

Daratumumab (Darzalex[®])

AL amyloidosis
Treatment Guide

What is daratumumab?

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

How does it work?

Treatment for AL amyloidosis aims to kill the abnormal plasma cells, preventing more amyloid being produced and enabling the body to clear existing deposits gradually.

Daratumumab works by attaching to a protein that is present on the surface of abnormal plasma cells which are responsible for producing amyloid protein in AL amyloidosis.

Abnormal plasma cells in AL amyloidosis produce a protein called CD38 which is present on the cell surface. Daratumumab attaches to the CD38 protein found on the surface of abnormal cells, which flags the cell to the immune system. This allows the immune system to target and kill it.

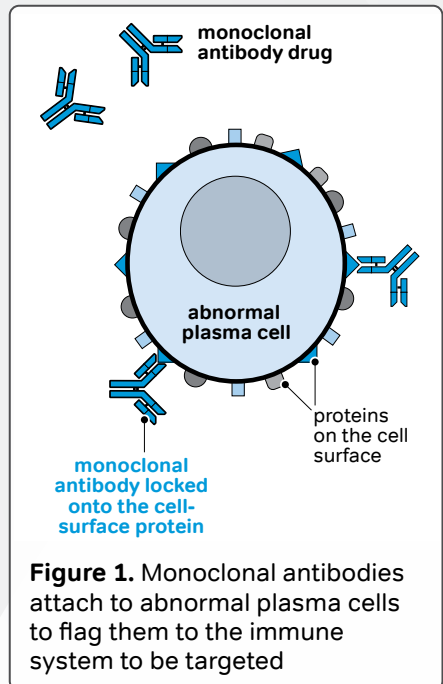


Figure 1. Monoclonal antibodies attach to abnormal plasma cells to flag them to the immune system to be targeted

How is daratumumab given?



Daratumumab is given by intravenous (into a vein) infusion over a number of hours.



Daratumumab is given as a monotherapy (on its own) or in combination with cyclophosphamide, bortezomib and dexamethasone (this combination is known as Dara-CyBorD).



Daratumumab is given once a week for the first 8 weeks, once every 2 weeks from week 9 to week 24, and then every 4 weeks from week 25. Daratumumab is given until there is disease progression, meaning there are signs your AL amyloidosis is becoming more active.

Individual treatment plans may vary, your healthcare team will let you know your specific plan.

Other information about daratumumab



If you could become pregnant, you must use effective contraception during and for 3 months after treatment. This is because the risk to an unborn baby is unknown.



If you would like to breastfeed when taking daratumumab, you should discuss this with your healthcare team. This is because daratumumab may pass to your milk and it is not known if this is safe for your baby.



Daratumumab can affect test results used to match your blood for blood transfusions. This effect can last for up to 6 months after your final infusion of daratumumab. You should have this test done before you start treatment and all your healthcare team should be informed.

Possible side effects

Daratumumab has a number of possible side effects which can vary considerably from patient to patient. It is important to report any side effects to your doctor or nurse so they can be treated or managed promptly.

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



Fluid retention

Daratumumab can cause excessive fluid to accumulate in the body (oedema). This is particularly problematic for patients with amyloid deposits in their heart and/or kidneys who are more prone to fluid retention. Fluid can collect in the face, hands, ankles and feet, and may also collect in the abdomen, making you feel bloated. Occasionally, fluid may collect in the chest leading to a shortness of breath. Your doctor will discuss a treatment plan for your fluid retention with you. This will usually involve taking diuretics (water tablets) to help your body remove the excessive fluid.



Low blood counts

Daratumumab may cause a decrease in the number of red blood cells, white blood cells and platelets in your blood. This can cause anaemia (which can cause shortness of breath, tiredness and weakness) and fatigue, as well as making you more susceptible to infection and increasing your risk of bleeding. If necessary, you will be given supportive treatment to help with these side effects and to boost your blood cell counts.



Gastrointestinal disturbances

Daratumumab can cause diarrhoea, vomiting and/or nausea. While usually mild and manageable, these side effects can become problematic in some cases. Maintaining a balanced diet is important. Your doctor may prescribe specific treatment which can help prevent or control the symptoms.



Fever

You may experience fever after receiving your daratumumab treatment. This should last no more than 24 hours. If it does last longer or occurs a few days after the treatment, it may be a symptom of infection and you should inform your healthcare team as soon as possible.

 **Fatigue**

Fatigue usually resolves shortly after treatment has finished. There are a number of medical and nonmedical strategies you may try to help manage fatigue. For example, treatment for anaemia may reduce fatigue if it is caused by low red blood cell counts. Increasing your levels of activity and having complementary therapies, such as aromatherapy or massage, may also help.

 **Peripheral neuropathy**

Peripheral neuropathy is damage to the nerves in the hands, feet, arms or legs. This can lead to numbness, tingling, increased sensitivity and pain, most often in the feet or hands.

For most patients, symptoms will improve or disappear after the dose and/or frequency of administration of daratumumab is reduced. However, in some cases daratumumab may need to be temporarily stopped or discontinued and other options discussed. If you have severe peripheral neuropathy you may not be able to have other treatments that are also known to cause it, in the future.

Pain and discomfort can be alleviated by gentle massage, warm baths, heat/cold packs and specific nerve painkilling drugs, such as pregabalin and gabapentin.

 **Infusion reaction**

The most commonly observed side effect of daratumumab is an 'infusion reaction', which most often occurs within 3–4 hours of receiving the infusion or injection.

Symptoms can include a throat tickle, cough, fever, chills, nausea, changes in blood pressure, flushing, rash and fatigue. You will be given supportive treatment alongside the daratumumab treatment to try to reduce the risk of an infusion reaction occurring. If you notice any of these side effects, report them to your doctor or nurse immediately. You will need to have further treatment to stop the reaction.

 **Muscle spasms**

Muscle spasms or cramps can be a side effect of daratumumab. There are a number of medical and nonmedical strategies you may try to help manage this. Some nonmedical strategies include keeping well hydrated, stretching and drinking tonic water or sports drinks (however, you must make sure to stay within your fluid intake limit), which some other patients have suggested may help to ease cramping. Your doctor may prescribe specific treatment which can help prevent or control the symptoms.



If you have any questions about your treatment, speak to your medical 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.



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

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