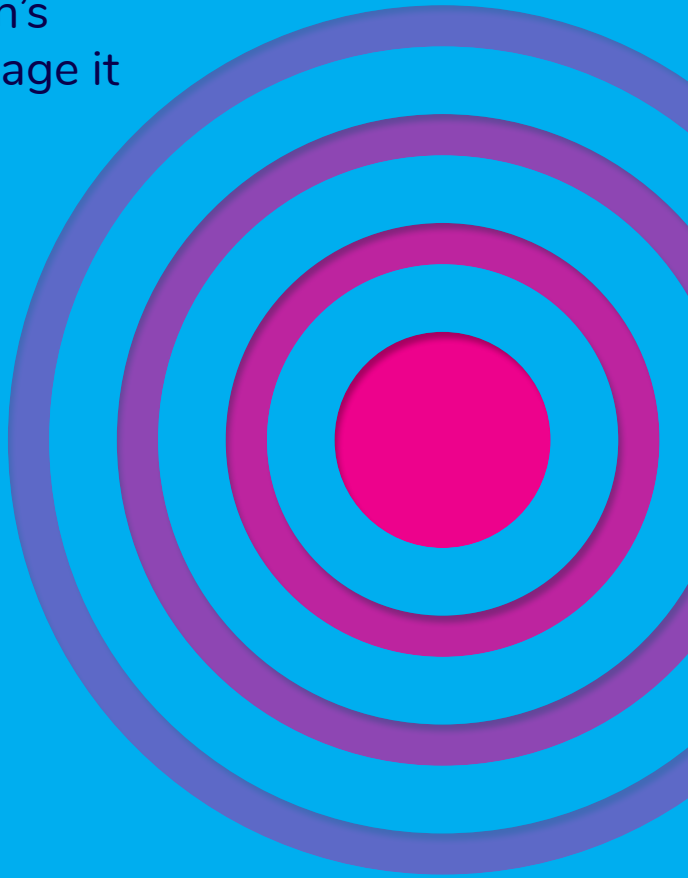


PAIN IN PARKINSON'S

Symptoms

Find out more about
pain in Parkinson's
and how to manage it



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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 leg 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 leg 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](https://www.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 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 pain killer

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 ibuprofen 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
therapy 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 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.

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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Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

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)
hello@parkinsons.org.uk
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Parkinson's UK, 215 Vauxhall Bridge Road,
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