MyelomaUK

Fatigue and myeloma

Symptoms and complications Infoguide

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Contents

2 Myeloma – an overview

4 What is fatigue?

5 Assessment of fatigue

6 Causes of myeloma-related fatigue

11 Treatment and management of fatigue

19 Living with fatigue

24 Top ten tips for living with fatigue

25 Caring for someone with fatigue

26 Questions for your healthcare team

27 Medical terms explained

31 Appendix 1: Statements used to assess fatigue

34 Useful organisations

35 We're here for everything a diagnosis of myeloma brings

36 We need your help

It can be challenging to read a lot while experiencing symptoms like fatigue. The sections in this Infoguide do not have to be read in order and you can choose to pick out the parts you find most useful, at the time that is best for you. Myeloma UK can provide a range of different types of support. If you would like to find out more about these, see page 35.

You will find a definition of the terms highlighted in **bold** throughout this booklet in the 'Medical terms explained' section on page 27.

Throughout this Infoguide, "Healthcare team" is used to refer to your hospital team (doctors, nurses and other specialists).

The quotes in this Infoguide are from myeloma patients and carers.

Disclaimer: The information in this Infoguide is not meant to replace the advice of your healthcare team. They are the best people to ask if you have questions about your individual situation.

This publication is intended for a UK audience. It therefore may not provide relevant or accurate information for a non-UK setting.

Myeloma – an overview

This section explains some key facts about myeloma, including what it is, how it affects patients, and how it is treated. If you are newly diagnosed this section can be a good place to start. If you have been living with myeloma for some time, this information might be familiar but it can still be a useful reminder before reading about specific aspects of myeloma.

Myeloma is a type of cancer arising from **plasma cells** that are normally found in the **bone marrow**. Plasma cells are a type of **white blood cell** which form part of the **immune system**.

Normal plasma cells produce different types of **antibodies** to help fight infection. In myeloma, some of the plasma cells become cancerous (sometimes called **malignant**) and usually release a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. It is often through the measurement of paraprotein that myeloma is diagnosed and monitored.

Sometimes, myeloma cells produce only part of the paraprotein, known as **light chains**. These also have no useful function. In other types of myeloma, the myeloma cells only produce small amounts of paraprotein or no paraprotein at all. There are other ways to diagnose and monitor these types of myeloma.

Myeloma affects multiple places in the body where bone marrow is normally active, such as the bones of the spine, pelvis, rib cage and the areas around the shoulders and hips. This is why it is sometimes referred to as 'multiple myeloma'.

Most of the complications and symptoms of myeloma are caused by a buildup of the cancerous myeloma cells in the bone marrow and the presence of paraprotein or light chains in the body.

Common problems in myeloma include bone pain, bone fractures, fatigue, frequent or recurrent infection and kidney damage.

Myeloma is highly treatable in most cases. Treatment is aimed at controlling the disease, relieving the complications and symptoms

it causes, and extending and improving the **quality of life**. Treatment for myeloma is often most effective when two or more drugs, with different but complementary mechanisms of action, are given together.

Myeloma is known as a relapsing and remitting cancer: patients are treated and generally go into **remissions** when their cancer is not active and often is not being treated, followed by **relapses** when the myeloma is active and needs treatment again. Remissions can last for long periods of time, and many patients have a number of remissions and relapses during their lifetime. Although myeloma is not currently curable, the outlook for patients has improved greatly over recent years and is continuing to improve. There are a large number of treatments available, and others are being developed in clinical trials.

The causes of myeloma are not fully understood but it is believed to be caused by an interaction of both genetic and environmental factors.

Key facts

- There are approximately 5900 people diagnosed with myeloma every year in the UK
- There are over 24,000 people living with myeloma in the UK at any one time
- Myeloma is the third most common type of blood cancer, and accounts for 2% (1 in every 50) of all new cancer cases diagnosed each year
- Although more common in older people, around a quarter (1 in 4) of myeloma patients are diagnosed under the age of 65

What is fatigue?

Fatigue is a feeling of extreme tiredness, lethargy or exhaustion, which persists most or all of the time.

It is different from everyday tiredness and is not fully relieved by rest or sleep. Fatigue can affect you physically, psychologically and emotionally and can seriously affect you.

Fatigue is a common symptom of myeloma and a side effect of some of its treatments, affecting almost all myeloma patients at one time or another.

In a Myeloma UK survey of over 1,000 patients, around 3 in every 5 patients said that fatigue affected them 'a lot'.

Living with fatigue can have a significant impact on your quality of life and can be very challenging both for you and for those close to you.

Symptoms of fatigue

The symptoms and severity of fatigue can vary from patient to patient. It may be mild and have little impact on your day-to-day activities. However, if it is more severe, it can substantially reduce quality of life.

Fatigue can be constant, occur at regular points throughout the day or may hit unexpectedly.

Common symptoms of fatigue include:

Reduced energy levels

Feeling weak or lethargic

Reduced concentration and/or poor memory

Mood swings and tearfulness

Feeling dizzy or disorientated

Shortness of breath after minimal activity

Difficulty in sleeping or sleeping more than usual

Loss of, or reduction in, sex drive

Loss of, or reduction in, appetite

Assessment of fatigue

It is important that you tell your healthcare team how you feel, so that they can assess your fatigue. There are a number of different tools that they may use to assess fatigue and quality of life.

It may help to think about your answers to the following questions before seeing your healthcare team:

- Do you sleep well at night?
- Do you wake up feeling tired?
- Do you need a nap during the day?
- Are there certain times of the day when you feel more tired?
- Does anything make your tiredness better or worse?
- Do you find activities and jobs around the house more difficult?
- What have you tried to do to combat tiredness and how well has this worked?
- How would you describe the effect that tiredness has on your day-to-day life?

There are no right or wrong answers – it is how you feel that is important.

You may also find it useful to consider the statements (taken from a fatigue assessment) in Appendix 1 on page 31.

Your healthcare team will assess for fatigue at each consultation, which may simply involve asking you a few questions about your energy levels and how you are feeling in general. Make sure to let them know about any other factors you think may be adding to your fatigue.

Studies have shown that healthcare professionals perceive fatigue differently from patients and may underestimate its impact on your quality of life. However, there is much that can be done to help improve your fatigue if it is tackled promptly. It is not something you have to put up with nor should you try to avoid 'bothering' your medical team with it.

The following pages will explore some of the more common causes of myeloma-related fatigue. Sometimes a combination of these factors can contribute to your overall fatigue.

> **"Be honest with your healthcare team and tell them how you're feeling. They will be able to help you."**

Causes of myeloma-related fatigue

Identifying the cause (or causes) of your fatigue is the first step in treating and managing it.

The most common causes of fatigue in myeloma patients include:

- Symptoms and complications of myeloma
- Treatment for myeloma
- Emotional impact of having myeloma
- Lifestyle changes due to myeloma

It is often difficult to define the exact cause of fatigue – in reality there are usually many things playing a part, and some of the causes are still not fully understood.

Anaemia

Anaemia occurs when there are fewer **red blood cells**, or less **haemaoglobin** (the part of red blood cells which carries oxygen). This results in less oxygen being carried around the body.

Anaemia can occur as a direct result of the myeloma or as a side effect of some of its treatments. Both of these can suppress blood cell production.

Symptoms of anaemia include:

Fatigue

Breathlessness

Dizziness or light-headedness

Fast heart beat

Anaemia is a common cause of fatigue in myeloma. You will be monitored regularly for it with a simple blood test that measures your haemoglobin levels. The normal range of haemoglobin is:

- 135–180 g/L (grams per litre) in men
- 115–150 g/L (grams per litre) in women

A haemoglobin level below these normal ranges is a sign that you are anaemic.

However, some patients may find that a haemoglobin level of 100 g/L does not affect their daily activities, while others may not be able to cope

well even when their haemoglobin level is 120 g/L. This is one of the reasons why it is very important that you openly discuss your fatigue with your healthcare team, particularly if it is affecting your ability to carry out the **activities of daily living.**

Kidney problems

The kidneys produce a hormone called **erythropoietin (EPO)** which stimulates the production of red blood cells. Myeloma and its treatments can sometimes affect the production of EPO, which means your body will produce fewer red blood cells and you may become anaemic.

The kidneys also control the balance of fluid and salts in the body and filter the blood to remove waste substances. If your kidneys are not working normally, waste products can build up in the body and this can also cause fatigue.

Pain

Pain is a common symptom of myeloma. It is often due to myeloma bone disease. Living with pain can make you less active, affect your appetite, cause sleep problems and cause depression – all of which can lead to fatigue.

Infection

Myeloma weakens the body's immune system, leaving you more prone to bacterial, viral and fungal infection. In addition, many of the treatments used for myeloma may also reduce your ability to fight infection. Your body uses a lot of energy every time you have an infection and this can lead to increased fatigue.

For more information see the **Infection Infosheet** from Myeloma UK

Signs of infection include:

Cough or sore throat

Raised temperature (above 38°C)

Lowered temperature (below 35.5°C)

Rash

Shivering

Diarrhoea

Vomiting

Pain, redness or swelling around a cut or wound, or around a **Hickman® catheter** or **PICC**

Myeloma treatments

Fatigue is a common side effect of many of the treatments for myeloma, including **chemotherapy**, radiotherapy, and treatments such as:

- **Bortezomib (Velcade®)**
- **Carfilzomib (Kyprolis®)**
- **Daratumumab (Darzalex®)**
- **Lenalidomide (Revlimid®)**
- **Pomalidomide (Imnovid®)**
- **Thalidomide**

Fatigue may build up during a course of treatment. Once the treatment course is complete, if your myeloma is more stable, you may notice an improvement in your fatigue.

It is normal to have some degree of fatigue if you have had **high-dose therapy** and **stem cell transplantation (HDT-SCT)**. You may find that your fatigue has lessened within three to six months but it may be six to 12 months before your energy levels have returned to normal. It is important to remember that each patient's recovery after a transplant is different and therefore it is difficult to predict how long your fatigue may persist.

For more information see the **High-dose therapy and autologous stem cell transplantation Infoguide** from Myeloma UK

Some supportive treatments (treatments used to manage symptoms and side effects) can also cause fatigue. This includes some painkillers and anti-sickness **(anti-emetic)** treatments. Fatigue caused by these types of drugs should wear off after a few days, once your body has adjusted to the treatment.

It is important that you let your healthcare team know about any side effects you have with your treatment and the impact this has on your quality of life.

Cytokines

Myeloma can cause an increase in the production of specific chemicals called **cytokines.** These cytokines have complex effects in the body, and it is thought that they contribute to fatigue in cancers including myeloma.

Poor nutrition

Some of the treatments for myeloma can cause side effects that make it more difficult to eat and drink.

Side effects that can lead to poor nutrition may include:

Nausea and vomiting

Sore mouth

Loss of appetite

Taste changes

Lack of energy or motivation to prepare food

If you are not eating a healthy balanced diet you will not be getting the energy you need from food, which can contribute to your fatigue.

Emotional effects of having myeloma

Coming to terms with a diagnosis of myeloma can have a huge emotional impact on you and this can be exhausting in itself. Anxiety, depression and prolonged stress can have significant impacts on your energy levels, and it is helpful to recognise that this can be one of the causes of fatigue.

There is a well-established link between fatigue, chronic pain and depression. These can affect daily activities, relationships with others and self-esteem. This can, in turn, lead to feelings of isolation, fear and loss of confidence. These can be very draining emotions and easily increase feelings of fatigue.

> **“Don’t waste time and energy on things you can’t do anymore. There are still lots of things you can do.”**

Difficulty sleeping

Stress, anxiety and some treatments, particularly **steroids** such as dexamethasone, can make it difficult to get a good night’s sleep. If you are not getting enough sleep then you may find that you are tired all the time, find it hard to concentrate and make decisions, and that you are more irritable and emotional than normal.

Reduced activity and lack of exercise

If you have bone damage due to myeloma, you may find it harder to walk, manage stairs or exercise as much as you used to. This will mean you are probably less active than you once were. A lack of physical activity can make you feel lethargic, tired and less able to sleep. It can also contribute to frustration and feeling ‘low’, particularly if you used to be very active. If you are already feeling fatigued, you may be less inclined to exercise, and this can worsen these feelings.

Causes unrelated to myeloma

Your healthcare team will check for any other factors that may be causing or worsening your fatigue. This might be another medical condition that you have, or a vitamin deficiency, for example.

Treatment and management of fatigue

The treatment and management of your fatigue will depend on the causes of it. It is likely that your treatment will include more than just one approach – for example, it may involve medical treatment supported by complementary therapies, such as relaxation techniques.

Usually, treatment and management will involve:

Resting and improving sleep quality

Treating underlying conditions like anaemia or kidney problems

Controlling pain

Treating infection

Adjusting your myeloma treatment

Eating better

Emotional Support

Exercise

Though it may take several weeks or even months before you see an improvement, recognising fatigue as a problem and finding ways to treat or manage it, however small, can help you take some control of your situation and improve your quality of life. The following sections look in more detail at some of the ways in which fatigue can be treated and managed.

Rest

Rest is an important part of managing fatigue. By identifying when you feel most fatigued and planning rest periods around these times, you can return a measure of control to your life. This can also mean that you do not exhaust yourself during the middle of a task and come to a sudden halt.

> **“Try and build in time to rest during the day and don’t feel guilty about this.”**

Some people may feel they have more energy following a long rest, while others may feel replenished by

several shorter breaks throughout the day or during a task. Try both to see which suits you better.

Anaemia

Treating any underlying anaemia will help to relieve fatigue. One treatment option is a blood transfusion. This increases the number of red blood cells in the blood and therefore can help to bring your haemoglobin level up to, or near, normal levels quickly.

Blood transfusions are often used following excessive blood loss, for example, after an injury. Myeloma patients may also be given blood transfusions in the short term to increase haemoglobin levels. However, as the level is not maintained long term, you may need regular transfusions.

In some cases you may be given an injection of a synthetic (man-made) version of erythropoietin (EPO) to stimulate production of red blood cells. EPO can take several weeks to relieve some of the symptoms of anaemia, so you may be given blood transfusions in the interim.

Kidney problems

Kidney problems in myeloma may be prevented or reduced by taking the following steps:

- Maintaining a good intake of fluids per day (as recommended by your healthcare team – usually about 2 to 2.5 litres per day)
- Regular monitoring of your kidney function with blood and urine tests to pick up problems as early as possible
- Avoiding the use of treatments that are known to affect the kidneys such as **non-steroidal anti-inflammatory drugs (NSAIDs)**. These include painkillers such as ibuprofen (Nurofen®) and diclofenac (Voltarol®)

In the majority of patients, kidney problems are temporary. In a small number of patients, problems may become more severe and require **dialysis** to help clear the blood of waste products.

For more information see the **Myeloma and the kidney Infoguide** from Myeloma UK

Pain

If your pain is not well controlled, you may find it helpful to see a pain management or **palliative care** team. Palliative care is care or treatment that concentrates on relieving symptoms (including pain) and improving quality of life. The palliative care team will be able to assess your pain accurately and prescribe effective painkillers to help improve some of the consequences of pain, including fatigue.

Different painkillers work best for different patients and so treating pain can initially be a case of 'trial and error' until a suitable option is found.

As with all drugs, painkillers can have side effects and, unfortunately, can contribute to your fatigue. Some of the stronger painkillers (such as morphine) may initially make you feel very tired, but this should lessen after a couple of weeks as your body adjusts to the treatment. Your healthcare team will monitor you closely and will modify your painkillers to find the best balance between pain relief and side effects like fatigue.

For more information see the **Pain Infoguide** from Myeloma UK

Infection

It is important to report any suspected infection to your healthcare team immediately, even if this is out of hours. It is important that any infection is appropriately treated with **antibiotic, antifungal** or **antiviral** treatments quickly. This can help to reduce the length of the infection and the amount of energy your body uses fighting it.

Myeloma treatments

If your myeloma treatment is causing fatigue then your doctor may suggest reducing the dose or temporarily stopping your treatment. This does not necessarily mean the treatment will be less effective against your myeloma.

However, as with all treatment, if the side effects continue to outweigh the benefits even after dose reduction, other treatment options may be explored. It may also help to change the time you take certain treatments. If taking them in the morning makes you tired during the day, ask if you can take them around bed time to see if that makes a difference.

Cytokines

Treatment for your myeloma will destroy the myeloma cells and reduce the amount of cytokines being produced. You may find your fatigue increases initially while on treatment. However, in the longer term, once treatment has finished and if your myeloma is stable, you should find that your fatigue improves.

Poor nutrition

It may help to get a referral to see a dietician who can fully assess your diet, offer advice and also prescribe food supplements if necessary.

You must speak to your doctor before taking any kind of supplement or alternative treatment that they have not prescribed, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements, to ensure it is safe to do so and will not have any harmful effects when taken alongside your prescribed treatment.

Other tips for good nutrition:

- Eat a well-balanced healthy diet containing all the food groups with plenty of fruit and vegetables
- If you find 'three square meals' a struggle, eat little and often instead
- Cook when you have more energy and freeze some of the prepared food for the days that you feel tired
- Ensure you are drinking plenty of fluid. Your healthcare team will advise you but normally this would be at least 2 to 2.5 litres of fluid each day
- Keep your mouth clean and moist. Use mouthwashes as prescribed

For more advice and tips about diet and myeloma, see the **Infopack for living well with myeloma** from Myeloma UK

Emotional effects of having myeloma

There are different ways to support your emotional wellbeing, which can help reduce fatigue.

Talking therapies

You may find a talking therapy helpful if you are finding it difficult to cope with the emotional effects of having myeloma. Talking therapies include **counselling** and **cognitive behavioural therapy (CBT)**.

Counselling involves a trained therapist listening to you and helping you explore your feelings and experiences in a supportive, confidential environment. They do not give advice but help you develop coping strategies and find your own answers to the problems you are facing.

Cognitive behavioural therapy (CBT) is a type of talking therapy that aims to change the way you think and act, in order to help you cope with problems you face in your life.

You can get talking therapies on the NHS. For more details, visit **nhs.uk/conditions/counselling**

Mind-body therapies

Mind-body therapies such as meditation, mindfulness and relaxation can be helpful in reducing stress and anxiety, which can contribute to fatigue.

Many cancer centres offer mind-body therapies and you can ask what is available locally.

Emotional wellbeing tool

Myeloma UK has an emotional wellbeing tool, which is an interactive digital tool designed to help support wellbeing. The tool gives you space to work through how you're feeling, and find strategies and sources of support to help you.

Go to **myeloma.org.uk/wellbeing** to access the emotional wellbeing tool

Talking with other patients

You might also find that talking with other patients helps you to cope emotionally with the effects of fatigue. You can join a Support Group (either in-person or online), or meet other people affected by myeloma at our Patient and Family Events. We also have Peer Buddies for one-to-one support, and an online Myeloma UK Discussion Forum.

To find out more about emotional support in myeloma, see the **Infopack for living well with myeloma** and **myeloma.org.uk/connect**. You can also phone the Myeloma Infoline on **0800 980 3332**

Difficulty sleeping

The following tips might help you get a more restful sleep:

- Sleep for just long enough to feel refreshed
- Try to establish a regular sleep routine. This includes going to bed and getting up at the same time every day including the weekend. You should do this even if you haven't slept well the previous night. Set yourself a time to start winding down before bedtime
- Try to reduce noise and light in the bedroom. Consider thick curtains or blackout blinds to reduce early morning light
- Keep the temperature of the bedroom steady and cool
- Avoid stimulants such as coffee, tea, alcohol, cigarettes, chocolate and cola drinks during the late afternoon and evening
- A warm bath or shower may help relax you
- Try using lavender (or other calming scents) in your bedroom and on your bed linen
- Know how naps affect you – do they help or do you feel worse afterwards? It is often better to have short naps (30 minutes or less), to avoid interfering with the next night's sleep
- Learn how to use relaxation techniques to help you get to sleep

Reduced activity and lack of exercise

Although it may be hard to even think about exercise when you are feeling exhausted, just a small increase in physical activity can improve your general health and wellbeing, reduce stress, boost energy levels and help you get a better night's sleep.

Talk to your healthcare team about suitable exercise routines for you. You may want to ask for a referral to a physiotherapist. A physiotherapist will work out an exercise plan for you, taking into account your current fitness, fatigue and any pain or bone damage you may have.

Exercise that puts a lot of strain on your bones such as high impact or contact sports should be avoided.

Gentle forms of exercise, such as walking, swimming, cycling, light gym work, yoga and Tai Chi, are likely to be suitable.

You can exercise without having to do any sports. For example, take a walk along a route with regular buses, where you are likely to find a seat and can take the bus back home if you start to feel very tired. Simple exercises such as lifting your arms and legs, rotating your ankles and flipping your feet up and down from the ankles can help to increase muscle tone and flexibility.

You should not try to exercise if you feel excessively tired or breathless. Your healthcare team or physiotherapist will be able to guide you on exercise that is appropriate for you.

For more information see the **Exercises for myeloma patients Infosheet** from Myeloma UK

Living with fatigue

Many patients find that fatigue can be one of the most difficult side effects to live with. However, there are steps you can take to help you manage living with fatigue.

During treatment, fatigue is sometimes better understood and managed as patients are aware it can be a potential side effect. The time that many struggle most with fatigue is after treatment has finished, when patients expect everything to be back to 'normal'. During this time, it can be frustrating that your energy levels aren't what you'd hoped or expected they'd be, and you may experience a disconnect between the expectation that comes from looking well on the outside and how you are really feeling.

Though it may feel like fatigue is dominating your life at times, small lifestyle changes can help. The following pages contain some practical tips to help you manage your day-to-day life with fatigue.

Having a routine

A key to managing fatigue is having a balanced and sustainable daily routine. When people have a good day, they can be tempted to do more. This, however, can make fatigue worse and can contribute to a cycle of fatigue. Try to keep a regular routine and slowly build up your activities so you don't overdo it quickly.

Keeping a diary

Though keeping a detailed diary may be too tiring, a few brief entries every day can be useful. This can help you identify the times you feel most tired, determine what makes you tired and discover what helps you combat the fatigue.

The **Patient Diary** from Myeloma UK is designed to help patients easily keep a record of their symtoms and side effects, including fatigue. Order your free copy today from **myeloma.org.uk**

Some things that might be useful to write down include:

- What you eat and how much
- How much you exercise – this doesn't have to mean running a marathon – include walking to the shops, around the supermarket, etc.
- What activities you do. Include details, for example 'pushed a heavy shopping trolley', how long it took to unpack the shop from the car and so on
- How well you sleep and how you felt when you woke up (rested or tired)
- When you are most tired
- What you have tried to alleviate the fatigue and whether it worked

It can also be useful to score your fatigue between zero (not at all fatigued) and four (very fatigued) for each activity. This might also be useful to refer to when talking to your healthcare team about fatigue.

> **"Plan what you want to do and what you need to do."**

Coping at home

Fatigue can make even the simplest task seem daunting. It may help to plan ahead and pace yourself throughout the day so that you do more energetic tasks at times when you know you will be less fatigued.

Tips for coping at home:

- Break big jobs into smaller tasks
- Space chores out throughout the day and week or ask someone to help do some of the tasks for you
- Tell those close to you about your fatigue and explain to them that you are unable to do all the things you did previously. Ask for help
- Be flexible with your schedule and allow yourself to rest when you need to
- Prepare meals when you feel less tired. If you have a freezer, cook extra and freeze for a later date
- If you have little appetite, eat little and often and use ready made meals or snacks when necessary
- Limit strenuous work, use long-handled tools and sit down whenever you can

If you are having difficulty coping at home, then speak to your healthcare team to see what additional support might be available, such as help with housework or aids around the home. Ask for a referral to the social work department to get a home assessment and to ensure you are claiming any benefits you are entitled to.

For more information see the **Benefits and financial support Infosheet** from Myeloma UK

Complementary therapies

Complementary therapies such as aromatherapy and relaxation techniques can be helpful in reducing stress and therefore improving fatigue. Yoga and Tai Chi, which combine gentle exercise with deep breathing, may help to boost energy levels.

If you are considering using a complementary therapy, you should talk to your healthcare team first, and look for a qualified, registered therapist who has experience of treating cancer patients.

The Complementary and Natural Healthcare Council (**cnhc.org.uk**) can be contacted for a list of registered practitioners in your area. Many cancer centres offer complementary therapies (but not always free of charge) or can give you contact details of services available locally.

Before you go ahead with a complementary therapy, you should ask about costs and ask for proof of their qualifications, registration and insurance.

For more information about complementary therapies see the **Infopack for living well with myeloma** from Myeloma UK

Coping with work

When you have fatigue, you may find work difficult and may need to make changes to your work life, for example reducing the number of hours that you work. It is a good idea to speak to your employer at an early stage and discuss what support you may need.

If you have a health condition such as cancer, employers are required to consider making 'reasonable adjustments' to ensure you are not substantially disadvantaged when doing your job. This may include, for example, allowing you to work wholly or partly from home, changing where you work in the building, or allowing you to work more flexible hours.

Some patients find they need to change their job, particularly if their work is strenuous and involves heavy manual labour, and some people decide that their best option is to take early retirement.

Work can often provide us with a sense of purpose and so it's normal for giving it up or reducing your hours to be daunting. At the same time, a diagnosis of a serious illness often leads to a shift in priorities which may affect your decisions about work.

You might be worried that, if you do decide to stop work or reduce your hours, you might find yourself in financial difficulty. There may be government benefits that you are entitled to claim. You may also be able to apply for help with travelling costs to and from the hospital.

For more information about work and finances, see the **Infopack for living well with myeloma** and the **Benefits and financial support Infosheet** from Myeloma UK

Family, friends and social life

Fatigue can have a huge impact on close relationships as you may no longer be able to do the things you once could. This can be frustrating and, at times, you may feel that you are letting people down. Try not to be too hard on yourself.

Those close to you may not fully understand the effect fatigue is having on you unless you tell them, particularly if you 'look well' on the outside or are no longer on treatment. They may be unaware that you need extra support or are more limited in your activities. Try to explain the practical impact fatigue is having and how that's making you feel. They may also like to read this Infoguide.

Although asking for help can be hard, you might find that by asking, you are making your family or friends feel involved by giving them something practical to help with.

It is important that you are still able to do things that you enjoy. This may mean planning ahead and prioritising what you are able to do. Try to plan to keep some of your energy for hobbies or socialising. This can help to keep a sense of 'normality' in your life. But prioritise what you do and don't be afraid to say no to things.

If you have young children or grandchildren, it may help to explain to them that you are feeling tired and that, for a while, you may not be able to play with them as much as normal. Remember that children are adaptable. They may be very happy, for example, to play games with you that you can do whilst sitting down. There are also activities that you can still do that do not require a lot of energy such as watching a film together or reading a bedtime story. Again, ask family and friends if they can help you with childcare.

Our illustrated children's book 'Kelsey and the Yellow Kite' touches on the impacts of fatigue in myeloma. The book was written to help explain myeloma in a child-friendly way, and tells the story of a little girl called Kelsey whose dad is diagnosed with myeloma.

To order a copy of **Kelsey and the Yellow Kite** contact Myeloma UK on **0131 557 3332** or order online at **myeloma.org.uk**

Top ten tips for living with fatigue

1. Plan, pace and prioritise
2. Do things that matter to you each day
3. Spread chores throughout the week
4. Do things when you have energy and rest when you don't
5. Maintain a well-balanced diet and eat little and often
6. Take gentle exercise
7. Ask for help
8. Keep a diary to help you identify the times you feel most tired and what helps you combat the fatigue
9. Try a complementary therapy, such as learning relaxation techniques
10. Be realistic about what you can do

Caring for someone with fatigue

If you are are providing care or support for someone who has fatigue, you may find it hard to know how best to help them – whether you should be doing things for them or encouraging them to do more for themselves. You may also feel frustrated at times, especially if you are not able to do some of the things you used to do together.

There are ways of helping a loved one or family member with fatigue. They include understanding what fatigue is and how it affects the person you are caring for. Reading this Infoguide is a good first step.

Talk to your loved one or family member about how they feel and plan your day together. It can be easy to forget the impact fatigue is having when someone looks well, and you may be expecting them to be back to their 'normal' self too soon. Discussing it a day at a time can help you work to their capabilities. Even small activities can help, for example a short walk together or a visit to see a friend.

It might help to go along to the hospital with the person you are caring for, and talk to the healthcare team. If the patient is happy for you to do so, you can discuss what might be causing the fatigue and talk about possible treatment and management options.

You should also acknowledge the impact that caring for someone with fatigue has on your own life. How you feel and your quality of life may be changed or affected. Caring for someone can be exhausting and you may have some degree of fatigue yourself.

Look for ways of taking a break from caring, even for a few hours, perhaps by visiting friends, having a hobby or exercising. This can make a huge difference to the way you feel and cope. Remember, if you don't look after yourself you will not be able to look after anyone else.

For more information see the **Infopack for carers of myeloma patients** from Myeloma UK

Questions for your healthcare team

If you are finding fatigue an issue, it is important to talk to your healthcare team about it, so you can discuss ways to manage it. It can be helpful to write your questions down and give a copy to your healthcare team at the start of your consultation. You might want to carry a piece of paper with you so you can make a note of questions as they occur to you.

Some questions you may need answering include:

- Is my treatment causing, or likely to cause, fatigue?
- Am I anaemic?
- What is my haemoglobin level?
- Are there any treatments that could help treat my fatigue?
- What can I do to help my fatigue?
- Will my fatigue improve once my treatment stops?
- What support is available to help me at home?
- What exercise can I do?
- Who can help me manage my fatigue?

The **Patient Diary** provides space for you to make a note of any questions you have for your medical team. Order your free copy from Myeloma UK at **myeloma.org.uk**

Medical terms explained

Activities of daily living: The things that a person does to look after themselves – includes washing, dressing, eating and taking care of personal hygiene. Sometimes known as performance status.

Anaemia: A condition in which the amount of haemoglobin in the blood or the number of red blood cells is below the normal levels, causing shortness of breath, weakness and tiredness.

Antibiotic: A type of drug used to prevent or treat an infection caused by bacteria.

Antibodies (immunoglobulins): Proteins found in the blood which are produced by cells of the immune system, called plasma cells. Their function is to bind to substances in the body that are recognised as foreign, such as bacteria and viruses, enabling other cells of the immune system to destroy and remove them.

Anti-emetic: A type of drug used to prevent or minimise nausea and vomiting.

Antifungal: A type of drug used to prevent or treat an infection caused by a fungus.

Antiviral: A type of drug used to prevent or treat an infection caused by a virus.

Bone marrow: The soft, spongy tissue in the centre of bones that produces blood cells.

Bortezomib (Velcade®): A proteasome inhibitor drug which is given as a subcutaneous injection.

Carfilzomib (Kyprolis®): A proteasome inhibitor drug which is given as an intravenous infusion.

Chemotherapy: A type of drug intended to kill cancer cells. Chemotherapy drugs can be injected into a vein (intravenous or IV) or swallowed as tablets (orally).

Cognitive behavioural therapy (CBT): A type of talking therapy that aims to change the way you think and act, in order to help you cope with problems you may face in your life.

Counselling: A talking therapy that involves a trained therapist listening to you and helping you find your own ways to deal with emotional issues.

Cytokine: A protein produced mainly by cells of the immune system that acts as a chemical messenger between cells. Cytokines can stimulate or inhibit the growth and activity of various types of cells.

Daratumumab (Darzalex®): A monoclonal antibody drug which is given as an intravenous infusion or subcutaneous injection.

Dialysis: A procedure which removes waste products from the blood, performed when a patient's kidneys have stopped working.

Erythropoietin (EPO): A hormone produced by the kidneys, which is involved in the production of red blood cells. Injections of synthetic EPO can be given to patients who are anaemic.

Haemoglobin: The protein found in red blood cells that carries oxygen around the body.

Hickman® catheter/line: A brand name for the catheter (tube) that is inserted under the skin in the chest into a large vein just above the heart. It can be kept in for several months and is used to administer treatments and to take blood samples. Also known as a central line and a central venous access device.

High-dose therapy (HDT): Treatment with high doses of chemotherapy given intravenously, usually via a central line or a PICC, prior to patients receiving healthy stem cells as part of the stem cell transplantation procedure. Also known as conditioning treatment.

Immune system: The complex group of cells, tissues and proteins (including antibodies), that protect the body against infection and disease.

Lenalidomide (Revlimid®): An immunomodulatory drug that is given orally.

Light chains: Part of an antibody (or immunoglobulin). An antibody is made up of two heavy chains and two light chains. There are two types of light chain, kappa and lambda.

Malignant: A term for cancerous cells which have the ability to spread.

Nausea: The sensation of feeling sick.

Non-steroidal anti-inflammatory drug (NSAID): A type of drug used to prevent or treat pain or inflammation, which do not contain steroids. Examples are ibuprofen and diclofenac. NSAIDs should not be used in myeloma, because they can worsen kidney damage.

Palliative care: A type of care or treatment that concentrates on preventing and relieving symptoms and improving quality of life, for patients with an incurable illness.

Paraprotein: An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease. Also known as M protein.

PICC (Peripherally Inserted Central Catheter): A catheter (tube) inserted into one of the large veins of the arm (or leg) and threaded into the vein until the end sits in a large vein just above the heart. It is used to administer treatments, commonly chemotherapy.

Plasma cells: A type of white blood cell that produces antibodies (immunoglobulins) to fight infection.

Plateau: A period of time when the myeloma, and the paraprotein level, is relatively stable. Often referred to as stable disease.

Platelets: A type of blood cell involved in blood clotting.

Pomalidomide (Imnovid®): An immunomodulatory drug which is given orally.

Quality of life: A term that refers to a person's level of comfort, enjoyment, and ability to pursue daily activities. It is a measure of an overall sense of wellbeing.

Red blood cells: A type of blood cell that transports oxygen around the body.

Relapse: The point where disease returns or becomes more active after a period of remission or plateau.

Remission: The period following treatment when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Stem cell transplant (SCT): The infusion of healthy stem cells into the body. This allows the bone marrow to recover and renew its blood-forming capacity following the administration of high-dose chemotherapy.

Stem cells: A type of cell from which a variety of cells develop. Haematopoietic stem cells give rise to red blood cells, white blood cells and platelets. They are harvested for stem cell transplantation.

Steroid: A group of hormonal substances produced by the body. They are also produced synthetically and used to treat many conditions.

Thalidomide: An immunomodulatory drug that is given orally.

White blood cells: A type of blood cell involved in the body's immune system, which help to fight infection and disease.

Appendix 1: Statements used to assess fatigue

This is an example of the type of statements that may be used to assess your fatigue. You may be asked to 'rate' statements like this according to how you have been feeling over the last week on a scale from 'not at all' to 'very much'.

- I feel fatigued
- I feel weak all over
- I feel listless ('washed out')
- I feel tired
- I have trouble starting things because I am tired
- I have trouble finishing things because I am tired
- I have energy
- I am able to do my usual activities
- I need to sleep during the day
- I am too tired to eat
- I need help doing my usual activities
- I am frustrated by being too tired to do the things I want to do
- I have to limit my social activity because I am tired

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Notes

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Useful organisations

Carers UK carersuk.org
0808 808 7777
Provides advice, information and support for carers.

Citizens Advice citizensadvice.org.uk
www.adviceni.net
England: **0800 144 8848** Wales: **0800 702 2020**
Scotland: **0800 028 1456** Northern Ireland: **0800 915 4604**
Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support macmillan.org.uk
0808 808 0000
Provides practical, medical and financial information and support to all cancer patients and their carers.

Maggie's www.maggies.org
0300 123 1801
Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind mind.org.uk
0300 123 3393
Provides advice and support for anyone with mental health problems.

NHS 111 Service nhs.uk/111
111
Call 111 when you need medical advice fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

Samaritans samaritans.org
116 123
Listening and support free, 24 hours a day, to anyone who's struggling to cope

We're here for everything a diagnosis of myeloma brings

Myeloma UK is here with information and support to help you and to connect you with others with shared experiences.

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; with videos, news and articles to help you keep up to date and live well with myeloma.

Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.

Get answers to your questions by emailing our Myeloma Information Specialists at **AskTheNurse@myeloma.org.uk**

Order or download our **information booklets**, which cover all aspects of myeloma – call **0800 980 3332** or visit **myeloma.org.uk/publications**

Learn about myeloma from experts and meet other patients at our **Infodays** and **Digital Infoday Sessions**.

Join a **Myeloma Support Group** to meet other people living with myeloma face to face or online.

Get matched up with a trained **Peer Buddy** for one-to-one support from someone with direct experience of myeloma.

Chat and share experiences with others affected by myeloma, including our peer volunteers, on the **Discussion Forum**.

We need your help

Thanks to our generous supporters we are able to provide information and support to patients and their families, as well as fund vital research that will help patients live longer and with a better quality of life.

Myeloma UK receives no government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a single donation or setting up a Direct Debit**
  Online at **myeloma.org.uk/donate**
  Over the phone **0131 230 0429**
  Or by posting a cheque payable to **Myeloma UK** to:
  Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG
- **Fundraising** – fundraising is a positive way of making a difference and every pound raised helps. As myeloma is a rare, relatively unknown cancer, fundraising is also a great way to raise awareness
- **Leaving a gift in your will** – legacies are an important source of income for Myeloma UK and help us to continue providing practical support and advice to myeloma patients and their families. They also help us to undertake research into the causes of myeloma and investigate new treatments

However you decide to raise funds, our Fundraising Team is here to support you. Contact us on **0131 230 0429** or email **fundraising@myeloma.org.uk**

Nobody ever forgets the moment they are diagnosed with myeloma. Myeloma UK advances the discovery of effective treatments, with the aim of finding a cure. That is what patients want, it's what they deserve and it's what we do.

Judy Dewinter – President, Myeloma UK

We appreciate your feedback. Please fill in a short online survey about our patient information at **myeloma.org.uk/pifeedback** or email any comments to **myelomauk@myeloma.org.uk**

For a list of references used to develop our resources, visit **myeloma.org.uk/references**

Symptoms and complications Infoguide:
Fatigue and myeloma

MyelomaUK

We're here for everything a diagnosis of myeloma brings

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

Call the Myeloma Infoline on
0800 980 3332

Email Ask the Nurse at
AskTheNurse@myeloma.org.uk

Visit our website at
myeloma.org.uk

Trusted Information Creator
Patient Information Forum

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