



Guide to Living with RLS

What is RLS?

Restless legs syndrome (RLS), also known as Willis-Ekbom disease, is a disruptive neurologic disorder that seriously affects 2–3 percent of the adult population. RLS results in an irresistible urge to move the legs, which is often accompanied by unusual or unpleasant sensations in the legs that may be described as *creeping*, *tugging* or *pulling*. RLS most often occurs in the evening and can severely disrupt sleep, leading to a reduced quality of life.

How do I know if I have RLS?

To be correctly diagnosed with RLS, you must meet these five diagnostic criteria:

1. You have a strong urge to move your legs that you can't really resist.
2. Symptoms start or become worse when resting.
3. Symptoms get better with leg movement. Relief persists as long as the movement continues.
4. Symptoms are worse in the evening with rest.
5. The urge to move your legs and any unpleasant sensations cannot be explained by another medical condition, such as leg cramps, positional discomfort, leg swelling or arthritis.

What if I think I have RLS?

If you think you are experiencing RLS symptoms, it is important to schedule an appointment with your physician. Your doctor will review your medical history, complete a physical exam, listen to a description of your symptoms, complete a diagnostic interview, and rule out conditions that may be confused with RLS. In addition, your doctor may check your iron levels. If another sleep disorder is suspected, you may be asked to stay overnight for a sleep study in a sleep lab. Your physician will consider all of these factors in determining whether or not you have the disease; there is no test available to confirm a diagnosis of RLS.

What causes RLS?

Research into the cause of RLS is ongoing. Researchers have discovered gene variants that contribute to the risk for RLS. While RLS often runs in families, it also sometimes appears as the result of another condition. A substantial number of women develop RLS during pregnancy. In addition, anemia, low iron (ferritin) levels, endstage renal disease with dialysis, and peripheral neuropathy are all associated with RLS.

What treatments are available?

While there is currently no cure for RLS, there are many nonpharmaceutical and pharmaceutical therapies that help

ease RLS symptoms. There are three common drug classes that offer relief from RLS symptoms:

- *Dopamine agents*
 - Dopamine agonists (pramipexole, ropinirole and rotigotine) mimic activity of the chemical dopamine in the brain.
 - Carbidopa/levodopa (Sinemet) works by increasing dopamine levels in the brain. This class of drugs is not used for daily RLS symptom management due to increased risk of augmentation; when taken infrequently, risk of augmentation is low.
- *Alpha-2-delta ligands* (gabapentin, gabapentin enacarbil and pregabalin) are thought to relieve discomfort by changing the excitability of nerves that carry RLS sensations or pain.
- *Opioid pain relievers* (codeine, oxycodone, methadone) are used when RLS symptoms are moderate to severe and other treatment options are no longer tolerated or effective.

In addition, you and your doctor can:

- Check for iron deficiency (ferritin level).
- Look at eliminating over-the-counter medications that contain first-generation sedating antihistamines (diphenhydramine), and some antidepressants that are known to worsen RLS symptoms.
- Develop a daily schedule of exercise and/or physical activities that help you deal with RLS.
- Engage in mentally stimulating activities to keep your mind occupied when RLS presents itself.
- Consider eliminating caffeine, alcohol and nicotine.
- Identify and eliminate activities that worsen your RLS symptoms.
- Implement a program of good sleep habits.
- Download the Foundation's *RLS Triggers* handout from www.rls.org.

How do I live with RLS?

Living with RLS can be challenging. You can lessen your symptoms through treatments and lifestyle strategies. You can also find coping practices that work for you. Here are some suggestions:

- *Talk about RLS.* Share information with family and friends.
- *Don't fight it.* Don't suppress the urge to move. Get out of bed and find an activity to get your mind off of RLS.
- *Keep a sleep diary.* Keep track of your medications and strategies to discuss with your physician. Dictate a voice memo if you can't sit still to write. You can also record daily activities like diet and exercise.

- *Occupy your mind.* Find an activity you enjoy to keep your mind engaged and help you through troublesome times.
- *Rise to new levels.* Elevate your desktop or bookstand to a height that will allow you to stand as you work or read.
- *Stretch out your day.* Begin and end each day with stretching or gentle massage.
- *Help others.* Consider joining or starting a support group. There are more than 75 groups throughout the United States and Canada.

What is the RLS Foundation?

The Restless Legs Syndrome (RLS) Foundation is a nonprofit patient organization dedicated to improving the lives of the millions of men, women and children living with this devastating disease. The Foundation's goals are to promote better treatment by educating patients and healthcare providers, to distribute educational materials to inform individuals about available treatments and to fund the only research grant program dedicated to pursuing new treatments and a cure for RLS.

Where can I get more information?

The fastest and easiest way to get accurate RLS information is on our website. At www.rls.org you'll find information about support groups, publications about RLS, a searchable healthcare provider directory, and information about current research on RLS. Through the Member Portal, you can access past issues of *NightWalkers* quarterly magazine, and much more. You can also contact the RLS Foundation at 512-366-9109 or by email at info@rls.org.

How can I find a support group?

Through RLS support groups, people come together to share their experiences with RLS and to offer support to others. You can find a list of support groups on www.rls.org and in each issue of *NightWalkers*. The Foundation's social media pages and online discussion board also offer the opportunity to connect informally with people all over the world who are living with RLS.

How can I find a doctor?

The RLS Foundation does not have any physicians on staff, but on www.rls.org offers an extensive directory of healthcare providers who have expressed an interest in treating RLS patients. You will also find a list of RLS Quality Care Centers. These centers have expert RLS physicians with experience in treating mild to severe cases of RLS.

How do I become a member?

For \$35 a year in the US (\$45 internationally) you can become a member of the RLS Foundation by visiting www.rls.org. Member benefits include:

- *NightWalkers* quarterly member magazine subscription
- Medical Alert and Special Accommodations Card
- The RLS Foundation's *Medical Bulletin* (a comprehensive guide to diagnosis, treatment and management of RLS)

3006 Bee Caves Road | Suite D206 | Austin, Texas 78746 | 512.366.9109
www.rls.org | rlsfoundation.blogspot.com | Discussion Board: bb.rls.org

- 24/7 online access to RLS publications, past webinars and the *NightWalkers* archive

The RLS Foundation also offers a healthcare provider membership. For \$49 a year, providers receive a sample of RLS publications, an RLS Powerpoint slide deck, subscription to *NightWalkers*, access to online resources, complimentary publications, and a listing in our online healthcare provider directory. Patients may also provide gift memberships for their doctors.

What can I do to help?

The work of the Foundation is supported by individuals like you. Your tax-deductible gift in any amount will help support the Foundation's mission. You can also become a member of the RLS Foundation. Your membership not only entitles you to many benefits but also helps enhance awareness and educational outreach activities. Additionally, your support benefits the only grant program whose sole purpose is to fund research leading to new treatments and a cure for RLS.

Remember: You are not alone!

Up to 10 percent of the population experiences RLS symptoms. Contact the RLS Foundation or your local support group for more information about how you can find help in dealing with RLS or how you can make a difference for others.

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Become a member today and receive the Foundation's quarterly magazine, NightWalkers, as well as access to a library of handouts and brochures with the most current information available about RLS. Go to www.rls.org to help find new treatments and a cure.



The RLS Foundation is dedicated to improving the lives of the men, women, and children who live with this often devastating disease. The organization's goals are to increase awareness, improve treatments and, through research, find a cure for restless legs syndrome.

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