

# Daratumumab (Darzalex®)

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AL amyloidosis Treatment Guide

# What is daratumumab?

Daratumumab, also known as Darzalex®, is a monoclonal antibody used in the treatment of AL amyloidosis.

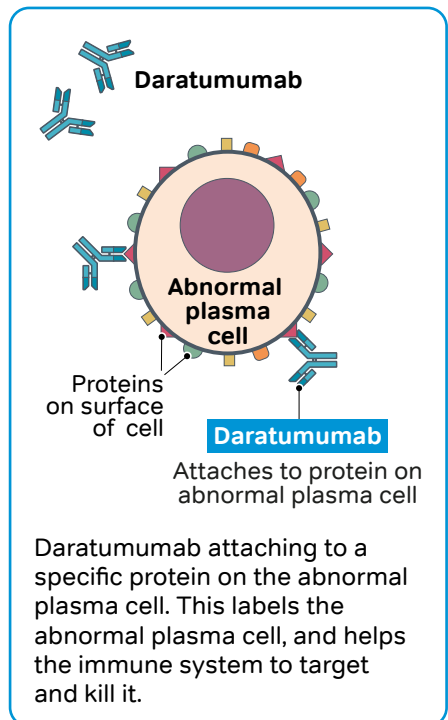
## How does it work?

Treatment for AL amyloidosis aims to kill the abnormal plasma cells. This prevents more amyloid being produced and enables the body to clear existing deposits gradually.

All cells of the body, including abnormal plasma cells, have proteins on their surface.

Abnormal plasma cells produce a specific protein called CD38. Daratumumab works by attaching to this protein.

When daratumumab attaches to the CD38 protein, it labels the abnormal plasma cell. This helps the immune system to target and kill the abnormal plasma cell.



## How is daratumumab given?



Daratumumab is given into the vein (intravenous infusion) or as an injection under the skin (subcutaneous).

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Daratumumab can be given in combination with other AL amyloidosis treatments.

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Daratumumab is usually given once a week for the first 8 weeks. The timing of doses after 8 weeks will vary between treatment plans.

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Individual treatment plans vary, your healthcare team will discuss your specific plan.

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## Possible side effects

Daratumumab has a number of possible side effects which can vary from patient to patient. You will experience some side effects, but it is unlikely you will experience all of them. Most side effects will ease once treatment has finished. Always report any side effects to your healthcare team as soon as possible so they can be treated quickly.

The side effects listed here are those experienced most often. For a complete list of side effects please refer to the patient information leaflet which is included in the pack with the treatment. If you do not have this, ask your healthcare team for it.



Myeloma UK provides a wide range of information booklets about side effects and their management. Relevant booklets are signposted beneath each side effect on the following pages.

You can find these along with all of our information booklets online at [myeloma.org.uk/library](https://myeloma.org.uk/library).

You can also find out more about the management of these side effects by asking your healthcare team or by contacting Myeloma UK.



**0800 980 3332**



**AskTheNurse@myeloma.org.uk**



**[myeloma.org.uk](https://myeloma.org.uk)**



## **Infusion reaction (cytokine release syndrome)**

This is a very common side effect of daratumumab and usually occurs within 24 hours of the first dose. Symptoms include: chills, nausea and vomiting, sore throat, cough, itchy or runny nose, feeling short of breath, and feeling dizzy. You will be given other medicines alongside your daratumumab to reduce the risk of an infusion reaction. However, if you notice any of these side effects, report them to your healthcare team immediately.



## **Peripheral neuropathy**

Daratumumab can cause damage to nerves in the hands, feet, arms, or legs. This is called peripheral neuropathy. This causes numbness, tingling and pain, often in the hands or feet. These sensations can be eased with gentle massage, using hot or cold packs, and nerve painkillers such as gabapentin and pregabalin. Symptoms generally improve or disappear after the dose of daratumumab is reduced or stopped.



For more information see the **Peripheral neuropathy (AL amyloidosis) Infosheet** from Myeloma UK.



## Risk of infection

Daratumumab may affect your immune system, increasing your risk of infection. Common signs include: high or low temperature (37.5°C or above, or below 36°C), feeling shivery or cold, peeing (passing urine) more often or pain when peeing, and cough or cold symptoms.



Infections can become serious if not treated quickly. Contact your healthcare or out of hours service immediately if you think you have an infection.



For more information on infection see the Coping with symptoms and side effects of the **AL amyloidosis: Your Essential Guide** from Myeloma UK.



## Muscle spasms

You may experience muscle cramps or spasms. Some patients find that keeping well hydrated and stretching can help to control the cramps. You may also be prescribed treatment to help with muscle cramps.



## Gut problems

Daratumumab can cause diarrhoea or constipation. Unless you have been advised otherwise, drinking at least 2 litres (3 to 4 pints) a day and having a balanced diet can help to ease these symptoms. You may also be prescribed laxatives to help you go to the toilet, or medicine to reduce any diarrhoea.



For more information on gut problems see the **Diarrhoea (AL amyloidosis) Infosheet** and the **Constipation (AL amyloidosis) Infosheet** from Myeloma UK.



## Anaemia and bleeding

Daratumumab can decrease the number of red blood cells, causing anaemia. Symptoms include: looking pale, shortness of breath, and fatigue. Daratumumab can also decrease the number of platelets, increasing your risk of bleeding or bruising. Treatment for these side effects can ease symptoms and boost your blood cell counts.



For more information on fatigue and anaemia see the [AL amyloidosis: Your Essential Guide](#) from Myeloma UK.



## Headaches

Daratumumab can cause headaches. Try to drink plenty of fluids and speak to your healthcare team about suitable painkillers.



## Fluid retention

Daratumumab can cause swelling of the hands, feet, or ankles. This is called peripheral oedema. Fluid may also collect around the stomach area making you feel bloated, or in the chest, causing you to feel short of breath. If you are struggling with fluid retention, your healthcare team may prescribe some water tablets (diuretics) to help your body remove the excess fluid.



For more information on fluid overload see the Coping with symptoms and side effects of the [AL amyloidosis: Your Essential Guide](#) from Myeloma UK.

## Important information about daratumumab



Daratumumab can affect the test used to match your blood for blood transfusions. This can last up to 6 months after your final daratumumab treatment. You should have this test done before you start any daratumumab treatment. You should also tell any healthcare professionals that you are having daratumumab treatment.



If you could become pregnant, you should use effective contraception during treatment, and for 3 months after treatment has finished.



It is generally advised that you should not breastfeed when taking daratumumab, as it is not known if it could pass to the milk.



Supplements or herbal medicines that have not been prescribed by your haematologist may cause harm when taken alongside your prescribed treatment.

You must speak to your healthcare team before taking any kind of supplement or alternative treatment, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements, to ensure it is safe to do so.



If you have any questions about your treatment, speak to your healthcare team. They are the best people to ask if you have questions about your individual situation. The information in this publication is not meant to replace their advice.



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### We're here for everything a diagnosis of AL amyloidosis brings

Get in touch to find out more about how we can support you

Call the Myeloma UK Infoline on

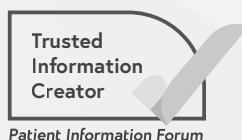
 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk/al-amy**



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For a list of references used to develop our resources, visit **myeloma.org.uk/references**