



# A Quick 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% 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?

In order for you to be correctly diagnosed with RLS, you must meet the criteria described in the five bullet points below:

- A strong urge to move your legs which you can't really resist.
- RLS symptoms start or become worse when resting.
- RLS symptoms get better with leg movement. Relief persists as long as the movement continues.
- RLS symptoms are worse in the evening with rest.
- 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 causes RLS?

Research into the cause of RLS is ongoing. Researchers have discovered gene variants that contribute to the risk for RLS. We do know that 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 if I think I have RLS?

If you think you have RLS, 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. There are no tests available to confirm a diagnosis of 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) - not used for daily RLS symptom management due to increased risk of augmentation, works by increasing dopamine levels in the brain, 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 exercise schedule and/or physical activities that help you deal with RLS
- engage in mentally stimulating activities to keep your mind occupied when RLS presents itself
- discuss eliminating caffeine, alcohol and nicotine from your diet
- identify and eliminate activities that worsen your RLS symptoms
- implement a program of good sleep habits
- download the Foundation's *RLS Triggers* handout on our website

## How do I live with RLS?

Living with RLS involves finding coping strategies that work for you. Below are some coping strategies:

- *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 RLS.
- *Keep a sleep diary.* Keep track of your medications and strategies to discuss these with your physician. Dictate a voice memo if you can't sit still to write. You can also record daily activities like diet, exercise, etc.
- *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 Foundation is a nonprofit patient organization dedicated to improving the lives of the millions of men, women and children living with this devastating disease. Our goals are to promote activities that improve awareness of the disease among members of the public and health care communities, to distribute educational materials to inform individuals about available treatments and to fund the only dedicated Research Grant Program for the purpose of discovering new treatments and a cure for RLS.

### Where can I get more info?

The fastest and easiest way to get accurate RLS information is on our website. At [www.rls.org](http://www.rls.org) you'll find information about support groups, publications about RLS, our searchable healthcare provider directory, current research on RLS. Access the Member Portal for past issues of our *NightWalkers* quarterly magazine, and much more. You can also call the RLS Foundation at 512-366-9109 or email us at [info@rls.org](mailto:info@rls.org).

### How can I find a support group?

All over the country, people are coming together to share their experience about living with RLS and to offer support to others. You can find a list of support groups on our website. The list is also included in each issue of *NightWalkers*. Our social media pages and online discussion boards also offer the opportunity to connect more 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. However our website ([www.rls.org](http://www.rls.org)) features an extensive directory of healthcare providers who have expressed interest in treating RLS patients. You will also find a list of Quality Care Centers on our website. 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 and \$45 internationally, you can become a member of the RLS Foundation at [www.rls.org/become-a-member](http://www.rls.org/become-a-member). Membership entitles you to a wide assortment of benefits including:

- *NightWalkers* quarterly news magazine subscription
- Medical Alert and Special Accommodations Card
- The RLS Foundation's *Medical Bulletin* (a comprehensive guide to diagnosis, treatment and management of RLS)
- 24/7 online access to RLS publications, past webinars & magazine archive

Your Foundation membership supports our work to spread awareness and through research to identify new treatments and ultimately, a cure for RLS.

The RLS Foundation also offers a Healthcare Provider Membership. For \$49 a year providers receive a sample of RLS publications, subscription to our quarterly magazine, *NightWalkers*, access to online resources, complimentary publications as well as being listed in our online healthcare provider directory. Patients may also provide a gift membership for their doctor.

### What can I do to help?

The work of the Foundation is supported by individuals like you. Your tax-deductible gift in any amount educate and raise RLS awareness, and help fund vital research. You can also become a member of the RLS Foundation which not only entitles you to a long list of benefits but also will help to enhance our awareness and educational outreach activities and to support the only dedicated research 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% of the population experiences occasional 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 living with restless legs syndrome.

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

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