Myeloma

Your Essential Guide

Contents

Disclaimer

The information in this Essential Guide is not meant to replace the advice of your medical team. They are the best people to ask if you have questions about your individual situation.

Introduction

This Essential Guide has been written for myeloma patients. It may also be helpful for their families and friends. It provides information about myeloma, its treatment and management. It is intended to help you understand the disease and to make informed decisions about your care and treatment options.

The table of contents on the previous page will help you to use this Essential Guide and find the answers to any specific questions you may have.

Some of the more technical or unusual words appear in bold the first time they are used and are described in the **Medical terms explained** section at the back of this Essential Guide.

This Essential Guide aims to:

- Help you understand more about myeloma and its treatment
- Help you to make informed treatment decisions
- Provide information to carers and family members

Myeloma UK provides a range of specific Infoguides and Infosheets which cover all aspects of the treatment and management of myeloma. You will find a list of these at the back of this Essential Guide.

For more detailed information about living with myeloma, see *Living with Myeloma – Your Essential Guide* from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** This information is also available to download at **www.myeloma.org.uk**

To talk to someone about any aspect of myeloma, call the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** The Myeloma Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from the UK and Ireland. From outside the UK and Ireland, call +44 (0) 131 557 9988 (charged at normal rate).

What is myeloma?

Myeloma, also known as multiple myeloma, is a type of bone marrow cancer arising from **plasma cells**, which are normally found in the **bone marrow**. Plasma cells form part of your **immune system**.

Normal plasma cells produce **antibodies** (also called immunoglobulins) to help fight infection. In myeloma, the abnormal plasma cells release only one type of antibody, known as **paraprotein**, which has no useful function. It is often through the measurement of this paraprotein that myeloma is diagnosed and monitored.

Bone marrow is the 'spongy' material found in the centre of larger bones in the body (see Figure 1). As well as being home to plasma cells, the bone marrow is the centre of blood cell production (**red blood cells**, **white blood cells** and **platelets**).

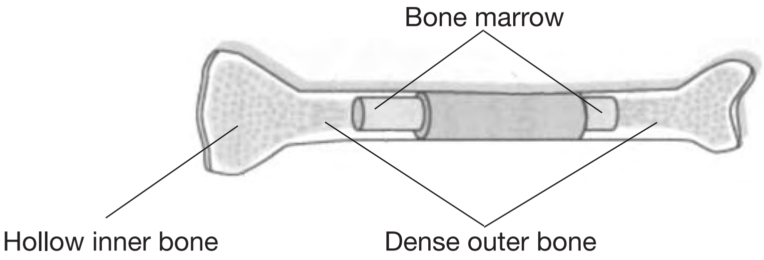

Figure 1 – Bone marrow

In myeloma, the **DNA** of a plasma cell is damaged causing it to become malignant or cancerous. These abnormal plasma cells are known as myeloma cells. Unlike many cancers, myeloma does not exist as a lump or tumour. Instead, the myeloma cells divide and expand within the bone marrow.

Myeloma affects multiple (hence the term 'multiple myeloma') places in the body where bone marrow is normally active in an adult, i.e. within the bones of the spine, skull, pelvis, the rib cage and the areas around the shoulders and hips.

The areas usually not affected are the extremities – the hands, feet and lower arm/leg regions. This is very important since the function of these critical areas is usually fully retained.

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.

Common problems are bone pain, bone fractures, tiredness (due to **anaemia**), frequent or recurrent infections (such as chest and bladder infections), kidney damage and **hypercalcaemia** (raised calcium level in the blood).

Some people go on to develop myeloma after having been diagnosed with a condition called **MGUS** which stands for Monoclonal Gammopathy of Undetermined Significance. This term describes the condition of the raised abnormal protein seen in myeloma (the paraprotein), but where there are no other features of the disease (less than 10% plasma cells in bone marrow and no evidence of bone disease).

The risk of transition from MGUS to active myeloma is very low; only a 1% chance each year of follow-up. Even if the myeloma cells are at a higher level of 10 – 30% of the total bone marrow, the growth rate can be very slow and represent asymptomatic or smouldering myeloma.

Both of these conditions can change very slowly over a period of years and do not require active treatment. It is very important to establish the correct diagnosis, distinguishing MGUS and smouldering myeloma from active or symptomatic myeloma, which does require treatment.

For more information see the *MGUS* and *Smouldering Myeloma* Infosheets from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** This information is also available to download at **www.myeloma.org.uk**

There have been many new developments in the treatment and management of myeloma over the last few years that have had a significant impact on the way myeloma is treated. Research is ongoing to develop new treatments and to use existing treatments in a better, more effective way. Many of the current and new developments are discussed in this guide.

Treatments for myeloma can be very effective at halting its progress, controlling the symptoms, and improving quality of life, but they are not able to cure it.

For more detailed information about living with myeloma, see *Living with Myeloma – Your Essential Guide* from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** This information is also available to download at **www.myeloma.org.uk**

Basic facts

- There are approximately 4,000 new cases per year in the UK
- Between 14,000 – 20,000 people are living with myeloma in the UK
- Myeloma accounts for 15% of blood cancers and 1% of cancers generally
- Myeloma mostly affects older people, although it appears to be on the increase in younger people

Types of myeloma

Myeloma is often described as being a very individual disease, both in terms of the way patients experience complications and in the way they respond to treatment, all of which can vary greatly. Some of this variation is due to the different types and sub-types of myeloma.

Different types and sub-types of myeloma are based on the type of immunoglobulin (paraprotein) produced by the myeloma cell.

Each immunoglobulin is made up of a specific structure containing two principal components – heavy and light chains. Within these components, there are two heavy chains and two light chains (see Figure 2).

There are five possible types of heavy chain component denoted by the letters G, A, D, E and M and there are two possible types of light chain component denoted by the Greek letters, kappa (κ) and lambda (λ).

Each individual immunoglobulin (Ig for short), can have only one of the five possible heavy chain types and only one of the two possible light chain types.

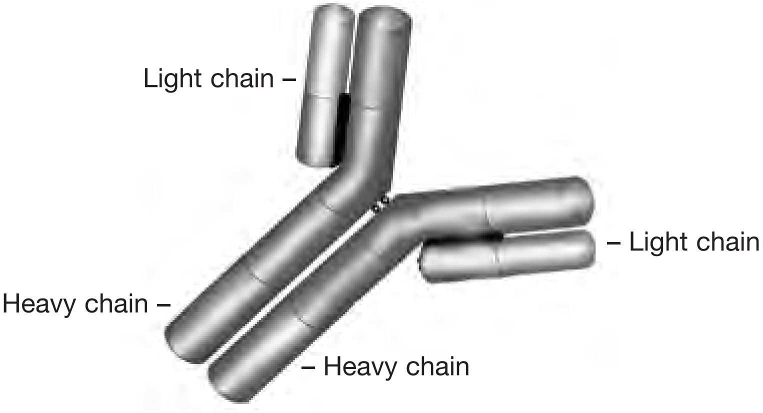

Figure 2 – Immunoglobulin structure

Most people with myeloma, about 65%, have what is called IgG type myeloma. That is immunoglobulin type G (one of the five possible heavy chains), with either the kappa or lambda light chain component.

The next most common type is IgA myeloma. IgM, IgD and IgE type myeloma are all quite rare.

At the same time as producing one type of whole immunoglobulin, approximately 30% of patients will also produce light chains (such as kappa light chains) which are detectable in the urine as well as the blood.

In about 20% of patients, the myeloma cells produce light chains only (no whole immunoglobulins at all). This is called ‘light chain’ or ‘Bence Jones’ myeloma.

More rarely, in about 1 – 2% of cases, the myeloma cells produce very little or no immunoglobulin of any type which is known as ‘non-secretory’ myeloma making diagnosis and monitoring very difficult. However, a recently developed test called the Freelite™ test has been able to detect minute amounts of light chains in the blood and urine in most ‘non-secretory’ patients, therefore making diagnosis and monitoring easier.

There are often differences in the characteristics of the different types of myeloma. The most common type, IgG, has all the usual features of myeloma, while IgA myeloma can sometimes be associated with tumours outside the bone, and IgD myeloma can be accompanied by plasma cell leukaemia and is more likely to cause kidney damage.

Light chain or Bence Jones myeloma is the type of myeloma most likely to cause kidney damage and/or lead to deposits of the light chain component in the kidneys and or in nerves and other organs, a condition known as AL amyloidosis, or light chain deposition disease.

For more detailed information about AL amyloidosis and living with AL amyloidosis, see *AL amyloidosis – Your Essential Guide* and *Living with AL amyloidosis – Your Essential Guide* from Myeloma UK. To order your free copies, contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk/amyloidosis**

What causes myeloma?

Although a large amount of research has been done to investigate the potential causes of myeloma, nothing has been proven to date.

Exposure to certain chemicals, radiation, viruses and a weakened immune system are thought to be potential causal or trigger factors. It is likely that myeloma develops when a susceptible individual has been exposed to one or more of these factors.

As it is more common to develop myeloma later in life it is thought that susceptibility may increase with the ageing process and the consequent reduction in immune function, or that myeloma may result from a lifelong accumulation of toxic insults or antigenic challenges.

There is a rare tendency for myeloma to occur in families, but the likelihood is very low and no tests are currently available for this. Even when myeloma occurs more than once within a family, this may be due to a common exposure to environmental factors, rather than it being hereditary.

Diagnosis, tests, investigations and staging

In order to diagnose myeloma, several tests and investigations need to be carried out. This is often a difficult and uncertain time for patients and their families. Tests and investigations are done to:

- Establish a diagnosis
- Help determine a treatment plan and monitor progress
- Detect complications of the disease so that they can be treated

Myeloma is a very individual disease and results from these tests may vary from patient to patient. It is not enough just to make a diagnosis of myeloma; it is critical to have an accurate picture of the disease in each patient before an appropriate treatment plan can be developed.

Paraprotein measurement

As well as being important in diagnosing myeloma, changes in the paraprotein level are a good indicator of changes in the activity of the myeloma. For this reason, regular blood tests are done to measure your paraprotein level. This allows your doctor to see how well treatment is working and to check that the myeloma is remaining stable during periods when you are not receiving active treatment.

If you have no paraprotein detectable after treatment you are normally considered to be in complete remission. Complete remission is unusual except after high-dose therapy and stem cell transplantation.

If your paraprotein has fallen and is still detectable, but stable after treatment you are normally considered to be in partial remission, also called a plateau phase. It is termed a ‘plateau phase’ because a graph of the paraprotein results appear flat like a plateau.

Both the level (amount the paraprotein decreases) and duration of response (length of plateau or remission) are important when measuring how successful treatment has been.

X-rays of skeleton (skeletal survey)

As myeloma can damage the bones, one of the first investigations performed is a skeletal survey. This is a series of X-rays used to detect any old or more recent bone damage. Areas of bone damage show up on X-ray film as black shaded areas and are known as ‘**lytic lesions**’.

Sometimes an even clearer picture of the bone is needed and you may have an MRI (magnetic resonance imaging) or CT (computerised tomography) scan. MRI and CT scans can provide more detail and can identify areas of bone damage which may not show up on X-ray.

Bone marrow biopsy (aspirate)

This involves putting a needle into a bone (usually the hip bone) to get a small sample of the bone marrow, this sample is sometimes called an aspirate, and is done under a local anaesthetic. This sample is then examined to count the number of plasma cells present in your bone marrow. Normal bone marrow has less than 5% plasma cells; bone marrow in patients with myeloma may have between 10% and 90% plasma cells. This test may also be done at the end of treatment.

A further indication of the number of plasma cells can be gained by doing a ‘trephine biopsy’ which means taking a small core of bone together with the marrow inside. This is usually done at the same time as the bone marrow aspirate.

Full blood count

The full blood count is a blood test that measures the levels of cells in the blood and is done regularly throughout the course of the disease. It measures the red blood cells, which transport oxygen; white blood cells, which help fight infection; and platelets, which help the blood to clot.

These cell counts are important as the counts can be affected by myeloma itself and treatment:

- White cell count shows if you are more at risk of infection
- Haemoglobin level (red cell count) shows if you are anaemic
- Number of platelets shows if you are at risk of bleeding or bruising more easily than normal

Kidney function

Kidney function can be affected by certain unique features associated with myeloma, particularly increased light chains and blood calcium levels, and also by the effects of some of its treatment.

Blood tests are used to help measure levels of urea and creatinine which are waste products that are normally filtered out by the kidney. High levels of urea and creatinine indicate poor kidney function.

Calcium measurement

Calcium is a mineral which is normally found in the bone. In patients with active bone disease due to myeloma, calcium is released from the bone into the blood stream, which can lead to higher levels of calcium in the blood (hypercalcaemia).

Albumin measurement

Albumin is a type of protein that normally makes up most of the protein found in the blood, but in myeloma, chemical messengers (also called **cytokines**) produced by the myeloma cells suppress albumin production in the liver. Where kidney function is affected, albumin may also be lost into the urine; both these factors can lead to a low albumin level. Albumin levels are important in the staging of myeloma (see below).

Beta 2 microglobulin

A blood test to measure levels of a molecule called **beta 2 microglobulin (ß2M)** will also be done. ß2M is one of the most important indicators of both the amount and activity of the myeloma, and therefore is crucial in determining the outcome of treatment (prognosis) of individual cases.

The appendix at the back of this guide includes a complete list of potential tests as well as some of the normal values.

Staging

On completion of a wide range of tests, your doctor should have a clear and in-depth picture of the specific characteristics of your myeloma. With this information, the myeloma is normally staged.

Staging indicates the amount of myeloma and therefore reflects the expected outlook for individual patients. The most commonly used staging system is called the International Staging System (ISS), which classifies myeloma into three stages:

- Stage one: Early, low level of myeloma
- Stage two: Active, moderate level of myeloma
- Stage three: Active, high level of myeloma

This system uses two factors to predict potential response to treatment. These factors are beta 2 microglobulin (ß2M) level and albumin level, which can both be assessed by doing a simple blood test.

To help identify patients with myeloma that may not be causing symptoms but which requires treatment, doctors may also use other criteria. The acronym ‘CRAB’ describes these criteria: (C) calcium elevation, (R) renal (kidney) insufficiency, (A) anaemia and (B) bone abnormalities (lytic lesions or bone loss).

Further details of this staging system are provided in Appendix three on page 58.

Treatment of myeloma

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

There are now a number of different treatments for myeloma, which are used at different stages of the disease. These include the traditional treatments of **chemotherapy**, steroids, high-dose chemotherapy and stem cell transplantation, and also newer treatments such as Thalidomide Celgene™, Velcade® (bortezomib), Revlimid® (lenalidomide). There are also novel treatments, which may be accessed as part of a **clinical study**.

There are also a number of supportive treatments to help treat the symptoms and complications that myeloma can cause. These include a group of drugs called **bisphosphonates** used to treat bone disease and bone pain and **erythropoietin** (EPO) for anaemia. In addition, blood and platelet transfusions can be given for anaemia and low platelet levels. Antibiotics can be given to treat infections. A drug called Allopurinol may also be given in the initial stages of treatment to prevent a build up of uric acid in the blood, which can cause kidney damage.

Before embarking on treatment, however, patients and doctors need to make important decisions about what treatment is best or most appropriate and when to receive it.

The next few sections look at some important points in making treatment decisions and provide a brief overview of the range of treatments available to treat both the underlying problem and the complications and symptoms due to myeloma.

Decision-making

Choosing treatment for myeloma is not a simple decision as no single treatment or treatment combination has been identified as being the best. In addition to this, myeloma is a very individual cancer and each patient will respond differently to different treatments. The advantages, disadvantages and side-effects arising from available treatments are also quite different.

You may prefer just to follow the advice of your doctor or to take a more active role in the decision-making process. Your doctor should be able to adapt his or her approach accordingly to suit you.

Generally, the best treatment for you will take account of:

- Your general health, including your kidney function
- Your age (for example, this may affect whether high-dose therapy and stem cell transplantation is possible)
- Your personal circumstances and lifestyle
- Your priorities and preferences
- The nature of your disease
- Any previous treatments
- Level of complications
- Results and response to any previous treatment received

Making an informed decision is important and you should take as much time as you need to make one. However, in some situations there may be an urgent need to start treatment, for example, if you have significant kidney damage.

To help you understand more about your myeloma and the treatment options available, try to collect as much information as you feel you need. Information is available from doctors, nurses, other patients, the Internet and Myeloma UK.

Listing the pros and cons of each option is a good way to help you decide what the best treatment for you is. Talking things over with your family, friends or another patient can help to clarify your thoughts.

Your decision should take into account your personal priorities, your lifestyle and how you feel about the pros and cons of the treatment options that are available and their potential side-effects. The important thing is that you and your doctor agree together on the treatment you will receive.

Getting more than one opinion

The way cancer services are currently organised in the UK means that the hospital where you are being treated should involve a range of healthcare professionals working together as a team known as a multidisciplinary team.

Your treatment will be discussed by the team, which usually includes more than one consultant haematologist. As myeloma is not common, and choosing the right treatment is sometimes as challenging for doctors as it is for patients, you may feel that you want more than one opinion to be sure that the diagnosis is correct, that the treatment plan is appropriate for your situation and that all other options have been considered.

Doctors are normally happy to arrange another opinion and you should not feel that asking for one will offend them or the medical team. You may, however, find it easier to approach your GP about this.

Sometimes people have difficulty in communicating with their doctor and want the chance to talk to another doctor. In this circumstance, you might ask to see a different doctor in the same hospital or to have another opinion at another hospital.

Your hospital doctor or GP can organise an appointment for you with another doctor (usually another consultant haematologist). While this can be done through the NHS, some people prefer to have another opinion privately. Your notes will be passed on to the second doctor before your visit so they are familiar with your particular situation.

What if I don’t want any treatment at all?

Some people feel that 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 choose not to have treatment for your myeloma there are many supportive measures available to help alleviate its symptoms.

Whether or not you choose to have treatment, it may be helpful to be seen by a palliative care specialist, who will be able to provide expertise in symptom control and supportive care.

What if I want to try alternative therapies?

Some patients do not want to have any type of toxic treatment and prefer to try an alternative approach, using special diets, alternative therapies or remedies instead of the conventional treatments described in the next section.

Conventional treatments have been well tested in clinical studies and doctors have a clear understanding of how they work. It is important to remember that almost no alternative approaches have been studied in the same way and there is currently no evidence that they work in treating myeloma.

If you choose to use alternative ways of trying to control your myeloma, it is important to discuss this with your doctor as there are potential risks involved and you may choose to try conventional treatment at a later date.

Alternative approaches to treatment should not be confused with complementary therapies. Complementary therapies are used alongside, and complementary to, conventional treatment. Complementary therapies may include dietary and herbal supplements, relaxation and visualisation, massage and aromatherapy. Before starting any complementary therapy it is important to discuss it with your doctor.

Indications for starting treatment

The decision whether or not to start treatment is an important one, because not everyone diagnosed with myeloma will need treatment to control their myeloma immediately.

As currently available treatment is not curative and has side-effects, it is usual to wait until the myeloma is actively causing problems before starting treatment. Results from the tests and investigations listed earlier, together with other individual factors, will help determine when treatment should begin, what that treatment should be, and provide a baseline against which response to treatment and disease progression can be measured.

What treatments are available?

You can think of the treatment and management of myeloma as being in three categories. These are:

- Active monitoring
- Treatments to control the myeloma itself
- Treatments for the symptoms and complications caused by the myeloma (discussed in a later section)

There is some overlap between these categories, since any treatment that controls your myeloma will have the added benefit of reducing the complications and symptoms you experience.

The following chapters describe the various treatments that are available and some of the circumstances under which particular treatments are used.

Initial treatment

Once you and your care team have decided that you require treatment to control your disease, you will need to decide jointly with your doctor what type of treatment is best for you. It is important to remember that, although these treatments can be very effective in controlling the myeloma, they do not generally cure the disease.

Treatment for myeloma can be broadly categorised into two groups:

1. Less intensive treatment for older and/or less fit people

2. More intensive treatment for younger and/or fitter people

The reason for this is that the more intensive treatment brings with it the risk of increased side-effects and complications, which could be particularly risky for older, less fit patients. The treatments used in the older patient group are more easily tolerated, often with fewer side-effects and are still very effective at treating myeloma.

Your doctor will explain to you which group you fit into, based on a number of factors, including your age and general 'fitness', i.e. previous medical history, level of symptoms and complications.

The following sections will discuss the treatment options for patients in each group.

Initial treatment options

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

The specific treatment combination prescribed for myeloma patients depends on the individual and what is most suitable for them and their myeloma.

At present there are a number of treatment combinations that may be used as initial treatment for myeloma in older and/or less fit patients. These include:

1. Cyclophosphamide (chemotherapy), Thalidomide Celgene™ (immunomodulatory drug) and dexamethasone (steroid) (also called CTD)

or

2. Melphalan (chemotherapy), prednisolone (steroid) and Thalidomide Celgene™ (immunomodulatory drug) (also called MPT)

or

3. Thalidomide Celgene™ (immunomodulatory drug) and dexamethasone (steroid) (also called TD)

For younger and/or fitter patients, the initial treatment options include:

1. Cyclophosphamide (chemotherapy), Thalidomide Celgene™ (immunomodulatory drug) and dexamethasone (steroid) (also called CTD)

or

2. Vincristine (chemotherapy), Adriamycin® (chemotherapy) and dexamethasone (steroid) (also called VAD)

followed by

3. High-dose therapy and autologous stem cell transplantation (also called HDT & ASCT) (discussed in the following section on page 25)

These drugs will be discussed in the following sections.

Chemotherapy
(Adriamycin, cyclophosphamide, melphalan and vincristine)

The type of chemotherapy prescribed for myeloma patients depends on the individual and what is most suitable for them and their myeloma at any particular point in time.

Chemotherapy works by destroying myeloma cells in the bone marrow, preventing them from being able to divide and reproduce.

Chemotherapy drugs attack all rapidly dividing cells in the body. This includes the myeloma cells, but also may affect other rapidly dividing cells such as normal developing blood cells in the bone marrow, hair follicles and the lining of the mouth and the stomach. It is this that causes some of the side-effects of chemotherapy treatment.

Cyclophosphamide and melphalan, when given in the combinations outlined above, are usually given orally (by mouth in tablet form).

Vincristine and Adriamycin (also called doxorubicin) are given intravenously (into a vein).

Steroids
(dexamethasone and prednisolone)

Steroids are hormonal substances naturally produced in the body. There are many different types of steroids; those used in the treatment of myeloma are known as glucocorticoids. These steroids can suppress inflammation and the immune response. While not everything is known about how steroids work, it is recognised that they are effective in killing myeloma cells. It has also been found that, when steroids are used with chemotherapy, the result is a greater response to treatment than when chemotherapy is used alone.

Steroids are usually given in tablet form, or more rarely intravenously (into a vein). Tablets should be taken with food or milk to help protect the lining of the stomach from irritation.

Thalidomide

Thalidomide is classified as an immunomodulatory drug (IMiD), which means that it acts on the cells involved in the body's immune system and directly kills the abnormal plasma cells.

Thalidomide is given as a tablet, usually in the evening. The dose is usually between 50 – 200mg a day depending on the individual and any side-effects they experience.

How long will my treatment last?

A course of treatment usually lasts for several months. It is given in cycles, e.g. treatment over a few days or weeks, followed by several days or weeks without treatment before the next dose is given. This is to give the healthy cells time to recover between treatments.

The exact details of the treatment schedule vary depending on the individual patient and the type of treatment they are going to receive. If you have specific questions about the timing of your treatment, your doctor is the best person to answer them.

The total length of the treatment course often depends on which one you are taking and how you respond to it, but a single course is unlikely to last less than three months and no longer than 12 months.

Unfortunately, these combination treatments do not always work for everyone. Your doctor will monitor your progress carefully and, if you do not respond to one particular treatment, it will be stopped and other options/combinations will be explored.

What side-effects could I have?

The drugs used to treat myeloma can be quite toxic and, while they can kill the myeloma cells, they can also cause significant side-effects. Each drug has its own side-effects and even the same kind of drug produces different reactions in different people.

Most side-effects are only short term, can be managed with supportive treatments, and gradually disappear once the treatment has stopped. The length of time it takes for side-effects to resolve after stopping treatment varies from person to person.

Common side-effects of:

Chemotherapy include nausea, vomiting, diarrhoea, infections, sore mouth and hair loss. Chemotherapy can also cause infertility. If this is a consideration for you, you should talk to your doctor.

Steroids include stomach pain, increased blood sugar, increased risk of infection, increased appetite, mood changes, and muscle weakness.

Thalidomide include drowsiness and constipation. Thalidomide can also cause damage to the nerves in the hands and feet resulting in tingling, numbness, increased sensitivity and pain. This is called peripheral neuropathy. Thalidomide can also cause blood clots, this may be treated with drugs called anticoagulants, which help prevent blood clots forming.

For more information see the *Constipation, Fatigue, Peripheral Neuropathy,* and *Steroids* Infosheets from Myeloma UK. To order your free copies contact the Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland. Also available to download at www.myeloma.org.uk

If you want to know about the side-effects that may be caused by your treatment, you should ask your doctor or nurse. You should be given patient information leaflets for all of your drugs. If you are not, ask your doctor or pharmacist for them.

If you experience any side-effects that you think may be due to your treatment, it is important that you tell your doctor straight away. He or she may be able to give you drugs or suggestions to help, or may change your treatment to reduce the effects.

High-dose therapy and stem cell transplantation

What is high-dose therapy and stem cell transplantation and why is it used?

Standard dose chemotherapy as described in the previous section is an effective way of treating myeloma. However, a major drawback of chemotherapy is the inability to give high doses safely. This is because high doses of chemotherapy kill the blood-forming **stem cells** (Figure 3) in the bone marrow. This results in blood cell production being severely affected, with blood counts falling to dangerously low levels causing potentially life-threatening problems.

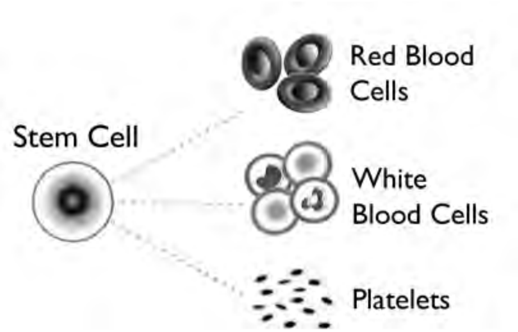

Figure 3 – Stem cell divisions

High-dose therapy and stem cell transplantation involves giving high doses of chemotherapy to kill the myeloma cells, and then giving back stem cells previously collected from the patient (or more rarely, a donor). This effectively 'rescues' the patient's bone marrow, allowing blood cell production to continue.

Blood-forming stem cells exist in the bone marrow and have the capacity to divide and develop into the three main types of cells found in the blood. They are a vital component of high-dose therapy and stem cell transplantation (see Figure 3).

High-dose therapy and stem cell transplantation is a standard treatment for myeloma and can lead to a better overall response to treatment.

What happens during the stem cell transplant procedure?

Stem cell harvesting

Stem cells can either be taken from the patient, or, more rarely from a donor (usually the patient's brother or sister).

The stem cells are collected, or harvested, from the blood prior to the high-dose chemotherapy, by a process called **apheresis**. This involves passing the blood through a machine, which separates and collects the stem cells and returns the remainder of the blood back to the body.

Transplant

Once enough stem cells have been collected they are stored frozen. You then receive the high-dose chemotherapy and have the stem cells given back to you intravenously, in a similar way to a blood transfusion. Receiving your own stem cells back is called an autologous transplant or autograft, while receiving stem cells from a donor is called an allogeneic transplant or allograft.

Recovery

Bone marrow recovery (also called engraftment) takes about two weeks. Blood and platelet transfusions may be required until the bone marrow recovers and **antibiotics** may be given to prevent infection.

Most people stay in hospital until their blood counts return to a safe level; this normally means spending two to four weeks as an inpatient. During this time you may feel quite unwell and be kept in protective isolation in hospital to help you avoid infections.

The high-dose therapy and stem cell transplantation process can be quite debilitating and after the procedure, a period of several weeks of slow convalescence at home is often needed.

Advantages/disadvantages

The main advantage of autologous transplant is the possibility of achieving an excellent response and long remission with a fairly low level of risk from the treatment. Disadvantages include more toxicity than standard dose chemotherapy and the reality that relapses still occur.

Allogeneic transplantation

The section above outlines the procedure for an **autologous transplant**. This is where a patient's own stem cells are used for the transplant. This is the most common form of transplantation used in myeloma.

For a small number of younger patients, an **allogeneic transplant** may be considered. This is where stem cells from a donor with a matched tissue type are used for the transplant. Allogeneic transplants have important differences compared with autologous stem cell transplants both in the potential benefits and the risks involved.

Allogeneic transplants aim to use the immune system of the donor to help fight against myeloma in the patient. The donated stem cells are transplanted into the patient where they mature into functioning cells of the immune system. They can then potentially attack any myeloma cells present – this effect is known as '**graft-versus-myeloma**' and is thought to be responsible for the lower rate of relapse often seen when compared with an autologous transplant.

The donated cells need to be a suitable match and so the donor is usually a sibling. Allogeneic transplants are possible from an unrelated donor, but carry much higher risks as there is more incompatibility between the patient and donor and are not commonly carried out for myeloma patients.

The main disadvantage of an allogeneic transplant is the risk of **graft-versus-host disease** (GVHD), which is a potentially life-threatening condition. This can happen because the donated cells not only attack the myeloma cells but can also recognise the patient's own body tissue as foreign. GVHD is a major problem and is one of the reasons why allogeneic transplants have a higher mortality rate than autologous transplants.

For more information see the *High-Dose Therapy and Stem Cell Transplantation* Infoguide from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk**

Treatment for relapsed or refractory myeloma

While there are effective treatments for myeloma, currently there is no cure. This means that even after successful treatment your myeloma will return. When your myeloma returns after a period of remission or **plateau**, this is called a **relapse**.

If your myeloma stops responding, or does not respond, to treatment this is referred to as **refractory** myeloma.

Being told your myeloma has stopped responding to treatment, or has returned, can be a very disappointing and distressing time for patients, their families and carers. Talking things over with your doctor, family or another patient can help. Myeloma UK may also be a good source of support and information at this time.

For patients who had a good response, their initial treatment may be repeated. In other relapsed and refractory patients, a different treatment will need to be given.

While it can be a worrying time, it is important to remember that there are now a number of different treatment options for myeloma. Many of these treatments work in different ways, so if you have not responded well to one type of treatment this does not necessarily mean you won't respond well to a different type of treatment.

Velcade

At first relapse, myeloma patients are most likely to receive Velcade. Velcade, also known as bortezomib, is classified as a **proteasome inhibitor**, and works in a different way to chemotherapy.

The proteasome has an important role in all cells, especially the myeloma cells. Inhibiting, or preventing the proteasome from working, causes the myeloma cells to die, while leaving normal cells less affected.

Velcade is given intravenously (into a vein) twice per week for two weeks, followed by a week's rest period. This completes one cycle of treatment, and up to eight treatment cycles are usually given.

Although patients do not normally need to be admitted to hospital, they do have to travel to the hospital quite regularly for several weeks to have their treatment.

For more information see the *Velcade* Infoguide from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk**

A second stem cell transplant

If you had a good response and remission period following your first stem cell transplant, it may be an option for you to have another transplant when you relapse. This option is normally only used if you have had greater than 18 months remission from your first stem cell transplant, as the remission period following a second transplant is usually shorter than the first.

Revlimid

At second relapse, myeloma patients may receive Revlimid. Revlimid, also known as lenalidomide, is similar to thalidomide and is classified as an immunomodulatory (IMiD) drug.

Revlimid is given in tablet form, usually for 21 days with 7 days rest.

For more information see the *Revlimid* Infoguide from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk**

Steroids

Steroid treatment with dexamethasone can be effective in controlling myeloma in patients who cannot have chemotherapy because of their general health, or in patients who have relapsed more than once following chemotherapy.

Maintenance treatment

Maintenance treatment aims to prolong the period of response to initial treatment and further decrease any remaining myeloma cells in the body, especially in patients who do not achieve a complete response after high-dose therapy and stem cell transplantation. A low-dose of thalidomide, for example, may be given after high-dose therapy and stem cell transplantation.

Not all patients will benefit from maintenance treatment and any potential benefits must always be balanced against the potential side-effects that may occur.

How do I know if my treatment has worked?

As mentioned earlier, the aim of treatment is to control the myeloma and its effects on the body. In order to find out how a patient responds to treatment, several tests will be carried out on a regular basis.

These tests may vary from patient to patient, but generally would include regular blood and urine testing, between one and two bone marrow aspirates per year and occasional X-rays or scans.

The signs that treatment is working include:

- A fall in the paraprotein level
- Less bone pain
- Improvement in anaemia
- A reduction in the number of myeloma cells in the bone marrow

One of the best indicators of response to treatment is an improvement in the general health of the patient.

In general terms, disease response is measured according to the categories in Table 1.

It is important to note once again that the duration of response is as important as the level of response.

Treatment outcome –	Definition
Stringent Complete Response	CR as defined below plus normal **free light chain** ratio and absence myeloma cells in bone marrow
Complete Response (CR)	≤ 5% plasma cells in bone marrow, no detectable paraprotein
Very Good Partial Response (VGPR)	90% or greater reduction in blood and urine paraprotein
Partial Response (PR)	≥ 50% reduction of paraprotein in blood and 24 hr urinary paraprotein by ≤ 90%
Stable Disease (SD)	Not meeting criteria for CR, VGPR, PR or progressive disease

Table 1 – Measuring response to treatment

Treatment for symptoms and complications due to myeloma

Unlike many other cancers, myeloma can affect the body in several ways. This is due both to the activity of the myeloma cell itself, and to the release of a variety of proteins and other chemicals into the bone marrow and bloodstream.

The most common symptoms and complications of myeloma, how they affect the patient and how they are managed, are described below.

It is important to remember that not everyone will experience all of these and that effective treatments are available.

Myeloma bone disease

Bone disease is one of the most common complications of myeloma. The myeloma cells release chemicals that activate **osteoclast** cells, which destroy bone, and block **osteoblast** cells, which normally repair damaged bone.

When this happens, bone is broken down faster than it can be repaired, leading to bone pain, bone lesions or even fractures. The middle or lower back, the rib cage and the hips are the most frequently affected areas. Fractures occur most often in the spine (vertebrae) or ribs. Fractures can sometimes occur with only minor pressure or injury. Fractures of the vertebrae can lead to their collapse, causing pain, loss of height and curvature of the spine.

The treatment for myeloma bone disease was revolutionised about a decade ago by a group of drugs called bisphosphonates. Bisphosphonates correct hypercalcaemia (high calcium level), control existing bone disease and slow down any further bone destruction. They work by coating the bone and blocking the activity of the osteoclast cells that break down the bone.

Three bisphosphonates are currently licensed for the treatment of myeloma bone disease:

- Sodium clodronate (Bonefos®, Loron®), which is taken orally in tablet form

- Pamidronate (Aredia®), which is given as a monthly intravenous infusion
- Zoledronic acid (Zometa®), which is given as a monthly intravenous infusion

The three drugs listed above are all effective and there is no evidence that one is more effective than the other. The important difference between them is that clodronate can be taken by mouth rather than through an intravenous infusion.

For more information see the *Myeloma Bone Disease and Bisphosphonates* Infoguide from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk**

Pain control

Pain is the most common symptom for patients diagnosed with myeloma and is often related to underlying bone disease. The effective management of pain and its relationship to quality of life are critical and just as important as treatment for the actual myeloma.

As with myeloma more generally, pain is very specific to the individual and treatment will vary. Medication should aim to provide continuous pain relief whenever possible with a minimum of drug related side-effects.

For more information see the *Pain* Infosheet from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk**

Complementary therapies such as relaxation techniques, aromatherapy and massage have been shown to have some benefit for individual patients.

Where pain is more severe, medication and/or complementary therapies may be supplemented by other types of treatment such as:

- Localised **radiotherapy** – this has been shown to help control 'hot spots' of active myeloma bone disease and pain
- Percutaneous Vertebroplasty – vertebral collapse in the spine can often occur with myeloma. Percutaneous Vertebroplasty is a procedure which involves the injection of cement into the vertebral body; it has been shown to have the potential to reduce pain significantly
- Balloon Kyphoplasty – similar to Percutaneous Vertebroplasty but involves the insertion of a small inflatable balloon into the vertebral body to restore vertebral height before injecting the cement. This procedure has also been shown to reduce pain significantly

For more information see the *Percutaneous Vertebroplasty* Infosheet and the *Balloon Kyphoplasty* Infoguide from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk**

Fatigue

The most important part of treating fatigue is actually recognising it. It is important that you tell your doctor how you feel because there are several things that he or she can do to help treat some of the causes of fatigue. Fatigue is often described as a vicious cycle, but the cycle can be broken, allowing you to manage it. There are things you can do to help yourself or be helped by those caring for you.

Planning activities to avoid overtiring yourself is something that you and your carers can do together. Eating a healthy, balanced diet, taking regular light exercise and ensuring that you get enough sleep can all play a part in reducing the impact fatigue has on your quality of life.

Fatigue caused by anaemia can also be treated with blood transfusions and also with a drug called erythropoietin (EPO).

For more information see the *Fatigue* and *Erythropoietin* Infosheets from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** This information is also available to download at **www.myeloma.org.uk**

Kidney damage

Kidney problems can occur in myeloma for a variety of reasons. The abnormal protein produced by myeloma cells can damage the kidneys; this is particularly common with the **Bence Jones protein**. Other complications of myeloma, such as dehydration and hypercalcaemia (see above), as well as some of the drugs used to treat myeloma and its complications, can also cause kidney damage.

The most important thing you can do to reduce the risk of kidney damage is to drink plenty of fluid. You should try to drink at least three litres (five pints) of water per day.

Avoid using a certain type of drug called a non-steroidal anti-inflammatory drug (such as aspirin or ibuprofen (Neurofen®), which are commonly used as pain-killers. These drugs may contribute to kidney problems.

There are different ways to treat kidney damage in myeloma, depending on the cause. In many cases, the kidney damage is temporary and your kidneys can recover. In a small proportion of patients, the kidney problems become permanent, so they require a regular treatment called dialysis. This is a way of filtering the blood using a dialysis machine in the same way that kidneys would do if they were healthy.

Anaemia and infection

In adults, almost all red blood cells, white blood cells and platelets are made in the bone marrow. Red blood cells contain a protein called haemoglobin which carries oxygen around the body. White blood cells help your body fight infection. Platelets are small cells that circulate in your blood and are important for helping your blood to clot.

Myeloma cells affect the production of these blood cells and a shortage of blood cells can lead to conditions such as anaemia or to more frequent infections.

Complications of reduced blood cells include:

- Too few red blood cells results in a low haemoglobin level, causing anaemia, which can lead to tiredness, weakness and breathlessness
- Low levels of white blood cells can make you more likely to get infections
- Low levels of platelets may mean that you may bruise or bleed more easily

Anaemia is a reduction in the number of red blood cells and 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 symptoms of fatigue, weakness and breathlessness.

Anaemia does not always need treatment because bone marrow is often able to recover, especially if treatment is bringing the myeloma under control.

If anaemia needs treatment, a blood transfusion can help. There is also a drug called erythropoietin (or EPO) which can stimulate the body to produce more red blood cells.

Low white cell counts may not always need to be treated, but you should be alert to symptoms of infection (such as fever, cough, pain in passing urine) and tell your doctor about them straightaway.

If your white cell count falls very low, your doctor may give you a course of antibiotics to try to prevent infections before they take hold. There are also drugs (called growth factors) that can stimulate the body to produce more white blood cells.

If your platelet count falls to very low levels, it can be boosted by a transfusion of platelets.

Key points

- Be honest about any problems you are having; describing them as accurately as possible will help you get the right treatment
- Acting early can reduce the number and severity of the complications associated with myeloma
- Bone disease can be treated effectively with bisphosphonates and early treatment can slow down bone problems
- Drink lots of water to prevent kidney problems
- If you buy pain-killers, tell the pharmacist that you need to avoid non-steroidal anti-inflammatory drugs
- Tell your doctor or nurse straightaway if you think you have an infection

New treatments and clinical studies

A great deal of research is going on to find more effective treatments with less severe side-effects. Many new treatments are in development and some of the most promising ones are discussed here.

The best and safest way to take any new drug or treatment is as part of an approved clinical study. It is important to understand that not every patient is suitable for every new treatment but if you are interested in trying a new treatment, you should discuss this with your doctor or nurse.

Clinical studies are planned investigations involving patients and designed to test new treatments or to compare different types of current treatment. They are run according to a strict set of guidelines called a protocol.

All patients involved in a study are closely monitored. The information collected during the course of the study is combined and analysed by trained researchers.

The results will help to determine which are the best treatments and so help improve care for patients in the future.

Being asked to participate in a clinical study does not necessarily mean that you are being asked to try a new treatment. The study may be testing new ways of using current treatments. In some hospitals, treating cancer patients in clinical studies is part of standard practice.

As more is discovered about these new treatments, their role alongside the more established treatments will become clearer. In time, if they are proved to be more effective and safer, they may replace some of the existing treatments.

To keep abreast of new treatments in myeloma and those in development, subscribe for free to our quarterly magazine, *Myeloma Matters* by calling + 44 (0) 131 557 3332.

Living with myeloma

Being diagnosed with myeloma affects every patient differently. At first you might be overwhelmed, in shock and feel numb. Information may not sink in at this point but don't worry, you will have many opportunities to ask questions again.

Sometimes you might feel totally in control of your feelings and at other times strong emotions may catch you unawares. You may feel a great deal of fear, anger and frustration. These feelings are common and a natural part of coming to terms with the diagnosis.

You may also experience a sense of relief that you now have an explanation for the symptoms you have been experiencing over recent months.

Learning more about myeloma, your treatment options and life after a diagnosis of myeloma can help to ease these feelings. Those around you may feel some of the same things you are feeling – they will also need support. Talking together about how you feel can help.

Many patients experience depression and anxiety at some stage in their illness. Although sometimes you may feel optimistic, there may be other times when you feel overwhelmed. You may have difficulty sleeping, become irritable, or lose interest in the things that you normally enjoy. It is important to recognise these symptoms and to discuss them with your doctor or nurse.

Emotional support

Emotional support is important in helping you to live with myeloma. It is very easy for patients and family members to feel isolated and strong emotions often make it difficult to discuss worries or fears. Talking to someone, such as your specialist nurse, who understands what is happening can ease these feelings of isolation.

To talk to someone about any aspect of myeloma, call the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from the UK and Ireland. From outside the UK and Ireland, call +44 (0) 131 557 9988 (charged at normal rate).

You may find it helpful to talk to a counsellor. Counsellors offer you the chance to explore your feelings and experiences in a supportive, confidential environment. A counsellor does not give you advice but helps you to develop coping strategies and find your own answers to the problems you are facing.

Counselling may not always be available in your hospital but your GP or consultant should be able to refer you to a professionally trained counsellor in your area. Alternatively you can contact the British Association for Counselling and Psychotherapy, for a list of registered counsellors in your area. See the 'Further information and useful organisations' section on page 60 for their contact details.

Support Groups

Support Groups provide an informal and comfortable atmosphere in which members can share experiences and information. Many people assume that they will be full of doom and gloom, but generally they are not. They are a supportive group of people who are facing the same things that you are. Some support groups are run by patients and family members, others by healthcare workers or professional group facilitators. If there is not a myeloma group, there may be a general cancer/haematology group that meets locally.

For details of Support Groups in your area call the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** There is also a Discussion Group on the Myeloma UK website where you can connect with others affected by myeloma, post messages to the group, ask questions and help to support each other. To join the Discussion Group go to **www.myeloma.org.uk**

Patient and Family Myeloma Infodays

Myeloma UK holds regular Patient and Family Myeloma Infodays across the UK and Ireland. These are full day educational meetings specifically for patients and families, where you can learn about the latest in the treatment and management of myeloma from a panel of myeloma experts. Infodays also provide the opportunity to meet others affected by myeloma, to share experiences and gain support. For more information contact Myeloma UK on +44 (0) 131 557 9988.

For more information see the *Living with Myeloma – Your Essential Guide* from Myeloma UK. To order your free copy contact the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** Also available to download at **www.myeloma.org.uk**

Communication with your medical team

Your relationship with your medical team will involve trust and collaboration. You should feel comfortable asking questions and discussing treatment options with them. Learning more about myeloma and the different treatments that are available will help you to communicate more easily with your medical team and help you to make informed decisions about your care.

Sometimes medical 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. Many people find it helpful to receive written information they can take away and read at home.

Remember that there are likely to be uncertainties, and that your doctor might not be able to answer specific questions about your future. For example, you might want to know how successful your treatment is likely to be before you decide to have it. Whilst your doctor will probably be able to give you average figures, they will not be able to predict exactly how you are likely to respond to the treatment.

Tips

- Carry paper and a pen with you to write down questions as they occur to you
- Give your doctor a list of the questions you have written down at the beginning of your consultation
- Consider taking someone with you to your appointments, both as moral support and for an extra 'listening ear'
- Don't be afraid to ask for extra time to make a decision about treatment; you may want to discuss things with family and friends first

- Always tell your doctor if you are taking any medications you have bought over the counter (without a prescription) or any supplements or complementary therapies you are using

- Tell your doctor if you are experiencing any side-effects or new symptoms

Questions for your doctor/medical team

Diagnosis

- What tests will I need to have?
- When will I get the results?
- Will I need to have treatment?
- What is the treatment likely to be?
- Are my bones affected?
- Are my kidneys affected?
- Who will be my main point of contact at the hospital from now on?

Treatment

- What are my treatment options?
- Can I choose which treatment to have?
- What is the aim of this treatment?
- How successful has it been in the past?
- What would happen if I chose not to have this treatment?
- Is this treatment part of a clinical study?
- How experienced are you and your team in delivering this treatment?
- How is the treatment given, how long will it take?

- Will a hospital visit/stay be needed?
- How will I feel before, during and after this treatment?
- Will there be side-effects, when will I experience them and how long will they last?
- Will treatment affect my chances of having children in the future?

After treatment

- How often should I have check-ups and blood tests?
- Will I receive any other treatments, e.g. bisphosphonates and maintenance treatments?
- How will I know if the myeloma has come back?

Carers

Carers often have different information needs. If you are a carer you will want to know what you will need to do for your family member/friend. You may want to ask the following questions:

- Will they require a stay in hospital and for how long?
- Will they require a lot of looking after?
- What kind of quality of life do you expect them to have?
- Who can I call in an emergency?

Self-help checklist

- Learn about myeloma and its treatment – order free booklets from Myeloma UK and use the Myeloma UK website
- Join a support group – it can help to talk to other patients and relatives about how you feel
- Use the **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland** for information on treatment and emotional support
- Find out from your GP which support services and benefits are available and ask for help if you need it
- Check your entitlement to free prescriptions and buy a pre-payment certificate if you need one
- Ask for a contact name and number for a member of staff in your medical team and keep the number handy – you could write it in this booklet
- Describe symptoms simply and accurately to your doctor or nurse – do not underplay them or assume they are not important. Try keeping a diary of your symptoms
- Take all medication as agreed – use a chart or a segmented pillbox to help you remember what to take and when
- Bring any side-effects to the attention of your doctor or nurse
- Try to drink three litres of water each day
- Put aside time for rest and relaxation; make getting enough sleep a priority
- Be aware of ongoing signs of depression and anxiety and speak to your GP about them

- Try to do something that you enjoy every day
- Think positively, but allow yourself to have ‘off days’
- If you are a carer, make sure you take care of your own health, and take some time for yourself each day

Medical terms explained

AL amyloidosis: A disease in which an abnormal protein, usually produced by cells in the bone marrow, deposits and accumulates in the tissues and organs of the body, disrupting their function and causing symptoms.

Allogeneic transplant: A procedure in which stem cells from a compatible donor (usually a sibling) are collected, stored and given to the patient after high-dose chemotherapy treatment.

Anaemia: A decrease in the normal number of red blood cells, or the haemoglobin that they contain, causing shortness of breath, weakness and tiredness.

Antibiotics: Drugs used to treat bacterial infections.

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

Apheresis: A procedure in which stem cells are collected from the blood using a machine that separates them out and returns the remainder of the blood components to the patient or donor.

Autologous transplant: A procedure in which a patient's own stem cells are collected, stored and then given back following high-dose chemotherapy.

Bence Jones Protein: Free light chains filtered from the blood by the kidney and found in the urine. The presence of any Bence Jones protein is abnormal.

Beta 2 microglobulin (ß2M): A small protein found in the blood. High levels occur in patients with active myeloma. Low or normal levels occur in patients with early myeloma and/or inactive disease.

Bisphosphonate: A type of drug that binds to the surface of bone and protects the bone from the destroying action of osteoclasts. Commonly used bisphosphonates include clodronate (Bonefos®), pamidronate (Aredia®) and zoledronic acid (Zometa®). In myeloma, these drugs may also be used to treat high levels of calcium in the blood (hypercalcaemia).

Blood count: The number of red blood cells, white blood cells and platelets in a sample of blood.

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

Bone marrow biopsy/aspiration: The removal, by a needle, of a sample of cells/fluid from the bone. The cells are examined to see whether they are cancerous. If cancerous plasma cells are found, the pathologist estimates how much of the bone marrow is affected. Bone marrow biopsy (trephine) is usually done at the same time as bone marrow aspiration.

Chemotherapy: The treatment of cancer with drugs that kill all rapidly dividing cells, particularly cancerous cells.

Clinical study: A research study of new or existing treatment that involves patients. Studies may be designed to find better ways to prevent, detect, diagnose, or treat cancer or to answer specific scientific questions.

Cytokine: Proteins produced by cells of the immune system that act as chemical messengers between cells. Cytokines can stimulate or inhibit the growth and activity of various immune cells in response to the particular type of disease present.

Dialysis: When a patient's kidneys are unable to filter blood, the blood is cleaned by passing it through a dialysis machine.

DNA: Or deoxyribonucleic acid, is the hereditary material in humans and almost all other organisms.

Erythropoietin (EPO): A hormone produced by the kidneys, which is involved in the production of red blood cells. Myeloma patients with damaged kidneys may not produce enough erythropoietin and can become anaemic. Injections with synthetic erythropoietin may be beneficial.

Free light chain: Part of an immunoglobulin (antibody) that circulates freely in the blood.

Graft-versus-host disease (GvHD): A reaction of donated stem cells against a patient's own tissue.

Graft-versus-myeloma effect: A beneficial reaction of donated stem cells against the myeloma cells.

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. Common in myeloma patients and usually resulting from bone destruction with release of calcium into the blood stream. Often associated with reduced kidney function since calcium can be toxic to the kidneys and usually treated using IV fluids combined with bisphosphonates to reduce bone destruction together with direct treatment for the myeloma.

Lytic lesions: A damaged area of a bone that shows up as a dark spot on an X-ray. Lytic lesions look like holes in the bone and are evidence that the bone is being weakened.

MGUS: Monoclonal Gammopathy of Undetermined Significance – a condition which may occur prior to myeloma where there is a paraprotein present in the blood. There are, however, no symptoms and the risk of transition from MGUS to myeloma is very low; only a 1% chance per year of follow-up.

Osteoblast: Specialised bone forming cells.

Osteoclast: Specialised cells that break down old bone. In myeloma, the osteoclast cells are over-stimulated while osteoblast cell activity is blocked. The combination of accelerated bone breakdown and blocked new bone formation results in lytic lesions.

Paraprotein: An abnormal immunoglobulin (antibody) produced by myeloma cells and measured in the blood. Measurements of paraprotein are used to monitor the disease.

Plasma cells: Specialised white blood cells that produce immunoglobulins (antibodies). Plasma cells are the malignant (cancerous) cell in myeloma. Normal plasma cells produce antibodies to fight infection. In myeloma, malignant plasma cells produce large amounts of abnormal antibodies (paraprotein) that lack the capability to fight infection. Abnormal plasma cells (myeloma cells) also produce other chemicals that can cause organ and tissue damage (i.e. anaemia, kidney damage and nerve damage).

Plateau: A period of time when the myeloma, and the paraprotein level, is relatively stable.

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

Proteasome inhibitor: A drug that interferes with the normal functioning of part of a cell called the proteasome. This causes abnormal cells to die while leaving normal, healthy cells less affected.

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

Red blood cells: Blood cells which transport oxygen around the body.

Refractory: Myeloma that has failed to respond to treatment.

Stem cells: The cells from which all blood cells develop. Stem cells give rise to red blood cells, white blood cells and platelets. Stem cells are normally located in the bone marrow and can be harvested from the blood for transplant.

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

Appendix one: Tests and investigations

Test	Purpose
Bone testing	To assess the presence, severity and location of any areas of bone damage
X-rays	X-rays are still the gold standard in searching for myeloma bone damage. A full skeletal survey for myeloma using a series of X-rays is needed to show loss or thinning of bone (osteoporosis or osteopenia caused by myeloma bone destruction), lytic lesions and/or any fracture or collapse of bone
MRI	Used when X-rays are negative and/or for more detailed testing of particular areas such as spine and/or brain. Can reveal the presence and distribution of disease in the bone marrow when X-rays show no bone damage. Can also reveal disease outside of bone, which may be pressing on nerves and/or spinal cord
CT scan	Used when X-rays are negative and/or for more detailed testing of particular areas. Especially useful for detailed evaluation of small areas of possible bone damage or nerve pressure
Nuclear medicine scans	Routine bone scans used for other cancers. Not useful in myeloma and should not be performed
Whole body FDG/ PET scan	A much more sensitive whole body scanning technique
Bone density testing	Helpful to assess the severity of diffuse bone loss in myeloma and to measure the serial improvement with bisphosphonate therapy

Test	Purpose
Bone testing	
1. Complete blood count	• To assess presence/severity of anaemia • To assess for low white cell count • To assess for low blood platelet count
2. Urea and electrolytes	• Particularly important to assess kidney function and calcium level
3. Special protein testing: • Serum protein electrophoresis (SPEP) • Immunofixation • Freelite™ test	This shows the presence of the monoclonal myeloma protein (paraprotein) • The amount of the abnormal myeloma protein as well as the normal albumin protein level are measured • Shows the type of myeloma protein (i.e. heavy chain [G, A, D or E], light chain, Kappa [k], Lambda [λ]) • Can be used to measure the amount of free kappa or lambda if no SPEP abnormality discovered
Urine testing Special protein testing as for serum above: • Urine protein electrophoresis (UPEP) • Immunofixation • Freelite™ test	Shows the presence, amount and type of abnormal myeloma protein in urine (Bence Jones)
Bone marrow biopsy	This is the single most critical test to determine the percentage of myeloma cells in the bone marrow. In Stage I disease or for a solitary plasmacytoma, direct biopsy of the tumour mass is performed
Special tests Can be done to assess prognosis (e.g. chromosomes, immune typing, staining for amyloid)	Chromosome analysis (cytogenetic testing) can reveal good or poor chromosome features using direct and/or FISH analysis

Appendix two: Blood tests

Blood tests	Test name	Normal range*	Units	Notes
Full blood count	White cell count	4.0 – 11.0	x 10^9/L	A low count makes you less able to fight infections
	Red cell count (men)	4.5 – 6.5	x 10^{12}/L	A low red cell count is anaemia, which can cause fatigue
	Red cell count (women)	3.9 – 5.6	x 10^{12}/L	
	Haemoglobin (men)	13.5 – 18.0	g/dL	A low haemoglobin level, also called anaemia, can cause fatigue
	Haemoglobin (women)	11.5 – 16.0	g/dL	
	Platelets	150 – 400	x 10^9/L	A low count makes you bruise or bleed easily
Urea, electrolytes and creatinine	Urea	2.5 – 6.7	mmol/L	Measure of kidney function
	Creatinine	70 – 150	umol/L	Measure of kidney function
	Calcium (total)	2.12 – 2.65	mmol/L	Raised by myeloma bone disease
Proteins	Albumin	35 – 50	g/L	Often lowered in myeloma because of presence of paraprotein
	Total protein	60 – 80	g/L	Often raised in myeloma because of amount of paraprotein
	Paraprotein	0	g/L	Abnormal protein found in several conditions, including myeloma

* The normal range is an average, but each hospital laboratory has its own 'normal range' of values.

Explanation of units

g/dL	number of grams there are in a decilitre (one tenth of a litre) of blood
g/L	number of grams there are in a litre of blood
x 10^{12}/L	number of thousand million cells there are in a litre of blood
mmol/L	number of thousandths of a mole** in a litre of blood
umol/L	number of millionths of a mole** there are in a litre of blood
**mole	a standard measurement for the amount of any chemical

Please note that doctors do not use a litre of blood to make these measurements; they just take a small sample (a few millilitres) and then multiply the results.

Appendix three: Staging systems

Durie and Salmon Staging System

Criteria	Measured myeloma cell mass (cells x 1012/m2)
Stage I (low cell mass)	< 0.6
All of the following: • Haemoglobin value > 10.0g/dl • Serum calcium value normal or < 2.60 mmol/l • Bone X-ray, normal bone structure (scale 0) or solitary bone plasmacytoma only • Low M component production rates IgG value < 50g/l IgA value < 30g/l Urine light chain M component on electrophoresis < 4g/24h	
Stage II (intermediate cell mass)	0.6 – 1.2
Fitting neither stage I nor stage III.	

Stage III (high cell mass)	> 1.2

One or more of the following:

- Haemoglobin value < 8.5g/dl
- Serum calcium value > 3.00mmol/l
- Advanced lytic bone lesions (scale 3)
- High M component production rates

  IgG value > 70g/l

  IgA value > 50g/l

  Urine light chain M component on electrophoresis > 12g/24h

Sub-classification (either A or B)

A: relatively normal renal function	(serum creatinine value < 170umol/l)
B: abnormal renal function in mg/dl	(serum creatinine value = 170umol/l)

International Staging System (ISS)

B2M = serum beta 2 microglobulin in mg/dl

ALB = serum albumin in g/dl

Stage I	B2M < 3.5 ALB > 3.5
Stage II	B2M < 3.5 ALB < 3.5 or B2M 3.5-5.5
Stage III	B2M > 5.5

Further information and useful organisations

ACCORD **www.accord.ie**
01 505 3112
Caring for marriage and relationships. They are the largest marriage-care agency in Ireland.

Association of Registered Complementary Health Therapists of Ireland
053 938 3734 **www.irishtherapists.ie**
They act as an umbrella association in order to promote better awareness of complementary health medicine.

Benefit Enquiry Line
0800 88 22 00 (Monday – Friday, 8.30am–6.30pm; Saturday 9am – 1pm)
The Benefit Enquiry Line is a confidential advice and information service for people with disabilities, and their carers and representatives. The enquiry line provides information about social security benefits and how to claim them, and can provide assistance, over the phone, with filling out benefit application forms.

Bereavement Counselling Service **www.bereavementireland.com**
01 839 1766 (Monday – Friday, 9am – 1pm)
Offers support and counselling to enable people to deal with their grief in Ireland.

Blue Badge Scheme **www.dft.gov.uk/transportforyou/access/bluebadge**
0207 944 2914 (Blue Badge Helpline; Monday – Friday, 9am – 5pm)
The Blue Badge Scheme provides a national arrangement of on-street parking concessions enabling people with severe walking difficulties who travel, either as drivers or passengers, to park close to their destinations. To apply for a badge, contact the social services department (or in Scotland the social work department) of your local authority or council.

British Association for Counselling and Psychotherapy (BACP) **www.bacp.co.uk**
01455 883300 (General enquiries; Monday – Friday, 8:45am – 5pm)
01455 883316 (Client Information Helpline; Monday – Friday, 8:45am – 5pm)
BACP provides advice on a range of services to help meet the needs of anyone seeking information about counselling and psychotherapy. To find a local counsellor call the Client Information Helpline, or use the search facility on their website.

British Red Cross **www.redcross.org.uk**
0844 412 2804 0844 412 2804 (General enquires; Monday – Friday, 9am – 5pm)
Volunteers assist with a range of local services – including care in the home, transport and medical loans – to help those with health issues lead a full and independent life. The Medical Equipment Service has a wide range of products and equipment available for short-term loan. The Home from Hospital Service provides short-term practical assistance and support to help people settle back into their own homes. A Transport and Escort Service offers help to people who cannot get about easily or use ordinary transport.

Cancer Black Care **www.cancerblackcare.org**
020 8961 4151 (Monday – Friday, 9am – 5pm)
Cancer Black Care provides a unique service of information, advice and support for the black and minority ethnic community.

The Cancer Counselling Trust **www.cancercounselling.org.uk**
020 7843 2292 020 7843 2292 (Monday – Friday, 9am – 5pm)
The Cancer Counselling Trust offers a free telephone counseling across the UK. They support cancer patients, their families, friends and care givers who seek counselling to help them through the difficult issues precipitated by a cancer diagnosis. They provide free, specialist counselling for anyone impacted by cancer, across the UK.

Cancer Research UK **www.cancerhelp.org.uk**
0808 800 4040 (Nurse information line; Monday – Friday, 9am – 5pm)
CancerHelp UK is the patient information website of Cancer Research UK. They provide a free information service about cancer and cancer care for patients and their families

Care **www.carers.ie**
01 679 3188
Carers provides practical information and guidance for people who are caring for someone who has been diagnosed with a life-threatening illness in Ireland.

Carer’s Allowance Unit
01253 85 61 23 (Switchboard, ask for the Carer’s Allowance Unit;
Monday – Thursday, 9am – 5pm; Friday 9am – 4:30pm)
General information about the carer’s allowance, and assistance with filling in the application form.

Carers UK **www.carersuk.org**
0808 808 7777 (Wednesday and Thursday, 10am – 12pm, 2pm – 4pm)
Carers UK provides advice, information and support for carers. It produces a directory of national and local carer organisations and can show you where to get help in your area.

Chronic Pain Ireland **www.chronicpainireland.org**
01 804 7567 (Monday – Thursday, 9.30am – 5pm)
Chronic Pain Ireland provides information and support to those living with chronic pain, their families and friends.

Citizens Advice Bureau (CAB) **www.nacab.org.uk**
020 7833 2181 (Monday – Friday, 8am – 6pm)
Citizens Advice Bureau offers advice about debt and consumer issues, benefits, housing, legal matters and employment. They provide assistance with claiming welfare benefits, including practical help with filling out benefit application forms. Contact the number listed above, use their website, or check your local telephone directory for details of your nearest branch.

Citizens Information **www.citizensinformation.ie**
Citizens Information is an Irish eGovernment website provided by the Citizens Information Board. The site provides public service information for Ireland.

Crossroads **www.crossroads.org.uk**
0845 450 0350 (Monday – Friday, 9am – 5pm)
Crossroads employs trained care support workers whose role is to relieve the family carer by giving them a break from their caring responsibilities, providing the carer ‘time to be themselves’.

Cruse Bereavement Care **www.cruse.org.uk**
0844 477 9400 (Monday – Friday, 9:30am – 5pm)
Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable anyone bereaved to understand their grief and cope with their loss. The organisation provides face-to-face and telephone support, counselling and information.

Depression Alliance **www.depressionalliance.org**
0845 123 2320
(Information pack request line only; Monday – Thursday, Friday; 10am – 2pm)
Provides information, support and understanding for those affected by depression and coordinates a network of self-help groups throughout the UK. Depression Alliance also produces a wide range of publications covering various aspects of depression.

DIAL UK **www.dialuk.info**
01302 310 123 (Monday – Friday, 10am – 4pm)
DIAL UK is a national organisation for a network of approximately 120 local disability information and advice services run by and for disabled people. DIAL provides information and advice on all aspects of living with a disability, including welfare benefits, transport, mobility and equipment.

Directgov **www.direct.gov.uk**
A government website which provides information about a wide range of public services including benefits such as Attendance Allowance, Disability Living Allowance and Carer's Allowance.

Disability Benefits Unit
0845 712 3456 (Monday – Friday, 7.30am – 6.30pm)
Provides advice and information about the Attendance Allowance and the Disability Living Allowance. Call to request a claim pack.

Financial Services Authority (FSA) **www.moneymadeclear.fsa.gov.uk**
0845 606 1234 (FSA Consumer Helpline; Monday – Friday, 8am – 6pm)
The Financial Services Authority is the watchdog set up by government to regulate financial services. Money Made Clear is an online service from the FSA to provide clear, impartial information about financial products and services, helping you to make an informed decision.

Help the Hospices **www.hospiceinformation.info**
Hospice Information Service
020 7520 8222 (Monday – Friday, 9am – 5pm)
Help the Hospices provides information to health professionals and the general public about hospice and palliative care services in the UK. Their online and telephone service can help you find a local hospice.

Help with Health Costs **www.nhs.uk/Healthcosts**
0845 850 1166 (Monday – Friday, 8am – 6pm; Saturday, 9am – 3pm)
Help with Health Costs gives information about prescription charges and getting help with health costs. They also issue exemption from health costs certificates, and prescription pre-payment certificates.

Independent Financial Advice Promotion (IFAP) **www.ifap.org.uk**
Independent Financial Advice Promotion is the industry body responsible for promoting independent financial advice in the UK. They provide a UK-wide list of authorised financial advisers on their website. IFAP also produces a wide range of publications covering various aspects of financial management including mortgages, savings, investments and pensions. The IFAP do not operate a helpline service.

Institute for Complementary and Natural Medicine (ICNM) **www.i-c-m.org.uk**
0207 922 7980 (Monday – Friday, 10am – 4pm)
The Institute for Complementary and Natural Medicine (ICNM) provides the public with information about all aspects of complementary medicine. They also administer the British Register of Complementary Practitioners, providing details of local registered practitioners of various complementary therapies.

Irish Cancer Society	**www.cancer.ie**

1 800 200 700 (Monday – Thursday, 9am – 7pm; Friday, 9am – 5pm)
From UK dial 00 353 1 2310 500
The Irish Cancer Society provide advice, support and information to people in the Republic of Ireland affected by cancer. They also publish a range of patient information, including a booklet on myeloma.

The Irish Hospice Foundation	**www.hospice-foundation.ie**

01 679 3188 (Monday – Friday, 9am – 1pm, Monday – Thursday, 2pm – 5.30pm, Friday 2pm – 5pm)
Work independently and in partnership with the statutory, voluntary and professional bodies with hospice and palliative care in Ireland

Job Centre Plus	**www.jobcentreplus.gov.uk**

0800 055 6688 (Monday – Friday, 8am – 6pm)
Information and claims service for income support, incapacity benefit, job seekers allowance and employment and support allowance. (Incapacity benefit has been replaced by Employment and Support Allowance for new claims from October 27 2008.)

Leukaemia CARE	**www.leukaemiacare.org.uk**

0800 169 66 80 (24 hours a day, 7 days a week)
Leukaemia CARE exists to provide care and support to all those whose lives have been affected by leukaemia, lymphoma, myeloma and the allied blood disorders. Leukaemia CARE also offers discretional financial assistance and caravan holidays in the UK.

Leukaemia & Lymphoma Research	**www.llresearch.org.uk**

020 7405 0101 (Monday – Friday, 9am – 5pm)
Leukaemia & Lymphoma Research funds research into leukaemia and related blood disorders including lymphoma and myeloma. They also provide free patient information booklets with accessible and accurate information on blood cancers and the related disorders.

Macmillan Cancer Support **www.macmillan.org.uk**
CancerBackup **www.cancerbackup.org.uk**
0808 808 2020 (Macmillan helpline; Monday – Friday, 9am – 9pm)
0808 800 1234 (CancerBackup Nurse information helpline;
Monday – Friday, 9am – 8pm)
18001 0808 800 1234 (CancerBackup nurse information helpline RNID typetalk;
Monday – Friday, 9am – 8pm)

Emotional and practical support in different languages

Hindi – 0808 808 0100
Punjabi – 0808 808 0101
Urdu – 0808 808 0102

Cancer Information Nurses in different languages

Arabic – 0808 800 0130
Bengali – 0808 800 0131
Chinese – 0808 800 0132
French – 0808 800 0133
Greek – 0808 800 0134
Gujarati – 0808 800 0135
Hindi – 0808 800 0136
Polish – 0808 800 0137
Punjabi – 0808 800 0138
Turkish – 0808 800 0139
Urdu – 0808 800 0140
Vietnamese – 0808 800 0141

For information and support in languages not listed here, call 0808 800 1234 and ask for an interpreter.

Please note that Macmillan Cancer Support can only give information about healthcare and support services available in the UK. CancerBackup merged with Macmillan Cancer Support in 2008. Together they provide a wealth of high quality, expertly developed information about cancer.

Macmillan Cancer Support Benefits Advise
www.macmillan.org.uk/Get_Support/Financial_help/Financial_help.aspx
0800 500 800 (Monday – Friday, 10am – 5pm)

Macmillan Cancer Support offer information about how to access benefits and other kinds of financial support.

Marie Curie Cancer Care **www.mariecurie.org.uk**
0800 634 4520 (Monday – Sunday, 9am – 10:30pm)

Marie Curie provides specialist palliative nurses and has ten Marie Curie Centres providing free respite and hospice care throughout the UK.

Medic Alert® **www.medicalert.org.uk**
0800 581 420 (Monday – Friday, 9am – 5pm)
MedicAlert is a non-profit charity that provides a life-saving identification system for individuals with hidden medical conditions.

Medical Research Council (MRC) **www.mrc.ac.uk**
020 7636 5422 (Head office switchboard; Monday – Friday, 9am – 5pm)
The MRC promotes research into all areas of medical and related science.

Medicine Guides **www.medguides.medicines.org.uk/**
Medicine Guides, developed in partnership with NHS Choices, provide members of the public with up to date, reliable and understandable information about medicines.

Midlands Myeloma Support Group **www.dochasoffaly.ie**
086 780 4007
Dochas Cancer Support Centre, Tullamore CO Offaly.

Multiple Myeloma Research Foundation (MMRF) **www.multiplemyeloma.org**
00 1 203 6520219
The MMRF is a US-based private funder of worldwide myeloma-specific research. Its website provides information about myeloma treatments and international clinical studies.

MyMyeloma **www.mymyeloma.ie**
087 233 7797
Dedicated Irish myeloma website for patients, family members and those with an interest in myeloma.

Myeloma Euronet **www.myeloma-euronet.org**
00 49 30 2887 9755
Myeloma Euronet, a non-profit network organisation of myeloma patient groups, is a European initiative dedicated to raising the awareness of myeloma, providing information on diagnosis, treatment and care, as well as support for their families and loved ones.

National Amyloidosis Centre (NAC) www.ucl.ac.uk/medicine/amyloidosis/nac
020 7433 2725 (General enquiries; Monday – Friday, 9am – 5pm)
Based at the Royal Free and University College Medical School, the NAC is the only centre in the UK specialising in amyloidosis. The centre has state of the art clinical and research facilities and a team of highly qualified clinical, research and support staff.

National Cancer Research Institute (NCRI) www.ncri.org.uk
020 7061 8460 (Monday – Friday, 9am – 5pm)
The National Cancer Research Institute is a partnership of health departments, the Medical Research Council and major cancer charities which aims to develop common plans for cancer research.

National Debtline www.nationaldebtline.co.uk
0808 808 4000 (Monday – Friday, 9am – 9pm; Saturday 9:30am – 1pm)
Offers free, confidential and independent advice on how to deal with debt problems.

NHS Direct/NHS 24 www.nhsdirect.nhs.uk www.nhs24.com
0845 46 47 (NHS Direct; England, Northern Ireland and Wales)
08454 24 24 24 (NHS 24; Scotland)
Staffed by trained medical professionals, these organisations provide 24-hour access to information about all aspects of health and healthcare.

National Institute for Health and Clinical Excellence (NICE) www.nice.org.uk
0845 003 7780 (Monday – Friday, 9am – 5pm)
NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. NICE produces guidance on health technologies (the use of new and existing medicines, treatments and procedures) and clinical practice (guidance on the appropriate treatment and care of people with specific diseases) within the NHS.

National Kidney Federation (NKF) **www.kidney.org.uk**
0845 6010 209 (Monday – Friday, 9am – 5pm)
The National Kidney Federation provides information about kidney disease and dialysis, and promotes best practice in renal medicine.

NHS National Library for Health **www.library.nhs.uk**
The NHS National Library for Health is aimed at NHS staff, patients and the general public and provides information on all aspects of health, illness and treatment.

OvercomeDepression **www.overcomedepression.co.uk**
OvercomeDepression aims to offer a unique reference point for information and practical advice on depression.

Pain Association (Scotland) **www.chronicpaininfo.org**
0800 783 6059 (Monday – Friday, 9:30am – 4pm)
Pain Association Scotland offers support to people with chronic pain and organises pain management support groups across Scotland.

Pain Concern **www.painconcern.org.uk**
01620 822 572 (Monday – Friday, 9am – 5pm; Friday, 6:30pm – 7:30pm)
Pain Concern provides a range of information about self-help and managing pain. Their helpline offers information, support and a listening ear.

Patient Advice and Liaison Services (PALS) **www.pals.nhs.uk**
This service is available in England to provide patients and their families with information regarding health related enquiries, NHS services and other support available. They can provide information about the NHS complaints procedure and how to get independent help if you decide you may want to make a complaint. PALS do not have a central office however you will be able to find your local service through your hospital.

Penny Brohn Cancer Care **www.pennybrohncancercare.org**
(formerly Bristol Cancer Help Centre)
0845 123 2310 (Monday – Friday, 9:30am – 5pm)
Based in Bristol, Penny Brohn Cancer Care offers specialist support including complementary therapies, nutritional advice and counselling for people affected by cancer. Their helpline provides emotional support and information about complementary therapists and services in your area.

The Pensions Advisory Service **www.pensionsadvisoryservice.org.uk**
0845 601 2923 (Monday – Friday, 9am – 5pm)
The Pensions Advisory Service is an independent non-profit organisation that provides free information, advice and guidance on the whole spectrum of pensions covering state, company, personal and stakeholder schemes.

The Pension Service **www.thepensionservice.gov.uk**
0845 6060 265 (Pension helpline; Monday – Friday, 8am – 8pm)
0800 99 1234 (Pension credit information; Monday – Friday, 8am – 8pm)
08459 15 15 15 (Winter fuel payments helpline; Monday – Friday, 8am – 5pm)
Part of the Department for Work and Pensions, the pension service provides information about pensions and benefits, for current and future pensioners.

Princess Royal Trust for Carers **www.carers.org**
0844 800 4361 (Monday – Friday, 9am – 5pm)
The Princess Royal Trust for Carers is the largest provider of comprehensive carers support services in the UK. Through its unique network of 144 independently managed Carers' Centres , 85 young carers services and interactive websites, the Trust currently provides quality information, advice and support services to almost 354,000 carers.

Relate **www.relate.org.uk**
0300 100 1234
(Monday – Thursday, 8am – 10pm; Friday, 8am – 6pm; Saturday, 8am – 4pm)
Relate offers a confidential counselling service for couples or individuals experiencing difficulties in their relationship. Relate provide support face-to-face, by phone and through their website.

Royal Association for Disability and Rehabilitation (RADAR) www.radar.org.uk
020 7250 3222 (Monday – Friday, 9am – 5:30pm)
RADAR is a national organisation for disabled people. It publishes information on all aspects of living with disability, including transport and mobility. RADAR runs the National Key Scheme, which offers disabled people access to 7,000 locked public toilets around the country.

Samaritans www.samaritans.org
08457 90 90 90 (24 hours a day, 7 days a week)
Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair. They offer services by telephone, email, letter and face to face

Tenovus Cancer Information Centre www.tenovus.org.uk
0808 808 1010 (Monday – Friday, 9am – 5pm)
Tenovus is a charity committed to the control of cancer through research, education, counselling and patient care. Its helpline offers information and support to those affected by cancer.

UK Myeloma Forum (UKMF) www.ukmf.org.uk
The UK Myeloma Forum is an organisation of people professionally engaged in the field of myeloma who are working to improve the outlook for patients with myeloma and related disorders. On behalf of the British Committee for Standards in Haematology, UKMF has produced guidelines on the diagnosis and management of multiple myeloma.

Ulster Cancer Foundation (Northern Ireland) www.ulstercancer.org
0800 783 3339 (Monday – Friday, 9am – 5pm)
The Ulster Cancer Foundation offers information, support and counselling to people affected by cancer in Northern Ireland. Their helpline is staffed by specially trained nurses with experience in cancer care. They also run a myeloma support group.

With Myeloma UK you can...

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

You will receive immediate access to information and support provided by telephone on all aspects of myeloma. Your call will be answered by Myeloma Information Specialists who are supported by medical advisors. Open Monday to Friday, 9am to 5pm. Calls are free from the UK and Ireland. From outside the UK and Ireland, call +44 (0) 131 557 9988 (charged at a normal rate).

Get free Infopacks, Infoguides and Infosheets

These provide a range of information on all aspects of the treatment and management of myeloma. They are presented in three different formats depending on the level of detail required. You will find a list of the information available from us at the back of this Infoguide.

Attend Patient and Family Myeloma Infodays

These are full-day educational meetings specifically for patients and families, where you can learn about the latest in the treatment and management of myeloma from a panel of myeloma experts. Infodays also provide the opportunity to meet others affected by myeloma, to share experiences and gain support.

Subscribe to *Myeloma Matters*

Our quarterly magazine, *Myeloma Matters,* provides a comprehensive range of features and articles to help keep you abreast of the latest developments in treatment and research as well as living with myeloma.

Visit our website www.myeloma.org.uk

A comprehensive and interactive website providing immediate 24-hour access to information about myeloma.

Join a Myeloma Support Group

There are 50 Myeloma Support Groups across the UK. To find one near you, visit www.myeloma.org.uk

Other information and support available from Myeloma UK

Essential Guides

Living with myeloma – Your Essential Guide

Infoguides

Infoguide topics include:

- Balloon Kyphoplasty
- Myeloma Bone Disease and Bisphosphonates
- Caring for someone with myeloma
- Chemotherapy
- Clinical Studies
- Fatigue
- High-Dose Therapy & Stem Cell Transplantation
- Myeloma XI
- Revlimid and myeloma
- Serum Free Light Chain Assay
- Thalidomide and myeloma
- Velcade and myeloma

Leaflets

- Myeloma – An Introduction
- About Myeloma UK
- Myeloma UK – Publications list

Infosheets

Infosheet topics include: Constipation, Copayments, Diet and Nutrition, Erythropoietin, Fatigue, Growth Factors, Managing Your Finances (Benefits and General), MGUS, Mouthcare, Osteonecrosis of the Jaw, Pain, Peripheral Neuropathy, Percutaneous Vertebroplasty, Plasmacytoma, Plasmapheresis, Prescription Charges, Radiotherapy, Setting up a Support Group, Smouldering Myeloma, Steroids, Strength activities for people with myeloma, Stretches for people with myeloma, Support Groups, Swine Flu, The kidney, Travel Insurance, Travelling.

Horizons Infosheet Series:

These provide information on a number of treatments and procedures that are currently in the final stages of research or development and which are showing a great deal of promise. Current Horizons Infosheets available: Bendamustine and Denosumab.

Patient diary

This diary helps patients keep a track of hospital appointments and key test results in a practical, simple way. The diary (A5 in size) contains 11 sections which are neatly divided and tabbed for ease of reference as follows: Your myeloma diary, Appointments, Blood tests and results, Treatment records, Complementary therapies record, Symptoms and side-effects record, Questions to ask your doctor or nurse, Key myeloma terms, Further information and useful organisations, About Myeloma UK and Your notes.

PEER Network

PEER Members are patients, family members and carers who are willing to share and communicate with others affected by myeloma who contact Myeloma UK and are seeking information, support and reassurance from someone who has been in or is currently in a similar situation.

To order any of our free publications or for information about any of the support that we can offer, call our **Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.** The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK and Ireland. From outside the UK, call +44 (0) 131 557 9988 (charged at normal rate).

Myeloma UK also provides information on conditions associated with myeloma; this includes information about AL amyloidosis, plasmacytoma, MGUS (Monoclonal Gammopathy of Undetermined Significance) and Waldenström's Macroglobulinaemia.

We need your help

Every year, Myeloma UK sends Infoguides and Infosheets to hundreds of patients, their families and friends, and helps many more by providing services such as the Myeloma Infoline and Patient and Family Myeloma Infodays.

That is why we need your help.

We depend on the support and generous donations from people like you to provide these important services, which are available free to myeloma patients, their families and carers.

A guide to how your donation will help others:

- £2 will ensure that another patient receives a booklet about myeloma
- £12 will fund an Information Pack for a newly diagnosed patient and their family
- £75 will pay for our quarterly newsletter, *Myeloma Matters*, to be sent to three people for a year
- £100 will enable us to provide a start-up grant to a new Myeloma Support Group
- £188 will pay to genotype one DNA sample
- £582 will fund a month’s worth of information to be mailed out to patients, their families and carers
- £1,019 will pay for a Myeloma Nurse Specialist for a working week
- £35,000 will pay for one research nurse for a year

All donations are greatly appreciated and allow us to continue our vital work.

How to donate

You can make your donation online at www.myeloma.org.uk, over the phone by calling +44 (0) 131 557 3332, or by posting a cheque or CAF voucher made payable to Myeloma UK to our office – the address is on the back of this Infoguide.

Gift Aid it

Remember to let us know if you are a UK tax payer, so we can increase your gift by claiming the tax back from the Government. If you are a UK tax payer, Myeloma UK can claim Gift Aid on your donation. At present for every £1 that you donate we can claim 25p. This extra money comes from the Government, so it doesn't cost you any extra.

There are other ways you can support Myeloma UK such as taking part in an organised event, or by fundraising for Myeloma UK in your local community - this is a very important income stream for us.

When so much about myeloma is beyond the control of the people that it affects and those that care for them, fundraising can be a rewarding and fun way of doing something positive for yourself and for others affected by myeloma.

Contact the fundraising team on +44 (0) 131 557 3332 for more information or visit www.myeloma.org.uk

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