Pain in Parkinson’s

Pain affects many people with Parkinson’s. This information sheet looks at how common a symptom it is for people with Parkinson’s and examines the causes of and treatments for pain. It will also explain where to go for help if you are experiencing pain.

How common is pain in Parkinson’s?
When most people think about the symptoms of Parkinson’s they are likely to think about the obvious symptoms that affect movement, such as stiffness, tremor, falls and involuntary movements. However, pain is a symptom that affects up to 50% of people with Parkinson’s and for some people it can be the main symptom of their condition. Therefore, both people with Parkinson’s and their carers need to be aware of the problems pain may cause.

What are the causes and types of pain in Parkinson’s?
Researchers have attempted to identify the different types of pain in Parkinson’s. Information about treatments for each kind of pain follows on page 3.

Musculoskeletal pain is a common type of pain in Parkinson’s. This pain comes from muscles and bone and is usually felt as an ache around joints, arms and legs. The pain stays in one area and does not move around or shoot down a leg or arm. This sort of pain is due to cramps and spasm caused by muscle stiffness, a common symptom of Parkinson’s.

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 a burning feeling in the toes and/or fingers is also common in people with Parkinson’s. This type of pain is usually the result of a trapped nerve within the spinal cord around the neck or back region. Nerves can get trapped by protruding discs that normally act as pillows between the bony vertebrae, or due to arthritis of the spine.

Dyskinetic pain occurs because of involuntary movements (dyskinesias) that some people with Parkinson’s experience. Pain due to involuntary movements can occur either before, during or after the movements. Some people with Parkinson’s experience pain just as involuntary movements are about to start. Here, pain could be a warning sign of the beginning of the involuntary movements. 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 involuntary movements, possibly because of the twisting movements. Involuntary movements can also aggravate radicular pain if there is an underlying trapped nerve.

Dyskinetic pain can also result from fluctuations in a person’s response to standard anti-Parkinson’s drugs, such as levodopa. These fluctuations may include early morning or night-time dystonia and this may cause pain in the affected limb. Dystonia is 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 often occurs in the early morning, or at night as drugs ‘wear off’.

Akathisia – a sense of restlessness – may also cause pain. This restlessness often occurs at night and people with Parkinson’s may find it
difficult to sleep because of fidgeting in bed and a desire to move their limbs. Restlessness at night may be the result 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 can occur in Parkinson’s. For more information on restless leg syndrome see our Information Sheet Restless Leg Syndrome and Parkinson’s.

Are there any other types of pain that occur in Parkinson’s?
Sometimes pain can occur in Parkinson’s that is different from the types of pain described above. These atypical forms of pain are described below.

Shoulder or limb pain is pain and stiffness affecting just one side of the body, usually an arm or leg, may be the first sign of the development of Parkinson’s. In such situations, diagnosis of Parkinson’s may be delayed and people may be mistakenly referred to doctors from other disciplines such as rheumatologists (doctors specialising in conditions affecting the joints). The pain is constant, aching, and associated with a reduced ability to undertake fine movements with the fingers, or the dragging of a foot. The onset of Parkinson’s may be suspected if a constant aching pain develops in an arm or leg, and the limb becomes progressively stiffer.

Burning mouth 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. One study suggested that burning mouth might affect up to 24% of people with Parkinson’s. Dryness of the mouth induced by drug therapy with anticholinergic drugs (such as benzhexol) and ill-fitting dentures may be responsible.

Coat-hanger pain is a rare type of pain that is occasionally seen in people with Parkinson’s who also suffer from postural hypotension (a drop in blood pressure on standing due to a problem with the nervous system). 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 Systems Atrophy Trust, Southbank House, Black Prince Road, London SE1 7SJ Tel: 020 7940 4666, Mon-Fri, 9.30am-4.30pm.) 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. The cause of this type of pain is unclear and it has been suggested that the pain may occur because of reduced blood supply (due to postural hypotension) to the muscles in the neck and shoulder area.

Akinetic crisis and pain is occasionally, experienced by people with Parkinson’s when they have 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.
Headaches 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 are dopamine agonists, amantadine and entacapone. Further information about the drugs used to treat Parkinson’s is available in the Parkinson’s Disease Society (PDS) booklet *The Drug Treatment of Parkinson’s Disease*.

Muscle cramps occur in Parkinson’s and can happen 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 in Parkinson’s may also occur when the effect of drugs, such as levodopa, is ‘wearing off’. This may be a dystonic phenomenon (sustained involuntary contraction of the muscles) and can be painful. Cramps may also occur in internal organs with muscles such as the bowel (causing abdominal pain) or bladder (leading to urgency of urination or pain).

How is pain in Parkinson’s treated?
Successful treatment of pain in Parkinson’s is based upon correctly identifying the cause of the pain. The treatments are discussed below.

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

Radicular pain is usually linked to a trapped nerve. You should discuss this with your GP and, in some cases, an X-ray of the affected area may be required. In most cases, simple 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 is mostly related to ‘off’ periods (periods of relative immobility) when the anti-Parkinson’s drugs are ‘wearing off’. 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 (abnormal spasm or posturing of body parts), 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. Occasionally, pain related to involuntary movements may occur 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. Pain related to involuntary movements is complicated and needs specialist attention through referral to a neurologist with an interest 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, together with a sleep-promoting agent such as amitriptyline or zopiclone.

**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 local ‘pain’ team or rheumatologist may be required. Frozen shoulders may need injection of steroids to the joints.

The cause of **burning mouth pain** is unclear, but if it occurs, referral to a dentist is important. 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 drugs such as benzhexol, 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** arises from postural hypotension and so this needs to be treated. 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 pain** is usually improved by treatment with levodopa drugs.

**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. The tablets need to be ‘spaced’ out, as together they may, in fact, cause headaches. Severe, drug-resistant headaches are rare in Parkinson’s and if present, need to be investigated by a neurologist.

**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 and using a controlled-release preparation. Otherwise, soluble levodopa dissolved in fizzy orange juice 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. Some tonic waters contain quinine and may help if taken at night. However, check that the brand of tonic water you use does contain quinine (e.g. Schweppes), as we understand that not all products do. The drug diazepam may sometimes be useful too.

**Where can I get help for pain?**
Firstly, you need to make your GP, or Parkinson’s consultant aware of the problem. You can also discuss this with your Parkinson’s Disease Nurse Specialist, if there is one in your area. Usually, your GP will be able to manage the more common types of pain such as musculoskeletal shoulder pains and headache. However, certain other types of pain such as dyskinetic pain, burning mouth or coat-hanger pain may need referral to a neurologist with an interest in Parkinson’s.
Is any research being done into pain and Parkinson's?

The author of this information sheet, Dr K Ray Chaudhuri, and Professor David Brooks are currently investigating the mechanism of pain in Parkinson's by undertaking research using special brain scans (known as PET scans) at the Hammersmith Hospital in London. Further information on this research project will be available at a future date.

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