

Fatigue

What is fatigue?

Fatigue means feeling exceptionally tired, lethargic or exhausted – all, or most, of the time. It is a very common complication of myeloma and learning to live with fatigue can be extremely challenging as it can affect all areas of your life.

Unlike normal tiredness, which is a natural response to the demands of everyday life, the fatigue associated with myeloma, is often not improved by sleep or rest.

Fatigue can affect between 70–100% of myeloma patients at some point. Fatigue has physical, mental and emotional components and many people have said that living with fatigue can be one of the most debilitating side-effects of myeloma.

It is difficult to predict exactly how fatigue may affect you as everyone's experience is different. For some people fatigue can be mild and will have little impact on their day to day life. However, for other people it can be a serious problem which has a great impact on quality of life.

What are the causes of fatigue in myeloma?

There are many potential causes of myeloma related fatigue. Knowing about some of the most common ones may help you to cope with your fatigue, and the impact it has on your life, a little bit better.

Some of the causes of fatigue in myeloma are:

- **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. This is one of the main causes of fatigue in myeloma. Anaemia can be caused either by the myeloma itself or by some of the common treatments for myeloma (e.g. chemotherapy). Haemoglobin levels are measured by a simple blood test (full blood count or FBC) and will be regularly monitored by your doctor.
- **Medical treatments** Chemotherapy, steroids, thalidomide, VELCADE® (bortezomib) and radiotherapy can all cause fatigue.
- **Poor nutrition** As nutrition is so important for our general well being, an unbalanced diet can have a great impact on energy levels. So, a diet that is lacking in some of the essential vitamins and minerals may add to your feelings of fatigue.

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- **Nausea, vomiting and loss of appetite** 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. As well as affecting your appetite, ongoing nausea and vomiting can make you feel very lethargic. Some of the reasons why you may be experiencing nausea and vomiting include receiving chemotherapy treatments, strong opiate painkillers and medications that protect the bones (bisphosphonates). If your nausea and vomiting are persistent, you should speak to your doctor or nurse as there is a wide range of anti-sickness treatments available.
- **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 your pain may need to be reassessed.
- **Anxiety and depression** Coming to terms with a diagnosis of myeloma 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.
- **Cytokines** Myeloma can cause the release of chemicals called cytokines which affect the way the body makes use of nutrients in food (metabolism). This may result in weight loss and can enhance feelings of fatigue.

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.

Initially, treatment for your myeloma may seem to be adding to your level of fatigue. However, once your treatment has finished, and if your myeloma is stable, you may notice an improvement in your fatigue. Anaemia related fatigue may be improved by treating the underlying anaemia. Blood transfusions can be given to bring the haemoglobin level up quickly, although the higher level might not be maintained and more than one blood transfusion is often needed.

Another way of treating anaemia is by giving erythropoietin (EPO). This is a synthetic version of a naturally occurring hormone which increases the production of red blood cells. Erythropoietin is given as an injection over a period of weeks to restore and maintain a normal level of haemoglobin.

Recent research shows that exercise is very effective in reducing fatigue. A regular exercise programme that is aerobic but not load bearing, 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, can help to boost energy levels.

Fatigue related to shorter-term treatments such as chemotherapy, radiotherapy and Velcade should improve once treatment has finished. Fatigue can sometimes occur for several months after high-dose therapy and stem cell transplant, and when on longer-term treatments such as thalidomide.

Some tips for self-management

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

These include:

- Making sure that your doctor and / or nurse are aware that fatigue is a problem for you and of 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 (liver, spinach, fortified cereals).
- Cooking when you have more energy and freeze 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.

The future

Whilst recent research has recognised fatigue as one of the most distressing side-effects of cancer and its treatment, its assessment and management remain limited. Treatments for cancer-related anaemia, such as EPO, have been shown to reduce levels of fatigue and improve quality of life. It is hoped that further research and increased awareness will allow fatigue to be 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's publications are extensively reviewed by patients and healthcare professionals prior to publication.

Other information available from Myeloma UK

Myeloma UK has a range of Essential Guides, Infoguides and Infosheets available, covering many areas of myeloma, its treatment and management. To order your free copies, contact the **Myeloma Infoline** on **0800 980 3332**. This information is also available 24/7 on our website at www.myeloma.org.uk.

If you would like to talk to someone about any aspect of myeloma, its treatment and management, call the **Myeloma Infoline** on **0800 980 3332**. Your call will be answered by Myeloma Nurse Specialists who are supported by medical and scientific advisors. The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK. From outside the UK, call +44 131 557 3332 (charged at normal rate).

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