the symptoms worse. Neuropathy can also cause discomfort in the legs and is usually described as a numbing, tingling, or burning sensation. The symptoms of neuropathy are usually persistent throughout the day but can be worse at night. The sensation in RLS is also different from muscle cramps or a "Charlie horse," which usually affects one leg, with tightening of the muscle, and is relieved by stretching.

How is Restless Leg Syndrome diagnosed?

WED/RLS is a clinical diagnosis based on the 5 key features above. There are no specific tests to prove RLS. If you think you have symptoms of RLS, you should talk to your health-care provider, especially if the symptoms are disrupting your sleep and/or affecting your quality of life. Your healthcare provider may refer you to a sleep specialist or neurologist who specializes in management of this condition. Your healthcare provider will ask you questions about your symptoms and do a physical examination to see if you meet the criteria for the diagnosis and to rule out other conditions that may have similar symptoms.



PATIENT EDUCATION | INFORMATION SERIES

Keep a diary for a few weeks of what your symptoms are, the severity and timing of your symptoms, and what relieves the symptoms to share with your healthcare provider. Note the start of your symptoms. You should record if the symptoms bothered your sleep, when you got into bed, when you fell asleep, how many times you woke up throughout the night, and when you woke up the next morning. Bring a list of medications you take. Find out whether any of your family members have similar symptoms, even if they do not yet have a diagnosis. Your healthcare provider may order blood tests to look for possible conditions that can be seen with RLS such as iron deficiency. A ferritin level is a blood test that looks at iron stores in the body. Your healthcare provider may order tests to rule out other conditions if he or she suspects a different cause for your symptoms.

How is RLS treated?

There is no cure for RLS. Symptoms may come and go. Many different treatment options for RLS exist. What treatment is tried and whether you need to try one, depends on whether your symptoms occur frequently and are disruptive to your sleep and/or quality of life. If you have a medical condition that may be causing the problem, treating it may resolve your symptoms. Your healthcare provider may recommend an iron supplement if you have blood tests suggesting deficiency.

Mild symptoms may be managed by lifestyle changes, which include avoiding substances that can trigger symptoms, such as alcohol, tobacco, and some prescription and over-the-counter medications. Limiting caffeine intake may also help. Moderate aerobic exercise during the day can also help with symptoms. Activities that can reduce your symptoms include walking, stretching, massaging the affected area, taking a warm or cool bath, applying hot or cold packs, performing relaxation techniques, or doing a mentally distracting activity, such as crossword puzzles, crochet, or talking to someone. If you need to travel for long periods of time, consider traveling at a time when your symptoms are least severe (usually in the morning). Try to plan for breaks or periods of time when you can walk around and stretch.

Moderate to severe symptoms may need medications in addition to lifestyle changes. Many different medications have been used to treat RLS and no single medication or dose of medication works for all people. Therefore, your healthcare provider may have you try several different medications or different doses to find the one that works best for you. The two most common types of medications prescribed are dopamine agonists (such as ropinirole and pramipexole) and alpha-2-delta ligands (such as gabapentin and pregabalin). Your healthcare provider will want to see you regularly to see how well your medication is working and watch out for any side effects.

Possible side effects of dopamine agonists include daytime sleepiness, nausea, dizziness, and impulse control disorders,

which may cause a desire to do activities such as excessive shopping or gambling. The dopamine agonists can also be associated with a phenomenon called augmentation. With augmentation, over time the symptoms may become more intense, affect other body parts, and start earlier in the day. Increasing the dose will usually make the symptoms worse, but changing to a different type of medication usually stops this progression.

Possible side effects of alpha-2-delta ligands include sleepiness, dizziness, and weight gain.

If you think you are having side effects from a medication, talk to the healthcare provider who prescribed it for you.

Authors: Stephanie M. Stahl, MD; Shalini Manchanda MD

and Ninotchka Liban Sigua, MD

Reviewers: Marianna Sockrider MD, DrPH,

Hrishikesh Kulkarni MD, Pamela DeYoung, RPSGT and Atul Malhotra, MD

R Action Steps

- Talk with your healthcare provider if you are having symptoms of RLS, especially if they are disrupting your ability to sleep or your quality of life.
- ✓ Make lifestyle changes that can improve your symptoms.
- Let your healthcare provider know if you are on a medication for RLS and are concerned with possible side effects or worsening symptoms.

Healthcare Provider's Contact Number:

Resources:

Willis-Ekbom Disease Foundation

http://www.rls.org

https://willis-ekbom.org

National Sleep Foundation

http://sleepfoundation.org

 $\label{lem:http://sleepfoundation.org/sleep-disorders-problems/restless-legs-syndrome$

National Institute of Neurological Disorders and Stroke http://www.ninds.nih.gov

National Heart, Lung, and Blood Institute

http://www.nhlbi.nih.gov/health/health-topics/topics/sdd

Sleep education – American Academy of Sleep Medicine

http://www.sleepeducation.com

http://www.sleepeducation.com/essentials-in-sleep/restless-legs-syndrome

This information is a public service of the American Thoracic Society. The content is for educational purposes only. It should not be used as a substitute for the medical advice of one's health care provider.

