



Paget's Disease & Pain

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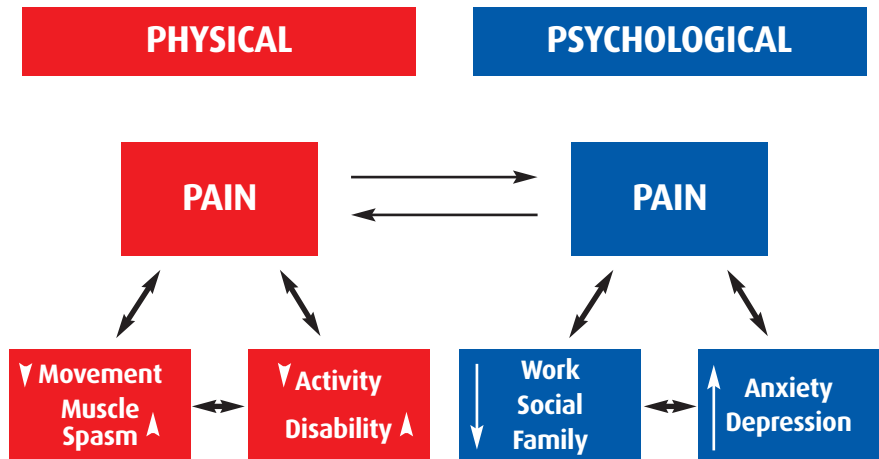




PAGET'S DISEASE AND PAIN

- Pain in general is one of the commonest reasons for visiting a doctor in the UK. It affects more than one million people and costs £7.4 billion a year.
- Pain has many inter related physical and psychological factors that can impact on optimal physical, social and emotional functioning.
- Pain is the commonest presenting symptom associated with Paget's disease.
- 86% of patients with Paget's disease attending a Sheffield clinic presented with pain.
- Findings from USA showed that pain was a presenting feature in more than 80% of patients attending a specialist clinic from 1950-1994.

EFFECTS OF PAIN



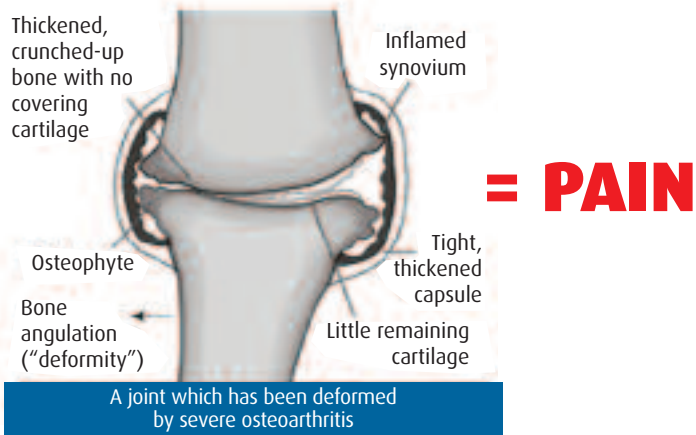
BONE PAIN

- Pain in Paget's disease may arise from the affected bone and is often described as "persistent and nagging"; it is usually present at rest particularly at night and is not relieved by exercise.
- Although it is not fully understood why a pagetic bone causes pain it is probably related to the increased activity of osteoclasts and elevated bone turnover. In turn this imbalance is detected by specialised transmitters that are located on the bone surface that then pass "messages" through the nervous system to the brain where the signals are recognised as pain.
- It is possible that microfractures (small cracks) can occur in lower weight bearing bones affected by Paget's disease and if these occur they may cause discomfort for a period of days to weeks.
- Occasionally a complete fracture may occur through a pagetic bone resulting in pain and
- Extremely rarely a malignant tumour can occur at the site of Paget's disease causing new pain.

JOINT PAIN

- Osteoarthritis is commonly associated with Paget's disease, due in part to the abnormal mechanical stresses placed on adjacent joints. For example a bowed limb is typically shortened resulting in specific gait abnormalities that can lead to abnormal mechanical stresses on joints adjacent to pagetic bone.
- Should a joint become severely affected this will lead to increased pain and stiffness.

OSTEOARTHRITIS IN THE KNEE



BACK PAIN

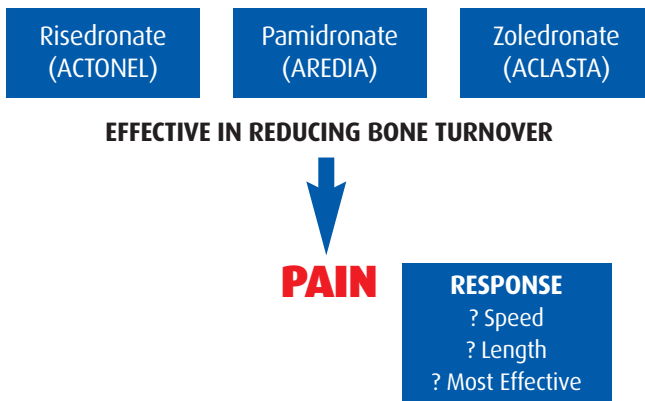
- Non specific aches and pains may arise from enlarged pagetic vertebrae and vertebral fractures can occur at pagetic sites giving rise to acute pain.
- Occasionally an enlarged vertebra may press on the spinal cord leading to pain radiating down the legs and possible loss of function.
- Back pain is very common and in many instances it is likely to be related to degenerative ("wear and tear") changes throughout the spine rather than Paget's disease.

SKULL PAIN

Amongst other symptoms, if Paget's disease is present in the skull it may give rise to headaches or a band like tightness around the head that results in an unpleasant sensation.

TREATING PAIN WITH MEDICATION

If the pain is directly related to the site of Paget's, treatment with one of the bisphosphonates generally provides pain relief.



- Although these drugs may occasionally cause an increase in bone pain for a few days after administration they will then tend to have positive effects in the following months.
- It is difficult to predict how effective they will be for all patients as each individual can respond differently to treatment but various studies have shown that risedronate, pamidronate and zoledronate all lead to a reduction in bone pain 6 months after treatment.
- As zoledronate is the strongest type of bisphosphonate this may offer the best pain relief. One study by an Italian group demonstrated that a greater

number of zoledronate treated patients reported disappearance or decrease in pain after 6 months compared to those taking pamidronate (97% v 74.6% respectively). Another study comparing zoledronate with risedronate suggested that it was more effective at 3 and 6 months following treatment.

- In addition to treatment with bisphosphonates additional analgesia (pain relief) may be necessary if some of the underlying cause of pain is from the degenerative changes seen in the joints.
- Regular paracetamol (up to 8 tablets daily) is one of the safest options and may prove beneficial
- Non steroidal anti inflammatory drugs (NSAIDS) such as brufen taken orally or applied as a cream to the painful area may also be effective.
- Although paracetamol and brufen can be purchased without a prescription, it is very important that their use is discussed with a doctor or pharmacist, particularly if taken on a frequent and long term basis.
- Occasionally pain associated with Paget's disease can be so severe that strong analgesic drugs, narcotics may be prescribed; these are morphine derivatives and imitate the body's own morphine like endorphins. Whilst very effective for severe pain it is unlikely that these would be recommended on a long term basis.
- Pain in Paget's disease may also be associated with nerve damage (neuropathic pain) and will then require treatment with drugs that aim to "calm" the nerves. Gabapentin and amitriptyline are examples that are commonly prescribed for this type of pain relief, both will need to be taken for several weeks before they will be effective and long term use needs to be reviewed by a doctor.

TREATING PAIN WITH SURGERY

- Few patients with Paget's ever need surgery, but successful surgical management of severe orthopaedic complications can reduce pain and improve quality of life.
- The commonest surgical intervention is hip and knee replacement for associated osteoarthritis, others include fracture fixation, osteotomy to correct bone deformity, surgery to correct spinal stenosis and surgery to resect a malignant tumour.
- Whilst joint replacement can be very successful this type of surgery may be more technically challenging due to deformity and the altered bone quality. In addition to normal surgical risks there is a slight increase in the risk of heterotopic ossification (formation of bone outside the skeleton) and non union of the trochanter in hip replacement.



Hip Replacement



Surgery to Fractured Tibia

- Fracture surgery may be more complex in patients with Paget's disease because of the size and structure of the bone and in some cases healing may be more protracted. In femoral neck fractures treated

with internal fixation non union is common and hence the best option in these patients will be prosthetic replacement.

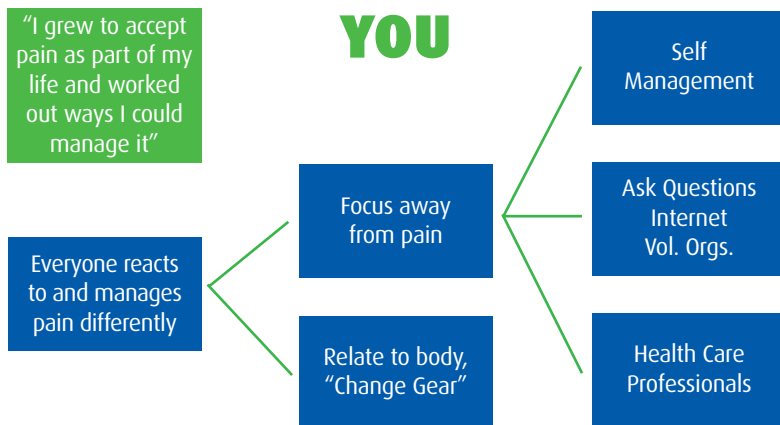
- Osteotomy when a bone is cut to shorten, lengthen or change its position is occasionally used if there is marked deformity, fissure fractures and pain that has not responded to medical management. Recent advances in the field of external fixation techniques have allowed correction of complex deformities.
- Neurological complications associated with Paget's disease in the lumbar spine usually respond to drug treatment but on rare occasions spinal decompression may be performed to relieve pain and improve mobility.

TREATING PAIN WITH OTHER METHODS

- The use of trans electrical nerve stimulation (TENS) machines, physiotherapy, heat and cold pads, specialised footwear and walking aids may directly or indirectly afford pain relief.
- In response to a survey from The Paget's Association members also commented on the benefits of copper jewellery, massage and acupuncture.

TREATING PAIN WITH SELF MANAGEMENT

- Each individual perceives and subsequently manages pain differently but the underlying principle is to try and control the condition rather than letting it control you.
- It is important to try and focus away from the pain and concentrate on different activities that are enjoyable. Consider setting goals that are achievable by breaking them down into workable parts.
- Sources of advice on self management of pain include books, magazines, the internet, self help programmes and many organisations that provide literature and support.
- Doctors, nurses, physiotherapists and occupational therapists can provide information and support and in the case of severe pain it may be appropriate to consider the specialist services provided by a pain management clinic.



USEFUL RESOURCES

Pain Concern

P.O. Box 13526

Haddington

EH41 4YD

Tel: 01620 822572

www.painconcern.org.uk

Provides information and support for people who live with pain and those who care for them and about them

The British Pain Society

Third Floor

Churchill House

35 Red Lion Square

London

WC1R 45G

Tel: 020 7269 7840

www.britishpainsociety.org

Largest UK multidisciplinary professional organisation in the field of pain.

Provides information for patients on related organisations, frequently asked questions and publications

Useful reading: Help the Aged- Pain in Older people: Reflections and Experiences from an Older Person's Perspective (2008)

Available free of charge, either on website or from The British Pain Society



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