

Life in Motion Restless Legs Syndrome Fact Sheet

Symptoms

Restless legs syndrome (RLS) is a movement and sleep disorder. People who have RLS have difficult-to-describe feelings deep in their legs. They also have an overwhelming need to move their legs. RLS can feel like *pulling, burning, tingling, creepy-crawly, grabbing, buzzing, jitteriness, or gnawing* or even like *ants crawling in the legs or Coca-Cola in the veins*. Some people call these symptoms the *heebie-jeebies, fidgets, Elvis legs, crazy legs* or *Jimmy legs*. Most people with RLS have trouble falling asleep and staying asleep.

More than 12 million people in the United States have symptoms of RLS, but many of them do not know that this is a real disorder that can be treated.

Causes

No one knows for sure what causes RLS. Doctors think that the problem might involve a substance called dopamine. Dopamine is a chemical that your body makes and that is necessary for your nerve cells to “talk” to each other. In this way, dopamine helps to control the way you move. Your body must have iron to make dopamine. If you do not have the right amount of iron, you cannot make enough dopamine.

Some medicines that are used to treat colds, allergies, upset stomach, or depression or other mental problems may make the symptoms of RLS. Other things that may also make RLS worse include chocolate, nicotine, alcohol (especially red wine), or anything that has caffeine, such as coffee, tea, and colas.

Some people with RLS are healthy and do not have any other medical conditions. However, they may have a mother, father, brother, sister, or children who have RLS. This kind of RLS may be genetic—that is, when one or more parents have RLS, they may pass it on to their children. This is called primary RLS and usually starts slowly when the person is young—usually less than 50 years old.

RLS may also be worsened by pregnancy, kidney failure, low amounts of iron in the body, thyroid problems, or trouble with the nerves in the hands and feet. This is called secondary RLS. Secondary RLS usually starts more suddenly when the person is older than 50 years of age.

Diagnosis

There is no test to tell if you have RLS. Your doctor may check your blood to see if you have enough iron or may order other tests to see if you have conditions that might make you more likely to having symptoms of RLS. Your doctor will talk with you about your symptoms. To be diagnosed with RLS, your symptoms have to include:

- Hard-to-describe feelings in your legs that are tied to a need to move your legs. Some people only have the sense that they need to move their legs and cannot describe feelings.
- The feelings and need to move are better when you move your legs.
- The feelings and need to move are worse when you are resting or not active.
- The feelings and need to move are worse in the evening and at night than during the day.

Some other signs that you might have RLS are:

- Your RLS goes away when you take a dopamine-like drug.
- You have a family member with RLS.
- Your legs jerk in a regular pattern just as you are falling asleep, or while you are asleep. Doctors call these periodic limb movements of sleep.

Treatment

You will need to work closely with your doctor to help make your RLS better. Sometimes people need to try different medicines to find one that works for them. If you have RLS, you should:

- Not drink coffee or alcohol
- Not smoke
- Exercise every day
- Go to bed before you get very tired
- Keep a regular schedule with set times to go to bed and wake up

If you have another condition that is making your RLS symptoms worse, your RLS symptoms may be better if the other condition is treated. For example, if blood tests show that you do not have enough iron, your doctor may tell you to take iron pills.

Two medicines—pramipexole (Mirapex®) and ropinirole (Requip®)—have been approved by the US Food and Drug Administration (FDA) for the treatment of moderate to severe primary RLS. These medicines act like dopamine and have been found to decrease the symptoms of RLS and improve quality of life.

Other medicines may be used for treating the symptoms of RLS, but they are not approved by the FDA for this use. They include drugs that increase dopamine (carbidopa/levodopa), relieve pain, treat seizures, or help you relax and sleep.

Sometimes when people take dopamine drugs for RLS, especially carbidopa/levodopa, they may develop something called augmentation. Augmentation is when the symptoms start earlier in the day than they started before you began taking the medicine. The symptoms also become more intense or spread to other parts of the body. If you experience augmentation, you should tell your doctor. You may need to change the way you take your medicine or switch to a different medicine or combination of medicines.

Questions to Ask Your Doctor

- What is my ferritin level? Ferritin is the most common blood test that helps to see how much iron is stored in your body.
- Do I have another condition that might be causing my RLS or making it worse?
- What are my choices for treatment?
- How can I contribute to research studies on RLS?

If you would like more detailed information on the symptoms, diagnosis, and treatment options or additional support (such as discussion forums and chat rooms), please visit www.wemove.org.