Paget’s Disease and PAIN

Diana Wilkinson
Healthcare & Education Officer
Paget’s Association

Revised: August 2013
Review: August 2015
Version: 3
Contents

Introduction 2
Paget’s disease and pain 3
Medication 7
Surgery 11
Who can help? 13
Other methods of pain relief 14
Self-help 16
Relaxation techniques 18
The Paget’s Association: Here to help 20
Which other organisations can provide information? 22
Introduction

The Paget’s Association has produced this booklet for anyone with Paget’s disease who has pain. It will help you understand your pain and how it might be dealt with.

This booklet aims to provide up to date information enabling you to participate in relevant discussions with your medical team. It is not designed to replace specific guidance you may receive from a health professional with respect to your individual care.

Pain is a personal experience. No two people experience or deal with pain in the same way. This can make it difficult to treat. Only the person experiencing it knows how it affects them. Pain can affect daily life, relationships, activity levels, sleep and ability to work. How you deal with your pain can affect the way in which you feel it. Many factors, such as anxiety and fatigue, determine how your body will react to pain and whether your nerves will transmit or block a potentially painful message. You can become locked in a cycle of pain, depression and stress. Understanding your pain is the first step to breaking this cycle and achieving pain control.

Diana Wilkinson, RGN, BSc (Hons)
Healthcare and Education Officer
Paget’s Association
Paget’s disease and pain

Not all those with Paget’s disease experience pain. Pain is however, the commonest presenting symptom of Paget’s disease.

Pain can be a warning that something is wrong and should not be ignored. It is therefore important to have pain assessed by your doctor.

Pain in Paget’s disease may be directly related to the disease itself as a consequence of increased bone activity. Pain can also occur as a result of damage to the adjacent joints (osteoarthritis), a break in the bone (fracture), pressure on the nerves from enlarged bone or as the result of deformity of the bones, which can put stress on joints and soft tissues.

Pain in the muscles, joints and bones, is common. It may be acute or chronic. Acute pain is related to direct damage caused by many factors including fracture and inflammation; it is self-limiting and usually settles when healing is complete. Chronic pain is pain that will not go away and outlasts the normal healing process. Many things will influence the development and intensity of chronic pain (figure 1).

Figure 1
Effects of musculoskeletal pain
What is bone pain?

Bone pain at a specific site is detected by specialised transmitters located on the bone surface, which then pass messages through the nervous system to the brain where signals are recognised as pain. Pain in Paget’s disease may arise from the affected bone and is often at night, is not relieved by exercise and may respond poorly to painkillers. It is not fully understood why pain arises from pagetic bone but it may be caused by:

- Increased bone activity and blood supply to the affected area
- Stretching of the lining of the bone
- Fissure fractures that occur in deformed weight bearing bones
- Complete fracture
- The extremely rare occurrence of a type of bone cancer, called sarcoma at the site of Paget’s disease

What is joint pain?

Osteoarthritis is a common condition and those with Paget’s disease are more prone to develop it at joints adjacent to pagetic bone due partly to the abnormal stresses placed on these joints. For example if a tibia (shin) becomes bowed, this will cause shortening of the leg resulting in gait (walking) problems that can place extra mechanical stresses on the ankle and knee joints.

When there are marked arthritic changes in a joint the joint surface becomes damaged, the underlying bone thickens, the cartilage becomes worn and eventually bone surfaces will rub against each other (figure 2). This leads to increased stiffness and pain, which is usually worse on moving the affected joint or on weight bearing.
Figure 2  Osteoarthritis
A series of pictures illustrating the progression from a normal joint at the top, to one with advanced osteoarthritis at the bottom. Note the progressive loss of cartilage and reduction in joint space.
Image reproduced with kind permission of Arthritis Research UK.
Back pain

Back pain is very common and in many instances is likely to be related to degenerative (“wear and tear”) changes throughout the spine and not just Paget’s disease. Non-specific aches may arise from enlarged pagetic vertebrae (spine bones) and vertebral fractures (breaks) can occur, resulting in acute pain that may be felt in the spine and may move round to the ribs. Occasionally an enlarged vertebra may press on the spinal nerves leading to pain where the nerve goes to e.g. felt down the legs with possible loss of function.

Skull pain

Paget’s disease of the skull can be associated with several symptoms including headaches and a band-like tightness around the head resulting in an unpleasant sensation.
Medication: What is available for treating pain associated with Paget’s disease?

Bisphosphonates

Bisphosphonates are effective in reducing bone turnover and when pain is associated with active Paget’s disease, they will provide a degree of pain relief. The drugs commonly used in the UK are:

- Zoledronate 5mgs (e.g. Aclasta). Given intravenously (directly into the bloodstream)
- Pamidronate (e.g. Aredia). Given intravenously
- Risedronate 30mgs (e.g. Actonel). Taken orally for 2 months

In a small number of people, bisphosphonates may initially cause a slight increase in bone and muscle pain but this usually subsides after a few days. Whilst individual response may vary, pain related specifically to Paget’s disease usually responds well to bisphosphonates within a few months.

For further information, regarding bisphosphonates see our booklet: Paget’s disease – The Facts.

What other types of medication may be required?

Most people with Paget’s disease require painkillers (analgesics) as well as bisphosphonates to control pain, especially if the disease has led to damage to the bones and joints. Always start with small doses of weak drugs that can be gradually increased or changed to stronger drugs until you have the best possible pain relief.
Examples of analgesics (figure 3)

**Paracetamol.** One of the safest options that may prove beneficial. It is important to take paracetamol regularly (up to 8 tablets daily) and not wait until the pain becomes intolerable. It has few side effects when taken as prescribed. An overdose however is dangerous, therefore if you take any other painkillers (or cold remedies), check for paracetamol content.

**Non-steroidal anti-inflammatory drugs (NSAIDS)** e.g. aspirin, ibuprofen. Some NSAIDs can be purchased without a prescription. **It is important however, that their use be discussed with your doctor.** Some NSAIDS are available as creams, gels or as suppositories.

**Weak Opioids** e.g. codeine, dihydrocodeine and tramadol. Used for more severe pain that has not been helped by the above.

**Combination therapies** e.g. co-codamol, which contains paracetamol and codeine.

**Strong Opioids.** Occasionally pain associated with Paget’s disease can be so severe, such as following a fracture, that stronger opiate drugs are recommended (e.g. morphine). These would be used for short periods only. They may be associated with nausea, vomiting, constipation and dependence.

**Topical medicines.** Some medicines for pain relief are available in creams or gels (NSAIDs). Patches, applied to the skin, can also be used (e.g. buprenorphine).
Pain in Paget’s disease may also be associated with nerve damage. Drugs that were originally created to treat other illnesses, such as depression (e.g. amitriptyline) or epilepsy (e.g. gabapentin), are commonly used to treat pain associated with the nerves (figure 4). These treatments may take several weeks before they begin to have an effect.
Calcitonin

In the past, calcitonin was frequently used to treat Paget’s disease. It is now rarely given as a standard treatment but is sometimes recommended for pain relief.

Taking medication correctly

Bisphosphonates and other medications will only help to reduce pain if they are taken at the correct time and in the correct way.

Oral bisphosphonates should be taken first thing in the morning, on an empty stomach. Wait at least 30 minutes before eating or drinking anything (other than water). If you take a bisphosphonate with food, or drinks other than water, only a small amount of the medicine is absorbed. Swallow the tablet with a full glass of water and do not lie down but remain upright (sit, stand or walk) for at least 30 minutes afterwards. This is because bisphosphonates can irritate your oesophagus (the tube that takes food into your stomach).

When taking any medication, make sure you read the patient information fully. If you are concerned about any side effects talk to your GP.
Is surgery required to treat pain associated with Paget’s disease?

Few people with Paget’s disease ever need surgery, but successful surgical management of severe complications can reduce pain and improve quality of life.

Joint replacement

Hip and knee replacements may be required for associated osteoarthritis. These replacements can be very successful but the operation may be more technically challenging due to deformity and the altered bone quality. In addition to normal risks associated with an operation, there is a slight increase in the risk of formation of bone outside the skeleton (heterotopic ossification) and non-union of the bone.

Fracture (broken bone)

If a bone affected with Paget’s disease breaks, it may require either a plaster cast or an operation to stabilise the fracture. Surgery to repair a fracture may be more complex in those with Paget’s disease because of the size and structure of the bone and in some cases healing may take longer.

Osteotomy

Osteotomy, when a bone is broken to shorten, lengthen or change its position, is occasionally used and the bone is then reset in a more normal position. This may be performed if there is marked deformity, fissure fracture or pain that has not responded to painkillers.
Spinal surgery

Paget’s disease in the spine can press on the spinal cord causing a narrowing that only very occasionally needs to be corrected surgically, if medical treatment is unsuccessful.

Tumour removal

Malignant tumours associated with Paget’s disease occur very rarely, when surgery can be used to remove them.
Who can help?

Do not be frightened to ask for help when you need it. Many professionals including doctors, nurses, physiotherapists and occupational therapists, can all provide information and support. In the case of severe, persistent pain, it may be necessary to consider the specialist services provided by a pain clinic. To find the best treatments for you, it is often necessary to try various options and see if they help.

Questions you may be asked about your pain

When you see a healthcare professional about your pain, they will need to piece together a picture of your pain, how it is linked with other medical problems that you might have and how it affects you as a person.

You may be asked:

- Does anything make the pain worse?
- Does anything ease the pain?
- Does the pain prevent you from doing anything?
- Is the pain worse at rest / at night?
- Does the pain wake you from your sleep?
- Describe your pain. Is it sharp, burning, aching or nagging?
- Does your mood or stress affect your pain?
- What medication are you currently taking for the pain and what effect does it have?

You may also have questions. Make a list of questions to put to your healthcare professionals concerning your pain management.
What other methods may be used to treat pain associated with Paget’s disease?

Although there is limited scientific evidence to support other methods used to treat pain, some may find the following helpful. Always ensure that the therapist is appropriately trained and registered.

**Do seek advice from your GP before trying any of these methods.**

**Physiotherapy**

Physiotherapists help people through movement and exercise, manual therapy, education and advice. Your GP can refer you to a physiotherapist.

**Use of walking aids**

There are many different walking aids and it is important to seek advice. Physiotherapists can advise. If you use a walking stick for instance, it is usually held on the opposite side to the affected leg and it is important to have the stick at the correct height to achieve adequate support.

**Specialised footwear**

The orthotics department of your hospital can provide specialised footwear to balance deformity.

**Transcutaneous electrical nerve stimulation (TENS)**

The use of a TENS machine involves stimulation of the nerves by low-level electrical impulses. Small electrodes are placed onto the skin near the painful area and then connected to a small battery-
operated stimulator. It does not hurt, but may tingle. TENS is believed to work by stimulating nerves to release natural endorphins, which close the pain barrier. It must not be used by anyone who has a pacemaker or by women in the early stages of pregnancy.

Heat and cold packs

Care must be taken to ensure you do not burn yourself. Always put a towel between your skin and any warm or cold pack. Never use heat or cold on any area for more than 15 to 20 minutes. Do not use cold packs if you have poor circulation or sensation. Some find alternating between heat and cold packs helpful.

Massage

Some find that massage helps. Having a massage to an area of the body that is not painful, such as a hand or foot massage, can be relaxing.

Acupuncture

Acupuncture involves the stimulation of points on the body using a variety of techniques, such as penetrating the skin with needles that are then manipulated manually or by electrical stimulation. There has not been any rigorous assessment of the use of acupuncture for pain associated with Paget’s disease. Currently, the National Institute for Health and Care Excellence (NICE) recommends acupuncture as a treatment option only for lower back pain (not specifically associated with Paget’s disease). Acupuncture may decrease pain in other circumstances for some people.
Other complementary therapies

There are many complementary therapies available. There is no evidence to show that any are effective in treating the pain of Paget’s disease. If you are considering trying any therapy, it is very important that you discuss it with your GP first.

Self-help: What can I do myself to cope with the pain associated with Paget’s disease?

Each individual perceives and subsequently copes with pain differently but the most important thing is to try and control the pain rather than letting it control you.

Sources of advice on self-management include books, magazines, the internet, self-help programmes and many organisations that provide literature and support. Here are some suggestions:

Pace daily activities. Pacing, in short, is taking breaks throughout the day before they are needed. Pacing an activity can enable you to carry out activities, without causing extra pain. It helps prevent you having bouts of over or under activity. The amount of activity you do is often based on how you feel. When you have a good day, you find that you want to make the most of this and get extra tasks done. This can often lead to over doing it and feeling much worse later in the day or the following day. Don’t overdo things on the days you feel well, or rest too much and lose fitness.

Stay positive. Pain can make you tired, anxious and depressed. This can make the pain worse.

Distract yourself. The amount of time you spend consciously thinking about pain will influence how much pain you feel. Try to
focus your attention onto something else so the pain is not the only thing on your mind. Try doing something you really enjoy and if a certain hobby is no longer possible, perhaps due to restricted mobility, why not discover a new one?

**Music.** Whilst the relevance of music for pain relief in clinical practice is unclear, there have been some positive effects shown in the use of music for pain reduction. Choose music that really engages and distracts you.

**Share your story.** When you do need to discuss how you are feeling, it can help to talk to someone else who has experienced similar pain and understands what you are going through. Consider joining the Paget’s Association’s Support Network, the Paget’s Online Community or contact other organisations who can provide support (you will find information on these later in this booklet).

**Socialise.** Keep in touch with friends and family, aiming to talk about anything other than pain.

**Relax.** Trying to relax is a crucial part of easing the pain because muscle tension, caused by worrying about your condition, can make things worse. Practising relaxation techniques regularly can help to reduce persistent pain. Relaxation techniques can make you feel more able to deal with pain, as the tension in your body is released. There are many types of relaxation techniques. Most combine breathing more deeply with relaxing the muscles. Relaxation is a skill that needs to be acquired and so gets better with practice. There are various forms of exercise classes which can help to improve breathing and relaxation. Discuss these with your GP first.
Relaxation Techniques

Diaphragmatic breathing technique

Diaphragmatic breathing exercises may make you feel tired at first but with practice, diaphragmatic breathing will become easier.

• Choose a quiet place where you will not be disturbed. You may want to play some soothing music. Make yourself feel comfortable by loosening or removing any tight clothes and clear the room and your mind of any distractions.
• Lie on your back in bed or on a flat surface, supporting your head with a pillow. Slightly bend your knees and support them with a pillow if you wish.
• Place one hand on your upper chest and the other just below your rib cage, allowing you to feel your diaphragm move as you breathe.
• Breathe in slowly and deeply through your nose so that the hand on your chest remains as still as possible and your stomach moves out against your other hand. Fill up the whole of your lungs with air, without forcing. Breathe in slowly, counting from one to five (do not worry if you cannot reach five at first).
• Tighten your stomach muscles, letting them fall inward as you breathe out slowly, through pursed lips, again counting from one to five. Ensure the hand on your upper chest remains as still as possible.

Practice this exercise 3-4 times per day for 5-10 minutes or whenever you feel stressed. You can gradually increase the amount of time you spend doing this exercise. Although it is easier to do this lying down, you can perform this exercise whilst sitting in a chair.
Deep muscle relaxation

Releasing tension from the body and relaxing the mind, deep muscle relaxation stretches different muscles in turn and then relaxes them. It requires practice before you will start to feel its benefits.

- Get completely comfortable, either sitting or lying down, somewhere quiet without distractions. Close your eyes and focus on breathing slowly and deeply, as described previously.
- For each of the following, hold the stretch for a few seconds, and then relax. Repeat a couple of times, working through the muscle groups:
  - Face: push the eyebrows together, as though frowning, then release.
  - Neck: tilt the head forwards, pushing the chin down towards the chest and slowly lift again.
  - Shoulders: pull them up towards the ears as though shrugging, and then relax them down low.
  - Chest: breathe in slowly and deeply through the nose and then breathe out slowly through the mouth.
  - Arms: stretch the arms away from the body, reach, and then relax.
  - Legs: push the toes away from the body, then pull them towards the body, and then relax.
  - Wrists and hands: stretch the wrist by pulling the hand up towards you, and stretch out the fingers and thumbs, then relax.

Spend some time lying quietly after your relaxation with your eyes closed. When you feel ready, stretch and slowly turn on to your side, bend your knees and push up with your arms until sitting.
The Paget’s Association: Here to help

Paget’s Support Network

The Paget’s Support Network is available free to members of the Paget’s Association, enabling communication by telephone, email or letter, with others who have Paget’s disease. Contact the Association using the details below.

Paget’s Online Community

Share your experiences or ask a question via the Paget’s Online Community. This can be accessed either from our website www.paget.org.uk or www.healthunlocked.com

The Helpline

The Paget’s Association has a Helpline managed by an experienced Registered Nurse. The Helpline is available to everyone and can be accessed by telephone, email or letter.

Call the Nurse Helpline direct on 077 135 681 97 or call our offices on 0161 799 4646 and ask to speak to the Healthcare and Education Officer. You can also email helpline@paget.org.uk or write to The Healthcare and Education Officer, The Paget’s Association, Suite 5, Moorfield House, Moorside Rd, Swinton, Manchester, M27 0EW

For General Enquires please call the office on 0161 799 4646
Information

Information available from the Paget’s Association includes newsletters and booklets. Information is also available via the Association’s website: www.paget.org.uk

Information booklets available:

Paget’s Disease - The Facts
Paget’s Disease & Pain
Paget’s Disease - Investigations Explained

If you require information in large print or any other format please contact the Association.

Tell us what you think of our booklets

Please send your views to helpline@paget.org.uk or write to us at The Paget's Association, Suite 5, Moorfield House, Moorside Rd, Swinton, Manchester, M27 0EW. Alternatively, if you have received a feedback form please complete and return it.

Medical and lay trustees of the Paget’s Association have reviewed this booklet. The Paget’s Association holds references on specific sources of information. Should you require these, please contact us.
Which other organisations can provide information?

**Arthritis Research UK**  
Tel: 0300 790 0400  Website: www.arthritisresearchuk.org

**Arthritis Care**  
Tel: 020 7380 6500  Website: www.arthritiscare.org.uk

**The British Pain Society**  
Tel: 020 7269 7840  Website: www.britishpainsociety.org.uk

**Pain Concern**  
Helpline: 0300 123 0789  Website www.painconcern.org.uk

**Pain UK**  
Tel: 0207 8705683  Website: www.painuk.org

**Pelvic Pain Support Network**  
PO BOX 6559, Poole, Dorset, BH12 9DP  
Website: www.pelvicpain.org.uk

**Pain Relief Foundation and Research Institute**  
Tel: 0151 529 5820  Website: www.painrelieffoundation.org.uk

**Exercise leaflets are available from:**  
**Later Life Training**  
Tel: 01838 300 310  Website: www.laterlifetraining.co.uk
The Paget's Association
Suite 5, Moorfield House, Moorside Rd,
Swinton, Manchester, M27 0EW

Telephone: 0161 799 4646
www.paget.org.uk

Registered Charity No.: 266071