

Osteoporosis Passport
You have been administered

Denosumab on_____



Introduction?

This information leaflet is about a medicine called Denosumab which is used to treat people with osteoporosis. This leaflet describes how Denosumab is given and some of its benefits and possible side effects.

What is osteoporosis?

The word osteoporosis literally means spongy (porous) bone. It causes your bones to become fragile so they break more easily.

Bone is a living, active tissue that constantly renews itself. Old bone tissue is broken down by cells called osteoclasts and replaced by new bone material produced by cells called osteoblasts.

The balance between old bone breakdown and new bone formation changes as we grow older, in that bone starts to be broken down more quickly than it is replaced, so our bones slowly begin to lose their density and therefore strength. This usually starts at about the age of 40 and continues for the rest of our lives.

We all have some degree of bone loss as we get older, but the term osteoporosis is used only when the bones become quite fragile. This disease is especially common in women after the menopause, but it can also occur in men. Osteoporosis is also common in patients receiving steroids (e.g. prednisolone).

What does Denosumab do and how does it work?

Denosumab isn't usually given as a first treatment for osteoporosis. It'll probably only be an option if you've already tried one of the more common **drug treatments**, or if other treatments aren't suitable for you.

Denosumab can help to make your bones stronger and reduce your risk of broken bones, including hip and spinal fractures. Denosumab works by blocking the formation and activity of cells that break down bone. This helps to restore the balance and make your bones stronger.

How is Denosumab given?

You will have an injection every six months at the hospital or your GP surgery. The injection will be given just under your skin in either your tummy, top of your arm or upper thigh. The needle is thin and people say they experience very little pain.

It's important to have the injection every six months. This is because the effects of the drug wear off very quickly. You can have injections up to four weeks early or late, if you need to.

How will my treatment be monitored?

You'll have an appointment every six months to receive your injection. You should have a blood test before each injection, unless your doctor decides you don't need one. This is to check your calcium levels, how well your kidneys are working, and sometimes your vitamin D levels. Some people will also have a blood test two weeks after each injection. After about five years on denosumab you should have a formal treatment review. At this review, your doctor will check if denosumab is still the right treatment for you. You may have a **bone density scan**, which will give your doctor some information about your bone strength.

<u>Next Dose Due</u>	<u>Pre treatment blood test on</u>	<u>Injection Date</u>

How long can I have Denosumab?

Most people stay on Denosumab lifelong. Your doctor can advise you on what's best for you, based on your own situation.

Can I stop having Denosumab for a while?

No. Denosumab wears off quickly and stops helping your bones when you stop taking it. If a dose is missed, the injection should be given as soon as possible. Injections should be scheduled 6 months from the date of the last injection.

What are the possible side effects?

- ♦ Skin infections - talk to your doctor immediately if any of your skin becomes red, swollen or sore to touch.
- ♦ Low blood calcium levels – your calcium and vitamin D levels are checked pre-infusion. Tell your doctor immediately if you have:
 - numbness or tingling in your fingers, toes or around your mouth
 - muscle stiffness, spasms, twitches or cramps.
- ♦ Osteonecrosis of the Jaw - this is an extremely rare problem where healing inside the mouth is delayed, usually after major dental treatment. The general advice is to have maintain good oral hygiene and have regular dental check-ups.
- ♦ Atypical (unusual) thigh bone fracture - Can occasionally happen after many years of treatment, even with little or no force. Talk to your doctor if you have unexplained pain in your thigh, groin or hip that does not go away.

Do I need to take extra supplements?

Most people having treatment with Denosumab should also take calcium and vitamin D supplements. Your doctor will advise you about this.

Leading a healthy lifestyle to keep your bones strong

Factors that can help to maintain healthy bones are a well-balanced diet with adequate calcium rich foods, safe exposure to sunlight to obtain vitamin D, regular weight bearing exercise, avoiding smoking and keeping alcohol consumption within the recommended limits.

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Friday from 8.30am to 4.00pm. Please be aware that you may need to leave a voicemail message, but we aim to return your call within one working day.

If you are unable to understand this leaflet, please communicate with a member of staff.