CONDITION

Fibrous dysplasia

Fibrous dysplasia is a condition in which fibrous tissue replaces healthy bone, making affected bones weaker or misshapen.

WHAT IT IS
Noncancerous bone condition replacing healthy bone with fibrous tissue

BODY SYSTEM
Bones and skeleton

MAIN SYMPTOMS
Bone pain, fractures, deformity, uneven facial bones

WHAT CAUSES IT
Random GNAS gene change after conception

HOW IT IS DIAGNOSED
X-rays and CT, sometimes bone biopsy

MAIN TREATMENT
Monitoring, pain relief, bone medicines, and surgery

CAN IT BE CURED?
No - abnormal bone cannot be fully reversed

IS IT AN EMERGENCY?
Sometimes - sudden fracture signs or new vision loss

LONG-TERM OUTLOOK
Often stable after growth, though complications can continue

Overview

Fibrous dysplasia is a condition in which areas of normal bone are replaced by weaker, fibrous tissue. This tissue contains poorly formed bone and can make an affected bone more likely to bend, break, become enlarged, or cause pain.

The abnormal areas are not cancer. They may affect one bone, called monostotic fibrous dysplasia, or several bones, called polyostotic fibrous dysplasia. Common sites include the thigh bone, shin, ribs, pelvis, skull, and facial bones.

Some people have one small area that is found by chance on an X-ray. Others have more extensive changes that affect movement, appearance, hearing, vision, or hormone function.

Fibrous dysplasia may occur as part of McCune-Albright syndrome. This condition combines

fibrous dysplasia with other features, such as patches of darker skin and glands that produce too much of certain hormones. Not everyone with fibrous dysplasia has this syndrome.

Symptoms

Symptoms depend on which bones are affected and how much of each bone has changed. A small area may never cause symptoms.

Bone pain is common in people who do have symptoms. It may be a dull, ongoing ache or become worse with activity. Sudden severe pain can mean that the bone has cracked or broken.

Possible symptoms include:

Fibrous dysplasia near a joint can change how weight passes through that joint. Over time, this may contribute to stiffness or arthritis.

If the condition affects bones around the eyes, ears, or nerves, it can occasionally interfere with vision, hearing, balance, or facial sensation. These problems need prompt assessment, especially when they are new or worsening.

People with McCune-Albright syndrome may also have signs of hormone overactivity. These can include puberty beginning unusually early, symptoms of an overactive thyroid, or unusually rapid growth. Some people lose too much phosphate through their kidneys. Phosphate is a mineral needed for strong bones.

- Bone pain or tenderness
- Repeated fractures or small stress fractures
- Bowing or other changes in the shape of a limb
- A difference in leg length, walking, or posture
- Uneven growth or enlargement of the skull or facial bones
- Headaches, hearing changes, blocked sinuses, or dental problems
- Scoliosis, meaning a sideways curve of the spine

Causes and risk factors

Fibrous dysplasia is caused by a change in a gene called GNAS . This change happens by chance after conception, while an embryo is developing. It affects only some groups of cells, a pattern called mosaicism.

The timing of the gene change helps determine how much of the body is affected. An earlier change may involve several bones and hormone-producing glands. A later change may cause one small bone lesion.

Fibrous dysplasia is not inherited from a parent and is not known to be passed to children. Nothing a parent did before or during pregnancy causes it.

There are no established lifestyle risk factors for developing the condition. The effects are often more active during childhood and adolescence, while bones are growing. However, pain and other complications can continue or first become noticeable in adulthood.

Diagnosis

Fibrous dysplasia is often first seen on an X-ray taken because of pain, a fracture, or another concern. The affected area may have a hazy or "ground-glass" appearance, although not every lesion looks the same.

A CT scan gives more detailed pictures of bone. It is particularly useful for the skull and facial bones. MRI may be used when the appearance is unclear or when nearby soft tissues, nerves, or other structures need to be assessed.

A bone scan may help show how many bones are involved. Blood and urine tests can check bone metabolism, phosphate levels, and signs of hormone overactivity. These tests do not confirm fibrous dysplasia on their own.

A biopsy removes a small sample of tissue for examination under a microscope. It may be needed if scans do not show a typical pattern or if another condition must be ruled out. A biopsy is not always necessary when the imaging findings and medical history are characteristic.

When several bones are involved, assessment may include checks of growth, puberty, thyroid function, phosphate balance, hearing, vision, and dental health. This helps identify features of McCune-Albright syndrome and complications that may need separate care.

Treatment and management

Treatment is based on symptoms, the bones involved, the risk of fracture, and whether the condition is changing. There is no treatment that can replace every area of abnormal bone with normal bone.

A small, painless lesion that is not weakening the bone may only need monitoring. Follow-up

can include an examination and occasional imaging. Repeated scans are not always needed once a lesion is known to be stable.

Pain management may include suitable non-opioid pain medicines, physical therapy, pacing activities, and treatment of a fracture or joint problem. Persistent or unexplained pain should be assessed rather than assumed to come from fibrous dysplasia.

Bisphosphonates are medicines that slow bone breakdown. Intravenous bisphosphonates may be considered for some adults with ongoing moderate or severe bone pain. Evidence that they prevent lesion growth, deformity, or fractures is limited. They are not a cure and require clinical review of kidney function, mineral levels, and dental health.

Surgery may be used to:

Abnormal bone may grow back after some operations, particularly while a person is still growing. Surgical planning is usually handled by a team familiar with fibrous dysplasia.

Any hormone disorder associated with McCune-Albright syndrome needs its own treatment. Correcting phosphate loss or excess hormone production can improve bone health and may reduce complications.

Radiation therapy is generally avoided. Fibrous dysplasia is noncancerous, and radiation can increase the risk of a later bone cancer in the treated area.

- Repair or stabilise a fracture
- Strengthen a bone at high risk of breaking
- Correct major bowing or deformity
- Treat pressure on a nerve or another nearby structure
- Address selected skull or facial changes

Complications

Weak bone can develop small cracks or complete fractures. A weight-bearing bone may gradually bow, leading to a limp, unequal leg length, or reduced mobility. Hip deformity can become severe in some people with extensive disease.

Changes in the spine may cause scoliosis. Skull or facial involvement can affect facial symmetry, teeth, sinuses, hearing, or vision. Simply having bone around the optic nerve does not mean that sight will be lost; changes in vision are assessed using symptoms, eye examinations, and imaging.

Long-term pain can affect sleep, work, activity, and mood. Pain severity does not always match

the size of a lesion, so other causes such as arthritis, a stress fracture, or a vitamin or mineral problem may need to be considered.

Cancer developing within fibrous dysplasia is rare. New swelling, a rapidly enlarging area, or severe pain that is different from usual should be assessed. These symptoms often have causes other than cancer, but they should not be ignored.

Prevention

Fibrous dysplasia cannot be prevented because the gene change happens by chance during early development. It is not caused by diet, exercise, injury, or something a parent passed on.

You may be able to reduce some complications by attending planned follow-up, reporting new pain early, and following advice about safe activity. Adequate vitamin D, calcium, and phosphate matter for overall bone health, but supplements should be based on your needs and test results. They do not remove fibrous dysplasia lesions.

Avoiding unnecessary radiation treatment is important. Routine diagnostic X-rays and CT scans are different from radiation therapy and may still be appropriate when their medical benefit is clear.

Living with it and what to expect

The course of fibrous dysplasia differs according to the number, size, and location of affected areas. Lesions usually develop during childhood. They often become less active after the skeleton has finished growing, but they do not disappear.

Many people with one stable lesion live without major restrictions. They may need only occasional follow-up or may be discharged from regular specialist care if the area remains harmless.

People with several affected bones, major deformity, or McCune-Albright syndrome may need long-term care from bone, hormone, orthopaedic, dental, hearing, or eye specialists. Follow-up focuses on function and symptoms rather than repeatedly scanning every lesion.

Activity can often continue, but it may need to be adjusted if a bone is weak or has fractured. Physical therapy can help maintain muscle strength, movement, and balance without placing unsafe force on an affected bone. Advice should be matched to the bones involved rather than applying a blanket ban on exercise.

Pain may remain stable, come and go, or change over time. A clear plan for flare-ups, work,

sleep, and physical activity can make it more manageable. New or sharply worsening pain deserves review because it may signal a stress fracture or another treatable problem.

When to get medical help

Arrange a routine appointment if you develop ongoing bone pain, a new lump or change in bone shape, a limp, repeated fractures, hearing changes, or dental problems near an affected facial bone. If you already have fibrous dysplasia, report pain that is becoming more frequent or limiting normal activity.

Seek urgent medical assessment for:

Call emergency services for a serious injury, an open fracture, a limb that becomes pale or cold, sudden loss of vision, or new weakness with loss of bladder or bowel control.

Routine follow-up is appropriate for stable symptoms and planned monitoring. Sudden fracture signs, major neurological symptoms, or abrupt visual loss are not routine concerns.

- Sudden severe bone pain, swelling, or inability to bear weight
- A visible new deformity after a fall or injury
- New double vision, reduced vision, or rapidly changing eyesight
- New weakness, numbness, loss of balance, or severe nerve-like pain
- A rapidly enlarging or unusually painful area of bone

Common questions

Is fibrous dysplasia cancer?

No. Fibrous dysplasia is a noncancerous bone condition. Cancerous change is rare. A rapidly changing area or new severe pain should still be assessed.

Can fibrous dysplasia spread to other bones?

It does not spread like cancer or an infection. The affected areas are set by which cells received the GNAS gene change early in development. Previously unnoticed lesions may be found later, but this does not usually mean the condition has spread.

Does fibrous dysplasia go away with age?

The abnormal bone usually remains. Lesions often become less active after growth ends, but pain, deformity, fractures, or hormone-related problems can continue into adulthood.

Can I exercise with fibrous dysplasia?

Many people can remain active. The safest type and intensity depend on which bones are involved and how strong they are. Weight-bearing exercise may help general bone health, but high-impact activity may be unsafe when a major leg, hip, or spinal bone is weakened.

Can fibrous dysplasia be passed to my children?

Fibrous dysplasia is not considered inherited. The GNAS change occurs after conception and is present in only some of the body's cells, rather than in the egg or sperm.

Will I need surgery?

Not everyone needs surgery. It may be considered for fractures, major deformity, an unstable weight-bearing bone, or pressure on nearby structures. Stable lesions without troublesome symptoms are often monitored instead.

Sources

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