



Paget's Disease of Bone

Paget's disease of bone is an unusual, chronic bone condition that occurs in only about 1% of people in the United States and slightly more often in men than in women (3 to 2). Individuals with Paget's disease experience rapid bone repair, which causes a variety of symptoms from softer bones to enlarged bone growth, typically in the pelvis, low back (spine), hips, thighs, head (skull) and arms. Medical therapies have proven effective in reducing the frequency of pain, fractures and arthritis that may be caused by this condition.

Fast facts

- Paget's disease typically occurs in an older population and usually in only a few of their bones.
- Bones become large and soft, leading to problems such as bending, breaking, pinched nerves, arthritis and reduced hearing.
- Effective and safe treatment methods can help most people with Paget's disease.

What is Paget's disease?

Normally, as people age, their bones rebuild at a slower rate. For those with Paget's disease, however, this process of rebuilding bones takes place at a faster rate. As a result, the rebuilt bone has an abnormal structure. The involved bone can be soft, leading to weakness and bending of the pelvis, low back (spine), hips, thighs, head and arms. Or, the rebuilt bone can enlarge, making it more susceptible to arthritis, hearing loss, fractures and discomfort.

Given that this takes place in those over the age of 40, the symptoms often are mistaken for changes associated with aging.



What causes Paget's?

The cause of Paget's disease is unknown. It does appear to be, at least partially, due to heredity, perhaps when activated by exposure to a virus.

Who gets Paget's?

Indicative of the heredity consideration, Paget's disease occurs more commonly in European populations and their descendants. In 30% of cases, disease incidence often involves more than one member of a family.

How is Paget's diagnosed?

Paget's is rarely discovered in individuals before they reach the age of 40, and the number of people identified increases in each progressive age group.

Typically, it is the appearance of the bones on an X-ray that signals the physician to make the diagnosis. Blood tests taken most often will indicate an increase in serum alkaline phosphatase (SAP), which is reflective of the rapid new bone turnover. Urine test results also will indicate the speed at which this rebuilding is taking place.

Physicians usually obtain a non-invasive bone scan to determine the extent of bone involvement. Only if cancer is suspected will it be necessary to biopsy the bone to examine it under a microscope.

How is Paget's treated?

Treatment approaches can focus on providing physical assistance, including the addition of wedges in the shoe, canes as walking aids and the administration of physical therapy.

Medications that help reduce the pain associated with Paget's include acetaminophen (e.g., Tylenol) and anti-inflammatory drugs such as ibuprofen and naproxen. In addition, a group of medications called bisphosphonates reduce the pain and help the body regulate the bone-building process to stimulate more normal bone growth. Your physician may prescribe an oral medication:

- Alendronate (Fosamax) or etidronate (Didronel) to be taken by mouth every day for 6 months.
- Tiludronate (Skelid) to be taken by mouth every day for 3 months.
- Risedronate (Actonel) to be taken by mouth every day for 2 months.

All oral medications should be taken with a large glass of water (6-8 oz) upon arising in the morning. Patients should remain upright for the next 30 minutes and not eat until that time has passed. Any of these treatments can be repeated if necessary. Side effects of these medicines may involve heartburn and sometimes increasing bone pain for a short period of time.

There are also injectable medications. Injectable medications that can be given for Paget's include:

- Pamidronate (Aredia), which is injected in the vein once a month or once every few months. The injection takes a few hours. Unusually, there can be inflammation of the eye or loss of bone around the teeth (osteonecrosis).



- Zoledronate (Reclast), which is injected in the vein once a year. The injection takes less than 30 minutes.
- Calcitonin, a hormone that is injected under the skin several times a week.

Surgery for arthritis caused from Paget's disease is effective in reducing pain and improving function.

Medical treatment is not expected to correct some of the changes of the Paget's disease that have already occurred, such as hearing loss, deformity or osteoarthritis.

Living with Paget's

Paget's disease does not seriously affect quality of life and, for most people, the outcome is good. In fact, most people with Paget's disease of bone have no complaints.

Rather, it is the fast bone rebuilding that leads to complications: bone pain, enlarged head, bowed arms or legs, arthritis (osteoarthritis), back pain, loss of hearing, broken bones (fractures), heart failure, and, rarely, a form of bone cancer.

Points to remember

- Pain associated with bones and joints, headaches, hearing loss, enlargement or bowing of bones, tingling or numbness may indicate Paget's disease.
- While this is a chronic condition, it does not spread to new bones. Instead it is focused in one or a few of the bones of the pelvis, back (spine), hips, thighs, head and arms.
- A physician needs to evaluate the condition to make sure there are no related problems.

The role of the rheumatologist

Paget's disease often causes an arthritic condition and can be diagnosed and treated by your rheumatologist as well as medical care practitioners who focus on bone disorders.

To find a rheumatologist

For a listing of rheumatologists in your area, [click here](#). Learn more information about [rheumatologists](#) and [rheumatology health professionals](#).

For more information

The American College of Rheumatology has compiled this list to give you a starting point for your own additional research. The ACR does not endorse or maintain these Web sites, and is not responsible for any information or claims provided on them. It is always best to talk with your rheumatologist for more information and before making any decisions about your care.

The Paget Foundation

www.paget.org

The Arthritis Foundation

www.arthritis.org/conditions/DiseaseCenter/Pagets_disease.asp



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