Disclaimer

The information in this Infopack is provided for the benefit and personal use of myeloma patients.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified healthcare professional. In respect of legal, financial or other matters covered by this information, you should also consider seeking professional advice about your personal circumstances.

Whilst we try to ensure this information is accurate, we do not accept liability arising from its use.

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

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Introduction

Who is this Infopack for?
This Infopack has been written for all myeloma patients to help them live well. It may also be helpful for carers, family and friends to read.

What does this Infopack contain?
Myeloma is a unique and individual cancer. It can affect all areas of life, sometimes in unexpected ways. This Infopack covers the many different ways in which myeloma can affect your life and aims to help you navigate any challenges that may occur, both practical and emotional.

The quotes throughout this Infopack are from myeloma patients and their families and friends. Many of them are taken from The small things that make a difference, a book of hints and tips written for people affected by myeloma by people affected by myeloma. It is available for order from Myeloma UK via the website or the Myeloma Infoline.

When and how should I use this Infopack?
This Infopack can be read at any time following a myeloma diagnosis. There are some topics and issues that will affect you immediately and some that may not yet apply to your situation.

You may like to read this Infopack to be aware of and prepare for any challenges that may occur while living with myeloma, even if you are not facing them yet.

You do not have to read this Infopack all at once. It has been split into sections to help you navigate the information as and when you need to. You may wish to read it in sections or use it to find answers to specific questions. You can read the parts you feel are relevant now and refer back to the Infopack later.

We have highlighted some key terms in bold throughout the Infopack, the definitions of which you can find in the Medical terms explained section.

How has this Infopack been developed?
The information in this Infopack has been gathered together from patients, their families and carers who have gone through what you are going through. The information in this Infopack has also been reviewed by healthcare professionals prior to publication.

Further information and support
The Myeloma Infoline provides information and emotional support to people affected by myeloma. You can call the Infoline on 0800 980 3332 or 1800 937 773 from Ireland.

We have also listed some useful organisations at the end of this Infopack in section 10 that you may want to contact for help and information or to talk about how you feel.
Coping with symptoms and side effects
Coping with symptoms and side effects

There are a number of symptoms and side effects that myeloma and treatment can cause. These can greatly affect you not just physically but psychologically too, as having to live with them day-to-day can be frustrating and tiring. Planning ahead and preparing can help you to cope with them.

This section describes the symptoms and side effects caused by myeloma and its treatment along with practical tips to help you cope with them.

Pain

Approximately 80% of myeloma patients will experience some kind of pain. Pain can affect you significantly both physically by limiting what you can do, and emotionally as it can be very mentally wearing. There are two main types of pain in myeloma: bone pain and pain caused by peripheral neuropathy.

Bone pain

Bone pain is a common problem for myeloma patients. It is caused by myeloma bone disease; myeloma cells in the bone marrow affect the surrounding bone, causing it to be broken down faster than it can be repaired. This leaves patients with areas of thinned bone, which can fracture easily. The extent of myeloma bone disease varies considerably from patient to patient. It most often occurs in the middle or lower back, the hips and the rib cage.

If you have myeloma bone disease you will be treated with drugs called bisphosphonates, which help to stop further bone damage. You will also be given painkillers to help manage the pain.

Myeloma bone disease can prevent you from doing certain activities which put you at risk of fracturing bones, such as high impact exercise or contact sports. You may feel a sense of loss if you enjoyed these types of activities, so try exploring new ways of exercising or hobbies.

The pain itself can interrupt your normal activities and prevent you from feeling able to live as you normally would.
Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to the nerves that make up the peripheral nervous system (the nerves outside the brain and spinal cord, which includes nerves in your face, arms, legs, chest and some in your skull).

This is a fairly common side effect of certain drugs such as thalidomide and bortezomib (Velcade®), and approximately 80% of patients develop it at some point. The nerves most commonly affected are those of the hands and feet, which causes symptoms such as altered sensation, tingling, numbness or pain.

Symptoms of peripheral neuropathy often start off gradually but can become more problematic over time. Therefore, it is extremely important that you inform your doctor or nurse as soon as you start to experience any symptoms. Peripheral neuropathy is often more manageable if diagnosed early.

Tips for managing pain:

- Take painkillers regularly as prescribed. They will be more effective if you take them before the pain takes hold
- If you are taking your painkillers as prescribed but your pain is not being managed properly, speak to your doctor or nurse. They will be able to change the dosage or give you a different painkiller to help. There are many different pain-relieving treatments available and it is often a case of trial and error to find the best pain treatment plan
- Avoid taking non-steroidal anti-inflammatory drugs (NSAIDs), e.g. ibuprofen, as they can damage the kidneys
- Be honest with your doctor or nurse about any pain you are experiencing. You should not feel you have to put on a brave face – remember that your doctor and nurse are there to help you
- Describe your pain as accurately as you can, i.e. dull and aching, piercing, transient or constant. It may be helpful to keep a diary of when you feel pain and what it is like
- Learn relaxation, meditation or visualisation techniques. A combination of these can be helpful in relieving pain. They need to be practised regularly to get maximum benefit

Peripheral neuropathy can affect your ability to drive. You must tell the Driver and Vehicle Licensing Agency (DVLA) if you develop this side effect.

For more information see the Peripheral neuropathy Infosheet from Myeloma UK
Try to reduce your anxiety levels – anxiety and stress can make pain worse. Talking, counselling and complementary therapies can help.

Complementary therapies can be used in addition to the treatments prescribed by doctors. However, it is very important that patients report the use of any complementary therapies to their doctor to enable them to discuss any possible harmful effects.

Massage may help with relaxation and pain, but make sure it is gentle to avoid further discomfort or damage to your bones. Only use an experienced massage therapist and explain your situation to them.

Find something to take your mind off the pain – watching television, a favourite film, listening to music or chatting to a friend won't make your pain go away but it can distract your attention from it.

Make use of heat and cold – hot water bottles and ice packs can be effective pain relievers. Wrap them in a towel before placing them onto the skin. They may only give short-term relief and you may need to alternate between warm and cold.

Make sure you are sitting comfortably – the way you sit or lie can affect your pain. Try using special v-shaped pillows to help you get more comfortable when sitting in bed.

If your pain is not being controlled by your prescribed painkillers, or with the addition of any of the above, ask your doctor or nurse for a referral to a pain specialist who will be able to adjust your painkillers for a better response.

“Seek advice – don’t suffer in silence. Get the pain relief that works for you.”

For more information see the Pain Infoguide from Myeloma UK.

Fatigue

Fatigue is an extreme ongoing tiredness, lethargy or exhaustion which persists most or all of the time and isn't relieved by sleep. It can be caused by myeloma and/or its treatment and is a very common problem for myeloma patients, affecting over 90% of patients. Living with fatigue can have a huge impact on your quality of life and can be extremely challenging for you and your family.

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

Fatigue is like hitting a brick wall head on whilst carrying heavy lead weights – no way round it and no way over it.

Fatigue may be caused or made worse by many things, including anaemia (low red blood cell count), poor nutrition, pain, drugs used to treat myeloma, anxiety and depression. There is a well-established link between fatigue, chronic pain and depression. These can affect daily activities, relationships with others and self-esteem, which can in turn lead to increasing feelings of isolation, fear and loss of confidence. These can be very draining emotions and easily increase feelings of fatigue.

During treatment, fatigue is sometimes better understood and managed as patients are usually told it can be a potential side effect. The time many struggle most with fatigue is after treatment has finished when everything should, in theory, be back to “normal”. Fatigue can stop you doing the things that matter to you and can be upsetting and distressing to live with, but coping strategies can help.

There are a number of ways to cope with fatigue:
• Make sure you are eating a well-balanced diet
• Ask your doctor to refer you to a dietician if you are having trouble eating
• Ensure any pain is being managed effectively
• Make getting enough sleep a priority and get into a routine – going to bed and getting up at the same time every day
• Try complementary therapies
• Take gentle exercise every day – this can actually help to improve your energy levels. You can ask your doctor to refer you to a physiotherapist who can recommend some suitable exercises for you. See section 6 for more information about exercising as a myeloma patient
• Pace yourself and keep a diary so that you can recognise when you are most likely to need rest and when you are most likely to be able to do chores or gentle exercise
• Allow yourself rest periods during the day. This can be a nap or just a sit/lie down

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

For more information see the Fatigue Infoguide from Myeloma UK
Nausea and vomiting

Nausea and vomiting are two of the main side effects of some myeloma treatments. Many myeloma patients find these side effects very upsetting but there are things that can be done to control them. Often you will be prescribed anti-emetic (anti-sickness) drugs to prevent and control nausea and vomiting.

It is important to tell your doctor if you are vomiting as it can lead to dehydration and other complications if left untreated.

Tips for managing nausea and vomiting:

- Take your anti-emetics regularly as prescribed. Do not wait until you feel sick, as the drugs won’t be as effective this way.
- If you find the anti-emetics you have been prescribed are not effective when taking them as prescribed, ask to try a different one as there are several types available.
- Sometimes you may feel sick before having your treatment, especially if treatment has made you sick previously. Ask your doctor or nurse if it is ok to take your anti-sickness treatment before your myeloma treatment to help avoid this.
- Certain smells may make you feel sick, for example strong food smells. Avoid cooking foods with strong smells and keep the window open during food preparation.
- If hospital smells make you feel sick, try putting light perfume onto a handkerchief that you can use to help mask the smell.
- Certain scents may help with nausea, for example lavender can be soothing. Speak to a complementary therapist who should be able to recommend some aromatherapy scents to help with your nausea.
- Ginger flavoured drinks may help settle your stomach, or flat fizzy drinks.
- Mints or chewing gum can help with nausea and freshen your mouth after vomiting.
- Try to take your mind off how you feel – talk to people, watch a film or listen to soothing music to distract yourself.
- Relaxing breathing exercises or lying down in a darkened room may help to reduce feelings of nausea.
- Fresh air may also help calm nausea – try sitting near an open window or outside.
- It is important to keep drinking as vomiting can dehydrate you. Allow your stomach to rest after vomiting then sip drinks such as still or sparkling water or fizzy drinks.
- If vomiting is severe, fluid can be replaced by special preparations available through your GP or from a chemist.

“...I found soda water was good for nausea and it keeps you hydrated...”
**Gastrointestinal problems**

Gastrointestinal problems Diarrhoea and constipation are common side effects of myeloma treatment. They can be very unpleasant to live with and can lead to serious problems if they are not dealt with.

**Diarrhoea**

Diarrhoea is the passing of loose or watery stools more than three times a day. It may last for only a short while (acute) or longer term (chronic). Excessive loss of water can lead to dehydration, so it is important that you speak to your doctor or nurse if you have diarrhoea for more than a few days. They will be able to give you treatment for it if they feel it is necessary. They may also suggest you use rehydration salts which are available over the counter.

"Do expect a ‘runny-tummy’. Pre moistened toilet tissues are a great help!"

Tips for dealing with diarrhoea:

- Drink plenty of water and clear fluids
- Avoid caffeine and alcohol
- Eat small frequent meals made from light foods – avoid highly fatty or spiced foods
- Wear comfortable clothes
- Use soft, good quality toilet paper; moistened, quilted or infused with shea or cocoa butter can be more comfortable to use

**Constipation**

Constipation is defined as difficulty emptying your bowels. When you are constipated, bowel movements occur less often than they would normally and may be dry, hard and painful. It can be acute or chronic.

Constipation may cause excessively runny diarrhoea, as your bowel is blocked with hard faeces.

Your doctor may prescribe you laxatives to help treat constipation.

Tips for dealing with constipation:

- Drink plenty of water and clear fluids
- Increase the amount of fibre in your diet
- Avoid caffeine and alcohol
- Exercise regularly
- Use natural remedies like flaxseed or linseed oil or syrup of figs, but discuss this first with your doctor
- Only take laxatives if recommended to do so by your doctor

"Try to adjust your diet to make sure you’re getting enough fruit, veg and nuts. I bought a juicer which I used daily in the first year."

Diarrhoea while on treatment with **lenalidomide (Revlimid®)** can be the result of a condition called bile acid malabsorption (BAM). This can be managed with treatment.
Hair loss or thinning

Hair loss is common with some kinds of chemotherapy. However, generally speaking, with the chemotherapy drugs used to treat myeloma, you may experience some thinning of the hair, rather than losing it all. The exception to this is the very high dose of chemotherapy used as part of the high-dose therapy and stem cell transplantation (HDT-SCT) process, when losing your hair is more likely.

Going through hair loss or thinning can be very emotional as it can affect your self-image and your identity, and you may feel like it is visibly labelling you as a cancer patient. Speak to your nurse about how it is making you feel and how best to manage it.

If you do lose some or all of your hair, remember that it will grow back once your treatment has finished. When your hair starts to grow back it is often very fine, but you will probably have a full head of hair after 3 – 6 months. You may also find that your new hair is curlier or finer than it was before and it may be a slightly different colour.

Cutting your hair short or shaving it off before treatment can give you a sense of control over your appearance and may keep it looking better during loss and re-growth.

You can lose a lot of heat through your head so you’re likely to feel the cold more. Some patients find soft hats, hoods, headscarves or wigs useful.

Many hospitals have a wig fitting service available, so if you think you may want a wig, ask your nurse about it. It may be easier to get a wig while you are in hospital receiving treatment. Usually wigs are available for free on the NHS in all parts of the UK but you may need to meet certain requirements depending on where you live and you may be limited in the type or number of wigs you are able to get. You can ask your hairdresser to style your wig on you to make sure it sits how you like it.

In some cases you may lose your eyelashes and eyebrows as well. You can use make up like eyebrow pencils and eyeliner, and false eyelashes if you like. Some cancer support groups may have workshops to help you learn application techniques. For example, Look Good Feel Better are a charity that hold workshops and classes that teach make up techniques for people with cancer.

"It was only with high-dose chemotherapy that I lost my hair, which knocked my confidence. I took hats and caps in with me in anticipation."

Mouth problems

Some chemotherapy drugs can cause mucositis, which can make your mouth sore, inflamed and blistered. Your mouth may become so sore that your eating is affected.

Your doctor will be able to give you something to treat or prevent these ulcers, such as a mouthwash. You can also help by making sure you clean your teeth gently and regularly using a soft toothbrush. You can try sucking on ice cubes or ice lollies during treatment to minimise the risk of mucositis.
Tips for when you have mucositis:
- Avoid food that sticks to the roof of your mouth such as chocolate, peanut butter or pastry
- Avoid spicy, salty or tangy foods
- Avoid mouthwashes that contain alcohol
- Drink cold drinks
- Moisten your food with gravy or sauces
- Allow food or drinks to cool slightly before consuming
- Drink through a straw
- Suck ice cubes or ice lollies
- Try using boiled sweets or chewing gum to stimulate saliva production

Some treatments can cause a change in your sense of taste and you may find that some foods taste unusually sweet, salty or metallic – this can be especially true after HDT-SCT.

Your sense of taste should return to normal after treatment has stopped.

Tips for when your sense of taste changes:
- Try different drinks and foods that you might not normally like to find something that tastes good
- Try not to worry if you can’t face eating three meals a day – snack throughout the day instead or eat little and often
- Season your food with spices and herbs
- Marinade food before cooking and use strongly flavoured sauces
- Try using plastic cutlery if your food tastes metallic
- Try drinking sugar-free flavoured drinks if water is unappealing
- Rinse your mouth before and after eating

“Experiment with food as taste changes.”

Loss of appetite

Your appetite may change over the course of your myeloma and treatment. Sometimes you may feel that you simply cannot face food. If this happens, try not to be discouraged by the fact that you are not hungry and just eat when you can.

Eating little and often may help, as well as planning meals around when you generally feel most hungry. For example, have a large breakfast and a smaller evening meal if you are always hungry in the morning. Always drink plenty of fluids, especially on days when you don’t feel like eating.

If your loss of appetite does not improve after a couple of weeks, or you lose a lot of weight, tell your doctor or nurse. They will be able to refer you to a dietician who can offer advice on how to eat a balanced diet and may recommend special high-calorie and high-nutrient foods and drinks.

See section 6 for more information about how myeloma patients should be eating.
Infection

Infections are more common in myeloma patients because myeloma and its treatments can reduce your white blood cell count, affecting your ability to fight infection. It may help to make some changes to reduce your chance of infection. This is particularly important if you have recently undergone HDT-SCT, or if you are neutropenic (very low level of neutrophils, a type of white blood cell). See page 91 for more information about eating when neutropenic.

Signs of infection include:

- Raised temperature (above 38°C)
- Feeling generally unwell or feverish
- Shivering
- Rash
- Cough or sore throat
- Diarrhoea
- Pain, redness or swelling around a cut or wound or around the entry point of your central line or Peripherally Inserted Central Catheter (PICC) line if you have one

If you develop signs of an infection, it is important that you contact your doctor or hospital immediately, especially if you are feeling unwell/shivering, as it may be necessary to start treatment as soon as possible. If you do not have contact details for your healthcare team for out-of-hours, phone NHS 111.

A course of oral (by mouth) antibiotics may resolve the infection, but if it persists, you may need an intravenous infusion of antibiotics given in hospital or other treatment.

Tips for avoiding infection:

- The most important thing you can do to avoid infection is wash your hands – you should wash your hands with warm water and soap regularly, particularly after using the bathroom, before handling and eating food, and after returning home from being out, using public transport or visiting other busy places like the supermarket
- Carry alcohol hand gel when you’re out and about to make it easier to keep your hands clean
- Avoid being in enclosed spaces like buses or trains when they are very busy
- Ask people not to visit if they or anybody in their household have colds, flu, stomach bugs or other infections such as chickenpox and shingles
- All food should be as fresh as possible, fruit should be washed and meat should be cooked thoroughly

Although it is important to try and avoid getting an infection as much as possible, you should avoid shutting yourself away or becoming paranoid. Take sensible precautions so that you can still enjoy life. Speak to your doctor or nurse if you are unsure about what you should be doing to avoid infection, particularly if your white blood cell count is low.
"Be sensible but not over cautious. At first I was reluctant to have takeaways, go to gigs or go on the tube. There is a middle ground, you can be careful but not paranoid."

For more information see the Infection Infosheet from Myeloma UK

Mind and memory problems
Mind and memory problems are common in myeloma and can be extremely frustrating. ‘Chemo brain’ is used to describe these issues as they are usually due to the effects of treatment. Everyone can be affected differently, but in general it is a feeling of mental fogginess, of being out-of-sorts and struggling to remember words or things.

Most people who experience chemo brain can still carry on with everyday activities but will find that certain tasks are harder than they used to be. The impact of chemo brain usually depends on what and how much you are doing, and often it is more noticeable once you are back at work or if you are trying to juggle many things at once. It can be incredibly frustrating and stressful, particularly if it is hindering your normal activities.

Although chemo brain is so called because of the effects of treatment – for example it is particularly common after HDT-SCT – other factors such as tiredness, infection and emotional state increase the likelihood of developing chemo brain.

Tips for coping with chemo brain:

- Try to minimise fatigue, stress and anxiety
- Try one or more complementary therapies as they may help reduce stress, such as massage or aromatherapy
- Make sure you’re resting well
- Write important details down – use post-its, a notepad or noticeboard
- Put everything in a diary or wall calendar – the Myeloma UK patient diary can help you keep track of appointments and treatments
- Prioritise tasks and activities so you’re not trying to do many things at once
- Set alarms and reminders on your phone
- Exercise regularly
- Do mental exercises like puzzles and crosswords
- Take time in the evening to reflect and process the day
- Tell your doctor, nurse, family and friends so you don’t have to cope on your own

myeloma.org.uk
Infoline: 0800 980 3332
“My philosophy now is that I don’t beat myself up when I have one of those moments.”

There are a range of different **supportive treatments** available to treat complications and side effects of myeloma and its treatment, so if your current treatment isn’t working, speak to your doctor or nurse who may be able to change the dose or type of treatment until they find something that works for you.

**Moods and emotions**
Moods and emotions

A myeloma diagnosis can be devastating and affect you and those closest to you in a number of ways. Your emotional and psychological wellbeing can be affected at any point following a myeloma diagnosis and can change over time. This can also affect how you are able to cope with any complications of myeloma or side effects of treatment.

This section describes some of the ways myeloma can affect your moods and emotions and also some ways to help you cope.

How you may be feeling

There is no right or wrong way you should feel. Sometimes you might feel positive and upbeat; at other times you may feel numb or sad. Your feelings are a natural reaction to your situation.

You may go through any or all of these emotions at some point, and revisit them often:

- Shock
- Denial
- Relief
- Hope
- Fear
- Anxiety
- Sadness
- Depression
- Anger
- Frustration
- Guilt

Sometimes you may be surprised by how you feel, and you may not know the reason why you feel the way you do, but this is common.

“You've got a sort of roller-coaster of emotions running through your treatment and indeed through your life with myeloma.”

The consequences of living with myeloma can be wide-reaching and may affect areas of your life that you were not expecting to change. Understanding and being aware of any changes and how they may make you feel can help you to work through them constructively.
Changes that you may face include:

- Loss of identity – many patients feel like they lose all or parts of their identity when they are diagnosed with myeloma. You may feel as though your life now centres on hospital appointments and treatments; who you were and your hobbies and interests before your diagnosis seem lost

- Loss of independence – you may feel like you are becoming increasingly dependent on others physically and emotionally. It can be very challenging for both you and those you are relying on for help to adjust to this

- Finances – a reduced income because you have had to stop working may cause you to worry

- The future – the unpredictable nature of myeloma can make planning for the future hard. Looking ahead and considering what needs to be done, feeling pressure to provide for others after you’ve gone or sorting legal matters can be upsetting and difficult

Although the effects of myeloma can be wide-ranging, there is support and advice available to help you sort through any of the issues affecting you. Some of the changes you face may be harder to adjust to than others, but some can be short-lived. See section 10 for more on help and support available.

Other factors can contribute to how you’re feeling which will be discussed in the following sections.

Treatment and monitoring

Being monitored and treated for myeloma can greatly affect how you feel. Below are some examples of how you may be affected at each stage post-diagnosis.

Diagnosis and pre-treatment

Most people have not heard of myeloma before receiving a diagnosis, which can make an already uncertain and difficult situation all the more confusing and scary. There is no ‘normal’ way to respond to a cancer diagnosis. You may experience a mixture of emotions and go through periods of feeling a certain way and then ‘revisit’ previous emotions.

For more information see the Infopack for newly diagnosed myeloma patients from Myeloma UK

During treatment

Treatment for myeloma can have a significant impact on your moods and feelings. This may be due to physical side effects or to the often mentally wearing routines of appointments and treatment schedules that have to be followed.

Anxiety before appointments and test results, and not knowing whether the treatment is working, can be stressful. If your test results don’t show as much of an improvement as you had hoped, you may feel discouraged and frustrated. Conversely, results can also bring encouragement if they show treatment is having an effect.
While you are on treatment you may rely more heavily on those around you, such as your partner, family or friends, for both physical and emotional support. It is not unusual to feel guilty because of this increased dependence.

**Reaching treatment ‘goals’**

If treatment gets your myeloma into remission, this can be hugely uplifting and be a cause for celebration. This can be a time where you may be able to put your myeloma aside and enjoy not being on treatment.

However, for some people the time and space available once treatment has finished allows their emotions to ‘catch up’ with them and they may be hit with feelings now they have time to process them. This can be particularly true if your diagnosis and beginning on treatment happened rapidly. Once the action and treatment plan is over, you may have time to take stock and the delayed impact of your diagnosis can catch up with you.

This can also be a time of worry, where the question of “When will my myeloma return?” sits in the background. This can cause underlying fear and anxiety that can affect both you and those around you. You may feel nervous about not having the same level of support from your healthcare team as you had whilst on treatment.

You may be left with long-term changes, both physically and emotionally, which others may not realise. People around you may struggle to understand the relapsing and remitting nature of myeloma – they may have assumed that you were ‘cured’ after your first round of treatment, or that because you are perhaps looking well, there is nothing wrong with you. This can lead to unmet expectations and resentment in your relationships, but acknowledging how you feel can encourage understanding and increased consideration. (For more information on the effect of myeloma on relationships see section 3.)

**Relapse**

Being told that you have relapsed or are refractory to treatment can be incredibly disheartening and distressing. It is normal to feel a mixture of disappointment, anger and frustration. You may be distressed in general that your myeloma has returned, but you may also be dealing with the added disappointment of a shorter remission period than you had hoped for or expected. You might be disappointed about imminent plans that may not go ahead and, understandably, you may worry about coping with another round of regular hospital appointments, tests, treatment and possible side effects.

You may also find yourself concealing your stress in an effort to protect those close to you, which can contribute to difficult or distressing feelings and emotions. Worry about family, work, finances or a feeling of vulnerability can place additional demands on your mental strength and spirit.

However, there are many treatments available for myeloma and your doctor will explain what the next steps are. Once your initial reaction has subsided and with some extra support, it’s possible for negativity to give way to hope and positivity.
Complications and side effects of myeloma and its treatment

Certain symptoms and complications of myeloma and side effects of treatment can significantly influence your mood, emotional wellbeing and coping mechanisms. Having to live with these unwanted effects can be wearing, making you tired, frustrated or sad. This can include complications and side effects such as:

- Pain – can make you irritable and affect your relationships with others
- Insomnia/lack of sleep – can make you depressed and easily upset
- Drowsiness and fatigue – can make you less sociable or unable to do as much as you’d like
- Risk of infection – can limit your activities e.g. holiday/travel, which can be frustrating and upsetting
- Risk of bone fractures – can limit your movement e.g. restricting what you can lift, which can be frustrating and upsetting
- Changes to your appearance – can change how you feel about yourself and may decrease your self-esteem

How to cope with these side effects and complications and to minimise the impact they have on you is explored more in section 1.

Steroids

Steroids, such as dexamethasone and prednisolone, are the backbone of myeloma treatment and have been shown to improve patients’ response to treatment. Unfortunately however, for most myeloma patients, already challenging emotions can be exacerbated by the side effects of steroids, the most troublesome of these often being the ‘neuropsychiatric’ effects. These can range from mild irritability to acute psychosis, with everything such as mania, euphoria, agitation, panic, mood swings, anxiety, insomnia, depression, distractibility, memory issues and delirium in between.

Living with these side effects can be particularly challenging; some patients have described themselves as completely different people when having treatment with steroids. Be aware of any changes in your mood or personality and discuss them with your doctor. They may suggest lowering the dose or changing the dosing schedule to help reduce the side effects.

For more information see the Steroids Infosheet from Myeloma UK

“...The steroids just messed with his emotional and mental state so hugely. ...”
How your emotions can affect you physically

As well as your physical symptoms and side effects affecting your emotional wellbeing, the reverse is also true; how you are feeling emotionally can influence your physical wellbeing. For example, stress, depression and anxiety can manifest themselves in physical ways, such as:

- Sleep disturbance
- Loss of appetite
- Loss of interest in sex
- Fatigue
- Diarrhoea
- Constipation
- Skin problems
- Difficulty coping with pain

Finding ways to cope with and manage your emotions can help to relieve the physical symptoms they may be causing.

Your healthcare team is there to treat both your physical and emotional wellbeing, so speak to them about how you’re feeling so they can treat you as appropriately as possible.

Depression

It is not uncommon to feel like you’re having more down days following a diagnosis of myeloma, but it is important to be able to recognise patterns in your behaviour and know when to seek help. Symptoms of depression can range from mild to severe and from person to person, but in general include:

- Feeling low or down for long periods of time
- Feeling numb or emotionless
- Feeling hopeless and helpless
- Being tired or lacking energy
- Changes in sleep habits – wanting to sleep a lot, having difficulty sleeping or waking up early in the morning
- Having difficulty making decisions
- Lacking any enjoyment in life
- Avoiding social contact with friends or family
- Lacking desire or motivation to do things you used to
- Having thoughts of suicide or harming yourself

It can be difficult to identify signs of depression in ourselves and it may be those around us who first begin to notice the signs. It can be a tough topic for others to bring up or to bring up yourself. It is important to remain as open and honest as you can with those closest to you and to let them know how you’re feeling. This can be challenging if you don’t feel you’re being listened to or are becoming increasingly withdrawn, but it is important to persevere and make sure you get any support you need.
There are many support services available including the NHS and independent mental health organisations and charities. Talk to your doctor or nurse if you notice signs of depression, they will be able to refer you to other services which may be of benefit. There can be a long waiting time for NHS services such as counselling, so if you are waiting for a referral appointment, try to take steps to help your depression as best you can, and access other services like charity helplines and online forums.

“Some side effects should be less of a taboo. At times I have felt very down and depressed and always wondered if others felt like this too or if it was just me.”

Addressing how you feel

Whether you’ve just been diagnosed, you’re on treatment or in remission, it is important for you to acknowledge how you are feeling and how it is affecting you. You are not expected to be positive all the time; how you are feeling will change with time and your circumstances. Difficult feelings may still be present at times. For the times you are not feeling so positive it is a good idea to give some thought to how you prefer to access support and what you find most helpful; whether this is informal support from family and friends, or more formal support through a counsellor or psychologist.

It can be challenging for patients to be aware of and access emotional and psychological support services, however there are a number of resources available to help you. If this isn’t something being addressed in clinic, you can speak to your GP or other non-NHS services like Maggie’s centres, the Myeloma Infoline, or local cancer support centres. See section 10 for a list of places and people to whom you can turn for help and support.

Self-help tips

Learning to cope with your emotions will involve a degree of self-care. Below are some methods that may help you cope with how you are feeling.

Continue with what’s important

It’s important to continue to enjoy the things that matter in your life. Hobbies, people and spirituality can make a big difference to your wellbeing. Focussing on what’s important to you and carrying on with the things that matter can help you feel better. Try to plan an enjoyable activity every day.

Talking

Talking to your friends and family about how you feel will help them understand what you are feeling and how this is affecting your relationships. Talking could also take the form of counselling, if you prefer speaking to someone outside your circle of friends or family. Talking through problems or getting feelings off your chest can be a key step in improving relationships and often can improve your mood.
I was trying at that point to deal with work and home and fit everything in. I found it very useful just to talk things over and get things straight in my head.

Diet and exercise
Maintaining a healthy diet and exercise programme can help you feel better and can boost your mood. Although myeloma and treatment can interfere with your desire to eat and your taste preferences, you will feel better if you maintain a healthy and balanced diet. Gentle exercise can be a good way of relieving stress and tension.

Information
Being informed about your myeloma can help you feel more in control and can make it easier to discuss your treatment with your doctor. Myeloma UK provides publications covering an extensive range of topics, which you can access in your own time and get as much information as you feel comfortable with. These can be downloaded or ordered from the Myeloma UK website or via the Infoline. If you have questions that need answering, you can call the Myeloma Infoline and speak to one of the Myeloma Information Specialists on 0800 980 3332.

Mindfulness or meditation
Mindfulness or meditation is about paying attention to the present and being aware of your thoughts and feelings. They can be useful tools to help you feel calmer and less anxious.

Releasing emotions
It is much healthier to let out your emotions than to bottle them up. Expressing yourself creatively by painting, drawing or playing music etc., or releasing them by allowing yourself to cry or throw a pillow can be beneficial. Whatever you feel like doing, channelling your negative emotions into something is likely to help you feel less stressed and tense.

Recording feelings
You may find it useful to write down how you feel, as physically putting things down on paper can help you sort through how you feel. It may be particularly of benefit for those who prefer not to talk about how they feel.

Writing can also reveal any patterns in your emotions that may occur, like feeling grumpy in the afternoon when you are tired or anxious before appointments. You can then take steps to help alleviate these emotions – for example, by having a short nap in the afternoon or planning a fun activity to do following an appointment.

Positive changes
Although it may seem like a myeloma diagnosis will only bring negative changes, it can bring positive changes to your life. As you are forced to slow down and deal with a whole new range of practicalities and issues, you may begin to appreciate different things and change your priorities in life. Many patients gain a new perspective
after diagnosis and choose to make more time for family and friends, passions and hobbies, and other things that bring them joy.

You can watch videos on the emotional impact of myeloma online at myeloma.org.uk/videos

“It makes you not quite so caught up in what is – in the grand scheme of things – quite insignificant day-to-day fluff and to focus on what’s really important.”
Relationships

A myeloma diagnosis will affect many people, not just the patient. It can bring significant challenges and impact on the different relationships you have. The emotional, psychological and physical challenges that you, your family and friends go through can affect your relationships.

This section describes some of the ways myeloma can affect your relationships with your partner, children and grandchildren, and other family members and friends.

Whether you live alone or with many people, myeloma can alter the different relationships in your life.

Experiencing periods of depression and anxiety is not unusual when living with myeloma but these periods can put your relationships under strain and you can feel more withdrawn and reluctant to see friends and family. This may also be true if your myeloma or treatment has affected your self-esteem, for example if the way you look or feel about yourself has changed and so you would rather not see those around you.

Relationship with your partner

Each relationship is unique so the impact of myeloma will vary between couples. For most couples, however, dealing with a myeloma diagnosis on top of the usual challenges and stresses of life can be difficult, and may cause extra strain on your relationship. Living with myeloma can change the dynamic of your relationship with your partner and accepting these changes can be challenging.

Role changes

Financial or practical reasons may force you to take on new roles within your relationship, particularly relating to work. For instance, you may not be able to work anymore or your partner may need to work more than before. Changing your work situation can have a big impact – you may feel like you have lost part of your identity if you stop working or your partner might feel like they are trying to take on a new identity as the main breadwinner.
Further role changes may come if there is a transition in your relationship from partners to a patient/carer dynamic. This can be difficult to adjust to and it is not uncommon for this to cause resentment from both parties.

**Anger and guilt**

You may experience feelings of loss for your old relationship if you are no longer able to do the things that you used to enjoy. This can lead to resentment, anger and guilt as you look back on what you used to have and find your ‘new normal’ difficult to come to terms with. Either partner can become frustrated that life seems to revolve around hospital appointments and treatment, and the chance for spontaneity is reduced.

Often it can feel like you must remain positive at all times and keep any negative fears or concerns hidden away from your partner. However, this can bring feelings of guilt when you don’t feel upbeat and when you’re unable to cover up these emotions. It is normal to have days where you don’t feel positive, and allowing yourself to express how you really feel can stop things building up and getting worse.

Anger and guilt can also arise from feeling like a burden to your partner or through setting unrealistic expectations of each other.

“It’s perfectly normal to have bad days and there’d probably be something quite wrong with me if I didn’t, but that doesn’t stop me feeling guilty for it.”

**Facing the future**

Coming to terms with the prospect of a different future from the one you and your partner had planned can be painful – it’s hard and sad to see your horizons shrinking. It can also make the carer think more about their own frailty and mortality. As a patient you may become so focused on providing for your partner when you’re gone that you stop living in the ‘here and now’, which can cause difficulty between partners.

“I feel angry that I’m not going to get the future I wanted.”

**Dealing with changes**

Some of the changes that come from living with myeloma can be stressful and difficult, and people process circumstances in different ways, which can lead to problems within a relationship. Sometimes couples push each other away emotionally so they can process their emotions or as a way of coping with the situation. You and your partner might feel different emotions at times, which will require a great deal of understanding for each other.

Although this can be hard, it can strengthen a relationship as it can offer a chance to discuss issues and problems you have had and develop a deeper love and understanding for each other. It can also bring you closer as a couple and spur you on to make the most of the time you have together by doing things that are...
important to you both, such as spending time with each other, going on holiday and enjoying your mutual interests.

For more information about the impact of myeloma on carers see the Infopack for carers of myeloma patients from Myeloma UK

Relationship with your children and grandchildren
It’s natural to want to protect your children and/or grandchildren from difficult news. It can also be very distressing for you to think that you may not see your child grow up and reach their significant milestones. The physical limitations that myeloma might impose on you may also change your relationships with your children and grandchildren. This can all be very upsetting.

Telling your children or grandchildren about your myeloma
Children are often very sensitive and can pick up when something is wrong which can cause them to worry and be distressed. It can be daunting telling children about your diagnosis but talking about myeloma can provide them with the opportunity to ask questions and express their worries. This can help to support them as they come to terms with what’s happening. There is no right or wrong way of telling your children or grandchildren about your myeloma but you may find it helpful to have a partner, friend or family member there with you to help answer any difficult questions. If you have just been diagnosed you may want to wait a while before telling them to allow yourself to come to terms with your diagnosis first and find answers to questions your children may have. It can be helpful to use information books or leaflets to help you explain. Myeloma UK have developed a book for children to help explain what myeloma is in an easy and child-friendly way. ‘Kelsey and the Yellow Kite’ 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/publications

Older children
Older children may feel that they have to take on a bigger role within the family, particularly if you are a single parent or don’t live near other family members. It can feel at times like a reversal of roles between parent and child which can be difficult, especially if your children are still living at home and aren’t able to do ‘normal’ things like their friends. Your children may find it difficult to communicate with you, particularly when you are feeling unwell, or to communicate their feelings, and it may take time for you to adjust to a different way of being a family.

Positive impact
In some cases, your myeloma may bring you closer to your children and family as a whole. It can give you a shared focus and help to reassess what is important. You may choose to focus on them rather than on work or other things in life.
Relationship with other family and friends

Everyone deals with cancer differently. For some people, talking about cancer can make them feel uncomfortable. They feel like they don't know what to say or don't want to upset you and so avoid the topic entirely. Some patients find that family and friends avoid them and spend less time with them because of this. Try not to let it upset you if you find this happens to you – it’s not a reflection on you but is their own coping mechanism.

It can be difficult for you and the people in your life to have to learn new information and cope with the different tasks, activities and emotions that come with myeloma. The amount of information to take in can be overwhelming and family and friends may struggle to comprehend what is happening. Some may choose to ignore the topic while others may want to talk about it all the time at the expense of asking you anything else about your life. People often take their cue from the patient so you should decide whether or not to bring it up in conversation.

Many patients find it hard “looking well on the outside” to family and friends while dealing with challenging issues, either physical or emotional, on the inside. This can cause family and friends to forget what you’re dealing with and possibly expect too much of you. As you go into remission or improve there may be an expectation for things to return to “normal”. This can be difficult to deal with, because you may have continuous worries in the background, or you may feel differently from how you did before your diagnosis. Try to be open and honest if you are in this situation, your family and friends may have made assumptions and will appreciate being told how you really feel.

Sometimes the way in which some family and friends may offer or provide support may not be what you need. Although they are well-meaning, you should talk to them and explain what you need from them to prevent misunderstandings or hurt feelings. This may be particularly beneficial if you need some space so your family and friends don’t feel pushed away.

“Be open and honest about your myeloma. It’s not your fault that you have myeloma and you shouldn’t feel guilty.”

Positive changes to relationships

Not all changes to your relationships will be negative and for some, a diagnosis of myeloma can have a positive outcome on relationships. A common focus and desire to spend quality time with people you love can renew and strengthen relationships and bring families closer together, especially more distant families. It may provide the opportunity to reassess your priorities, spend quality time with your family and friends and do the things you have always wanted to do with them.
Coping with relationship changes

Coming to terms with the changes in your relationships can be difficult. Feelings of loss and sadness are common, but there is support available to you to help you and your relationships.

Talking to your friends and family can be key in helping you get through difficult patches or challenges. This will help you understand how each of you are feeling and what your needs are. It might be helpful to do this in a more formal environment, such as in counselling. You can have counselling alone or with your partner or family member to help you get through any difficulties you may be facing in your relationship.

Myeloma can be unpredictable and things can change quite quickly. This can be disheartening for people if you have plans that need to be cancelled. Encourage them to be understanding and flexible. You might find it helpful to set aside time to spend with those close to you on a regular basis so if you have to cancel you know when you’ll be seeing them next.

If continuing with your usual routines is challenging, explore new ways of relating to your family and friends. Trying out different activities and methods of staying in contact that suit your needs and ability can be a good way of maintaining relationships under new circumstances.

“Obviously it has had massive implications for our future, but it’s there and we can’t change that. We can just live in this moment we’re in and make the best of it.”

Starting a new relationship

Sometimes you might feel that myeloma has caused you to put your life on pause, but it doesn’t have to. Life doesn’t have to stop because you live with myeloma and if you are single it can be completely normal to think about starting a new relationship. You may be nervous about starting a new relationship while living with myeloma.

Telling a new partner about your myeloma

Openness and honesty should be part of any relationship but it can be difficult to find the right time to bring up serious topics. There is no hard and fast rule about what to tell your new partner or when to tell them. Consider how secure and safe you feel in your new relationship and when you are ready to tell your new partner, try telling them somewhere you feel relaxed, safe and comfortable discussing it.

People will respond in different ways, they may feel overwhelmed, anxious or upset, or they could be relieved that you told them. They might not understand fully, particularly if you appear to be fine on the outside. Give them time and space to come to terms with it.
Sex and intimacy
Sex and intimacy

Sex and intimacy form an important part of who we are, how we see ourselves and how we relate to others. The changes myeloma can have on your body can affect how you view yourself physically and emotionally and so can have a significant impact on your capacity for sexual feelings.

This section explores the effect myeloma can have on sex and intimacy and how you can still enjoy a fulfilling intimate relationship when living with myeloma.

Everybody has different sexual wants and needs and there is no “normal”, only what is normal for you. Your capacity for sexual and intimate feelings is made up of and affected by biological, emotional, psychological and social factors. Your thoughts, feelings and physical and physiological changes in your body can affect your desires.

Challenges with sex and intimacy

There are many reasons why your sex life and desire to be intimate might be affected by myeloma. The physical complications myeloma can cause can have a significant impact on how confident you feel, how you view yourself and how your partner views you sexually. Often there are a number of both physical and psychological factors which can contribute to issues with intimacy.

Myeloma and its treatment

Myeloma can cause several complications which can be challenging, such as pain and fatigue, and treatment can also have physical side effects like nausea and sickness. These complications and side effects can prevent you from feeling sexual and/or reduce your desire to have sex and ability to be intimate with someone.

Physical complications and side effects can also affect you emotionally and psychologically. Physical changes caused by myeloma and its treatments, such as hair loss, height loss and weight change, can affect your self-esteem and how you see yourself as a sexual partner.
Non-physical changes associated with a myeloma diagnosis, such as anxiety, uncertainty about the future, financial worries and concerns for your family, can pre-occupy your thoughts and you may feel that you don’t have the time or energy to be intimate with someone and you can find it hard to ‘switch off’ from these worries to enjoy intimate moments.

The impact on the partners of patients

It is important to discuss any changes in feelings that you have with your partner but consider that your diagnosis may also affect your partner’s attitude to sex and being intimate.

Any changes in your self-esteem can affect how your partner views you as a sexual partner and they may too become more withdrawn sexually.

Partners may think it is selfish to be thinking about sex when you are living with a serious diagnosis and having to cope with the complications and side effects of myeloma and treatment. Your partner may be concerned that being intimate will hurt you or initiating sex will make you feel pressured.

Worry about finances and uncertainty about the future can preoccupy partners as well as you and affect their sexual drive. Taking on additional household and domestic tasks can also leave them feeling exhausted and reduce their desire and energy to have sex or to be intimate.

Physical problems

In some cases you may have some physical limitations caused by myeloma and/or its treatment which can make it more difficult for you to have sex. Physical changes, such as erectile dysfunction and vaginal dryness, can occur as a result of getting older, but some myeloma treatments such as bortezomib can also cause or contribute towards these physical problems.

The psychological factors previously discussed can also exacerbate things. Stress and anxiety in particular can disrupt how you would normally respond physically to sexual desire and arousal.

"When you’ve got that much structural damage to the body, it affects the ability to be intimate. You couldn’t even give him a cuddle or anything because everything hurts."

Challenges discussing sex

Discussing your sex life with your partner or doctor can be uncomfortable and there may be particular reasons you feel unable talk about it.

With your partner

It can be hard to discuss sexual issues with your partner when there are many other competing priorities in your day-to-day life. Hospital appointments, myeloma treatment, financial concerns can all prevent you from setting aside time to talk to your partner about how
you or they are feeling about being intimate. This is particularly true if you also feel guilty for worrying about sex when there are other issues to consider, so you may be reluctant to bring it up.

You may be unsure how best to bring up the subject without offending your partner. If you have a reduced libido or are not physically able to have sex, you might feel like you have let down your partner.

With your doctor or nurse

It is also very normal for patients to feel reluctant about talking to their doctor or nurse about changes to their sex life. You may feel that your clinic appointments are too short and more focussed on your blood results and treatment plans so you don’t have the opportunity to discuss problems with your sex life. However, being intimate and our sexuality forms a huge part of who we are and it is very important to discuss any challenges or concerns.

Private and personal matters can be uncomfortable to bring up with your doctor. If you are a different gender, or if you have religious or cultural differences, discussing sex and opening up to your doctor or nurse may be too uncomfortable. Other barriers can also hinder openly discussing any sexual problems. If you are already feeling embarrassed or awkward and you feel your doctor or nurse is not encouraging the topic this may make you feel reluctant to bring it up yourself.

Overcoming sexual difficulties

Changes to your relationship and sex life are very rarely permanent and there are things you can do to improve them. Your relationship with your partner and your sex life may not necessarily go back to the way they were before you were diagnosed, but you can make adjustments, find a new normal and still enjoy a fulfilling sex life.

If changes to your sex life have occurred because of myeloma, there are a number of strategies that can help you to maintain an intimate relationship with your partner.

Talking to your partner

Often the best thing to do is to talk to your partner about your feelings, as this can help you both understand what the other is feeling and relieve some of the fears or issues you may have. Being open and honest with each other can prevent misunderstandings.

Try setting aside time in a comfortable place where you can both talk freely so you can bring up the topic with as little difficulty as possible. It may be uncomfortable at first, but once you start talking honestly, it may encourage your partner to do the same. Showing a willingness to talk and taking the first step can show your partner that it’s ok to talk about it.
Talking to your doctor or nurse

If you are finding it difficult to talk to your doctor or nurse, you can try:

- Writing down your concerns before your clinic appointment
- Practising what you want to say
- Briefly mentioning that you’d like to discuss it at the next appointment so the doctor/nurse is prepared to talk about it
- Phoning ahead and saying you’d like to discuss your sex life
- Speaking to another member of your healthcare team

If you still feel unable to talk to your doctor or nurse, you can phone the Myeloma Infoline on 0800 980 3332 to speak to a Myeloma Information Specialist, who will be able to talk through any issues or challenges and answer any questions you have.

“*The Myeloma Infoline really helped me formulate the questions I wanted to ask the doctors at the hospital.*”

Sexual counselling

Sexual counselling can be a helpful way of discussing any emotional or psychological difficulties you are facing in your relationship or sex life. A sexual counsellor is a trained professional who is used to discussing and helping to resolve sexual challenges. They will provide a relaxed environment so you are comfortable talking about your difficulties.

Boosting your self-esteem

Boosting your self-esteem can make you feel better about yourself and can also help to remove any sexual barriers which may stem from this. You can try ways to change your appearance that will help you feel more confident, for example by dressing to suit a new body shape and size or trying a new wig. Organisations such as Look Good Feel Better offer a free beauty service which will teach you make-up techniques to suit you and may help to give you confidence.

You can gain confidence in yourself through activities you enjoy and are good at. It can also be helpful to spend time with people who make you feel good about yourself.

Sometimes a deeper and longer-term change is needed which can involve changing the way you think about yourself. This can be done through mental exercises like mindfulness or Cognitive Behavioural Therapy (CBT). Your GP can refer you for CBT, however it is important to be aware that appointments through the NHS may take some time.
Helping to encourage sexual confidence

If physical barriers are getting in the way of sex, there are a number of strategies which can help, such as:

- Planning ahead to avoid times when you know you will be more fatigued or nauseated
- Using vaginal lubricants and moisturisers
- Using erectile dysfunction equipment e.g. vacuum pumps or constriction rings
- Trying new or less demanding sexual positions

Your doctor or nurse may be able to recommend other ways of improving your sex life. This may include treatment for erectile dysfunction such as Viagra, however your doctor will tell you whether this is suitable or not.

Other ways of being intimate

If you do not feel like having sex or you are unable to, you can still be intimate with your partner by exploring different ways to show intimacy.

This can be fun and a good opportunity to try something different to see what you enjoy. You could try:

- Holding hands
- Cuddling
- Touching
- Bathing or taking a shower together
- Non-penetrative sex

The important thing is to do what feels comfortable and enjoyable for you and your partner. Intimacy is an important part of a relationship and can help you express your feelings and make your partner feel valued. Set aside quality time for each other to do the things you enjoy.
Fertility and myeloma
Fertility and myeloma

If you are of child-bearing age, you may need to think about the effect myeloma treatment can have on your fertility and how it might affect you, if not now then in the future.

This section describes the potential effect myeloma can have on your fertility and the subsequent effect this may have on your emotional wellbeing.

There are a significant number of myeloma patients who are diagnosed in their thirties and forties or even younger. For these patients, as well as facing the challenges of the diagnosis and treatment, there may also be the additional need to consider the potential impact of treatment on fertility and their ability to have children in the future.

Most myeloma treatments have little or no effect on your fertility, however, certain myeloma treatments can affect your fertility temporarily or permanently, for example the high-dose melphalan used as part of the HDT-SCT process.

Dealing with potential fertility issues in addition to everything else you have to cope with following a myeloma diagnosis can feel overwhelming. It can be very difficult to deal with a potential future without children if you had always hoped to have children or to have more children in the future. It can bring up a wide range of complex emotions even if you were not considering having children. It is important to discuss fertility with your doctor and/or nurse so they are aware of how you feel and can advise on your options before you begin treatment. It may be possible to have your sperm or eggs frozen and stored for future use and/or discuss other options such as fostering, adoption and surrogacy.

Effect of fertility issues

Sometimes questions around fertility can affect your relationship with your partner or how you feel about sex and intimacy. Finding out you may be unable to have children can impact how you feel about yourself and affect your relationship with your partner.
It is important to discuss with your partner and doctor any effect on your ability to have children that myeloma and treatment may have. This can be a difficult and unexpected situation to find yourself in and may bring forward a conversation with your partner that you perhaps didn't feel ready for. However, it is important that you and your partner are both aware of your options before you begin treatment.

If you are currently single but were hoping to have children in the future, you should discuss this with your doctor. There are several options you may want to discuss with your healthcare team including the possibility of storing your sperm or eggs before treatment begins.

Sometimes doctors may make assumptions about your desire to have children based on your age or relationship status; they may be so focussed on starting treatment that they do not check with you how you feel about any potential consequences to your fertility. If it is something you are concerned about and your doctor does not bring it up, it is important for you to bring it up yourself and to discuss your options.

**Egg, sperm and embryo freezing and storage**

Freezing your eggs or sperm may be a way of preserving your fertility until after your myeloma treatment or until you are ready to have a baby. This can be a complicated and difficult process so clinics should offer you the chance to have counselling before you begin treatment.

Egg freezing requires two to three weeks of hormone treatment to mature several eggs at once and then they are collected while you are under local or general anaesthetic. Your eggs will then be cryogenically frozen until you are ready to use them. The success rate for frozen eggs producing viable embryos in the future can be quite low and each stage of the process can be quite expensive.

Freezing sperm is more straightforward as no hormone treatment is required. A fresh sample can be provided at any time before your myeloma treatment starts. Using previously frozen sperm is usually as successful as using fresh sperm.

Embryos can also be frozen and may have a higher success rate than freezing eggs alone.

You may be able to get funding for egg, sperm or embryo freezing and storage from the NHS if you are freezing them because of your myeloma. However, this will vary according to where you live and what your circumstances are. Speak to your doctor if you are considering this as an option. Before any of your eggs, sperm or embryos are frozen, it is important to be clear on your legal rights and any consent given.

In some cases there may not be enough time to go through this process before beginning myeloma treatment and your doctor may not recommend delaying. You should take time to discuss it fully with your doctor before any decisions are made that may be irreversible.
Pregnancy prevention programmes
With some myeloma treatments, such as immunomodulatory drugs (IMiDs) i.e. thalidomide and its derivatives, lenalidomide and pomalidomide (Imnovid®), you will be required to adhere to a Pregnancy Prevention Programme, because these drugs are known to cause defects in unborn babies.

You will need to use contraception to prevent pregnancy while you or your partner are receiving treatment. These drugs can affect an unborn baby if either partner is being treated with them, so male patients must use condoms whenever they have sex with a woman of childbearing potential and female patients must use an effective method of contraception.

If you are a woman, you will need to confirm that you are not pregnant before starting treatment and you will need to take a pregnancy test before each cycle of treatment.

Your doctor will explain this programme in more detail before you begin treatment with any of these drugs.

Contraception
Some myeloma treatments can be found in semen, so men being treated with them will need to use a condom when having sex. These include the chemotherapy drugs melphalan and cyclophosphamide. You should also continue to use contraception for a year after chemotherapy treatment to prevent any of the drugs affecting an unborn child.

Menopause
Going through the menopause while living with myeloma can be an added challenge for women. It is a significant change and can affect how you feel about yourself and how you cope with myeloma and myeloma treatment.

Menopause is a transitionary period for your body and you will go through a variety of symptoms which can be very uncomfortable. Menopausal symptoms like fatigue, hot flushes and low mood can make coping with the side effects of treatment more difficult, and may heighten their severity. It can be particularly common to experience mood swings, low moods, depression and anxiety around this time and you may find that certain treatments for your myeloma increase/compound these symptoms.

Menopause may occur naturally with age for some women with myeloma, but certain myeloma treatments can induce early menopause, for example it is particularly common after HDT-SCT. You may find it emotionally difficult, particularly if you are younger than the typical age that menopause occurs, as you are faced with the loss of your fertility earlier than expected, and if you were hoping to have (more) children.

Hormone replacement therapy
Hormone replacement therapy (HRT) can be used to lessen some of the symptoms of menopause by replacing some of the hormones that are reduced as you go through menopause. Most women take a combination of the hormones oestrogen and...
progestogen which can be given in a variety of ways, such as tablets, skin patches, gels, creams and vaginal rings.

Your doctor will advise you whether HRT is suitable for you.

Diet and exercise
Diet

Myeloma patients often have questions about diet and nutrition – about what type of foods are best to eat or should be avoided. Many patients also want to know if there are alternative diets they should try. Despite the interest in special diets, there has been no rigorous scientific study of them in myeloma so their effects are unknown and unproven. Because of this lack of scientific evidence, no alternative diets are recommended for myeloma patients.

Myeloma patients should therefore follow the same basic principles of healthy eating that apply to everyone. Eating a healthy and balanced diet will help to maintain your muscle tone and strength, increase your energy and perhaps aid recovery after treatment. A balanced diet is also rich in essential vitamins and minerals which help the immune system to function more effectively.

A healthy, balanced diet should include:

**Carbohydrates**

Carbohydrates are a good source of energy. You should aim to have more complex carbohydrates like bread, pasta, cereals and rice, than simple carbohydrates, like sugar. A portion of a carbohydrate is about 80g and you should aim for three portions of carbohydrates a day, one with each meal. Try to have whole-wheat breads and cereals which have more fibre in them, as this can help with digestion.
Protein

Protein helps to build new cells and replace old ones. Foods that contain protein include dairy products, beans, pulses, nuts, fish and meat. Aim for 2-3 portions of protein per day from a variety of sources, and aim for at least two portions of fish a week, including one of oily fish. A portion of meat is about 70g, fish is about 140g and two eggs are a portion. Try to avoid processed meats, such as bacon and sausages.

Fruit and vegetables

Fruit and vegetables contain vitamins and minerals which are essential for many body processes, including the body's ability to resist infection and maintain healthy nerves and tissues. They are also a good source of fibre. Aim for at least five portions (about 80g or a handful) of fruit and vegetables a day and a mixture of colours. Fresh, frozen, tinned and juice all count towards your daily goal. If you're trying to lose weight, increase the proportion of fruit and vegetables you're eating and decrease the carbohydrate and fat content of your meals.

Dairy and dairy alternatives

Dairy and dairy alternatives, such as soy, oat and nut based products, are an important source of calcium, which is needed for bone health. They also are a good source of protein, vitamin A and vitamin B12. Dairy products can contain higher amounts of fat than other types of food so choose low-fat options if you are trying to lose weight. Aim for three portions a day (a portion of milk is about 200ml, yoghurt is 125ml and hard cheese is about 25g).

Fats

Fats are essential for vitamin absorption, body processes and a source of slow-release energy, however, not all fats are the same. A healthy diet consists of more fat from fish, nuts, seeds and olive oil (known as mono and polyunsaturated fats) than from meat, cheese, other dairy foods, cakes, biscuits and chocolate (known as saturated fats). Men should limit the amount of saturated fat they eat to 30g per day and women to 20g per day. Your total daily amount of fat should be limited to approximately 60g per day.

Other aspects of a healthy diet

- Salt – you should have no more than 6g a day. Ready-made and processed foods can contain a surprising amount of salt so be sure to check the labels
- Sugar – is found in many foods in our diet. Sugar that is added to foods should be limited to a maximum of seven cubes of sugar a day. Artificial sweeteners can be used to help ween yourself off sugar

Dietary supplements

In most circumstances a well-balanced diet with plenty of fruit and vegetables should provide adequate vitamins and nutrients to maintain general health, so vitamin supplements are not necessary. However, your doctor may prescribe a vitamin supplement if you have a specific deficiency, such as vitamin D.
Vitamin and mineral supplements such as magnesium, vitamin B complex (including vitamin B12), folic acid and alpha-lipoic acid are sometimes considered helpful in managing the symptoms of peripheral neuropathy. However, there is no firm research to support their use in myeloma.

If you decide to take any vitamins or dietary supplements, it is very important to let your haematologist know. This is because of possible interactions with treatment you might be on, or other complications you might not be aware of. For example, if you are having treatment with bortezomib you should avoid drinking green tea, taking green tea supplements or taking vitamin C supplements as they are known to interfere with the way the drug works.

You should avoid taking vitamin C in large doses (i.e. more than 500mg a day), as this can increase the acidity of urine which can damage the kidneys.

It is also best to avoid any supplements aimed at boosting the immune system (e.g. echinacea) since it is not known how these may affect your myeloma.

**Supplements as anti-myeloma treatment**

There is no evidence to support the use of dietary supplements in the treatment of myeloma.

Some dietary supplements have been studied in myeloma, but as yet there is no clear clinical evidence that these are of any benefit to patients. Of these, curcumin, the main ingredient in the spice turmeric, has been the focus of several laboratory studies as it is thought to have some anti-cancer properties. This has been studied in very small numbers of patients, but the results have been inconclusive.

Like with any supplement, if you are considering taking curcumin you must speak to your haematologist beforehand as it is known that it can interfere with some other drugs such as cyclophosphamide and some anti-coagulants (sometimes used as a supportive treatment for myeloma patients).

Green tea has also been reported to have beneficial effects in myeloma patients because of its antioxidant properties. At the moment however, there is no clear scientific evidence for the use of curcumin or green tea in myeloma.

**Drinking and fluids**

It is important to drink a lot of fluids as a myeloma patient, as myeloma can sometimes damage the kidneys and limit how well they work. Drinking plenty of fluids can help to keep the kidneys healthy and reverse the damage.

You are recommended to drink two to three litres of fluid a day. Most liquids count, including water, sparkling water, juice or squash, decaffeinated tea and coffee and milk. Caffeinated tea and coffee can be included, as can alcohol, but only in moderation as they can cause dehydration.
However, some complications, treatment side effects, and other treatments such as kidney **dialysis**, may mean that you should limit your fluid intake. Your doctor will always advise you if this is the case.

“A jug of water is useful to have next to your bed to remind you to drink.”

**Alcohol**

It is generally fine to have an occasional drink of alcohol but, as with most things, only in moderation. Some drugs can cause dizziness and/or drowsiness, so if you are affected in this way it may be best to avoid alcohol as it may make these symptoms worse. Your doctor or clinical nurse specialist will be happy to advise you on your specific situation in terms of the treatment you are receiving and with regard to your health overall.

**Impact of myeloma on your diet**

You may find that your appetite and dietary requirements will vary and eating and drinking may be difficult at times. Myeloma and its treatment can cause several temporary complications that may make it difficult to maintain a healthy balanced diet. They include:

- Loss of appetite
- Taste changes – e.g. a slightly metallic taste after chemotherapy
- Sore and/or dry mouth
- Nausea and vomiting
- Tiredness or fatigue
- Diarrhoea or constipation
- Anxiety and depression
- Increased appetite and weight gain – due to steroid use

It can be particularly difficult for patients to eat after HDT-SCT because of some of the side effects of treatment including nausea, vomiting and oral mucositis.

During these times when you feel unable to eat as you normally would, it is important to eat what you can and try not to worry too much. Tips that may help include:

- Eating small amounts regularly throughout the day
- Eating higher calorie foods
- Ensure that you are using any treatments for your mouth as prescribed by your doctor to clean and to maintain the health of your mouth. Ice lollies, fruit juice and soft drinks can help to keep your mouth feeling fresh
- Gentle exercise (e.g. walking) may stimulate your appetite
- If you are suffering from fatigue, try to cook larger portions on days you have more energy and freeze the leftovers for another day. Ask other people to help you with cooking and shopping or make use of online shopping and food delivery
- Maintain a high fluid intake even if you are unable to face food
- Speak to your nurse or dietician, they can provide nutritional, high-calorie, supplement drinks

For more tips to help you cope with mouth problems see page 21.

**Steroids and weight gain**

Some people find that they have an increased appetite while having treatment with steroids. You can ask to be referred to a dietician who can provide you with an eating plan to help minimise weight gain and/or to help weight loss if necessary.

**Neutropenia and a ‘clean diet’**

Although there is no evidence to support specific long-term diet recommendations for myeloma patients, there may be short periods when your diet needs to change. Specifically, this is when you are neutropenic as your risk of infection is much higher.

You will be recommended to avoid foods which can increase your risk of infection until your white cell count is normal again. This ‘clean diet’ will be explained to you by your doctor or nurse and they should provide you with a list of the foods that should be avoided during this time. These foods include:

- Raw or undercooked eggs
- Soft and blue cheeses
- Live yoghurts, e.g. probiotic yoghurts

- Meringue
- Shell fish
- Pâté
- Mayonnaise
- Unpasteurised dairy products, e.g. some soft ice creams

In addition, it is important to follow good kitchen hygiene i.e. chilling foods, separating raw and cooked meats, eating food within the use-by date, and using separate chopping boards for meat and vegetable preparation.

**Exercise**

Regular exercise is an important part of a healthy lifestyle and has many benefits for maintaining good health. It can boost energy levels, lessen fatigue, improve muscle strength, reduce feelings of anxiety and depression, increase appetite and improve quality of life. While you may not always feel like exercising, it is important to maintain a certain level of physical activity to improve muscle tone and strength, which can be lost after long periods of rest and inactivity.

The type of exercise you can do safely depends on your individual circumstances, for example your symptoms, any complications of myeloma and its treatment, your age and your general fitness before diagnosis. Some patients will have been very fit before their myeloma diagnosis – however, it is still important to be aware of the impact that myeloma may have had on your body and to adjust your exercise routine accordingly.
You should always speak to your doctor before you start exercising, regardless of your fitness levels before diagnosis. They may refer you to a physiotherapist who will be able to design a tailored exercise programme for you.

Benefits of exercising with myeloma

During periods of treatment and when myeloma is active you may feel like exercising less and it is ok to have periods where you are less active. However, prolonged inactivity can lead to muscle weakness, making everyday activities like climbing stairs, getting in and out of the car and housework more difficult, demanding more energy and making you feel more tired.

Whenever possible, you should aim to return to normal daily physical activities as soon as possible following treatment. Myeloma patients who maintain physical activity or exercise can maintain or improve their fitness levels, making day to day activities easier and improving quality of life.

Other benefits of regular gentle exercise include:

- Reducing feelings of stress, anxiety and depression
- Increasing appetite
- Improving quality of life

“Exercise as often as you can. I try and do a bit every day. It makes me feel and sleep better.”

Types of exercise

The most important thing to consider as you plan your exercise is the impact it will have on your bones. Myeloma patients often have weakened bones and should avoid sports and exercise that put them at risk of fractures. This means that high-impact exercises, such as jogging, tennis, squash or golf, and contact sports such as rugby, should be avoided if you have bone damage.

Gentle forms of exercise that myeloma patients can do include:

- Walking
- Swimming
- Cycling
- Aqua-aerobics
- Gentle gym work e.g. cross trainer
- Yoga, tai chi and other gentle stretching exercises
You should always warm up and cool down before and after exercising to help avoid muscle strains.

Aim to increase your physical activity slowly. Set yourself realistic and achievable goals and build up gradually until you are doing some form of exercise on a regular basis every few days. It is inevitable that you will have days when you feel more tired and other days when you have more energy. Try not to push yourself. Remember that improving fitness and mobility will take time and a ‘little and often’ approach is best.

**Exercise safety tips**

You should stop exercising and consult your doctor if you have any of the following:

- Shortness of breath
- Dizziness or nausea
- A sharp pain in a specific area
- Increased fatigue or weakness

Other exercise tips include:

- Avoid public gyms and swimming pools if you are at a higher risk of infection. This can occur if your white blood cell count is low, for example after HDT-SCT
- Minimise activities which have an increased risk of falling or jarring such as walking on uneven ground, especially if you have any altered sensation or numbness in your feet caused by peripheral neuropathy
- Avoid lifting heavy weights

- Wear supportive, laced shoes that fit well for exercising and make sure your trousers or skirt don't trail on the ground
- Always make sure your exercise space is clear and free of clutter
- Stop to rest if you are feeling breathless, don’t push yourself too hard
- Stop immediately if you feel any new or increasing pain and let your doctor/nurse know
- Build up gradually, a ‘little and often’ approach to exercising is best
- Pace yourself and listen to your body

Always speak to your doctor before starting any exercise programme or ask to be referred to a physiotherapist.
Finances
Finances

A diagnosis of myeloma can affect all areas of your life, including your finances. You may find yourself facing unexpected financial concerns.

This section covers some of the things you may need to think about as a myeloma patient regarding your work and finances.

Work

Whether or not you will need to give up work is a personal choice. It will depend on the nature of your job, how your myeloma and treatment is affecting you, the advice of your doctor, and your family and caring situation.

Much of myeloma treatment is oral which means you can take it at home. This can allow you to continue working during some of your treatment. However, you are likely to have ups and downs with treatment which can affect your ability to work, so you will probably need to take some time off at points. Similarly, the side effects and complications of myeloma that you have can restrict what you’re able to do.

It is a good idea to speak to your employer to explain the situation and what support you will need. Speak to your line manager and/or human resources (HR) representative at your place of work to see where you stand.

Some patients find a change of job is necessary, particularly if their work is strenuous and involves heavy manual labour, and some people decide that early retirement is necessary. Carers and family members who are proving support may also need to adjust their working lives.

Most financial worry for myeloma patients comes from having to reduce their working hours or to give up work completely and the subsequent loss of income. It is normal to worry if you find yourself in this situation, but taking practical and sensible steps can help.
Assessing your situation

A good starting point is to assess your current financial situation. This can help to identify any potential consequences your myeloma diagnosis may have on your finances and what steps you may need to take. It may also be helpful to talk through your finances with a bank manager or independent financial adviser.

It is not possible to know exactly what will happen in the future and how it will affect you or your finances but taking sensible precautions and planning for a number of eventualities can help you alleviate some financial worry.

Pensions

If you have a pension plan, it is recommended that you check your entitlements under the scheme and if payments will be affected by your change in circumstances e.g. if you are unable to work for a while or take early retirement. If you have a private pension it may help to discuss your financial position, needs and concerns with an independent financial adviser.

If you are considering early retirement on the grounds of ill health, you should discuss this with your doctor, your pension provider and HR department at work.

Budgeting

Budgeting is key to managing your finances. It will make you aware of your income and expenses and how you can balance them to stay out of debt.

To begin with, make a list of any regular income and assets (valuable items such as property) that you may have e.g. savings accounts, investments, pension schemes, endowments and insurance policies. Then make a list of your regular outgoings and financial commitments including bills and debts.

Work out how much money you have left once you have paid all your essential outgoings and then your non-essential expenses can be added or removed as your budget allows.

Cut back on and/or cut out what you do not need. It can be quite easy to identify ways of reducing non-essential expenses but you may need to get used to putting it into practice.

Reducing your non-essential expenses

Here are a few practical tips to help you spend less and stay in budget:

- Make use of special offers or discounts at hairdressers, shops, and other necessary service providers
- Turn off all electrical appliances rather than leaving them on standby and turn off lights when you are not in the room
- Take out a pre-budgeted amount of cash and only use that for the week. Leave your credit or debit card at home so you are not tempted to spend more
Keep a spending diary. Making a note of all your spending can be very useful and eye-opening – small expenditures here and there may not seem like much at the time but they can add up.

If your budget does not balance and your outgoings are higher than your income, you are at risk of building up debt. Once you have reduced all non-essential expenses, the next step is to look for any way to reduce your essential expenses and/or increase your income.

Reducing your essential expenses
Reducing the cost of your essential expenses like energy bills, mortgage and food can help prevent you getting into debt. However, you should not cut essential expenses to the extent that will potentially affect you and your health e.g. by not eating enough healthy food and not heating your home.

A few ways of reducing costs include:
- Shop for deals at supermarkets. Often buying in bulk can be cheaper
- Go shopping once and stick to a pre-planned list. Shopping when you are hungry or bored can tempt you into spending more than you need to. Online food shopping can be a good way to help you stick to a list and stop you picking up extra unnecessary items
- Use all your fresh produce and do not let it go to waste. If you are unlikely to use it all before the use-by date, freeze it or make a meal using it and freeze that

- Make your own meals and drinks at home instead of having meals and drinks out or getting a take-away
- Alter your mortgage payments, if you can
- Switch energy supplier to a cheaper one
- Change your mobile phone package so you are only paying for what you need and use
- Move to a flat/house with lower rent

Increasing your income
If you are unable to increase your working hours there are several ways you can increase your income. Possible ways of doing this include:
- Claiming any benefits you are entitled to
- Making any relevant insurance claims (e.g. if you have income protection, critical illness or private medical insurance)
- Claiming any tax rebates you may be due. Contact HM Revenue and Customs for more details and to make a claim

For information on benefits see the Managing your finances (benefits) Infosheet from Myeloma UK

Debt
If financial problems mean that you are getting into increasing debt or you cannot pay off the debts you already have, it is important to seek help as soon as you can. Make sure that you are receiving all the benefits
and help you are entitled to by looking online at www.gov.uk, speaking to a social worker or going to your local Citizens Advice.

If possible try to deal with any essential debts first e.g. outstanding mortgage or rent payments and utility bills, and in order of interest rate. If you are unable to pay your bills then it is important to explain to your creditors the reasons why you cannot keep up any payments – they may be prepared to accept reduced payments if they are aware of your circumstances. If you need to temporarily stop payments, ask them to freeze interest and penalty fees as well so your debt does not increase. Further help regarding debt can be obtained from the National Debtline and from your local Citizens Advice.

**Borrowing money**

Reducing work hours, stopping work altogether or retiring can put a strain on your finances and there may be times you are unable make ends meet, particularly if unexpected costs arise. Borrowing money will leave you in debt so it is advisable to explore all other options first and consult an independent financial adviser before committing to a loan.

If you do decide that borrowing money makes the most sense financially, look for a loan with as low an interest rate as possible. Sometimes friends or family will lend you money interest-free, however, this can lead to awkwardness or tension in some cases. Payday lenders offer small short-term loans but the high interest rates can end up costing you far more than you borrowed. When looking to borrow money, it is important to be aware of how much the loan will actually cost you.

**Credit cards**

Credit cards can be helpful to pay for extra expenses but relying on them can make you build up debt. Look for cards that offer low interest rates and try to pay them off quickly. Look out for penalties that incur fees which are attached to some cards.

**Credit score**

Your credit score depends on a variety of factors, but your health is not one of them. Effects of your myeloma may influence your credit score though, for example if you have had to stop working. A poor credit score may stop certain lenders letting you borrow money or they may increase the interest rate.

**Mortgages**

If you do not have mortgage payment protection insurance (PPI) and are experiencing financial difficulties then you should inform your mortgage lender as soon as possible. Sometimes it is possible to suspend payments for a short time, pay only the interest part of the mortgage or extend the term of your mortgage.

If the value of your house is much more than your outstanding mortgage then you may be able to remortgage your property and release some money.
If you are receiving Income Support or Universal Credit then you may be entitled to help with the interest part of your mortgage repayments.

If you are applying for a mortgage it is not always necessary to give your medical details. However, if life insurance or payment protection insurance are required then it is likely that you will have to give your full medical history.

Will
You may want to update your will or make a will if you do not already have one, to take into account any changes in your circumstances. A will lets you leave instructions about what will happen to your money, property and possessions when you die. A simple will is not usually expensive and could save your family costs in legal fees.

November is National Will Aid month. Will Aid is a partnership between the UK legal profession and nine charities. Every November, participating solicitors waive their fee for writing a basic will. Instead, they invite their clients to make a donation to charity. For more information go to willaid.org.uk

It is often advisable to discuss your situation with an independent financial adviser.

Energy bills
Often myeloma patients who have chemotherapy can feel the cold more than they used to, which may mean you need to increase the heating in your home. This can put an added strain on your finances. Some energy companies have special deals or offers for people on low income or who are in need of help with paying their bills.

- Energy Company Obligation – the big six energy suppliers (British Gas, EDF, E.ON, Npower, Scottish Power and SSE) have to help low income or vulnerable households (which includes those living with a long-term disability or illness) to save on their bills
- The Priority Services Register – myeloma patients can be added to this list of people who need extra care. It can give you access to free extra services and prevent your services being cut off if you fall behind on your payments
- Warm Homes Discount scheme – this scheme gives a rebate on energy bills to those receiving certain benefits or those on a low income
- Grants and awards – some energy providers award grants for cancer patients, which are administered by Charis Grants
- Fuel Management Programme – Npower can put cancer patients on the Fuel Management Programme which cuts their bills

Check with your energy provider to see if they can help you reduce your bills.
Insurance

Insurance can protect your finances from unexpected events. If you have myeloma, it is important to think about insurance. Insurers cannot discriminate against you because of your myeloma, unless it increases the risk of you making a claim. However this has to be backed up with evidence.

Life insurance

You may find it very difficult to start a new life insurance policy once you have been diagnosed with myeloma. Existing policies should continue but check with your provider about the terms and conditions of your policy.

Car insurance

Your car insurance should not be affected by your myeloma unless your myeloma or treatment is directly affecting your driving ability. If you have been advised against driving by your doctor, the cost of your car insurance may increase. Some insurance policies have a duty of disclosure clause which can mean a claim can be denied if you have not disclosed all relevant details. Speak to your insurance provider if you are unsure whether they need to know about your myeloma.

If you have had special modifications made to your car to suit your needs, it may cost more for insurers to repair it, which can make your policy more expensive.

Viatical settlement (also known as living benefit)

A viatical settlement is the name given to the transaction when an independent financial company buys an existing life insurance or endowment policy from a person who is not expected to live for longer than three years. This enables the person to have access to part of their policy value before they die.

If you are considering a viatical settlement, it is very important to discuss this with an independent financial adviser who will be able to advise you whether or not this is the best course of action.
Travel
Travel

Going on holiday should be an exciting and relaxing time, but myeloma patients can often be concerned about whether it is safe to do so and what extra precautions need to be taken.

This section outlines some practical guidance on travelling with myeloma to help make your trip as safe and enjoyable as possible.

Going on holiday is often one of the highlights of the year, offering a welcome break from routine and a change of scenery. This does not necessarily need to change after a myeloma diagnosis. With careful planning and a few sensible precautions, you can still enjoy holidays both in the UK and abroad.

Before you go

Driving

Whether or not you can drive is generally a personal decision based on how well you’re feeling. However, your doctor may advise you against driving, for example if you’re on particular treatments that can cause drowsiness, such as thalidomide. If you are intending to drive, you do not have to tell the DVLA that you have myeloma, however you must do so if it will affect your ability to drive. In particular, you are required by law to tell them if you develop peripheral neuropathy. They will judge on a case by case basis whether they feel it is safe for you to continue driving. You should check with your doctor (and the DVLA if necessary) in advance of your holiday plans.

Letters and treatments

It is always advisable to chat through your holiday plans with your doctor, especially if you are receiving treatment for your myeloma. Check that they are happy for you to travel before you make arrangements.

If you are currently receiving treatment, it may be necessary to wait until you’ve finished treatment before you travel.
Most doctors will be happy to write a letter for you to carry with you, outlining your previous and current treatment(s) and details about your myeloma. This could be invaluable should you fall ill whilst you are away.

It is very important that you have enough drugs with you to last for your whole trip and it is sensible to carry extra in case of any unforeseen delays.

Speak to your doctor about taking a course of emergency antibiotics with you, so if you pick up an infection you can treat it. As an added precaution you may also want to take some ‘just in case’ drugs with you – for example to deal with the onset or increase of diarrhoea, constipation or pain.

When travelling, the Home Office advise that all prescription drugs should be carried:

- In their original packaging
- In your hand luggage
- With a copy of your (repeat) prescription, or a note from your doctor detailing any treatments that you are taking with you

**Restrictions**

If you are travelling abroad and taking any controlled drugs with you (e.g. opiate painkillers), you will need a letter of ownership to prove you own the drugs.

If you are travelling for three months or more, or you have enough drugs to last you three months or more, you will need to apply for an export licence from the Home Office. You may also need to check with the Embassy or High Commission of the country you are visiting, or with the Home Office, in case they have any restrictions on taking your treatments (e.g. opiate painkillers) into the country.

Check the security guidelines of any airlines you are travelling with, particularly if you are carrying syringes, as you may need an accompanying doctor's letter.

**Treatment abroad**

If you know that you will need to have treatment (e.g. infusions or injections) whilst you are away in a country within the European Economic Area (EEA) or Switzerland then you will need to apply for an S2 form. The S2 form entitles you to state-funded treatment in these countries. Treatment will be provided under the same conditions of care and payment as for residents of that country. This could mean you have to pay a percentage of the costs personally.

Alternatively, you can apply for funding for treatment in the EEA via the EU Directive route. If you choose to do this however, you will usually need to pay for treatment up front and claim the cost back once you are in the UK. You may also need to apply for permission to have certain treatments in advance. The treatment can be given in the country’s state or private sector, but you will only be reimbursed up to as much as the treatment would have cost on the NHS.

You should speak to your GP or consultant haematologist about how to apply for funding for your treatment abroad.
Vaccinations
Depending on which country you are planning to visit you may need to have vaccinations before you go. As most myeloma patients have a weakened immune system, there will be restrictions on which vaccinations are safe for you to receive. Again it is important to discuss this with your doctor or nurse well in advance of your proposed travel dates.

Vaccines that are safe to receive include so-called ‘inactivated’ vaccines such as diphtheria, hepatitis A and B, inactivated polio injection, rabies, tetanus and typhoid injection.

Live vaccines that you should not receive include oral polio, oral typhoid, yellow fever and rubella.

Travel insurance
Getting travel insurance can be more difficult when you have myeloma, so it’s a good idea to start looking as soon as you can. Insurance for travel to some countries, particularly the US and Canada, can often be difficult to obtain and very expensive. You may therefore want to look into obtaining insurance before booking your holiday.

Some countries in Europe have reciprocal health arrangements with the UK. This means you will get the same care as the people who live in the country you’re visiting, which may not be the same as the care you’d expect to get from the NHS. To access this you need a free European Health Insurance Card (EHIC) from the NHS, which you can apply for online at www.nhs.uk/ehic or by phoning 0300 330 1350. An EHIC entitles UK residents to access state-provided healthcare in EEA countries and Switzerland on the same basis as a resident of that country, either at a reduced cost, or sometimes for free.

Each country’s health system is different, and might not include all the things you would expect to get free of charge on the NHS. This means you may have to make a contribution to the cost of your care and not every treatment will be available, so the EHIC is not an alternative to travel insurance. It will not, for example, cover any private medical costs nor help with getting back to the UK should you become unwell while on holiday. There are several specialist companies who provide tailored insurance for people with existing medical conditions such as myeloma.

For more information, including a list of travel insurance companies who specialise in providing insurance to people with pre-existing medical conditions, see the Travel Insurance Infosheet from Myeloma UK

Travel arrangements
Going on holiday or travelling as a myeloma patient can still be enjoyable and relaxing and you should not try to avoid it if you don’t want to. If you feel anxious about travelling, try planning trips closer to home to start with or plan trips that only require travelling by train rather than aeroplane.
When planning your trip, it is important to make sure that your travel plans are realistic and that you’re not going to be overdoing it on holiday.

You might want to think about how you can factor in plenty of rest during your travel.

It is advisable to think about any assistance that you may need whilst travelling. Most travel and airline companies will have a medical officer who should be contacted before your journey. They can then help with any special arrangements that you may need to make your trip more comfortable.

You can still travel the world with myeloma, albeit with a suitcase full of drugs.

Travelling

Long haul flights
Before you go on a long haul flight, you may want to discuss preventative measures to help reduce the risk of deep vein thrombosis (DVT) or blood clots with your GP, particularly because myeloma patients are at an increased risk of developing venous thromboembolic events (VTEs).

During the flight it is important to try to exercise by regularly moving your feet/legs as this will help prevent stiffness and can reduce your risk of DVT. Your doctor may give you prophylactic drugs, such as aspirin or warfarin, or suggest you wear compression stockings (flight socks) to reduce your risk of DVT. It is important to speak to your doctor before you take prophylactic drugs or wear compression stockings of your own accord.

All flights
It is important that you keep well hydrated throughout your flight. You may find it handy to have your own supply of bottled water rather than relying on the catering on the flight. However, you should remember that there are restrictions placed on what liquids you can take through the security checks at airports – bottled water can usually be purchased in the shops in the departure lounge after you have passed through security. It may also be worthwhile taking a small travel cushion or neck collar with you for extra comfort, particularly if your journey is quite long.

Ask to sit near the toilet or for a seat with extra leg room if you think this may help. It is often helpful to get up and move around at regular intervals throughout the flight to minimise pain and discomfort.

While you are away

Food and drink
When away it is important to remember to keep well hydrated. If you are in a hot climate you will need to drink more than you usually would. It is sensible to drink bottled water when away from home to minimise the risk of infection. Alcohol should be limited as it will cause dehydration and drowsiness.
You should try to maintain a well-balanced diet and eat regularly while you are away. It is not uncommon to develop stomach upsets whilst abroad so it is wise to adopt some sensible safety precautions when eating out. Try to eat only in restaurants that serve freshly cooked foods and avoid foods such as:

- Salads
- Ice in drinks
- Uncooked meat or fish
- Unsealed condiments like mayonnaise
- Street food that you don’t know has been freshly prepared or that has been sitting in the sun for a while

**Sun safety**

You will need to be particularly careful in the sun, especially if you are on, or have just completed, chemotherapy or radiotherapy treatment, as your skin will be much more sensitive to the sun's rays. It is important to apply an adequate sun block liberally and regularly, especially to exposed areas. Staying in the shade, wearing a hat and covering up with loose cotton clothing can all help minimise the risk of burning.

**Activities**

It is important that you enjoy your holiday, however, you should be sensible about any physical activities you do during your holiday. Just as you would when at home, you should avoid activities that pose a risk to your bones. This includes activities such as skiing or hiking. Swimming in the sea or a pool is a great way to exercise and can be very relaxing. It is best to avoid alcohol before swimming and remember that taking exercise on a full stomach can be uncomfortable. Don’t forget to reapply your sun block after swimming. You should avoid swimming if you have a central or PICC line in place as it can increase the risk of infection. You should also avoid swimming if your immune system is compromised, for example for the first three to six months after HDT-SCT.

The main thing for you to concentrate on when you are away is enjoying your well-deserved break. Remember to pace yourself throughout the day – if you normally have a rest in the afternoon, for example, try to schedule this into your day.

**Treatment away from home**

If you do need to buy drugs abroad, be certain about what you are buying and do not take anything you are unsure about. Do not bring any treatments bought abroad home with you.

If you are taking erythropoietin (EPO), or any other treatments that have to be stored below room temperature, remember to check that the hotel/apartment you are staying in has a refrigerator and that they will be happy for you to store your treatments.

If you do become ill when you are away, make sure a doctor reads your letter detailing your medical history. You should contact your insurance company as soon as possible – they should make all the necessary arrangements for you, and your travel companions, to get home safely.
Within the UK

If you are on holiday in the UK, take the phone numbers of your doctor, your nurse and the out-of-hours doctor at your hospital so that you can call them if you need any medical advice.

If a nurse normally administers regular treatment to you, it is often possible to arrange in advance for a local nurse to do this whilst you are away. It is also possible to arrange in advance to have dialysis away from home in the UK and even abroad. Your doctor or nurse will be able to tell you more about this.

When you return

You will hopefully return home rested and rejuvenated after an enjoyable time away. However, if you do start to feel unwell, particularly if you have persistent diarrhoea, an infection or a nasty insect bite, it is important that you see your GP immediately to receive the appropriate treatment. If necessary, try to make any insurance claims as soon as you return home, as you are more likely to remember events clearly.

For some, post-holiday blues are normal and you may feel that arriving home after your holiday is like coming “back to reality”. Try to focus on the positives of your holiday and not the negatives of coming back to your normal routine. Planning fun things to do after your holiday can help keep your mood up and give you something else to look forward to. If you feel like you’ve pushed yourself too much while you’ve been away and you’re a bit more run down than usual, take sensible precautions to avoid the increased risk of infection. Try to plan ways of keeping your mood up while still getting plenty of rest.

“Visit people and places that uplift you.”
Living alone
Living alone

Concerns about how you will cope with myeloma are normal, but for those living alone there may be additional challenges. You may be concerned about how you will cope with both the emotional impact of myeloma and the practical impact of complications and side effects.

This section describes additional considerations for myeloma patients who live alone.

Reaching out for emotional support

Myeloma can be an individual and isolating cancer and sometimes living alone can heighten these feelings. Asking for help is key for patients who live alone. Connecting to people and services in your community can help alleviate a sense of isolation. Even though you may value your independence, at some points most patients really value having support networks which they can reach out to and connect with to get the emotional support they need.

Reach out to family and friends

Don’t be afraid to ask for support from your friends and family. Being honest about how you’re feeling and when you need support is important. Sometimes people can be swept up in their own world and not realise how you are feeling until you tell them. They may not want to appear to be fussing or implying that you can’t cope, and so they take a step back.

All relationships are different and will have their own dynamic but often family and friends will take the cue from you when it comes to emotional support. They may not want to initiate a discussion about your myeloma if you don’t get in touch with updates, for fear of bad news or that chasing implies they don’t think you are coping. Even though it can feel tiring, making the first move to update family and friends or asking them to attend appointments with you will let them know when and how you need support.
It will be different for all families and relationships as some people are closer than others, so they may know when you need support without much prompting from you. However, it's important to ask for help if you need it if there is no one to see you day to day.

"Allow people to help you and make the effort to help yourself. Telling your family and friends when you need them will bring you closer together."

Use support services

Asking for help and support can be daunting but many patients wish they had done so earlier.

Other myeloma patients can be a good source of support as they will understand what you are going through and can provide reassurance that you're not alone in it. There are over 100 Myeloma Support Groups (including a number of general haematology groups) that meet all over the UK, where patients and carers meet and provide mutual support. Your local hospital or Maggie’s Centre may also run myeloma or general haematology support groups.

For more information see the Support Groups Infosheet from Myeloma UK

Online forums can be a way good way of connecting with others from your own home. They provide a space for myeloma patients to discuss things and share tips and experiences. Online forums such as the Myeloma UK Discussion Forum and groups on social media are open all day every day, giving you the opportunity to chat with others any time of day or night.

If you prefer chatting one to one, phone support lines such as the Myeloma Infoline are available. The Myeloma Infoline is answered by Myeloma Information Specialists who provide a listening ear, emotional support and practical advice. You can call the Infoline for free on 0800 980 3332 Monday – Friday, 9am – 5pm.

If you want to speak to another myeloma patient, the PEER Network is a group of myeloma patients, family members and carers who are happy to talk on the phone about their experience, giving practical advice and reassurance by answering your questions. Contact Myeloma UK to be matched up with a suitable PEER member.

For more information on the Myeloma UK services see Our information and support services booklet from Myeloma UK

Your multi-disciplinary team (MDT) are there to support you throughout your myeloma and treatment, which includes emotional support. Your Clinical Nurse Specialist or key worker can provide support and can point you towards useful local facilities and resources. Most patients will also be supported by their social/support worker.
Relieve negative emotions

It is normal not to feel positive all the time and there will be points when you feel down. It is important to get through these times and not isolate yourself from your support networks.

Counselling, complementary therapies and self-care are different ways of relieving negative emotions and can be helpful. These suggestions are covered in more detail in section 10.

Take up new hobbies and interests

It can not only be refreshing to speak to someone that doesn't know you or your situation but it can be a good distraction to take up new hobbies and interests. You will need to be realistic about what you can do but taking up a new hobby or interest or pursuing something you have always wanted to do can be good for you and a good way to meet new people and broaden your support networks. Local leisure or community centres are usually a good place to start and have a range of options and classes to choose from. You may find that your local council website also has a list of local events and classes.

Practical support

Sometimes you may need practical assistance to help you retain your independence while coping with myeloma. Living alone may present some challenges if you are in need of practical assistance day to day.

Side effects of treatment

One of the main practical challenges of living with myeloma is living with the complications of myeloma and the side effects of treatment. Side effects such as fatigue or peripheral neuropathy may limit your ability to do as much as you are used to. Coping with these on your own can be a challenge so when your doctor is discussing your treatment options with you, ask them to factor in your ability to cope with potential side effects by yourself.

You can also access help at home to help you manage with side effects of treatment. This can relieve some of your worries or any pressure on yourself.

Home and household duties

In some cases planning ahead can help you to work around side effects. Fatigue, pain and nausea, among other side effects, can affect you at different times of the day or in a treatment cycle. Plan ahead as best as you can. For example, if you know you will be too tired to prepare an evening meal late in the day, make up meals in the morning that you can re-heat and eat later, or freeze for another day.

Getting someone to help you with your household duties can be extremely beneficial and ease some of the pressure on yourself. You can ask friends, family or neighbours to help out with small tasks like moving the bins or popping in with dinner once or twice a week. Tasks like these may not seem like large commitments on their part but can be very helpful for you.
Alternatively, there are a number of professional companies that can help with almost every aspect of home and household duties. For instance, supermarkets can deliver groceries and remove the hassle of going shopping, and cleaning services can help out around the home. There are a range of services available, from private hire companies to volunteers and charities. It is important to remember that there will be a cost associated with private companies. Speak to social services and occupational health services for more information about what help you are able to access for free.

**Getting to and from appointments**

If you don’t drive or aren’t able to drive because of the treatment you will receive in an appointment, often the easiest thing to do is to ask a friend or family member to give you a lift to and from your hospital appointment. Public transport and taxis are normally reliable alternatives, but they can be expensive, particularly if you need to travel frequently. Healthcare Travel Costs Scheme (HTCS) can reimburse your travel to hospital if you are on low income, but to qualify you must fulfil certain criteria, including receiving one of the following benefits:

- Income Support
- Income-based Jobseeker’s Allowance
- Guarantee Pension Credit
- Income-related Employment and Support Allowance

You can be reimbursed for the cheapest suitable transport for you, which in most cases will be public transport, however, you may be able to agree in advance if a taxi is the only suitable option.

Some hospitals offer non-emergency ambulance transport for patients with limited mobility. Check with your doctor or nurse whether you are eligible to use these patient transport services.

If you do drive yourself and have a disability, you may be eligible for certain benefits. The Blue Badge Scheme enables you to park nearer to your destination if you’re disabled. Hospitals will often have reserved blue badge spaces near the entrance of the hospital. You can apply for a badge from your local council.

The Motability Scheme enables people receiving either of two mobility benefits – Enhanced Rate of the Mobility Component of Personal Independence Payment (PIP) or Higher Rate Mobility Component of Disability Living Allowance (HRMC DLA), to exchange the allowance for a lease on a disabled access car.

**In appointments**

An extra pair of ears in an appointment can be beneficial so ask someone you trust to come with you. If you do not have someone to bring with you, take a pen and paper to write down some notes, or ask your doctor to, so you can take away the key points and can refer back once you are back at home. You may also be able to record your appointment using a dictaphone or smart phone to listen back to later. Discuss this with your doctor or nurse at the start of your appointment.
Mobility difficulties in the home

If you have problems with mobility and getting around the house, there are modifications that can be made to your house to make it easier to get around, such as stair lifts and handrails.

If you have more severe mobility difficulties, you might need to consider getting someone to help you with personal care duties (e.g. washing, dressing etc.). There are many companies that provide a help service, and sometimes your local council may be able provide funding. You will need to have a care assessment to see the level of care you need. Your social worker will be able to help with finding a suitable care solution.

Whatever level of care is needed, there are a variety of solutions available that can help. In some cases extra help might be needed so you might need to consider moving to somewhere that can provide you with the level of care you need, such as moving in with family or friends. More formal arrangements are available, such as sheltered housing which offers support and security while enabling you to maintain your independence. Usually there is 24-hour emergency help available and someone who can come and check on you throughout the day. A care home can provide round the clock help if needed.

Having treatment

Remembering which drugs to take and when to take them can be difficult, so it can be helpful to set up a system to help you remember. Some of the side effects to treatments can affect your memory, for example ‘chemo brain’, and it can be difficult to remember which drugs to take and when (see section 5 for more information on how to deal with chemo brain). A drugs chart can be particularly useful to help you keep track of your doses. Organising your tablets into pill boxes at the start of the week can make it easier for the rest of the week – your nurse or pharmacist could help with this.

The Patient diary from Myeloma UK can be a helpful way of keeping yourself organised. Contact Myeloma UK on 0131 557 3332 to order a copy or order online at myeloma.org.uk/publications

Finances

Living on one income or one set of savings/pension can be very difficult, especially if you have to give up work. There are a number of benefits and tax credits which you may be eligible for which could help ease financial pressures. Your social worker will be able to help you apply for them.

For more information see section 7 and the Managing your finances (benefits) Infosheet from Myeloma UK
Help and support

A myeloma diagnosis can impact almost every area of your life and the unique challenges that living with myeloma brings make it all the more important that you access help and support when you need it.

This section describes what help is available and how to access it.

No myeloma patient is alone in their diagnosis. There is a lot of support available for your emotional and practical needs so don’t be afraid to reach out for support as and when you feel you need it. Remember that asking for help and support is not a sign of weakness or failure, it is a positive action to help you live well.

**Your healthcare team**

One of your key sources of help should be your healthcare team. A good relationship with your healthcare team can help you feel supported through your treatment, confident in their judgements and can provide a helpful place to alleviate emotional and psychological concerns.

If you are experiencing complications of myeloma and/or side effects of treatment, you should report them to your healthcare team so they can help you manage them. They can modify treatment if necessary, recommend other sources of help and refer you to counsellors or therapists. This can help you to live more comfortably and remain positive, which can benefit those around you too. For example, effective pain relief can stop you feeling irritable and frustrated. It is therefore very important that you report any side effects and complications to your healthcare team so that they can be properly managed.

Ideally you should feel comfortable discussing any side effects or complications that arise during your treatment. Being open and honest with your team...
will lead to better care as they can understand what's bothering you and work to fix it, so explain how you are feeling and what concerns you.

Learning more about myeloma and various treatment options can help you communicate better with your doctor and make you feel more involved in decisions about your treatment. If you don't understand something, ask your doctor to explain it in a different way.

If you are finding it difficult to create a good relationship with your doctor and you’re having trouble communicating what you want to, you may find it helpful to write down your questions or concerns, or you can try speaking to another member of your healthcare team.

Myeloma is a complex cancer and choosing the right treatment can be challenging for doctors as well as for patients. You may feel that you want to talk to another doctor to confirm that a treatment is appropriate for you. Doctors are usually happy to arrange another opinion and you should not feel like you will offend them. Your consultant or GP will need to refer you for a second opinion.

Seeing your healthcare team less often than you used to can be difficult and you may feel a sense of abandonment. This can happen when you have finished treatment and is particularly common after HDT-SCT. A dip in mood is normal, particularly after your 100 days check. Be reassured that you are still their patient and you can contact them when you need to. Other support services are available to help you in the transition.

It is a good idea to get contact details for your healthcare team and to know who to contact when you have concerns, especially for out of office hours.

“Be honest with your healthcare team and tell them how you are feeling. They will be able to help you.”

Counselling
Counselling can provide a safe environment for you to discuss any issues or worries you have. It can have different approaches and focuses, such as relationships or sex. Counselling can be a long-term support or can be used short-term to get you through particular issues or challenges.

You can ask to be referred to a counsellor by your doctor or you can find a private practice yourself. It can sometimes take a while to get an appointment through the NHS, but if you choose to go through a private practice you will need to pay for the service.

A particular technique called Cognitive Behavioural Therapy (CBT) can be helpful for anxiety, depression and a number of other mental health problems. It aims to break down negative thoughts and the cycles they can cause. There are specialist CBT counsellors, general counsellors that will use CBT in their sessions and similar courses that can be done online. Like general counselling, you can be referred to CBT through the
NHS, but there is often a long delay before you are seen. If you choose to find a private therapist be aware that it can be costly.

“Don’t be afraid to talk to someone – this can be a counsellor rather than a friend or family member, sometimes it’s easier to talk to someone outside of your immediate family and friends.”

Support groups
Many patients find talking things through with people who have been in similar circumstances a great form of support. There are Myeloma Support Groups around the country where patients and carers get together regularly. There may also be myeloma or haematology groups at your local hospital, Macmillan or Maggie’s centre.

Online forums
Online forums can provide a space for discussion and sharing experiences. You may also like this if you prefer the anonymity of an online platform. Online forums such as the Myeloma UK Discussion Forum and groups on social media are open all day every day, giving you the opportunity to chat with others any time of day or night.

Cancer centres and Maggie’s centres
Many hospitals have cancer centres or Maggie’s centres attached to them, where you can find information and support, complementary therapies and a listening ear. Other local centres may have clubs and hobby groups, which can be a good way of meeting people.

Complementary therapies
Complementary therapies can be useful in providing some ‘you’ time, and time out of the everyday hustle and bustle. Complementary therapies go alongside your myeloma treatment and aim to help you relax and unwind. There are many different types of complementary therapy available, from aromatherapy and massage to mindfulness and yoga.

Your doctor or nurse can refer you to a complementary therapist or you can find a private one. Some hospitals and cancer centres have complementary therapists on site who provide their services for free. If you do decide to find one yourself, make sure they are a registered and accredited practitioner and have experience in dealing with cancer patients. You should speak to your doctor before you start a complementary therapy and your complementary therapist should be made aware of any treatment you are having.
Help and support from Myeloma UK

As well as providing Support Groups and the Discussion Forum as mentioned above, Myeloma UK has a number of services to help you live well with myeloma.

**Myeloma Infoline**
Our friendly and experienced Myeloma Information Specialists are on hand to provide information, emotional support and practical advice to anyone affected by myeloma. Our freephone service is available on Monday to Friday from 9am-5pm. We don't put any time limits on your call, you don't have to tell us who you are and won't share your information with anyone else unless you say we can.

**Ask the Nurse**
As well as being able to call our Myeloma Information Specialists, you can email questions you have about any aspect of myeloma to AskTheNurse@myeloma.org.uk.

**Infodays**
We provide the chance to hear from experts and meet others affected by myeloma at our Infodays throughout the UK. Our Infodays have a positive supportive atmosphere with lots of opportunities for attendees to ask questions and share experiences.

**PEER network**
Sometimes you just want to speak to someone who has been in your shoes. Our PEER programme (Patient Experience Exchange Resource) provides access to a network of patients, family members and carers who are willing to share experiences with you. Just give us a call and we will introduce you to someone who can offer a perspective on life with myeloma that’s relevant to you.

You can find out more about all of our services on the Myeloma UK website at [myeloma.org.uk](http://myeloma.org.uk).
Other useful organisations

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

Citizens Advice  www.citizensadvice.org.uk
England: 03444 111 444, Wales: 03444 77 20 20
Scotland: 0808 800 9060
Northern Ireland: call your local Bureau
Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

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

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

Mind  www.mind.org.uk
0300 123 3393
Provides advice and support to empower anyone experiencing mental health problems.

NHS 111 Service  www.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.
Medical terms explained

**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.

**Anaesthetic:** A type of drug used to temporarily reduce or take away sensation so that otherwise painful procedures or surgery can be performed. A general anaesthetic makes the patient unconscious and therefore unaware of what is happening. A local anaesthetic numbs the part of the body that would otherwise feel pain.

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

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

**Bisphosphonate:** A type of drug that slows down or prevents bone damage.

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

**Bortezomib (Velcade®):** A proteasome inhibitor drug which is given either as an intravenous infusion or subcutaneous injection.

**Central line:** A catheter (tube) which 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 HICKMAN® line and a central venous access device.

**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).

**Chronic:** A disease or illness that persists over a long period and causes continuous or episodic periods of ill health.

**Clean diet:** A diet recommended for people who have a compromised immune system. Excludes ‘higher risk’ foods e.g. soft cheeses, live yogurts and pâté.

**Complementary therapy:** A therapy used alongside conventional treatment e.g. reflexology, acupuncture or reiki.

**Cyclophosphamide:** A chemotherapy drug which is given orally or as an intravenous infusion.

**Deep vein thrombosis (DVT):** A blood clot in one of the veins of the leg.

**Dexamethasone:** A steroid which is given orally or as an intravenous infusion.

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

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

**Embryo:** The earliest stage in the development of a baby.
**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.

**Fatigue:** A feeling of being exceptionally tired, lethargic or exhausted all or most of the time. It does not result from activity or exertion and is not relieved by rest or sleep.

**Haematologist:** A doctor who specialises in the study of blood and blood-related disorders.

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

**Hormone:** A chemical messenger released by a cell or organ in one part of the body that affects another part of the body.

**Immune system:** The complex group of cells and organs that protect the body against infection and disease.

**Immunomodulatory drug (IMiD):** A type of drug used to act on the body's immune system.

**Intravenous infusion:** A slow "drip" of drugs or fluids into a vein over a set period of time.

**Key worker:** A member of the multidisciplinary team (MDT), usually a clinical nurse specialist, who will be the patient's primary point of contact during treatment and care.

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

**Melphalan:** A chemotherapy drug which is given orally or intravenously.

**Mucositis:** Pain and inflammation of the lining of the mouth and/or gastrointestinal tract.

**Multi-disciplinary team (MDT):** The team of health and social care professionals who provide patient care.

**Neutropenic:** When the patient is at a greater risk of infection due to a low level of neutrophils, a type of white blood cell important for fighting infection.

**Oral:** By mouth.

**Peripheral neuropathy:** Damage to the nerves that make up the peripheral nervous system causing pain, tingling and altered sensation.

**Peripherally Inserted Central Catheter (PICC) line:** 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.

**Physiotherapist:** A healthcare professional who treats patients with physical difficulties resulting from injury, illness, disability or ageing. They work with patients to identify and improve their movement and function.
**Pomalidomide (Imnovid®):** An immunomodulatory drug which is given orally.

**Prednisolone:** A steroid given orally or as a subcutaneous injection.

**Prophylaxis:** A preventative measure taken to reduce the risk of disease or infection.

**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.

**Radiotherapy:** Treatment with X-rays, gamma rays, or electrons to damage or kill malignant cells.

**Red blood cell:** A type of blood cell which transports oxygen around the body.

**Refractory:** Disease that has failed to respond to treatment or has stopped responding to treatment.

**Relapse:** The point where disease returns or becomes more active after a period of remission or plateau (often referred to as stable disease).

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

**Shingles:** An infection of a nerve area caused by the same virus which causes chickenpox. Symptoms include painful skin rash. Shingles can affect adults with a weakened immune system who have previously had chickenpox.

**Side effects:** The undesired effects caused by a drug or treatment, for example fatigue or nausea.

**Stem cell transplantation:** 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.

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

**Supportive treatment:** Treatment intended to relieve symptoms and complications – or the side effects of treatment – rather than treating the underlying disease.

**Thalidomide:** An immunomodulatory drug which is given orally.

**Vaccine:** Treatment which boosts the body’s immune system and helps to protect the body against a specific disease.

**Venous Thromboembolic Event (VTE):** A term used to describe the formation of a blood clot (thrombus) within a vein. The most common location for a VTE is in the veins of the legs, known as a deep vein thrombosis (DVT). Sometimes part of a clot can break away and travel to the lungs, causing a pulmonary embolism (PE).

**White blood cell:** A type of blood cell involved in the body’s immune system, which help to fight infection and disease.
About Myeloma UK
We’re here for everything a diagnosis of myeloma brings

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

Get answers to your questions by emailing AskTheNurse@myeloma.org.uk

Learn about myeloma from experts and meet other patients at our Patient and Family Myeloma Infodays.

Read our information publications, which cover all aspects of myeloma – call 0800 980 3332 or visit myeloma.org.uk

Join your nearest Myeloma Support Group to meet up and talk to other people face to face.

Visit myeloma.org.uk, a one-stop-shop for information on myeloma.

Watch Myeloma TV, videos about myeloma presented by experts, patients and family members.

Use the Discussion Forum for the opportunity to share experiences and advice about living with myeloma.

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 557 3332
  - 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 557 3332 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