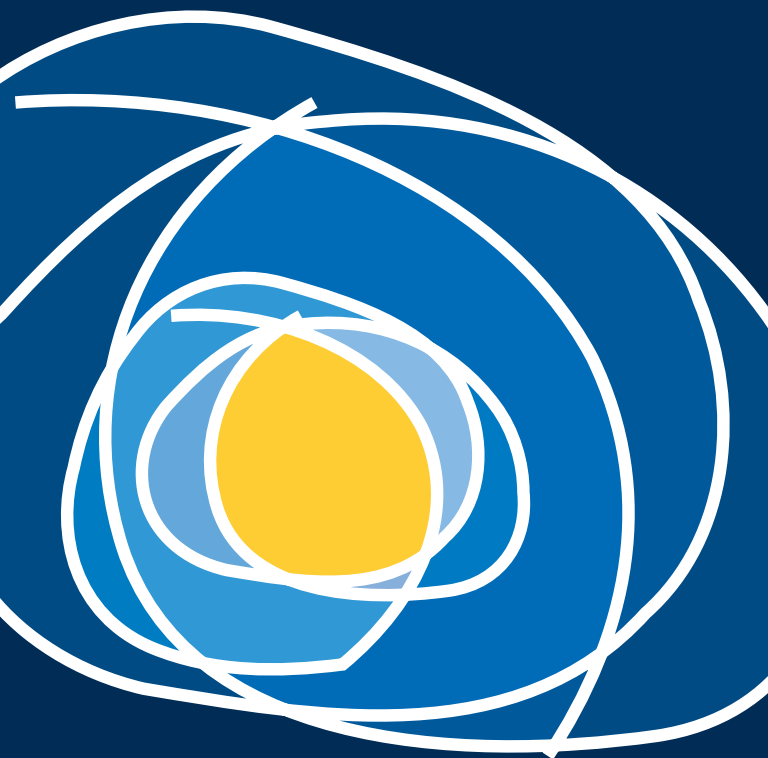


Living with
Restless Legs
Syndrome



Do you have restless legs syndrome?

1. When you sit or lie down, do you have a strong feeling or urge to move your legs that may prove impossible to resist?
2. Is this urge to move your legs associated with unpleasant or creepy-crawly sensations deep in your legs?
3. Do the sensations and urge to move tend to occur during periods of rest or inactivity?
4. Are these symptoms reduced or relieved by voluntary movement of your legs?
5. Do the sensations and urge to move bother you more in the evening and at night, especially when you lie down, than during the day?
6. Do you often have trouble falling asleep or staying asleep?
7. Does your bedpartner tell you that you jerk your legs when you are asleep? Do you sometimes have involuntary leg jerks when you are awake?
8. Are you frequently tired or unable to concentrate during the day?
9. Do you have family members who experience those same urge to move and unpleasant sensations?
10. Have medical tests failed to reveal a cause for your urge to move and unpleasant sensations?

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If you do have restless legs syndrome (RLS), you are not alone. Up to 8% of the U.S. population may have this sensorimotor condition. Many people have a mild form of the disorder, but RLS severely affects the lives of millions of individuals.

Primary features of RLS

In order for a diagnosis of RLS to be made in an adult patient, each of these four features must be present:

- The primary RLS symptoms involve a strong urge to move the legs that may be impossible to resist. This urge to move the legs is usually associated with other uncomfortable sensations which are described as occurring deep in the legs and usually involve a sense of movement in the leg. These feelings are usually very uncomfortable, and in a minority of patients may be described as painful. Some words used to describe these sensations include *creeping*, *itching*, *pulling*, *creepy-crawly* or *tugging*. When the uncomfortable sensations occur they are linked to the urge to move the leg, but many patients do not report any sensation aside from the need to move the leg. (Although their presence is most common in the legs, these sensations may also occasionally occur in the arms or, rarely, in other body parts.)
- The RLS symptoms start or become worse when the affected individual is at rest. The longer the period of rest, the greater the likelihood that the symptoms will occur and the more severe they are likely to be.
- The RLS symptoms are reduced by voluntary movement of the affected extremities. This relief can be complete or only partial, generally starts immediately or soon after the onset of activity, and persists as long as the motor activity continues. Walking is the most commonly selected activity,

particularly for the more severely affected patients. Increased motor activity during periods of rest and during sleep is common with this disorder.

- The RLS symptoms are worse in the evening and at night, especially when the individual lies down. (Sitting or lying down in the morning does not produce RLS symptoms as severe as those that occur with sitting or lying down at night.)

Associated features of RLS

RLS symptoms can cause difficulty in falling and staying asleep. Approximately 80% of people with RLS also have periodic limb movements of sleep, which are jerks that typically occur every 20 to 30 seconds on and off throughout the night, often causing partial awakenings that disrupt sleep.

If you have trouble falling asleep and staying asleep at night, you may be abnormally tired or have trouble concentrating during waking hours. Chronic sleep deprivation and its resultant effect on your ability to concentrate can adversely affect your ability to work, take part in social activities, and enjoy recreational pastimes. It can cause mood swings that can affect your personal relationships.

Cause

Research into the cause of RLS is ongoing, and answers are limited. Researchers believe that RLS may have different but perhaps overlapping causes.

RLS often runs in families. Researchers are currently looking for the gene or genes that may be responsible for this form of RLS, known as *primary* or *familial RLS*.

RLS appears sometimes to be a result of another condition, which, when present, worsens the underlying RLS. This is called *secondary RLS*. During pregnancy, particularly during the last few months, up to 15% of women develop RLS. After delivery, their symptoms often vanish. Anemia and low levels of iron in the blood are associated with symptoms of RLS, as

are chronic conditions such as peripheral neuropathy (damage to the nerves in the legs and feet) and kidney failure. Recent literature also points toward an association between RLS and symptoms of attention-deficit hyperactivity disorder.

If you have no family history of RLS and no underlying or associated conditions causing the disorder, your RLS is said to be *idiopathic*, meaning without a known cause.

Age of onset

Though RLS is diagnosed most often in people in their middle years, many individuals with RLS, particularly those with primary RLS, can trace their symptoms back to childhood. These symptoms may have been called “growing pains,” or the children may have been thought to be hyperactive because they had difficulty sitting quietly.

Diagnosis

With its classic symptoms, a diagnosis of RLS begins with a review of your medical history. After ruling out other medical conditions as the cause of your symptoms, your healthcare provider can make the diagnosis of RLS by listening to your description of the sensations. No laboratory test exists that can confirm a diagnosis of RLS. However, a thorough physical examination, including the results of necessary laboratory tests, can reveal temporary disorders, such as iron deficiency, that may be associated with RLS. Some people (including those with periodic limb movements of sleep and without the typical abnormal sensations of RLS) may require overnight sleep testing to determine other causes of their sleep disturbance. The diagnostic interview should confirm the four principal RLS diagnostic criteria and should rule out conditions which potentially mimic RLS such as diabetic neuropathy, leg cramps, positional discomfort, arthritic pains, or neuroleptic-induced akathisia.

Treatment

The goal of any medical therapy, including the treatment of RLS, is to achieve the greatest benefit while incurring the fewest risks. Sound treatment strategy, therefore, involves weighing these risks and benefits and beginning with the least-risky treatments. Low-risk therapies include making lifestyle changes and treating any symptoms caused by underlying disorders.

If an underlying iron or vitamin deficiency is found to be the cause of your restless legs, supplementing with iron, vitamin B12, or folate (as indicated) may be sufficient to relieve your symptoms. Because the use of even moderate amounts of some minerals (such as iron, magnesium, potassium, and calcium) can impair your body's ability to use other minerals or can be toxic, you should use mineral supplements only on the advice of your healthcare provider. Current recommendations include measuring a serum ferritin level (to evaluate iron-storage status) and supplementing with iron if your ferritin level is lower than 50 mcg/L.

Some medications seem to worsen the symptoms of RLS. These include calcium-channel blockers (used to treat high blood pressure and heart conditions), most anti-nausea medications, some cold and allergy medications, major tranquilizers, phenytoin, and most medications used to treat depression. Always be sure the healthcare provider overseeing your RLS treatment is aware of all the medicines you're taking, including herbal and over-the-counter medicines.

Lifestyle changes begin with identifying, on an individual basis, habits and activities that worsen or improve your RLS symptoms. A healthy balanced diet is important in reducing the severity of your RLS. Though caffeine consumption may initially appear to relieve your symptoms, the use of caffeine most likely only postpones, and often intensifies, your symptoms until later in the day. The best solution is to avoid all caffeine-containing products, including chocolate and caffeinated beverages such as coffee, tea, and soft drinks. For most people, the consumption of alcohol

increases the span or intensity of symptoms, and refraining from its use is your best solution.

Because fatigue and drowsiness tend to intensify the symptoms of RLS, implementing a program of good sleep hygiene should be a first step toward resolving your symptoms. You may find that your best sleep comes later in the 24-hour cycle when your symptoms are minimal. Some people find that a few minutes of isometric exercise before bed is helpful.

Self-directed activities that counteract your RLS symptoms appear to be very effective temporary solutions to managing the disorder. You may find that walking, stretching, taking a hot or cold bath, massaging your affected limb, applying hot or cold packs, using vibration, performing acupressure, and practicing relaxation techniques (such as biofeedback, meditation, or yoga) may help reduce or relieve your symptoms. You may also find that keeping your mind actively engaged through such activities as a stimulating discussion or argument, intricate needlework, or video games helps during times when you must stay seated, such as during travel.

Sleep hygiene

Ideally, sleep hygiene involves maintaining a cool, quiet, and comfortable sleeping environment, going to bed at the same time every night, arising at the same time every morning, and getting enough sleep to feel well rested. Some people with RLS find that going to bed later and arising later in the day helps them get adequate sleep. Good sleep hygiene also includes a program of regular, moderate exercise. Sleep experts typically recommend that exercise should take place at least 6 hours before bedtime to avoid an adverse impact on sleep; however, many people with RLS find that exercising immediately before bedtime, such as with a stationary bike or a treadmill, is useful.

In many cases, unfortunately, the symptoms of RLS either fail to resolve with the treatment of underlying disorders and the implementation of lifestyle changes or, over time, progress so that any initial relief with these methods is no longer sufficient. In either case, the use of medications (pharmacologic therapy) may prove to be necessary.

Pharmacologic therapy

No drugs have been approved by the U.S. Food and Drug Administration for the treatment of RLS, but several drugs approved for other conditions have undergone clinical studies in RLS and found to be helpful. These medications fall into four main classes — dopaminergic agents, sedatives, pain relievers, and anticonvulsants. Each drug or class of drugs has its own benefits, limitations, and side-effect profile. The medication best suited to your situation depends, among other factors, on the timing and severity of your symptoms.

Dopaminergic agents

The primary and first-line treatment for RLS is with dopaminergic agents — primarily dopamine-receptor agonists like cabergoline (Cabaser), pergolide (Permax), pramipexole (Mirapex), and ropinirole (Requip), as well as drugs like carbidopa/levodopa (Sinemet/ Restix) that add dopamine to the system. Cabergoline is used most frequently in Europe where its price is moderate.

Although dopaminergic agents are used to treat Parkinson's disease, RLS is not a form of Parkinson's disease. All of these drugs should be started at low doses and increased very slowly, with the guidance of your healthcare provider, to decrease potential side effects.

Of the dopaminergic agents, L-Dopa (Sinemet/ Restix) has been used the longest, but its use has recently been found to lead to a serious problem, known as *augmentation*, in the majority of patients who take it for the treatment of RLS. If you are taking L-Dopa, you need to be aware of this problem and

should discuss it with your physician. Also, you should not take L-Dopa within 2 hours after eating a high-protein meal.

Sedatives

Sedative agents are most effective for improving sleep quality. They are used either at bedtime in addition to a dopaminergic agent, or are chosen for individuals who have primarily nighttime symptoms. Commonly used sedatives are clonazepam (Klonopin), temazepan (Restoril), and triazolam (Halcion).

Pain relievers

Pain-relieving drugs are used most often when symptoms of RLS are severe and relentless. Some examples of medications in this category include codeine, fentanyl (Duragesic), hydrocodone (Vicodin), methadone, morphine, oxycodone (Percocet), and propoxyphene (Darvon or Darvocet).

Augmentation

When augmentation — which is most common with L-Dopa (Sinemet) — occurs, your usual dose of a dopaminergic agent will relieve your symptoms so that you are able to sleep at night, but eventually the unpleasant sensations, the need to move, and the restlessness will develop (frequently with an increased intensity) earlier in the day, in the afternoon or even in the morning. The RLS symptoms may also spread to other parts of the body, such as your arms.

If augmentation does develop, increasing your medication dosage will probably worsen your symptoms rather than improving them. Most people who develop augmentation must switch to another medication; no one, however, should ever stop taking a medication abruptly. Your healthcare provider should oversee any changes in your medication regimen.

Anticonvulsants

These drugs are particularly effective for some, but not all, patients with marked daytime symptoms, particularly those who describe their sensory discomfort as painful. Gabapentin (Neurontin) is the anticonvulsant that has shown the most promise in treating the symptoms of RLS. Other drugs in this category used to treat RLS include valproate (Depakene) and carbamazepine (Tegretol).

Summary

By arming yourself with information, you have taken the first step toward defeating RLS. Your optimum treatment plan requires that you interact closely with your healthcare provider. Choosing a healthy lifestyle, eliminating symptom-producing substances, taking vitamin and mineral supplements as necessary, and engaging in self-directed activities can all work toward reducing or eliminating the need for pharmacologic intervention.

If you do need medications, careful trials are typically necessary to find the medication and dosage most appropriate for you. Many patients find that a combination of medications works best, and sometimes a medication that has worked well over an extended period suddenly becomes ineffective and another medication must be substituted. Quite clearly, you must be extremely cautious in combining medications, and should only do so under the supervision of your healthcare provider.

Because no single treatment for RLS is entirely effective for everyone, continued research is of vital importance. Until we find the cause of RLS and a cure for it, your best approach is to work closely with your healthcare provider, interact with a local support group, and explore nondrug treatments as well as pharmacologic therapy. These strategies offer the most reliable approach to living a happy and productive life in spite of having RLS.

The Restless Legs Syndrome Foundation

The Restless Legs Syndrome Foundation, a 501(c)3 organization, provides the latest information about RLS. Through the quarterly newsletter *NightWalkers*, Foundation supporters receive the most up-to-date information on treatment and research findings, abstracts of articles in current medical journals, listings of support groups, and insights from readers in our Bedtime Stories. Says one doctor, “The *NightWalkers* newsletter is the most comprehensive source of information available about RLS.”

Members of the RLS Foundation receive the following member benefits:

- Our quarterly newsletter, *NightWalkers*
- Medical Bulletin and an enrollment form to the Healthcare Provider Directory (to share with your healthcare provider)
- Medical information card
- Medical chart stickers
- Membership card
- Free shipping on all publications ordered

From small towns to metropolitan areas, people come together to share their feelings about living with RLS, discuss ways of communicating with their families and friends about this disorder, learn about the latest treatments, and arm themselves with information to educate healthcare providers about RLS. If you would like to learn more about support groups, or are interested in starting a group in your community, please contact the RLS Foundation.

The RLS Foundation also provides information on our web site at www.rls.org. You'll find information about support groups, our searchable healthcare provider directory, current research on RLS, an *eFriends* newsletter and back issues of *NightWalkers*, and links to other sources of RLS information. You can also find out more about how to help fund the RLS Foundation's work.

In 1998 the Foundation initiated a competitive grants and fellowship program, and in 2000 the RLS Foundation Collection at the Harvard Brain Resource Center was established. Each research dollar donated to the RLS Foundation goes directly to these programs and the scientists who are investigating the cause of and a cure for RLS.

*The Restless Legs Syndrome 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 of Restless Legs Syndrome (RLS),
to improve treatments, and,
through research, to find a cure.*

The work of the Foundation is supported by individuals like you. Your tax-deductible gift in any amount will help disseminate information about RLS as we reach toward our goal of universal awareness. Your gift will also help fund vital research to find medications and other therapies for RLS, thereby fulfilling our goal of identifying effective treatments. And finally, your gift will support the research that will unlock the mysteries of RLS, allowing us to reach our goal of finding a cure for the millions of today's RLS sufferers and for future generations. Please join us today, using the envelope provided in the center of this brochure, to begin receiving your member benefits and to help us reach these goals.

RLS can be a serious disorder, but it is treatable. If you suspect that you may have RLS, consult a qualified healthcare provider. Literature distributed by the Restless Legs Syndrome Foundation, including this brochure, is offered for information purposes only, and should not be considered a substitute for the advice of a healthcare provider. The Restless Legs Syndrome Foundation does not advertise, endorse, or sponsor any products or services.

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Living with RLS

Living with RLS involves finding coping strategies that work for you. Here are some of our favorites.

- **Talk about RLS** Sharing information about RLS will help family members, friends, and co-workers understand what's happening when they see you pacing the halls at night, standing at the back of the theater, or walking to the water cooler many times throughout the day.
- **Don't fight it** If you attempt to suppress the urge to move, you may find that your symptoms only get worse. Get out of bed. Find an activity that takes your mind off of your legs. Make frequent stops while traveling.
- **Keep a sleep diary** If you can't sit still to write, dictate into a small tape recorder. Keep track of your medications and the strategies that help or hinder your battle with RLS, and share this information with your healthcare provider.
- **Occupy your mind** Keeping your mind actively engaged may ease your symptoms. Find an activity that you enjoy to help you through times when your symptoms are particularly troublesome.
- **Rise to new levels** You may be more comfortable if you elevate your desktop or bookstand to a height that will allow you to stand while you work or read.
- **Stretch out your day** Begin and end your day with stretching exercises or gentle massage.
- **Help others** Support groups bring together people affected by RLS, including family members and individuals battling this disease. Group participation allows you to help yourself and to offer your insights to others.



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