

The background of the lower half of the page is a dynamic, abstract graphic consisting of concentric, swirling lines in shades of blue and green, creating a sense of movement and depth.

Paget's Disease
and
PAIN

Paget's Disease and Pain

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Introduction

The Paget's Association has produced this booklet to help you understand pain in relation to Paget's Disease of Bone and how it might be dealt with. Our aim is to provide information that can help you to discuss pain with your medical team.

Pain is the most common reason for those who have Paget's disease to see their doctor. It is important to define the cause of pain, to determine whether it is caused by Paget's disease or whether it is the result of other conditions.

No two people experience or deal with pain in the same way. This can make it difficult to treat. Understanding your pain is the first step to breaking this cycle and achieving pain control. I hope the following pages will help you.

Diana Wilkinson, RGN, BSc (Hons)
Paget's Association



What is pain?

Pain can be described as an unpleasant sensory and emotional experience. It can be a warning that something is wrong, especially when it is severe and increasing. It is therefore important to have pain assessed by your doctor.

Pain in the muscles, joints and bones, is common and can be acute or chronic. Acute pain usually comes on suddenly and is caused by something specific, such as an injury or a break in the bone (fracture). Acute pain usually settles down when the fracture has healed or when you have recovered from an injury. Chronic pain is ongoing and persistent. Some people with Paget's disease can experience chronic pain, either as the result of the disease being active or because of complications like osteoarthritis.

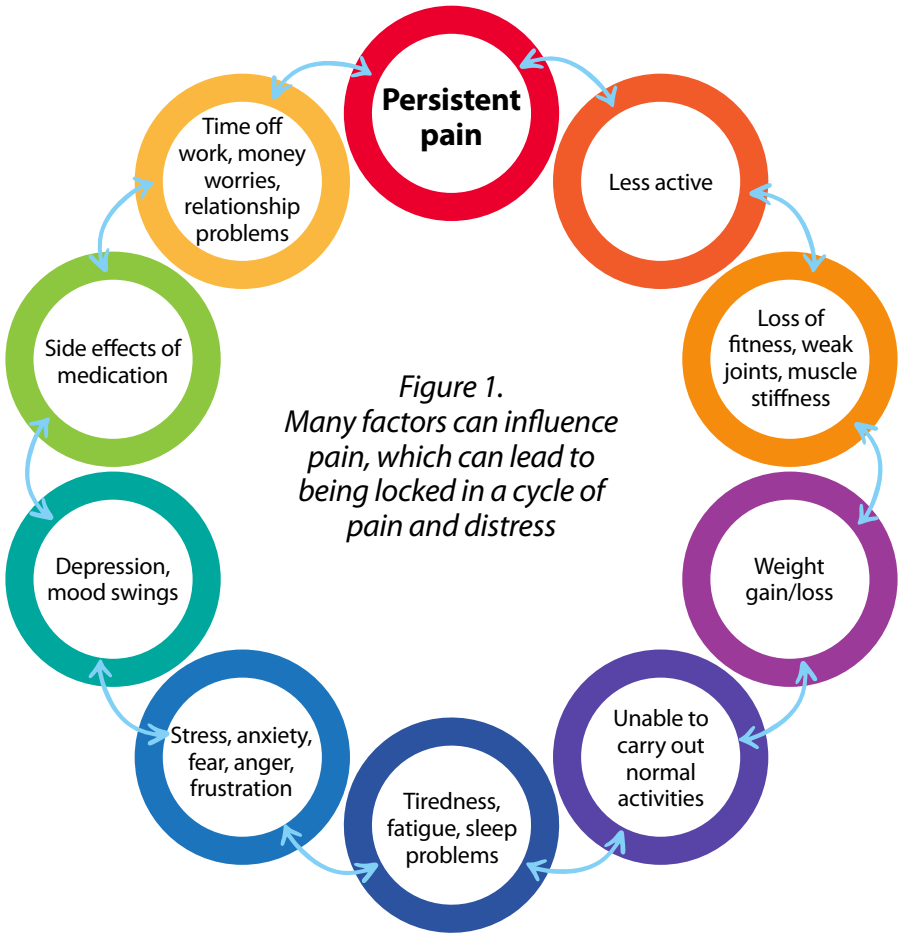
Several things can influence the development and intensity of chronic pain (*Figure 1*). It can have a considerable impact on quality of life, affecting relationships, activity levels, sleep and the ability to work. In addition, many factors, such as anxiety and fatigue, determine how your body will react to pain and whether your nerves will transmit or block a potentially painful message. Some people can become locked in a cycle of pain, depression and stress.

Paget's disease and pain

Not all people who have Paget's disease experience pain. It is, however, the commonest presenting symptom of Paget's disease. It is important to define the cause of pain so that the correct treatment can be given.

In many people, Paget's disease affects a single bone, whereas in others, several bones may be affected. In general, pain caused by Paget's disease is localised to the affected site. For example, if you have Paget's disease in your skull, it might result in the occurrence of headaches.

What can influence chronic pain?



*Figure 1.
Many factors can influence pain, which can lead to being locked in a cycle of pain and distress*

Paget's disease and pain (...continued from page 5)

Pain in Paget's disease may be related to what is known as "increased metabolic activity" of the disease. The reason why this pain occurs isn't entirely clear, but it is thought to be a consequence of increased bone cell activity. Such pain can respond well to treatment with a bisphosphonate, such as zoledronic acid. Many people, however, who have Paget's disease, experience pain related to other causes, and if that is the case, it is unlikely to be helped by bisphosphonate therapy. For detailed information on treatment see our booklet, '*Paget's Disease – The Facts*'.

Pain can also occur because of damage to the joints next to affected bones (osteoarthritis), a break in the bone (fracture), pressure on the nerves from enlargement of the bone or as the result of deformity of the bones, which can put stress on joints and soft tissues.

What is bone pain?

Bone pain at a specific site is detected by specialised transmitters located on the bone's surface, which then pass messages through the nervous system to the brain where signals are recognised as pain. Pain in Paget's disease may be caused by increased metabolic activity. This can occur at rest or at night, but can also be provoked by weight bearing on an affected bone.



Other causes of pain

Other causes of pain related to Paget's disease include:

■ **Deformity of the bone**

This is thought to be due to abnormal stresses on the surrounding tissues and stretching of the membrane surrounding the bone.

■ **Stress fractures**

These are small cracks in the bone that tend to occur in deformed weight-bearing bones, such as the thigh bone (femur) and shin bone (tibia).

■ **Fractures**

These usually occur as the result of a fall, causing the bone to break.

■ **Osteosarcoma**

This is a very rare type of bone cancer that can occur in people with Paget's disease.

Pain from Paget's in the skull

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. If the pain is the result of increased metabolic activity of Paget's disease, then treatment with a bisphosphonate, such as zoledronic acid or risedronate may help the pain.

People with Paget's disease can also get headaches as the result of other causes like a migraine. If you have Paget's disease and you experience headaches, it is important that you speak with your GP or specialist to seek advice on whether they are likely to be due to Paget's disease or another cause.

Osteoarthritis and Paget's

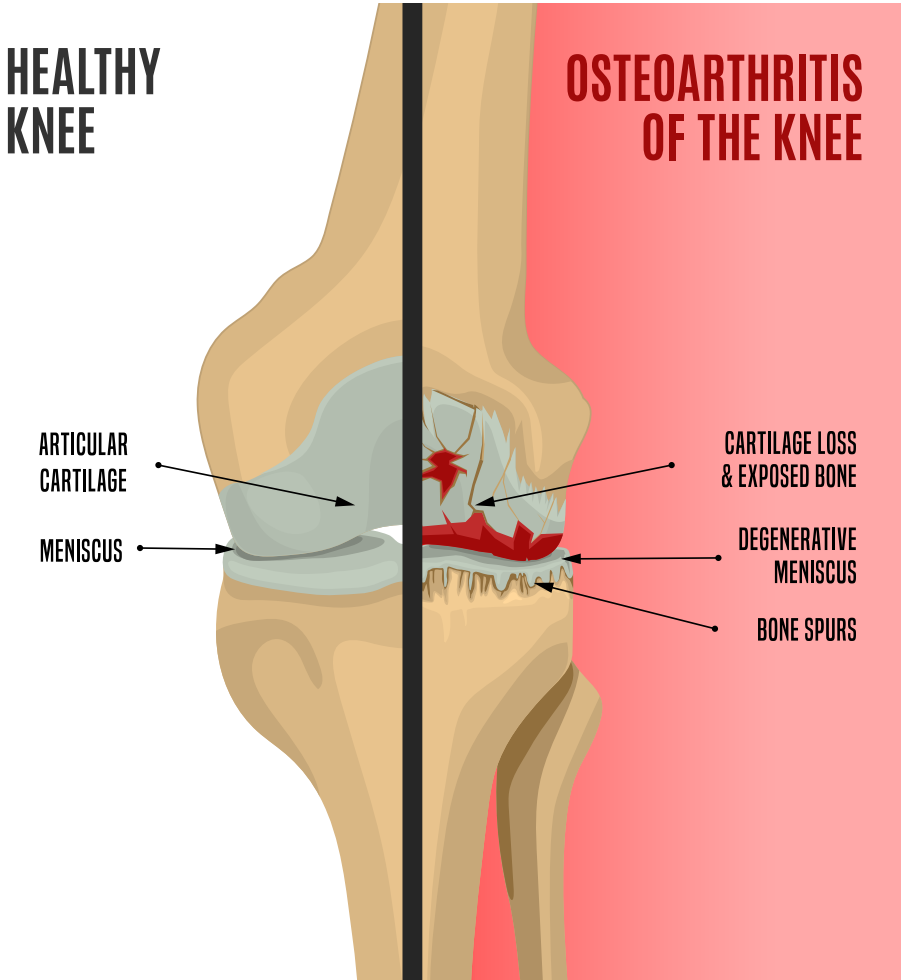
Osteoarthritis is a common condition, even in people without Paget's disease. There is evidence that people with Paget's disease are more prone to develop osteoarthritis in joints adjacent to bones that are affected by Paget's and the most commonly affected sites are the hip and knee.

Paget's disease is thought to predispose to osteoarthritis for two main reasons. The first is whether there is deformity of the bone. This can place abnormal stresses on the joints nearby. An example would be if a tibia becomes bowed, this can cause shortening of the leg, which can predispose to arthritis of the knee or ankle. The second reason is that the bone in Paget's disease is denser than normal. If there is increased density of the bone next to a joint, it results in abnormal strain being put on the cartilage (lining of the joint), causing the surface of the joint to become worn. When osteoarthritis is advanced, the joint surface becomes damaged, and the underlying bone becomes even denser, eventually resulting in loss of all cartilage so that the bone surfaces 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.



The hips and knees are the most common joints to be affected by osteoarthritis in people with Paget's disease, but osteoarthritis may also affect the back (see page 11).

Figure 2.
A healthy knee joint (left) and a knee joint with osteoarthritis (right)



What can help pain from osteoarthritis?

- Make sure you are not carrying too much weight. If you are overweight, losing weight can help reduce the pain of osteoarthritis a great deal, especially when the knees and hips are affected.
- Muscle strengthening exercises can help reduce pain associated with osteoarthritis of the knees.
- Anti-inflammatory creams and gels, which are rubbed into the affected area can help ease the pain of osteoarthritis.
- When required, painkillers such as paracetamol may help, or, if this doesn't work, anti-inflammatory tablets, like ibuprofen, can be tried.
- If osteoarthritis becomes severe, particularly in your knees and hips, joint replacement surgery may be required. The most common reason for having a joint replacement is if the joint pain has not responded adequately to the measures listed above and it is having a negative impact on your quality of life. The results of joint replacement surgery for osteoarthritis in Paget's disease are excellent.

Back pain

Back pain is very common. There are many causes, but in older people, it is often due to osteoarthritis affecting the joints of the spine. If osteoarthritis is the cause of the pain, it can be treated by medication. You may also find physiotherapy, acupuncture or TENS helpful, as discussed later in this booklet.

Paget's disease can also cause back pain as the result of increased metabolic activity of the disease. If this is the case, it may be helped by therapy with a bisphosphonate such as risedronate or zoledronic acid.

(continued overleaf...)

Back pain can also occur as the result of what is called spinal stenosis. This can affect people with Paget's disease of the spine because the affected bone enlarges, and this can cause pressure on the nerves that emerge from the spinal canal. The main symptom of spinal stenosis is pain, often radiating to the buttocks or down the legs, but there may also be numbness, weakness, and a tingling sensation in the legs. Patients with severe spinal stenosis may experience difficulty walking.

The diagnosis of spinal stenosis is usually made by an MRI scan. If symptoms are severe or worsening, surgical treatment may be offered to release the pressure (decompression) and give the nerves more room. Surgical treatment can sometimes involve removing sections of the bone or the bones may be fused together.

Medication to treat pain associated with Paget's disease

Bisphosphonates

When necessary, a group of drugs known as bisphosphonates are used to treat active Paget's disease because they effectively reduce bone cell activity.

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 responses may vary, pain, related specifically to active Paget's disease, often responds well to bisphosphonates within a few months.

The bisphosphonates commonly used in the UK are:

- Zoledronic acid 5mgs – Given intravenously (directly into the bloodstream), in a clinic setting.
- Risedronate 30mgs – Taken orally for two months.

For further information regarding bisphosphonates, see our booklet '*Paget's Disease – The Facts*'.

What other types of medication may be required?

Analgesics

Some 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/or joints.

Individual responses to analgesia vary considerably, both in terms of efficacy and side effects. 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.

A variety of analgesics are used in the treatment of pain (*Table 1*). Each type works in a different way to relieve pain and some products contain more than one kind of analgesic.

Paracetamol

Paracetamol is 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. When taken correctly, it has few side effects. An overdose, however, is dangerous, therefore, if you are taking any other analgesics or cold remedies, check them for paracetamol content so you know how much you are taking.

Table 1

Examples of analgesics	
First-line	Paracetamol
Non-steroidal anti-inflammatory drugs (NSAIDs)	Ibuprofen Diclofenac Etoricoxib Ketorolac Piroxicam Naproxen Celecoxib
Weak opioids	Codeine Dihydrocodeine Tramadol
Combination therapies	Co-codamol Co-dydramol
Strong opioids	Morphine Fentanyl Tapentadol Buprenorphine Oxycodone

Non-steroidal anti-inflammatory drugs (NSAIDs)

Examples of NSAIDs include ibuprofen, diclofenac, naproxen, etoricoxib, and celecoxib. They can be used to reduce pain caused by osteoarthritis as well as a number of other painful conditions. Ibuprofen can be purchased without a prescription. It is important, however, that their use be discussed with your doctor, especially if you have had a stomach ulcer, asthma, heart, liver or kidney problem. To minimise the risk of serious side effects, you should take the lowest effective dose, for the shortest time.

Some NSAIDs are available as creams, gels or suppositories.

Weak opioids

Opioids should be considered carefully for short to medium term treatment when other therapies have not worked. Examples of weak opioids are codeine phosphate and dihydrocodeine. Tramadol is classified as a weak opioid in the UK, but in some countries is considered to be a strong opioid.

Continuous longer-term use of opioids is not advised as tolerance and dependence on the medication can compromise both safety and effectiveness.

Combination therapies

Some tablets contain a combination of drugs, such as co-codamol, which contains both paracetamol and codeine.

Strong opioids

Occasionally pain associated with Paget's disease, or its complications, can be so severe, such as following a fracture, that stronger opiate drugs, such as morphine, may be recommended.

These would be used for short periods only as strong opioids are associated with dependence. Side effects can include nausea, vomiting and constipation, therefore other medication may be required to help with these effects.

As an alternative to oral medication, patches can be used, which are applied to the skin (e.g., buprenorphine).

Side effects

Any medicine can have side effects or interact with other medicines that you are taking. This will vary from one patient to another, but you can ask your pharmacist or GP for individual advice. A list of possible side effects, and how common they are, can be found on the information leaflet, which normally accompanies each medication.

You should give your body a chance to get used to the side effects of a medication before deciding to stop taking it. Usually, its benefits are more important than its minor side effects, which sometimes go away after a short while. Some side effects, such as constipation, can be treated effectively and should not prevent you from taking the medication, therefore, ask your pharmacist or GP for advice.

Contact your GP or pharmacist immediately if you experience a side effect that is listed as severe in the information leaflet, or you have a side effect that you think is serious. If you think that you or someone you are with may be having a serious allergic reaction to a medicine, telephone 999.



Nerve pain

Pain in Paget's disease may also be associated with nerve damage. This is sometimes referred to as neuropathic pain. 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 neuropathic pain (*Table 2*). These treatments may take several weeks before they begin to have an effect.

Table 2

Medication for nerve pain	
Type of medication	Examples
Anti-depressants These improve the effects of some of the chemicals in the brain and spinal cord that reduce when you suffer from long-term pain	Amitriptyline Nortriptyline Duloxetine Fluoxetine
Anti-epileptics These can reduce the pain produced by overactive nerves associated with pain, in the same way that they reduce the overactivity of the brain cells in epilepsy	Gabapentin Pregabalin Carbamazepine

Calcitonin

In the past, calcitonin was used to treat Paget's disease. It is sometimes recommended for pain relief.

Could surgery be required to treat pain associated with Paget's disease?

Successful surgical management of severe complications of Paget's disease can reduce pain and improve quality of life. The most common surgical treatments for those with Paget's include joint replacement (hip and knee), osteotomy (see page 19), and fracture fixation.

Visit the Paget's Association's website to read personal experiences of surgery.

Joint replacement

When Paget's disease causes strain on adjacent joints, it can lead to osteoarthritis. Joint replacement, of the hip or knee, may be required, and is usually very successful. The operation itself may be more technically challenging due to deformity and the altered bone quality. Joint replacement in those with Paget's disease is highly successful and the results are comparable to those of people who don't have Paget's disease. Whilst there is some evidence that blood loss during the operation is higher in patients with Paget's disease, than those who do not have Paget's, the overall incidence of complications is low. Careful pre-operative planning, together with the consultant caring for the patient in terms of their Paget's disease, can ensure optimal outcomes.

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, however, in general, the results are good.

Osteotomy

Osteotomy means 'cutting of the bone'. This may be carried out to shorten, lengthen or change the shape of a bone. The bone is then reset in a more normal position. This may be performed if there is marked deformity, such as a bowed leg, fissure fracture or pain that has not responded to painkillers.

Spinal surgery

Rarely, Paget's disease in the spine can press on the spinal cord causing a narrowing that may need to be corrected surgically if medical treatment is unsuccessful.

Tumour removal

Malignant tumours, associated with Paget's disease, occur very rarely, when surgery may be used to remove them.

Who can help?

To find the best treatments for you, it is often necessary to try various options and see whether they help. Do not be frightened to ask for help when you need it. Many professionals including doctors, nurses, pharmacists, 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 management team in a pain clinic.

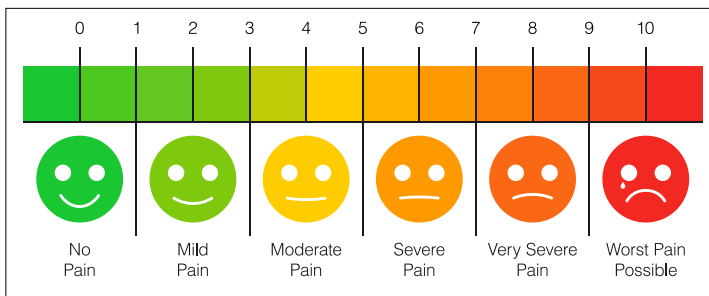
Seeing a healthcare professional

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. Keeping a pain diary can be useful to see whether it reveals patterns in intensity or anything that makes the pain better or worse. It can also ensure that you are using your painkillers most effectively. You may also have questions, therefore, make a list to put to your healthcare professionals.

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 or at night?
- Does the pain wake you from your sleep?
- Describe your pain. Is it sharp, stabbing, 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 be asked to rate your pain on a scale similar to this:



Drug free methods to help with pain

Although there is limited scientific evidence to support other methods used to treat the pain of Paget's disease, some may find the following helpful. Always ensure that any therapist involved in your care is appropriately trained and registered and seek advice from your GP in the first instance.

Physiotherapy

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

Walking aids

There are many different walking aids, and it is important to seek advice from a physiotherapist or an occupational therapist. 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 may be able to help. They can, for example, provide specialised footwear to correct an abnormal gait (manner of walking) caused by misshapen bone.

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.

The electrical impulses can reduce the pain signals going to the spinal cord and brain, which may help relieve pain and relax muscles. They may also stimulate the production of endorphins, which are the body's natural painkillers. TENS must not be used by anyone who has a pacemaker or by women in the early stages of pregnancy.

Heat and cold packs

Whilst there is no evidence that heat and cold therapy helps with pain specifically from Paget's disease, it is often recommended to help relieve aching in muscles and joints.

(continued overleaf...)

Heat promotes blood flow which may help sore muscles and tissues to heal. It may also help block some of the pain signals going to the brain. Apply warmth to the painful area for up to 20 minutes, using either a covered hot water bottle, pads or wheat bags that can be heated in a microwave. You could also try a warm bath or buy special heat products such as creams, gels and patches.

Cold treatment reduces inflammation by decreasing blood flow. Try a covered bottle filled with cold water, a pad cooled in your freezer or reusable ice gel packs from your chemist. Only apply for up to 15 minutes at a time to avoid skin damage. You can reapply them every few hours. Do not use cold packs if you have poor circulation or sensation.

Alternating heat and cold may help reduce exercise-induced muscle pain, as it will greatly increase blood flow to the injury site.

Never use extreme heat or cold and never use heat or cold on any area for more than 15 to 20 minutes.

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.

Complementary and alternative therapies

There are many complementary and alternative therapies available. There is no evidence to show that any are effective in treating the pain of Paget's disease. Complementary therapies often do not follow generally accepted medical methods and may not have a scientific explanation for their use. It can also be difficult to separate actual direct benefit from a placebo effect, which is a psychological response where people feel better because they have received a treatment, and not because the treatment itself has specifically improved their condition. If you are considering trying any therapy, discuss it with your GP first.

Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) can help you cope with your situation and involves either working with a therapist, who will help you challenge unhelpful thoughts and behaviour, or completing a course online. CBT teaches techniques to change your attitude, overcome your anxieties about pain and successfully change your behaviour to help you feel better. Your GP can refer you for this.

What about diet?

There is no evidence to suggest that special diets or supplements can help chronic pain. Maintaining a healthy weight and a healthy diet is important for overall health. Being overweight puts extra strain on joints.

Don't allow pain to control you

Everyone 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. There are some suggestions overleaf.

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 from 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 overdoing it and feeling much worse later in the day or the following day. In summary, do not overdo things on the days you feel well, nor rest too much and lose fitness.

Stay positive

Pain can make you tired, anxious and depressed. This can make the pain worse. Staying positive can really help.

Distract yourself

The amount of time you spend consciously thinking about pain will influence how much pain you feel. Try to focus your attention on 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?



Listen to 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 Facebook Support Group or Paget's Virtual Support Groups. Contact the Association for details.



Socialise

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

Exercise

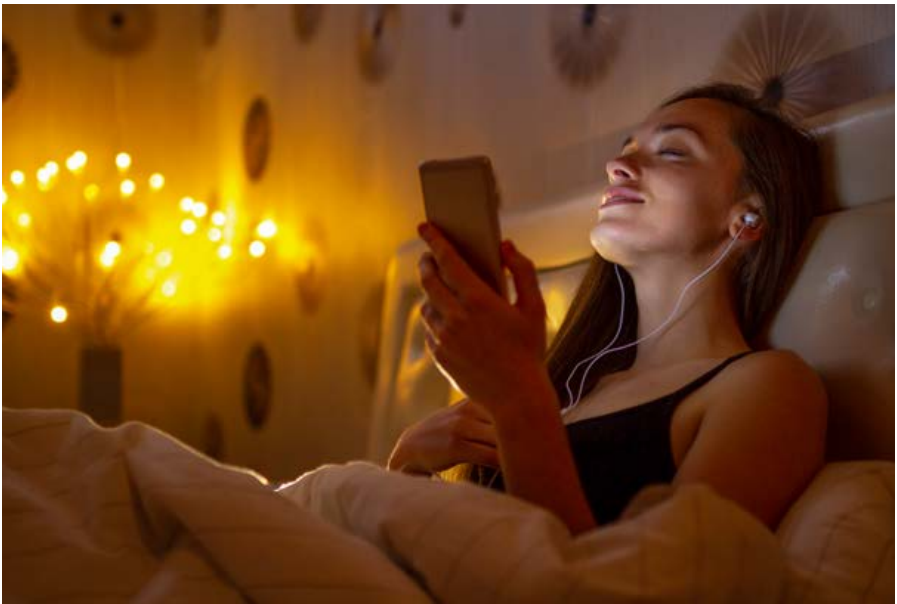
Activities such as walking, swimming and exercise classes, can improve or maintain your overall fitness and quality of life. Your doctor or physiotherapist can advise you on the different types of exercise and can explain how to contact local services.

Find an exercise routine that suits you – what works for some people may not work for you. You should start slowly with any exercise routine and gradually increase it over time.

With any exercise routine, your pain will not usually improve straight away, but if you keep exercising regularly, you may start to see improvements in both your pain and many other parts of your life and health.

Relax

Trying to relax is a crucial part of easing 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 enable you 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. Various forms of exercise classes can help to improve breathing and relaxation.



Try health apps

There are several pain management and relaxation apps you can download to a smart mobile phone.

Diaphragmatic relaxation breathing technique

Try the diaphragmatic breathing exercise below. It may make you feel tired at first, but, with practice, it will become easier. 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. Try carrying out this exercise for 5 to 10 minutes, 3 or 4 times per day, or whenever you feel stressed.

- 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 clothing 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.

The Paget's Association: here to help

The Paget's Association is the only UK charity to focus solely on Paget's Disease of Bone in adults.

The Association:

- acts as a resource for patients, carers and professionals, offering high-quality information and support
- funds and encourages quality research projects
- provides educational awards
- promotes excellence in care and research, through the Paget's Association Centre of Excellence (PACE) Award
- raises awareness of the condition

Educational videos

Search the Paget's Association's website and YouTube channel for our educational videos. These include both experts and patients discussing many aspects of Paget's disease.



Research

The Paget's Association encourages and funds high-quality research into many aspects of Paget's disease, including pain. For further information regarding current studies and the results of past Paget's research, please see the Association's website.

Support services

For local meetings, virtual support groups and information about our events, visit our website or contact us using the details on page 29.

Contact us

Telephone: 0161 799 4646

Email: membership@paget.org.uk

Via our website: www.paget.org.uk

Paget's Nurse Helpline

The Paget's Association has a Helpline managed by an experienced Registered Nurse, who can provide information, advice and support.

Email the Paget's Nurse Helpline: helpline@paget.org.uk

Alternatively, use the contact details above.

Paget's Facebook Support Group

To connect with others in our Facebook Support Group visit

www.facebook.com/groups/pagetsdiseaseofbone

Connect with us

Find us on Facebook

www.facebook.com/PagetsAssociation

Follow us on Twitter

@PagetsDisease



Which other organisations can provide information?

NHS	www.nhs.uk
Patient	www.patient.info
Versus Arthritis 0300 790 0400	www.versusarthritis.org email: enquiries@versusarthritis.org
British Pain Society 020 7269 7840	www.britishpainsociety.org.uk email: info@britishpainsociety.org
Pain Concern 0300 123 0789	www.painconcern.org.uk email: info@painconcern.org.uk
Pain UK	www.painuk.org email: info@painuk.org
Pelvic Pain Support Network	www.pelvicpain.org.uk email: info@pelvicpain.org.uk
Pain Relief Foundation and Research Institute 0151 529 5820	www.painrelieffoundation.org.uk
Pain Association Scotland 0800 783 6059	www.painassociation.com email: info@painassociation.com

Paget's Association

[paget.org.uk](https://www.paget.org.uk)

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