

# Restless legs syndrome and Parkinson's

**S**ome 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 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 you do to relieve the symptoms?
- Do they 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 in Parkinson's or restless legs syndrome.

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.

[helpline@rls-uk.org](mailto:helpline@rls-uk.org)

[www.rls-uk.org](http://www.rls-uk.org)

### Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at [parkinsons.org.uk/nurses](http://parkinsons.org.uk/nurses)

### Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk).

We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

Our website [parkinsons.org.uk](http://parkinsons.org.uk) has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at [parkinsons.org.uk/localtoyou](http://parkinsons.org.uk/localtoyou)

Visit [parkinsons.org.uk/forum](http://parkinsons.org.uk/forum) to chat to other people with similar experiences on our online discussion forum.

## Thank you

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

**Dr Richard Grunewald, Consultant Neurologist, Division of Clinical Neurosciences,  
Royal Hallamshire Hospital**

**Lee Kieft, Parkinson's Nurse, Queen Elizabeth Hospital NHS Trust**

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

## 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 Services team on **0800 138 6593** or visit our website at **[parkinsons.org.uk/donate](https://parkinsons.org.uk/donate)**. Thank you.

## Our information

All of our most up-to-date information is available at **[parkinsons.org.uk/information-support](https://parkinsons.org.uk/information-support)**. If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **[parkinsons.org.uk/ordering-resources](https://parkinsons.org.uk/ordering-resources)** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **[publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk)**

## Restless Legs Syndrome and Parkinson's (PKFS83/2018)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to **Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**, or email [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thank you!

### 1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in   I care for someone with Parkinson's  
 I have a friend or family member with Parkinson's  I'm a professional working with people with Parkinson's  
 Other (please specify)
- 

### 2. Where did you get this information from?

- GP  Specialist  Parkinson's nurse  Parkinson's UK local group  Parkinson's UK local adviser  
 Ordered directly from us  Call to the helpline  
 Other (please specify)
- 

### 3. Has it answered all your questions?

- Yes, completely  Yes, mostly  Not sure  Partly  Not at all

### 4. How easy was it to understand?

- Very easy  Easy  Not sure  Quite difficult  Very difficult

### 5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- It helped a lot  It helped a little  No change  It didn't help  It made things worse

### 6. What is your ethnic background?\*

- Asian or Asian British  Black or Black British  Chinese  Mixed  White British  White other  
 Other (please specify)
- 

\*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

### Want to hear more from us?

- I would like a response to my feedback  I would like to be a member of Parkinson's UK  
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name

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Address

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Email

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Telephone

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How would you prefer us to contact you?  Email  Post  Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](http://parkinsons.org.uk/termsandconditions)



Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day when no one fears Parkinson's.**

## **Parkinson's UK**

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see **[www.ngts.org.uk](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**

**[parkinsons.org.uk](http://parkinsons.org.uk)**



Last updated February 2019. We review our information within three years.  
Please check our website for the most up-to-date versions of all our information.  
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