

# Pain in Parkinson's

**N**ot everyone with Parkinson's has the same symptoms. Pain can be a major issue for some people with Parkinson's, but not for others. This information sheet looks at the types of pain associated with the condition and how they can be managed.

Sometimes, common ways of reducing pain, such as doing regular gentle exercise, massage or taking painkillers, can help. But treating pain in people with Parkinson's can be difficult. The best thing to do is to find the cause of the pain, so speak to your GP, specialist or Parkinson's nurse.

Usually, your GP will be able to help you manage the more common types of pain, such as shoulder pains and headaches. Certain other types of pain, such as pain caused by involuntary movements or burning mouth, may need the help of your specialist.

It may help if you, or your carer (if you have one), keep a diary about how pain affects you and when. This will help you explain your symptoms to your healthcare professional.

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

## What are the main types of pain associated with Parkinson's?

### **Muscle (musculoskeletal) pain**

This is the most common type of pain experienced by people with Parkinson's. It comes from the muscles and bones, and is usually felt as an ache around your joints, arms or legs. The pain stays in one area and doesn't move around your body or shoot down your limbs. These pains may increase as you get older and may also get worse because of your Parkinson's.

Simple painkillers and regular exercise should help. You may also find physiotherapy useful.

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

## Muscle cramps

Muscle cramps may have a variety of causes in Parkinson's and may be painful. Muscle cramps associated with Parkinson's can happen at any time, night or day. At night they may cause pain in your legs and calf muscles, as well as restlessness, which leads to disrupted sleep.

Trying to move around may help. You can also try to soothe cramps by stretching and massaging the affected muscle.

Although there is limited evidence to show that physiotherapy can help with muscle cramps, some people may find it helpful.

For some people, a drink of tonic water at night or taking a quinine tablet may help. Speak to your healthcare professional to find out whether this is a good option for you.

## Pain caused by involuntary muscle contractions (dystonia)

Involuntary muscle contractions (dystonia) can affect body parts, such as toes, fingers, ankles or wrists, and make the affected part go into spasm.

Contractions are often connected to levodopa and are affected by changes in the type and timing of your Parkinson's medication. The pain caused by the contractions often happens in the early morning. Taking medication at night that enters your body slowly, instead of all at once, may help. Some people also say that relaxation techniques help to manage the pain.

Speak to your specialist or Parkinson's nurse (if you have one) about how best to manage any pain caused by involuntary contractions.

**Find out more:** see our information sheet *Muscle cramps and dystonia*.

## Shooting pain (radicular pain)

This is a sharp, often shock-like, shooting pain that travels down the arm or leg, and may involve the fingers and toes. Tingling and numbness in the toes and/or fingers is also common in people with Parkinson's.

Shooting pain is usually the result of a trapped nerve within the spinal cord around the neck or lower back. Nerves can get trapped by discs that stick out, which normally act as pillows between the bony vertebrae.

Speak to your GP if you are experiencing this type of pain. In most cases, simple painkillers and regular, gentle exercise may be enough to treat the problem. Heated wheat sacs and massage may also be helpful.

Shooting pain that won't go away is rare, but if you experience this speak to your specialist. You may need some tests, such as an MRI scan of the spine, to rule out compression of the nerve roots at the spinal cord.

## Pain caused by involuntary movements (dyskinetic pain)

This sort of pain is not limited to any body part and can be described as a deep, aching sensation. It can occur because of involuntary movements (dyskinesia) that some people with Parkinson's experience. It can happen before, during or after movement.

“ I tend to get muscle cramps and rigidity in the morning when I wake up. It can be difficult to cope with. ”

**Judy, diagnosed in 1990**

People with Parkinson's have said that when pain starts before involuntary movements, it is sometimes a warning sign that they are about to start. In other cases, pain starting during severe involuntary movements may be caused by the twisting action of the movements.

Speak to your GP, specialist or Parkinson's nurse if you are experiencing dyskinetic pain – your Parkinson's medication may need adjusting.

**Find out more:** see our information sheet *Muscle cramps and dystonia*.

“ I tend to experience pain if I stay in the same position for a long period of time. I find taking regular breaks and moving around can help. ”

**Ali, diagnosed in 2005**

## Restless legs syndrome

This can cause symptoms such as pins and needles, painful sensations or burning of the legs. You may feel an irresistible urge to move your legs when relaxing, for example while sitting watching TV or going to sleep.

Night-time pain related to restless legs may be treated with Parkinson's medication, such as dopamine agonists. Your health professional may also recommend other medicines. Speak to your GP, specialist or Parkinson's nurse for more information.

**Find out more:** see our information sheet *Restless legs syndrome and Parkinson's*.

## Are there any other types of pain associated with Parkinson's?

Other types of pain associated with Parkinson's are less common. These are described below.

### Shoulder or limb pain

This is a pain and stiffness affecting just one side of the body, usually an arm or leg. It is constant and aching. People who experience this type of pain report having trouble making fine finger movements, or may find that one of their feet drags when they walk.

For some people, shoulder pain may be the first sign of Parkinson's and it is sometimes called 'frozen shoulder', though this kind of pain may be caused by many other issues, such as being immobile for an extended period of time.

If Parkinson's is diagnosed, this pain may improve with Parkinson's medication. For some people, a regular course of physiotherapy may be useful.

If the pain doesn't go away, you may need to take painkillers. You may also be referred to a local 'pain team' or rheumatologist (a doctor who specialises in arthritis and related conditions). If you have a frozen shoulder, you may need an injection of steroids into the joint.

### Pain in the mouth and jaw

Some people with Parkinson's can experience a burning sensation or pain in their mouth or jaw area. This is sometimes called 'burning mouth syndrome'. This is a rare problem and can happen at any stage of the condition.

A dry mouth can lead to higher rates of tooth decay and gum disease. It may also cause dentures to become loose and difficult to control, which can cause pain. It's very important that you visit the dentist if you are in pain or feel a burning sensation in the mouth.

Dryness of the mouth can be caused by some Parkinson's medications (particularly anticholinergics). Speak to your GP, specialist or Parkinson's nurse if you have any concerns, but do not stop taking the drugs before getting professional advice.

There are also things that you can do yourself to ease pain in the mouth. These include drinking water regularly to keep your mouth moist and removing dentures at night to give your mouth a chance to recover.

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

## **Akinetic crisis and pain**

This type of pain may occur in the advanced stages of Parkinson's. The symptoms include severe stiffness and fever. People with Parkinson's report feeling pain in the muscles and joints, headaches and, sometimes, whole-body pain during akinetic crisis.

Some people occasionally experience this type of pain if their Parkinson's symptoms suddenly get worse. This can be brought on if you suddenly stop taking Parkinson's medication or by infections. Severe stiffness in the muscles may also be the cause.

If you have any concerns about this type of pain, speak to your GP, specialist or Parkinson's nurse.

## **Headaches**

Headaches can occur at any stage in your condition and occasionally may be caused by the medication used to treat Parkinson's.

Normally, over-the-counter painkillers are enough to help with the pain. If you do experience drug-resistant headaches, tell your GP, specialist or Parkinson's nurse.

Try not to take a large number of tablets at one time, particularly if you are also taking medication for high blood pressure or heart problems. You should space out the time between taking different types of tablets because together they may actually cause headaches. Speak to your GP, specialist or Parkinson's nurse about the best way to take your medication.

## **Central pain**

Sometimes people with Parkinson's can have a constant, dull, aching pain that affects most of the body. This type of pain is called 'central pain' and is related to Parkinson's itself. Normally, pain happens because of damage to the tissues of the body.

Parkinson's can affect the way the body experiences pain and can cause pain in the body even when there is no obvious cause. This type of pain is not properly understood and can be difficult to treat. Central pain sometimes improves with Parkinson's medication, and drugs such as duloxetine may help with this type of pain.

If you have any concerns about central pain, speak to your GP, specialist or Parkinson's nurse, as it may not be related to your Parkinson's.

## **How is pain assessed?**

If you're experiencing pain, the best thing to do is speak to your GP, specialist or Parkinson's nurse in the first instance, as they can advise you on appropriate treatments. You may find it helpful to fill in the non-motor questionnaire for Parkinson's. This will help your healthcare professional to assess your non-motor symptoms, including pain. The questionnaire can be downloaded from the Parkinson's UK website at [parkinsons.org.uk/publications](https://parkinsons.org.uk/publications) or you can order a copy using the details on page 9.

It may also be helpful to write down some details about the pain you experience. For example, you could record where the pain is in your body, the type of pain, when you feel it and how often, whether it is worse at certain times of day, and any other details that you think are important. This can help you to explain your pain symptoms to your specialist or Parkinson's nurse, who may use the King's Parkinson's Disease Pain scale to find out more.

## Common painkillers

There are a number of painkillers that are available without a prescription, which may help ease your pain, including paracetamol and ibuprofen.

You can also buy paracetamol in combination with codeine (co-codamol), although higher doses require a prescription. For many people, paracetamol has few side effects, and you can take two tablets of paracetamol up to four times a day.

Ibuprofen may work better for inflammatory pain and is available as tablets, gels, sprays or liquids. Ibuprofen is not recommended for people with some other conditions, such as stomach ulcers or a history of kidney or liver disease. Also long term use can increase the risk of stomach, kidney and heart problems.

You should discuss your choice of painkiller with your GP or specialist. If your pain is severe or prolonged don't be tempted to go above the recommended doses – see your GP for advice on managing more severe pain.

## Complementary therapies

There may also be other things you can use to manage pain, including complementary therapies.

Complementary therapies are treatments used alongside conventional medicine. They take a more holistic approach than conventional medicine, aiming to treat the whole person including mind, body and spirit, rather than just the symptoms.

There is evidence to show that some complementary therapies have benefits, but for other therapies, there is no research to prove it has any benefits for people with Parkinson's. However, we hear from many people affected who feel complementary therapy helps them.

The benefits of complementary therapies will also depend on what you expect from them. For example, you may not feel a particular therapy is having a positive effect on your Parkinson's symptoms, but you may enjoy the experience. In these circumstances, you may feel this is enough of a reason to continue.

Some therapies people have found helpful for pain include acupuncture, Alexander technique, Bowen technique, chiropractic, Feldenkrais method, herbal medicine, massage therapy, osteopathy and reiki.

You should always make sure you go to a trained, registered (where relevant) and fully insured therapist. Your GP, specialist or Parkinson's nurse may be able to recommend someone.

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

## Is any research being done into pain and Parkinson's?

At the moment, relatively little is known about pain in Parkinson's. Recent studies investigating the use of analgesics (painkillers, such as oxycodone) to ease severe pain associated with Parkinson's have shown some positive results, though more research is needed.

We are also currently funding the largest-ever study into pain, which we hope will help us understand why people with Parkinson's experience pain and the best way to manage it.

To find out more about Parkinson's research, our current research projects and how you can get involved visit [parkinsons.org.uk/research](https://parkinsons.org.uk/research) or call **020 7931 8080**.

## 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](https://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](mailto: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 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 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](https://parkinsons.org.uk/selfmanagement)

Our website [parkinsons.org.uk](https://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](https://parkinsons.org.uk/localtoyou)

You can also visit [parkinsons.org.uk/forum](https://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:

**K Ray Chaudhuri, Professor and Head, National Parkinson Foundation Centre of Excellence, Kings College Hospital**

**Patsy Cotton, Advanced Nurse Practitioner**

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**Monty Silverdale, Consultant Neurologist**

**and Movement Disorder Specialist,**

**Salford Royal 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](https://parkinsons.org.uk/donate)**. Thank you.

## Our information

All of our most up-to-date information is available at **[parkinsons.org.uk/information-support](https://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](https://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](mailto:publications@parkinsons.org.uk)**



## Pain in Parkinson's (2016)

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
- ☐ Parkinson's local adviser
- ☐ 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/Asian British ☐ Black/Black British ☐ White

☐ Mixed/multiple ethnic backgrounds ☐ Other (please specify) .....



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](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**

**[parkinsons.org.uk](http://parkinsons.org.uk)**

Last updated June 2016. 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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