Infopack for newly diagnosed myeloma patients
Disclaimer

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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.

Sections

Receiving a diagnosis of myeloma 1
The symptoms and complications of myeloma 2
The treatment and management of myeloma 3
Treatment side effects and their management 4
Treatment for the symptoms and complications of myeloma 5
The healthcare professionals involved in your treatment and care 6
Living well with myeloma 7
Medical terms explained 8
About Myeloma UK 9
Introduction

This Infopack is for newly diagnosed myeloma patients. It focuses on what you need to know following your diagnosis and provides some practical tips for the weeks and months ahead. Your family members and friends may also find it useful to read.

How should I use this Infopack?
You should read this Infopack at your own pace. There are some things you will want to know now; some things can be left until later on. You may find it easiest to read in bite-size chunks. It has been split into sections to help you navigate the information as and when you need or want to.

The 'Medical terms explained' section contains definitions for the medical terms used throughout the Infopack. These are highlighted in **bold** when they first appear.

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 currently going through.

Patients were also involved in reviewing it prior to publication.

Further information and support
If you have questions after reading this publication, you can find out more about any aspect of myeloma via the Myeloma UK website. Visit [myeloma.org.uk](http://myeloma.org.uk) to order or download information publications, watch videos and find out more about how we can support you.

You may also find it helpful to speak to a Myeloma Information Specialist on the Myeloma Infoline.

The Myeloma Infoline provides information, practical advice and emotional support to people affected by myeloma. You can call the Infoline on **0800 980 3332** or **1800 937 773** from Ireland.
## 10 facts about myeloma

1. **Myeloma** is a cancer arising from plasma cells, a type of cell made in the bone marrow that forms part of your immune system.

2. Unlike many other cancers, myeloma does not exist as a lump or tumour.

3. The most common symptoms of myeloma include bone pain, recurring infection, kidney damage and fatigue. Not everyone will experience all or any of these.

4. There are approximately 5,700 people diagnosed with myeloma every year in the UK. It is the second most common form of blood cancer, but only represents 2% of all cancers.

5. The causes of myeloma are not fully understood but it is thought to be caused by interactions between genetic and environmental factors.

6. Myeloma is a very individual cancer, both in terms of what symptoms and complications patients can have and in the way they respond to treatment.

7. Myeloma is a relapsing-remitting cancer. This means there are periods when the myeloma is causing symptoms and needs to be treated, followed by periods of stable disease where the myeloma does not cause symptoms and does not require treatment.

8. Treatment for myeloma is most effective when two or more drugs with different but complementary mechanisms of action are given in combination.

9. Other treatments will also be prescribed to help prevent or manage potential side effects of treatment combinations and treat the symptoms and complications of myeloma.

10. The availability of improved treatments in the last 10 years has meant that survival rates in myeloma are increasing at the fastest rate among all cancer types in the UK.
Receiving a diagnosis of myeloma
Receiving a diagnosis of myeloma

A diagnosis of myeloma affects everyone differently. To begin with, most people have not heard of myeloma before receiving their diagnosis. This can make an already difficult situation all the more confusing and scary.

Being diagnosed with cancer can be a huge shock, even if your doctors have prepared you for this possibility.

Patients and their families can feel overwhelmed, numb and can also experience a great deal of fear, anger and frustration. For other patients it comes as a relief that they finally have an answer to why they have felt so poorly for so long. All these feelings are common and are a natural part of coming to terms with a diagnosis.

Common questions and concerns at diagnosis

- I have never heard of myeloma, what is it?
- How long am I going to live?
- Who gets myeloma?
- Is it hereditary?
- Why me?
- What caused it?
- How do I tell people?
Introduction to myeloma

Myeloma, also known as multiple myeloma, is a cancer arising from plasma cells, a type of white blood cell that is made in the bone marrow. Bone marrow is the ‘spongy’ material found in the centre of the larger bones in the body. The bone marrow is where all blood cells are made.

Plasma cells form part of your immune system. Your immune system is a complex groups of cells and organs that protect your body against infection and disease. Normal plasma cells produce proteins called antibodies (also known as immunoglobulins) to help fight infection. Antibodies attach to proteins (known as antigens) on the surface of faulty or disease causing cells, such as bacteria, which enables other immune system cells to destroy the cell.

In myeloma, these plasma cells become abnormal, multiply uncontrollably and produce a large amount of a single type of antibody – known as paraprotein – which has no useful function. The paraprotein can be found in the blood and urine and it is often through the measurement of this paraprotein that myeloma is diagnosed and monitored.

Paraprotein is made up of two heavy chains and two light chains.

- In about 80% of patients, the abnormal plasma cells (also known as myeloma cells) produce the whole paraprotein structure.
- In about 20% of patients, the abnormal plasma cells produce only the light chain part of the paraprotein. This is called ‘light chain myeloma’.

- More rarely, in less than 1% of patients the abnormal plasma cells produce no detectable paraprotein or light chains. This is known as ‘non-secretory myeloma’.

Unlike many cancers, myeloma does not exist as a lump or tumour. Instead, the myeloma cells multiply and expand within the bone marrow. This can occur in multiple places in the body (hence ‘multiple’ myeloma) where bone marrow is normally active in an adult i.e. within the bones of the spine, skull, pelvis, the rib cage, long bones of the arms and legs and the areas around the shoulders and hips. The extremities, such as the bones of the hands and feet, are not usually affected.

Most of the medical problems related to myeloma are caused by the build-up of myeloma cells in the bone marrow and the presence of the paraprotein in the blood or in the urine. For example, the build-up of myeloma cells in the bone marrow prevents an adequate amount of normal blood cells being made. (The symptoms and complications of myeloma are covered in more detail in Section 2.)

Myeloma is a relapsing-remitting cancer. This means there are periods when the myeloma is causing symptoms and/or complications and needs to be treated, followed by periods of stable disease where the myeloma does not cause symptoms and does not require treatment.
This Infopack is intended as an introduction to myeloma for newly diagnosed patients. We have much more detailed information available on every aspect of myeloma – visit myeloma.org.uk for more information.

Diagnosing myeloma

GPs may only come across one or two cases of myeloma throughout their career. Some of the symptoms of myeloma are non-specific and can therefore be attributed to other illnesses or be put down to expected changes as people get older (back pain and tiredness, for example).

This means GPs may not consider myeloma when someone presents with symptoms and you may have experienced a delay in being referred on for further tests because of this.

To diagnose myeloma, several tests and investigations need to be carried out. These tests also help to determine a treatment plan, monitor progress and help to detect complications of myeloma so they can be managed effectively.

Throughout this Infopack ‘doctor’ refers to your hospital doctor. Your GP is always referred to as such.

Three of the main tests/investigations are:

- **Paraprotein or light chain measurement**
  Paraprotein levels in the blood are measured. Light chains can be measured in the urine or in the blood.

  The presence of paraprotein and/or light chains is a strong indicator of myeloma and can be used as a measure of how active it is, although not in all patients.

- **Bone marrow biopsy**
  This involves taking a small sample (known as a biopsy) of the bone marrow, usually from the back of the hip bone. It is carried out under local anaesthetic. The sample is examined under a microscope. Normal bone marrow contains less than 5% normal plasma cells. Myeloma patients may have between 10-90% abnormal plasma cells.

- **X-rays (skeletal survey)**
  As myeloma can thin or erode the bones, one of the first investigations carried out may be a skeletal survey. This is a series of X-rays of the entire skeleton to check for bone damage.

  Myeloma is a very individual cancer so you may have had additional tests/investigations carried out around the time of your diagnosis. For example, you may have had another imaging test, such as a magnetic resonance imaging (MRI) or computerised tomography (CT) scan, as well as a skeletal survey to help your doctor get a clearer and more in-depth picture of any bone damage and the specific characteristics of your myeloma.

  Some people go on to develop myeloma after having been diagnosed with a condition called Monoclonal Gammopathy of Undetermined Significance (MGUS). MGUS is a benign (non-cancerous) condition characterised by the presence of paraprotein in the
blood but where no other features of myeloma are present (i.e. fewer than 10% abnormal plasma cells in the bone marrow and no evidence of bone damage).

The risk of transition from MGUS to active myeloma is very low – only 1% of MGUS patients per year progress to myeloma. Even if the abnormal plasma cells are at a higher level (e.g. 10–30%) within the bone marrow, the growth rate can be very slow and represent smouldering myeloma (also sometimes called ‘asymptomatic’ myeloma). Both MGUS and smouldering myeloma can change very slowly over a period of years and do not require active treatment.

**Who gets myeloma?**

Myeloma is relatively rare with approximately 5,700 new diagnoses each year in the UK.

Around 17,600 people have myeloma in the UK at any one time. Its rarity is one of the main reasons why many people have not heard of it before diagnosis.

Myeloma mainly occurs in people over the age of 65. It affects slightly more men than women, and is also more prevalent in people of African descent.

**Prognosis and life expectancy**

Myeloma is highly treatable in the majority of patients but unfortunately there is currently no cure. However, the life expectancy of myeloma patients has improved at a faster rate than any other cancer in the UK, quadrupling in the last 40 years, mainly due to the availability of new drugs.

It can be difficult, if not impossible, to predict with any degree of certainty how well you will respond to treatment and how long you are likely to live. Myeloma is a very individual cancer and there are many different factors that will affect the treatment you have and your **prognosis**. This will include the individual nature of your myeloma and the complications it is causing.

According to the most recent statistics available, almost half (47%) of myeloma patients in England and Wales live for at least 5 years, and a third (33%) will live for at least 10 years.

A number of new treatments are currently being investigated in clinical trials. If successful, they should further improve outcomes for patients. With the improvements in treatment and life expectancy, myeloma has the potential to become a **chronic** cancer in some patients.

**Causes of myeloma**

The cause(s) of myeloma are not fully understood but a complex interaction of both genetic and environmental factors is thought to be involved.

Myeloma develops when genetic ‘errors’ occur within the DNA of a plasma cell but we do not currently know why these errors occur.

Although we do not know what causes myeloma, some risk factors have been identified by researchers. A risk factor is anything that increases an individual’s chance of developing myeloma. The risk of myeloma increases as people get older and myeloma is slightly more common
in men than women, and slightly more common in black populations than in white or Asian populations. It is generally now also accepted that all myeloma patients have had MGUS first, whether it was identified or not.

There are also thought to be multiple environmental factors which may increase the risk of developing myeloma. These include exposure to certain types of industrial and agricultural chemicals, exposure to high doses of radiation, viruses and a weakened immune system.

There is a slight tendency for myeloma to occur in families. Although rare, this suggests there are inherited genetic factors in myeloma.

However, these alone are not enough to cause myeloma but may make an individual have a slightly higher risk of developing myeloma – other environmental factors also need to have an impact before it develops.

It is likely that myeloma develops when a susceptible (at risk) individual has been exposed to one or probably several of these factors. In the majority of cases, however, the causes are unclear and are likely to be unique to each patient.

**Practical tips for initially coping with your diagnosis**

There are various strategies you can adopt for dealing with a diagnosis of myeloma in the first few months and beyond. Some patients may not yet feel ready to take on these strategies.

Whether immediately or through the passage of time, here are some suggested ways to help you and your family members come to terms with a diagnosis of myeloma.

**Information**

Information helps you to make sense of your diagnosis and to make informed decisions about treatment and care. It can also provide support to family members. Everyone has different needs with respect to information. How much information you want, and on what topics, may vary throughout the course of your myeloma. Information on myeloma should be made available to you through your doctor or nurse. You can also access a wide range of information through organisations such as Myeloma UK.

For many, the internet has become the first place to go to when looking for information. It gives you instant access to any topic you can think of. Unfortunately, a lot of what passes for cancer information on the internet is made up of opinion and biased information that isn’t necessarily accurate. The wrong information can be very misleading and even harmful. Therefore:

- Select your internet sources carefully. Remember that the information found on the internet should not replace the advice you get from your medical team
- Choose your own pace for accessing information; it’s easy to get overwhelmed
- Myeloma UK can provide a large range of printed and online (including audio-visual) information about myeloma
Talking

Emotional support plays a very important role in helping to deal with a diagnosis. It is easy for patients and family members to feel isolated and strong emotions often make it difficult to discuss worries or fears.

- Talking to someone who understands what is happening can reduce anxiety and ease many of the challenging and often negative feelings associated with a diagnosis of myeloma
- Many patients find that their specialist nurse is a good person to talk to, or you can call the Myeloma Infoline to talk to a Myeloma Information Specialist
- While no two cases are the same, often it is extremely beneficial to talk to another patient who is going through, or has recently gone through, what you are experiencing now. Myeloma UK can put you in touch directly with other patients. You can also connect with others through the online Discussion Forum on the Myeloma UK website
- Myeloma Support Groups provide an informal and comfortable atmosphere in which members can share stories and information. Groups consist of supportive people who are facing the same things that you and your family members are. Visit myeloma.org.uk to find details of Myeloma Support Groups in the UK.

Call the Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland

Telling people

It can sometimes be hard to get beyond the negative connotations of the word cancer. There is no doubt that deciding to share your diagnosis with others is a big step. You may find it difficult to talk about what’s happening to you and how you feel, or be worried about how your family or friends will react. These tips may be helpful:

- Tell people in the way that feels best for you. Sometimes it’s easier to give the news over the telephone, through a letter or by email rather than face-to-face
- It’s often a good idea to give a warning shot, ‘I have some bad news’ for instance can prepare someone for what you are about to tell them
- Give the information in small chunks. Start with a few sentences and check every now and then that the other person understands you before you carry on
- There may be silences. If you find that a silence makes you feel uncomfortable, the easiest way to break it is with simple questions such as, ‘What are you thinking about?’
- Be truthful. The truth may be painful for your relative or friend. However, it’s better for them to know the truth than to find out the seriousness of your situation later on. This will help them understand your situation and support you better
Don’t be afraid to ask for help with telling others. You may want to ask someone you’ve told if they can let others know your news. This will save you having to repeat difficult and emotional information.

How you talk to people about your myeloma will depend very much on your personality and how you usually talk to the people around you. Be prepared for some unexpected reactions from family and friends – they do not always react the way you think they will. Some will become closer and others more distant. Don’t get too upset about this; cancer provokes different emotions in different people.
The symptoms and complications of myeloma

The most common symptoms and complications of myeloma are described in this section.

It is important to remember that not everyone will experience all of these.

Supportive treatments are commonly used alongside and after anti-myeloma treatment to relieve, stabilise and, in some cases, help prevent these symptoms and complications. These are discussed in Section 5.

Common questions and concerns about the symptoms and complications of myeloma

● What symptoms and complications will I have?
● Will I be in pain?
● What treatment will I have for my symptoms?
● What do I need to tell my doctor?
The symptoms and complications of myeloma

Unlike many other cancers, myeloma can affect the body in several ways.

**Pain**
Unfortunately, pain is one of the most common symptoms of myeloma and will affect up to 80% of patients at some point. The principal cause of pain for myeloma patients is myeloma bone disease. Effective control and management of pain is an important aspect of myeloma treatment.

**Fatigue**
Persistent fatigue, or an overwhelming tiredness, is common in myeloma. Many patients say that fatigue is the hardest symptom of myeloma to cope with. It may be due to the myeloma itself, to one or more of its complications (e.g. anaemia), or it can be a side effect of treatment.

**Myeloma bone disease**
Myeloma bone disease is another common and often debilitating feature of myeloma. This is where the myeloma cells interfere with the normal bone maintenance process and cause holes, or lesions, to appear in the bone. This can make the bones more fragile and susceptible to fractures, and, as bone is high in calcium, can release large amounts of calcium into the bloodstream. Bone pain is a common symptom of myeloma bone disease. The middle or lower back, the rib cage and the hips are the most frequently affected places. This pain is often persistent and described as dull and aching, and usually made worse by movement.

**Bone fractures**
The bones that most commonly fracture due to myeloma bone disease are the spine and the ribs and breaks can sometimes occur with only minor pressure or injury. Fractures of the bones of the spine (vertebrae) can lead to collapse of the vertebrae with associated height loss and occasionally, compression of the spinal cord which can be very serious.

**Recurring infection**
Infections are more common in myeloma patients because the myeloma and its treatments interfere with the immune system making patients more susceptible to infection.

**Anaemia**
This is a reduction in the number of red blood cells or the oxygen-carrying haemoglobin they contain. It can occur as a result of the myeloma or as a side effect of treatment and can cause fatigue, weakness or breathlessness.

**Hypercalcaemia**
This is a condition in which the level of calcium in the blood is too high. It can occur as a result of bone disease in which calcium is released into the bloodstream.
when the affected bone is broken down. The symptoms of hypercalcaemia include thirst, nausea, vomiting, confusion and/or constipation.

**Kidney damage**

This can occur in myeloma patients for a variety of reasons. The abnormal protein produced by myeloma cells can damage the kidneys, as can some other complications of myeloma, such as hypercalcaemia. Dehydration caused by lack of fluids or vomiting can also cause kidney damage. In addition, some of the drugs used to treat myeloma can sometimes cause kidney damage.

**Peripheral neuropathy**

This is damage to the nerves that make up the peripheral nervous system (the part of the nervous system that consists of the nerves outside the brain and spinal cord). In myeloma, the nerves that are most commonly affected by **peripheral neuropathy** are those of the hands and feet, causing tingling and altered sensation and sometimes pain. It can be caused by the treatments for myeloma and also the myeloma itself.

Practical tips for dealing with the symptoms and complications of myeloma

Acting early can reduce the number and severity of the complications associated with myeloma. Watch out for and contact your nurse about:

- Signs of infection, which can vary – temperature, shivery feeling, sore throat, painful rashes, diarrhoea, nausea, vomiting. It is important to take your temperature if you are not feeling well and to contact your doctor if you have a temperature over 38°C
- Symptoms that might be the result of **spinal cord compression** – constipation, not being able to pass urine, incontinence, increased or sudden severe back pain, tingling or loss of sensation in your legs
- New or increasing symptoms e.g. pain, fatigue

Be honest with your doctor or nurse about any pain you have. You should not feel you have to put a brave face on it – remember they are there to help you. Accurately recording your pain is a key part of effective pain management:

- Score your pain between 0–10, where 0 = no pain and 10 = worst pain, as bad as you can imagine
- Record your pain score immediately before and 30 minutes after taking your pain medication
- Describe your symptoms as accurately as you can, e.g. where your pain is located and whether it is dull, aching, piercing, transient or constant

Supportive treatment for the symptoms and complications of myeloma is covered in Section 5
Keep a **Patient Diary** so that you can refer to it when describing your symptoms and patterns of symptoms to your doctor or nurse. Order your free copy from myeloma.org.uk or via the Myeloma Infoline.

In a survey carried out by Myeloma UK, 88% of patients said that fatigue made their life more difficult. You could consider:

- Spreading chores throughout the week and doing the things that matter to you each day
- Asking for help from family and friends
- Allowing yourself rest periods during the day
- Preparing meals when you feel less fatigued – cook extra and freeze for a later date
- If you work, asking if you can work from home some days or reduce your hours
- Keeping a Patient Diary to identify the times you feel most tired to help determine what makes you tired and what helps you combat the fatigue

Staying well hydrated helps to protect your kidneys. Drinking between 2 and 3 litres of fluid a day is recommended if you have myeloma, to help keep the kidneys working well. All liquids count, so include everything non-alcoholic you drink throughout the day. Some complications may mean that your fluid intake should be reduced – your doctor will always advise you.
The treatment and management of myeloma

The treatment and management of your myeloma will depend on how active the myeloma is and the degree to which it has affected your body.

This section deals with treatment to control the myeloma itself.

Section 5 deals with supportive treatment for the symptoms and complications that myeloma can cause. There is some overlap between these sections since any treatment that controls your myeloma will have the added benefit of reducing the complications and symptoms you have.

Common questions and concerns about the treatment of myeloma

• What treatment will I have? How long will it last?
• Why am I only being monitored? What are the doctors looking for?
• How will I know if my treatment is working?
• What will happen if treatment doesn't work?
• Will I have to stay in hospital and if so, for how long?
• Do I have to have treatment?
Treatment for myeloma

Treatment for myeloma aims to control the growth of the myeloma, disease control, relieve the complications and symptoms it causes, and extend and improve quality of life.

Myeloma is usually characterised by periods when treatment is required followed by periods of stable disease when treatment is not required.

Not everyone diagnosed with myeloma will need immediate treatment. Results from various tests and investigations, together with any symptoms you have, will help determine when treatment should begin. If your myeloma does not need immediate treatment, you will still be seen regularly by your doctor. If this is the case, doctors will monitor your myeloma for signs of it progressing and causing problems and you will be asked to be vigilant for any changes in symptoms and general health.

If your myeloma does need treatment, there are a range of factors that need to be taken into account before a treatment approach is decided. In some situations, there may be an urgent need to start treatment, for example if you have significant kidney damage, spinal cord compression or hypercalcaemia.

Some patients decide they do not want to have any treatment for their myeloma. The decision not to have treatment is a very personal one and you should talk this through with your doctor if you’re thinking about taking this approach. If you choose not to have treatment there are many supportive options available to help alleviate symptoms.

Initial treatment

Initial treatment for myeloma is almost always with a combination of drugs. These drugs are given in a set pattern over a period of time known as a cycle. Cycles may last from weeks to months.

Treatment for myeloma is most effective when two or more drugs with different but complementary mechanisms of action are given in combination. In fact, treatment combinations are usually made up of two or three different types of drugs which work well together and can include chemotherapy drugs, steroids and other types of anti-myeloma drugs.

For ease, your doctor may refer to all of your treatment as “chemotherapy” or “chemo”.

There may also be other treatment prescribed to:

- Help prevent or manage potential side effects of treatment combinations (discussed further in Section 4)
- Treat symptoms and complications of myeloma (discussed further in Section 5)

Drugs tend to have two names: the name of the drug (its ‘generic’ name) and the name of the brand. For example, the generic drug bortezomib is sold under the brand name Velcade®.
**Drug types**

**Chemotherapy**
Chemotherapy drugs interfere with the way rapidly dividing cells, such as myeloma cells, work and in doing so, aim to stop or slow down their growth. Chemotherapy drugs are given in cycles, usually by mouth (orally) but sometimes by injection, over a period of months, with rest periods in between each cycle to allow healthy blood cells to recover. The two most commonly used chemotherapy drugs in myeloma are *cyclophosphamide* and *melphalan*.

**Steroids**
Steroids are drugs which mimic naturally occurring hormones produced in the body (they are different from steroids used to build muscle). They work in many different ways to stop myeloma cells from growing. They are also useful in preventing inflammation in areas affected by myeloma, which can help relieve associated pressure and pain. The most commonly prescribed steroids are *dexamethasone* and *prednisolone*.

**Immunomodulatory drugs (IMiDs)**
These drugs work by modifying the immune system. IMiDs have been shown to have many mechanisms of action that may affect myeloma cell survival. IMiDs used in myeloma include *thalidomide*, *lenalidomide* (*Revlimid®*) and *pomalidomide* (*Imnovid®*).

**Proteasome inhibitors**
These drugs work by temporarily blocking the actions of proteasomes in cells. Proteasomes are involved in the removal, breakdown and recycling of damaged or unwanted proteins. Proteasome inhibitors allow proteins to build up which become toxic within the cell, causing it to die. Myeloma cells are more sensitive to this action than normal cells. Proteasome inhibitors used in myeloma include *bortezomib* (*Velcade®*) and *carfilzomib* (*Kyprolis®*).

**Monoclonal antibody drugs**
These drugs work in the same way that natural antibodies work in the body. Antibodies recognise proteins, called antigens, found on the surface of potentially harmful cells. An antibody binds to the antigen, which flags the harmful cell for destruction by other immune cells. Monoclonal antibody drugs recognise and bind to a specific antigen on the surface of myeloma cells, flagging the cells for destruction. Currently, the only monoclonal antibody drug used in the treatment of myeloma is *daratumumab* (*Darzalex®*).

**Histone deacetylase inhibitors (HDACs)**
HDACs work by blocking the action of histone deacetylase in myeloma cells. Histone deacetylase is a protein that changes the way other proteins, called histones, bind to DNA within cells. Myeloma cells use histones to switch off genes that would stop their growth. HDACs prevent histones from binding to the DNA and switching off the genes that control cell growth. The genes are therefore “switched on” and can prevent
myeloma cells from growing and multiplying. Currently, the only HDAC used in the treatment of myeloma is **panobinostat (Farydak®)**.

Commonly used initial treatment combinations in myeloma include:

- Bortezomib (Velcade), thalidomide and dexamethasone (known as VTD)
- Melphalan, prednisolone and thalidomide (known as MPT)
- Cyclophosphamide, thalidomide and dexamethasone (known as CTD)

After receiving an initial course of treatment (generally for 6-8 months), you may be suitable to go on and have a more intensive treatment called **high-dose therapy and stem cell transplantation (HDT-SCT).**

Contact Myeloma UK for detailed information about HDT-SCT if your doctor considers you to be suitable for this procedure

**Which treatment combination will I receive?**

Choosing treatment for myeloma is often not a simple decision as no single treatment combination has been identified as being the best. You may prefer just to follow the advice of your doctor or to take a more active role in the decision-making process. Information can assist you in understanding more about the treatment and care options available.

Your treatment combination will take account of:

- What is licensed and approved for use on the NHS
- Evidence-based national guidelines
- Your general health
- Your age
- Your personal circumstances and lifestyle
- Your priorities and preferences
- The characteristics, activity and stage of your myeloma
- Any previous treatment/other medical conditions you have
- The extent to which your myeloma is symptomatic and causing problems
- Whether or not you take part in a clinical trial

**Signs that treatment is working**

To find out how you are responding to treatment, tests will be carried out regularly. These will vary but generally will include regular blood and/or urine tests and occasional X-rays or **bone marrow biopsies**.

The signs that treatment is working include:

- A fall in the paraprotein or light chain level
- An improvement in symptoms and/or complications such as bone pain, anaemia and kidney function
• A reduction in the number of myeloma cells in the bone marrow
• An improvement in your general health

Myeloma can respond very well to treatment and go into remission. This means that there is no sign of active myeloma in your body. Or, the paraprotein or light chain level can be reduced and remain at a stable level following treatment. This is called a plateau or stable disease.

If your myeloma does not respond to your initial treatment, your doctor will discuss the available options with you and you’ll decide together on the next steps. Many of the available drugs work in different ways so if you have not responded to one type of drug this does not mean you won’t respond well to a different type.

Relapse

Myeloma is a relapsing-remitting cancer. This means there are periods when the myeloma is active and needs to be treated, followed by periods of stable disease where the myeloma does not need to be treated.

A relapse is when myeloma returns or becomes active again after a period of successful treatment.

Relapse can be a very disappointing time for patients and their families but there are effective treatments available for relapsing myeloma.

This is true regardless of whether it is your first relapse or if you have experienced one or more relapses previously.

Myeloma research and clinical trials

The key goals of current myeloma research include:
• Giving each patient the best treatment for their disease-specific and individual needs
• Overcoming resistance to treatment
• Developing better drugs with fewer side effects
• Identifying new targets for treatment
• Preventing the onset and progression of myeloma
• Finding a cure

Patient involvement is the cornerstone of myeloma research. Myeloma patients can help research by taking part in clinical trials and donating blood and bone marrow samples so these can be banked and used for research purposes.

As a newly diagnosed patient, your doctor may well talk to you about taking part in a clinical trial. Clinical trials are planned research investigations in which patients take part. They are intended to test new drugs or new combinations of current drugs, or to compare different ways of using current drugs. The treatments that are available today are only available because patients took part in clinical trials in the past.

There is a promising pipeline of new anti-myeloma treatments being looked at in clinical trials, including newer versions of current types of drug, as well as drugs that work in different ways.
Before making a decision about whether to take part in a clinical trial, it is important you understand what is involved so you can make an informed decision. Understanding what is involved could include:

- Reading information specifically related to the trial – provided by the doctor, nurse or Myeloma UK – describing what is involved and what you should expect
- Talking to the doctor, research nurse, the Myeloma Infoline team at Myeloma UK and other patients
- Discussing the trial and/or treatment with family and friends

You can find out about clinical trials running in the UK on the Myeloma Trial Finder at trials.myeloma.org.uk

Some questions that you may want to ask your doctor include:

- What are the benefits and risks of taking part in the trial?
- How long will the trial last?
- Will I need to undergo additional tests and investigations?
- What will the treatment involve?
- Is this the best treatment for me?
- What treatment would I be offered if I decided not to take part in the trial?
- Where will the treatment be carried out?
- If I benefit from the new treatment can I continue to have it when the trial has finished?
- What happens if I want to come off the trial early?
- How long has the trial been running and how many patients have been treated so far?
- What will happen to me when the trial is finished?
- How long is the follow-up for?

You will be given the opportunity and time to discuss every aspect of the trial before making a decision

Practical tips for dealing with myeloma treatment

Discussions with your doctor or nurse

- Write a list of questions before your appointment and bring them with you
- Don’t be afraid to ask for extra time to make a decision about treatment; you may want to discuss things with family members first
- It is a good idea to bring someone with you to your doctor appointments. Another pair of ears can be very useful and there can be a lot to take in
- Always tell your doctor if you are taking any medicines you bought over-the-counter (without a prescription), or any supplements (e.g. vitamins) or complementary
therapies you are using before starting treatment. This is because some drugs can interfere with how others work.

**Prescriptions**

- Your doctor will write you a prescription for all of your oral myeloma drugs and the hospital pharmacy will be able to provide you with them. A family member can also pick up your prescription from the hospital pharmacy.

- For treatment that is to be given intravenously (into a vein), you will not be provided with a written prescription.

- You may be being prescribed treatment by your GP for existing conditions – speak to your hospital doctor about all the drugs that you are taking. They'll let you know how things will work from now on regarding your prescriptions.

- Prescriptions are free for all myeloma patients in the UK. In Wales, Scotland and Northern Ireland this happens automatically. In England, patients over 60 are automatically exempt from prescription charges. If under 60, you must apply for a Medical Exemption Certificate. You can get this from your GP or hospital clinic. It should be renewed every five years or until your 60th birthday, whichever is sooner.

**Keeping track of your medication**

You may be on many different drugs at one time, which have to be taken at different times or on different days. Drugs confusingly can have different names (e.g. lenalidomide is also called Revlimid). The packaging and/or the colour and size of certain drugs (e.g. aspirin or paracetamol) can also look different from time to time.

This can be difficult to keep track of and may put you at risk of forgetting certain tablets. Setting up a process at home, with help from your nurse and a family member, can help make the whole process easier:

- To begin with, ask your nurse to sit down with you and go over all of your different drugs – how many you are supposed to take of each, on what days and at what times of the day.

- Get a pill box marked with the days of the week to help you keep track of the drugs you have to take. It's a good idea to make sure at least one other family member is fully up-to-speed with this.

- It is very important to take your medication at the right times. If you miss a dose at the time you normally take a medication, it's best to check with your doctor or nurse who can advise on what to do. Generally, if it is less than 12 hours since you missed the dose you can take the tablet(s). If more than 12 hours you should wait and take your next dose at the usual time the next day.

Speak to your doctor or nurse if you have any concerns about keeping track of your medication.

**If you have questions between appointments**

If you have any questions or notice any new symptoms between appointments, let your doctor or nurse know as soon as possible. You don't have to wait until your
next appointment. If you are worried and require non-emergency but immediate medical advice, call your out-of-hours doctor at the hospital. You will have been given this number at your first clinic appointment.

Treatment side effects and their management
Treatment side effects and their management

The drugs used to treat myeloma can cause some side effects. Each drug has its own set of side effects but can produce different reactions in different patients. Some patients will have few side effects, others will have more.

Most side effects are short-term, can be avoided, managed well and usually resolve once treatment is finished.

Common questions and concerns about the side effects of treatment

- What side effects are likely from treatment?
- Can any side effects be prevented?
- Who do I report side effects to?
- What should I do if I'm at home and worried about a side effect?
- What should I do if I get a temperature?
- Will treatment affect my fertility?
- Will I lose my hair?
Side effects of myeloma treatment

Common side effects of:

- **Chemotherapy** include nausea, infection, diarrhoea, anaemia (and therefore fatigue), sore mouth and hair loss or thinning
- **Steroids** include insomnia, stomach pain, increased blood sugar, increased risk of infection, increased appetite, shaky/trembling fingers, mood swings and muscle weakness
- **IMiDs** include birth defects if taken during pregnancy, drowsiness, constipation, peripheral neuropathy, blood clots, decreased blood counts
- **Proteasome inhibitors** include peripheral neuropathy, nausea, constipation, anaemia (and therefore fatigue) and loss of appetite
- **Monoclonal antibodies** include diarrhoea, nausea, fluid retention, muscle spasms, decreased blood counts
- **HDACs** include diarrhoea, nausea, appetite loss, heart problems, decreased blood counts, low blood pressure

Fertility

Some treatments may affect fertility and therefore your ability to have children in the future. Chemotherapy for example can cause infertility or early menopause by affecting the way the ovaries work. It can also slow down or stop sperm production. Infertility will often be temporary, but some chemotherapy can cause permanent infertility.

The risk of infertility often depends on the following:

- **The drugs you have** – some chemotherapy drugs have a higher risk of causing infertility than others. In myeloma, the drugs most likely to affect fertility are the alkylating drugs such as cyclophosphamide and melphalan. Infertility may also be caused by radiotherapy, especially if it is given to the pelvic area where it may indirectly damage the ovaries, the womb or the testicles. The risk of infertility depends on the dose of radiotherapy you have
- **The dose** – permanent infertility is more likely with higher doses of chemotherapy, such as the high doses myeloma patients are given as part of the stem cell transplant process

Hair loss

Hair loss is rare with oral chemotherapy but you may have some hair thinning. However, hair loss is more common with the higher doses of chemotherapy associated with stem cell transplantation.
**Practical tips for dealing with side effects**
Side effects can be prevented or managed with a range of supportive treatments, or with dosing adjustments. For example:

- Anti-sickness (anti-emetics) tablets can help prevent nausea and vomiting
- Anti-diarrhoea, laxative and antacid tablets can help with gastrointestinal problems
- Anti-clotting drugs such as warfarin or low-dose aspirin can prevent clots forming when on thalidomide or lenalidomide
- Blood transfusions or treatment with a drug called erythropoietin (EPO) can help boost your red cell count if you become anaemic
- Antibiotics and antivirals can prevent or treat infection
- Reducing the dose and frequency of administration of the drug responsible can help with peripheral neuropathy. It is important to report any symptoms as soon as possible so as to reduce the risk of permanent damage. In the majority of cases, symptoms will improve or disappear after the dose and/or frequency of treatment is reduced. In some cases, treatment may need to be temporarily stopped or, if the neuropathy is severe, discontinued and other options discussed. Nerve pain from peripheral neuropathy can be treated with drugs such as gabapentin and amitriptyline

**Infertility**
The prospect of infertility can be very difficult to live with:

- Talk to your doctor or nurse who can explain the possible risks of your particular treatment on fertility and what can be done to address them
- You may be referred to a fertility expert to discuss your options. Sperm banking or egg collection may be options available to you
- Your nurse may be able to offer additional support, and fertility clinics usually have a counsellor you can talk to

**Coping with hair loss**
One practical way of coping with hair loss is to wear a wig. Wigs are available for free on the NHS in Scotland, Wales and Northern Ireland. In England, you are entitled to a free, acrylic wig on the NHS if you meet certain requirements. More information is available through the NHS help with health costs website. You can also buy your own wig privately. It’s a good idea to organise a wig before you start to lose your hair so that you have the time to find the right style for you and get used to wearing it.
Reporting side effects
You may find that side effects are quite intrusive on your life and that you feel worse than you did before you started treatment. If you have any side effects that you think may be due to your treatment, let your doctor or nurse know straight away.

- You should be honest about any side effects with your doctor or nurse. Many patients worry that treatment will be stopped if they report side effects but there are lots of ways of dealing with these without needing to stop treatment. For example, with a temporary dose reduction or a supportive drug such as an anti-sickness tablet.

- Use a Patient Diary to accurately track your side effects and use it to inform your doctor or nurse.

- If you are concerned about any new side effects between appointments, call your out-of-hours doctor at the hospital. You will have been given this number at your first clinic appointment.

Trendco are a wig and hairpiece specialist who provide wigs through NHS prescription. Visit their website www.trendco.co.uk
Treatment for the symptoms and complications of myeloma

There are a range of supportive treatments available to help deal with the symptoms and complications of myeloma (described in Section 2).

Common questions and concerns about the treatment of symptoms and complications

- Are there supportive treatments to help manage my symptoms and complications?
- Can pain be effectively treated?
- Are there any non-medical treatments I can try?
Treatment for the symptoms and complications of myeloma

**Bisphosphonates**

Help minimise myeloma bone disease, hypercalcaemia and bone pain.

- Current national guidelines on myeloma recommend the long-term use of **bisphosphonates** for all patients requiring treatment for their myeloma

- There are three bisphosphonates licensed for use in the UK – sodium clodronate (Bonefos®) which is oral; and zoledronic acid (Zometa®) and disodium pamidronate (Aredia®), which are both given by intravenous infusion

- Zoledronic acid is the recommended bisphosphonate of choice in light of a large clinical trial called Myeloma IX. This trial showed that zoledronic acid was not only better than sodium clodronate in treating myeloma bone disease, but also had anti-myeloma effects and survival benefits in newly diagnosed patients

- Treatment with bisphosphonates can cause complications when having dental treatment. You should make your doctor and dentist aware if you require dental treatment

**Surgical intervention**

For the reduction of pain and/or the restoration of vertebral height due to bone fractures.

- **Percutaneous vertebroplasty** and **Balloon Kyphoplasty** are two surgical procedures that can treat fractures of the spine in myeloma. In general, more conservative treatments for back pain will be tried first

- Plates and screws can also be surgically introduced to stabilise fractured non-spinal bones

**Painkillers**

- There are many types of painkillers available to treat varying levels of pain, ranging from over-the-counter drugs such as paracetamol, to those for mild to moderate pain (e.g. co-codamol, codeine) to those for moderate to severe pain (e.g. morphine, high-dose tramadol)

- Nerve pain from peripheral neuropathy can be treated with drugs such as gabapentin and amitriptyline

- Avoid non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and diclofenac because these drugs may contribute to kidney problems

- People react differently to painkillers so what works for someone else may not necessarily work for you, so it’s important to tell your doctor if what’s been prescribed does not work
Radiotherapy
For areas of localised bone disease and pain.

- Radiotherapy is the use of high-energy radiation (usually X-rays) to kill cancer cells. Radiotherapy can often relieve pain more quickly than chemotherapy and/or painkillers and may sometimes be the initial treatment given.

Non-medical treatments
For pain.

- TENS machines deliver small electrical pulses to the body via electrodes placed on the skin. This stimulates the brain to release endorphins, which are painkilling hormones. TENS machines are available from a physiotherapist or you can buy one from a large chemist.

- Acupuncture is often used to help alleviate pain and is thought to work by switching to the area of the brain associated with the processing of pain. It is important to inform your doctor or nurse if you are receiving acupuncture and to consult a qualified practitioner.

- Gentle massage can be used to relieve muscle pain and tension. If you have peripheral neuropathy, gently massaging the affected area with cocoa butter twice a day can help alleviate any pain or discomfort.

- Hot water bottles and ice packs can be very effective in providing short-term pain relief.

High-dose steroid treatment
For kidney damage.

- In most cases, prompt treatment of the myeloma will reverse damage and restore kidney function.

- Early treatment with high-dose dexamethasone to reduce inflammation can also help with recovery.

Growth factors and/or antibiotics
For low white blood cell counts.

- To increase numbers of white blood cells and help reduce the risk of infection, synthetic growth factors such as G-CSF (granulocytecolony stimulating factor) are sometimes given.

- Antibiotics can be given to treat or prevent infections.

Blood transfusions and/or erythropoietin
For anaemia.

- A blood transfusion increases the number of red cells in the blood and therefore can help to bring your haemoglobin level up to, or near, normal levels quickly.

- Anaemia can also be treated with erythropoietin (EPO), a synthetic version of the hormone that your kidneys produce naturally to stimulate the production of red blood cells.

All of these supportive treatments have the potential to alleviate fatigue, which affects over 70% of myeloma patients at some point during the course of their myeloma.
The healthcare professionals involved in your treatment and care
The healthcare professionals involved in your treatment and care

Your care will involve a number of different healthcare professionals. It is important to know who is responsible for your treatment and care so you know who to contact in various circumstances.

Common questions and concerns about the people involved in your treatment and care

- Who should I contact if I have any questions?
- How often will I see my doctor?
- When do I speak to my GP, and when to my hospital doctor?
- What do I need to ask my doctor?
- Can I get a second opinion?
Who is involved in my treatment and care?

Your myeloma treatment and care will be coordinated by a team of healthcare professionals led by a consultant haematologist. You may hear this team being referred to as the Multidisciplinary Team, or the MDT.

Your consultant haematologist will be responsible for leading your care throughout your treatment for myeloma. They will plan your treatment with the other members of the MDT and will involve you in all decisions relating to your care.

The MDT approach is particularly important in myeloma because the diagnosis, treatment and care of patients can be very complicated, involving different types of specialists.

The core MDT should include:

- At least two haematologists – doctors who specialise in blood conditions. They will have expertise in treating and managing myeloma
- A radiologist – a doctor who specialises in the use of imaging techniques (such as X-rays and MRI scans) to both diagnose and direct the treatment of myeloma
- A haematology clinical nurse specialist (CNS) – a senior nurse who has special training in haematology and/or myeloma
- A palliative care specialist – a doctor who specialises in alleviating the symptoms and complications of myeloma and the side effects of its treatment

Appointments with your doctor

How often you see your doctor will depend on many factors, including how active your myeloma is, whether or not you are on treatment, what treatment you are on and how well you are responding to it:

When you are being treated you will have an appointment after each cycle of your treatment regime (usually monthly). Your doctor will be checking your response to treatment and for any side effects.

Following the end of treatment, your checkups will usually be every 1 to 3 months. Your doctor will be checking for any signs that your myeloma is becoming active again so it can be treated.

During your check-ups you will have blood tests and/or urine tests, depending on your type of myeloma. If you have any new or increasing pain in your back or bones, you may have further X-rays.

Your relationship with your healthcare team

Your relationship with your healthcare team will involve trust and collaboration. Learning more about myeloma and the different treatments that are available will help you to communicate more easily with your healthcare team and help you to be involved in and make informed decisions about your care, should you wish to do so.

Getting more than one opinion

Myeloma is a relatively rare and complex cancer and choosing the right treatment can sometimes be challenging for doctors as well as for patients.
You may feel that you want more than one opinion to be sure that the treatment plan is appropriate for your situation and that all other options have been considered. Occasionally, some patients have difficulty communicating with their doctor and want the chance to talk to another doctor.

Doctors are normally happy to arrange another opinion – either a different doctor in the same hospital or at another hospital – and you should not feel that asking for one will offend them. However, you may find it easier to approach your GP about this.

Practical tips for getting the most out of your healthcare appointments

- Keep a list of questions to ask your doctor or nurse next time you see them – no question is too small or silly and don’t worry about asking for things to be repeated if they aren’t clear
- Take a piece of paper and a pen to your appointments and write things down if you think they might be important
- Bring a family member or friend who can take notes and be an extra listening ear
- Being able to accurately describe symptoms (when and what) is important – a Patient Diary may help
- Sometimes healthcare professionals forget that most patients do not understand medical jargon. If you do not understand something, don’t be afraid to say so and ask for information to be given in everyday language (layman’s terms). Doctors and nurses would rather explain something twice than have you go home confused and worried
- Ask and write down who will be your main point of contact at the hospital
- Ask and write down who you should contact if you need to speak to someone ‘out-of-hours’
Living well with myeloma
Living well with myeloma

A diagnosis of myeloma can bring with it many changes to daily life. Juggling commitments with hospital appointments, ongoing tests and possible side effects from treatment can be a challenge.

However, myeloma does not need to mean that the rest of your life must be put on hold. Adjustments may be needed – for example to your working life, travelling or your exercise regime – but they can often still remain an important part of your life, if you want them to.

Common questions about living well with myeloma

- Can I continue working?
- Should I avoid alcohol, or change my diet?
- Can I still exercise?
- Can I travel?
- Am I entitled to any benefits?
Living well with myeloma

Some common day-to-day concerns that myeloma patients face are listed below, along with some practical tips for dealing with them.

Work

Following a diagnosis of myeloma, making decisions regarding work will need a bit of forward planning and ongoing review of your options. You will need support from your employer at different times following your diagnosis and during treatment. Adjustments may be needed not only to your working life, but to the working lives of your family members and friends who are providing support too.

Depending on the nature of your job, your responsibilities may be restricted following your diagnosis or by the treatment that you are on. A lot of myeloma treatment is oral (by mouth) and taken outside of the hospital setting. This means you may be able to continue working during some of your treatment.

Nevertheless, going through treatment for myeloma will have its ups and downs and may at times affect your ability to work. Similarly, the symptoms and/or complications of myeloma are likely to impact on your working life at times.

Practical tips

If you work, it is a good idea to ask a few questions of your healthcare team (e.g. your doctor or specialist nurse) and line manager or HR representative at your place of employment to get a better idea of where you stand. Some examples are given in the following table.

<table>
<thead>
<tr>
<th>Questions for healthcare team</th>
<th>Questions for line manager/HR representative</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td></td>
</tr>
<tr>
<td>• How much time will I need to take off work for each of my treatments e.g. chemotherapy, radiotherapy, stem cell transplant?</td>
<td>• Who should I contact if I have to take very short-notice sick leave?</td>
</tr>
<tr>
<td>• Which treatments and side effects are most likely to interfere with my work? When will these side effects occur and how long will they last?</td>
<td>• Will I have to use my annual leave entitlement instead of taking sick leave?</td>
</tr>
<tr>
<td><strong>Careener/ family</strong></td>
<td></td>
</tr>
<tr>
<td>• When am I most likely to need to take time off work or reduce my hours to provide support?</td>
<td>• If I take time off work, what do I need to do to make sure my job is secure?</td>
</tr>
<tr>
<td>• To help me plan my working time, how long will each appointment last, including possible delays?</td>
<td>• Which support services are available to me e.g. counselling, employee-assistance programmes, occupational therapy?</td>
</tr>
<tr>
<td>• So that I can book time off work, how far in advance can appointments be made for the person I care for?</td>
<td></td>
</tr>
</tbody>
</table>
Benefits
There are a number of benefits both you and your carer may be entitled to. These include, but are not limited to: statutory sick pay; universal credit; personal independence payment (PIP); carer’s allowance; a Blue Badge for parking.

Practical tips
Find out which benefits you are entitled to on www.gov.uk or by calling your local Citizens Advice. There may be a social worker at the clinic you attend who can advise you about benefits and help you complete the forms.

Diet and nutrition
Whilst there are no specific dietary recommendations for myeloma patients, those who eat healthily and follow certain tips can benefit in many ways. Eating a healthy, well balanced diet will help:

- Maximise your body’s healing ability and keep energy levels high
- Better prepare your body for treatment as well as improve tolerance and response to treatment
- Manage some side effects of treatment
- Improve your quality of life

There are certain times when you may have more difficulty eating. For example, you may experience loss of appetite and/or nausea, usually caused by the treatment you are on.

Alcohol
Generally, it is 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.

Practical tips
- Eat more frequent, smaller meals rather than three large ones and keep your fluid intake up
- Take advantage of the times when you do feel like eating and have a larger meal. Many people have a better appetite in the morning, when they are rested
- Go for a short walk. Exercise also stimulates appetite
- If you are really struggling to eat, try liquid or powdered meal replacements, such as Fortisip™ or Complan™. You can also ask your doctor or nurse to be referred to the dietician who is part of the MDT
- Try to avoid fatty, greasy or fried foods as well as foods that are very sweet, spicy or have a strong smell until your nausea subsides

There will be times when you may need to pay greater attention to the foods you eat. For example, you may need to alter your diet if your immune system is
compromised and your white blood cell count is low (your doctor may say you are ‘neutropenic’) because you are at increased risk of picking up a bug.

If you are immunocompromised, you will be advised to be very careful about food hygiene and also to avoid certain types of food such as shellfish, paté, unpasteurised dairy products and raw or undercooked eggs. Sometimes this is referred to as a “clean diet”.

**Vitamins and supplements**

There are no specific recommendations for myeloma patients about taking vitamins and supplements – in most cases a well-balanced diet with plenty of fruit and vegetables should provide an adequate amount of vitamins and minerals to maintain general health.

Some people do want to take a general vitamin supplement if they feel they may not be getting enough vitamins and nutrients from their diet.

You should avoid taking vitamin C in large doses (more than 500mg a day), as this can increase the acidity of urine which can damage the kidneys. You also need to avoid taking vitamin C if on bortezomib as research has shown that it can block the action of bortezomib against the myeloma. In addition, patients receiving bortezomib should not drink green tea or take green tea supplements as green tea can stop bortezomib from working properly.

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 the use of these supplements.

You should talk to your doctor to ensure that supplements you want to take are safe to use and that they will not interact with any treatments you are on.

**Infection**

Infection is more common in myeloma patients because myeloma and its treatment can reduce your white blood cell count, which affects your ability to fight infection. Don’t shut yourself away from people but do take a common sense approach to minimise the risk of infection whilst maximising the need to be close to family and friends.

**Practical tips**

- Wash your hands frequently
- Avoid crowded situations (e.g. public transport)
- Be vigilant for signs of infection e.g. temperature, shivery feeling, sore throat, painful rashes, diarrhoea, nausea, vomiting. It is important to take your temperature if you are not feeling well and to contact your doctor if you have a temperature over 38°C
- Take antibiotics as prescribed
- Get your annual flu vaccination
Exercise
Being physically active can improve your physical and emotional ability to carry on with day-to-day life whilst increasing your confidence and enjoyment of social activities. The most important thing for you to think about when planning any sort of exercise is the effect it might have on your bones.

Practical tips
- Before starting, discuss exercise with your doctor or nurse
- You should avoid contact sports and more adventurous sports in case of injury
- Gentle forms of exercise such as walking, swimming, cycling, gentle aqua-aerobics, gentle gym work, yoga and tai chi are good for overall health and for muscle strengthening
- Avoid crowded gyms, swimming pools, saunas and spas at times when you're immunocompromised (vulnerable to infection)
- Walking with others can be a great way to stay motivated and enjoy some social chit-chat
- Enquire at your local Support Group for others who might be interested in starting a walking or cycling routine

Driving
Whether to drive or not is generally a personal decision based on how well you're feeling at the time. However, your doctor may specifically recommend you should avoid driving, for example if you're on drugs that can cause drowsiness such as thalidomide and morphine-based painkillers. If you drive, you are now required by law to inform the DVLA if you have peripheral neuropathy. You will need to complete the DVLA CN1 form which can be downloaded from the DVLA or call the DVLA on 0300 790 6806.

You may be entitled to join the Blue Badge scheme which allows people with mobility disabilities to park in parking-restricted areas. Visit www.gov.uk/apply-blue-badge to apply.

Travelling
Being diagnosed with cancer sometimes makes people more motivated to travel. Some people decide to bring forward trips they had always imagined going on. However, there are some challenges you may experience when travelling or planning your trip. With careful planning and a few sensible precautions, though, you can still enjoy holidays both in the UK and abroad.

Firstly, it's important that you and your doctor think through any potential problems and make a realistic assessment of whether or not you're well enough to travel. Your doctor can also help you plan the best time for your holiday to ensure it doesn't interrupt your treatment.
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), which you can apply for at the Post Office or online at www.nhs.uk/ehic. The EHIC entitles UK residents to free or reduced-cost emergency treatment when temporarily visiting the European Union (EU) and certain other European countries. The EHIC is not an alternative to travel insurance. It will not cover any private medical costs nor help getting back to the UK should you become unwell while on holiday.

Depending on which country you are planning to visit you may need to have vaccinations before you go. You should avoid ‘live’ (also called ‘attenuated’) vaccinations, which you need in order to travel to some parts of the world. Inactivated or ‘killed’ vaccines are permitted however. This may affect your choice of holiday location.

### Practical tips

You might find it helpful to work through this checklist as you’re making arrangements for travel:

- Have you discussed your travel plans with your doctor?
- Are you fit enough to travel safely?
- Do you need any particular vaccinations for the destination? Remember to take any relevant certificates with you
- Have you let the travel company and your accommodation know about any particular needs?
- If you’re taking regular medication, have you got enough for the whole time you will be away? Remember to take additional supplies in case your return is delayed
- Do you have your travel insurance policy and certificate?
- Ask your doctor to write a letter for you to carry with you outlining your previous/current treatment and details about your myeloma. This could come in handy if you fall ill whilst away
- If you are prone to picking up infection, speak to your doctor about taking a course of emergency antibiotics with you
- If you are going on a long flight and are considered at risk of developing blood clots, talk to your doctor about anti-clotting drugs and compression stockings

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myeloma.org.uk
If you’re travelling to a European Economic Area country or to Switzerland: do you have your European Health Insurance Card?

Myeloma UK can provide a list of travel insurance companies that have insured myeloma patients in the past.

For more information about all aspects of living well with myeloma see the Infopack for living well with myeloma from Myeloma UK. You can also hear from other patients in The small things that make all the difference, a book of hints and tips written by people affected by myeloma for people affected by myeloma. Contact Myeloma UK for a copy.
Medical terms explained

Anaemia: A decrease in the normal number of red blood cells or haemoglobin level in the blood. Myeloma in the bone marrow blocks red cell production, which causes anaemia and results in shortness of breath, weakness and tiredness.

Antibody (immunoglobulin): Proteins found in the blood and produced by specialised white blood cells (plasma cells) to fight infections and disease.

Balloon Kyphoplasty: A surgical procedure used to stabilise, reshape and restore height to damaged vertebrae. This is achieved by inserting a small balloon into the fractured vertebra and inflating it before bone cement is inserted.

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

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

Bone marrow biopsy: A procedure to remove of a small sample of bone marrow tissue (for examination under a microscope).

Bortezomib (Velcade®): A proteasome inhibitor drug which is given either by intravenous (into a vein) infusion or subcutaneous (under the skin) injection.

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

Chemotherapy: Treatment with potent drugs intended to kill cancer cells. Chemotherapy may be intravenous (into a vein) or oral (in tablet form).

Chronic: A cancer or disease that persists over a long period which causes continuous or episodic periods of ill health. In medicine the opposite of chronic is acute. An acute disease is a disease with a rapid onset and/or a short duration.

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

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

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

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.

Growth factor: A protein used to stimulate the development and growth of cells.

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.

Hypercalcaemia: A higher than normal level of calcium in the blood, which may cause loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion.
**Light chain:** The smaller of two components that make up the structure of antibodies (or immunoglobulins). There are two types of light chain, kappa and lambda.

**Light chain myeloma:** A type of myeloma where only the light chain portion of the abnormal antibody is produced.

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

**Non-secretory myeloma:** A type of myeloma characterised by the absence of a paraprotein in both the blood and the urine. It occurs in less than 1% of patients.

**Panobinostat (Farydak®):** A histone deacetylase inhibitor drug which is given orally.

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

**Percutaneous vertebroplasty:** A procedure used to repair/stabilise a compression fracture in one or more vertebrae and to relieve pain. It involves injecting bone cement into the vertebra to stabilise and strengthen it.

**Peripheral neuropathy:** Damage to the peripheral nerves, particularly in the hands and feet causing pain, tingling and altered sensation.

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

**Platelets:** Small blood cells which are involved in normal blood clotting.

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

**Prognosis:** A medical term for predicting the probable course and outcome of a disease.

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

**Red blood cells:** Blood cells which transport oxygen, in the form of haemoglobin, around the body.

**Spinal cord compression:** The term used to describe pressure on the spine. In myeloma, it can be caused by collapsing vertebra or by the growth of a plasmacytoma within the spinal canal.

**Stem cell transplant:** 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.

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

**Thalidomide:** An immunomodulatory drug (IMiD) that works by affecting and modifying the immune system.

**White blood cells:** Blood cells involved in the body’s immune system, which help to fight infection.
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

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