Parkinson's UK

Restless legs syndrome and Parkinson's

Symptoms

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

Some people with Parkinson's experience restless legs syndrome (RLS)

This information explains what RLS is, its symptoms, how it's diagnosed and what treatments are available.

What is restless legs syndrome?

Restless legs syndrome (RLS) makes you feel an overwhelming urge to move your legs. This can sometimes be very uncomfortable.

It's also called Willis-Ekbom disease. It's a common problem for people with Parkinson's, but also affects lots of people who don't have Parkinson's. More research is needed to know whether RLS is more common for people with Parkinson's.

Some people get mild RLS symptoms. For others, symptoms can be more serious and can make sitting still or going to sleep difficult.

RLS can be upsetting, but there are treatments and changes which can help.

Causes of restless legs syndrome (RLS)

We don't know for certain why RLS happens.

It can be linked to a chemical in the brain called dopamine. Dopamine is important for helping you move.

If nerve cells in the brain become damaged, the amount of dopamine is reduced, which can lead to muscle spasms and involuntary movements. More research is needed to work out the exact relationship between dopamine and RLS symptoms.

You might have RLS for a reason unrelated to Parkinson's.

Idiopathic or primary RLS

Often, there's no known cause for RLS. This is called idiopathic (or primary) RLS. Idiopathic means the cause is unknown.

You're more likely to have idiopathic RLS if people in your family have had it. If RLS runs in your family, symptoms are likely to start before the age of 40.

Secondary RLS

If your doctor can work out what's causing your symptoms, you may get a diagnosis of secondary RLS. For example, RLS can be a secondary condition of Parkinson's.

RLS can be linked to having a shortage of iron in your body. Not getting enough iron can lead to a condition called iron deficiency anaemia.

Read more about this on page 18. Iron deficiency anaemia can also be caused by bleeding in your stomach or intestines, stomach ulcers, piles (hemorrhoids) or certain medicines like aspirin or ibuprofen.

RLS can also be linked to:

- pregnancy - if you had RLS when you were pregnant, you're more likely to have symptoms again as you get older
- kidney failure- also known as stage 5 chronic kidney disease.

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

Anxiety disorders, depression and attention deficit hyperactivity disorder (ADHD) may also be connected to RLS, although more research is needed to better understand the link.

Who can get RLS?

RLS is common. It can affect people at any age, although middle aged people are more likely to have it than younger people. RLS is as common in men as women up to the age of 35. But after 35, women are twice as likely as men to have it.

Symptoms of restless legs syndrome (RLS)

RLS can give you a sensation in your legs that is:

- tingly
- burning or hot
- itchy
- like a painful cramp.

You might also notice an aching or a throbbing feeling in your legs.

RLS can also cause unpleasant feelings in your:

- arms
- chest
- face.

People have described it as a "creepy-crawly" feeling, or that it feels like they have "fizzy water" in their veins. This can be uncomfortable when your legs touch your bedding or other surfaces.

The uncomfortable urge to move your legs can temporarily go away or get better when you:

- walk
- stretch your legs
- massage your legs.

Many people's symptoms are not severe or frequent enough to need treatment. For some symptoms appear occasionally, while for others they happen every day. People often feel symptoms when resting – for example, when watching TV or lying in bed.

Symptoms generally get worse in the evening or at night, so RLS can have a major effect on your sleep. Read more on page 16.

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

Some medications can make RLS symptoms worse, including some antidepressants (but not bupropion), sedating antihistamines or drugs used to treat hallucinations.

Your specialist is there to help if you are worried that your medications are contributing to your symptoms. You can also ask your local pharmacist for advice. But always talk to your doctor before stopping any medications you've been prescribed.

Other things that can make RLS symptoms worse include:

- alcohol and caffeine
- not getting enough exercise
- being overweight
- smoking
- stress.

You can find out more about free NHS services to help you stop smoking by searching "stop smoking adviser" at **www.nhs.uk**

Diagnosing restless legs syndrome (RLS)

If you have RLS symptoms, make an appointment to see your GP, Parkinson's nurse or your specialist. 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.

We have advice on using a diary to monitor your Parkinson's symptoms at: **parkinsons.org.uk/diary**

There isn't one specific test to diagnose RLS. Clinical guidelines say that, for your doctor to diagnose RLS, you will have:

- a strong, often uncomfortable desire to move your legs
- symptoms that start or get worse when you're not moving
- symptoms that get worse in the evening or at night
- symptoms which get better if you move or stretch your legs.

Your doctor will rule out other conditions which may have similar symptoms, such as fibromyalgia or leg cramps.

To understand your symptoms, your doctor may ask you:

- how often they happen, and when
- if anything has helped reduce them
- how uncomfortable they make you feel
- if they cause you a lot of distress
- if they stop you getting to sleep, or wake you up at night
- if anyone in your family has had RLS.

Your doctor may also ask if:

- your symptoms improve or get worse when you take your Parkinson's medication
- if your symptoms only happen from time to time
- your symptoms stop you doing things you want to do, such as watching TV, or spending time with friends or family
- you have symptoms such as numbness and tingling, or a burning or shooting pain in your hands or feet, which could be a sign of damage to your nervous system, such as peripheral neuropathy
- you have disturbed sleep or insomnia

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

Periodic limb movements

It's likely that your doctor will check if you have periodic limb movements (PLM). PLM is where your leg or legs twitch, usually while you're asleep. PLM is very common for people who have restless legs syndrome.

PLM usually causes very quick, similar movements. These movements happen without you meaning to make them and might wake you or your partner up at night. They can also happen during the day.

PLM is different from dyskinesia. Dyskinesia causes jerky, involuntary movements. Your specialist or Parkinson's nurse will explain the difference between PLM and dyskinesia.

Diagnosing restless legs syndrome (RLS) in people with Parkinson's

Because there isn't a specific test for RLS, it can be difficult to diagnose. Your doctor will help you work out if your symptoms are RLS or your Parkinson's itself.

Parkinson's itself, or Parkinson's medication, can cause similar symptoms to RLS, including dyskinesia. Taking levodopa over a longer period of time is linked to dyskinesia. Dyskinesia can cause involuntary movements, including in your legs, and this can also disturb your sleep.

If you're worried about dyskinesia speak to your specialist or Parkinson's nurse.

Find out more: see our information on wearing off and involuntary movements.

Treatments for restless legs syndrome (RLS)

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

Medication

Moderate to very severe symptoms of RLS may need to be treated with medication. Medication for RLS aims to make your symptoms better, rather than cure the condition.

Don't worry if your doctor or Parkinson's nurse suggests changes to your prescription for RLS from time to time. This is normal and will help you get the most relief from your symptoms. You can always ask them any questions about treatment options.

Dopamine agonists

Dopamine agonists, such as ropinirole or pramipexole, may be prescribed if you're experiencing RLS.

Dopamine agonists act like dopamine to stimulate the nerve cells in your brain.

Side effects of dopamine agonists can include:

- drowsiness
- nausea or dizziness
- impulsive or compulsive behaviors, such as an urge to gamble, shop or drink too much alcohol.

Drugs prescribed for RLS often work less well over time.

Drug holidays

Your doctor may recommend short "drug holidays" each year where you stop taking your RLS medication to see if your symptoms have got better or gone away. They will explain how these work and if and when to have them. It's important to never stop taking a prescribed medication without talking to your doctor first.

Augmentation

Taking dopamine agonists for RLS can cause a complication called augmentation.

Augmentation is when your RLS symptoms may:

- feel worse, especially after increasing the dose of your medication
- come on earlier in the day or more quickly when you start resting
- appear in other places in your body, such as your arms or torso (the middle part of your body, also called your trunk).

Clinical guidelines say that your doctor should explain the risks of augmentation before you start taking medication to treat RLS. This will help you to watch for the signs of augmentation and report anything unusual to your doctor.

If your restless legs symptoms feel worse than they did before starting your medication, speak to your doctor about augmentation.

If your doctor thinks your RLS medication is causing augmentation, they will check your symptoms and discuss your options with you. This may include changing your dose or stopping your prescription.

Everyone's Parkinson's is different and it can sometimes be tricky to tell if a symptom is caused by your Parkinson's or something else. If you think your RLS drugs are causing augmentation, try not to worry. You and your doctor will be able to decide together what the best course of action for you is.

Loss of efficacy

It's normal for all RLS drugs to not work as well over time. This is a complication called loss of efficacy. It's important to note that loss of efficacy is not the same as augmentation, which is when your symptoms become worse than they were before you started taking your medication. Speak to your doctor if you notice your medicine working less well than before.

Rebound and RLS medication

"Rebound" is where your RLS symptoms come back in the morning when your medication has worn off. It's not the same as augmentation and your doctor should explain the difference.

The charity RLS-UK has more information about augmentation and rebound, at: **rls-uk.org/augmentation-rebound**

Impulsive and compulsive behaviours

Impulsive and compulsive behaviors can be a problem if you take dopamine agonists for either RLS or Parkinson's. These behaviours can include things like gambling or shopping too much, or binge eating.

Clinical guidelines say that your doctor should explain the risk of developing these types of behaviours before you start taking your medication. Ideally, they should speak with a close friend or family member too, so they can help you spot impulsive or compulsive behaviours if they appear. Your doctor should do this even if you already take levodopa or dopamine agonists for your Parkinson's.

If you notice these behaviours, speak to your specialist or Parkinson's nurse straight away so they can help you address them.

Find out more: see our information on impulsive and compulsive behaviors in Parkinson's.

Painkillers

Painkillers like codeine, gabapentin and pregabalin can also be prescribed for RLS. However, these drugs can cause headaches and can make you feel tired or dizzy. These painkillers need to be prescribed by a doctor or nurse, who will keep track of side effects and update your prescription if needed.

Sleeping pills for restless legs syndrome symptoms

Sleeping pills (also called hypnotics) are not now usually prescribed by GPs for insomnia. They can cause side effects, such as headaches and dizziness, and can cause you to become dependent on them.

These include “Z-drugs”, such as Zopiclone or Zolpidem. Z-drugs are usually only prescribed for a short time, and not for longer than four weeks.

However, sleeping pills may be helpful if your RLS symptoms are significantly disturbing your sleep. Speak to your GP or specialist if you’re worried about taking sleeping pills.

Driving and medication that makes you drowsy

It is illegal to drive if your ability to drive is impacted by any medication that you’re taking, including any sleeping medications mentioned in this information. This includes prescribed drugs and medication bought over the counter.

Talk to your doctor if you’re not sure whether it’s safe for you to drive if you’re taking any medication that causes drowsiness or tiredness, or if you're worried about driving and Parkinson’s generally.

Read more about the law on medication and driving at: **gov.uk/drug-driving-law**

Find out more about sleeping pills: see our information on driving and Parkinson’s and sleep and night-time problems.

Things you can try at home

There are some things you can try yourself to help with RLS.

Trying to follow all the tips over the next few pages might seem overwhelming. No-one has a perfect diet, exercise plan or sleep routine.

Parkinson's is a complicated condition to manage, so don't feel you have to do everything "right" all the time. Making manageable changes which work for you, with the support of your specialist and Parkinson's nurse, can help.

Our expert helpline can also give advice with any lifestyle changes you’re thinking of making. Call free on **0808 800 0303**.

Moving and stretching

When the symptoms of restless legs syndrome are bothering you, the following things may help:

- Giving your legs a massage. If you go for a professional massage, don’t forget to let your massage therapist know about your restless legs syndrome, so they can try to help you with it specifically.
- Walking around. If your symptoms are worse at night, you could try taking a few steps around your bedroom, but make sure to turn the light on if your room is dark.
- Stretching. Your physiotherapist or Parkinson’s nurse will be able to advise you on the types of stretches that might help.
- Placing a warm compress like a hot water bottle on your legs. Take care that your compress isn’t too hot. You can buy reusable hot and cold compresses from your pharmacy.
- Taking a hot bath, but avoiding very hot water.
- Distracting yourself, for example by playing a game, reading or listening to the radio.

Getting enough exercise during the day may help your RLS symptoms too.

Find out more: see our information on physical activity and exercise.

You might find the following helpful:

- mental and physical relaxation exercises
- gentle relaxing movements, like those in tai chi or yoga.

The charity Mind has information on simple mental and physical relaxation exercises you can do on your own at home. Search "relaxation exercises" at **mind.org.uk**

Relaxation exercises include things like connecting with your senses and the room around you to focus on the present moment. This may distract you from uncomfortable feelings in your legs.

Mindfulness is a type of relaxation exercise which may help. Search for "mindfulness" at **nhs.uk**

Having a good sleep routine

Keeping up a good sleep routine, sometimes called sleep hygiene, is important generally. It may also help reduce RLS symptoms.

You can help yourself get a good night's sleep by going to bed at around the same time each night and getting up at the same time in the morning.

The NHS has information about sleep issues at: **nhs.uk/every-mind-matters/mental-health-issues/sleep**

Parkinson's generally can make it more difficult to get to sleep, which makes a good sleep routine even more important. Your specialist and Parkinson's nurse can give you support and guidance on getting a good night's sleep.

We have more tips about getting a good night's sleep on our online magazine at **parkinsons.org.uk/sleep-tips**

Sleep aids from a pharmacy

Some people find sleep aids from their local pharmacy helpful for getting to sleep. They should only be taken for 1 to 2 weeks.

Some sleep aids contain plants like lavender or valerian. Others have antihistamines in them, which are medicines that can make you feel sleepy.

Antihistamines are often not recommended for people with Parkinson's. This is because some antihistamines can make your Parkinson's drugs work less well, or have side-effects which could make your movement (motor) symptoms worse. This could include stiffness (rigidity) and dyskinesia (involuntary movements).

Speak to your local pharmacist or doctor before you start taking any sleep aids.

As sleep aids can make you feel sleepy, they can affect whether you can drive or ride a bike.

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

Diet changes

Not having enough iron in your body can cause symptoms of restless legs syndrome. This is because a lack of iron in the body can cause lower levels of dopamine in your brain.

Ferritin is a protein that stores iron.

If you have low ferritin levels, your body will not have lots of iron stored. This can contribute to RLS. Your GP, specialist, or nurse may check the ferritin levels in your blood.

They may advise you to increase your iron intake by taking an iron supplement. Iron supplements can have side effects and you should speak to your GP, specialist, Parkinson's nurse or dietitian before starting to take any supplement.

Your healthcare professional may also advise you to eat more iron-rich food, such as:

- red and white meat, fish and shellfish
- dark, leafy green vegetables
- iron-fortified bread and breakfast cereals
- dried fruit like apricots, raisins or prunes
- beans and pulses
- brown rice
- seeds or nuts
- eggs
- tofu
- chickpeas.

You can speak to a dietitian for more advice.

Speak to your GP, specialist or Parkinson's nurse about getting referred to a registered dietitian through the NHS.

You can also pay to see a dietitian privately. The British Dietetic Association has more information about how to find a dietitian in your area at: **bda.uk.com/find-a-dietitian.html**

Some people have a lack of iron stored in their body even though they are getting plenty of iron in their diet. This could be due to your body having trouble breaking down and absorbing iron (a process called metabolising). Let your dietitian or Parkinson's nurse know if you think you're getting enough iron in your diet, but are having RLS symptoms.

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

More information and support

British Dietetic Association

Has information about dietitians and how to find one.

info@bda.uk.com
www.bda.uk.com
0121 200 8080

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
www.rls-uk.org

The Sleep Charity

Offers information and support and a helpline about sleep and sleep problems.

info@thesleepcharity.org.uk
www.thesleepcharity.org.uk
01302 751416
Sleep Helpline Number: 03303 530 541

Parkinson's UK information and support

Whatever your journey with Parkinson's, you're not alone.

From the moment you or someone you care about is diagnosed, we have information and support for you.

Speak to one of our friendly expert advisers, including specialist Parkinson's nurses, care advisers, and benefits and employment advisers. We've got information and advice on all aspects of living with Parkinson's.

Get help managing your diagnosis. Our information packs, webinars, courses and support groups can help you and your loved ones understand your Parkinson's diagnosis and better manage your symptoms.

Read our up to date, reliable health information. Our website, booklets and magazines can help you better understand Parkinson's. They're full of tips and advice on managing your condition and supporting a loved one.

Find ways to get active, stay active and live well with Parkinson's. Whatever your fitness level, we'll help you find the right activities for you.

Connect with other people with Parkinson's, families, friends and carers. Across the UK, in your local area or online. We'll help you meet others who understand what you're going through, because they're going through it too.

Find out more

- Call our helpline on **0808 800 0303** or email **hello@parkinsons.org.uk** to speak to an expert adviser.
- Visit **parkinsons.org.uk/information-and-support** to read our information or find support that's local to you.
- Call **0330 124 3250** or visit **parkinsons.org.uk/order-print-booklets** to order free printed information.

Thank you

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

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

All of our information is checked by experts and other people with Parkinson's, so you know it's information you can trust.

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, 50 Broadway, London, SW1H 0BL.

If you'd like to find out more about how we put our information together, or be part of the team that reviews our health content, please contact us at **healthcontent@parkinsons.org.uk** or visit our website at **parkinsons.org.uk/health-content**.

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**.

Thank you.

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Restless legs syndrome and Parkinsons

We're Parkinson's UK, the charity that's here to support every Parkinson's journey. Every step of the way.

Free confidential helpline **0808 800 0303**
Monday to Friday 9am to 6pm,
Saturday 10am to 2pm (interpreting available)
Relay UK **18001 0808 800 0303** (for textphone users only)
hello@parkinsons.org.uk | parkinsons.org.uk

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