Diarrhoea

Symptoms and complications of AL amyloidosis 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 healthcare team.

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 healthcare team are used to talking about it and 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
- Stomach cramping or pain
- 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 healthcare team treat it effectively and prevent it from recurring. There are several reasons why you may have diarrhoea.

AL amyloidosis

AL amyloidosis itself can cause autonomic neuropathy, which is damage to the nerves that control the functions of internal organs. If amyloid deposits damage the nerves controlling your bowels, the motility (movement) of the bowels may be disrupted which can cause diarrhoea.

For more information about autonomic neuropathy see the **AL autonomic neuropathy infosheet** from Myeloma UK

Side effects of 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.

Late onset diarrhoea, which may start many months after treatment begins, can occur with a class of of drugs called immunomodulatory drugs (IMiDS). This includes lenalidomide (Revlimid®) and pomalidomide (Imnovid®).

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.

For more information about drugs used in AL amyloidosis treatment see the **AL amyloidosis Treatment Guides** from Myeloma UK

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. This is especially since AL amyloidosis patients have a higher risk of developing infections.

Other symptoms of an infection include nausea, vomiting, abdominal cramps and pain, a high temperature and loss of appetite.

It is important to tell your doctor if you suspect your diarrhoea is caused by an infection.

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 having 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 healthcare team 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. This is because 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

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.

Type	Examples	Side effects
Antimotility drugs	Loperamide (Norimode®, Imodium®)	Abdominal cramps, dizziness, drowsiness, skin reactions
Opioid painkillers	Codeine phosphate, Morphine	Abdominal pain, nausea and vomiting, feeling sleepy
Antispasmodic drugs	Dicycloverine, Hyoscine (Buscopan®), Atropine	Bloating, heartburn, constipation, dry mouth

Table 1. Types of treatment for diarrhoea

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 you need treatment for your diarrhoea then you may be prescribed a treatment to slow down the motility (movement) of your bowel. Examples of which are listed in Table 1.

Over-the-counter treatments

There are treatments for diarrhoea available over-the-counter, for example Norimode®, Imodium® and Buscopan®, many of which have the same active ingredients as prescribed treatments.

It is advisable to check with your healthcare team 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.

Painkillers, 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.

For more information see the **AL amyloidosis and the kidney Infosheet**

Treating complications of diarrhoea

Diarrhoea can result in complications including dehydration and anal discomfort. It is important to manage these as they impact on daily life or have more serious complications if left untreated.

Dehydration

Rehydration salts (for example Dioralyte™ and Electrolade®) 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 the anus irritated. Here are some tips to help:

- Use high quality, soft toilet tissue
- Try using moist toilet tissue or damp cotton wool to wipe the area as both can be less aggravating than dry toilet tissue
- Avoid any wipes that 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. However, make sure to stay within your daily fluid intake limit. Ask your healthcare team to find out how much you should be drinking
- 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 take a change of clothes, spare toilet roll, a bottle of water and a plastic bag with you when you go out
- 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.

Key points

- Diarrhoea is the passing of loose or watery stools more than three times a day
- Diarrhoea can be acute (short term) or chronic (long term)
- Diarrhoea can happen as a result of your AL amyloidosis itself, the side effect of its treatment and complications of your AL amyloidosis such as infection, stress, anxiety or depression
- Prescribed drugs can be used to treat diarrhoea
- If your diarrhoea is caused by your AL amyloidosis treatment, there may be a temporary change in your treatment until your diarrhoea improves
- There are a number of self-management tips to help manage diarrhoea

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your healthcare 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

We value your feedback about our patient information.
For a short online survey go to myeloma.org.uk/pifeedback or email comments to patientinfo@myeloma.org.uk

Other information available from Myeloma UK

Myeloma UK has a range of information booklets available covering all aspects of AL amyloidosis, its treatment and management. Download or order them from myeloma.org.uk/publications

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call our Myeloma UK Infoline on 0800 980 3332 or 1800 937 773 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

Notes

Notes

MyelomaUK

We're here for everything a diagnosis AL amyloidosis brings

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

Call the Myeloma UK Infoline on

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