



Paget's disease

- Paget's disease of bone causes abnormal enlargement and weakening of bone
- Commonly affected bones include the skull, pelvis, spine and the long bones of the arm and thigh
- Although there's no cure, there are treatments available to help you live well and manage your symptoms

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 upper arms.

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

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. The abnormal growth results in new bone tissue that's weak and unstable. The new bone also contains more blood vessels than normal bone.

The reason for this accelerated bone growth is unknown. A combination of genetic and environmental factors (e.g. a virus) are suspected.

Risk factors

While the cause of Paget's disease is unknown, risk factors include:

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

Symptoms

Many people don't realise they have Paget's disease because they don't have any symptoms, or only 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 warm
- if your skull is affected you may experience problems with hearing, headaches, vertigo or tinnitus.

Diagnosis

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 particular blood test that checks for an enzyme crucial to bone growth called alkaline phosphatase.

Complications

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, your heart has to work harder. This doesn't usually 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.

Treatment

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

Medications

- 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 relievers (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. If you're concerned that you aren't getting enough calcium and vitamin D, talk with your doctor about whether you need to take supplements.

Self-management

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/or 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, gentle exercise can help relieve muscle tension. Try different techniques until you find the things that work 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 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 doctor
- Endocrinologist
- Rheumatologist
- Physiotherapist
- Exercise physiologist
- Occupational Therapist
- Musculoskeletal Australia

www.msk.org.au

MSK Help Line: 1800 263 265

How we can help

Call our MSK Help Line and speak to our nurses.
Phone 1800 263 265 or email helpline@msk.org.au.

We can help you find out more about:

- Paget's disease and musculoskeletal conditions
- ways to live well with these conditions
- managing your pain
- upcoming webinars, seminars and other events.

More to explore

- Australian Physiotherapy Association
www.physiotherapy.asn.au
- Exercise and Sports Science Australia
www.essa.org.au
- Versus Arthritis <https://www.versusarthritis.org>
- Ortho-Info – American Academy of Orthopaedic Surgeons <https://orthoinfo.aaos.org>
- Better Health Channel
www.betterhealth.vic.gov.au

The whole or part of this material is copyright to the State of Victoria and the Better Health Channel. Reproduced with permission of the Victorian Minister for Health. Users are permitted to print copies for research, study or educational purposes.

This information has been produced in consultation with and approved by: Musculoskeletal Australia.

May 2019