

RESTLESS LEGS SYNDROME AND PARKINSON'S

Symptoms

Find out more about restless legs syndrome in Parkinson's, and what treatments can help



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SOME PEOPLE WITH PARKINSON'S EXPERIENCE RESTLESS LEGS SYNDROME.

This information explains what restless legs syndrome is, what the symptoms are, how it's diagnosed and what treatments are available.

What is restless legs syndrome?

Restless legs syndrome is a condition that causes an overwhelming urge to move your legs. It's also known as Willis-Ekbom disease. It's a common problem for people with Parkinson's, but it can also be a separate condition that is unrelated to Parkinson's.

Restless legs syndrome can be mild or more severe, based on the strength of the symptoms, how often you experience them and if they affect your ability to carry out daily tasks.

What causes restless legs syndrome?

It is more common for women than men to experience restless legs syndrome.

Restless legs syndrome can be linked to a chemical called dopamine in the brain. If nerve cells in the brain become damaged, the amount of dopamine is reduced, which causes muscle spasms and involuntary movements.

In most cases, there's no known underlying cause for restless legs syndrome.

This is called idiopathic (or primary) restless legs syndrome.

You're more likely to have idiopathic restless legs syndrome if people in your family have had it.

People can also get restless legs syndrome because of another condition, such as Parkinson's. This is called secondary restless legs syndrome. It happens in some people who don't have enough iron in their body. It is also linked to pregnancy and chronic kidney failure.

If you're concerned about these potential causes, speak to your GP, specialist or Parkinson's nurse.

What are the symptoms?

The symptoms of restless legs syndrome include discomfort, sometimes described as tingling, burning, itching or throbbing in your legs.

People have described it as a 'creepy-crawly' feeling, or that it feels like they have fizzy water in their veins. This can make contact with bedding feel uncomfortable. Walking around or rubbing your legs can give you temporary relief.

Symptoms can start at any age, but it's more common as you get older.

Many people's symptoms are not severe or frequent enough to need medical treatment. The condition varies from person to person. Some people experience it occasionally, while for others it happens every day. It often happens when you're resting – for example, when you're sitting watching TV or lying in bed.

Symptoms generally occur, or get worse, in the evening or at night, so the condition can have a major effect on your sleeping pattern. This lack of sleep can cause daytime tiredness and sleepiness. Because of this, people with restless

legs syndrome are also more likely to experience anxiety and depression.

Find out more: see our information on depression and Parkinson's, and anxiety and Parkinson's.

You can read more about sleep in the next section. Some medications, smoking, caffeine, alcohol, being overweight, and a lack of exercise may make symptoms worse.

How is restless legs syndrome diagnosed?

If you're experiencing symptoms of restless legs syndrome, you should make an appointment to see your GP. They can refer you to a specialist if necessary. Before your appointment, you may find it useful to keep a diary of your symptoms, including when and how they affect you.

Find out more: see our information on monitoring your Parkinson's.

To assess your symptoms, your healthcare professional may ask you:

- How often do your symptoms occur?
- When do they generally occur?
- What do you do to relieve the symptoms?
- Do your symptoms affect your quality of life?
- How uncomfortable are your symptoms?
- Do your symptoms cause you a lot of distress?
- Is your sleep disrupted?
- Do you have a family history of restless legs syndrome?

There isn't a single test to diagnose restless legs syndrome, but there are some basic things a healthcare professional will look for, including:

- discomfort causing an overwhelming urge to move your legs, along with feelings of itching or tingling
- symptoms that happen or get worse when you're resting, especially while sitting or lying down
- symptoms that get better immediately after you move your legs
- symptoms that tend to occur or get worse in the evening or at night

Your healthcare professional may also consider:

- whether you find your symptoms improve when you take your Parkinson's medication
- if you experience 'periodic limb movements of sleep'. This condition causes involuntary arm and leg movements while you're asleep, and may cause you to wake up briefly
- how the condition develops – sometimes restless legs syndrome is ongoing, but sometimes symptoms may only happen from time to time
- your age – most people with restless legs syndrome are middle-aged or older, but symptoms can start at any age
- symptoms such as numbness and tingling, or a burning or shooting pain in your hands or feet. This could be a sign of damage to your nervous system, such as in peripheral neuropathy
- if you have disturbed sleep or insomnia. Insomnia is a sleep disorder in which a person is unable to fall asleep or stay asleep.

Depending on your medical history, you may be sent for further tests to rule out other underlying conditions. Sleep tests may be recommended if your sleep is very disrupted. These can help diagnose periodic limb movements of sleep.

Find out more: see our information on sleep and night-time problems in Parkinson's.

Is it difficult to diagnose restless legs syndrome in people with Parkinson's?

Because there isn't a specific test for restless legs syndrome, it can be difficult to diagnose the condition. Sometimes symptoms only happen briefly or from time to time. Also, the condition can cause discomfort at night-time and this can be mistaken for arthritis in people with Parkinson's.

Another reason why a person with Parkinson's may experience disturbed sleep is due to dyskinesia. Dyskinesia is involuntary movements sometimes seen in people with Parkinson's. If you're concerned about this, speak to your GP, specialist or Parkinson's nurse.

How is restless legs syndrome treated?

Your treatment will depend on how severe your symptoms are and what may be causing them.

Lifestyle changes

Lifestyle changes can help with mild symptoms of restless legs syndrome.

You could try:

- massaging your legs
- walking and stretching
- applying a hot (but not too hot) or cold compress to your legs
- relaxation exercises – yoga or tai chi, for example

Find out more: see our information on complementary therapies and Parkinson's.

You might also find the following helpful:

- taking a hot bath in the evening (avoid very hot water)
- avoiding alcohol, caffeine and smoking in general, and particularly at night
- establishing a regular sleeping pattern
- having a cool, comfortable sleeping environment
- avoiding heavy blankets or clothing

Find out more: see our information on sleep and night-time problems in Parkinson's.

Diet changes

Your healthcare professional may check the ferritin levels in your blood. Ferritin is a

protein that stores iron. If you have low ferritin levels, your body will not have lots of iron stored, and this can contribute to restless legs syndrome.

You may be advised to increase your iron intake by taking an iron supplement, or eating iron-rich food such as:

- red meat, fish and shellfish
- dark green vegetables
- iron-enriched bread and breakfast cereals
- apricots
- raisins
- prunes

A dietitian will be able to give you more advice on this.

Find out more: see our information on diet and Parkinson's.

Medication

Moderate to very severe symptoms of restless legs syndrome are normally treated with medication. Levodopa is a chemical building-block that your body converts into dopamine. Levodopa occurs naturally and taking it as a drug treatment – which many people with Parkinson’s do – boosts the supply. It may be recommended if you only have symptoms now and again.

Dopamine agonists are usually prescribed if you’re experiencing restless legs syndrome. Dopamine agonists act like dopamine to stimulate the nerve cells in your brain. A problem with these drugs is that they often lose their effectiveness at stopping restless legs syndrome over time (but don’t lose their effectiveness at treating Parkinson’s symptoms generally).

Both levodopa and dopamine agonists need to be prescribed by a specialist.

Painkillers like codeine, tramadol and pregabalin can also be prescribed for restless legs syndrome and are often very effective. However, these drugs can cause constipation, and must be prescribed and monitored by a doctor or nurse.

In some cases anticonvulsant drugs may be used to relieve symptoms. However, these drugs are usually only prescribed by a specialist as they need close monitoring.

Sleeping pills may be helpful if your symptoms flare up at night. Usually you’ll be prescribed a low dose for a short period of time only.

In general, prescription sleeping tablets are safe and effective when taken as prescribed. However, speak to your healthcare professional if you have any concerns.

No treatment is ideal, and sometimes people have to switch between different options from time to time to get the best relief from their symptoms.

Find out more: see our information on drug treatments for Parkinson's.

More information and support

RLS-UK

This is a charity dedicated to helping people who experience restless legs syndrome. It has a useful FAQs section and a forum.

www.rls-uk.org

Parkinson's nurses

Parkinson's nurses have specialist experience and knowledge of Parkinson's.

They can:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects
- make referrals to other professionals such as speech and language therapists and physiotherapists

Some nurses are based in the community, such as your GP surgery. Others are based in hospital settings and clinics. Talk to your GP or specialist for more details on speaking to a Parkinson's nurse.

Parkinson's UK information and support

You can read our most up-to-date information at parkinsons.org.uk. You can order printed information by calling **0330 124 3250** or visiting parkinsons.org.uk/orderingresources

If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on: **0808 800 0303** or email **hello@parkinsons.org.uk**

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups. Go to **parkinsons.org.uk/localgroups** or call our helpline to find out more.

Our forum is also a very active space to share and

chat with others who really understand, at a time that suits you. Visit **parkinsons.org.uk/forum**

Thank you

Thank you very much to everyone who contributed to or reviewed this information.

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Feedback

If you have any comments or feedback about our information, please call **0800 138 6593**, email **feedback@parkinsons.org.uk**, or write to us at

Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at **healthcontent@parkinsons.org.uk** or visit our website.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do.

There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Care team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**

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