

Restless Legs Syndrome

Do I have restless legs syndrome?

Chances are, if you are reading this brochure, it is because you are concerned that you or someone you love may have restless legs syndrome (RLS). How many of the questions below are true for you?

- When you sit or lie down, do you have a strong desire to move your legs?
- Does your desire to move your legs feel impossible to resist?
- Have you ever used the words *unpleasant*, *creepycrawly*, *creeping*, *itching*, *pulling*, or *tugging* to describe your symptoms to others?
- Does your desire to move often occur when you are resting or sitting still?
- Does moving your legs make you feel better?
- Do you complain of these symptoms more at night?
- Do you keep your bed partner awake with the jerking movements of your legs?
- Do you ever have involuntary leg movements while you are awake?
- Are you tired or unable to concentrate during the day?
- Do any of your family members have similar complaints?
- Does a trip to the doctor only reveal that nothing is wrong and there is no physical cause for your discomfort?

If you answered “yes” to a majority of these questions, you may have RLS. If you do have RLS, you are not alone! Up to 8% of the U.S. population may have RLS. Many people have a mild form of the disorder, but RLS severely affects the lives of millions of individuals. Read on for details about the syndrome, treatment options, and information about the RLS Foundation.

What are the primary features of RLS?

In order for you to be officially diagnosed with RLS, you must meet the criteria described in the four bullets below:

- You have a strong urge to move your legs which you may not be able to resist. The need to move is often accompanied by uncomfortable sensations. Some words used to describe these sensations include: *creeping*, *itching*, *pulling*, *creepy-crawly*, *tugging* or *gnawing*.
- Your RLS symptoms start or become worse when you are resting. The longer you are resting, the greater the chance the symptoms will occur and the more severe they are likely to be.
- Your RLS symptoms get better when you move your legs. The relief can be complete or only partial but generally starts very soon after starting an activity. Relief persists as long as the motor activity continues.
- Your RLS symptoms are worse in the evening especially when you are lying down. Activities that bother you at night do not bother you during the day.

What other symptoms might I experience if I have RLS?

RLS can cause difficulty in falling or staying asleep which can be one of the chief complaints of the syndrome. A substantial number of people who have RLS also have periodic limb movements of sleep (PLMS). These are jerks that occur every 20 to 30 seconds on and off throughout the night. This can cause partial awakenings that disrupt sleep. Sleep deprivation can seriously impact your work, relationships, and health.

Do only older people get RLS?

While RLS is most often diagnosed in middle-aged individuals, RLS affects people of all

ages. People can often trace their symptoms back to their childhood. They often remember hearing things like, “Those are growing pains” or “quit wiggling so much.”

What causes RLS?

Extensive research into the cause of RLS is occurring worldwide. A single unifying cause has not been identified, but we are getting closer.

Here is what we know:

- RLS often runs in families. This is called primary or familial RLS. Researchers are currently looking for the gene or genes that causes RLS.
- RLS sometimes appears to be a result of another condition, which, when present, worsens the underlying RLS. This is called secondary RLS.
- Up to 25% of women develop RLS during pregnancy but symptoms often disappear after giving birth.
- Anemia and low iron levels frequently contribute to a worsening of RLS.
- RLS is very common in patients requiring dialysis for end-stage renal disease.
- Damage to the nerves of the hands or feet (i.e., peripheral neuropathy) from any number of causes including diabetes contributes to RLS.
- Attention Deficit Disorder (ADHD) is common in children and adults with RLS.

How do doctors diagnose RLS?

Your doctor should:

- Listen to a description of your symptoms.
- Complete a diagnostic interview checking for symptoms highlighted on the previous page.
- Review your medical history.
- Complete a thorough physical exam.
- Rule out conditions that may be confused with RLS.

Your doctor might:

- Check your iron (ferritin) levels.
- Ask you to stay overnight in a sleep study lab to determine other causes of your sleep disturbance.

Currently, there are no lab tests available to confirm or deny the presence of RLS.

What treatment options are there for RLS?

In addition to medications, there are other things you and your doctor can consider when trying to help you deal with RLS. These options may include:

- Checking to see if there is an underlying iron or vitamin deficiency and then possibly supplementing your diet with iron, vitamin B12 or folate.
- Looking at medications you may be taking which make RLS worse. These may include drugs used to treat high blood pressure, heart conditions, nausea, colds, allergies and depression.
- Looking at any herbal and over-the-counter medicines you may be taking to see if they could be worsening your RLS.

- Identifying habits and activities that worsen RLS symptoms.
- Looking at your diet to assure it is healthy and balanced.
- Discussing whether or not antihistamines could be contributing to your RLS.
- Eliminating your alcohol intake.
- Looking at various activities that may help you personally deal with RLS. These could include walking, stretching, taking a hot or cold bath, massaging, acupuncture, or relaxation techniques.
- Attempting to keep your mind engaged with activities like discussions, needlework or video games when you have to stay seated.
- Implementing a program of good sleep habits.
- Possibly eliminating caffeine from your diet to aid in general sleep hygiene.

Good sleep habit tips

- Maintain a cool, quiet, and comfortable sleeping environment
- Go to bed at the same time every night
- Get up at the same time every morning
- Get enough sleep to feel well rested
- Consider going to bed later and arising later
- Get moderate and regular exercise
- Find the exercise time that works best for you

What drug options do I have?

On May 5, 2005, the FDA approved Requip (ropinirole) for treatment of restless legs syndrome. While this is the first drug specifically approved for RLS, several other drugs have been approved for other conditions and have undergone clinical studies in RLS. These medications fall into four major classes.

Dopaminergic agents: are also used to treat Parkinson's disease even though RLS is not related to PD. Started at low doses and increased gradually, using these drugs may cause augmentation (see below).

Generic name	Brand name
ropinirole	Requip
pramipexole	Mirapex
carbidopa/ levodopa	Sinemet/Restix
pergolide	Permax
cabergoline	Cabaser, Dostinex*

* Prohibitively expensive in the U.S.

Sedatives: are most effective for improving sleep quality for people who experience their RLS symptoms at night.

Generic name	Brand name
clonazepam	Klonopin
temazepam	Restoril
triazolam	Halcion
zolpidem	Ambien
zaleplon	Sonata

Anticonvulsants: are particularly effective for some patients with painful daytime RLS symptoms.

Generic name	Brand name
gabapentin	Neurontin
carbamazepine	Tegretol, Epitol

Pain relievers: are used when RLS is severe and relentless.

Generic name	Brand name
codeine	none
fentanyl	Duragesic
hydrocodone	Vicodin
methadone	none
morphine	none
oxycodone	Percocet, Roxicodone, OxyContin
propoxyphene	Darvon, Darvocet
hydromorphone	Dilaudid
pentazocine	Talwin NX

Always inquire from your doctor about potential side effects and medication interactions.

What is augmentation?

If augmentation 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

will develop earlier in the day. Augmentation of RLS symptoms may occur after an initial period of relief with dopaminergic agents, and unfortunately, increasing your dosage will probably worsen your symptoms. If augmentation occurs, you and your doctor can work together to find a new drug regimen that will work for you. No one should ever stop taking a medication abruptly.

What else can I do to help myself?

By arming yourself with information, you have taken the first step toward defeating RLS. However, your optimum plan requires that you work together with your healthcare provider. Some things that you can do to help eliminate or reduce the need for drugs include:

- Living a healthy lifestyle.
- Eliminating symptom-producing substances.
- Taking vitamin and mineral supplements as necessary.
- Engaging in activities which help take your mind off of RLS.
- Avoiding or eliminating foods or medicines that aggravate your symptoms.

If you do need medication, careful trials may be necessary to find the medication and dosage that works best for you, and sometimes a medication that worked well in the past may become ineffective. 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, join a local RLS support group, and explore both non-drug and drug treatments. These strategies offer the most reliable approach to living a happy and productive life in spite of having RLS.

How do I live with RLS?

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

- 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 that takes your mind off of RLS.
- Keep a sleep diary. If you can't sit still to write, dictate into a tape recorder. Keep track of your medications and strategies and share these with your physician.
- Occupy your mind. Keeping your mind actively engaged may ease your symptoms. Find an activity you enjoy to help you through troublesome times.
- 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.
- Stretch out your day. Begin and end your day with stretching or gentle massage.
- Help others. Consider joining a support group. There are over 100 groups throughout the United States and Canada to help support RLS patients and their families.

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