Paget's disease of bone

**Summary**

- Paget's disease of bone causes abnormal enlargement and weakening of bones.
- Commonly affected bones include the skull, pelvis, spine and the long bones of the arm and thigh.
- The cause of Paget's disease is not fully understood.
- Paget's disease of bone is not related to the skin disease that also bears Paget's name.

Paget's disease of bone is a chronic condition that causes abnormal enlargement and weakening of bones. Any part of the skeleton can be affected, but the most common sites include the skull, spine, pelvis, thigh bone, shin and the bone of the upper arm.

Paget's disease of bone tends to affect people over the age of 50. It affects slightly more men than women.

Paget's disease of bone is not related to the skin disease that also bears Paget's name.

**Bone growth and Paget's disease**

Your bones are living tissue that is constantly growing, rebuilding, replacing and repairing. Bone tissue is maintained by cells called osteoblasts and osteoclasts. The osteoblasts build new bone, while the osteoclasts help to dispose of old bone.

In a person with Paget's disease, the balance between these two groups of cells is disturbed. The osteoblasts become overactive and too much bone tissue is produced, leading to enlargement. The abnormal growth means that the new bone tissue is weak and unstable. The new bone also contains more blood vessels than normal bone.

The reason for this accelerated bone growth is unknown. Genetic and environmental factors, such as a virus, are suspected.

**Risk factors for Paget's disease of bone**

While the cause of Paget's disease is not known, risk factors include:

- ethnicity — it’s more common in people from England, Scotland, central Europe and Greece — as well as countries settled by European immigrants (such as Australia and New Zealand)
- age — the condition becomes more common with increasing age, but it’s rare before the age of 55
- genetics — you’re more likely to develop it if you have a family history of Paget’s disease.

**Symptoms of Paget's disease of bone**

Many people don't realise they have Paget's disease because they don't have any symptoms, or they only have mild symptoms. Paget's disease is sometimes discovered by accident when a person has a blood test or x-ray for another reason.

Depending on how severe your condition is, symptoms may include:

- pain and aching in your bones
- affected bones may become deformed or misshapen
- affected bones can feel warmer than the rest of your body
- if your skull is affected you may experience problems with hearing, headaches, vertigo or tinnitus.

**Complications of Paget's disease of bone**
For most people, Paget's disease progresses slowly and can be managed effectively. However, in some cases, complications can arise including:

- osteoarthritis – in joints close to bones affected by Paget's disease, the cushioning cartilage on the ends of the bones can break down, causing pain and stiffness
- broken bones – the new bone growth is weak and fragile, and is more susceptible to fracture than healthy bone
- hearing loss – caused by pressure on nerves in the ear
- numbness or tingling in the spine – caused by pinched nerves in the spinal cord
- heart disease – due to the increased number of blood vessels in the affected bones, the heart has to work harder. This usually does not result in heart failure, except in some people who already have heart disease
- too much calcium in the blood – when several bones have active Paget's disease, the increase in bone breakdown can lead to an elevated blood calcium level. This is rare, but it can cause symptoms such as fatigue, weakness, abdominal pain, constipation, loss of appetite.

Diagnosing Paget's disease of bone

Paget's disease is often discovered by accident during x-rays taken for some other reason. The diagnosis can be confirmed by further x-rays, bone scans or by a blood test that checks for an enzyme crucial to bone growth called alkaline phosphatase.

Treating Paget's disease of bone

Although there is no cure for Paget's disease of bone, there are treatments available to help you live well and manage your symptoms.

Medications

Medications used to treat Paget's disease of bone include:

- bisphosphonates – are used to slow the progression of Paget's disease. They help the body control the bone-building process to stimulate more normal bone growth
- pain relieving medications (analgesics) and non-steroidal anti-inflammatory drugs (NSAIDs) – are used to provide temporary pain relief
- calcium and vitamin D – are both important for bone health. You can get calcium through your diet and vitamin D through safe exposure to sunlight. Or talk with your doctor about whether you need to consider taking supplements.

Self-management

The following strategies can help you to manage your condition:

- learn more about Paget's disease – knowing as much as possible about your condition means that you can make informed decisions about your healthcare and play an active role in the management of your condition
- stay active – exercise helps to maintain bone health and joint mobility, as well as strengthen muscles. However, as bones are weaker and more likely to fracture, certain forms of exercise are not suitable for people with Paget's disease. It's best to consult a physiotherapist or an exercise physiologist for an exercise program tailored specifically for you
- seek supportive therapies – as well as tailored exercises, physiotherapists and occupational therapists can also provide techniques and devices that can help to improve movement, reduce pain and make everyday activities easier. Examples include:
  - a walking stick to reduce the weight placed through affected bones
  - braces to correct position
  - foot orthotics to support and correct abnormal foot position or motion
- enjoy a healthy well-balanced diet – this can help you reach and maintain a healthy weight and reduce your risk of other health problems. Make sure you include calcium-rich foods
- learn new ways to manage pain – there are many things you can do to manage pain, and different strategies
will work for different situations. For example, heat packs can help ease muscle pain, cold packs can help with inflammation, and gentle exercise can help relieve muscle tension. Try different techniques until you find what works best for you

- stay at work – it’s good for your health and wellbeing. Talk to your doctor or allied healthcare professional about ways to help you to get back to or to stay at work
- join a peer support group – dealing with a chronic condition like Paget’s disease can be isolating. Being able to speak with others who understand your condition can be a great relief.

**Surgery**

In severe cases, surgery may be required to relieve pinched nerves or bone fractures, or to replace a joint severely affected by arthritis.

**Where to get help**

- Your **GP (doctor)**
- **Endocrinologist** – specialist in hormonal and metabolic conditions
- **Rheumatologist** – specialist in joint and muscle conditions
- **Physiotherapist**
- **Exercise physiologist**
- **Occupational therapist**
- **Musculoskeletal Australia** National Help Line Tel. **1800 263 265**

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