Restless legs syndrome

Kidney Care UK

Working together for better patient information
Restless legs syndrome is an uncomfortable or unpleasant feeling in your legs and an irresistible urge to move them. It usually happens when you are resting, for example when lying in bed at night. It is far less common during the daytime or when moving around. The same urge to move may also occur in the arms.

Restless legs syndrome is common in people with kidney disease. This leaflet gives more information about the condition and its treatment.
Restless leg syndrome affects around 1 in 10 people. It is more common in people with chronic kidney disease (CKD), especially if you are on haemodialysis.

Restless leg syndrome can be caused, or made worse by, anaemia (low blood count), iron deficiency (low iron stores in the body), or high calcium levels in the blood. These are all common in people with kidney disease.

Why might I have restless legs syndrome?

- End stage kidney disease and haemodialysis
- Stimulants such as caffeine, chocolate, alcohol and nicotine
- Medications: anti-depressants, antipsychotics and anti-histamines (allergy tablets)
- Pregnancy
- Neuropathy (nerve damage)
- Sleep deprivation and other sleep conditions (sleep apnoea)
Restless leg syndrome affects people in different ways. You may just find it slightly annoying or it may be severely distressing and painful. You may feel an irresistible urge to move, along with uncomfortable feelings in your legs. These feelings are temporarily relieved when you move the affected limbs but can also cause pain. It can be difficult to describe the feeling but it may be aching, creeping, crawling or itching. You may get similar feelings in other areas of your body like your arms, chest or head. You may get the feelings in just one side of your body or both at the same time.

As restless leg syndrome usually occurs in the evenings, it can lead to disturbed sleep as you toss and turn in bed to ease the symptoms. It usually improves in the early hours of the morning but this disturbance can make you tired and affect your mood the next day. A similar condition called periodic limb movement disorder is very common in people with restless leg syndrome, affecting around 8 out of 10 people. It causes involuntary jerks of the arms or legs which usually occur just before falling asleep or can wake you up during the night.
How will restless leg syndrome affect my day to day life?

Restless leg syndrome affects people in different ways. It may only affect you once or twice a week but in more severe cases it can occur every day.

Severe restless leg syndrome can also affect your relationships, family life and social activities. For example, you may find eating out, going to the cinema or long-haul flights very difficult due to the urge to move your legs. However many people with restless leg syndrome do find effective treatments that reduces or relieves their symptoms.

It is important that your healthcare team understand how restless leg syndrome affects you so that they can help plan the best form of treatment. You may find it helpful to keep a symptom diary to track the severity of your restless leg syndrome and to help identify any triggers.
How is restless leg syndrome diagnosed?

There are no specific tests to diagnose restless leg syndrome which means that your healthcare team will usually make the diagnosis after asking you a series of questions and carefully examining both you and your medication history.

You may be asked to have a nerve conduction study which is a test to see how well your nerves pass on electrical impulses. This can be used to rule out a condition called peripheral neuropathy, which has similar symptoms to restless leg syndrome but needs different treatment.

Blood tests such as iron stores (ferritin) and kidney function tests may help to identify any other medical conditions which may be causing your restless leg syndrome. You may also be referred to a Neurologist (a doctor specialising in the nervous system) or a sleep expert if the diagnosis is not certain or treatment for restless leg syndrome does not work.

Diagnostic criteria for restless leg syndrome

1. Overwhelming need or urge to move the legs, usually associated with an abnormal, uncomfortable or unpleasant sensation.
2. The urge or need to move starts or gets worse when resting
3. The urge to move is at least temporarily and partially relieved by moving
4. The urge to move starts or is worse in the evening or at night
5. These sensations are not due to any other condition.
How is restless leg syndrome treated?

Treatment aims to help you manage the symptoms of restless leg syndrome. You may need to try different treatments before you find one that works for you.

Your healthcare team will work with you to try and find triggers for your restless leg syndrome which can then be avoided or adjusted. This might include cutting down on caffeine and/or alcohol, stopping smoking if you do smoke and changing some of your medications.

You may find that light exercise like walking and stretching helps, or relaxation techniques such as having a bath before going to bed. Trying to establish a regular sleep pattern, with a calming night time routine, can also help.

Most people will experience some relief in the severity of their restless leg syndrome symptoms with these techniques.

If your symptoms do not improve, your healthcare team may prescribe medication to help.

Iron supplements can be given if blood tests have shown that your restless leg syndrome is caused by iron deficiency.

You may be given specific medication to suppress restless leg syndrome. These include painkillers, sleeping tablets (sedatives) and medications commonly prescribed for neurological conditions.

You should always follow your healthcare teams’ advice regarding medications.
Talk to your healthcare team about any symptoms that you are experiencing. It is particularly important that you consult them before changing or starting medications.

Other sources of information include:

• Restless leg syndrome support group: www.rls-uk.org
• NHS website: www.nhs.uk/conditions/restless-legs-syndrome
• NICE Clinical Knowledge Summary: https://cks.nice.org.uk/restless-legs-syndrome#!topicSummary
• Kidney Care UK: About Kidney Health: www.kidneycareuk.org/about-kidney-health
• Renal Association/Kidney Care UK Patient Information Leaflets – includes leaflets on Haemodialysis, Peritoneal Dialysis and Anaemia – www.renal.org/information-resources/patient-leaflets
• Patient View - www.patientview.org - Online access to your health records. Ask your renal unit for details about how to join

Where can I find out more information?

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