

Osteonecrosis of the jaw (ONJ) and drug treatments for osteoporosis

Osteonecrosis of the jaw (ONJ) is a very rare side effect linked with some osteoporosis drug treatments. The drug treatments are alendronate, ibandronate, risedronate, zoledronate, denosumab and romosozumab. ONJ has been linked with taking these treatments for many years. It doesn't happen often.

ONJ is a condition where healing inside the mouth is delayed. This can happen after some dental treatments such as a tooth extraction (taking a tooth out) or an implant. The delayed healing inside the mouth means the jawbone stays exposed.

The benefits of taking a drug treatment for osteoporosis are likely to far outweigh any possible risks of getting ONJ.

Who is this fact sheet for?

We often get asked questions about ONJ on our Helpline. We hope this fact sheet will help you feel more informed about this very 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
- have been offered or are taking a drug treatment for osteoporosis and are worried about the risk of ONJ
- want to understand why dental check-ups may be recommended with some osteoporosis drug treatments.

It includes the following information:

- What is ONJ?
- What drug treatments are linked with ONJ and how do they increase risk?
- Why do I need a drug treatment?
- How common is ONJ?
- What can I do to reduce my risk?
- How do I know if I have ONJ?
- What happens if I have ONJ?
- Going to the dentist
- What can I do if I'm worried about ONJ?
- 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 is ONJ?

ONJ is a condition which affects the jaw. It happens when there is delayed healing in the mouth and the jawbone isn't covered by gums for more than eight weeks. This can cause problems with the health of your jawbone.

ONJ can happen after dental treatments that go into the jawbone like a tooth extraction (taking a tooth out) or implant. You might hear these treatments described as invasive.

What drug treatments are linked with ONJ and how do they increase risk?

Bisphosphonates are a type of medication linked with ONJ. 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 ONJ.

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

Many of the osteoporosis drugs are also used to treat cancer. But they are given in higher doses and more frequently than when used to treat osteoporosis. In other words, people who are on these treatments for cancer will get more of the drug over time than people who are on these treatments for osteoporosis. This may be why ONJ affects more people who are taking these drugs for cancer treatment rather than for osteoporosis.

ONJ can sometimes happen in people not taking a drug treatment for osteoporosis or cancer.

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.

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 is ONJ?

ONJ in people taking drug treatments for osteoporosis is very rare. We don't know exactly how many people get it because there isn't much information available.

Research estimates between 1 to 10 people in every 10,000 who take osteoporosis drug treatments will get ONJ. This means at least 9,990 people out of 10,000 won't get ONJ.

There are some factors that increase your risk of getting ONJ. You may be at an increased risk if you:

- have cancer
- are having chemotherapy
- are taking steroids (glucocorticoids) tablets
- have unhealthy teeth and gums.

The risk of getting ONJ is **very 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 ONJ is smaller than your risk of breaking a bone if you don't have treatment.

What can I do to reduce my risk?

You can reduce your risk of ONJ while taking an osteoporosis drug treatment by:

- keeping your teeth and gums healthy
- seeing a dentist regularly.

It may also help to:

- use fluoride toothpaste and mouthwash
- eat a well-balanced diet
- stop smoking
- reduce how much alcohol you drink.

We often get asked whether you need to have a dental check-up before starting a drug treatment for osteoporosis. This isn't always the case. It's unlikely you'll need a check-up if your teeth and gums are healthy.

How do I know if I have ONJ?

ONJ is a very rare problem. If it does happen, it's most likely to be after a dental treatment such as a tooth extraction.

If you notice your gums haven't healed eight weeks after your dental treatment, talk to your dentist.

Symptoms of ONJ include:

- pain or swelling in your gums
- loose teeth
- difficulty chewing.

It's unlikely these symptoms will be ONJ. These are also symptoms of infection which can happen after dental treatment. But it's worth checking with your dentist if you're worried, especially if your symptoms haven't improved after eight weeks.

What happens if I have ONJ?

If your dentist thinks you might have ONJ, they should refer you to a dental specialist.

A dental specialist can advise on treatment for ONJ. This could be:

- taking antibiotics
- taking pain-relieving drugs
- keeping your teeth and gums healthy.

ONJ can take about a year to heal. In very severe cases, an operation may be needed to help your jaw heal.

Your osteoporosis drug treatment will likely be stopped if it's linked to ONJ.

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

Going to the dentist

Can I have a tooth extraction or dental implant if I'm taking an osteoporosis drug treatment?

You should be able to have a tooth extraction or implant if your dentist thinks it's the best treatment option for you. The risk of ONJ with these types of dental treatment is very small.

Your dentist may also explore less invasive treatment options if the tooth can be saved. For example, if you need a tooth extraction, your dentist may suggest trying root canal treatment instead.

Some dentists think dental implants are not an essential procedure. This means they may choose not to offer you this treatment. If you're keen to get an implant, you'll need to speak to a dental implant specialist.

All dentists should be aware of how to manage patients on osteoporosis drug treatments. NHS Scotland has produced a guide for dentists available on their website at **sdcep.org.uk**

Do I need to have a tooth extraction in hospital?

The type of osteoporosis drug treatment and the length of time you've been on it should not affect where you receive your dental treatment.

You'll only need to be referred to a dental hospital if you have a complicated dental need.

What happens if my dentist won't offer me dental treatment?

If you're on an osteoporosis drug treatment linked to ONJ, your dentist may suggest that a tooth extraction or dental implant isn't suitable for you. But current guidance states that it's possible to have these procedures if they are thought to be necessary. It's likely your dentist will explore other dental treatments first though.

Talk to your dentist about the risks and benefits so you can make a choice together about the dental treatment that's right for you. It may also be helpful to encourage your dentist to speak to an osteoporosis specialist.

If you're struggling to agree on dental treatment, it may be helpful to ask for a second opinion from a different dentist. We know it can be difficult to access a dentist as many do not accept new patients. Visit the NHS website for more information about how to find a dentist.

Will stopping my osteoporosis drug treatment before I have a dental treatment reduce my risk of ONJ?

It's unlikely that stopping or pausing your osteoporosis drug treatment will reduce your risk of ONJ.

If you're on denosumab, talk to your osteoporosis specialist for advice. There may be a benefit to planning your dental treatment around your denosumab injections.

What can I do if I'm worried about ONJ?

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 very low risk of getting ONJ when taking bisphosphonates, denosumab and romosozumab. But ONJ is very 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 very rare side effect, such as ONJ. 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**

#BoneMatters online events

We have a very popular series of online information events, where you can hear leading health experts discussing everything from drug treatments to nutrition and exercising safely.

You may be interested in our 'Understanding side effects of drug treatments' recorded discussion.

For details of upcoming sessions, and to watch past events, visit theros.org.uk/bone-matters

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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.

To give us feedback on this fact sheet, email us at health.info@theros.org.uk

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