

Diet and nutrition

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 special diets, there has been no rigorous scientific study of them in myeloma so their effects are unknown and unproven. Because of this lack of scientific evidence, no

alternative diets are recommended for AL amyloidosis patients.

Dietary, salt or fluid restrictions may be necessary due to heart or kidney problems in some patients (see page 3). Otherwise, AL amyloidosis patients should follow the same basic principles of healthy eating that apply to everyone. 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** – a good source of energy. You should aim to have more complex carbohydrates such as bread, pasta, cereals and rice, than simple carbohydrates, like sugar

- **Protein** – helps build new cells and replace old ones. Foods that contain protein include dairy products, nuts, beans, pulses, meat and fish

- **Fats** – essential for vitamin absorption, body processes and a source of slow-release energy. Not all fats are the same, however. A healthy diet consists of more fat from fish, nuts, seeds and olive oil (mono and polyunsaturated fats) than from meat, cheese, other dairy products, 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** – 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 enough 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, Vitamin C and green tea can block the actions of bortezomib (Velcade®) so you must not take these supplements while being treated with 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 '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.

Summary

AL amyloidosis patients should try to maintain a health, well-balanced diet. You may need to reduce your risk of fluid overload by monitoring your diet, taking diuretics and weighing yourself daily. Treatment for AL amyloidosis can interfere with your appetite but it is important to try to keep eating.

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 www.myeloma.org.uk/references

To provide feedback about this publication, email myelomauk@myeloma.org.uk

Other information available from Myeloma UK

Myeloma UK has a range of publications covering all aspects of AL amyloidosis, its treatment and management. To download any of these publications go to www.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** 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 www.myeloma.org.uk/amyloidosis

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