PARKINSON'S MUSCLE CRAMPS AND DYSTONIA

Symptoms

Find out more about muscle cramps and dystonia in Parkinson's, and ways to help manage the symptoms

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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're more common in people with Parkinson's.

You're most likely to get muscle cramps in your legs, especially in your calf muscle at the back of your leg. You may also experience cramps in muscles in your feet or thighs.

What are muscle cramps?

Our muscles can shorten or tighten when we use them to do any type of activity, such as picking something up or chores around the house.

Muscle cramps happen when your muscles shorten more than they are used to, or when they suddenly tighten, causing sharp pain.

A cramp usually lasts a few seconds but it can last up to 10 minutes. Your muscles can feel tender for up to 24 hours afterwards.

What causes muscle cramps?

It's not always possible to know what causes muscle cramps.

They may be the result of:

- not moving around enough
- physical activity and exercise
- poor circulation
- dehydration

Some people with Parkinson's say that muscle cramps happen when they have done something specific. This could be sleeping in a particular position or doing an activity involving an unusual muscle movement.

But other people say muscle cramps appear to happen without any cause.

What can I do to help ease my muscle cramps?

Most muscle cramps happen before you can do anything to stop them, but there are lots of things that can help ease them.

You may find it helpful to try the following:

- stretching
- massaging your muscles
- raising your feet in bed using a pillow, or raising the foot of the bed

Being more active and trying to move around more during the day may help too.

Physical activity is good for everyone and it's especially good for you if you have Parkinson's. 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 look at 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.

Sometimes, cramps can happen when you stretch the whole length of your body as you wake up. You may be able to prevent this kind of cramp by pulling your toes up towards you as you stretch out, rather than pointing them downwards away from you.

Your specialist, Parkinson's nurse or GP can refer you for physiotherapy. In some areas, you will be able to self-refer. If you're referred to an NHS service, there may be a waiting list for treatment.

You can also choose to see a physiotherapist privately, which you will need to pay for. The Chartered Society of Physiotherapy can help you find a private physiotherapist. You can find their contact details in the 'More information and support' section.

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

How are muscle cramps treated?

If exercises aren't working and you're still having problems with muscle cramps, your GP may suggest medication, such as:

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

Quinine is sometimes prescribed for leg cramps. Although clinical guidelines recommend that it should not generally be used for leg cramps, it may be prescribed if your cramps are very painful. Your doctor also might prescribe quinine if other ways of managing your leg cramps, such as stretching, haven't worked.

Quinine can worsen irregular heart rhythms. If you have a history of heart problems, tell your healthcare professional.

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

Quinine is not recommended for dystonia, which is managed differently from muscle cramps. You can read more 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 a symptom of your Parkinson's. It's more common in people who are diagnosed with Parkinson's at a younger age.

What is dystonia?

Dystonia happens when incorrect brain signals cause uncontrolled muscle movements (spasms). Spasms happen when muscles become tighter and shorter than normal, making them stiff. Dystonia can feel painful and uncomfortable.

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

Sometimes dystonia may happen when your body needs to be in a particular position for a period of time. For example, if you're writing or playing an instrument. This is referred to as 'task-specific' dystonia.

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 wearing off and involuntary movements (dyskinesia).

What causes dystonia?

Dystonia appears to be caused by 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. This is called 'secondary' dystonia. It can also be a side effect of levodopa.

Dystonia and levodopa

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

'Off' dystonia

Dystonia mostly happens as levodopa is wearing off.

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 you take your last dose of medication before you go to sleep 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 and can cause parts of your body to twist or turn on their own.

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. Dystonia in your legs or feet may make it temporarily difficult for you to walk or exercise. Speak to your specialist or Parkinson’s nurse if dystonia is making it difficult for you to get around.

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 doing things like writing. This is known as 'writer's cramp' and can be associated with hand tremor.

Eyelids

Your healthcare professional may refer to dystonia in your eyelids as 'blepharospasm'.

It 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.

Vocal cords

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

Speech and language therapy may be able to help. Speak to your specialist or Parkinson's nurse about getting a referral to a speech and language therapist. In some areas, you may be able to self-refer.

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's causing your dystonia. If your dystonia is connected to levodopa, your medication regime may need changing.

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

It might not always be obvious to other people that you're experiencing these symptoms, so don't be embarrassed about asking your specialist or Parknson's nurse for help if dystonia is making life difficult for you.

The timing of medication for different types of dystonia

Taking medication in different ways and at different times may help your dystonia. For example, before going to bed, 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 reduce dystonia when you wake up

First thing in the morning you could try taking:

- dissolvable levodopa medication. This takes effect more quickly but 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 before making any changes to your medication.

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

Other things that may help

Medication

If your dystonia doesn’t respond to changes to your Parkinson’s medication, there are other medications that may help. These include:

- drugs that relax your muscles, such as clonazepam (Rivotril) and baclofen (Lioresal)
- 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 or Parkinson’s nurse about what’s best for you.

Botulinum toxin

Botulinum toxin (often referred to as Botox), blocks the signals in your brain causing dystonia. This weakens your muscles for a short period, which might help ease your symptoms.

The drug is injected into your muscles and needs 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’s no evidence to explain why these tricks might work. But 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.

Dystonia UK also has a list of sensory tricks for reducing dystonia that people have shared with them. You can find their details in the 'More information and support' section.

Physiotherapy and occupational therapy

A physiotherapist can use massage or exercises to help retrain muscles.

Occupational therapy may also help if your dystonia is making it more difficult to do some of the everyday tasks and activities that you used to do easily.

Surgery

Deep brain stimulation (DBS) is the main type of surgery used to treat Parkinson's if your symptoms are no longer well controlled by medication. DBS may also help treat dystonia.

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 part of the brain that controls movement.

Like all types of surgery, there are risks involved with DBS. Speak to your specialist or Parkinson's nurse to discuss whether surgery is an option for you.

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

More information and support

Dystonia UK

Support for anyone with dystonia with information on the different forms of

the condition and treatments available.
020 7793 3651
info@dystonia.org.uk
www.dystonia.org.uk

The Chartered Society of Physiotherapy

For details of qualified physiotherapists in your area.
020 7306 6666
www.csp.org.uk

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

You can read our most up-to-date information at **parkinsons.org.uk**. You can order printed information by calling **0330 124 3250** or visiting parkinsons.org.uk/orderingresources
If you'd like to speak to someone, our specialist adviser team can provide information about any aspect of living with Parkinson's.

They can talk to you about managing symptoms and medication, social care, employment rights, benefits, how you're feeling, and much more.

Call our team on:
0808 800 0303 or email **hello@parkinsons.org.uk**

We'll provide expert information over phone or email or put you in touch with an adviser locally.

If you'd like to meet other people living with Parkinson's in your local area, you can find friendship and support through our network of volunteers and local groups.

Go to **parkinsons.org.uk/localgroups** or call our helpline to find out more.

Our forum is also a very active space to share and chat with others who really understand, at a time that suits you. Visit **parkinsons.org.uk/forum**

Thank you

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

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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, 215 Vauxhall Bridge Road, London SW1V 1EJ.

If you'd like to find out more about how we put our information together, please contact us at **healthcontent@parkinsons.org.uk** or visit our website.

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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Free confidential helpline **0808 800 0303**
Monday to Friday 9am–6pm, Saturday 10am–2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
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