CONDITION

Paget disease of the bone

Paget disease of the bone disrupts normal bone renewal, causing affected bones to become enlarged, misshapen, or weaker.

WHAT IT IS
Long-term disorder of abnormal bone renewal

BODY SYSTEM
Bones and joints

MAIN SYMPTOMS
Often none, bone pain, deformity, hearing loss

WHAT CAUSES IT
Unknown; genetic and environmental factors likely

HOW IT IS DIAGNOSED
Characteristic X-rays; blood tests assess bone activity

MAIN TREATMENT
Bisphosphonate medicines, pain relief, and supportive care

CAN IT BE CURED?
No - treatment can suppress abnormal bone turnover

IS IT AN EMERGENCY?
Sometimes - sudden weakness or bladder changes need emergency care

LONG-TERM OUTLOOK
Often stable; established bone changes may persist

Overview

Paget disease of the bone is a long-term condition that changes how bone is renewed. Healthy bone is constantly broken down and rebuilt. With Paget disease, this process becomes too fast and disorganized.

The new bone may be larger than normal, but its structure is less orderly. This can make an affected bone weaker, misshapen, or more likely to cause pain. The condition often affects the pelvis, spine, skull, thigh bone, or shin bone. One bone or several bones may be involved.

Many people have no symptoms. The condition may be found after a blood test or X-ray done for another reason. When treatment is needed, it can often control abnormal bone activity for a long time. It cannot reliably reverse bone deformity, arthritis, or hearing loss that has already developed.

Paget disease of the bone is not the same as Paget disease of the breast or vulva. Those are separate conditions.

Symptoms

Most people with Paget disease have no clear symptoms. When symptoms occur, bone pain is the most common. It may be a deep, ongoing ache that is present at rest or during the night.

Other possible symptoms include:

Pain does not always come directly from active Paget disease. It may instead come from osteoarthritis, a fracture, muscle strain, or pressure on a nerve. This distinction matters because treatment that slows Paget disease may not relieve pain caused by permanent joint damage.

Warmth may sometimes be felt over an affected bone because it has increased blood flow. Redness and fever are not typical features and may point to another problem.

- Pain and stiffness in a nearby joint
- An enlarged or misshapen bone, such as a bowed leg
- Headaches or an increase in hat size if the skull is affected
- Hearing loss when skull bones affect structures around the ear
- Tingling, numbness, or weakness if enlarged bone presses on nerves

Causes and risk factors

The exact cause is unknown. Paget disease appears to result from a combination of genetic and environmental factors. Changes in genes involved in bone renewal, including a gene called SQSTM1 , are found in some families.

Having a close relative with the condition raises the chance of developing it, but most relatives will not necessarily be affected. Genetic testing is not routinely needed for every person.

Paget disease is mainly found in older adults and is unusual before age 50. It is more common in some populations, including people with British or European ancestry, but it can occur in any ethnic group.

Past research explored whether a viral infection might contribute. No infection has been confirmed as the cause, and the condition is not contagious.

Diagnosis

Paget disease may first be suspected because of bone pain, a characteristic X-ray, or a raised level of alkaline phosphatase, often shortened to ALP. ALP is an enzyme that can rise when bone is being rebuilt quickly. It can also come from the liver, so other blood tests may be needed to identify the source.

An X-ray of the affected area usually shows the bone changes needed to support the diagnosis. These may include enlargement, thickening, or an abnormal pattern of bone breakdown and rebuilding.

A bone scan may then be used to find which bones are active and how much of the skeleton is involved. During this scan, a small amount of radioactive tracer is given and collects in areas with increased bone activity.

Further tests may include:

A bone biopsy, which removes a small sample for examination, is rarely required. It may be considered when imaging is unusual or another bone condition needs to be excluded.

- Blood tests for calcium, kidney function, and liver function
- Hearing tests when the skull is affected
- CT or MRI scans if nerve pressure or another complication is suspected

Treatment and management

Not everyone needs immediate treatment. If Paget disease is inactive, causes no symptoms, and is unlikely to threaten an important structure, monitoring may be appropriate.

The main medicines are bisphosphonates. They reduce the activity of cells that break down old bone. Zoledronic acid, given by infusion, can produce a long period of reduced disease activity in many people who are suitable for it. Oral bisphosphonates are alternatives in some situations.

Treatment decisions consider whether the disease is active, which bones are involved, whether symptoms come from Paget disease, and whether complications are likely. Kidney function, blood calcium, vitamin D status, and dental health may be checked before some treatments.

Bisphosphonates can cause side effects. An infusion may cause temporary flu-like symptoms. Rare but important problems include damage to the jawbone and unusual thigh-bone fractures, especially in certain treatment settings. Your care team can explain how these risks

relate to the treatment being considered.

Other management may include:

Joint pain caused by osteoarthritis may continue even after abnormal bone turnover has been controlled. It may need separate treatment.

- Pain-relieving medicine for bone or joint pain
- Physiotherapy to support movement, strength, and balance
- Walking aids, shoe inserts, or other devices for altered bone shape
- Hearing assessment and hearing aids when needed
- Surgery for a fracture, severe arthritis, or major bone deformity

Complications

Complications are not inevitable. They are more likely when disease is active, extensive, or located near a joint, nerve, or other important structure.

Possible complications include osteoarthritis, bowed limbs, and fractures. Enlarged bones in the spine or skull can narrow the space around nerves. This may cause pain, hearing loss, numbness, weakness, or difficulty walking.

If the skull is involved, changes around the ear can lead to hearing loss. Treatment may control bone activity, but established hearing loss does not always improve.

Very extensive disease can place extra demand on the heart because affected bones receive increased blood flow. Heart failure from this mechanism is rare and is mainly a concern when a large amount of bone is involved.

A bone cancer called osteosarcoma can develop in a Paget-affected bone, but this is very rare. New swelling or rapidly worsening, persistent bone pain needs medical assessment rather than an assumption that it is part of the usual condition.

Prevention

There is no proven way to prevent Paget disease of the bone. It is not caused by exercise, diet, or something you did.

Healthy habits cannot prevent the underlying condition, but they can support bone strength, joint function, and balance. These may include appropriate weight-bearing activity, avoiding smoking, limiting excess alcohol, and getting enough calcium and vitamin D through food or

supplements when advised.

If a close relative has Paget disease, ask whether occasional ALP blood testing would be useful as you get older. Screening identifies possible disease earlier; it does not prevent it.

Living with it and what to expect

Paget disease is long term, but it does not always keep getting worse. Some people have a small area of inactive disease that causes no symptoms. Others need treatment and ongoing monitoring.

Successful bisphosphonate treatment can suppress abnormal bone turnover for months or years. Follow-up commonly includes symptom reviews and ALP blood tests. Repeat imaging is usually reserved for new symptoms, suspected complications, or uncertainty about disease activity.

Treatment does not rebuild an already bowed bone or reliably reverse arthritis and hearing loss. These problems may remain stable, progress slowly, or need their own treatment. New pain should still be assessed because it may have another cause.

Many people continue their usual work, hobbies, and exercise. Activity may need to be adapted if a weight-bearing bone is weak, a joint is badly affected, or balance is reduced. Low-impact exercise can help maintain strength and mobility, but the safest type depends on the bones involved.

When to get medical help

Arrange a routine appointment if you have persistent unexplained bone pain, a gradually changing bone shape, increasing hat size, or hearing loss. If you already have Paget disease, report new pain or a change in your usual symptoms rather than waiting for a scheduled review.

Seek prompt medical assessment for rapidly worsening pain, new swelling over a bone, increasing difficulty walking, or new numbness or weakness. Sudden severe pain or inability to put weight on a limb may indicate a fracture.

Get emergency help for new leg weakness with loss of bladder or bowel control, numbness around the groin or buttocks, or severe difficulty walking. These symptoms can indicate pressure on the spinal cord or the nerves at the base of the spine.

Common questions

Is Paget disease of the bone cancer?

No. It is a disorder of bone renewal, not cancer. A rare bone cancer can occur as a complication, but most people with Paget disease do not develop it. Rapidly increasing pain or swelling should be assessed.

Can Paget disease be cured?

There is no cure that removes the condition completely. Bisphosphonate treatment can strongly suppress abnormal bone activity and may keep it under control for years. Existing deformity, arthritis, or hearing loss may not reverse.

Does Paget disease spread to other bones?

It does not spread from bone to bone like cancer or an infection. It may affect one bone or several separate bones. The pattern is usually established by the time it is diagnosed.

Is Paget disease hereditary?

It can run in families, and several related gene changes are known. However, having an affected relative does not mean you will develop it. A clinician can advise whether blood testing is reasonable based on your age and family history.

Can I exercise with Paget disease?

Many people can remain active. Walking, swimming, flexibility work, and suitable strength exercises may help mobility and balance. High-impact activity may be unsuitable if a leg bone is weakened, bowed, or at risk of fracture, so advice should reflect the bones involved.

Why do I still have pain after treatment?

Treatment slows abnormal bone turnover, but pain can have another source. Osteoarthritis, permanent bone changes, nerve pressure, or an unrelated muscle or joint problem may continue after blood test results improve. Ongoing or changing pain deserves reassessment.

Sources

- National Institute of Arthritis and Musculoskeletal and Skin Diseases: Paget's Disease of Bone
- Endocrine Society: Paget's Disease of Bone-An Endocrine Society Clinical Practice Guideline



- Ralston SH, Corral-Gudino L, Cooper C, et al. Diagnosis and Management of Paget's Disease of Bone in Adults: A Clinical Guideline . Journal of Bone and Mineral Research . 2019;34(4):579-604.
- NHS: Paget's disease of bone
- Singer FR. Paget's Disease of Bone . Endotext . National Center for Biotechnology Information.