

Pain in Parkinson's

Pain is an unpleasant and occasionally distressing experience of the senses, which may occur due to a variety of causes.

How common is pain in Parkinson's?

Pain may occur in up to 50% of people with Parkinson's disease. However, the symptoms of Parkinson's that affect movement, such as stiffness, tremor, falls and dyskinesias, may sometimes be the most obvious features and people with Parkinson's may not realise the impact of pain on their condition. Sometimes, however, pain may be the principal symptom of Parkinson's. In many cases, pain can precede the other symptoms of Parkinson's and diagnosis of Parkinson's by several years. It is not uncommon for people to undergo surgery or other interventions for symptoms such as "frozen shoulder" or "stiff joints", before it becomes apparent that the pain is related to Parkinson's and that replacing dopamine and exercise may be the best treatments. Therefore, both people with Parkinson's and their carers need to be aware of the problems pain may cause in Parkinson's.

What are the causes and types of pain in Parkinson's?

Recently, researchers have attempted to classify different types of pain in Parkinson's. Information regarding treatments for each kind of pain, and subsequently how to manage it, follows.

Musculoskeletal pain is a common type of pain in Parkinson's. This is pain arising from muscles and bone and is usually felt as an ache around joints, arms and legs. The pain remains local and does not move around or shoot down a leg or arm.

Muscle rigidity in Parkinson's leads to cramps and spasms and causes this type of pain.

Musculoskeletal pain may respond to a combination of simple analgesics (painkillers) such as Paracetamol along with regular exercise and, occasionally, physiotherapy.

Radicular pain is a sharp, often shock-like shooting pain that travels down a leg or arm and may involve fingers and toes. Tingling and numbness or burning feelings in the toes and/or fingers are common. This type of pain is usually the result of a trapped nerve within the spinal cord around the neck or back region. Nerves could be trapped by protruding discs that normally act as pillows

between the bony vertebrae, or due to arthritis of the spine.

In some cases, an X-ray of the affected area may be required to aid diagnosis. In most cases, simple analgesics (painkillers) and regular, gentle exercise are sufficient. Rarely, severe and unremitting pain may require referral to a neurologist to rule out compression of the nerve roots at the spinal cord. This may require specialist investigations such as magnetic resonance imaging (MRI) scans. Those with a significant degree of symptoms due to trapped nerves may need to wear a neck collar if the problem arises from the neck.

Dyskinetic pain arises as a secondary problem to the dyskinesias (abnormal involuntary movements) that some people with Parkinson's experience. See also the Parkinsons Information Leaflet M1.1 on Motor Fluctuations in Parkinson's (On/Off, Wearing Off, Dyskinesia) and M1.2 Dyskinesia. Pain due to dyskinesias may occur in the daytime either before, during or after the dyskinesias. Occasionally, people with Parkinson's experience body pain as dyskinesias are about to start. Thus, pain could be a warning sign of the beginning of dyskinesias. This sort of pain is not limited to any body part and can be described as a deep, aching sensation. Some people with Parkinson's experience pain during severe dyskinesias, possibly because of the twisting movements. Furthermore, dyskinesias may aggravate radicular pain if there is an underlying trapped nerve. Dyskinesia-related pain often occurs at the height of the action of the anti-Parkinson's drugs and, in such cases, the doses of relevant drugs will have to be reduced. Dyskinesia-related pain is complicated and needs specialist attention through referral to a neurologist with an interest in Parkinson's.

Dystonic pain refers to the abnormal spasm or posturing of body parts such as toes, fingers, ankles or wrists and it may, for example, cause the feet to turn inwards or toes to curl downwards. This type of dystonia may feel like a painful cramp and it may wake the person in the early morning or be evident in the morning during waking. Dystonic pain can also result from fluctuations in a person's response to standard anti-Parkinson's drugs, such as levodopa. The dystonia arises as the drug effects 'wear off' at night (known as the 'wearing-off' phenomenon).

Prolonging the 'on' period (when the anti-Parkinson's drugs are effective) as much as possible, therefore, can help this kind of pain. This can be achieved by frequent, small doses of levodopa drugs, combining levodopa with a COMT inhibitor such as entacapone (or using Stalevo), or using a long-acting dopamine agonist drug.

Sometimes, when 'off' period pain is caused by early morning dystonia, then self-injection of a drug called apomorphine can be helpful. Apomorphine works quickly and can be self-administered. In very severe 'off' period pain from dystonia, which does not respond to apomorphine, injection of a drug called botulinum toxin to the affected area may be helpful.

Akathisia or a sense of restlessness may also cause pain. This may often occur at night and people with Parkinson's may find it difficult to sleep because of fidgeting in bed and a desire to move the limbs.

Akathisia may be the consequence of drug treatment for Parkinson's. This pain is difficult to describe and is felt as a discomfort rather than pain. The discomfort usually involves the legs, and people who experience it may wander around to obtain relief. This may also be due to restless leg syndrome which may occur in Parkinson's.

Restless legs-related pain at night often responds to a combination of treatment at night-time with some anti-Parkinson's drugs, such as controlled-release levodopa or a long-acting dopamine agonist drug, sometimes in combination with a sleep-promoting agent or muscle relaxant such as clonazepam.

Are there any other types of pain that occur in Parkinson's?

Sometimes pain may occur in Parkinson's that is different from the types of pain described above. These atypical pain syndromes are described below.

Shoulder or limb pain: Occasionally, pain and stiffness affecting just one side of the body, usually an arm or leg, may be the first sign of development of Parkinson's.

Shoulder or limb pain may improve with successful control of Parkinson's using standard medications. In some cases, a regular course of physiotherapy is useful. If the pain continues in spite of this, then painkillers are required and in some cases referral to a specialist clinic may be required. Frozen shoulders may need injection of steroids to the joints.

Burning mouth: This is a rare problem where some people with Parkinson's experience a burning sensation or pain in the mouth. This can happen at any stage of Parkinson's and the cause is unclear. Dryness of mouth induced by drug therapy with anticholinergic drugs and / or ill-fitting dentures may be responsible.

Burning Mouth Pain requires referral to a dentist. The cause of burning mouth pain is unclear. Regular

rinsing of the mouth with an antiseptic mouthwash and keeping the mouth moist with drinks are also important. In hot weather, sucking on a piece of ice may also be useful. Ill-fitting dentures need to be replaced. If the Parkinson's is being treated with an anticholinergic drug (e.g. biperidion (Akineton) or procyclidine (Kemadrin), this may have to be discontinued after discussion with the GP and Parkinson's consultant, as such drugs can cause dry mouth.

Coat-hanger pain: This is a rare type of pain that is occasionally seen in people with Parkinson's who also suffer from postural hypotension (drop of blood pressure on standing due to autonomic nervous system dysfunction). However, this type of pain is more common in people who have a form of Parkinsonism called Multiple System Atrophy (MSA) rather than Parkinson's. (Further information about MSA is available from the Multiple System Atrophy Trust Founded by Sarah Matheson ([HYPERLINK "http://www.msatrust.co.uk" www.msatrust.co.uk](http://www.msatrust.co.uk))). The pain usually starts around the back of the neck and may radiate to the back of the head and the shoulder muscles. The overall shape of the area of the body where this pain occurs resembles a coat hanger. Those who experience this pain should discuss it with their doctor and seek referral to a specialist centre with expertise in movement disorders for diagnosis and management.

Akinetic crisis and pain: Occasionally, people with Parkinson's may experience a sudden worsening of their symptoms, which may be brought about by abrupt withdrawal of anti-Parkinson's treatment or by infections. The symptoms include severe stiffness, fever, pain in muscles and, joints, headache and, sometimes, whole-body pain. Severe stiffness in the muscles, causing the release of pain-producing chemicals, may be the cause.

Akinetic crisis pain is usually improved by treatment with levodopa drugs.

Headache: Headache can occur at any stage in people with Parkinson's and occasionally may be caused by the drugs used to treat the condition. Examples of these drugs may be dopamine agonists, amantadine and entacapone. Further information about the drugs used to treat Parkinson's is available in the Parkinsons Information Leaflet G4 on Medications.

Headaches in Parkinson's are rarely severe and normally over-the-counter painkillers are adequate. People with Parkinson's should take care not to take a large number of tablets together at one time, particularly if they are also taking medication for high blood pressure or heart problems. Severe, drug-resistant headaches are rare in Parkinson's and if present, need to be investigated by a neurologist.

Muscle cramps: Muscle cramps occur in Parkinson's and may come on at night or during the day. At night they may cause pain in the legs and calf muscles as well as restlessness, which leads to disruption of sleep. Cramps may also occur in internal organs with muscles and thus affect the bowel (causing abdominal pain and cramps) or bladder (leading to urgency of urination or pain).

Muscle cramps will often be alleviated by treatment for Parkinson's. For example, night-time cramps may be helped by prolonging the action of levodopa. Otherwise, soluble levodopa dissolved in water may help, taken when cramps are painful. In some situations, when there are severe 'off' period-related bowel cramps, apomorphine injections may be very helpful. Quinine sulphate tablets are often prescribed for cramps, but caution is required as these tablets may sometimes lead to abnormalities of blood cells and so require monitoring. The drug diazepam may sometimes be useful too.

Where can I get help for pain?

Firstly, make a GP or Consultant or Parkinson's Disease Nurse Specialist aware of the problem. They will advise the most appropriate ways to manage pain. This may include the following:

- Management by the GP (for the more common types of pain such as musculoskeletal shoulder pains and headache)

Treatment with physiotherapy

Management by a neurologist or geriatrician with an interest in Parkinson's (for dyskinetic pain, burning mouth or coat hanger pain)

Management by a pain specialist at a Pain Clinic. Pain specialists have advanced training in the diagnosis treatment and rehabilitation of people with chronic pain. Details of hospitals in Ireland with Pain Clinics can be obtained from the Chronic Pain Ireland (CPI) website ([HYPERLINK "http://www.chronicpain.ie"](http://www.chronicpain.ie) www.chronicpain.ie). The CPI also have a Support Phone Line for patients (01 8047567).

Acknowledgements

The PAI would like to thank Sean O'Sullivan, Consultant Neurologist for reviewing and endorsing this leaflet.

Other Relevant Information Sheets

G4: Medications and Parkinson's Disease

NM4: Muscle Cramps and Dystonia

M1.1: Motor Fluctuations in Parkinson's (On/Off, Wearing Off, Dyskinesias)

DISCLAIMER – The information on these pages is not intended to be taken as advice. No changes to your treatment should be made without prior consultation with your doctor or allied health professional.

Parkinson's Association of Ireland

National Office: Carmichael House, North Brunswick Street, Dublin 7, Ireland.

Tel: 00 353 1 872 2234 **Fax:** 00 353 1 872 5540

Parkinson's Association of Ireland is a registered charity with limited liability.
Company Reg. No. 123532. Charity Reg. No. CHY 10816. Registered address as shown

NM5 April 2014