

Fatigue

Symptoms and complications of AL amyloidosis Infosheet

This Infosheet explains what fatigue is and what causes it in AL amyloidosis. It also explains how fatigue is treated and some tips for self management.

It can be challenging to read a lot while feeling fatigued. You do not have to read the sections in order. You can choose to pick out the parts you find most useful, at the time that is best for you.

What is fatigue?

Fatigue is a feeling of being exceptionally tired, lethargic or exhausted all or most of the time.

Over time, fatigue can have a negative impact on your physical, emotional and psychological wellbeing.

There are different types of fatigue. You can have more than one kind of fatigue at once. These include:

- Physical fatigue, where you have reduced strength and energy
- Mental fatigue, where you have reduced memory and concentration

- Emotional fatigue, where you feel overwhelmed or emotionally exhausted

Fatigue is a common complication of AL amyloidosis. Living with fatigue can be challenging.

What are the symptoms of fatigue?

Fatigue can affect you in many different ways. The symptoms of fatigue can vary from person to person. It may be mild and have little impact on your day-to-day activities. However, if it is more severe it can reduce quality of life.

Symptoms include:

Physical symptoms

- Reduced energy levels
- Shortness of breath after minimal activity
- Having to rest for longer periods of time
- Dizziness
- Feeling weak or lethargic
- Loss of, or reduction in, sex drive

Emotional symptoms

- Feeling frustrated or overwhelmed
- Mood swings or irritability

Mental symptoms

- Reduced concentration
- Poor memory
- Difficulty sleeping, or sleeping more than usual

Many people find that fatigue can impact close relationships. Allowing people close to you, including friends and family, to understand your symptoms is a good way to start supporting your relationships.

What are the causes of fatigue in AL amyloidosis?

Fatigue is often caused by many contributing factors. This makes it hard to define an exact cause. Some factors are described in the following sections.

Anaemia

Anaemia occurs when there is a decrease in the amount of haemoglobin (a protein carrying oxygen) in the blood, or a decrease in the normal number of red blood cells. This means less oxygen reaches cells, which can leave you feeling tired, breathless and light-headed. Anaemia usually results as a side effect of treatment for AL amyloidosis, such as chemotherapy.

AL amyloidosis treatments

Fatigue is a common side effect of many of the treatments for AL amyloidosis, including chemotherapy, thalidomide, bortezomib (Velcade®), and lenalidomide (Revlimid®). Fatigue can often get worse during a course of treatment. Talk to your healthcare team if you think your treatment is affecting your fatigue. They can discuss ways to manage it and explore your treatment options.

Pain

Living with pain takes up a lot of energy and can leave you feeling tired. This is especially true if your pain is ongoing or not well controlled. Speak to your healthcare team if your current pain relief medicines are not working. They may be able to change the dosage or type of medicine prescribed.

Poor diet

Nutrition is important for general wellbeing. A poor diet can have a significant impact on energy levels. If you are not eating a healthy and balanced diet, you might not be getting the energy you need from food. This can contribute to your fatigue. AL amyloidosis and its treatment can affect your appetite. You may be unable to eat as much as you used to.



For more information see the [Diet and nutrition \(AL amyloidosis\) Infosheet](#) from Myeloma UK

Nausea, vomiting and diarrhoea

You may experience these side effects during treatment. Ongoing nausea, vomiting and diarrhoea can make you feel very lethargic.



For more information see the [nausea and vomiting](#) section (page 37) of the [AL amyloidosis Essential Guide](#) and the [Diarrhoea \(AL amyloidosis\) Infosheet](#) from Myeloma UK

Anxiety and depression

Anxiety and depression can contribute to feeling fatigued. These conditions can cause prolonged stress and irregular sleeping patterns. This can further contribute to fatigue levels. You might feel anxious or depressed for a number of reasons. Adjusting to an AL amyloidosis diagnosis can have a huge emotional impact, leaving you feeling exhausted.

What are the treatments for fatigue?

If fatigue is affecting your ability to carry out day-to-day activities it is important to speak to your

healthcare team. They will look for any underlying medical cause for the fatigue and treat it appropriately.

Treating anaemia

Fatigue due to anaemia may be treated with a blood transfusion. This increases the number of red blood cells which helps to raise your haemoglobin level up quickly. However, this increase is usually not maintained and you may need regular transfusions.

Anaemia can also be treated with erythropoietin (EPO) injections. This is most useful for treating chronic anaemia. This is a synthetic version of erythropoietin, a hormone that your kidneys produce naturally to stimulate the production of red blood cells.

Exercise

Research shows that regular, gentle exercise is very effective in reducing fatigue. Regular exercise such as walking or swimming may help to increase energy levels. You can ask your healthcare team to refer you to a physiotherapist, who can recommend some suitable exercises for you. Remember though that you may be limited in

what you can do, depending on how your organs are affected by AL amyloidosis.

Complementary therapies

Some complementary therapies, such as aromatherapy, reflexology and relaxation techniques are useful in reducing fatigue. Yoga and tai-chi, which combine gentle exercise with deep breathing, may help to boost energy levels. Talk to your healthcare team before starting a complementary therapy, to ensure that it is suitable for you.

Finishing treatments

When you start treatment for your AL amyloidosis you may feel more fatigued. If your AL amyloidosis is stable after treatment, you may notice an improvement in your fatigue. However, some people find that their fatigue continues for several weeks or months after treatment has finished.

Tips for self-management of fatigue

You may need to make adjustments to your life with fatigue. You may not be able to do everything you used to do. However, there are a number of ways you can help reduce the impact your fatigue may have on your life.

These are some tips that may help you:

- Make sure your healthcare team is aware fatigue is a problem for you and how it affects your day-to-day life
- Try to eat a well-balanced diet with foods rich in iron and vitamins
- Ask to be referred to a dietitian if your fatigue or AL amyloidosis treatment are affecting your appetite
- Cook batches of food on days when you have more energy, and freeze some for days when you have more fatigue. You can sit down to prepare meals to save your energy
- Try to maintain regular gentle exercise
- Keep a diary to help you identify the times you feel most fatigued, and try to schedule rest at these times
- Ask friends or family to help you with daily tasks
- Pace yourself – notice when you usually have more energy and plan to do more strenuous tasks at these times. Take short naps and rests, but balance them with some activity or exercise
- If you have a job, talk to your employer to discuss any possible changes in your work that may help. These might include reduced hours, extra breaks during the day, a quiet place to rest at work, or change of role or workload
- Talk about how you feel with family and friends. Consider counselling if you think this may help
- Ask to be referred to an occupational therapist for more support in managing your fatigue
- Use anxiety and stress management techniques to help you feel more relaxed
- Develop and maintain a regular sleep pattern by trying to go to bed and get up at the same time every day
- Do not drive if you feel very tired. If possible, ask friends or family to drive you. You may also be able to arrange hospital transport for appointments if you cannot drive
- Seek support from your nurse or phone the Myeloma UK Infoline on **0800 980 3332**

Key points

- Fatigue is a very common side effect in AL amyloidosis and its treatment
- Fatigue is a feeling of being exceptionally tired, which is not caused by activity or exertion and is not fully relieved by rest or sleep
- Fatigue can affect you in many different ways, including reduced energy levels, reduced concentration and dizziness
- The severity and symptoms of fatigue range from patient to patient
- Your healthcare team can assess you to determine any underlying medical cause for your fatigue to plan for appropriate treatment
- It is important to understand how fatigue affects you and adopt self-management strategies to lessen the impact it can have

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/pifedback 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 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 myeloma.org.uk/amyloidosis



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We're here for everything
a diagnosis of AL amyloidosis brings

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

Call the Myeloma UK Infoline on

 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk**



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