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 bed partner 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?

If you do have restless legs syndrome (RLS), you are not alone. Up to 8% of the US 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 become irresistible. This sensation of an urge to move the legs is usually associated with other uncomfortable sensations described as occurring deep in the legs and usually involves a sense of movement occurring in the leg. These are usually very uncomfortable feelings 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. (These sensations may also occasionally occur in the arms or rarely in other body parts).
- The RLS symptoms start or become worse when the afflicted individual is at rest. The longer the period of rest the more likely 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 preferred activity, particularly for the more severely affected patients. Increased motor activity during periods or rest and during sleep commonly occurs 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 with sitting or lying down at night).

Associated feature of RLS

RLS symptoms can cause difficulty in falling and staying asleep. Approximately 80% of people with RLS will 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 arousals 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
your ability to work, take part in social activities and enjoy recreational pastimes. It can cause mood swings that can affect your personal relationships.

Causes

Research into the cause of RLS is ongoing and answers are limited, but we do think 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 the 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. Anaemia 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 hands 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 health care provider can make the diagnosis of RLS by listening to your description of the sensations. No laboratory test exists that can confirm your diagnosis of RLS. However a thorough physical examination, including the results or necessary laboratory test, 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 abnormal sensations of RLS) will require an overnight testing of sleep to determine other causes of their sleep disturbance. The diagnostic interview should confirm the four principal RLS diagnostic criteria and should rule our 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 treatment, 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 health care provider. Current recommendations include checking a serum ferritin level (to evaluate iron-storage status) and supplementing with iron if your ferritin level is less than 50 mcg/L.

Some medications seem to worsen the symptoms of RLS. These drugs 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 health care 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 your RLS symptoms. A healthy balance diet is important in reducing the severity of your RLS. Though caffeine consumption may initially appear to relieve your symptoms, your use of caffeine most likely only delays, and often intensifies your symptoms to a time 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 of fatigue and drowsiness tend to worsen 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 exercises before bed helpful.

Self-directed activities that counteract your symptoms of RLS appear to be very effective, although 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 activities such as participating in a stimulating discussion or argument, performing intricate needlework, or playing video games helps during times that you must stay seated, such as when you are traveling.

Sleep hygiene. Ideally, sleep hygiene involves having 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 to obtain an adequate amount of sleep. Good sleep hygiene also involves 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 your sleep, however many people with RLS find that exercising immediately before bedtime, such as using a stationary bike or a treadmill is useful.

Unfortunately, in many cases the symptoms of RLS either initially do not resolve with the treatment of underlying disorders and the implementation of lifestyle changes or over time, progress so that relief is insufficient with these methods. In either case, the use of medications (pharmacologic therapy) may become necessary.

Pharmacologic therapy
No drugs have been approved by the US 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, sedative, 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 health care provider, to decrease potential side effects.
Of the dopaminergic agents, L-Dopa (Sinemet/Restix) has been used the longest, but it has recently been found to cause 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 not take L-Dopa within two hours after eating a high protein meal.

**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 dosage of medication will probably worsen rather than improve your symptoms. Most people who develop augmentation must switch to another medication; on one, however, should ever stop taking a medication abruptly. Your health care provider should oversee any changes in your medication regimen.

**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), Temazepam (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)

**Anticonvulsants**
These drugs are particularly effective for some but not for 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 a close interaction between you and your health care 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 best medication and the best dosage for you. Many patients report that a combination of medications works best, and sometimes a medication that has worked well for an extended period of time suddenly becomes ineffective and another medication must be substituted. Quite clearly you must be cautious in combining medications and should only do so under the supervision of your health care 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 health care provider, interact with a local support group and explore non-drug 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.
Living with RLS involves developing coping strategies that work for you. Here are some of our favorites.

1. **Talk about RLS.** Sharing information about RLS will help your family members, friends and you pacing the halls at night, standing at the back of the theatre, or walking to the water cooler many times throughout the day.

2. **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. Stop frequently when travelling.

3. **Keep a sleep diary.** Keep track of the medications and strategies that help or hinder your battle with RLS, and share this information with your health care provider.

4. **Occupy your mind.** Keeping your mind actively engaged may lessen your symptoms of RLS. Find an activity that you enjoy to help you through those times when your symptoms are particularly troublesome.

5. **Rise to new levels.** You may be more comfortable if you elevate your desktop or book stand to a height that will allow you to stand while you work or read.

6. **Stretch out your day.** Begin and end your day with stretching exercises or gently massage.

7. **Help others.** Support groups bring together family members and people with RLS. By participating in a group, you not only help yourself, but your insights may help someone else.

RLS can be a serious disorder and is treatable. Persons suspecting that they may have RLS should consult a qualified health care provider. Literature concerning RLS that is distributed by the Restless Legs Syndrome Foundation Inc including this brochure is offered for information purposes only and should not be considered a substitute for the advice of a health care provider. The Restless Legs Syndrome Foundation does not advertise, endorse, or sponsor any products or services.

This information was developed by the Restless Legs Syndrome Foundation Inc and is herewith used with permission.

Restless Legs Syndrome Foundation Inc. What is RLS? Available at: [http://www.restlesslegs.org/what_is_rls/living.htm](http://www.restlesslegs.org/what_is_rls/living.htm) accessed February 16, 2005

The information in this document is for general educational purposes only. It is not intended to substitute for personalized professional advice. Although the information was obtained from sources believed to be reliable, MedLink Corporation, its representatives, and the providers for the information do not guarantee its accuracy and disclaim responsibility for adverse consequences resulting from its use. For further information, consult a physician and the organization referred to herein.