

# Diarrhoea

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## AL amyloidosis symptoms and complications Infosheet

**This Infosheet explains what diarrhoea is, what causes it in AL amyloidosis patients, what the symptoms of it are, how it is treated and some tips for self-management.**

### What is diarrhoea?

Diarrhoea is the passing of loose or watery stools (poo) more than three times a day.

It can be acute (lasting only for a short time) or chronic (persisting for long periods, usually more than two weeks).

If you have diarrhoea it is important to deal with it straight away, as excessive loss of water through your stools can lead to dehydration, which can be serious. Any change

in your regular bowel pattern lasting longer than a few days should be reported to your doctor or nurse.

Diarrhoea can have a significant impact on your quality of life. It can make you anxious about leaving your home and stop you feeling able to perform your usual daily routine.

Though you may feel uncomfortable or embarrassed talking about diarrhoea, try to remember that your doctor and nurse are used to talking about it and they are there

to help prevent and manage any side effects of AL amyloidosis and its treatment.

## What are the symptoms of diarrhoea?

The symptoms of diarrhoea include:

- More than three loose or watery bowel movements per day
- Cramping stomach pains
- An urgent need to go to the toilet
- Nausea or vomiting
- Fever
- Headache
- Loss of appetite

## What are the causes of diarrhoea in AL amyloidosis?

It is important to know what has caused your diarrhoea, as this will help both you and your doctor or nurse treat it effectively and prevent it from recurring. There are several reasons why you may have diarrhoea.

### AL amyloidosis

Autonomic neuropathy, which is damage to the nerves that control the functions of internal organs, is a common complication and cause of diarrhoea in AL amyloidosis. If amyloid deposits damage the nerves controlling your bowels, the

motility (movement) of the bowels may be disrupted which can cause diarrhoea.

### Side effects of AL amyloidosis treatment

Some AL amyloidosis treatments can cause diarrhoea. These include drugs such as bortezomib (Velcade®) and panobinostat (Farydak®). They usually cause acute onset diarrhoea which can start very soon after treatment begins.

Other treatments that belong to a class of drugs known as immunomodulatory drugs (IMiDS) such as lenalidomide (Revlimid®) and pomalidomide (Imnovid®) can cause late onset diarrhoea which may start many months after treatment begins. Lenalidomide in particular has been linked to a condition called Bile Acid Malabsorption (BAM). This is where patients do not absorb bile acids properly from their intestine. This has been identified as the cause of diarrhoea in some patients taking lenalidomide.

### Infection

Certain bacterial and viral infections cause diarrhoea. These infections are often contagious, so if you have been around others who have had stomach bugs it is not uncommon to pick an infection up too.

It is important to tell your doctor if you suspect your diarrhoea is caused by an infection. Other symptoms of an infection include nausea, vomiting, abdominal cramps and pain, a high temperature and loss of appetite.

### **Other illnesses and conditions and their treatment**

Other illness and conditions can cause diarrhoea, for example inflammatory bowel syndrome (IBS) or coeliac disease.

Treatments for other illnesses or conditions may also cause diarrhoea. For example, antibiotics are known to cause diarrhoea by disrupting the balance of bacteria in your bowels.

You can check whether any other treatments you are taking can cause diarrhoea by seeing if diarrhoea is listed as a possible side effect on the patient information leaflet (PIL) included in the drug pack. You should also make your doctor and nurse aware of any treatments you are taking for any other illnesses and/or conditions.

### **Constipation and laxatives**

Excessively watery or runny diarrhoea may occur as a result of constipation, as your bowel is blocked with hard stools so only

loose stools can make their way past the blockage. Laxatives used to treat constipation may also cause diarrhoea.

### **Stress, anxiety and depression**

Emotional disturbances such as periods of stress or anxiety may cause diarrhoea. The chemicals produced by your body when you are stressed can speed up the digestive process so less fluid is absorbed in the bowels and this results in diarrhoea.

### **How is diarrhoea treated?**

Before prescribing any treatment your doctor will assess the cause of your diarrhoea to determine what treatment is right for you.

If your diarrhoea is caused by your AL amyloidosis, treatment to stop the production of the abnormal amyloid protein may help. If the production of amyloid can be stopped, amyloid deposits may be broken down and this may improve bowel function.

If your diarrhoea is a side effect of AL amyloidosis treatment, your doctor may adjust your treatment schedule, reduce the dose or temporarily stop treatment until it improves. If the diarrhoea does not improve after these adjustments, it may be necessary to stop the treatment and find an alternative instead.

Often other causes of diarrhoea, like a mild stomach upset, can resolve themselves and so treatment for diarrhoea may not be necessary. However, any complications that have arisen, such as dehydration, will need to be treated.

### Treatment for BAM

If your diarrhoea is caused by BAM, you will need to modify your diet to reduce your fat intake. Your doctor will usually also prescribe a treatment to help, for example colesevelam.

### Prescribed treatments

If your doctor decides that you need treatment for your diarrhoea then you may be prescribed a treatment to slow down the motility (movement) of your bowel. This includes those listed in the table below.

Type	Examples	Side effects
<b>Antimotility drugs</b>	<ul style="list-style-type: none"> <li>● Loperamide (Norimode<sup>®</sup>, Imodium<sup>®</sup>)</li> </ul>	<ul style="list-style-type: none"> <li>● Abdominal cramps</li> <li>● Dizziness</li> <li>● Drowsiness</li> <li>● Skin reactions</li> </ul>
<b>Opioid pain killers</b>	<ul style="list-style-type: none"> <li>● Codeine phosphate</li> <li>● Morphine</li> </ul>	<ul style="list-style-type: none"> <li>● Abdominal pain</li> </ul>
<b>Antispasmodic drugs</b>	<ul style="list-style-type: none"> <li>● Dicycloverine</li> <li>● Hyoscine (Buscopan<sup>®</sup>)</li> <li>● Atropine</li> </ul>	<ul style="list-style-type: none"> <li>● Bloating</li> <li>● Heartburn</li> <li>● Constipation</li> <li>● Dry mouth</li> </ul>

## Over-the-counter treatments

There are treatments for diarrhoea available over-the-counter, for example Norimode<sup>®</sup>, Imodium<sup>®</sup> and Buscopan<sup>®</sup>, many of which have the same active ingredients as prescribed treatments. It is advisable to check with your doctor or nurse before you take any over-the-counter treatments and do not take loperamide for more than two days for treatment of diarrhoea without checking with your doctor or nurse.

If your diarrhoea is caused by an infection, it is not advisable to use over-the-counter treatments as these may ease symptoms without dealing with the underlying infection. Your doctor will be able to determine the best course of treatment for the infection and diarrhoea.

Pain killers, like paracetamol, can be taken to help any discomfort or pain experienced. However, AL amyloidosis patients should not take non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen as NSAIDs can worsen kidney damage which is a common complication in AL amyloidosis.

## Treating complications of diarrhoea

### Dehydration

Rehydration salts (for example Dioralyte<sup>™</sup> and Electrolade<sup>®</sup>) provide a mixture of salts needed by the body to replace those that have been lost in your stools. Rehydration salts are available over-the-counter as a powder in sachets or in tablet form and are dissolved in water to drink.

### Anal discomfort

Frequent diarrhoea can cause discomfort to the skin around your anus and it may become sore. There are creams that can help to soothe the area and prevent the skin from breaking (which can happen in severe cases of diarrhoea). Ask your doctor or nurse about soothing creams.

Frequent wiping can make the skin around your anus irritated, so use high quality, soft toilet tissue. You can also try using moist toilet tissue to wipe the area or damp cotton wool, both of which can be less aggravating than dry toilet tissue. Avoid any wipes which contain alcohol.

It is important to keep the area clean and dry as much as possible. Avoid using soaps which can irritate

the skin and instead try warm (not hot) water baths, a bidet or a sitz bath and allow the skin to air dry or gently dab the area dry.

Sitting down for long periods of time may worsen any soreness so try to avoid prolonged sitting and use cushions to soften the seat.

## Some tips for self-management

There are ways to help manage diarrhoea at home:

- Keep hydrated by drinking clear fluids such as water, diluted juice or soup/broth. Take frequent small sips rather than drinking large amounts of fluid in one go
- Avoid alcohol and caffeine which can make you more dehydrated
- Use rehydration salts
- Try to keep eating small, frequent meals made from light foods – soup/broth, potatoes, bananas, bread, pasta or rice. Avoid highly spiced or fatty foods that might upset your stomach and eat your meals slowly
- Some bacteria found in live yoghurt or live-yoghurt drinks may help to ease diarrhoea caused by antibiotics. Antibiotics can kill off the healthy bacteria normally found in the bowel, but the bacteria found in live yoghurt may replace them. However, you should avoid live yoghurt if your white cell count is low. If you are unsure whether this affects you, check with your doctor or nurse
- Plan ahead and find out where the nearest toilet is if you need to go out, so if you need to get to a toilet quickly you know there is one nearby
- Be prepared and keep a change of clothes, spare toilet roll and a bottle of water in your car or a bag if you are out of the house
- Wear clothes that are easy to pull on and off, that are comfortable and not too tight, such as trousers with elasticated waists
- Wear cotton underwear
- Always wash your hands with soap after going to the toilet. If your hands are getting dry from the soap, use a hand moisturiser after washing

If you can't get to the toilet easily because you have difficulty with mobility or it is located in another area of the house (e.g. upstairs), you might find a commode

helpful. These can be positioned around the house and can help prevent accidents. Other toilet and bathroom aids are available which can help you access the toilet more easily. It is not uncommon to have an accident if you are experiencing diarrhoea.

## Summary

Diarrhoea, if left untreated, can be serious and it can have a significant impact on your quality of life and health. It is a common side effect of treatment for AL amyloidosis but there are ways to manage and treat it. It is important to always be honest with your doctor or nurse about the impact that diarrhoea is having on your life and report it as early as possible – they are there to help you.

## About this Infosheet

The information in this Infosheet is not meant to replace the advice of your medical team. They are the people to ask if you have questions about your individual situation.

For a list of references used to develop our resources, visit [myeloma.org.uk/references](https://myeloma.org.uk/references)

We value your feedback about our patient information.

For a short online survey go to

[myeloma.org.uk/pifeedback](https://myeloma.org.uk/pifeedback)  
or email comments to  
[myelomauk@myeloma.org.uk](mailto:myelomauk@myeloma.org.uk)

## Other information available from Myeloma UK

Myeloma UK has a range of publications available covering all aspects of AL amyloidosis, its treatment and management. Download them from [myeloma.org.uk/publications](https://myeloma.org.uk/publications)

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call the Myeloma UK Infoline on [0800 980 3332](tel:08009803332) or [1800 937 773](tel:1800937773) from Ireland. The Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK and Ireland.

Information and support about AL amyloidosis is also available around the clock at [myeloma.org.uk/amyloidosis](https://myeloma.org.uk/amyloidosis)



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Registered Charity No: SC026116



Published by:	Myeloma UK
Publication date:	May 2009
Last updated:	April 2019
Review date:	April 2022

**Myeloma Awareness Week • 21–27 June**