

AL amyloidosis and fatigue

Symptoms and complications of AL amyloidosis Infosheet

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

What is fatigue?

Fatigue is a feeling of near constant exhaustion that differs from the everyday tiredness that comes with the demands of a busy daily life. Unlike ordinary tiredness, it is not caused by activity or exertion and is not relieved by rest or sleep and poor sleep may worsen it.

Over time, fatigue can be profoundly debilitating as it can have an impact on your physical, emotional and psychological wellbeing.

Fatigue is a common complication of AL amyloidosis and its treatment, and living with fatigue can be challenging.

What are the symptoms of fatigue?

Fatigue can affect you in many different ways and symptoms and severity of fatigue can vary from patient to patient, including:

- Reduced energy levels
- Reduced concentration and/or poor memory
- Irritability
- Dizziness
- Shortness of breath after minimal activity
- Difficulty in sleeping or sleeping more than usual
- Loss of, or reduction in, sex drive
- Low mood or mood swings
- Feeling weak or lethargic

The nature of fatigue is such that many people find that it can also have a huge impact on close relationships, as they are no longer able to do the things they once could.

What are the causes of fatigue in AL amyloidosis?

Defining the exact cause of fatigue is difficult, it is often the result of many contributing factors, some of which are described in the following sections.

Anaemia

Anaemia is when there is a decrease in the normal number of red blood cells, or the haemoglobin (an oxygen carrying protein) they contain. This means less oxygen reaches the 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 build up during a course of treatment.

Pain

Living with pain takes up a lot of energy and can leave you feeling tired. This is especially so if your pain is ongoing or not well controlled. If your current painkillers are not working, speak to your doctor or nurse as they may be able to change the type of painkiller or dosage prescribed.

Poor diet

As nutrition is important for general wellbeing, a poor diet can have a great 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, which can contribute to your fatigue. AL amyloidosis and its treatment can affect your appetite and you may be unable to eat as much as you used to.

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



Nausea, vomiting and diarrhoea

You may experience these side effects during treatment. As well as affecting your appetite, ongoing nausea, vomiting and diarrhoea can make you feel very lethargic.

Anxiety and depression

Coming to terms with a diagnosis of AL amyloidosis can have a huge emotional impact on you and can be exhausting. Anxiety, depression, prolonged stress and an irregular sleeping pattern can all contribute to a feeling of fatigue.

What are the treatments for fatigue?

It is important your doctor is aware that fatigue is a problem for you and the impact it is having on your life. Your doctor will assess you so that any possible underlying medical cause is determined and treated appropriately.

Fatigue due to anaemia may be treated with a blood transfusion. This increases the number of red blood cells and therefore can help to bring your haemoglobin level up to, or near, normal levels quickly. However, this increase is usually not maintained and you may need regular transfusions.

Anaemia can also be treated with erythropoietin (EPO) injections which 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.

Research shows exercise is very effective in reducing fatigue. A regular gentle exercise programme such as walking or swimming may actually increase energy levels. You can ask your doctor to refer you to a physiotherapist who can recommend some suitable exercises for you, but remember

you may be limited in what you can do, depending on your organ involvement.

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.

Initially, treatment for your AL amyloidosis may seem to be adding to your level of fatigue. However, once your treatment has finished, and if your AL amyloidosis is stable, 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/ prevention of fatigue

There are a number of tips you can do to help lessen the impact your fatigue may have on your life.

These include:

- Make sure your doctor is aware fatigue is a problem for you and how it affects your day to day life
- Try to accept you may have to make some adjustments to your life and you may not be able to do everything you used to do
- Try to eat a well-balanced diet with foods rich in iron and vitamins
- Ask your doctor to refer you to a dietician if you are having trouble eating
- Cook when you have more energy and freeze some of the prepared food for the days that you feel tired
- Try to maintain a regular gentle exercise programme
- Keep a diary to help you identify the times you feel most tired and try to schedule rest at these times
- Enlist the help of family or friends to help you cope with daily tasks
- Pace yourself – try to do more strenuous tasks at times of the day when you know you will be less fatigued and spread jobs throughout the week if you can
- If you have a job, talk to your employer to discuss any possible changes in your work that may help, such as reduced hours, breaks during the day or change of role/workload
- Talk about how you feel with family and friends. Consider counselling if you think this may help
- Use anxiety/stress management techniques to help you feel more relaxed

- Develop and maintain a regular sleep pattern by trying to go to bed and getting up at the same time every day
- Seek support from your nurse or phon the Myeloma UK Infoline on [0800 980 3332](tel:08009803332)

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 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 doctor can assess you to determine any underlying medical cause for your fatigue to allow 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/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 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



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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