Paget's Association

Paget's Disease of Bone

THE ESSENTIAL FACTS

Version: 2 / 2019

What is Paget's Disease of Bone?

Paget's disease affects the normal repair and renewal process of bone.

Throughout life, bone is renewed and repaired through a process called bone remodelling. Paget's disease is characterised by abnormalities in this process. The affected bone is renewed and repaired at an increased rate, adversely affecting the bone's structure.

Paget's disease can occur in one or several bones and the affected bone may be enlarged and misshapen.

The risk of developing Paget's disease increases with age and it is most commonly diagnosed in those over 50 years.

Causes

There is a general understanding that Paget's disease is caused by a combination of genetic factors and unknown environmental triggers.

Symptoms

- Many people who have Paget's disease do not have symptoms.
- Of those who present with symptoms, pain is the most common.
- The blood flow to active areas of Paget's disease increases and this can lead to a feeling of warmth over the affected bone.
- The affected bone may become enlarged and misshapen. For example, if the shin (tibia) is involved, this may become bowed.

Assessment

- If you are concerned that you may have Paget's disease, you should see your GP who will assess your symptoms and may carry out initial investigations, such as blood tests.
- If Paget's disease is suspected, it is important that there is a detailed assessment process, ideally carried out by a hospital consultant who understands the condition.

How is Paget's Disease Diagnosed?

- In many cases, Paget's disease is found by chance when tests are carried out for another reason.
- A simple blood test may show an increased alkaline phosphatase (ALP) level that may indicate Paget's disease.
- Characteristic features can often be seen on an x-ray.
- A radionuclide bone scan is the best way of finding out which bones are affected by Paget's disease and how active the disease is.

Potential Complications

- The potential for complications will depend on which bones are affected by Paget's disease.
- Many people who have Paget's disease may never develop complications.
- Potential complications include deformity, fracture (figure 1) and deafness (if the skull is involved).

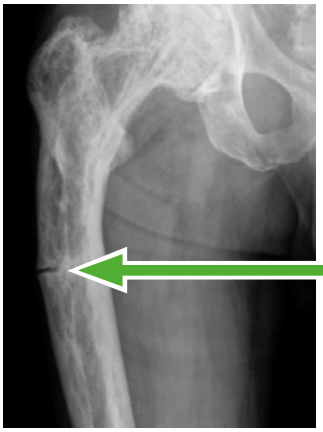

Figure 1
This x-ray shows Paget's disease in the femur (thigh bone). There is also a fracture.

How is Paget's Disease Treated?

- Paget's disease does not always cause symptoms and not everyone needs treatment.
- The main reason for treatment is if the affected bones are painful.
- If the pain is directly from Paget's disease, it often improves with treatment.

Bisphosphonates

Bisphosphonates are drugs which work by inhibiting the bone remodelling process. The main treatment goal is to control bone pain.

Zoledronic acid

The current first-line bisphosphonate, due to its potency and prolonged duration of action, is zoledronic acid. It is the bisphosphonate most likely to relieve pain from active Paget's disease. A single dose of 5mg is given through an infusion (a drip) directly into the bloodstream (intravenous), over 15 minutes. It is usually given in hospital, as an outpatient.

Over the following months, this treatment often normalises the abnormal bone remodelling and one dose can be effective for many years.

Pamidronate

Pamidronate is also an effective treatment but slightly less effective than zoledronic acid. Also given in the form of an infusion, the usual dose is 60mg, on three separate occasions. It can be used in people with borderline kidney function where zoledronic acid is not advisable.

Risedronate

Risedronate is given in tablet form. The usual dose is 30mg daily, taken for two months. The tablets need to be taken on an empty stomach. Risedronate is an effective treatment but is not quite as good as zoledronic acid at helping pain. Also, the effect doesn't last quite as long. It is useful for people who do not want to have infusions and in those with borderline kidney function where zoledronic acid is not advisable.

Clinical Guideline

In 2019, a new clinical Guideline* for the diagnosis and management of Paget's disease in adults, was published on behalf of the Paget's Association, the European Calcified Tissue Society, and the International Osteoporosis Foundation. The Guideline provides evidence-based recommendations, which enable health professionals to discuss all options with the patient.

**Ralston et al (2019), JBMR, Vol. 34, p 579-604.*

Further Information

This leaflet has been produced by the Paget's Association, a charity dedicated to supporting those affected by Paget's disease, as well as funding research into the condition. More detailed written information is available from the Association. The charity also provides a nurse helpline, support network, information events and a quarterly magazine.

How do I contact the Paget's Association?

Telephone **0161 799 4646**

Email **helpline@paget.org.uk**

www.paget.org.uk

Paget's Association

Registered Charity No. 266071

Paget's Association
Suite 5, Moorfield House
Moorside Road, Swinton
Manchester, M27 0EW