

Lenalidomide (Revlimid®)

AL amyloidosis Treatment Guide

What is lenalidomide?

Lenalidomide, also known as Revlimid®, is an immunomodulatory drug (IMiD) used in the treatment of AL amyloidosis.

How does it work?

Lenalidomide works by affecting the body's immune system. It helps to kill abnormal plasma cells in a number of different ways:

1. Directly killing or stopping the growth of the abnormal plasma cells
2. Blocking the growth of new blood vessels that supply the abnormal plasma cells with oxygen and nutrition
3. Helping the immune system to kill the abnormal plasma cells
4. Changing the production of chemical messages involved in the growth and survival of the abnormal plasma cells
5. Preventing the abnormal plasma cells from sticking to the bone marrow stroma (the tissue and cells within the bone marrow that are not involved in blood cell production)

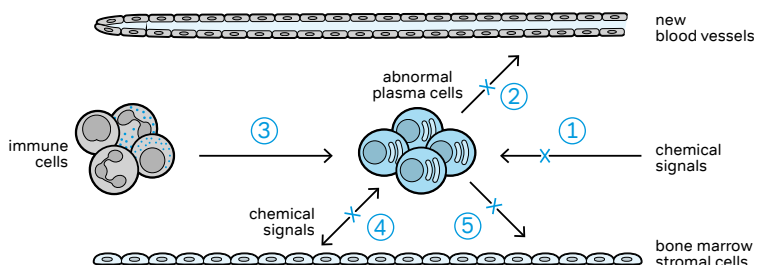


Figure 1. Different ways lenalidomide works to kill abnormal plasma cells

How is lenalidomide given?



Lenalidomide is a capsule given by mouth (orally).



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



Lenalidomide is normally taken for 21 days followed by a 7 day rest period. This forms one 28 day (4 week) cycle.



You should take lenalidomide about the same time each day.



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

Possible side effects

Lenalidomide 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.

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



0800 557 3332



AskTheNurse@myeloma.org.uk



myeloma.org.uk



Peripheral neuropathy

Lenalidomide 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 and cold packs, and nerve painkillers, such as gabapentin and pregabalin. Symptoms most often improve or disappear after the dose of lenalidomide is reduced or stopped.



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



Anaemia and bleeding

Lenalidomide can decrease the number of red blood cells, causing anaemia. Symptoms include: looking pale, shortness of breath, and fatigue. Lenalidomide 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 anaemia see the **AL amyloidosis: Your Essential Guide** from Myeloma UK.



Risk of infection

Lenalidomide 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 team 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 section of the **AL amyloidosis: Your Essential Guide** from Myeloma UK.



Mood changes

Lenalidomide can cause significant mood changes. You may feel low, tearful, have mood swings, or difficulty sleeping. This can be more noticeable when taking higher doses. Lenalidomide may also make you feel confused. If you find your judgement is affected, you should consider if it is safe for you to drive. Speak with your healthcare team if you are struggling with your mental health, especially if you are feeling depressed or having suicidal thoughts.



Fatigue

Fatigue is a feeling of extreme tiredness that is not relieved by sleep. It usually resolves after treatment has finished. Your treatment, any side effects and your mental health can all impact fatigue. It can be managed by treating any medical causes such as anaemia. Allowing time for rest, regular gentle exercise and complementary therapies such as massage, may also help.



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



Blood clots

Lenalidomide can cause blood clots to form in the veins. These are most often in the legs, known as deep vein thrombosis (DVT). Clots occasionally travel to the lungs, causing a pulmonary embolism (PE). You may be prescribed an anti-clotting (anticoagulant) medication to prevent or treat any blood clots. Common signs of DVT include areas of your body that are red, swollen, painful, and hot to touch, often in your calf. Signs of a PE require immediate attention and include: shortness of breath or chest pain.



Blood clots can become serious if not treated quickly. Contact your healthcare team, or out of hours service if you think you have an infection or clot. Call 999 if you have any chest pain or breathing difficulties.



Gut problems

Lenalidomide can cause diarrhoea or constipation. Unless you are advised to limit your fluid intake, 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.

Lenalidomide can cause bile acid malabsorption (BAM), where bile acids are not properly absorbed from the intestines. This can cause persistent diarrhoea. It can be controlled by reducing the amount of fat in the diet, but other treatments may be needed.



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



Eye problems

Lenalidomide can cause changes to your eyes including: blurred vision, clouding of your eye (cataracts), eye swelling, and eye infections. Book regular checkups with an optician and seek urgent advice if you experience any eye swelling.



Skin rash

Lenalidomide can cause a skin rash which may be itchy and need treatment with steroid creams or antihistamines. Some rashes need urgent treatment, including: rashes with swelling of the eyes or mouth, or any problems breathing; rashes that start in one area but begin to spread widely; and rashes with high temperatures.

Important information about lenalidomide



You must not take lenalidomide during pregnancy, as it is expected to be harmful to the baby. You will have to follow a strict pregnancy prevention programme. You must use effective contraception while on this treatment, and for at least 4 weeks after treatment has finished, if you or your partner could become pregnant.



You should not breastfeed when taking lenalidomide as it is not known if lenalidomide can 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

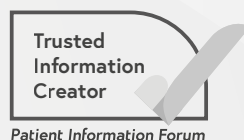
 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

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



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We appreciate your feedback

Please fill in a short online survey about our patient information at **myeloma.org.uk/pifedback** or email any comments to **patientinfo@myeloma.org.uk**



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