

Pain in Parkinson's

Pain is a common symptom in Parkinson's, affecting about 60% of people with the condition.

This information looks at the types of pain that can affect people with Parkinson's, and how it can be managed.

Pain in Parkinson's may be brought on by a specific Parkinson's symptom, such as rigidity. But there is some evidence that Parkinson's causes pain areas in the brain to become overactive. This can cause you to feel more pain than is normal for your situation.

For example, someone with Parkinson's who also has mild arthritis may experience a higher level of pain than normal, compared with someone who does not have Parkinson's

Doing regular gentle exercise, or taking painkillers, can help reduce pain. But management of pain in people with Parkinson's can be tricky. It's important to find out what's causing the pain, so speak to your GP, specialist, physiotherapist or Parkinson's nurse.

'Acute' and 'chronic' pain

Healthcare professionals may describe pain as being either 'acute' or 'chronic'.

'Acute' pain is short-term, normally lasting less than 12 weeks. It may be sharp and severe, and usually comes on suddenly. For example, it can start following surgery or an injury.

'Chronic' pain is persistent and long-term, usually lasting more than 12 weeks. Normally, the pain experienced after an operation or injury goes away in time, but in some cases it becomes chronic. Chronic pain is often caused by long-term health conditions, including Parkinson's.

The five main types of pain in Parkinson's

Musculoskeletal (muscle) pain

This is the most common type of pain people with Parkinson's experience. It's related to Parkinson's rigidity and reduced movement of the joints. It usually feels like an ache in the neck and back, but any part of the body can be affected.

Simple painkillers, regular exercise and physiotherapy can help. A physiotherapist can help you identify the source of the problem, and advise on helping to manage the pain.

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

It's not unusual for people with Parkinson's to experience muscle pain in one shoulder, which is sometimes diagnosed as 'frozen shoulder'. For some people with Parkinson's, shoulder pain is the first symptom they notice.

Dystonia

This type of pain is common in Parkinson's. It's caused by involuntary muscle contractions and for some people the pain can be severe. Contractions can happen in body parts such as the toes, fingers, ankles or wrists, and can cause spasms in that area. Sometimes the neck is affected too.

The spasms can feel like a severe cramp. They can make the affected body part take on an unusual posture. For example, the toes may curl up. The spasms can also cause twisting movements.

Sometimes, dystonia is related to the timing of Parkinson's medication. If spasms tend to happen early in the morning, it may help to take a controlled (slow) release Parkinson's drug before bed. These drugs release the dosage over a specified amount of time.

Speak to your specialist or Parkinson's nurse about the best ways for you to manage any pain caused by involuntary spasms.

Find out more: see our information sheet on muscle cramps and dystonia.

Radicular (shooting) pain

This is felt as a sharp, often shock-like, shooting pain that travels down the arm or leg, and sometimes the fingers and toes too. Tingling and numbness in the toes and 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. A trapped nerve happens when there is too much pressure on the nerve by the tissues that surround it. Dystonia and changes in posture related to Parkinson's can cause pressure on the nerve.

Speak to your GP or physiotherapist if you're experiencing this type of pain. In many cases, painkillers and regular, gentle exercise can be enough to treat the problem.

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

Central pain

This type of pain is not properly understood and can be difficult to treat. It may be caused by Parkinson's, but can also be caused by other conditions affecting the brain and spinal cord.

It's often described as a stabbing, burning or bloated feeling. It's usually a constant pain, moderate to severe in its intensity. It can be made worse by touch, movement, emotions and changes in temperature.

Central pain can sometimes be managed by adjusting Parkinson's medication, or by a prescription painkiller, such as Gabapentin.

To discuss your treatment options, speak to your GP, specialist or Parkinson's nurse. They may also arrange for tests to determine if your central pain is caused by Parkinson's or another condition.

Dyskinetic pain

Dyskinetic pain can be described as a deep, aching sensation. It can happen because of involuntary movements (dyskinesia) that some people with Parkinson's experience. It can also happen before, during or after movement. Some people with

Parkinson's report that when this pain begins, it's a warning sign that the involuntary movements are about to start.

In other cases, pain that starts 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're experiencing dyskinetic pain – your Parkinson's medication may need to be adjusted.

Find out more: see our information on wearing off and dyskinesia.

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

There are other less common types of pain that are associated with Parkinson's. These are described below.

Muscle cramps

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

Episodes of muscle cramp usually last less than 10 minutes, although your muscles can feel tender for up to a few hours.

Trying to move around might help. You can also try to soothe the cramps by stretching and massaging the muscles.

Speak to your GP, specialist or Parkinson's nurse for advice on easing muscle cramps. They may make a referral to a specialist such as a physiotherapist.

Find out more: see our information sheet on muscle cramps and dystonia.

Restless legs syndrome

This is felt as an irresistible urge to move your legs when resting. It usually occurs in the evening, when going to sleep or during the night.

The symptoms of restless leg syndrome include pins and needles, a burning sensation and pain.

Night-time pain related to restless legs can be treated with Parkinson's drugs, such as dopamine agonists. Your healthcare professional might also recommend other medicines.

Stretches and exercise, as well as relaxation can also help. Taking a warm bath in the evening, avoiding alcohol, caffeine and smoking can also help with this type of pain.

Find out more: see our information on restless legs syndrome and Parkinson's.

Pain in the mouth and jaw

Some people with Parkinson's 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.

Burning mouth syndrome can cause a dry mouth sensation and feeling of thirst. A dry mouth can lead to higher rates of tooth decay and gum disease. Dryness of the mouth can also 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.

Burning mouth syndrome can 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're in pain or feel a burning sensation in the mouth. 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 on dental health and Parkinson's.

Akinetic crisis and pain

This type of pain may occur in the advanced stages of Parkinson's. It's brought on by akinetic crisis, which is a rare and sometimes dangerous complication of Parkinson's. Akinetic crisis involves a worsening of Parkinson's symptoms, which can include severe rigidity, a complete loss of movement, fever and

difficulty swallowing. People with Parkinson's who have akinetic crisis pain say that they feel pain in their muscles and joints, and experience headaches. Some people also experience whole-body pain.

This type of pain can be brought on if you abruptly stop taking Parkinson's medication, or if you develop an infection, both of which can cause Parkinson's symptoms to suddenly get worse.

Akinetic crisis requires urgent medical help. If it looks like someone is experiencing akinetic crisis, call 999.

Headaches

Headaches can happen at any stage in your condition and are sometimes caused by Parkinson's drugs. They may also be related to musculoskeletal (muscle) pain in the neck and shoulders.

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

Your healthcare professional can advise you on your medication regime. They may advise that you try not to take a large number of tablets at one time, particularly if you're also taking medication for high blood pressure or heart problems.

Your healthcare professional can also advise you on how to space out the time between taking different types of tablets because together, they can actually cause headaches.

How is pain assessed?

If you're experiencing pain, the best thing to do is speak to your GP, specialist, Parkinson's nurse or physiotherapist. These healthcare professionals can advise you on appropriate treatments.

You might find it helps to fill in the non-motor symptoms questionnaire for Parkinson's. This will help your healthcare professional assess your non-motor symptoms, which includes pain.

The questionnaire can be downloaded from the Parkinson's UK website at **parkinsons.org.uk/ publications** or you can call the Parkinson's UK helpline on **0800 800 0303** to order one.

It might also be helpful to write down some details about the pain you experience. For example, you could explain:

- where the pain is in your body
- how the pain feels
- how long the pain lasts
- what time of day the pain occurs and how often
- whether the pain is worse at certain times of day
- any other details about the pain you think are important.

This information can help you 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.

It might help if you to keep a diary of how your pain feels and when it occurs. This will help you explain your symptoms to your health professional.

Find out more: see our information sheet on keeping a diary of Parkinson's symptoms.

Common painkillers

There are a number of painkillers available without prescription that can 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. But 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 of ibruprofen can increase the risk of stomach, kidney and heart problems.

It's important to discuss your choice of painkiller with your GP, specialist or Parkinson's nurse. If your pain is severe or prolonged, don't be tempted to go above the recommended doses, as this can cause other problems. Get advice from your healthcare professional on managing more severe or chronic pain.

How can exercise help?

If you experience pain, you may be put off by the thought of exercising, but exercise is an effective and safe way to manage pain. A lack of physical activity can actually make the problem worse, and can cause stiff joints, weight gain, muscle weakness and breathlessness.

When you first start exercising, you may find that it's uncomfortable in the short term. But as your body gets used to the new movement, in the long term it will have a positive impact on chronic pain.

There are specific exercises that work for different types of pain. For acute pain, it's best to start with gentle exercises. These exercises will usually be recommended by a healthcare professional such as a physiotherapist.

For chronic or persistent pain, it's a good idea to build on what you can already do, with functional exercise (see below). This involves training your muscles to perform common movements that you might do at home or at work.

Functional exercise for chronic/persistent pain

There are some simple exercises that you can try around the house to help:

- If you experience pain in your legs, keep them strong by practising standing up and sitting down in a chair.
- If your shoulders are aching, start by loosening them with some shoulder rolling actions, then by lifting an object that is slightly weighty (such as a tin of beans) from a shelf, and then replacing it. This increases the range of movement in your back, shoulders and arms, and then your strength.

Improve your general fitness

Increasing your level of fitness will help you manage your weight and ensure your joints aren't under any added pressure. You could try walking, swimming, dancing, cycling or aerobics — it's up to you. Many of Parkinson's UK's local groups have

physiotherapist-led exercise classes you can join. Visit **localsupport.parkinsons.org.uk** or call our helpline on **0808 800 0303** to find one near you.

Complementary therapies

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

There's evidence that some complementary therapies have benefits, but for others there's no evidence that they help people with Parkinson's. However, many people with Parkinson's report that complementary therapies help them.

Some therapies people have found helpful for pain include acupuncture, Alexander technique, Bowen technique, chiropractic treatment, 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 on complementary therapies and Parkinson's.

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

There's still a lot we don't yet know about pain in Parkinson's, but thanks to recent research, we do know that Parkinson's can cause pain areas in the brain to become overactive.

Researchers are working hard to find ways to try and reduce these overactive pain areas, although there is no proven treatment at the moment.

To find out more about Parkinson's research and how you can get involved visit **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

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**.

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.

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition.

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 to everyone who contributed to or reviewed this booklet, including experts and people 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 **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/informationsupport

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/orderingresources** 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!

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
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

We're the Parkinson's charity that drives better care, treatments and quality of life.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK 215 Vauxhall Bridge Road London SW1V 1EJ

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.nqts.org.uk**

hello@parkinsons.org.uk parkinsons.org.uk

at parkinsons.org.uk/termsandconditions

Order code: INFOS0027

Last updated June 2020. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

 \odot Parkinson's UK. Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).



 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.
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