

AL amyloidosis and fatigue

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.

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

It 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, including:

- Reduced energy levels
- An inability to concentrate/make decisions
- Irritability
- Dizziness

- Shortness of breath after minimal exertion
- Poor memory
- Difficulty in sleeping
- Loss of sex drive
- Low mood or mood swings
- Muscle weakness

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?

Anaemia

If the number of red blood cells in your blood is low then these cells are unable to carry sufficient haemoglobin around the body. This means that 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.

Medical 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 poorly managed. 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. AL amyloidosis and its treatment can affect your appetite and you may be unable to eat as much as you used to. This can contribute to feelings of fatigue.

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 that your doctor is aware that fatigue is a problem for you and the impact that 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.

Recent research shows that exercise is very effective in reducing fatigue. A regular gentle exercise programme such as walking or swimming may actually increase energy levels.

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

There are many things that you can do to help lessen the impact that your fatigue may have on your life. These include:

- Making sure your doctor is aware that fatigue is a problem for you and how it affects your day to day life
- Trying to accept that you may have to make some adjustments to your life and that you may not be able to do everything you used to do
- Trying to eat a well-balanced diet with foods rich in iron and vitamins

- Using high calorie drinks and shakes if you are unable to eat much
- Cooking when you have more energy and freezing some of the prepared food for the days that you feel tired
- Trying to maintain a regular gentle exercise programme
- Keeping a diary so that you are aware of the times of the day when your fatigue will be at its worst and trying to schedule in a rest at these times
- Enlisting the help of family or friends to help you cope with daily tasks
- Pacing 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, talking 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
- Talking about how you feel with family and friends. Consider counselling if you think this may help
- Using anxiety/stress management techniques to help you feel more relaxed
- Developing and maintaining a regular sleep pattern by trying to go to bed and getting up at the same time every day
- Seeking support from your nurse or phoning the **Myeloma UK Infoline on 0800 980 3332**

Summary

Fatigue is a very common side effect in AL amyloidosis due to a variety of causes and it can have a huge impact on your quality of life. To prevent it becoming a long-term problem it is important to try to understand how it affects you and to adopt self-management strategies.

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your GP or medical team. They are the best 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 give 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

Notes

Notes

Published by: Myeloma UK
Publication date: May 2009
Last updated: August 2018
Review date: August 2021



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 - 27 June