

Wearing off and involuntary movements (dyskinesia)

If you have 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 sheet 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 symptoms of levodopa?

Wearing off and Parkinson's

If you go from having good control of your symptoms to having less control, it is 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. These fluctuations can become more unpredictable in advanced Parkinson's.

Being 'on' or 'off' is different from 'freezing'. There are different ways of managing freezing and 'on/off' swings. During 'off' periods a person will 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.

Find out more: see our information sheet *Freezing in Parkinson's*.

As well as having an effect on the symptoms that affect your movement. You may also experience feelings of anxiety, sleepiness, low mood or pain as your medication wears off.

Involuntary movements (dyskinesia)

These are muscle movements that people with Parkinson's can't control. They can include twitches, jerks, twisting or writhing movements, or restlessness. Involuntary movements can affect various parts of the body such as the arms, legs and upper half of the body. They often start on the side of the body most affected by Parkinson's and usually occurs in the legs before the arms.

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, while 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 symptom 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.

Because dyskinesia causes people to move around so much it can sometimes cause weight loss. If you are worried about this, speak to your GP, specialist or Parkinson's nurse (if you have one). They may refer you to a dietitian.

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. Another factor may be the gradual loss of dopamine-producing cells that happens over time in people with Parkinson's.

Motor fluctuations and involuntary movements usually only happen to people who have had Parkinson's for some time, and who have used levodopa over a long period.

A lot of people with Parkinson's experience motor fluctuations or involuntary movements after five to 10 years of levodopa treatment. Some people may develop them earlier, especially if they are on a high dose of levodopa. People who develop Parkinson's before the age of 40 are also at a higher risk of developing motor fluctuations and involuntary movements.

How can I manage motor fluctuations and involuntary movements?

Medication

Motor fluctuations and involuntary movements can be complicated to treat. This is because if you cut the dose of levodopa to reduce involuntary movements, your Parkinson's symptoms may not be so well controlled and you may have more wearing-off or 'on/off'.

You will need to discuss any problems you have with your specialist or Parkinson's nurse at your next appointment – unless you become suddenly worse, in which case, speak to them as soon as possible. They will advise you on what changes you can make to your drug regimen to balance treating the motor problems while keeping your Parkinson's symptoms under control.

Options may be based around 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. There are also other Parkinson's drugs that can help levodopa to work better, which your specialist or Parkinson's nurse might suggest adding to your drug regimen.

If you take dopamine agonists from early on after your diagnosis of Parkinson's, there is some evidence to suggest that you may be less prone to motor fluctuations. However, this may mean your symptoms are less well controlled.

Find out more: see our information sheet *Drug treatments for Parkinson's*.

Diet

For some people eating protein (such as meat, fish, eggs, cheese and beans) can cause problems by reducing or slowing down the amount of levodopa that is absorbed into the bloodstream. Protein is needed by the body, so it's vital not to stop eating it. However, you may find it helpful to take your medication at least 30 minutes before you eat to allow the medication time to start working. Talk to your specialist or Parkinson's nurse about your medication timing. They can refer you to a dietitian.

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

Surgery

Surgery is not suitable for everyone. It is generally used to treat people whose symptoms are not responding well to medication. It may also be used for people who are experiencing particularly troublesome involuntary movements.

A type of surgery called 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 about it.

Find out more: see our booklet *Surgery 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 or exercises such as t'ai chi or yoga.

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

If you are 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 symptoms 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 is important that your drug regimen is managed so you get the most of your 'on' time.

This becomes more complicated if you also begin to have involuntary movements. You might then 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 or specialist.

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

Some women with Parkinson's have reported fluctuations in their motor symptoms 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 sheets *Keeping a Diary: People with Parkinson's* and *Keeping a diary: for carers*.

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 also put you in touch with one of our local information and support workers, 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 also 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

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

You can also visit parkinsons.org.uk/forum to speak with other people in a similar situation on our online discussion forum.

Thank you

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

Dr Peter Bain, Reader and Honorary Consultant Neurologist, Charing Cross Hospital, London

Dr Robin Fackrell, Consultant, Royal United Hospital, Bath

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



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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
- Information and support worker
- Parkinson's UK local group or event
- Ordered from us directly
- Our website
- 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
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We're the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

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 **020 7932 1303** or visit our website at **parkinsons.org.uk/support**. Thank you.

Parkinson's UK

Free* confidential helpline **0808 800 0303**

Monday to Friday 9am–8pm, Saturday
10am–2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

*calls are free from UK landlines and most mobile networks.

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

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We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you receive and will 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.

References for this information sheet can be found in the Microsoft Word version at **parkinsons.org.uk/publications**

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