



## Points To Remember About Fibrous Dysplasia

- Fibrous dysplasia happens when abnormal fibrous (scar-like) tissue replaces healthy bone. The disease can affect any bone in the body.
- Symptoms of fibrous dysplasia can include bone pain, misshapen bones, and broken bones.
- Although there is no cure for fibrous dysplasia, treatments may help to lessen pain, and physical therapy may help strengthen muscle and improve range of motion.
- To help you live with the disease, see your doctor regularly, follow your treatment plan, and reach out to others for help when you need it.

## What is fibrous dysplasia?

Fibrous dysplasia happens when abnormal fibrous (scar-like) tissue replaces healthy bone. The fibrous tissue weakens the bone over time, which can lead to:

- Broken bones.
- Bones that are misshapen (bowed or crooked). The disease can affect any bone in the body.

Some people have no symptoms or only a few symptoms. Other people may have more symptoms.

Although there is no cure for fibrous dysplasia, treatments may help to lessen pain, and physical therapy may help strengthen muscle and improve movement.

## Who gets fibrous dysplasia?

Fibrous dysplasia is not common, but anyone can develop the disease. It is usually diagnosed in children and young adults, who have likely had it since birth.

## What are the symptoms of fibrous dysplasia?

People with a milder form of the disease may not have any symptoms. Sometimes, they find out

they have fibrous dysplasia after having an x-ray for another reason. Other people may have more severe symptoms. The most common symptoms of fibrous dysplasia include:

- Bone pain.
- Misshapen (crooked or bowing) bones.
- Broken bones.

## What causes fibrous dysplasia?

Fibrous dysplasia happens when a gene mutates (changes) early in a pregnancy. There is nothing that the mother can do to prevent this from happening. Children do not inherit the gene from their parents and will not pass the disease to their children.

## Is there a test for fibrous dysplasia?

Depending on the symptoms, your doctor may order one of the following tests:

- X-rays, which, can show the bone structure as well as broken, crooked, or bowed bones.
- Magnetic resonance imaging (MRI) or computed tomography (CT), which are helpful in checking the skull and facial bones for the disease.
- Bone scan, which looks at the entire skeleton for the disease.
- Bone biopsy, which allows a doctor to look at a small amount of bone tissue under a microscope.

## How is fibrous dysplasia treated?

There is no cure for fibrous dysplasia. If you or your child has symptoms, treatments may include:

- Physical therapy to help strengthen muscle and movement.
- Cast, splint, or brace to help a broken bone heal or to help a person walk or move.
- Surgery to prevent and fix broken bones and other problems that symptoms may cause.

Your doctor may prescribe:

- Pain medicines to treat pain caused by broken bones and bone pain.
- Medicines to treat the hormone problems some people with fibrous dysplasia may have.

## Who treats fibrous dysplasia?

Most people with fibrous dysplasia work with a team of doctors and medical professionals, which may include:

- Orthopaedists, who treat and perform surgery for bone and joint diseases.
- Dental providers such as dentists and oral-maxillofacial surgeons, who provide dental care and treat problems of the mouth and jaw.
- Endocrinologists, who treat bone problems, or problems related to the glands and hormones.
- Mental health providers, who provide counseling and treat mental health disorders.
- Occupational therapists, who teach how to safely perform activities of daily living.
- Ophthalmologists, who specialize in treating disorders and diseases of the eye.
- Otolaryngologists, who treat ear, nose, and throat disorders.
- Physiatrists, who specialize in physical and rehabilitation medicine.
- Physical therapists, who teach ways to build muscle strength, recover from broken bones, and prevent broken bones
- Primary care physicians, who diagnose and treat adults and children.

When possible, try to work with health care professionals familiar with treating fibrous dysplasia.

## Living with fibrous dysplasia

Living with fibrous dysplasia is different for each person. Some people have few or no symptoms, while others have many symptoms that affect their daily lives. The following tips may help.

- See your health care providers on a regular basis to help keep bones as healthy as possible.
- Talk to your doctor or physical therapist about which types of exercises are best.
- Ask your doctor about taking calcium, vitamin D, and phosphorus supplements to support general bone health.
- Ask family and friends for help when you need it.
- Reach out to online and community support groups.

## For more info

### **U.S. Food and Drug Administration**

Toll free: 888-INFO-FDA (888-463-6332)

Website: <https://www.fda.gov>

Drugs@FDA at <https://www.accessdata.fda.gov/scripts/cder/daf>. Drugs@FDA is a searchable catalog of FDA-approved drug products.

### **Centers for Disease Control and Prevention, National Center for Health Statistics**

Website: <https://www.cdc.gov/nchs>

### **Genetic and Rare Diseases Information Center**

Website: <https://rarediseases.info.nih.gov/diseases/6444/fibrous-dysplasia>

### **National Institute of Dental and Craniofacial Research**

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

### **American Academy of Orthopaedic Surgeons**

Website: <https://www.aaos.org>

### **Fibrous Dysplasia Foundation**

Website: <https://www.fibrousdysplasia.org>

### **The MAGIC Foundation**

Website: <https://www.magicfoundation.org>

### **Rare Bone Disease Alliance**

Website: <http://rbdalliance.org>

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at [NIAMSInfo@mail.nih.gov](mailto:NIAMSInfo@mail.nih.gov).

- [Asian Language Health Information](#)
- [Spanish Language Health Information](#)