

Muscle cramps and dystonia

People with Parkinson's often experience pain caused by muscle cramps and/or dystonia.

This information sheet looks at what muscle cramps and dystonia are, what causes them, how they are treated and where you can go for more help and advice.

What are muscle cramps and dystonia?

Muscle cramps and dystonia are conditions where one of your muscles or a group of muscles tighten or shorten involuntarily, causing pain.

Muscle cramps and dystonia can be confusing as they can feel very similar. You may not always be able to tell the difference between them, but they are caused by separate problems and are also treated differently.

Dystonia can be a condition on its own (called 'primary' dystonia) or it can be connected to other conditions, including Parkinson's ('secondary' or 'symptomatic' dystonia).

What causes muscle cramps and dystonia?

Muscle cramps

It is not always possible to find out the cause of muscle cramps, and people who are otherwise healthy may experience them without there being an underlying cause. Sometimes they may be the result of not moving around enough, but at other times it may be due to doing too much. Cramps may also be caused by poor circulation or by dehydration. They are more common in people with Parkinson's, although we are unsure why.

Dystonia

Dystonia is caused by the muscles not relaxing after they tighten or shorten. For people with Parkinson's, this is often related to the effect of levodopa.

‘Off’ dystonia

Dystonia happens most often when levodopa treatment is ‘wearing off’. This is when the drug becomes less effective before your next dose is due.

If you take your last dose of medication last thing at night, you may experience off dystonia when you first wake up in the morning. This type of ‘morning off’ dystonia is most likely to affect your legs. You might experience painful spasms and may not be able to get out of bed until your first dose of medication begins to take effect.

‘On’ dystonia

Dystonia can also happen at ‘peak-dose’, when your levodopa is at its most effective. It is caused by having too much dopamine in your brain, which can overstimulate your muscles.

Other dystonia

More rarely, dystonia in Parkinson’s is not caused by the effect of levodopa and is actually a feature of the condition itself. This type of dystonia can happen at any time of the day, but usually lasts for a shorter time than dystonia connected to levodopa.

Dystonia is more common in people who have been diagnosed with Parkinson’s at a younger age (under 40), but it can affect anyone with the condition.

What parts of my body can muscle cramps and dystonia affect?

Muscle cramps

Muscle cramps can affect any muscle in your body, although the calf and neck muscles are some of the most commonly affected areas.

Dystonia

Legs and feet

Dystonia is more likely to affect the side of your body that is most affected by Parkinson’s. It can affect a single muscle or a group of muscles, but for people with Parkinson’s it often affects the feet. Spasms in your calf muscles may make your toes curl into a claw-like position. Your foot may also turn in at your ankle and your big toe may extend. This can be very uncomfortable, especially if you are trying to put your feet into tight-fitting shoes.

Find out more: see our information sheet *Foot care in Parkinson’s*.

Hands

Hand spasms may happen when you’re making small movements such as writing. This is known as ‘writer’s cramp’ and can be associated with arm tremor.

Head and neck

If you experience dystonia, you may find that your head stays turned to one side, bent forward, or more rarely, backward. Your healthcare professional may refer to it as ‘cervical dystonia’ or ‘spasmodic torticollis’.

Eyelids

If dystonia affects your eyelids, the eyelid muscles may contract when you close your eyes, either every now and again or for a longer period of time. It usually starts in one eye but can often spread to affect both. Symptoms include excessive blinking, irritation, a burning feeling in the eyes and sensitivity to light. Stress, looking up or down, reading, driving or bright lights can make these symptoms worse. Your healthcare professional may refer to this as 'blepharospasm'.

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

Vocal cords

Dystonia in the vocal cords can affect your speech and the quality of your voice. Your healthcare professional may refer to it as 'laryngeal dystonia' or 'spasmodic dysphonia'.

Side of the face or jaw

This usually affects one side of the face at a time. It may affect the muscles around the eye at first, before spreading gradually to other muscles on the same side of the face, particularly around the jaw and mouth. Your healthcare professional may refer to it as 'hemimasticatory' or 'hemifacial' spasm.

How are muscle cramps and dystonia treated?

Muscle cramps

There is no one treatment for pain caused by muscle cramps, but you may find it helpful to try the following:

- stretching and massaging the affected area
- being more active if you can, and trying to move around more during the day
- taking over-the-counter painkillers, such as paracetamol

Although it's worth remembering that it may not work for everyone, you may also find physiotherapy beneficial. A physiotherapist will assess your muscles and the movements that are affected. They can then give you stretching exercises that may help to ease stiffness and soreness. These types of exercises may also help to improve your posture. Doing this will prevent the affected muscles from becoming weaker or shorter.

Your GP may be able to refer you to a physiotherapist. However, some people may want to pay to see a private physiotherapist. If you choose to do this, we recommend that you contact the Chartered Society of Physiotherapy for details of trained and registered physiotherapists. See page 5 for contact details.

If you're still having difficulties, speak to your GP or specialist about medication that can help to ease cramping, such as quinine or muscle relaxants. See the section on 'other drugs' on page 4 for more information about medication options.

Find out more: see our information sheets *Physiotherapy and Parkinson's* and *Pain in Parkinson's*.

Dystonia

Medical treatment

The first step is to try to work out what is causing your dystonia. If the dystonia is connected to levodopa, your medication regimen may need adapting. You may find it helpful if you or your carer (if you have one) keep a diary that shows how your dystonia relates to your medication. This will help to explain the problem to your specialist or Parkinson's nurse.

Find out more: see our information sheets *Keeping a diary: people with Parkinson's* and *Keeping a diary: for carers*.

If you experience early-morning 'off' dystonia, it may help to take a controlled-release dose of your medication last thing at night or to take your first dose of the day crushed, to speed up its effect. Make sure you check with your specialist or Parkinson's nurse that your medication can be taken in this way – not all drugs are safe to be taken crushed or broken. Another strategy is to take a long-acting medication last thing at night.

There are also dissolvable medications available. These are quicker to take effect than standard tablets (although often shorter acting). Your specialist or Parkinson's nurse may suggest a combination of a standard tablet and a dissolvable one for your first dose of the day.

Some people also find it helpful to have more regular doses or to add other medications to their drug regimens to make their levodopa work for longer. Speak to your specialist or Parkinson's nurse for more information.

If you experience peak-dose dystonia, you may wish to speak to your specialist about replacing fast-acting medications with slower ones, or a medication that releases a continuous lower level of dopamine stimulation.

If you have any questions about dystonia or its treatment, speak to your specialist or Parkinson's nurse.

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

Other drugs

If your dystonia does not respond to changes to your Parkinson's medication, there are other drug treatments you can discuss with your GP, specialist or Parkinson's nurse, including:

- drugs that relax your muscles such as diazepam (Valium) and clonazepam (Rivotril)
- baclofen (Lioresal). Baclofen can also be used to treat cramp
- anticholinergics such as benztropine (Cogentin) and biperiden (Akineton)

Remember that not all of these treatments will be appropriate for everyone. So make sure you talk to your GP, specialist or Parkinson's nurse about what's best for you.

Botulinum toxin

Botulinum toxin (Botox, Dysport or NeuroBloc) is a powerful nerve toxin that is sometimes used to treat dystonia. It can be injected in small doses into the affected muscle. This treatment needs to be repeated every two to three months. Speak to your GP, specialist or Parkinson's nurse about whether this may help you.

Self-help

Many people find that 'sensory tricks' give temporary relief from spasms, although there is no scientific evidence to explain why. Tricks can involve touching the affected body part, or a nearby body part, before or while you make the movement that usually triggers a spasm. This seems to prevent or shorten the spasm by distracting the brain.

You can speak to your GP, specialist, Parkinson's nurse or a physiotherapist about sensory tricks. The Dystonia Society also has a list of tricks people have shared with them. Their contact details are listed in the more information section and support section.

You could also try the following:

- yawning to ease dystonia in your vocal cords
- talking, lying down, singing, laughing, chewing or putting pressure on the eyebrows to relieve dystonia in your eye lids

Relaxation

Some people may also find that being relaxed helps with their dystonia. What makes someone relax differs from one person to the next, but you may find having a warm bath or massage helpful, or trying complementary therapies such as yoga.

Surgery

Surgery for dystonia is not common, but may be considered if you don't respond to drug treatment. Surgical procedures that are already used for Parkinson's, such as deep brain stimulation, have been shown to help dystonia. Speak to your GP, specialist or Parkinson's nurse to see if this may be an option for you.

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

More information and support

The Dystonia Society

This organisation offers support to all people with dystonia. It has a range of information on the different forms of the condition and the treatments available. It also has a number of local branches throughout the UK.

020 7793 3658

info@dystonia.org.uk

www.dystonia.org.uk

The Chartered Society of Physiotherapy

This organisation can give you details of qualified physiotherapists in your area.

020 7306 6666

www.csp.org.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.

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:

Nin Bajaj, Consultant Neurologist, Nottingham University Hospitals.

Duncan Forsyth, Consultant Geriatrician, Cambridge University Hospitals.

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



Muscle cramps and dystonia (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 **Resources and Diversity, 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)

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

Download them from our website

at parkinsons.org.uk/publications

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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