

Diet and nutrition in AL amyloidosis

This Infosheet explains what a well-balanced diet is, what can make it difficult to maintain when you are an AL amyloidosis patient, when a special diet might be necessary and tips for eating a well-balanced diet.

What should I be eating?

AL amyloidosis patients often have queries about diet and nutrition – about what types of foods are best to eat or avoid, or if there are any special diets they should follow. Despite the significant interest in alternative diets, none have been scientifically studied so their effects are unknown and

unproven. This means there is a lack of evidence to support any alternative or specific diets in AL amyloidosis.

Dietary, salt or fluid restrictions may be necessary due to heart or kidney problems in some patients which your doctor will advise you of (see page 3). Otherwise, AL amyloidosis patients should follow the same basic principles

of healthy eating that apply to us all. Eating a healthy and balanced diet will help to maintain your muscles and strength, increase your energy levels and may help recovery after treatment. A balanced diet is also rich in essential vitamins and minerals and can help the immune system to function more effectively.

A healthy balanced diet should include:

- **Carbohydrates** – are a good source of energy. Foods that contain carbohydrates include: bread, pasta, cereals and rice
- **Protein** – helps build new cells and replace old ones. Foods that contain protein include: milk, yogurt, cheese, nuts, meat and fish
- **Fats** – are essential for vitamin absorption, body processes and a source of slow-release energy. Not all fats are the same. A healthy diet consists of more fat from fish, nuts, seeds and olive oil (mono and polyunsaturated fats) than from meat, cheese, other dairy foods, cakes, biscuits and chocolate (saturated fats)
- **Fibre** – maintains a healthy digestive system. Foods that are high in fibre include: bran, wholewheat bread and cereals,

as well as most fruit and vegetables. It is recommended that you eat five portions of fruit and vegetables per day

- **Vitamins and minerals** – are essential for many body processes, including the body's ability to resist infection and maintain healthy nerves and tissues. Brightly coloured fruit and vegetables such as broccoli, carrots, oranges, peppers and tomatoes are rich sources of vitamins and minerals

Should I take any vitamins or dietary supplements?

There are no specific recommendations about vitamin supplements for AL amyloidosis patients. In most cases a well-balanced diet with plenty of fruit and vegetables should provide an adequate amount of vitamins and nutrients to maintain general health.

Some people do take a general vitamin supplement if they feel they may not be getting enough vitamins and nutrients from their diet. It is advisable to avoid taking Vitamin C in large doses (i.e. more than 500mg a day) as this can increase the acidity of urine which can damage the kidneys.

Vitamin and mineral supplements such as magnesium, Vitamin B complex (including vitamin B12), folic acid and alpha-lipoic acid are sometimes considered helpful in managing the symptoms of peripheral neuropathy.

If you do decide to take any vitamins or dietary supplements then it is very important to let your doctor know, as some of them can inhibit the actions of drugs used to treat AL amyloidosis. For example, research has shown that Vitamin C and green tea can block the actions of Velcade® (bortezomib).

Fluid overload

One of the most common and serious side-effects of AL amyloidosis patients is fluid overload. This happens when your kidneys are unable to pass enough urine and fluid collects in your body. This can happen if your AL amyloidosis has affected your heart or kidneys. Fluid overload causes a variety of symptoms including:

- Swelling in the feet, ankles or lower legs (oedema)
- Swelling in the abdomen (ascites)
- Rapid increase in body weight due to fluid build-up

- Tiredness
- Difficulty breathing
- Coughing and/or trouble breathing at night (especially when lying flat)

Fluid overload can be avoided by careful attention to the three Ds:

- Diet
- Diuretics (something which increases passing urine such as caffeinated drinks)
- Daily weight checks

Diet

Fluid overload happens when you are taking in more fluid than your kidneys can remove. To prevent this, you should keep your fluid intake steady, try to keep it to no more than 1.5 litres (about 3 pints) a day. This includes all fluids – water, tea, coffee, soft drinks and alcohol. It is wise to limit your alcohol intake but you do not have to give up alcoholic drinks completely

You should also keep the amount of salt you have in your food to a minimum. This does not only mean salt which you add in cooking or at the table. A lot of ready-made foods have large amounts of salt, so you should check ingredients labels thoroughly.

Foods which have a particularly high salt content include:

- Crisps and snacks
- Bacon
- Canned meats
- Sausages
- Canned soups
- Smoked fish

It may be helpful to talk to a dietician to get detailed advice on a healthy diet.

Diuretics

Even with careful diet control, you may still have fluid overload. This can be treated with diuretics, often called water tablets, which are drugs that help your kidneys to pass more fluid. This helps your body to get rid of salt as well as excess fluid. Diuretics can help to ease ankle swelling and breathlessness caused by fluid overload. Diuretics are only effective if you continue to control your salt and fluid intake.

Daily weighing

It is important to recognise and treat fluid overload early. Usually, one of the first signs of excessive fluid is an increase in weight. If your doctor thinks you may develop fluid overload, you may be asked to weigh yourself daily.

You should do this at the same time each day. It is best to do this as soon as you have passed urine in the morning and just wearing your underwear. It is usual for your weight to vary a little from day to day. If your weight increases several days in a row, even slightly, you should tell your doctor or specialist nurse. They may wish to start you on diuretics or adjust your diuretic treatment.

How can AL amyloidosis affect your diet?

You may find that at certain times your appetite and dietary requirements will vary and that eating and drinking may be difficult. AL amyloidosis and its treatment can cause several complications that can make maintaining a balanced diet difficult.

They can include:

- Loss of appetite
- Taste changes - e.g. a slightly metallic taste after chemotherapy
- Sore and/or dry mouth
- Swelling of the tongue - macroglossia
- Nausea and vomiting
- Tiredness or fatigue

- Diarrhoea or constipation
- Anxiety and depression
- Increased appetite and weight gain – due to steroid use

Tips to maintain a healthy diet

Sometimes, particularly if you are receiving treatment and are feeling poorly, it may be difficult to ensure that you are eating and drinking enough and maintaining a healthy balanced diet. At these times it is important to eat what you can and try not to worry too much.

Tips that may help include:

- If your appetite is poor try eating small amounts regularly throughout the day instead of trying to eat ‘three square meals’
- A sore mouth or taste changes can put you off eating – ensure that you are using any treatments for your mouth as prescribed by your doctor to clean and maintain the health of your mouth. Ice lollies, fruit juice and soft drinks can help to keep your mouth feeling fresh
- Gentle exercise (e.g. walking) or a small alcoholic beverage may stimulate your appetite
- If you are suffering from fatigue try to cook larger portions on days you have more energy and freeze for another day. Ask other people to help you with cooking and shopping or make use of online shopping and food delivery
- Even if you are unable to face food it is important to maintain a healthy fluid intake

Is a special diet ever necessary?

As stated above, there is no evidence to support long-term diet recommendations for AL amyloidosis patients that differ from the general population. However, there could be periods when your diet may need to change. For example, you may need to alter your diet if your white cell count is low (your doctor may say that you are ‘neutropenic’) because you are at increased risk of picking up infection, and some foods may increase your risk of infection.

To reduce this risk when your white cell count is low (e.g. after high-dose therapy and stem cell transplantation) a ‘clean diet’ is usually recommended. This will last until your white cell count is normal again. A clean diet will be explained to you by your doctor or nurse and they should be able

to provide you with a list of the foods that should be avoided during this time.

Essentially, a clean diet eliminates certain 'high-risk' foods from your regular diet, including:

- Raw or undercooked eggs
- Soft/blue cheeses
- Live yoghurts, e.g. probiotic yoghurts
- Meringue
- Shellfish
- Pâté
- Mayonnaise
- Unpasteurised dairy products e.g. some soft ice creams

Remember – it is important to handle and store food correctly and use it by the 'use by' date.

In summary

Many of the factors that influence your desire to eat can be linked to treatment. Fatigue, nausea/vomiting and changes in taste may often be due to side-effects

of the drugs used to treat AL amyloidosis. In order to prevent this becoming a problem you should try to understand the potential causes of the disruption and to adopt some of the self-management strategies outlined in this Infosheet.

As part of ongoing research into AL amyloidosis drug development, drugs are being produced that cause fewer side-effects. It is therefore hoped that future drugs will have less of an impact on patients' diet and desire to eat.

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. All Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

Other information available from Myeloma UK

Myeloma UK provides a wide range of information covering all aspects of the treatment and management of AL amyloidosis.

For a full publication list visit www.myeloma.org.uk/publications

To order your free copies contact Myeloma UK. Our information is also available to download at www.myeloma.org.uk

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

Information and support about AL amyloidosis is also available around the clock at www.myeloma.org.uk/amyloidosis

Published by: Myeloma UK
Publication date: May 2009
Last updated: August 2016
Review date: August 2018

Myeloma UK 22 Logie Mill, Beaverbank Business Park, Edinburgh EH7 4HG
T: 0131 557 3332 **E: myelomauk@myeloma.org.uk** Charity No: SC 026116

Myeloma Infoline: 0800 980 3332 or
1800 937 773 from Ireland
www.myeloma.org.uk

Myeloma Awareness Week 21 - 28 June