



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 3% 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 criteria¹:

- Urge to move the legs associated with unpleasant leg sensations.
- Rest induces symptoms.
- Gets better with activity.
- Evening and nighttime worsening.
- Solely not accounted for by another medical or behavioral condition.

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?

In 2017, researchers revealed strong evidence for 19 genes that contribute substantially to the risk for RLS; 13 were new gene discoveries. 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. Additionally, anemia, low iron (ferritin) levels, end stage 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.
- *Opioids* (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 (serum 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. Download *Can an Active Lifestyle Prevent or Treat 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. Download *RLS Triggers*.
- Implement a program of good sleep habits.

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. Download *RLS Patient Symptom Diary*.
- *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 over 70 support groups and contacts throughout the United States and Canada.

What is the RLS Foundation?

The Restless Legs Syndrome 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 raise awareness and 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?

You will find the most comprehensive and accurate RLS information at www.rls.org. You will find information about RLS Quality Care Centers, a healthcare provider directory, a list of support groups in your area, as well as publications covering specific concerns like augmentation, medications, RLS and children, and much more. The Member Portal offers webcast recordings from RLS experts, past issues of *NightWalkers* quarterly magazine, and publications covering important RLS topics and concerns. 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 (bb.rls.org) also offer the opportunity to connect informally with people all over the world who are living with RLS.

How can I find a doctor?

You will find a list of RLS Quality Care Centers on www.rls.org. These centers have certified RLS healthcare providers with experience in treating mild to severe cases of RLS. We also offer a directory of healthcare providers who have indicated experience in treating RLS patients.

How do I become a member?

For \$35 a year in the US and Canada, or \$45 internationally, you can become a member of the RLS Foundation by visiting www.rls.org/join. Member benefits include:

- *NightWalkers* quarterly print magazine subscription
- Medical Alert and Special Accommodations Card
- The *RLS Medical Bulletin* (a comprehensive guide to diagnosis, treatment and management of RLS)
- 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 supply of RLS publications, an RLS Powerpoint presentation slide deck, subscription to *NightWalkers*, access to online resources including an on-demand

RLS education webinar series for healthcare providers, publications, and upon approval, a listing in our online healthcare provider directory. If you recommend your RLS healthcare provider, you may gift a membership, or refer them to www.rls.org to be listed in our provider list.

What can I do to help?

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. 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. Additionally, your support benefits the only grant program whose sole purpose is to fund promising research leading to new treatments and a cure for RLS.

You are not alone!

One in 33 Americans require daily treatment for their RLS. Up to 10% of the population experiences RLS symptoms. Contact the RLS Foundation or your local support group for more information, to find help in managing your RLS or to make a difference for others who live with RLS.

If you like this educational publication, we invite you to enjoy 24/7 online access to the most current RLS information and resources, recorded webinars featuring RLS experts, and our quarterly print magazine, *NightWalkers*. Become an RLS Foundation member now at www.rls.org/join. Join our community of support and hope at www.rls.org. You are not alone!

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¹Allen RP, Picchetti DL, Garcia-Borreguero D, et al. Restless legs syndrome/Willis-Ekbom disease diagnostic criteria: updated International Restless Legs Syndrome Study Group (IRLSSG) consensus criteria--history, rationale, description, and significance. *Sleep Med.* Aug 2014. 15(8):860-873



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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