

Fatigue

This Infosheet explains what fatigue is, what the causes of fatigue in AL amyloidosis are, what the symptoms are, what the treatments are 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 life. Unlike ordinary tiredness, it is not caused by activity or exertion and is not relieved by rest or sleep.

Over time it 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 learning to live with fatigue can be challenging.

What are the causes of fatigue in AL amyloidosis?

Some of the causes of fatigue in AL amyloidosis are:

Anaemia – if the number of red blood cells in your blood is low, less oxygen is circulated around the body, 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 myeloma, including chemotherapy, thalidomide, Velcade® and Revlimid®. Fatigue can often build up during a course of treatment, but once completed, and if your AL amyloidosis is more stable, you may notice an improvement to your fatigue.

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 pain-killers are not working, speak to your doctor or nurse as your pain may need to be reassessed.

Poor diet – as nutrition is so important for general wellbeing, a poor diet can have a great impact on energy levels. You may be unable to eat as much as you used to, and so your diet may be lacking in important components including protein, vitamins and minerals. This will contribute to fatigue.

Nausea, vomiting, diarrhoea and loss of appetite – 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. If you are eating less than normal, you will not be getting as much energy from your food. This can contribute to feelings of fatigue.

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 and may in turn leave you completely worn out.

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 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.

Some 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 that 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 specialist (if you have one) or phoning the **Myeloma UK Infoline on 0800 980 3332**

In summary

It is widely recognised that fatigue can be a serious problem and, if ignored, it can have a huge impact on your quality of life. In order to prevent it becoming a long-term problem it is important to try to understand how it affects you and to adopt some of the self-management strategies outlined in this Infosheet.

Whilst recent research has recognised fatigue as one of the most distressing side-effects of chemotherapy, its assessment and management remain limited. Research is ongoing into the role of various treatments and strategies in fatigue

management, including exercise therapy and complementary therapies. It is hoped that further research and increased awareness will allow fatigue to be recognised, assessed and managed with greater success.

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

Notes

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