

# Restless legs syndrome and Parkinson's

**S**ome people with Parkinson's experience restless legs syndrome. This information sheet explains what restless legs syndrome is, what the symptoms are, how it is 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 is also known as Willis-Ekbom disease.

It is experienced by more women than men in the general population and can be a common problem for people who have Parkinson's. Symptoms can start at any age, but it is more common as you get older.

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

Most people's symptoms are not severe or frequent enough to need medical treatment. When it happens can vary from person to person. Some people experience it occasionally, while for others it happens every day. It happens most often when you are resting – for example, when you are sitting watching the TV or lying in bed.

## What causes restless legs syndrome?

In most cases, there is no underlying cause for the condition. This is called idiopathic (or primary) restless legs syndrome.

Current research suggests that idiopathic restless legs syndrome can happen when people have low iron levels in the brain, which may affect how the chemical dopamine is processed. You are more likely to have idiopathic restless legs syndrome if people in your family have had the condition.

People with Parkinson's have secondary restless legs syndrome – this means there is an underlying cause for the condition. Secondary restless legs syndrome is also linked to pregnancy, iron deficiency and chronic kidney failure. If you are concerned about any of these, speak to your GP, specialist or Parkinson's nurse.

## What are the symptoms?

Symptoms include 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. You may need to walk around to get relief. Contact with bedclothes may also feel uncomfortable.

The symptoms of restless legs syndrome 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. Be aware that people with restless legs syndrome are also more likely to experience anxiety and depression.

**Find out more:** see our information sheet *Depression and Parkinson's*.

Some medications, smoking, caffeine, alcohol, being overweight, and a lack of exercise may make symptoms worse.

## How is it diagnosed?

If you are experiencing symptoms, 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 – when and how they affect you.

**Find out more:** see our information sheet *Keeping a diary: people with Parkinson's*.

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

- How often do your symptoms occur?
- How uncomfortable are your symptoms?
- Do your symptoms cause you a lot of distress?
- Is your sleep being 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:

- an overwhelming urge to move your legs, along with feelings of itching or tingling
- symptoms that happen or get worse when you are resting, especially while sitting or lying down
- symptoms that get better when you move or rub 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 are sleeping, but may cause you to wake up briefly
- how the condition develops. Restless legs syndrome is normally ongoing, but sometimes symptoms may only happen from time to time
- your age when diagnosed. Most people are middle-aged or older, but symptoms can start at any age

“When I get symptoms I retreat to a quiet, warm room and try to relax. I usually have a jigsaw puzzle on the go or some other activity and after an hour or so, the symptoms fade away and I go to bed. When my legs are really bad, my husband will massage my legs, which helps a lot.”

**Carole, diagnosed in 2005**

- 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, which could be a sign of another condition such as peripheral neuropathy
- disturbed sleep, usually insomnia. Insomnia is a sleep disorder that causes problems getting to sleep or staying 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 booklet *Sleep and night-time problems in Parkinson's*.

## Is it difficult to make a diagnosis in people with Parkinson's?

Because there isn't a specific test for restless legs syndrome, it can be difficult to diagnose the condition. Symptoms can be brief or only happen 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.

Rarely, a person with Parkinson's may experience disturbed sleep due to dyskinesia. These are involuntary movements caused by Parkinson's medication. If you are concerned about this, speak to your GP, specialist or Parkinson's nurse (if you have one). Do not stop taking your Parkinson's medication.

## How is restless legs syndrome treated?

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

### Lifestyle changes

Mild symptoms of restless legs syndrome may be treated with lifestyle changes. There are a number of things you can try, such as:

- massaging your legs
- walking and stretching
- applying a hot or cold compress to your legs
- relaxation exercises – yoga or t'ai chi, for example

**Find out more:** see our booklet *Complementary therapies and Parkinson's*.

You might also find the following helpful:

- taking a hot bath in the evening
- avoiding alcohol, caffeine and smoking at night
- establishing a regular sleeping pattern
- having a cool, comfortable sleeping environment

**Find out more:** see our booklet *Sleep and night-time problems in Parkinson's*.

### Diet

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

- dark green vegetables
- iron-enriched bread
- apricots
- raisins
- prunes

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

**Find out more:** see our booklet *Diet and Parkinson's*.

## Medication

Moderate to very severe symptoms 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 boosts the supply. It may be recommended if you only have symptoms now and again.

Dopamine agonists are usually prescribed if you are having more frequent symptoms. Dopamine agonists act like dopamine to stimulate your nerve cells.

Painkillers like codeine or tramadol can be prescribed if you are in pain. Your doctor may also recommend anticonvulsant drugs to relieve symptoms.

Sleeping pills may be helpful if your symptoms flare up. Usually you will 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.

**Find out more:** see our booklet *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.

**01634 260 483** (Mondays and Thursdays only, 9am-11am)

**helpline@rls-uk.org**

**www.rls-uk.org**

### NHS Choices

This health website contains lots of information about restless legs syndrome, its symptoms, causes and treatment.

**www.nhs.uk**

### 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.

“ I suffered terribly from restless legs syndrome. I could not cope at all well. Along came some medication my doctor prescribed for me, wonderful stuff – no more problems! ”

**Andrew, diagnosed in 1991**

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](https://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.

We have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you, visit [parkinsons.org.uk/selfmanagement](https://parkinsons.org.uk/selfmanagement)

Our website [parkinsons.org.uk](https://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](https://parkinsons.org.uk/localtoyou)

Visit [parkinsons.org.uk/forum](https://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 Nin Bajaj, Consultant Neurologist, Nottingham University Hospitals, Nottingham**

**Dr Paul Reading, Consultant Neurologist, James Cook University Hospital, Middlesbrough**

**Dr Sophie Molloy, Consultant Neurologist, Imperial College Healthcare NHS Trust, London**

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 (2014)

If you have comments or suggestions about this information sheet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to **Editorial and Creative Services, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**. Or you can email us at **publications@parkinsons.org.uk**. Thanks!

### Please tick...

- I have Parkinson's. When were you diagnosed? .....
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this information sheet from?

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other .....

How useful have you found the information sheet? (1 is not useful, 4 is very useful)  1  2  3  4

Have you found the publication easy to read/use?  Yes  No

Has this resource given you information that might help you manage your condition better?

- NA  It hasn't helped  It has helped a little  It has helped a lot

What aspects did you find most helpful? .....

Were you looking for any information that wasn't covered? .....

Do you have any other comments? .....

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group, please complete the details below and we'll be in touch.

- Membership  Information review group (who give us feedback on new and updated resources)

Name .....

Address .....

Telephone ..... Email .....

- What is your ethnic background?  Asian or Asian British  Black or Black British  Chinese  Mixed  White British  White other  Other (please specify) .....

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 July 2014. 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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