

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

If you go from having good control of your movement symptoms to having less control, it's called a motor fluctuation. This change can happen slowly or quickly.

Motor fluctuations usually happen when levodopa is wearing off, but they can happen at other times too. This is called 'end of dose wearing off' or just 'wearing off'. Sometimes the effects of wearing off happen quickly – this is called 'switching off' or 'on/off'.

Being 'on' is when a person's symptoms are controlled and when they feel at their most capable. Being 'off' is when Parkinson's symptoms come back and affect them the most.

Some people have described this as like a light switch being turned on and off, or going up and down like a yo-yo.

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 fluctuations 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'.

During 'off' periods a person may hardly be able to move at all, so walking, going up stairs or reaching for a cup will be impossible.

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, legs and torso.

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.

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?

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.

A lot 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.

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 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 or 'on/off'.

If you develop motor fluctuations, discuss this with 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. Strategies include taking smaller and more frequent doses of levodopa but keeping the overall amount the same.

You may also 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 30–60 minutes before you eat a meal to allow the medication time to start working.

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 isn't suitable for everyone with Parkinson's. It's only used to treat people whose symptoms aren't responding to the best medication regime. It may also be used for people who are experiencing particularly troublesome involuntary movements.

Deep brain stimulation 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 deep brain stimulation. Talk to your specialist to find out more.

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

Managing stress

As stress may also increase motor fluctuations and involuntary movements, try to find ways of staying relaxed. You could try complementary therapies such as massage, exercises such as tai chi or yoga, or breathing exercises.

Find out more: see our information on exercise and complementary therapies. If you're frequently highly stressed or anxious, ask your specialist or Parkinson's nurse for advice on managing these conditions.

Also, 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 with the least possible involuntary movements, it can be helpful for you or your carer 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 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

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.

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 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

Visit 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:

Alison Rose, Lead Movement Disorder Nurse Specialist, Darlington Memorial Hospital

Dr Richard Genever, Consultant Physician and Geriatrician, and Past Chair, British Geriatrics Society Movement Disorders Section

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**. Thank you.

Our information

All of our most up-to-date information is available at **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** 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**

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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. 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

Address

Email

Telephone

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

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**

hello@parkinsons.org.uk

parkinsons.org.uk



Last updated December 2018. 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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