

Muscle cramps and dystonia

If you experience tightness and pain in your muscles, you may have muscle cramps or dystonia. This information explains the difference between them in people with Parkinson's and how you can get help.

Muscle cramps

Anyone can experience muscle cramps but they are more common in people with Parkinson's.

What are muscle cramps?

Muscle cramps happen when your muscles shorten and tighten causing sudden, sharp pain. In many cases you will be able to feel them, but not see them happening.

Episodes of muscle cramps usually last less than 10 minutes, although your muscles can feel tender for up to a few hours. However, your Parkinson's is unique to you and people may experience muscle cramps differently.

What causes muscle cramps?

It is not always possible to know what causes muscle cramps.

They may be the result of:

- not moving around enough
- doing too much
- poor circulation
- dehydration

Some people with Parkinson's say that muscle cramps happen because of something specific.

This could be sleeping in a particular position or doing an activity involving unusual muscle movement. However, others say muscle cramps appear to happen without there being any cause.

What parts of the body do muscle cramps affect?

In people with Parkinson's, cramps commonly affect muscles related to movement. You are most likely to get them in your calves, feet and neck.

What can I do to help ease my muscle cramps?

There is no one way to get rid of your muscle cramps, but there are lots of things that can ease them. You may find it helpful to try the following things.

- Stretching.
- Massaging your muscles.
- Being more active and trying to move around more during the day.

Exercise

Exercise is good for everyone and it's especially good for you if you have Parkinson's. It can help you manage your physical symptoms and continue doing day-to-day activities.

If you experience muscle cramps it's important to do exercise that is right for you. This could be as simple as chair-based exercises or muscle stretches.

Find out more about the benefits of exercise and the different types to focus on at parkinsons.org.uk/exercise

Physiotherapy

You may also find physiotherapy helpful. A physiotherapist will assess your muscles and any movements that seem to cause your cramps or make them worse. They can give you stretching exercises that may help to ease stiffness and soreness and improve your posture. Your GP should be able to refer you to a physiotherapist. You could also see one privately.

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

How are muscle cramps treated?

If exercises are not working and you're still having problems with muscle cramps, talk to your GP about medication options. They may suggest:

- over-the-counter painkillers, such as paracetamol
- muscle relaxants
- quinine

Quinine

Quinine is sometimes prescribed for muscle cramps and can be effective.

You should only take quinine on the advice of your health professional. Speak to your GP, specialist or Parkinson's nurse to discuss if this treatment is right for you.

Quinine can worsen irregular heart rhythms. So if you have a history of heart problems, tell your health professional.

Some people with Parkinson's tell us that they find tonic water eases their muscle cramps because it contains quinine. However, tonic water only contains very small amounts of quinine and there is limited evidence that it is effective.

People with Parkinson's may also experience dystonia. This can feel similar to muscle cramps but it is managed differently. So make sure you get diagnosed correctly before taking quinine. You can read more about dystonia in the next section.

Dystonia

Dystonia is a condition in its own right. You may experience it separately from Parkinson's or your dystonia may be connected to your Parkinson's. It is more common in people who are diagnosed with Parkinson's at a younger age.

What is dystonia?

Dystonia is a movement disorder that happens when incorrect brain signals cause contractions in various muscles. This is when muscles become tighter and shorter than normal, making them stiff. Dystonia can feel painful and uncomfortable.

These contractions may also involve visible twisting movements, or spasms, which create unusual postures in the affected body part. They may be constant or last for a short period of time.

Sometimes dystonia may happen during a certain activity. This is referred to as 'task-specific' dystonia. You might also find your dystonia gets worse if your body is in a particular position.

Dystonia is often considered a type of dyskinesia, which can involve broader uncontrollable body movements. The features of dystonia and dyskinesia can be similar so it's useful to know how they are different.

Find out more: see our information on dyskinesia.

What causes dystonia?

Dystonia appears to relate to problems with the basal ganglia. This is the area of the brain that controls movement.

One type of dystonia is a genetic or hereditary condition called 'primary' dystonia. This means that it runs in families.

However, people with Parkinson's usually get dystonia as a symptom of their condition or as a side effect of levodopa. This is called 'secondary' dystonia.

Dystonia and levodopa

In Parkinson's, dystonia is most often linked to levodopa.

'Off' dystonia

Dystonia mostly happens as the levodopa treatment is wearing off. This is when the drug becomes less effective before you take your next dose.

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

'On' dystonia

Sometimes your levodopa creates too much dopamine stimulation and this can cause 'on' dystonia. It can happen as a 'switching on' effect as your levodopa starts to work. It can also happen at peak-dose, when your levodopa is most effective.

Dystonia as a feature of Parkinson's

More rarely and often in people diagnosed at a younger age, Parkinson's itself can cause dystonia. The spasms and movements may happen at any time of the day but usually last for a shorter time than dystonia linked to levodopa.

What parts of my body can dystonia affect?

Dystonia usually happens on the side of your body that Parkinson's affects the most. It can affect a single muscle or a group of muscles.

Legs and feet

Dystonia can cause spasms in your calf muscles. It can make your toes curl under your foot, or make your big toe extend out or up. Your foot may also turn in at your ankle.

Head and neck

Dystonia can cause unusual postures of your head, neck and shoulders. If you experience these postures, you may find that your head pulls to one side. It might also bend forward, sideways or backward.

Hands

Hand spasms may happen when you are performing fine movements, such as writing. This is known as 'writer's cramp' and is associated with hand tremor.

Eyelids

Dystonia can cause your eyelid muscles to contract, making you blink a lot. You may also experience irritation or a burning feeling, and your eyes may become sensitive to light. Stress, looking up or down, reading or bright lights might make these things worse.

Dystonia in your eyelids can be brief or last for a longer period of time. It usually starts in one eye and often spreads to both. Your healthcare professional may refer to dystonia in your eyelids as 'blepharospasm'.

Vocal cords

Dystonia can cause spasms in your vocal cords. This can affect your speech including the pitch, volume and quality of your voice.

If you experience problems with your voice you may find it helpful to see a speech and language therapist. Speak to your healthcare professional about getting a referral.

Find out more: see our information on speech and language therapy

How is dystonia treated?

The first step is to try to work out what is causing your dystonia. If your dystonia is connected to levodopa, your medication regime may need adapting.

The timing of medication for different types of dystonia

You may find it helpful if you or your carer keep a diary of when your dystonia happens, so you can work out if it is linked to your medication. This will help to explain the problem to your specialist or Parkinson's nurse.

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

Taking medication in different ways and at different times may help your dystonia. Some options are listed below. You should discuss these with your GP, specialist or Parkinson's nurse before making any changes to your medication.

Last thing at night you could try taking:

- a controlled-release dose of levodopa if you experience dystonia as your medication wears off in the morning. This allows the levodopa to enter your body slowly instead of all at once
- long-acting dopamine agonist medication, that will lessen the effects of dystonia when you wake up

First thing in the morning you could try:

- dissolvable levodopa medication. This takes effect more quickly but it does not last as long
- a combination of a standard levodopa tablet and a dissolvable levodopa tablet

Other options for your Parkinson's medication include:

- taking smaller doses more frequently
- adding other medications to your drug regime, which make your levodopa work for longer
- taking medication that releases a continuous, lower level of dopamine stimulation. This can help to reduce dystonia that happens when your levodopa is at peak-dose

If you have any questions about dystonia and your Parkinson's drugs, speak to your specialist or Parkinson's nurse about the best options for you.

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

Other things that may help

If your dystonia does not respond to changes to your Parkinson's medication, there are other options, including:

- drugs that relax your muscles such as clonazepam (Rivotril)
- Baclofen (Lioresal), which is also a muscle relaxant
- anticholinergics such as Trihexyphenidyl (Benzhexol) and Procyclidine

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

Botulinum toxin

Botulinum toxin is the medical name for a drug called Botox. It is also called NeuroBloc or Dysport.

It is injected into your muscles to block the signals in your brain causing your dystonia. This weakens your muscles for a short period, which might help ease your symptoms.

Botulinum toxin injections need to be repeated every three months.

Sensory tricks

Many people find that sensory tricks give short relief from dystonia. You could try:

- touching the affected body part
- touching a nearby body part
- stretching the affected limb

There is no evidence to explain why these tricks might work. However, it might be because your brain senses an unusual action which interrupts the dystonia, and gives you more control.

You can speak to your GP, specialist, Parkinson's nurse or physiotherapist about sensory tricks.

The Dystonia Society also has a list of tricks for reducing dystonia that people have shared with them. You can find their details at the end of this information.

Relaxation

Some people also find that being relaxed helps their dystonia.

Try taking a warm bath, having a massage, or doing some exercise, like yoga.

Find out more about the benefits of exercise and the different types to focus on at parkinsons.org.uk/exercise

Surgery

Deep brain stimulation (DBS) is sometimes used to control Parkinson's symptoms, including dystonia, if your medical treatment is no longer working effectively.

DBS involves putting very fine wires into the brain. The wires have electrodes at the ends, which allow small electrical currents to pass into the brain.

Some people with Parkinson's who have deep brain stimulation find that it is helpful for their dystonia. However, not everyone will have the same experience and there are risks. Speak to your specialist, Parkinson's nurse or GP to discuss whether surgery is an option for you.

Find out more: see our information on surgery.

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 3650

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 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.

We 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**

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:

Dr Vaithianathar, Consultant Neurologist, Derby Teaching Hospital

Lisa Brown, Parkinson's Disease Nurse Specialist, Derby Teaching Hospital

Stella Gay, Parkinson's Disease Nurse Specialist, Guys and St Thomas' NHS Foundation Trust

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 May 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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