

Fibrous Dysplasia of Bone: Pain, Fracture Risk and Treatment

A guide to the diagnosis, the reasons for further tests and the goals of treatment.

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In fibrous dysplasia, abnormal fibrous tissue develops within bone. The condition is benign, but the affected bone can weaken, bend or fracture. Some people have few or no symptoms.^[1]

After reading a scan report, it is reasonable to want a clear answer about whether anything needs to be done. Start with two questions: what is the condition doing to this bone, and what would the proposed treatment improve?

What does the diagnosis mean?

The word *monostotic* means one bone is affected; *polyostotic* means more than one. These terms describe the extent of fibrous dysplasia.^[1]

The underlying change in the GNAS gene arises during early development and is not inherited. Some people also have characteristic skin patches or hormone abnormalities as part of McCune-Albright syndrome. The combination of findings varies between individuals.^[2]

You do not need to learn every medical term before the appointment. Your doctor can use the images to show which areas are involved.

Why might I need more than an X-ray?

X-rays help assess the bone changes. CT, MRI or a bone scan may answer further questions about the affected area or the extent of disease. Sometimes a biopsy is needed to confirm the diagnosis.^[1]

Assessment also looks beyond the painful bone. It may include hormone testing and checks for phosphate loss through the kidneys. Low phosphate can contribute to bone pain, weakness of the skeleton and fractures. This helps explain why an endocrinologist or metabolic bone specialist may be involved in care.^[2]

These tests answer different questions: what the finding is, how the bone is affected and whether another problem needs attention. Previous fractures, operations and medicines also belong in that discussion.

What should a change in pain prompt?

New focal pain, pain on weight-bearing or persistent night pain needs reassessment. A stress fracture or another complication may be responsible; very rarely, malignant change is the cause. Contact the treating team promptly about a marked change rather than waiting for a routine review.^[3]

Dr. Vishnu's perspective

I want to understand more than a pain score. Tell me about a bad night, how walking feels and what you have stopped doing. With fibrous dysplasia, a change in pain also needs assessment for a complication.^[3] We should agree what improvement we are working towards, without promising that every symptom or scan abnormality will disappear.

If an affected area causes no symptoms, observation with periodic assessment and imaging may be appropriate. Monitoring is one of the recognised options.^[1]

What can medicines achieve?

Pain care may include appropriate pain medicines, physiotherapy and treatment of vitamin D or phosphate problems. International guidance does not recommend oral bisphosphonates for fibrous dysplasia pain. Intravenous bisphosphonates may be considered for persistent, moderate to severe pain after appropriate assessment. Their ability to prevent fractures or stop lesion progression has not been established.^[3]

Oral alendronate increased some bone-density measurements but did not show a significant pain or function benefit in a small trial of children and adults with polyostotic fibrous dysplasia. A denser bone on a scan is not the same as feeling or moving better.^[4]

More about the evidence

The trial used a placebo comparison. Its small size and the participants' generally modest pain at the start limited what it could establish about pain relief.^[4]

A small 2026 trial of burosumab reported improved phosphate levels in people with extensive fibrous dysplasia and low phosphate. It was an uncontrolled study of a specific associated problem; the findings do not establish a cure or a treatment for everyone with fibrous dysplasia.^[5]

More about the evidence

The trial had no control group, and some adults were taking other bone medicines. These features limit what can be attributed to burosumab itself.^[5]

Be clear about the treatment goal. Ask what change would count as success, how it will be checked and what would lead the team to reconsider the plan.

When is surgery considered?

Surgery may stabilise a fracture or address a bone that is becoming deformed or structurally unsafe. Planning should involve a surgeon familiar with fibrous dysplasia. Routine scraping out of the affected tissue followed by bone grafting is generally discouraged in international guidance; the operation should address the particular mechanical problem.^[3]

The explanation of surgery should start with the problem it aims to correct, using your images. You also need to know what support the bone will need afterwards and what that means for walking, work or school.

Activity, rehabilitation and longer-term care

Physiotherapy can help address weakness, restricted movement and loss of mobility. Follow-up also considers the affected bones and associated problems, including phosphate levels. A plan for someone with a single quiet lesion can differ from care for extensive disease.^[2]

Your care plan should cover:

- Which activities are suitable now, and which need adjustment.
- Who will arrange the next review and any tests.
- Which symptom changes should prompt earlier contact.
- Whom to contact with questions about medicines or recovery.

Frequently Asked Questions

Is fibrous dysplasia inherited?

It results from a genetic change during early development and is not inherited. GeneReviews reports no verified transmission from parent to child. A genetics consultation can address individual family-planning questions. [\[2\]](#)

Can fibrous dysplasia become cancer?

Malignant change is very rare. A rapidly increasing swelling or worsening pain, particularly pain at night or at rest, still needs reassessment rather than being assumed to be part of the known condition. [\[1\]](#)

Does every area of fibrous dysplasia need surgery?

No. An area that causes no symptoms may be monitored. Surgery is considered for particular problems, such as a fracture, progressive deformity or concern that the bone may break. [\[1\]](#)

Do osteoporosis tablets help fibrous dysplasia pain?

A controlled trial did not find a significant pain benefit from oral alendronate compared with placebo. Discuss the purpose of any prescribed medicine with your treating team before changing it. [\[4\]](#)

Your consultation

Discuss fibrous dysplasia care in Kannur

To discuss fibrous dysplasia, changing symptoms or the purpose of proposed treatment, you can book a consultation with Dr. Vishnu Baburaj at Aster MIMS Kannur.

[Book a consultation](#)

[Plan your visit](#)

The evidence behind this article

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4. Boyce AM, Kelly MH, Brillante BA, et al. *A Randomized, Double Blind, Placebo-Controlled Trial of Alendronate Treatment for Fibrous Dysplasia of Bone*. Journal of Clinical Endocrinology & Metabolism. 2014;99(11):4133-4140. [Full trial report](#).

5. de Jong O, Gun ZH, Asante-Otoo A, et al. *A phase 2 trial of burosumab for treatment of fibroblast growth factor-23-mediated hypophosphatemia in children and adults with fibrous dysplasia*. Bone Research. 2026;14:47. [Full trial report](#).
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