

Atypical thigh bone fractures and drug treatments for osteoporosis

Atypical thigh bone fractures are a rare side effect linked with some osteoporosis drug treatments. The drug treatments are alendronate, ibandronate, risedronate, zoledronate, denosumab and romosozumab. Atypical thigh bone fractures are linked with taking these treatments for many years. They don't happen often. You might hear these breaks described as atypical femoral fractures.

Atypical means 'unusual'. Atypical thigh bone fractures are unusual because they are different from fractures caused by osteoporosis. Most fractures caused by osteoporosis are in the wrists, hips and spine. But atypical thigh bone fractures happen in the large, main bone in your thigh (femur). The bone breaks without you falling over.

The benefits of taking a drug treatment for osteoporosis are likely to far outweigh any possible risks of getting an atypical thigh bone fracture.

Who is this fact sheet for?

We often get asked questions about atypical thigh bone fractures on our Helpline. We hope our fact sheet will help you feel more informed about this rare side effect.

This information may be helpful if you (or someone close to you) have:

- osteoporosis or a high risk of fractures (broken bones), and want to know more about rare side effects linked with some drug treatments
- been offered or are taking a drug treatment for osteoporosis and are worried about the risk of atypical thigh bone fractures.

It includes the following information:

- · What are atypical thigh bone fractures?
- What drug treatments are linked with atypical thigh bone fractures and how do they increase risk?
- Why do I need a drug treatment?
- How common are atypical thigh bone fractures?
- What can I do to reduce my risk?
- How do I know if I have an atypical thigh bone fracture?
- What happens if I have an atypical thigh bone fracture?
- What can I do if I'm worried about atypical thigh bone fractures?
- More ways to look after your bones
- Getting more information and support

What is osteoporosis?

Osteoporosis is a condition where the bones become weaker and break easily, even after a minor bump or fall. You might hear these breaks described as fragility fractures. The terms 'fracture' and 'broken bone' mean the same thing.

Fractures can affect almost any bone, but they are most common in the wrists, hips and spine. It's these broken bones that can cause pain, rather than osteoporosis itself. Spinal fractures can also cause height loss and a curved spine.

What are atypical thigh bone fractures?

Atypical thigh bone fractures are breaks that occur along the main part of the thigh bone. They can happen in one or both thighs.

Atypical thigh bone fractures are rare. They can happen in people taking some drug treatments for osteoporosis.

Why are atypical thigh bone fractures unusual?

Atypical thigh bone fractures are unusual. This is because they are different from fractures caused by osteoporosis.

Here are some of the main differences.

Fractures caused by osteoporosis:

- usually happen after a fall, except for spinal fractures
- are most common in the wrists, hips and spine.

Atypical thigh bone fractures:

- are often drug-related
- happen in one or both thighs.

What drug treatments are linked with atypical thigh bone fractures and how do they increase risk?

Bisphosphonates are a type of medication linked with atypical thigh bone fractures. This group of drugs includes:

- alendronate (also known as alendronic acid, Fosamax[®], Binosto[®] and Fosavance[®])
- ibandronate (also known as ibandronic acid and Bonviva®)
- risedronate (also known as Actonel®)
- zoledronate (also known as zoledronic acid and Aclasta[®])

Denosumab (also known as Prolia®) and romosozumab (also known as Evenity®) are also linked with atypical thigh bone fractures.

Research has shown that having these types of treatments for a long time increases the risk of atypical thigh bone fractures. But research has not proven why these treatments increase risk over time.

What do the drug treatments do and how do they work?

Bones are made up of living tissue. The inside of our bones is constantly being broken down and rebuilt by specialist bone cells. As long as this process is in balance, your bones should stay healthy and strong.

But if the process becomes out of balance, our bodies start to break down more bone than we build. This can cause the bones to become weaker and more likely to break easily.

Many of the osteoporosis drugs work by slowing down the cells that break down bone. This helps to restore the balance and make your bones stronger.

Some experts think taking these medications for many years might slow down the cells that break down bone for too long. This could increase the risk of atypical thigh bone fractures.

Why do I need a drug treatment?

Doctors follow guidelines when deciding whether to offer treatments. If your doctor has recommended a drug treatment, this means your risk of breaking a bone is high enough to need a drug treatment.

Drug treatments can help to strengthen and protect your bones, making you less likely to break a bone in the future.

It's your choice whether to take a drug treatment or not. There's information on our website at **theros.org.uk/treatment** to help you make a decision.

How common are atypical thigh bone fractures?

Atypical thigh bone fractures are rare. We don't know exactly how many people get them because there isn't much information available.

Some research has shown if 1,000 people were taking drug treatments linked to atypical thigh bone fractures, less than 1 person would have an atypical thigh bone fracture. The other 999 out of 1,000 people would not have an atypical thigh bone fracture.

The risk of having an atypical thigh bone fracture is **low**. If you've been offered a drug treatment for osteoporosis, this means your risk of breaking a bone is high enough that your bones would benefit from a drug treatment. For you, the benefits outweigh any possible risks. In other words, your risk of atypical thigh bone fractures is smaller than your risk of breaking a bone if you don't have treatment.

What can I do to reduce my risk?

Some research shows that stopping treatment for a while may reduce your risk of atypical thigh bone fractures.

If you've been taking a bisphosphonate treatment for about five years, you may be advised to pause your treatment. This will usually be for one to three years. It's called a 'treatment pause' or 'drug holiday'.

Bisphosphonates keep helping your bones for a while after you stop taking them.

If you're at a high risk of breaking a bone, your doctor may advise you to stay on your drug treatment without pausing.

You can only pause treatment if you're taking a bisphosphonate.

Denosumab and romosozumab don't continue helping your bones for a while after you stop taking them. A treatment pause won't be an option for this reason.

It is especially important **you don't pause denosumab**. Some people have had several spinal fractures in the following months after they've stopped denosumab. This is known as the 'rebound effect'. To stop the effect, you'll need to take another drug treatment.

For more information about denosumab, read our fact sheet 'Drug treatments for osteoporosis: Denosumab' or visit our website at theros.org.uk/info

It's important to take your drug treatment correctly. Make sure you read – and understand – the leaflet that comes with your treatment. If you don't have a copy, ask your doctor or pharmacist for one.

How do I know if I have an atypical thigh bone fracture?

The main symptom of an atypical thigh bone fracture is a new, unexplained pain in your thigh or groin area while taking an osteoporosis drug treatment. If you have this type of pain, speak to a doctor.

If your pain is severe, see a doctor in a few days. If you have less severe pain, speak to a doctor within a few weeks.

What happens if I have an atypical thigh bone fracture?

If your doctor thinks you might have an atypical thigh bone fracture, they will refer you for an an x-ray. They may also offer you crutches. The crutches will limit how much weight you put on your leg when walking or standing.

If your x-ray shows any unusual changes or fine cracks in your thigh bones, this may mean you have the start of an atypical thigh bone fracture. A specialist doctor may suggest an operation before your bone fractures fully or gets worse.

If your x-ray shows you have an atypical thigh bone fracture, your doctor will usually advise you:

- · stop taking the drug treatment
- have an operation to fix the bone.

If you're on denosumab, you must get advice from a hospital specialist before stopping treatment.

People who have an atypical thigh bone fracture in one leg might be more likely to have a fracture in the other leg. Stopping treatment may help prevent another fracture from happening. You are often offered an x-ray of your other thigh to make sure it's not affected too.

If you have an atypical thigh bone fracture, you'll likely need an operation to fix the bone. It could take about four to six months to heal after an operation, but this varies from person to person.

You should be offered crutches and referred to a physiotherapist. They can help you to stand and walk after your operation.

In a few cases, fractures don't heal properly after an operation. If this happens, you may need to have another operation to try and fix the bone again.

What can I do if I'm worried about atypical thigh bone fractures?

Some people might be concerned about the possible health risks of taking a drug treatment.

No-one can make you have treatment if you don't want it. But do take time to understand the benefits and possible risks – both of taking the drug treatment, and of not taking it.

Take care when visiting online forums or chat groups on social media. Reading about other people's experiences can be helpful. But you may not always see a balance of views online. People are more likely to seek support for bad experiences than good ones. This can make it seem that everyone has problems with drug treatments. In reality, most people have no side effects at all.

There is a low risk of having atypical thigh bone fractures when taking bisphosphonates, denosumab and romosozumab. But atypical thigh bone fractures are rare.

If you do feel worried, before or during your treatment, talk to your doctor or pharmacist, or contact our specialist Helpline nurses.

There may be another drug treatment you feel is more suitable for you.

The Medicines and Healthcare products Regulatory Agency (MHRA) makes sure drugs work well and are safe.

You can report medication side effects through the MHRA's 'Yellow Card Scheme'. This may be particularly helpful if you've experienced a rare side effect, such as an atypical thigh bone fracture. Visit yellowcard.mhra.gov.uk for more information.

More ways to look after your bones

As well as having a drug treatment, a healthy lifestyle is important for your bone health. This includes:

- a well balanced, varied and calcium-rich diet
- safe exposure to sunlight, so that your skin makes vitamin D
- regular weight-bearing impact exercise and muscle-strengthening exercise
- not smoking
- not drinking more than the recommended levels of alcohol

taking steps to lower your risk of falling as falls can lead to broken bones.

Calcium and vitamin D

Getting enough calcium and vitamin D is very important for your bones.

While you're having a drug treatment, your doctor may advise you to:

- aim to consume around 1,000mg of calcium a day
- take a daily 20 microgram (20µg or 800IU) supplement of vitamin D.

This is more than the usual recommended amount to make sure you are getting enough for your bones. Your doctor may sometimes recommend higher or lower doses, depending on your situation.

For more information on healthy living, including our calcium and vitamin D-rich food choosers, tips for preventing falls, and our films and fact sheets on how to exercise safely for your bones, visit our website at theros.org.uk/healthy-bones

Getting more information and support

We hope this fact sheet will help you feel more informed and confident when discussing your bone health with your medical team.

For more information about osteoporosis and bone health, including fact sheets on all available drug treatments, visit our website at theros.org.uk/info or order more of our printed publications.

If you need more information or support, talk to your healthcare professional. You can also call our specialist Helpline nurses with any questions or concerns about bone health or living with osteoporosis, for free, on 0808 800 0035 or email them at nurses@theros.org.uk







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This information is based on the latest evidence and clinical practice. It should not replace advice from your own healthcare professionals.

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