

Thalidomide

AL amyloidosis
Treatment Guide

What is thalidomide?

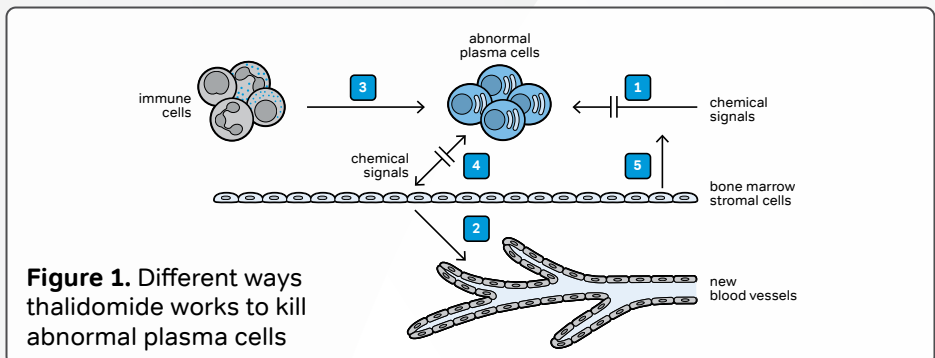
Thalidomide is an immunomodulatory drug (IMiD) used in the treatment of AL amyloidosis.

How does it work?

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

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. Boosting the immune response against the abnormal plasma cells
4. Altering 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 in the bone marrow that are not involved in blood cell production)



How is thalidomide given?



Thalidomide is a capsule which is taken orally (by mouth). The capsules should be swallowed whole with water.



Thalidomide is usually given in combination with other anti-AL amyloidosis drugs.



Individual treatment plans may vary. Your exact dose of thalidomide and your length of treatment will be discussed with you by your healthcare team. This is because your treatment will depend on some factors such as what treatment combination you are receiving.

Other information about thalidomide



You must not take thalidomide during pregnancy, as it can cause severe harm or death to an unborn baby. This means you must use effective methods of contraception 4 weeks before this treatment, during and for at least 4 weeks after treatment has finished if you could become pregnant, or during and for at least 7 days after treatment if your partner is, or could become, pregnant. You will be required to adhere to a strict pregnancy prevention programme.



You should not breastfeed whilst taking thalidomide. If you are already breastfeeding, you should stop before beginning thalidomide treatment. This is because thalidomide may pass to the milk.

Possible side effects

Thalidomide 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 as soon as possible 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 which is included in the pack with the treatment. If you do not have this, ask your healthcare team for it.



Skin rashes

Thalidomide can sometimes cause a rash which may begin on the trunk (body) and spread to the arms and legs. This can occur within the first 2–6 weeks of starting treatment but usually clears up by itself. Sometimes the rash may need treatment with antihistamines and/or steroid creams.

Rarely, some rashes are a sign of a potentially more serious reaction to thalidomide causing the skin to turn red, blister and peel (Stevens-Johnson syndrome or toxic epidermal necrolysis). If this happens, you should tell your doctor immediately and thalidomide should be stopped straight away.



Birth defects

It is important that anyone taking thalidomide is aware of the possible birth defects it can cause. This risk to an unborn baby can be passed on from either parent, if they are taking thalidomide. Every effort is therefore taken to ensure that this does not occur and thalidomide is stored, prescribed, handled and taken safely and a pregnancy prevention programme is in place.



Drowsiness

Drowsiness usually lessens with continued use at the same dose but you may need a dose reduction if severe drowsiness occurs.

Sleepiness during the day can be minimised by taking thalidomide in the evening before going to bed. It will vary from patient to patient but generally, thalidomide is best taken 2–3 hours before bedtime.



Constipation

Constipation can be a problem, particularly with higher doses of thalidomide. It can be prevented or minimised with a good fluid intake (staying within your daily allowance) and a high fibre diet with plenty of fresh fruit and vegetables. It may be necessary to use laxatives as prescribed by your doctor.



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. It is particularly problematic for patients whose AL amyloidosis is affecting their peripheral nerves, and for those taking other drugs that can cause peripheral neuropathy, such as bortezomib (Velcade®).

For most patients, symptoms will improve or disappear after the dose and/or frequency of administration of thalidomide is reduced. However, in some cases, thalidomide 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, cold/heat packs and specific nerve painkilling drugs such as pregabalin and gabapentin.



Heart problems

Thalidomide can cause or worsen heart problems in AL amyloidosis patients. You will be closely monitored for this if you are being treated with thalidomide.



Blood clots

Thalidomide can cause the formation of blood clots in veins, which is called a venous thromboembolic event (VTE). This most often occurs in the legs, where it is known as deep vein thrombosis (DVT). More rarely, clots can travel to the lungs causing a pulmonary embolism (PE). This can be a serious complication of thalidomide. You may be prescribed an anticoagulant (anti-clotting) drug such as aspirin, low-dose heparin or warfarin either to prevent or to treat VTE.

It is very important that you tell your doctor or nurse if you notice any red, swollen or painful areas in your body, particularly in your calf, and the area is warm to touch. Any new episodes of shortness of breath and/or chest pains must be reported immediately.



Low blood counts

Thalidomide 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.



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

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

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