MyelomaUK

Thalidomide

AL amyloidosis Treatment Guide

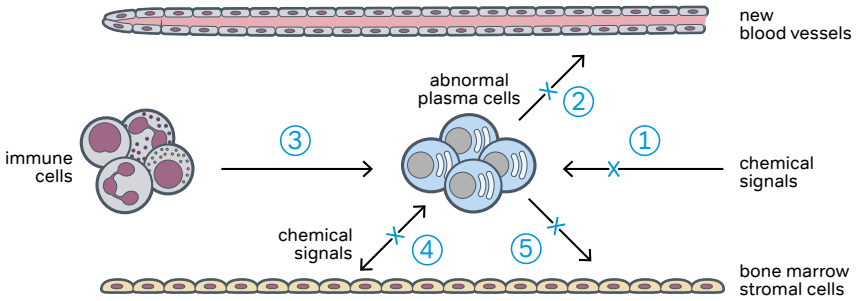
What is thalidomide?

Thalidomide is an immunomodulatory drug (IMiD) used in the treatment of AL amyloidosis.

How does it work?

Thalidomide 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 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 not involved in blood cell production)



Different ways thalidomide works to kill abnormal plasma cells

How is thalidomide given?



Thalidomide is a capsule which is taken by mouth (orally).



Thalidomide is usally given in combination with other AL amyloidosis treatments.



Thalidomide is usually given daily over a 6 week cycle, for up to 12 cycles. Individual treatment plans vary. Your healthcare team will discuss your specific plan.

Possible side effects

Thalidomide 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 980 3332 **AskTheNurse@myeloma.org.uk**

myeloma.org.uk

Risk of infection

Thalidomide 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 see the Coping with symptoms and side effects chapter of the **AL amyloidosis: Your Essential Guide** from Myeloma UK.

Skin rash

Thalidomide 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.

Blood clots

Thalidomide can cause blood clots to form in the veins. These are most often in the legs, known as deep vein thrombosis (DVT). Occasionally clots 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 and 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.

Heart problems

Thalidomide can cause or worsen heart problems . You will be closely monitored for this if you are being treated with thalidomide. Tell your healthcare team if you start to notice your heartbeat more or notice any changes in your heartbeat.

> Call 999 if you experience any severe chest pain or tightness.

Anaemia and bleeding

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

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



Peripheral neuropathy

Thalidomide 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, or nerve painkillers such as gabapentin and pregabalin. Symptoms generally improve or disappear after the dose of thalidomide is reduced or stopped.



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



Constipation

Thalidomide can cause 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 this symptom. You may also be prescribed laxatives to help you go to the toilet.



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



Drowsiness

Thalidomide may cause you to feel drowsy. Drowsiness usually improves after the first few doses. If severe tiredness occurs, then your healthcare team may reduce your dose.

Tiredness during the day can be reduced by taking thalidomide before going to bed. It will vary from patient to patient but generally taking thalidomide 2 to 3 hours before bedtime may help reduce drowsiness.



Do not drive or use any tools or heavy machinery if you experience severe tiredness. Ask friends or family to help you if you need.

Important information about thalidomide



You must not take thalidomide during pregnancy as it will 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 thalidomide as it is not known if the thalidomide 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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MyelomaUK

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

Trusted Information Creator
Patient Information Forum

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We appreciate your feedback

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

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