



Information for People Newly Diagnosed With Paget's Disease of Bone

National Institutes of Health Osteoporosis and Related Bone Diseases National Resource Center

2 AMS Circle
Bethesda, MD 20892-3676

Phone: 202-223-0344
Toll free: 800-624-BONE
TTY: 202-466-4315
Fax: 202-293-2356

Website: <https://www.bones.nih.gov>
Email: NIHBoneInfo@mail.nih.gov

The NIH Osteoporosis and Related Bone Diseases National Resource Center is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases with contributions from the National Institute on Aging, the National Institute of Diabetes and Digestive and Kidney Diseases, and the NIH Office of Research on Women's Health.

The National Institutes of Health (NIH) is a component of the U.S. Department of Health and Human Services (HHS).

December 2018

What is Paget's disease of bone?

Paget's disease of bone causes bones to grow larger and weaker than normal. The disease may affect one or more bones, but does not spread from affected bones to other bones in the body. Paget's disease can affect any bone in your body, but most people have it in their pelvis, skull, spine, or leg bones. These bones may become misshapen and, because they are weaker than normal bones, can break more easily. Some people with Paget's disease feel pain in these bones, too.

I've never heard of Paget's disease before. How common is it?

Uncommon in people under age 40, Paget's disease grows more common with age. The condition is more common in people of Anglo-Saxon descent in certain geographical areas, including England, the United States, Australia, New Zealand, and Western Europe. It is not common in Scandinavia, China, Japan, or India.

Is Paget's disease a form of arthritis?

People with Paget's disease often have arthritis at the same time, but they are different diseases. Sometimes Paget's disease is confused with arthritis because the pain from Paget's disease may be located on the part of the bone closest to a joint. So, it may feel a lot like the joint pain of arthritis. Paget's disease can cause arthritis over time when enlarged and misshapen bones put extra stress on nearby joints. Your doctor may use several tests find out if you have Paget's disease.

How did I get Paget's disease?

Doctors are not sure what causes the disease. Some people have hereditary Paget's disease, which means it runs in their family and was passed down by their parents. But most people do not have any relatives with Paget's disease. Doctors think a virus may cause Paget's disease in some cases. They are studying different kinds of viruses to try to find ones that may cause the disease.

Will my Paget's disease get worse? What should I expect?

Paget's disease does not affect everyone in the same way. Some people have a very mild case with few or no symptoms. Others have symptoms and complications. Pain is the most common symptom. Depending on which of your bones are affected by Paget's disease, you might have other symptoms and complications, such as those listed below. Although rare, the most serious complication of Paget's disease is bone cancer.

Can Paget's disease be treated?

Yes, Paget's disease can be treated. Finding and treating Paget's disease early is best to prevent complications. The U.S. Food and Drug Administration has approved several drugs to treat the disease. Doctors most often prescribe drugs called bisphosphonates. These help reduce bone pain and stop or slow down the progress of the disease.

Will these drugs also help improve the complications I have from Paget's disease?

The drugs may help prevent complications from starting or prevent them from getting worse, but they cannot correct problems that have already set in. In some cases, surgery can help. Your doctor can tell you if surgery might be a good idea for you.

How will the doctor know if the drug I take is working?

Your doctor will probably monitor your progress using two tests: an x-ray of your bones and a blood test to measure the level of a chemical called serum alkaline phosphatase (SAP) in your blood. The x-rays will show your doctor pictures of how your bones are healing. A decrease in the amount of SAP in your blood will tell your doctor that the disease is less active and you are getting better.

Other symptoms and complications of Paget's disease

If you have Paget's disease here:	You may have some of these symptoms and complications:
Pelvis	Pain or arthritis in the hip joint
Skull	Enlarged head, hearing loss, or headaches
Spine	Curved spine, back pain, or damage to nerves causing problems such as tingling and numbness
Leg	Bowed legs, pain, or arthritis in the hip and knee joints

Is there a special diet I should follow?

There is no special diet to prevent or help treat Paget's disease. For overall bone health, you should eat a balanced diet rich in calcium and vitamin D. The Institute of Medicine (IOM) of the National Academy of Sciences recommends 1,000 mg (milligrams) of calcium daily for adults age 19 to 50. Women over age 50 and men over age 70 should increase their intake to 1,200 mg daily. To help your body use the calcium, the IOM recommends 600 International Units (IU) of vitamin D up to age 70 and 800 IU after 70.

What about exercise? Can I still be active?

Exercise is important for people with Paget's disease. Being active can help you maintain healthy bones, control your weight, and keep your joints moving. But, you should talk with your doctor before starting an exercise program to make sure what you plan to do is safe and will not put too much stress on the bones that are affected by Paget's disease. For example, your doctor might advise you to try walking instead of jogging if you have Paget's disease in your legs.

Do I need to see a special doctor? What kinds of doctors specialize in this disease?

The doctor who diagnosed your Paget's disease may be a specialist in the disease. If not, he or she can refer you to someone who is. Doctors who are the most experienced in treating patients with Paget's disease are:

- Endocrinologists, who treat hormonal and metabolic disorders.
- Rheumatologists, who treat joint and muscle disorders.

Sometimes other doctors may be needed, such as orthopaedists; neurologists; and ear, nose, and throat specialists. Your doctor will help you find the specialists you need.

Will my children get this disease, too?

Paget's disease does not always run in families; however, research suggests that a close relative of someone with Paget's disease is more likely to develop the disease than someone without an affected relative. Finding and treating Paget's disease early is important, so a doctor may recommend that children and siblings of a person with Paget's disease be tested for the disease. To screen for Paget's disease, a doctor uses the SAP test. If the SAP level is high, suggesting that there might be Paget's disease, the doctor can perform a test called a bone scan to learn which bones may be affected. The doctor will typically order an x-ray of the affected bones to make sure the diagnosis of Paget's disease is correct.

Where can I get more information about Paget's disease?

There are many good sources of information about Paget's disease. These include:

NIH Osteoporosis and Related Bone Diseases National Resource Center

Website: <https://www.bones.nih.gov>

National Institute of Arthritis and Musculoskeletal and Skin Diseases

Website: <https://www.niams.nih.gov>

National Library of Medicine

Website: <https://www.nlm.nih.gov>

If you need more information about available resources in your language or another language, please visit our website or contact the NIH Osteoporosis and Related Bone Diseases ~ National Resource Center.

For your information

This publication contains information about medications used to treat the health condition discussed here. When this publication sheet was developed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration toll free at 888-INFO-FDA (463-6332) or visit its website at <https://www.fda.gov>. For additional information on specific medications, visit Drugs@FDA at <https://www.accessdata.fda.gov/scripts/cder/daf>. Drugs@FDA is a searchable catalog of FDA-approved drug products.

NIH Publication No. 18-7920