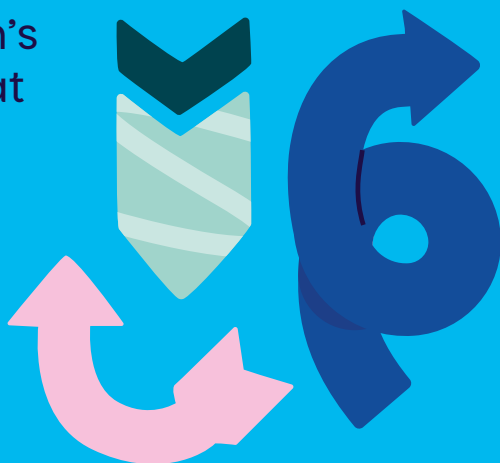


Wearing off and involuntary movements in Parkinson's

Treatments, therapies and side effects

Find out more about movement problems caused by Parkinson's medication and what can help



Wearing off and involuntary movements (Dyskinesia)

If you've been taking a Parkinson's drug that contains levodopa – for example co-beneldopa or co-careldopa – for some time, you may develop some side effects that can affect your movement.

This information describes the different movement problems that can happen after using levodopa for several years. It explains what might cause them and how they can be controlled.

What are the movement side effects of levodopa?

Wearing off and Parkinson's

Wearing off happens when the Parkinson's medication you've been taking is no longer working as effectively as it used to. Because of this, your Parkinson's symptoms may return towards the end of a medication dose, or near the beginning of the next dose.

If these symptoms are affecting your day-to-day life, then your specialist or Parkinson's nurse should review your medication.

In the early stages of Parkinson's, you may not notice when a dose of levodopa begins to wear off. But as Parkinson's progresses, some people find that a dose doesn't last as long as it used to, so changes can become more unpredictable. As well as having an effect on your movement, you may also experience feelings of anxiety, sleepiness, low mood or pain as your medication wears off.

Is 'on/off' the same as freezing?

Being 'on' or 'off' is different from 'freezing'.

If a person's symptoms are well controlled, this is known as the 'on' period, which means that medication is working well. When symptoms return, this is known as the 'off' period.

This might mean that a person who is out for a walk would suddenly be unable to continue walking, or when seated would feel unable to get up to answer the door.

'Off' periods usually come on gradually, but occasionally can be more sudden. When they come on suddenly, some people have compared this 'on/off' effect to that of a light switch being turned on and off.

But when a person freezes, it only affects certain movements. They may not be able to walk, for example, but they are still able to reach for a cup.

There are different ways of managing freezing and 'on/off' swings.

Find out more: see our information on freezing in Parkinson's.

Involuntary movements (dyskinesia)

These are muscle movements that people with Parkinson's can't control. They can include twitches, jerks, twisting or writhing movements. Involuntary movements can affect various parts of the body such as the arms, hands, legs, torso, jaw, face and neck.

There are different types of involuntary movements and when and how often they appear can be different for each person with Parkinson's.

Some people can have involuntary movements for most of the day. Others may only have them after taking their medication or just before the next dose is due.

People with Parkinson's can also experience this side effect when levodopa is at its highest level in the bloodstream (sometimes called 'peak dose'), and the dopamine levels in their brains are at their highest. Dopamine is a chemical messenger made in the brain. The symptoms of Parkinson's appear when dopamine levels become too low.

Dyskinesia can vary in intensity from person to person. You might not feel too affected by mild dyskinesia, or might even be unaware of it, even though it may be visible to another person. Others may experience more severe dyskinesia, which can prevent them from carrying out simple tasks.

For example, it might make walking difficult or impossible, and can sometimes affect talking.

Because dyskinesia causes people to move around so much, it can sometimes cause weight loss. If you're worried about this, speak to your GP, specialist or Parkinson's nurse. They can refer you to a dietitian, who will be able to help you maintain a healthy weight.

What causes motor fluctuations and involuntary movements?

The term 'motor fluctuations' refers to when you go from having good control over your Parkinson's symptoms to having less control. This change can happen slowly or quickly.

Motor fluctuations usually happen when levodopa is wearing off, but they can happen at other times too.

Lots of people with Parkinson's experience motor fluctuations or involuntary movements after a few years of levodopa treatment. Some people may develop them earlier, especially if they're on a high dose of levodopa.

No one knows for sure why motor fluctuations and involuntary movements happen, but researchers think it's connected to the way levodopa stimulates the brain cells to produce dopamine.

The difference between dyskinesia and other movement symptoms

Both dyskinesia and tremor are uncontrollable movements. But tremor is a symptom of Parkinson's, while dyskinesia is a side effect of levodopa.

The causes of tremor and dyskinesia, and the types of movement they each produce, are also different.

Tremors can sometimes be mistaken for dyskinesia because they share similar physical features.

However, it's also possible to experience both at the same time.

Key differences:

- Tremor is a common early symptom of Parkinson's, whereas dyskinesia develops after years of someone taking Parkinson's medication. Some people may develop dyskinesia earlier, especially if they're on a high dose of levodopa.
- Tremor is rhythmic in movement, while dyskinesia is usually more unsteady and disorganised.
- Notice what happens when you move a limb. Movement usually lessens or stops tremor, whereas it will normally increase dyskinesia.

If you think you're experiencing dyskinesia, or are unsure if it's a tremor, speak to your specialist or Parkinson's nurse. You should give them as much detail as possible about how movements are affecting you. This will help them to identify whether you have dyskinesia, or if it's another Parkinson's symptom, and manage the issue in the right way.

Find out more: see our information on tremor.

How can I manage motor fluctuations and involuntary movements?

Medication

Motor fluctuations and involuntary movements can be difficult to treat. This is because if you take a lower dose of levodopa to reduce involuntary movements, your Parkinson's symptoms may not be as well controlled and you may experience more wearing off.

If you develop motor fluctuations, talk to your specialist or Parkinson's nurse as soon as possible.

They will advise you on what changes you can make to your drug regime to balance treating the motor problems and control your Parkinson's symptoms.

Clinical guidelines say your specialist should discuss your individual circumstances with you, and offer a choice of drugs to take together with levodopa to try to improve your motor symptoms.

They may also give you advice on avoiding 'peaks and troughs' in doses of levodopa. This might include taking smaller and more frequent doses of levodopa but keeping the overall amount the same.

You may be advised to change to a different type of levodopa that helps even out levels in your bloodstream.

You could also take it in another format, for example, by intestinal gel.

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

Diet

For some people with Parkinson's, protein (which is found mainly in meat, fish, eggs, cheese, beans and pulses) seems to interfere with how well the body absorbs levodopa.

Because of this, you may benefit from taking your medication 30 to 60 minutes before you eat a meal to allow the medication time to start working.

Constipation can affect how well the body absorbs medication, making it less effective. Many people with Parkinson's experience constipation. This can be caused by Parkinson's symptoms, medication or other issues, such as difficulties with swallowing.

Talk to your specialist or Parkinson's nurse about the timing of your medication. They can also refer you to a dietitian for specialist advice.

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

Deep brain stimulation

Deep brain stimulation (DBS) is a type of surgery used to treat Parkinson's. It can be effective in helping to improve motor symptoms.

DBS isn't suitable for everyone, but it may be an option for people whose symptoms are no longer controlled well by the best available medication. It may also be used for people who are experiencing involuntary movements.

DBS can help increase the amount of time you are in the 'on' state. This can mean that you're able to reduce your Parkinson's medication and help reduce side effects such as involuntary movements.

Like any surgery, there are potential risks to having DBS. Talk to your specialist to find out more.

Find out more: see our information on deep brain stimulation for Parkinson's.

Apomorphine

Your specialist or Parkinson's nurse may recommend trying apomorphine if you experience dyskinesia or have severe 'off' periods that aren't controlled by other Parkinson's medications.

Apomorphine is a type of dopamine agonist which comes in liquid form. It's often used when pills or capsules no longer work well enough to control Parkinson's symptoms on their own. It can be used alone, but is often prescribed with levodopa medication to help it work better.

Find out more: see our information on apomorphine.

Managing stress

Stress may increase motor fluctuations and involuntary movements, so it's important to try to find ways to stay relaxed.

You could try complementary therapies, such as massage, physical activity or exercise, such as tai chi or yoga, or breathing exercises.

If you're frequently highly stressed or anxious, ask your specialist or Parkinson's nurse for advice on managing these conditions.

Find out more: see our information on physical activity, complementary therapies, and anxiety.

If you find dealing with people's reactions to your involuntary movements stressful or embarrassing, it may be worth explaining to those around you that the side effects are part of your condition, and they shouldn't be alarmed or concerned if they happen.

Making the most of 'on' time

If you start to experience your medication wearing off, it's important that your drug regime is managed so you can make the most of your 'on' time. This becomes more complicated if you also begin to have involuntary movements.

You might have to decide on a compromise between more 'on' time with involuntary movements, or more 'off' time with other Parkinson's symptoms.

Many people tend to prefer more 'on' time, even with the dyskinesia. But everyone is different and you should discuss your options with your specialist or Parkinson's nurse.

Keep a diary

To make the most of your 'on' time, it can be helpful for you or your family member or partner to keep a daily diary.

This will show when your symptoms and fluctuations happen, and for how long. Record this information along with the times you take your drugs, and the drug dosage.

Some women with Parkinson's have reported motor fluctuations in line with their menstrual cycle. Although there is no evidence of this link, keeping a diary will help you see whether your monthly cycle is having an effect on your movement symptoms.

Keeping a diary can help you and your healthcare professional understand how your medication affects you, and how often you're experiencing difficulties. It can also give a better idea of what strategies to use to smooth out fluctuations.

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

More information and support

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

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.

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, 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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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

Parkinson's UK, 50 Broadway, London SW1H 0DB



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