

*Understanding*

# Myeloma

*Caring for people with cancer*

## Understanding myeloma

This booklet has been written to help you understand more about myeloma. It has been prepared and checked by doctors, haematologists, nurses and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can also make a note below of the contact names and information you may need quickly.



Specialist nurses

Tel:

Tel:

Family doctor (GP)

Tel:

Haematologist

Tel:

Medical oncologist

Tel:

Radiation oncologist

Tel:

Emergency

Tel:

Treatments

Review dates



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If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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- *Cancer Nursing: Principles and Practice*, CH Yarbro, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 2000.
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## Introduction

This booklet has been written to help you understand more about myeloma. By reading it, you can learn about its symptoms, diagnosis and treatment. It also offers advice about possible side-effects of treatment. We hope that it answers some of the questions you may have.

The treatment for myeloma can vary a little between doctors and hospitals. As a result, you are likely to have questions and concerns about your own treatment which this booklet may not answer. It is best to discuss details of your own treatment with your doctor.

This booklet also discusses some of the feelings you and those close to you may have when a diagnosis of myeloma is made. At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time.



### Reading this booklet

Remember you do not need to know everything about myeloma cancer straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline 1800 200 700.

## What does that word mean?

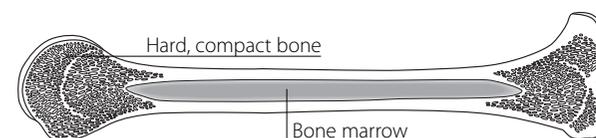
<b>Albumin</b>	A major protein normally found in blood.
<b>Alopecia</b>	Loss of hair or no hair where you normally have hair.
<b>Anaemia</b>	Less haemoglobin in red blood cells that causes fatigue and shortness of breath.
<b>Antibodies</b>	Proteins made by white blood cells (plasma cells) to help protect your body from infection and disease. Also called immunoglobulins (Ig).
<b>Anti-emetic</b>	A tablet, injection or suppository given to stop you feeling sick or vomiting.
<b>Autologous stem cell transplant</b>	When stem cells are collected from your blood and then after a high dose of chemotherapy are returned to your body.
<b>Beta-2 microglobulin</b>	A protein usually found on the surface of various cells in your body. It is increased in myeloma.
<b>Biological therapy</b>	A treatment that uses your body's immune system to fight cancer or to reduce side-effects caused by some cancer treatments.
<b>Bisphosphonate</b>	A drug used to treat osteoporosis and bone disease in cancer patients.
<b>Bone marrow</b>	Soft spongy material found in large bones that makes three types of blood cells: red blood cells, white blood cells and platelets.
<b>Bone marrow biopsy</b>	When a small amount of blood cells is taken from your bone marrow to find out if myeloma cells are present.
<b>Calcium</b>	A mineral found in your body that is needed to form bones. The levels are raised when bone cells are broken down.
<b>Chemotherapy</b>	A treatment that uses drugs to cure or control cancer.
<b>Fatigue</b>	Severe tiredness.

<b>Haematologist</b>	A doctor who specialises in treating patients with abnormal blood or bone marrow.
<b>Haematology</b>	The study of blood and bone marrow.
<b>Hypercalcaemia</b>	High levels of calcium in your blood.
<b>Immunoglobulins</b>	Proteins made by plasma cells to fight infection. Also called antibodies.
<b>Lenalidomide</b>	A drug used to control myeloma.
<b>Leukaemia</b>	Cancer of the white blood cells.
<b>Medical oncologist</b>	A doctor who specialises in treating cancer patients with chemotherapy or biological therapies.
<b>Nausea</b>	Feeling sick or wanting to be sick.
<b>Paraprotein</b>	A protein made by an abnormal plasma cell in myeloma. Paraproteins can be found in the blood and in urine. It can also be called monoclonal protein, myeloma protein, M spike or M protein.
<b>Plasma cell</b>	Cells found in the bone marrow that make antibodies to fight infection. With myeloma an abnormal antibody is made by the plasma cell and does not fight infection.
<b>Platelets</b>	Blood cells responsible for clotting.
<b>Radiation oncologist</b>	A doctor who specialises in treating cancer patients with radiotherapy.
<b>Radiotherapy</b>	A treatment of cancer and other diseases using high-energy rays.
<b>Red blood cell</b>	Blood cells that carry oxygen to every cell in your body.
<b>Staging</b>	Tests that measure the size and extent of myeloma.
<b>Thalidomide</b>	A drug used to control myeloma.
<b>Velcade</b>	A drug used to control myeloma.
<b>White blood cell</b>	Blood cells responsible for fighting infection.

## About myeloma

### What is myeloma?

Myeloma is cancer of the plasma cells in the bone marrow. It is also called plasma cell myeloma or myelomatosis. Bone marrow is the soft spongy material found in large bones that makes three types of blood cells: red blood cells, white blood cells and platelets. The red blood cells carry oxygen to all the cells in your body, white cells fight infection and prevent disease, and platelets are responsible for clotting.

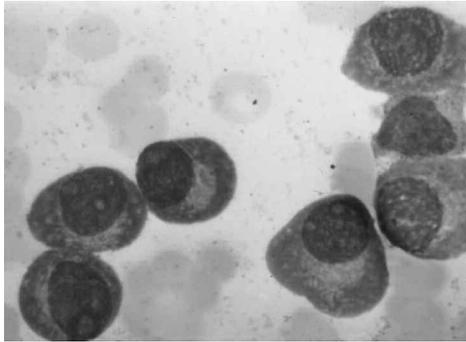


>>> Myeloma is cancer of the plasma cells in the bone marrow.

Plasma cells are a kind of white blood cell that are also found in bone marrow. Normally, plasma cells make proteins called antibodies (also called immunoglobulins) to fight infection and help build up immunity to disease. With myeloma the plasma cells are abnormal and are called myeloma cells.

These myeloma cells usually make a large amount of one type of abnormal antibody. This is known as a paraprotein or M protein and can be found in blood and urine. The paraprotein is unable to fight infection properly and can reduce the amount of normal antibodies being made. In the bone marrow, the myeloma cells can also leave less space for normal plasma cells to develop.

Myeloma cells can spread from the bone marrow into the harder part of bone and cause a **lesion** or damage to bone tissue. The marrow of more than one bone can be affected, sometimes several bones. For this reason, myeloma is often called **multiple myeloma**.



Myeloma cells

### Which bones are affected?

Myeloma affects bone marrow that is normally active in adults. Active bone marrow is found in the hollow area within the bones of your spine, skull, pelvic bones, the ribcage, and the areas around your shoulders and hips. Usually the bones of your hands, feet and lower arm or leg regions are not affected.

### Complex disease

Myeloma is a complex disease because many functions in the body can be affected. The build-up of myeloma cells can cause many medical problems. For example, when paraproteins made by the myeloma cells are released into the bloodstream, it can cause kidney damage.

Sadly, there is no cure for myeloma at present but it can be controlled and many of its symptoms treated. Current treatments can bring about a complete remission in some patients. This means that the symptoms of myeloma disappear and the bone marrow recovers, but it is not a cure of the disease. Even so, many people can lead full lives for years after diagnosis.

Myeloma is a highly individual disease. Very often it is slow moving but sometimes it is quicker. Because there is no standard treatment of myeloma your treatment will be individual too. Both you and your doctor will decide what is the best way to treat your myeloma. It is

important that you and your family are well informed, ask questions and consider other treatment options as well.

### Types of myeloma

Myeloma is just one of many disorders of the plasma cells. There are some benign conditions that may lead to myeloma, but this does not always happen. The two most common are:

- Monoclonal gammopathy of uncertain significance (MGUS)
- Smouldering myeloma (also called indolent myeloma)

If you are diagnosed with either of these conditions, you will be closely monitored with blood tests for a number of years. But the risk of developing myeloma is low. You will only be treated if the condition develops into true myeloma.

In most cases the type of myeloma that patients develop is multiple myeloma where several bones are affected. In some cases the myeloma cells can collect in a single bone and form a tumour called a solitary **plasmacytoma**. Usually this type of myeloma tumour is treated with radiotherapy. You will also be monitored with blood tests in case you go on to develop multiple myeloma.

A rare type of myeloma is non-secretory myeloma. In this case, no M protein occurs in the blood or urine.



### Immunoglobulins

There are different types and subtypes of myeloma. These are based on the type of abnormal immunoglobulin (Ig) made by the myeloma cell. Normally there are five types of immunoglobulin: IgA, IgD, IgE, IgG, and IgM and they have different functions in fighting disease. The letters A, D, E, G and M refer to the type of heavy protein chains in the immunoglobulins.

The immunoglobulins also have light chains of proteins which can be called K or L. You will only develop one abnormal immunoglobulin. The most common ones in myeloma are IgG and IgA.

Cancer Helpline 1800 200 700



## To sum up

- Myeloma is cancer of the plasma cells in the bone marrow.
- In myeloma, the abnormal plasma cells make an abnormal protein called paraprotein or M protein.
- When myeloma affects several bones, it is called multiple myeloma.
- Myeloma can affect the bones of the spine, skull, pelvis, ribcage, shoulders and hips.
- There are two conditions that may lead to myeloma: monoclonal gammopathy of uncertain significance (MGUS) and smouldering myeloma.

## What causes myeloma?

Myeloma is a rare condition and its cause is unknown. It is the second most common cancer of the blood. In Ireland, about 222 people are diagnosed each year with myeloma. The chances of developing it increase with your age. Generally people are over the age of 60 when first diagnosed, although in recent years more people have been diagnosed under 60. Myeloma is very rare in those under 40 and children do not develop it.

The cause of myeloma is unknown but there are some risk factors. A risk factor is anything that increases your chance of getting a disease. Myeloma may be the result of several factors working together. These include:

- **Age** – myeloma is more common in older adults, usually over 60
- **Gender** – it is more common in men than women
- **Race** – it is more common in black people than white or Asian people
- **Exposure to chemicals** – petrol, oil, benzene, pesticides, dioxins, paints, rubber, hair dyes
- **Occupation** – agricultural workers, wood or leather workers, hairdressers, painters and decorators

- **Exposure to viruses** – HIV, hepatitis, herpes virus 8, simian virus 40
- **Exposure to radiation** – atomic radiation, radiotherapy
- **Plasma cell conditions** – monoclonal gammopathy of uncertain significance (MGUS) and smoldering myeloma
- **Other conditions** – autoimmune illnesses, pernicious anaemia, ankylosing spondylitis
- **Family history** – if your parent, brother or sister or your child is diagnosed with myeloma, you are between 2 and 6 times more likely to develop it

Research is also looking to see if weight and diet can be a risk factor as well.

## What are the symptoms of myeloma?

The symptoms of myeloma may be vague at first. But as the condition develops it can affect your bone, blood and kidneys. You are unlikely to develop all of the following symptoms or complications of myeloma.

>>> Myeloma can affect your bone, blood and kidneys.

### Bone effects

The most common symptoms of bone disease include:

- Bone pain
- Bone fractures
- Osteoporosis
- Numbness, and/or pins and needles

The myeloma cells can destroy bone tissue. In most cases of myeloma, 'soft spots' or 'holes' develop where the bone structure has been damaged. These are known as **lytic lesions**. The bones are damaged because the bone cells are broken down faster than normally. This can cause bone pain and swelling, particularly in your middle or lower back, ribcage and your hips. Often the pain is dull and aching but persistent. Sometimes moving can make it feel worse.

Thinning of the bone or osteoporosis can also occur. Fractures of the spine and the ribs can develop because of the bone disease. In rare cases, it may cause the spine to collapse leading to height loss and spinal cord compression. Spinal cord compression is where the myeloma tumour presses on your spinal cord. It may cause pins and needles, numbness, tingling or weakness in your feet or legs, or difficulty passing urine or opening your bowels.

### Blood effects

The most common symptoms of blood problems include:

- Fatigue
- Anaemia
- Infections
- Bruising and bleeding

The making of red blood cells, white blood cells and platelets in the bone marrow can be affected by the growing number of myeloma cells. There may be little space for normal blood cells to develop. As a result, fewer red blood cells can lead to fatigue and anaemia. Because less oxygen is carried in the blood you may also have shortness of breath and weakness. The effect of fewer white blood cells is that you can develop infections easily. This includes repeated coughs, colds and flu's, and other infections, especially chest infections. It also may take longer to recover from any kind of illness. Because of fewer platelets you may have unexplained bruising or develop nosebleeds or bleeding gums.

### Kidney effects

The most common symptoms of kidney problems include:

- Hypercalcaemia
- Kidney problems or failure

The kidneys make sure that the level of calcium in your body is at a safe level. When bone tissue is destroyed, it causes the level of calcium to rise in the bloodstream. This is called **hypercalcaemia**. The kidneys can get overworked by trying to get rid of this excess calcium. You may find that you pass urine frequently and become dehydrated as a result. Hypercalcaemia can also cause loss of appetite, nausea and vomiting, hazy vision, muscle weakness, thirst, constipation, depression and drowsiness.

Other kidney problems may occur. The paraproteins released by the myeloma cells can make the blood thicker, which in turn can put pressure on your kidneys to get rid of them quickly. This can lead to kidney damage or sometimes kidney failure.

If you develop any of the above symptoms, contact your GP. Many of these symptoms are common to other less serious illnesses too. It may not mean that you have myeloma. If you are worried your doctor is not taking your symptoms as seriously as you think he or she should, you can always get a second opinion.



### To sum up

- The cause of myeloma is unknown. It is a rare cancer and the second most common cancer of the blood.
- Some risk factors that increase your chance of getting myeloma are being aged over 60, male, black, exposure to toxic chemicals, exposure to viruses and radiation, and a weak immune system.
- Myeloma can affect your bone, blood and kidneys.
- The bone symptoms include bone pain, fractures, osteoporosis, numbness and/or pin and needles.
- The blood symptoms include fatigue, anaemia, infections, bruising and bleeding.
- The kidney symptoms include hypercalcaemia and kidney problems or failure.

### How is myeloma diagnosed?

In the early stages of myeloma there usually are no symptoms. Sometimes myeloma can be picked up on a routine blood test when you have no symptoms at all. Or else you may have symptoms that are vague. These include fatigue, pain, infection or kidney problems that are common to many other conditions.

If your GP suspects that you have any symptoms of myeloma, he or she will refer you to a haematologist. This is a doctor who specialises in treating blood and bone marrow disorders. The haematologist will arrange for you to have a series of tests in hospital.

First, a full physical exam will be done to check your general state of health. Your full medical history will also be taken. Then a number of lab tests and other medical tests are done to confirm a diagnosis of myeloma. The tests can also show how far the myeloma has spread.

### Blood and urine tests

There are a number of blood and urine tests that can be done. New tests are being developed all the time but at present the most common ones include:

- Full blood count (FBC)
- Kidney function tests
- Calcium levels
- Blood and urine levels of normal proteins, for example, albumin
- Paraproteins in blood and urine
- Special blood tests for levels of beta-2 microglobulin
- Protein electrophoresis of blood and urine
- Serum free light chain test

**Full blood count:** Some tests will be done to check your general health, such as a full blood count (FBC) to measure the different types of blood cells. This is a simple blood test and will be done regularly during treatment too.

**Kidney function tests:** These tests will check how well your kidneys are working and for any signs of damage. In particular the levels of urea, electrolytes and creatinine will be checked. Again these are simple blood tests which will also be done regularly during treatment.

**Calcium levels:** This is a simple blood test to measure the level of calcium in your blood.

**Normal proteins:** The levels of normal proteins such as albumin are also checked in your blood and urine. This is because the level of

albumin in your blood decreases when myeloma occurs. This test will be done regularly during treatment.

**Paraproteins in blood:** This is one of the main blood tests to diagnose myeloma. It checks for any abnormal proteins called paraproteins in your blood. Paraprotein is measured regularly during treatment to see how active the myeloma is.

**Paraproteins in urine:** A paraprotein called Bence Jones is found in the urine of about 1 in 10 patients. This protein can be collected over a 24-hour period. You may be asked to bring a container home with you to collect your urine and return it the next day.

**Immunoglobulins:** This test measures the amounts of the antibodies or immunoglobulins found in your blood, such as IgA, IgD, IgE, IgG and IgM.

**Special blood tests:** There are also some specific blood tests to show the stage of the myeloma. For example, the level of beta-2 microglobulin may be measured. Beta-2 microglobulin is also known as a tumour marker.

**Protein electrophoresis:** A special test called protein electrophoresis will identify the specific paraprotein that is made by the myeloma cells. Electrophoresis can be done on both blood and urine. This test may be done regularly to check the progress of your myeloma.

**Serum free light chain (SFLC) test:** For a small number of myeloma patients, the regular tests cannot measure the paraprotein levels. Light chains are part of these abnormal proteins. See page 9 for more details. The serum free light chain can measure tiny amounts of the light chains floating in your blood. Once in the urine, the light chain is called Bence Jones protein.

### Bone tests

Because myeloma cells can cause bones to thin or wear away, you will have a number of tests done on your bones:

- X-rays of all your bones (skeletal survey)
- Bone marrow biopsy or aspirate

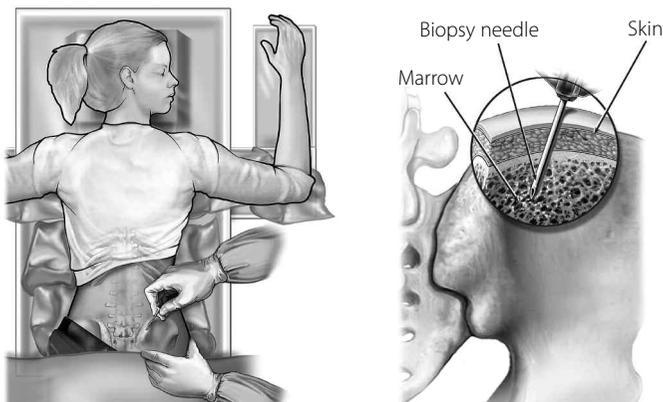
Other bone tests you may need are:

- CT scan
- MRI scan
- Ultrasound scan
- Bone density testing

**X-rays of skeleton:** This test is also called a **skeletal survey** to check for bone disease caused by myeloma cells. It includes X-rays of your skull, chest, whole spine, pelvis and the long bones of your limbs. It takes in total about 30 to 40 minutes to carry out all the X-rays. A skeletal survey may be done every 6 months to check the progress of your illness.

**Bone marrow biopsy or aspirate:** This is a test where a tiny sample of your bone or bone marrow is examined under a microscope. If a sample of bone marrow cells is taken it is called an **aspirate** and if solid bone is taken it is a **trephine biopsy**. Usually the sample is taken from the hip bone or sometimes the breast bone. Before the test, you will be given a local anaesthetic to numb the area. A needle is then passed gently through your skin into the bone marrow. A tiny sample of the bone marrow is then drawn off using a syringe. Altogether, it takes about 15 minutes and you may feel a little discomfort for a few minutes. But you will be given advice about suitable painkillers to take, if you need them.

In the lab, your haematologist will look to see if the number of plasma cells has increased. Normal bone marrow has less than 5% of plasma cells, while in myeloma it is between 10% and 90%.



Bone marrow aspiration

Bone marrow can also be checked to see if there are any abnormal chromosomes. This is called **cytogenetics** testing. About 7 out of 10 people with myeloma have chromosome changes. Chromosome 13 in particular can be abnormal.

## Other bone tests

There are many specialised bone tests which can give more information about the extent of your myeloma. New scanning techniques are being developed all the time. Some of the more common tests available are:

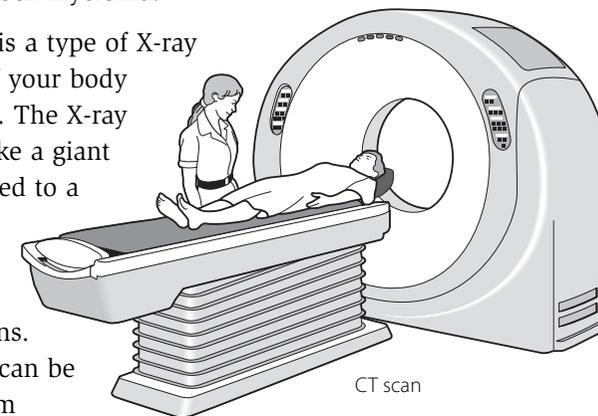
**MRI scan:** An MRI scan uses radio waves and magnetism to give a detailed picture of the bones in your body. The scanner is a tunnel surrounded by a giant magnet. You are placed on a table and this moves into the tunnel. If you have any metal implants or devices in your body, such as a pacemaker, the MRI scan cannot be done. The scanner is noisy and you may feel a little claustrophobic, but sedation can be given. You may be given a dye to make the images more accurate. The MRI scan can give your haematologist more information about the extent of your myeloma.

**CT scan:** A CT scan is a type of X-ray that takes pictures of your body from different angles. The X-ray machine is shaped like a giant doughnut and is linked to a computer. The computer can create a detailed picture of your bones and organs.

In some cases a dye can be injected into your arm which shows up your organs

better. Your haematologist may opt for a CT because it is better at showing up bone damage than a plain X-ray. The CT scans can take from 30 to 90 minutes to complete.

**Ultrasound scan:** This test uses high frequency sound waves to create a picture of any part of your body. It may be done to see if your kidneys have been affected by myeloma.



**Bone density testing:** This test involves a machine that measures the density of your bones, especially your hip, spine and wrist. It is done to see if you are at risk of developing osteoporosis. It is not a routine test for myeloma and not always possible to do.

### Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses.



### To sum up

The following tests are used to diagnose myeloma:

- Blood and urine tests such as full blood count, kidney function tests, calcium levels, paraprotein levels, normal proteins, beta-2 microglobulin, and electrophoresis.
- Bone tests such as full X-ray of body and bone marrow biopsy or aspirate.
- Scans such as MRI, CT, ultrasound, and bone density.

## What are the stages of myeloma?

Once all your test results are ready, you will be asked to return to the hospital to meet with your haematologist. Your haematologist will use the results to get an overall picture of your myeloma and to stage it. Staging means finding out the extent and severity of your illness. Your test results can help to rule out other conditions too such as amyloidosis, MGUS and smouldering or indolent myeloma. Staging the myeloma will help your haematologist to decide on your individual treatment plan.

>>> Staging is very important as it allows your doctor to decide the best treatment for you.

There are different systems used to stage myeloma. The International Staging System is the more modern system used, while the Durie-Salmon was used more in the past.

### International Staging System

This system looks at the levels of two blood proteins: beta-2 microglobulin and albumin. It has three stages:

- Stage 1** The beta-2 microglobulin is less than 3.5mg/L and the albumin level is greater than or equal to 3.5g/dL.
- Stage 2** Both the beta-2 microglobulin level and the albumin levels are less than 3.5, or the beta-2 microglobulin level is between 3.5 and 5.5mg/L.
- Stage 3** The beta-2 microglobulin level is greater than or equal to 5.5 mg/L.

If myeloma comes back after the first course of treatment, it is known as **relapsed** or **recurrent** myeloma.

### Durie-Salmon system

In the Durie-Salmon staging system, each stage is based on the level of calcium in your blood, how anaemic you are, how severe your bone



damage is, the presence of paraproteins in blood and urine, and how well your kidneys are working. This system may be used if you are taking part in a clinical trial.

**Stage 1** Early with low level of disease

**Stage 2** Active with moderate level of disease

**Stage 3** Active with high level of disease

Each of these stages is further classified as type A or type B. This refers to whether the myeloma has affected your kidneys or not.

**A** Kidney function is normal (or only a little affected)

**B** Kidney function is abnormal

## Other ways to classify myeloma

When it comes to treatment, your doctors may also put you into one of two groups: asymptomatic or symptomatic myeloma.

**Asymptomatic myeloma:** This is also called smoldering myeloma. This means that you have no blood, bone or kidney symptoms of the disease. But you do have higher levels of abnormal paraprotein in your blood and plasma cells in your bone marrow.

Because you have no symptoms your doctor will not start treatment but instead will monitor you closely for any signs of change.

**Symptomatic myeloma:** If you have symptomatic myeloma, this means you have blood, bone or kidney symptoms. You will need to have treatment in this case.



## To sum up

- Staging means finding out the extent of the disease.
- Myeloma can be staged using the Salmon-Durie System or the International Staging System.
- Patients can also be grouped into asymptomatic or symptomatic groups. If you have blood, bone or kidney symptoms, treatment will be given. If you do not have symptoms, you will be monitored closely instead.

# Treatment and side-effects

## How is myeloma treated?

There are several treatments that can slow down and control myeloma very well. They can also greatly improve your quality of life. No single treatment is enough. Most doctors will work out a treatment plan that includes different options at different stages so your disease is managed well. It is possible for you to live with this disease for some years.

**Remission:** In general the aim of treatment is to slow down and control the myeloma and to relieve the symptoms and complications it causes. With treatment, the bone marrow can recover and no longer make abnormal plasma cells. When this happens, the myeloma is said to be in **remission**. If myeloma returns, it is called a **relapse**. In reality, most patients experience a number of remissions and relapses. As a result, you may receive a number of different types of treatment over time.

In general there are a number of ways to manage myeloma:

- Active monitoring
- Chemotherapy
- Biological therapies: lenalidomide (Revlimid), thalidomide and bortezomib (Velcade)
- High-dose therapy and stem cell transplant
- Maintenance therapy
- Treatment of symptoms
- Treatment of relapsed myeloma

»» Myeloma is a complex disease so it can take time to plan the best treatment for you.

## How does my doctor plan my treatment?

Myeloma is a complex disease so it can take time to plan the treatment that is best for you. Your treatment plan will depend on the stage and severity of your myeloma, on your age and your general health.

Your doctor will also consider your lifestyle and personal preferences, and how you have responded to any treatments in the past. If you are unsure about what is best for you, ask as many questions as you can.

**Active monitoring:** You may be diagnosed with myeloma but show little signs of active disease. In this case your doctor may decide not to treat you but to watch (monitor) your condition closely. This is because the side-effects of treatments often outweigh the benefits in early myeloma. With active monitoring, you visit your doctor and have blood and urine tests every few months. You watch and wait to see if the myeloma develops further.

**Chemotherapy:** If your myeloma is active, your doctor may decide to treat you using chemotherapy. This is the most common way of treating myeloma. It aims to kill the myeloma cells with drugs that are toxic to the cells. Chemotherapy may be given on its own or with steroids or with new drug therapies. Sometimes radiotherapy may be given with chemotherapy, especially if you have a single myeloma tumour (plasmacytoma). See page 25 for more about chemotherapy.

**Biological therapies:** These therapies use the body's immune system to fight cancer. Drugs like thalidomide, lenalidomide (Revlimid) or bortezomib (Velcade) may be given on their own to control the myeloma cells. Or they can be given with chemotherapy. See page 27 for details.

**High-dose therapy and stem cell transplant:** Depending on your condition, you may be suitable for an intensive treatment called high-dose therapy and stem cell transplant. A high dose of chemotherapy is given first to mobilise and collect your stem cells which are then frozen and stored. A second high dose of chemotherapy is then given. Next your stem cells are thawed and returned to you by means of a large tube put into your chest called a central line. The benefit of this treatment is that the stem cells can help to keep the myeloma in remission. See page 30 for more details.

**Maintenance therapy:** After chemotherapy or a transplant, you may need to take other drugs for a number of months. These can include thalidomide, lenalidomide, interferon or steroids. This is called maintenance therapy. See page 33 for more details.

**Treating symptoms:** The treatment of symptoms (or supportive therapy) aims to heal or improve symptoms like bone disease, anaemia and kidney problems. The treatments can vary from person to person. Drugs known as bisphosphonates are often used to reduce bone damage caused by myeloma. They help to heal bones and reduce raised calcium levels in your blood. Treatments like radiotherapy and surgery can be done to strengthen the bone and reduce pain in the affected areas. Other treatments may include painkillers for bone pain, a blood transfusion for anaemia, or kidney dialysis if your kidneys are damaged. Not everyone will receive the same treatments. See page 34 for more about treating symptoms.

**Relapsed myeloma:** Even after a successful course of treatment, myeloma often returns. This is called relapsed myeloma. Certain drugs like lenalidomide, thalidomide and Velcade have been found to be good at controlling myeloma that has returned, especially after chemotherapy.

»»» Your doctor will discuss your treatment options with you.

It is important that you agree with your doctors' decision on what is the best treatment plan for you. Usually more than one doctor will be involved. In fact, there will be a team of specialists. Talk to your partner and friends about your treatment plan and any worries you may have. But if you are unhappy, you are free to get a second medical opinion. This may take some time, so it is best to do it as quickly as possible.



## Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You may be asked to sign a consent form saying that you give permission for treatment to be given. In some cases you may give verbal permission. No medical treatment will be given without your consent. Before treatment, you should have been given full information about:



- The type and amount of treatment you will have
- The benefits of the treatment
- Any major risks or side-effects of the treatment
- Any other treatments that may be available

If you are confused about the treatment, let your doctor or nurse know straight away. They can explain it to you again. Some myeloma treatments are complex, so it is not unusual for people to need repeated explanations. Even if you feel your doctors or nurses are too busy to answer your questions, do ask them. It is important that you know how the treatment is likely to affect you. You can always ask for more time to decide about your treatment, if you are unsure. You are also free to choose not to have the treatment. But first you should let your doctor or nurse know your concerns.



## To sum up

- The aim of treatment is to slow down and control the myeloma cells and treat your symptoms.
- When the bone marrow no longer has abnormal plasma cells, the myeloma is in **remission**.
- The treatment of myeloma includes active monitoring, chemotherapy, biological therapies, high-dose therapy and stem cell transplant, maintenance therapy, and treatment of symptoms.
- If myeloma comes back (relapses), it can be treated again.
- A team of specialists and you will decide which treatment is best for you.

## Chemotherapy

The main treatment for myeloma is chemotherapy. This is the use of drugs to kill or control the myeloma cells in your bone marrow. Depending on your hospital, your chemotherapy will be supervised by your haematologist or a medical oncologist. This is a doctor who specialises in chemotherapy. Chemotherapy is not a cure for myeloma but aims to bring about a remission. This is when the symptoms of myeloma disappear and your bone marrow recovers.

The chemotherapy drugs can be given as tablets or capsules or injected into a vein (intravenously). The most commonly used oral drugs are melphalan or cyclophosphamide. Those given by vein include vincristine and doxorubicin. In general the oral drugs have less side-effects than those given into a vein. The chemotherapy drugs are usually combined with steroids, for example, prednisolone or dexamethasone. In some cases a combination of drugs can be given. Sometimes oral tablets are given to older patients and drugs into a vein to younger patients, depending on your general health. Most of the oral treatments can be taken at home.

The following are some common chemotherapy combinations:

- **Melphalan (tablets) and prednisone (steroid tablets):** This is given for 4 to 5 days every 4 to 6 weeks. This is a mild treatment which does not usually cause hair loss or much nausea.
- **Vincristine, adriamycin and dexamethasone (VAD):** This chemotherapy is usually given through a central line (see below) in a hospital day ward or as an inpatient for a few days.
- **Idarubicin and dexamethasone:** This is another tablet combination that can be given as an outpatient.

Usually you receive one or more chemotherapy drugs for a few days every 3 to 4 weeks followed by a rest period. This is called a **cycle**. You may receive between 6 and 8 cycles of chemotherapy, or less sometimes. After about 4 cycles of chemotherapy your doctor should have a good idea if you are responding to the drugs or not. During this time you will have regular blood tests to check the effects of the drugs. Depending on the results of your blood tests, sometimes the

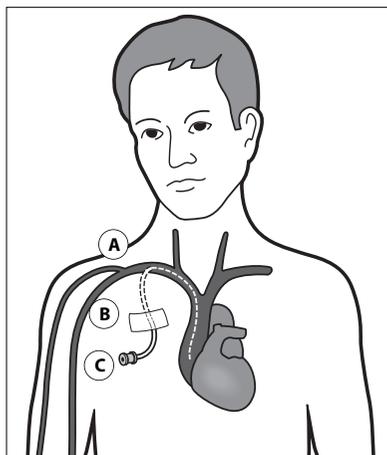
dosage of your drugs may be changed. If you are not tolerating the drugs well, the drug or dosage may be changed.

For details on side-effects of chemotherapy, see page 39.

### Giving chemotherapy into a vein

The most common way to give chemotherapy is through a drip placed in a vein in your arm or by a central line. A central line is a long, fine plastic tube put into a large vein in your chest. Blood samples can also be taken from the line or stem cells returned to your blood. The most common types of central lines are Hickman or Groshong. In some cases the tube may be first placed in a vein in your arm or leg and then threaded so that the tip lies in one of the large veins in your chest. This is called a peripherally inserted central catheter (PICC).

If you would like more information about central lines, a video is available from the Irish Cancer Society. Two versions are available: one for females and one for males. A free booklet called *Understanding Chemotherapy* is also available. Contact the National Cancer Helpline 1800 200 700 if you would like a copy of either.



**A** The central line is placed in a large vein here  
**B** The line is threaded under your skin  
**C** The line reaches the surface of your skin here

## Biological therapies

Biological therapies are being used more and more in the treatment of myeloma. Biological therapies use the body's immune system to fight cancer. They can be used with chemotherapy or if chemotherapy is no longer working. They can also be given if myeloma relapses.

Biological therapies are not considered chemotherapy drugs because they do not kill cancer cells directly and normal cells are usually not affected. They use other means to cause the myeloma cells to die.

### Thalidomide

In recent years the drug thalidomide has been used to control myeloma with good success. Patients who are newly diagnosed or who have not responded to other treatments are now responding well to thalidomide. Thalidomide works by blocking the blood supply to the myeloma cells and boosts the body's immune system. It also controls the amount of protein used in cell activity.

**Dosage and duration:** Thalidomide is taken orally once a day. It is best to take it at night because it can cause sleepiness or drowsiness. It can be given on its own but usually with dexamethasone or other chemotherapy drugs. Usually it is given for 6 months. It may take some weeks or months before your body responds to the drugs. Generally, an improvement is seen after about 3 months of treatment. Once a response is achieved, your doctor will decide if you need ongoing or maintenance therapy. Not everyone who takes thalidomide will have a good response and other therapies may be considered.

**Birth defects:** Many will remember that thalidomide was banned in the early 1960s for causing birth defects. Nowadays there are very strict guidelines for using it. Good contraceptive precautions for both men and women are essential and regular pregnancy testing will take place.

You will be registered on a special pregnancy prevention programme and your doctor will explain the details fully to you. You must phone the pharmaceutical company each month before you receive your drug. They will ask you a series of questions to make sure there is no chance

you or your partner could be pregnant. If you are a woman of childbearing age who has not had a hysterectomy or been menopausal for more than 24 months, you must use two forms of contraception. This should start 4 weeks before treatment and continue for 4 weeks after treatment. You must stop taking the drug immediately if any of the following occur:

- You have a late or an irregular menstrual period
- You stop practising abstinence (not having sex)
- You stop using contraceptives
- You think that you could be pregnant
- You become pregnant

Because thalidomide can be found in male sperm, there is a danger that it can affect sperm or your partner if she becomes pregnant. Men must use condoms in particular, and continue taking contraceptive precautions for 1 month after treatment. For more information on fertility issues, see page 50.

### Lenalidomide (Revlimid)

Lenalidomide is similar to thalidomide, except that it has less side-effects. It can be given at any stage of your myeloma. This means that it can be given as your part of your first treatment or if the myeloma returns. Lenalidomide is taken orally once a day for 21 days with a 7 day rest period. The cycle is then repeated. Normally it is given with a low dose of dexamethasone. You will have regular blood tests to measure your paraproteins during this time. These will show if the drug is working well. It may take 2 or 3 cycles before a good response happens.

Lenalidomide is very like thalidomide so there is a risk of it causing birth defects. For this reason, you cannot be or become pregnant while taking it. You must use two forms of contraception, starting 4 weeks before treatment and continuing until 4 weeks after treatment. You will be registered on a special pregnancy prevention programme to make sure you are not pregnant before receiving the drug each time. You must never take the drug if you are pregnant or breastfeeding. If you are male, you must use a condom when having sex to prevent your partner from getting pregnant.

### Bortezomib (Velcade)

Velcade is another drug that is more widely used now. At first it was only given to patients whose myeloma had relapsed or not responded to other treatments. But now research shows that Velcade is effective in treating newly diagnosed patients. Like thalidomide, Velcade works by preventing the normal growth of cells and speeding up cell death. It stops the breakdown of proteins within cells, which leads to a build-up of protein and causes the myeloma cell to die. Your normal cells are less affected by this drug, so side-effects are less severe than with chemotherapy. The drug can be given by injection into a vein.

For more information on the side-effects of biological therapies, see page 45.

### How does the doctor measure the response to treatment?

Your haematologist or oncologist will know if your treatment is working by doing some tests. These tests, mostly of blood, urine and bone, will be done regularly during and after your treatment. They include:

- Full blood count
- Skeletal survey and bone marrow biopsy
- Paraprotein in blood and urine
- Blood proteins levels, such as albumin
- Blood calcium levels
- Kidney function tests

The word remission is used to refer to the response of the myeloma cells to treatment. In general the response is measured by:

**Complete remission:** This means there are no myeloma proteins in your blood and/or urine when tested. No myeloma cells are present in your bone marrow or elsewhere. However, complete remission is not the same thing as cure.

**Partial remission:** This means there has been some response to treatment but it is not as good as a complete remission.

**Minor response:** This means that the response is not as good as a complete or partial remission. The level of paraproteins in your body has decreased by only a small amount.

**Refractory myeloma:** This means the myeloma is resistant to the treatment.

## High-dose therapy and stem cell transplant

Your doctor may consider you suitable for high-dose therapy and stem cell transplant. This may be early on in your treatment or later. Often after this treatment, your response or remission gets better and lasts longer. This is because stem cell transplants allow higher doses of chemotherapy to be given to treat myeloma. Even so, high-dose therapy and stem cell transplant is unable to cure myeloma. Your myeloma is still likely to recur at some point.

Because it is an intensive treatment it not suitable for everyone. If you are under 65 and your general health is good, you may benefit from this treatment. Your doctor will first do some tests on your kidneys, heart and lungs to check that you are suitable for a transplant. Deciding on a transplant may not be easy option for you. You will have your own concerns and issues that will play a part in making your decision too.

The most common type of transplant is called an **autologous transplant**. Here you donate your own stem cells. Autologous transplants are also called **autografts** or **peripheral blood stem cell transplants**.

>>> The most common type of transplant is an autologous transplant, where you donate your own stem cells.

### What's involved in stem cell transplants?

A transplant can take a number of months from the time you first discuss it with your haematologist until you go home after the surgery.

Stem cell transplants only take place in highly specialised treatment units. The steps involved in a stem cell transplant are:

- 1 You receive high-dose chemotherapy to mobilise your stem cells.
- 2 Your stem cells are then collected from your blood (harvested) and stored.
- 3 You receive another course of high-dose chemotherapy.
- 4 Your stored stem cells are returned to your blood.
- 5 You may be cared for in isolation until your stem cells grow and the number of your white cells is nearly normal.

#### 1 Mobilising stem cells

Stem cells are mainly found in your bone marrow. To collect them your doctors must mobilise or move them from your bone marrow into your bloodstream. For this to happen, you will be given a drug called a growth factor. Growth factors can increase the number of stem cells in your bone marrow and cause them to 'spill over' into your bloodstream. It is easier to collect them in your bloodstream. This growth factor is called G-CSF (granulocyte-colony stimulating factor). It is given in the outpatient clinic or at home either once or twice a day. Usually it is given as an injection under your skin for several days before collecting the stem cells. The course may last from 5 to 7 days, or over 10 days if given with chemotherapy.

Often a cycle of chemotherapy is given directly before the growth factor injections. A drug commonly used is cyclophosphamide, which is given for 1 or 2 days. Depending on your general health, you may need to stay in hospital for a few days while receiving the chemotherapy.

A blood test to see if there are enough stem cells in your bloodstream will also be done. This blood test is called a CD34 blood test.

#### 2 Removing stem cells from blood (harvesting)

The stem cells collected from your bloodstream are called peripheral blood stem cells (PBSC). A machine called a stem cell separator or **apheresis** machine is used to collect these cells. You will be attached to the machine by an intravenous line. This can either be as a drip in

a large vein in your arm or a tube called a Vas-cath or Perm-cath, which is placed in a large vein usually in your chest or groin.

Removing the stem cells does not hurt so you do not need an anaesthetic. Normally you can lie on a bed or sit in a comfortable chair. You may experience a cramp or tingling sensation in your hands, feet or around your mouth. This is because your calcium levels may drop. Drinking some milk usually helps this problem.

Normally it takes 3 to 4 hours to collect all the stem cells. Sometimes not enough cells are collected in one session. You may need two or three sessions over the following days as a result. All the stem cells are then frozen and stored until needed. It is normal to feel tired after the collection, so you will probably need to rest that evening and for a few days afterwards.

### **3 Giving high-dose chemotherapy**

When you return to the hospital you will be given another course of chemotherapy. Usually the drug melphalan is given alone for 1 or 2 days or it may be given in combination with other drugs. You will also need large amounts of fluids into a vein before you receive the drugs. This is to prevent any dehydration and kidney damage. You are likely to remain in hospital for 3 to 4 weeks.

### **4 Returning stem cells**

Once the high-dose therapy is given, you will receive the stem cells within 2 to 3 days. They are usually given into a vein through a Hickman line, PICC or Vas-cath. This takes about 1 hour. During it you may experience some nausea or vomiting, abdominal cramps, feel cold or have an unusual odour or taste of garlic or sweetcorn. Once in the bloodstream, your stem cells go directly to the bone marrow where they begin to develop into new blood cells. Normally it takes 10–14 days and this is known as engraftment.

### **5 Care in isolation**

After you receive the chemotherapy, your white cell count will become low. This means your immune system will be less strong and you are at risk of developing infections. For this reason, you may be nursed in a single room away from other patients and hospital staff

for about 10 to 14 days. You may need antibiotics during this time. There is also a risk of developing anaemia and bleeding, so you may need blood or platelet transfusions at this time too. During your time in isolation your visitors may be restricted. The hospital staff will explain any precautions you may have to take with food, etc. In general you can go home when your blood count is at a safe level. This means that your bone marrow is now making normal blood cells.

### **After transplant**

It may take several weeks to recover your strength after the chemotherapy and transplant. In some cases your doctors may suggest a second transplant immediately after your first one or 6 or 12 months later. How soon this is done depends on whether your doctor thinks it will improve your quality of life or if your myeloma has relapsed. A useful booklet called *Understanding Bone Marrow and Stem Cell Transplants* is available by calling the National Cancer Helpline 1800 200 700.

## **Maintenance therapy**

After chemotherapy or a transplant, you may be given drugs that can prevent or delay the myeloma from returning. This is called **maintenance therapy**. Not everyone will benefit from maintenance therapy. The benefits will have to be balanced against any side-effects that may occur.

In recent times thalidomide has been used as maintenance therapy. It can be given a few months after a transplant and for as long as it is tolerated. If thalidomide is not given, lenalidomide may be given instead. For more on the side-effects of thalidomide and lenalidomide, see page 45.

Interferon and steroids were commonly used in the past for maintenance therapy but are used less so nowadays. Interferon is a protein that strengthens your body's immune system. It is also given after a stem cell transplant to prevent the growth of abnormal plasma cells. Normally interferon is given by injection three times a week.

If you need interferon for some weeks or months, your nurses will teach you or a family member how to inject the drug at home. Or, if this is not possible, the public health nurse can take care of it instead.

There are some side-effects with both steroids and interferon. See pages 48–49 for more details.

## How are the symptoms treated?

The treatment of myeloma symptoms is also known as **supportive therapy**. Serious complications like infections, anaemia, bleeding, fractures and spinal cord compression need to be treated straight away. A lot of symptoms are discussed here but most people will only experience some of these.

### Bone disease

**Painkillers:** Bone pain is a common problem with myeloma, especially in the lower back, hips and ribcage. Regular painkillers will be given to help ease any bone pain you have. Check with your doctor before you take any painkillers of your own as they may affect your kidneys.



### Tips & Hints – bone pain

- Take your painkillers regularly or as prescribed. If your pain gets worse talk to your doctor.
- Sit comfortably. Get family or friends to help you move your position. Special v-shaped pillows are also helpful when in bed or sitting out.
- Have a gentle massage as it can be a good way to relieve pain.
- Relax as much as you can. Try visualisation or relaxation techniques to help you cope better with pain. Listen to music or watch your favourite TV programme.
- Ease your worries by talking about them with your family, friends, doctor or nurse.



**Bisphosphonates:** Certain drugs called bisphosphonates help to reduce bone pain and damage and can slow down any further bone disease. As a result, they help bones to heal and can greatly improve your quality of life. They work by coating the bone and blocking the activity of the cells involved in bone damage. These drugs include Zometa, Bonafos and Aredia. Bisphosphonates may also affect myeloma cells too, preventing their growth and survival.

Bisphosphonates can be taken orally as tablets every day or by injection into a vein, often once a month. Usually they are a long-term treatment. They can also help to lower raised calcium levels in your blood. Before treatment, your doctor may advise you to have a dental check-up, as bisphosphonates may cause some jaw problems. See page 47 for the side-effects of bisphosphonates.

**Surgery:** Depending on the severity of your bone disease, you may need orthopaedic surgery. This is done to repair any fractures in the bones of your spine (vertebrae) or to strengthen them. New surgical techniques are being developed all the time. For example, vertebroplasty involves shaping the bone when it has collapsed due to a fracture. After surgery you may need physiotherapy for some time too.

**Radiotherapy:** Radiotherapy can strengthen bone and reduce pain in the affected areas. It involves aiming careful doses of high-energy radiation at an area of bone damage and pain. It can also be used at the site where a myeloma tumour (plasmacytoma) has been removed. The use of radiotherapy to a specific area can kill myeloma cells quicker than chemotherapy and with fewer side-effects.

There are several ways of giving radiotherapy. Often it is given daily for one or more weeks, but once or twice a week courses or even single treatments are also used. For more information on radiotherapy, contact the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Understanding Radiotherapy*.

## Blood and bone marrow

When you have fewer red blood cells, white blood cells and platelets, it can cause the following symptoms and complications:

- Anaemia
- Fatigue
- Weakness
- Shortness of breath
- Infections
- Dizziness and feeling light-headed
- Bruising and bleeding

There are many ways to help these symptoms and they include:

**Blood transfusions:** A blood transfusion can be given if your red blood cells are low. This will help to improve anaemia and any symptoms like fatigue, weakness, shortness of breath or dizziness. The extra red cells you receive will quickly carry the oxygen from your lungs and take it around your body. You will then feel more energetic and less breathless.

**Erythropoietin:** Sometimes a drug called erythropoietin can be given to help severe anaemia. It causes the bone marrow to make red blood cells more quickly. It is sometimes called epoietin or epo.

Erythropoietin is given as an injection just under the skin in your thigh or abdomen, once or three times a week. You or a family member will be taught how to inject it at home. Usually it takes about 2 to 3 weeks for the level of red blood cells to rise. Erythropoietin should be kept in a fridge, and your nurses will explain everything you need to know about this drug.

**Plasmapheresis:** Your blood may become thick because of the abnormal proteins present. If you have kidney damage, your kidneys may not be able to get rid of these proteins quickly enough. Plasmapheresis may be done to thin your blood. It involves filtering your blood to remove the unwanted protein and replacing it with normal fluid. This fluid is called either plasma or albumin and is given the same way as a blood transfusion.

**Antibiotics:** Because your white blood cells are lowered, everything will be done to prevent you getting an infection. If you do develop an infection, an antibiotic will be given to bring it under control quickly.

In special cases, you may be given antibiotics to prevent you from getting an infection or for emergency use. This may apply if you are at home or when travelling.

**Growth factors and immunoglobulins:** In some cases, drugs called growth factors can help your bone marrow to make more white blood cells to prevent infection. Growth factors are special proteins normally made in the body but which can now be made in the laboratory. A commonly used growth factor to boost white cells is often referred to as G-CSF. If you get serious recurrent infections, your doctor may decide to give you immunoglobulins into your vein.

**Platelet transfusions:** If the platelets in your blood are reduced, you may bruise or bleed very easily. You may suffer from nosebleeds or bleed more heavily than usual from minor cuts or grazes. Or you may notice tiny red spots under your skin that look like a rash. In these cases you may be given a platelet transfusion. This is a fluid containing platelets which is given like a blood transfusion. These new platelets will start to work straight away to prevent bruising and bleeding.

## Kidney disease

**Fluids:** With kidney disease, you will be told to drink plenty of fluids. **You are advised to drink at least 3 litres or 5 pints of water every day.** Avoid drugs that can affect your kidneys. Also, talk to your GP when starting any medication. If you have ongoing vomiting or diarrhoea, you may need to go to hospital for fluids into your vein.

**Dialysis:** For a small number of patients, kidney damage may be permanent. In this case you may need to have a regular treatment called dialysis. This treatment uses a machine to filter your blood in the same way a healthy kidney does. You may need it once or several times a week.

»»» You are advised to drink at least 3 litres or 5 pints of water every day.

## How is relapsed or resistant myeloma treated?

When myeloma returns it is called a **relapse**. In some cases, the myeloma does not respond to treatment at all and is called **resistant** (or **refractory**) **myeloma**.

**Length of remission:** Remissions can last from months to years. But it is rare for remissions to be permanent. Sadly, most people relapse after their first treatment of myeloma. The first remission is usually the one that lasts the longest. Even if myeloma recurs, it can be treated again. You may find that you experience several remissions and relapses, but generally the length of each remission grows shorter each time. If you are in remission and respond well to maintenance therapy, you may have increased remission time.

**Treatment changes:** If you relapse, your treatment may have to be changed a number of times. This will depend on your age, your general health, your previous response to treatment and your lifestyle. Usually the most important factor is the quality of life you would like.

**Drugs given:** Sometimes melphalan and prednisolone are given again, especially if you responded well to them at first. Or you may be given drugs such as vincristine, adriamycin and dexamethasone (VAD) injected into a vein. However, certain drugs like thalidomide, lenalidomide and Velcade are now proving more beneficial for relapsed myeloma.

Lenalidomide can be given with dexamethasone orally. Thalidomide may be given on its own or in combination with dexamethasone or cyclophosphamide. Normally it is given orally for several months. Velcade can be given on its own or with dexamethasone. It is usually given in a cycle of treatment. You will receive an injection into your vein twice a week, for 2 weeks, followed by a rest period of 1 week. Sometimes eight treatment cycles can be given. However, research on these drugs and others is ongoing.

## What are the side-effects of treatment?

Before treatment, your haematologist or medical oncologist will explain any possible side-effects of the drugs you will be given. Each drug may have quite different side-effects. Some of these side-effects may be short term or long term.

»»» Before treatment, your haematologist will explain any possible side-effects of the drugs.

### Chemotherapy side-effects

Not all chemotherapy drugs cause the same side-effects. For this reason, side-effects can vary between people. Indeed some people may get very few. Most side-effects are short term and will gradually disappear once the treatment has stopped. Nowadays, some of the side-effects can be prevented or controlled very well.

The parts of your body usually affected by chemotherapy are those where normal cells grow quickly. These areas are your mouth, digestive system, skin, hair and bone marrow.

Do let your doctor and nurse know if you are having any side-effects. He or she may be able to give you medication or advice to help or make changes to your treatment to lessen the side-effects. Not all possible side-effects are listed here. Some of the more common ones include the following:

#### Blood count problems

Chemotherapy can affect the bone marrow and reduce the numbers of blood cells. A reduction in white blood cells means that you are more prone to infection. As a result you may need to take antibiotics frequently. If you have fewer red blood cells you may develop anaemia, which can cause fatigue and shortness of breath. This is treated by blood transfusions or erythropoietin. A reduction in platelets causes bruising and bleeding. You may need to receive a platelet transfusion and take great care to avoid cuts and grazes.

## >>> Tips & Hints – blood count changes

- Take plenty of rests and breaks if you are feeling tired or fatigued.
- Avoid close contact, such as hugging or kissing, with people who have colds, flu's and other infections, especially chickenpox, shingles or measles.
- Wash your hands often during the day, especially before eating and after going to the toilet.
- Take care to avoid injury. Use an electric razor when shaving or wear thick rubber gloves when gardening to protect yourself from cuts.
- Contact the hospital immediately if you have a temperature of 38°C (100.4°F) or higher, shortness of breath or bleeding that cannot be stopped.



### Fatigue

During chemotherapy and for some time afterwards, you may feel very tired. A feeling of overwhelming tiredness is known as fatigue. You might feel weak or find it hard to concentrate or make decisions.

Fatigue can also be due to the myeloma itself or the worry about the diagnosis and treatment.

Do allow yourself plenty of time to rest. In general the tiredness will ease off gradually once the chemotherapy has ended. For some people the tiredness may last for several months. A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

## >>> Tips & Hints – fatigue

- Stop before you get overtired.
- Save your energy for doing the things you most enjoy.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.



- Wear clothes that are easy to put on and take off.
- Ask for help at work or around the house, especially with cooking, housework or childcare.
- Sit down when getting dressed or doing the ironing, etc.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.
- Use relaxation techniques to help get to sleep: gentle exercise, relaxation tapes, etc.

### Changes in kidney function

Some chemotherapy drugs can cause damage to your kidneys. To prevent kidney damage, fluids may be given into your vein for several hours before you have any treatment. The state of your kidneys will be carefully checked by blood tests before each treatment. Drink as much fluid as you can – about 3 litres per day.

### Nausea and vomiting

Some chemotherapy drugs may make you feel sick (nausea) or vomit. On the other hand, many patients have no sickness at all with these drugs. But for those who do, there are very helpful treatments available. In fact, this is less of a problem than in the past. The sickness may last for a few hours or, in rare cases, for several days. Your doctor can prescribe anti-sickness drugs to stop or reduce this side-effect. These are called anti-emetics. They may be given by injection with the chemotherapy and as tablets to take home afterwards.

### Loss of appetite

Some chemotherapy drugs can reduce your appetite for a while. It may be a good idea to get advice from a dietitian if this occurs. A booklet called *Diet and Cancer* is available from the Irish Cancer Society and has helpful tips on boosting appetite. Call the National Cancer Helpline 1800 200 700 for a free copy.

### >>> Tips & Hints – eating and digestion

- Avoid eating or preparing food when you feel sick.
- Avoid fried foods, fatty foods or foods with a strong smell.
- Eat cold or warm food only, if the smell of hot food makes you feel sick.
- Eat several small snacks and meals each day, and chew your food well.
- Have a small meal a few hours before treatment, but don't eat just before treatment.
- Drink lots of fluid slowly during the day, taking small sips.
- Avoid filling your stomach with lots of liquid just before you eat.



#### Diarrhoea

Some chemotherapy drugs can affect the lining of your gut and may cause diarrhoea for a few days. Passing watery bowel motions more than twice a day is known as diarrhoea. You may also have cramping and/or abdominal pain. If this happens, drink lots of clear fluids to replace the fluid you are losing. You must tell your doctor or nurse if you have diarrhoea for more than 24 hours. There is medication that can stop this side-effect of treatment. Again it might be useful to talk to a dietitian who can offer advice at this time.

#### Constipation

Chemotherapy may slow down the movement of your bowel. As a result, your regular bowel habit may change and you may have difficulty passing a bowel motion. This is known as constipation. If this happens, let your doctor or nurse know as soon as possible. You may need to drink more clear fluids and/or take a laxative. In some cases, your doctor may have to adjust your treatment.

### >>> Tips & Hints – diarrhoea and constipation

- If you have diarrhoea, eat less fibre and avoid raw fruit, cereals and vegetables.
- Drink plenty of liquids (3 litres a day) to replace the fluid lost in diarrhoea.



- If you are constipated, eat more fibre, raw fruit, cereals and vegetables. Drink plenty of fluids. Prune juice and hot drinks can often help.
- Take as much gentle exercise as you can.

#### Mouth problems

High doses of chemotherapy can cause a sore mouth or inflammation of your mouth (**mucositis**). This in turn can lead to mouth ulcers. If this happens, it is usually about 5 to 10 days after the drugs are given. But it should clear up within 3 to 4 weeks. Mouthwashes can be helpful, in particular ones containing salt (saline). Avoid alcohol mouthwashes as they can irritate your mouth even more.

Ulcers can become infected easily when your white cell count is low. Cleaning your teeth regularly and gently with a soft toothbrush will help to keep your mouth clean. Your doctor will be able to give you medication, such as mycostatin, to help prevent or clear up infections. For very sore mouths there are many kinds of gels, creams or pastes available to ease the soreness. Your doctor can prescribe painkillers if your mouth becomes very sore.

### >>> Tips & Hints – mouth changes

- Eat fresh pineapple to keep your mouth fresh and moist.
- Clean your mouth or dentures gently every morning, evening and after each meal.
- Use a soft-bristled or child's toothbrush.
- Try a mouthwash if your toothpaste stings or brushing your teeth makes you feel sick.
- Use a mouthwash regularly to prevent soreness, as advised by your doctor.
- Keep your lips moist by using Vaseline® or a flavoured lip balm.
- Avoid spirits, tobacco, hot spices, garlic, onion, vinegar and salty food. These may irritate your mouth.
- Keep your mouth and food moist. Add gravies and sauces to your food to make swallowing easier.



- Aim to drink at least 3 litres (5 pints) of fluid a day. This can be water, weak tea, weak coffee, and soft drinks such as apple juice.
- Avoid acidic drinks such as orange and grapefruit juice. Warm herbal teas may be more soothing.

### Changes in taste

Chemotherapy can cause your sense of taste to change. Food may taste more salty, bitter or metallic. Normal taste will come back once treatment has ended. The Irish Cancer Society's booklet, *Diet and Cancer*, has some helpful advice on how to manage taste changes.

### Hair loss

Hair loss or alopecia is a common side-effect of chemotherapy. Some drugs cause no hair loss or so little that it is hardly noticeable. Others cause partial or complete hair loss for a time. The amount of hair lost will depend on the type of drug or drugs used, the dose given, and your individual reaction to the drug. Some chemotherapy drugs can make hair brittle.

**When it happens:** If hair loss happens, it is usually within a few weeks of treatment. Underarm, body and pubic hair may be lost as well. Some drugs also cause loss of your eyelashes and eyebrows. Try not to worry, as your hair will start to grow again once treatment stops. You may experience tingling or sensitivity of your scalp before your hair starts to fall out. This is normal and may last a day or so.

**Being upset:** It is natural to feel upset at the thought of losing your hair. Don't be afraid to talk to your nurse or medical social worker about your feelings. He or she will help you find ways to cope with your hair loss. If you like, you can get a wig or hairpiece when this happens. Or you may prefer to wear a hat, silk scarf or bandana. If you decide to get a wig, it is better to organise this before your hair falls out. This is because you will get a better match to your own hair colour at this time.

**Getting wigs/hairpieces:** Your medical social worker or nurse may be able to advise you about getting a wig. If your hospital does not have

a medical social worker, ask if they have the name of a wig fitter that you could visit. In some cases it is possible to get financial assistance towards the cost of a wig or hairpiece. Two useful booklets, *Understanding Chemotherapy* and *How to Cope with Hair Loss*, are available by calling the National Cancer Helpline 1800 200 700.

### Biological therapies side-effects

Thalidomide, lenalidomide and Velcade are relatively new drugs in the treatment of myeloma. They have many similar side-effects that are listed here. Do remember that not everyone will have the same side-effects. Your doctors and nurses will let you know beforehand of any possible side-effects. They will also give you any special advice that you may need. See page 50 on fertility and on contraception when taking these drugs.

With some biological therapies you may get a fever, headaches or shivering when first taking these drugs, but they usually only last a short while. Your doctor or nurse will let you know any other likely side-effects.

#### Thalidomide

The following have been known to occur when taking thalidomide:

- Tingling or numbness in the arms, hands, legs, feet called **peripheral neuropathy**
- Sleepiness and tiredness
- Dizziness
- Infections due to low white blood cells
- Rashes
- Constipation or diarrhoea
- Dryness of skin and mouth
- Blood clots in the legs (deep venous thrombosis)

#### Lenalidomide

The following have been known to occur when taking lenalidomide:

- Infections due to low white blood cells
- Bruising or bleeding
- Muscle cramps or weakness
- Rashes and itching
- Constipation or diarrhoea
- Fatigue
- Dryness of skin and mouth
- Blood clots in the legs (deep venous thrombosis) or lungs

## Velcade

The most common side-effects with Velcade are:

- Tingling or numbness in the arms, hands, legs, feet (peripheral neuropathy)
- Tiredness
- Fever
- Pneumonia
- Poor appetite
- Nausea and vomiting
- Diarrhoea or constipation
- Bruising and bleeding

Most side-effects will settle down after a while, especially nausea, vomiting, diarrhoea and constipation. If you have vomiting and diarrhoea, you may become dehydrated. It is best to drink plenty of fluids when taking these drugs. If you feel sleepy or drowsy, do not drive or operate machinery.

When taking thalidomide or lenalidomide, your haematologist may also decide to give you aspirin, warfarin or heparin to prevent blood clots. It is important to tell your doctors and nurses if you experience any of the above side-effects. There are many ways to relieve them and make you feel better. Sometimes the dosage and duration of the drug may have to be reduced.

## Peripheral neuropathy

Coping with peripheral neuropathy can sometimes be a little hard. Here the nerves in your feet and hands are affected, causing tingling, numbness or a burning pain. Your doctor may prescribe folic acid, vitamin B12 and/or other medications like Gabapentin to reduce the symptoms and promote nerve healing. He or she can also prescribe painkillers for any pain that is troubling you. You may also need some gentle exercise organised by your physiotherapist.



## Tips & Hints – peripheral neuropathy

- Keep hands and feet warm by wearing gloves and socks.
- Take regular exercise or as advised by your doctor or physiotherapist.
- Eat a well-balanced diet and take vitamin supplements if advised by your doctor.



- Get advice from your dietitian on how to lose weight if you are overweight. This can reduce pressure on your nerve endings.
- Quit smoking as cigarette smoke narrows the blood vessels to the nerves.
- Avoid alcohol or reduce the amount you drink.
- Treat any cuts or injuries to your feet or hands immediately.
- Take good care of your feet, especially if you also have diabetes or an impaired ability to feel pain. Keep feet clean and avoid any tight-fitting shoes, socks or tights.
- Avoid exposure to toxins like pesticides, heavy metals, etc.
- Acupuncture may help, so ask your doctor for advice.

## Bisphosphonates side-effects

There are several side-effects to bisphosphonates but many people experience none. Remember to tell your doctor and nurse how the drug is affecting you – good or bad. The side-effects can include:

- Flu-like symptoms such as fever, chill, headache, aching muscles and joints
- Bone pain
- Nausea, vomiting or diarrhoea
- Fatigue
- Skin rashes and eye irritations
- Kidney problems
- Jaw problems like pain, swelling, numbness, ‘heavy jaw’, loose teeth, poor healing

Many mild side-effects, such as bone pain and flu-like symptoms, happen at the start of treatment and last a few days only. Others like nausea, vomiting and diarrhoea can be easily controlled. Fatigue may last for a much longer time, so get as much rest as you can. See page 40 for more details on fatigue.

Blood and urine tests to check your kidneys will be done regularly. In recent times bisphosphonates, when given by injection, have been linked to jaw problems, with delayed healing after teeth extractions.

More than likely your haematologist or oncologist will advise you to visit a dentist before treatment. It is best to take very good care of your teeth or dentures and have regular dental check-ups. Let your doctor know straight away if your dentist advises any oral surgery or extractions.

### Steroids side-effects

Steroids may be given at any stage of your myeloma treatment. These complex drugs are hormones naturally made in your body. There are many types of steroids but in general dexamethasone and prednisolone are used widely in myeloma. In high doses they can give rise to several side-effects, but not everyone will experience the same ones. The more common side-effects include:

- Increased appetite
- Mood changes such as irritability, anxiety, sleep disturbances, tearfulness, or high spirits
- Stomach upset
- Increase in blood sugar levels that can lead to diabetes
- Fluid retention
- Higher risk of infections

While receiving steroids, blood tests will be done regularly to check your sugar levels. Your doctor may prescribe an antacid to prevent any stomach upsets.

### >>> Tips & Hints – steroids

- Take steroids in the morning as taking them at night may disturb your sleep.
- Talk to the hospital dietitian if you are putting on weight.
- Report any signs of infection to your doctor and nurse. This includes a high temperature, cough, swelling or any inflammation.
- Do not stop taking steroids suddenly or without your doctor's advice. This may lead to a sudden drop in blood pressure.



### Interferon side-effects

Interferon is a powerful drug that can boost your immune system and also kill any cancer cells. There are many drugs that can interfere with interferon so do let your doctor know if you have had any heart disease or are taking any other medications or vitamin or herbal supplements. You must also use good contraception if you are taking interferon.

Many people have one or more of the following side-effects:

- Flu-like symptoms such as fever, chill, headache, aching muscles and joints
- Nausea, vomiting or diarrhoea
- Fatigue
- Loss of appetite
- Skin rash or itchiness at injection site
- Hair thinning
- Bone marrow problems such as anaemia, infections and bleeding
- Mood changes (occasionally)

Many of the side-effects of interferon, for example flu-like symptoms, happen at the start of treatment and settle down after a few days. Others like vomiting and diarrhoea can be controlled with medication. Tiredness and loss of appetite may increase as the treatment goes on, which can sometimes be hard to cope with. In general most people find their energy levels are back to normal from 6 months to a year after their treatment ends. See page 40 for more details on fatigue. The fatigue may also be caused by anaemia as a result of bone marrow problems.

>>> Talk to your doctor and nurse if you experience any side-effects.

Tell your doctor immediately if you experience any problems such as fatigue, shortness of breath, infections, bruising or bleeding. In particular, you should tell your doctor if you have shingles or have been exposed to someone with chickenpox. Avoid all vaccinations for 3 months after your interferon treatment ends.

Talk to your doctor and nurse if you experience any side-effects, no matter how small or trivial you think they are.

## Will treatment affect my sex life and fertility?

### Sex and sexuality

Sometimes a diagnosis of myeloma can bring changes to your sex life. For some people sex is an important part of a relationship, while it is less so for others. As a result changes to your sex life can vary. The effect of myeloma and its treatment may cause you to lose the desire for sex for a while. This is normal and there are many reasons for it. You may feel too tired or physically unable for it, or else stress and anxiety may put you off. Some treatment drugs can also reduce your sexual desire (libido).

**Duration:** Any changes to your sex life are usually short term. Once treatment has finished or when the myeloma is in remission, you may want to resume your sex life. But remember there is no set time for you to be ready to have sex again. It varies from person to person.

**Contraception:** Some drugs used to treat myeloma may cause birth defects. It is important to use reliable contraceptives when having sex. See fertility on page 50 for more details.

**Talking about your concerns:** Talking about your feelings may help ease your anxieties, even though it may be hard to bring up the subject at first. Your partner too may be waiting for a sign that you are ready to discuss your worries. Even if you have lost the desire for sex, you can still enjoy a close and loving relationship with your partner.

If you feel it is important to you, discuss your worries before your treatment starts. You may feel embarrassed at first talking about it to your doctor or nurse, but they can give you good advice. A booklet called *Sexuality and Cancer* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy or for advice in confidence.

### Fertility

If you or your partner is of childbearing years, you should be aware of fertility issues. Some drugs used to treat myeloma may cause infertility

or birth defects. Thalidomide and lenalidomide in particular may cause serious birth defects and their use is tightly controlled nowadays. Before you can receive these drugs, you will be registered on a special programme. If you are a woman, you must use two forms of contraception, starting 4 weeks before treatment and continuing until 4 weeks after treatment. If you are a man you must use condoms in particular, and continue taking contraceptive precautions for 1 month after treatment. There is a danger that thalidomide and lenalidomide can affect sperm or your partner if she becomes pregnant. See page 27 for more details about this programme.

It is best to talk to your doctors and nurses if you are worried about any fertility issues relating to chemotherapy or thalidomide/lenalidomide. If you have high-dose chemotherapy before a stem cell transplant, there is a risk that it will cause long-term infertility. But you do have the option of freezing your eggs or sperm before treatment begins. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital, Dublin provides a service where eggs or sperm can be frozen. Talk to your doctor about this service or call the National Cancer Helpline 1800 200 700 for more information. For any fertility issues, a free booklet called *Fertility and Cancer* is also available from the Irish Cancer Society.

## How will treatment affect my lifestyle?

No two myeloma patients are the same. Myeloma can affect you in various ways. Sometimes the treatment may have little impact on your lifestyle. Or it can take some time for you to get back to a normal routine, especially if you have been in and out of hospital or need to rest at home for long periods. Myeloma can affect your lifestyle in the following areas:

- Exercise
- Eating and drinking
- Sleep
- Making adjustments
- Holidays and travel
- Anxiety and depression

Cancer Helpline 1800 200 700

## Exercise

It is important that you stay as active as you can. This is so that you keep calcium in your bones. Walking and swimming are some good ways to keep active. You should first check with your haematologist or oncologist about how much physical exercise is right for you, especially if you have bone disease or bone damage. At the hospital the physiotherapists will start off gently by helping you with exercises to strengthen your muscles. These in turn can boost your confidence in walking. At home do as much light exercise as you can. Even a short walk will be of benefit.

>>> Do stay as active as you can.

## Eating and drinking

There is no specific diet for myeloma patients other than a well-balanced one. But you should be cautious about taking vitamins and herbal supplements. With myeloma high doses of vitamin C may increase your risk of kidney damage. It is best to talk to your doctor about using vitamin and herbal supplements along with chemotherapy or other drug treatments.

It is important that you drink plenty of fluids to keep your kidneys working properly. This means taking about 3 litres (5 pints) of fluids each day. In general water is one of the best fluids to take. Also, you should reduce the amount of alcohol you drink. If you do take an alcoholic drink, make sure to drink extra fluids on that day also.

## Regular sleep

The benefit of a good night's sleep is vital no matter what your illness is. Sleep can boost your immune system and also help you cope better with your myeloma. See page 40 for more advice on sleeping.

## Making adjustments

Depending on the severity of your myeloma, you may have to make changes in your life. It is important to reduce any stress in your job,

family or social situation. Concentrating on getting better should be your top priority. As a result, you may have to make decisions regarding your job or family.

If you have bone damage or fatigue, your mobility may be reduced. You will be advised not to do any lifting, hovering or heavy housework. In some cases you may need to use a walking stick or a wheelchair for a while. Naturally, you will need time to adjust to this situation. The occupational therapists at the hospital will help you get back to doing your normal activities around the home. They can visit your home to see if you need special adaptations, such as bath rails or a higher chair.

## Holidays and travel

Taking a holiday break is a big part of some people's lifestyle. But pick the right kind of holiday for your level of energy, mobility and general health. In general it is best to avoid travelling long distances. Seek advice from your haematologist or oncologist before you book a holiday. It is not advised that you fly or travel abroad after having high-dose chemotherapy for a stem cell transplant.

Make sure that you are well prepared before you go on holidays, so that you enjoy it fully. Take precautions also in case you become ill while away.

- Get a doctor's letter stating your diagnosis and any treatments you are receiving. A list of all your medications and a contact number for your doctor would be useful too.
- Discuss with your doctor if you need any vaccinations before travelling to your holiday destination.
- Bring enough medication for the entire holiday and extra ones such as painkillers, sickness or diarrhoea tablets, and antibiotics.
- Check with your doctor if you need medication to prevent blood clots in your legs on long-haul flights. He/she may advise you to wear special stockings too. On the airplane, get up and walk up and down the aisle, or do regular leg exercises while sitting.
- Make sure you have travel insurance. Some insurance companies now provide cover for myeloma patients. Contact the National Cancer Helpline 1800 200 700 for further details.

- For sun holidays, make sure you use good sunscreen (SPF 30), especially if you have received chemotherapy, radiotherapy or interferon. In the sun, cover up your skin with a wide-brimmed hat and loose cotton clothing.
- Avoid dehydration. Drink at least 3 litres of fluid every day. It is best to use bottled water when abroad and avoid ice cubes in drinks.

## Anxiety and depression

Because myeloma is a complex disease, your treatments may not be straightforward. If the myeloma is not responding to the drugs, changes to your treatment plan may have to be made often. If the myeloma relapses it may cause you further distress and anxiety. It is normal to be upset at any setbacks in your treatment. But make sure that you are comfortable with the treatment planned. If you continue to feel anxious or become depressed it is important to seek help early. See page 60 for more details on anxiety and depression.

If you have any worries or queries, contact the National Cancer Helpline 1800 200 700. They can talk in confidence about any of your concerns from diagnosis, treatment issues, travel insurance to counselling.

## What follow-up do I need?

Once your treatment is over your doctor will want you to have regular check-ups. This is called follow-up. It will involve taking regular X-rays, and blood and urine samples to check your levels of paraproteins. The follow-up is likely to continue for many years. Your doctor will let you know how often he needs to see you.

If you notice any new symptoms between check-ups or have any problems, let your doctor know as soon as possible.



## Research – what is a clinical trial?



Research into new ways of treating myeloma and reducing side-effects goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating myeloma. Many patients with myeloma take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.

### Phases of research

There are many stages or **phases** when research is done. If a drug or treatment looks as if it might be useful in treating myeloma, it is given to patients in research studies called **clinical trials**. These aim to find a safe dose, see what side-effects may occur and see which myelomas can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

### Taking part in clinical trials

Your doctor might ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about myeloma and new treatments. There is no need for worry as you will be carefully monitored during and after the study.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called **informed consent**. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of myeloma, your doctors may ask your permission to store some samples of your myeloma cells, blood or bone marrow.

If you would like more information, call the National Cancer Helpline 1800 200 700.

## Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them helpful and beneficial during their illness. The way cancer is treated often depends on the culture of the country you live in. In Ireland, cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies.

### Conventional therapies

Conventional therapies are treatments that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy and biological therapies. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

### Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing and promote a sense of well-being. Nowadays complementary therapies are often provided in hospitals, cancer treatment centres and support centres where they can be given safely.

## Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. Most doctors do not believe that such treatments can cure or control cancer. This is because they are not based on scientific evidence and it is hard to prove if they are generally effective or not.



### If you decide to have complementary or alternative treatments...



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, it is important to talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies. A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline 1800 200 700.

## Coping and emotions

### How can I cope with my feelings?

A diagnosis of myeloma can bring many emotions. There is no set time to have these emotions and you may experience some or very few of them.

#### Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation



Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet which discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

>>> Information can help you overcome your fears.

#### Feelings and emotions

You may find that you are afraid because you do not know enough about your illness. Most people find that information can help them overcome their fears. Do ask your doctors and nurses for as much information as you need – and keep asking them.

The disease itself and the effect of treatment on your life may make you feel low. Often this is because of the change to your usual routine, at the side-effects of treatment, or perhaps the risk of infertility. Other times, you may feel nothing or just numb.

It is important to know, however, that you are not alone. Many people who have had myeloma have experienced similar feelings and emotions. For some people, the hardest time is when treatment has finished and things are getting back to normal. The end to your hospital visits may make you feel alone and neglected. You may feel you need the most support at this time.

With myeloma one of the hardest things to face is that there is no cure. It will take time to adjust to this fact, but there are many people and ways to help you. Remember it is not a sign of failure if you feel unable to cope on your own or to ask for help. Once other people understand how you are feeling, they can give more support.

*Who Can Ever Understand? Talking About Your Cancer* is a useful booklet written for people with cancer. Call the National Cancer Helpline 1800 200 700 for a free copy.

### Spiritual support

When faced with a myeloma diagnosis and treatment, you may start thinking about the meaning and purpose of life. Your illness may affect your spiritual well-being. Indeed you may be afraid that you are going to die, even if your treatment is going well and your doctor or nurse has reassured you. Talking to a leader or a member of your religious faith can be helpful in this situation. Ask your nurse, a family member or a friend to arrange it. Some complementary medicines may also help you to focus on being positive and hopeful. Remember your emotional well-being is just as important as your physical health.

### Anxiety and depression

If you feel that your low moods are getting the better of you, talk about your feelings with someone close to you who is a good listener. Or you may find it helpful to discuss your feelings with a trained counsellor, a leader or a member of your religious faith or a medical social worker. Medical social workers can offer valuable support and practical advice to you and your family, both in hospital and at home.

Sometimes you may just be unable to cope. If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can be helpful.

These can lift your spirits and have few side-effects in the short term.

Also, deep emotional difficulties linked with myeloma are not always easy to talk about. Often they can be hard to share with loved ones. In this case, talking to a counsellor or psychotherapist who is not personally involved in your situation can be a great help. They can help to make sense of your thoughts, feelings and ideas. Call the National Cancer Helpline 1800 200 700 for more advice, or for a copy of the booklet *Understanding the Emotional Effects of Cancer*.



### Positive emotions

A myeloma experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and the healthcare team. With that can come a sense of gratitude too. The experience of myeloma can also bring personal growth and knowledge. It can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.



## How can my family and friends help?

Families and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give advice if needed. Some may gather up-to-date information on myeloma to know what you can expect and what you are going through. Others may prefer to help in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your friend or relative best.

### How can I help my family?

Looking after or supporting a family can be hard work even when you are well. Trying to juggle the roles of father, mother, daughter, son or breadwinner at the same time as coping with myeloma and its treatment may seem impossible. Be realistic about what you can manage and seek help before things become too much for you to cope with.

»»» Be realistic about what you can manage and seek help when you need it.

Depending on your situation, you may need to give up some or all of your responsibilities for a short period of time. That way you can concentrate on yourself and your recovery. You may have to give up your job until you feel better. As a parent, you may not be able to do all the things you usually do for your children. This does not mean that you have failed them in any way, but that you must plan your time and save your energy for the most important tasks. Do talk openly with your partner or family. They may be feeling the same way, but may wish not to upset you by bringing up awkward subjects.



## How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about.



You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with own your feelings too.

Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may not think you are doing much by just listening. In fact, it is one of the best ways to help.

### Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

*Lost for Words: How to Talk to Someone with Cancer* is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline 1800 200 700 for a free copy.



## How can I talk to my children?

A myeloma diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life going as much as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.

Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or grandchildren or that you're letting the children down. These are all natural feelings to have at this time.

## Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your myeloma diagnosis. If this is not possible, then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

## Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt, anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse

or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a free copy, call the National Cancer Helpline 1800 200 700.



## Tips & Hints – for carers

**Information:** Find out as much information as possible about myeloma, especially its symptoms, treatment and side-effects. Talk to the doctor, nurses, National Cancer Helpline, etc. Your relative or friend can give permission for your doctors to pass on information to you, as their carer. Get information too about financial supports, community services, etc.

**Emergencies:** Find out who to call if you are particularly worried or in an emergency.

**Physical care:** Being a carer involves helping your relative or friend with mobility, bathing and dressing, giving meals and medication. Ask the nurse for advice with any these tasks.

**Eating and drinking:** Gently encourage your friend or relative to eat but don't push them. Pre-prepare snacks for the times when they feel like eating.

**Help:** Take up all offers of help, especially with finances, cooking, housework, shopping. Don't get weighed down by all your friend or relative's needs. Expect ups and downs with treatment. There are many healthcare professionals to help you if you find it hard to cope. Also, find out about self-help groups, especially those for carers of people with myeloma.



**Caring for yourself:** Look after your own health. Take regular meals and exercise. See your doctor sooner rather than later if you have any health concerns. Make sure to talk to your doctor about any concerns you have about caring for your relative or friend.

**Time for yourself:** Share your worries with someone else. Stay in touch with your own friends and get out when you can, even if you don't feel like it. Make time for a break each day: a walk to the shops, a trip to the library or cinema, or an evening out with friends. Give yourself little treats at home: read a favourite magazine, sit down for a leisurely cup of tea or coffee, or have a relaxing soak in the bath.

## Support resources

### Who else can help?

There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Haematology liaison nurses
- Cancer nurse co-ordinators
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society helpline nurses



**Medical social worker:** The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and advice on benefits, entitlements and services available when you go home.

**Cancer nurse specialists:** Some of the major cancer treatment hospitals have haematology liaison nurses and/or cancer nurse co-ordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. These experts along with other members of your medical team work together to meet your needs.

**Psycho-oncology services:** In some larger hospitals there are special units that have psycho-oncology services. This means you can get psychological care and support from a team of experts if you need it. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together. This support can be given during your diagnosis, treatment and recovery.

**Community health services:** When you go home, there are many community health services available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far

from the hospital where you have been treated, your community welfare officer can also help with practical issues, such as transport costs, financial worries, etc. All these people in community health services can provide advice and support. More information on the services is available either from the social worker in the hospital before you go home or at your local health centre.

**Support groups:** Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. Visit the website [www.myeloma.ie](http://www.myeloma.ie) for information on myeloma support groups in Ireland. There are also a range of general support groups to help you and your family at time of diagnosis, throughout treatment and afterwards as well. A list of these groups is given at the back of this booklet. Cancer support centres are found in every county in Ireland and can offer a wide range of services. Some of these are listed at the back of this booklet.

**Irish Cancer Society:** The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have, at any stage of your illness. Call 1800 200 700 for information about any of the services outlined above or for support services in your area.

Remember that there are many people ready to help you.

## Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other groups. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances



At the end of this section there are also some useful telephone numbers and addresses for further help.

## Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

## Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the A&E unit first.

## Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

## GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical

appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible.

### Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependent children pay a limit of €100 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

### Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Quinn Healthcare, Hibernian AVIVA Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

If you have private insurance, you may not always be able to have your tests done as quickly as you would like. Your health insurer has to approve some tests in advance, e.g. MRI scan, PET scan. In some cases, it may take 24–48 hours to get approval from your health insurer.

### Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Appliances
- Travel to hospital



### Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social and Family Affairs, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

### Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with a disability who are aged between 16 and 66. For this allowance you must satisfy a means test, normally live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year. This means that you are unlikely to be able to work for at least 1 year due to your illness.

You are allowed a free travel companion pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

### Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions and you must normally live in Ireland. You are allowed a free travel pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 704 3314, Ext. 48728.

### **Carer's Allowance**

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, normally live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are allowed a free travel pass and a home benefits package – including an electricity or gas allowance, telephone allowance and free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social and Family Affairs. You cannot get this allowance if you are receiving another social welfare payment.

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211 or Dublin (01) 704 3000.

### **Carer's Benefit**

Under carer's leave legislation, you may be entitled to unpaid temporary leave from your employment. Or if you are employed but wish to care for a sick relative full time, you may qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, normally live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information

is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford.  
Tel: (043) 45211 / Dublin (01) 704 3000.

### **Appliances**

For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every 6 months.

### **Travel to hospital**

You can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

### **Further information**

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

### **For social welfare queries contact:**

Information Service	Tel: 1850 662 244
Dept of Social and Family Affairs	Leaflet line: 1890 202 325
Oisín House	Email: <a href="mailto:info@welfare.ie">info@welfare.ie</a>
212–213 Pearse Street	Website: <a href="http://www.welfare.ie">www.welfare.ie</a>
Dublin 2	

If you have queries about health and social services, contact the HSE office in your area. The Health Service Executive is based in four regions: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

**HSE infoline:** 1850 241 850; **Email:** [info@hse.ie](mailto:info@hse.ie); **Website:** [www.hse.ie](http://www.hse.ie).

**HSE East Coast Area**

[Co Wicklow, South East Dublin]  
Southern Cross House  
Southern Cross Business Park  
Boghall Road  
Bray  
Co Wicklow  
Tel: 01 2014 200

**HSE North Eastern Area**

[Counties Cavan, Monaghan, Louth and Meath]  
Head Office  
Navan Road  
Kells  
Co Meath  
Tel: 046 9280 500

**HSE Northern Area**

[North Dublin]  
Swords Business Campus  
Balheary Road  
Swords  
Co Dublin  
Tel: 01 8131 800

**HSE North Western Area**

[Counties Donegal, Sligo, Leitrim and West Cavan]  
Head Office  
Manorhamilton  
Co Leitrim  
Tel: 071 9820 400 / 1850 636 313

**HSE South Western Area**

[Co Kildare, West Wicklow, South Dublin]  
Oak House  
Millennium Park  
Naas  
Co Kildare  
Tel: 045 880 400

**HSE South Eastern Area**

[Counties Carlow, Kilkenny, Wexford, Waterford, South Tipperary]  
Head Office  
Lacken  
Dublin Road  
Kilkenny  
Tel: 056 7784 100

**HSE Midland Area**

[Counties Laois, Offaly, Longford, Westmeath]  
Head Office  
Arden Road  
Tullamore  
Co Offaly  
Tel: 057 9321 868

**HSE Southern Area**

[Counties Cork and Kerry]  
Head Office  
Wilton Road  
Cork  
Tel: 021 4545 011

**HSE Mid-Western Area**

[Counties Clare, Limerick, Tipperary North]  
Head Office  
31/33 Catherine Street  
Limerick  
Tel: 061 483 286

**HSE Western Area**

[Counties Galway, Mayo and Roscommon]  
Head Office  
Merlin Park Regional Hospital  
Galway  
Tel: 091 751 131

Information is also available from your local Citizens Advice Centre. A list of these centres is available from:

**Citizens Information Board** (formerly Comhairle)

7th Floor, Hume House, Ballsbridge, Dublin 4  
Tel: 01 605 9000  
Citizen Information Service: 1890 777 121  
Email: [information@ciboard.ie](mailto:information@ciboard.ie)  
Website: [www.citizensinformationboard.ie](http://www.citizensinformationboard.ie)

**If you have financial worries...**

A diagnosis of myeloma can also bring the added burden of financial worries. You may find that you have a lot more expenses as well as your normal outgoings, such as medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from myeloma if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses arising due to your illness. See page 78 for more details. You can also call the National Cancer Helpline 1800 200 700 for ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 1890 283 438. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. See page 79 for contact details.

## Irish Cancer Society services

The Irish Cancer Society funds a range of cancer support services that provide care and support for people with cancer at home and in hospital.

- Cancer Information Service (CIS)
- Breast Cancer Information Service
- Prostate Cancer Information Service
- Counselling
- Night nursing
- Haematology and oncology liaison nurses
- Homecare nurses
- Cancer support groups
- Cancer information booklets
- Financial aid



### Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services: the **National Cancer Helpline** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline 1800 200 700 operates Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie).
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- **Message Board** is a bulletin board on our website ([www.irishcancer.ie](http://www.irishcancer.ie)) that gives you the chance to post your comments.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

## Breast Cancer Information Service

The Breast Cancer Information Service (formerly ABC) provides breast cancer information and support. It also funds breast cancer research. Its services are free and confidential. They include a national helpline, publications, one-to-one support, breast awareness talks and advocacy. The Breast Cancer Information Service freefone helpline 1800 90 30 40 runs weekdays from 9am to 5pm.

## Prostate Cancer Information Service

The Prostate Cancer Information Service provides prostate cancer information and support. A Prostate Cancer Information Service freefone 1800 380 380 runs Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm. All queries or concerns about prostate cancer can be emailed to [prostate@irishcancer.ie](mailto:prostate@irishcancer.ie)

## Counselling

Coping with a diagnosis of cancer can be very stressful. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

## Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

## Haematology and oncology liaison nurses

The Irish Cancer Society funds haematology and oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. These nurses work as part of the hospital team in specialist cancer centres.

## Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse. The Irish Cancer Society contributes financially to this service.

## Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards.

## Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.



## Financial aid

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid. If you would like to request this kind of help, contact your oncology or medical social worker at the hospital where you have been treated. He/she should then fill in an application form and return it to the Irish Cancer Society. If there is no social worker, another health professional involved in your care may apply on your behalf.



If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.



## Useful organisations

### Irish Cancer Society

43/45 Northumberland Road  
Dublin 4  
Tel: 01 231 0500  
National Cancer Helpline: 1800 200 700  
Breast Cancer Information Service:  
1800 30 90 40  
Prostate Cancer Information Service:  
1800 380 380  
Email: [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

### Myeloma UK

Broughton House  
31 Dunedin Street  
Edinburgh  
EH7 4JG  
Tel: 0044 131 557 3332  
Fax: 0131 557 9785  
Email: [myelomauk@myeloma.org.uk](mailto:myelomauk@myeloma.org.uk)  
Website: [www.myeloma.org.uk](http://www.myeloma.org.uk)

### The Carer's Association

Prior's Orchard  
John's Quay  
Kilkenny  
Tel: 056 772 1424  
Freefone 1800 024 0724  
Email: [ceo@carersireland.com](mailto:ceo@carersireland.com)  
Website: [www.carersireland.com](http://www.carersireland.com)

### Citizens Information Board (formerly

Comhairle)  
7th Floor, Hume House  
Ballsbridge  
Dublin 4  
Citizen Information Service: 1890 777 121  
Tel: 01 605 9000  
Email: [information@ciboard.ie](mailto:information@ciboard.ie)  
Website: [www.citizensinformationboard.ie](http://www.citizensinformationboard.ie)

### Dept of Social and Family Affairs –

Information Service  
Oisín House  
212–213 Pearse Street  
Dublin 2

Tel: 1850 662 244  
Email: [info@welfare.ie](mailto:info@welfare.ie)  
Website: [www.welfare.ie](http://www.welfare.ie)

### HARI Unit (Human Assisted Reproduction

Ireland)  
Rotunda Hospital  
Parnell Square  
Dublin 1  
Tel: 01 807 2732  
Website: [www.rotunda.ie](http://www.rotunda.ie)

### Health Promotion HSE

Website: [www.healthpromotion.ie](http://www.healthpromotion.ie)

### Irish Patients Association

Unit 1, 21 Church Road  
Ballybrack  
Co Dublin  
Tel: 01 272 2552  
Out-of-hours emergency: 087 652 9448  
Email: [info@irishpatients.ie](mailto:info@irishpatients.ie)  
Website: [www.irishpatients.ie](http://www.irishpatients.ie)

### Money Advice and Budgeting Service (MABS)

Commercial House  
Westend Commercial Village  
Blanchardstown  
Dublin 15  
Tel: 8129350  
Freefone 1890 283 438  
Email: [ndl@mabs.ie](mailto:ndl@mabs.ie)  
Website: [www.mabs.ie](http://www.mabs.ie)

## Health insurers

### Hibernian AVIVA Health (formerly VIVAS Health)

One Park Place  
Hatch Street  
Dublin 2  
Tel: 1850 717 717  
Email: [info@hibernianavivahealth.ie](mailto:info@hibernianavivahealth.ie)  
Website: [www.hibernianavivahealth.ie](http://www.hibernianavivahealth.ie)

**Quinn Healthcare** (formerly BUPA)  
Mill Island  
Fermoy  
Co Cork  
Locall: 1890 700 890  
Fax: 025 42122  
Email: info@quinn-healthcare.com  
Website: www.quinn-healthcare.com

**Voluntary Health Insurance (VHI)**  
VHI House  
Lower Abbey Street  
Dublin 1  
Tel: 01 872 4499  
CallSave 1850 44 44 44  
Email: info@vhi.ie  
Website: www.vhi.ie

## National support groups

**Bowel Cancer Support Group**  
Irish Cancer Society  
43/45 Northumberland Road  
Dublin 4  
Freefone 1800 200 700  
Email: support@irishcancer.ie  
Website: www.cancer.ie

**CanTeen Ireland**  
Young Peoples' Cancer Support Group  
Carmichael Centre  
North Brunswick Street  
Dublin 7  
Tel: 01 872 2012  
Email: canteen@oceanfree.net  
Website: www.canteen.net

**Lymphoma Support Ireland**  
Irish Cancer Society  
43/45 Northumberland Road  
Dublin 4  
Freefone 1800 200 700  
Email: info@lymphoma.ie  
Website: www.lymphoma.ie

**Men Against Cancer (MAC)**  
c/o Irish Cancer Society  
43/45 Northumberland Road  
Dublin 4  
Freefone 1800 200 700  
Email: support@irishcancer.ie  
Website: www.cancer.ie

**Reach to Recovery**  
Irish Cancer Society  
43/45 Northumberland Road  
Dublin 4  
Freefone 1800 200 700  
Email: support@irishcancer.ie  
Website: www.cancer.ie

## Support groups & support centres

**My Myeloma**  
Website: www.myeloma.ie  
[An Irish support group set up by Brenda Drumm]

**ARC Cancer Support Centre**  
ARC House  
65 Eccles Street  
Dublin 7  
Tel: 01 830 7333  
Email: info@arccancersupport.ie  
Website: www.arccancersupport.ie

**Beacon Cancer Support Centre**  
Suite 15  
Beacon Court  
Sandyford  
Dublin 18  
Tel: 01 213 5654

**Bray Cancer Support & Information Centre**  
36B Main Street  
Bray  
Co Wicklow  
Tel: 286 6966  
Email: bcsc@iol.ie  
Website: www.braycancersupport.ie

**Cancer Information & Support Centre**  
Mid-Western Regional Hospital  
Dooradoyle  
Co Limerick  
Tel: 061 485163  
Website: www.midwesterncancercentre.ie

**CARE – South Tipperary Cancer Support Centre**  
14 Wellington Street  
Clonmel  
Co Tipperary  
Tel: 052 82667  
Email: caresupport@eircom.net  
Website: www.cancercare.ie

**Cork ARC Cancer Support House**  
Cliffdale  
5 O'Donovan Rossa Road  
Cork  
Tel: 021 427 6688  
Email: karen@corkcancersupport.ie  
Website: www.corkcancersupport.ie

**The Cuisle Centre**  
Cancer Support Group  
Block Road  
Portlaoise  
Co Laois  
Tel: 057 868 1492  
Email: cuislecentre@eircom.net

**Dóchas – Offaly Cancer Support**  
Teach Dóchas  
Offaly Street  
Tullamore  
Co Offaly  
Tel: 057 932 8268  
Email: dochasoffaly@hotmail.com  
Website: www.dochasoffaly.ie

**Dundalk Cancer Support Group**  
Community Office  
Dundalk Partnership Court  
Park Street  
Dundalk  
Co Louth  
Tel: 042 933 0288  
Website: www.dconroy@actioncancer.org

**Éist – Carlow Cancer Support Group**  
Tel: 087 767 3240 /  
086 316 3838 / 085 144 0510

**Éist – East Inishowen Cancer Support Group**  
Moville  
Co Donegal  
Tel: 074 938 2874

**The Gary Kelly Support Centre**  
Georges Street  
Drogheda  
Co Louth  
Tel: 041 980 5100  
Email: services@gkcancersupport.com  
Website: www.gkcancersupport.com

**Greystones Cancer Support**  
La Touche Place  
Greystones  
Co Wicklow  
Tel: 01 287 1601  
Email:  
greystonescancersupport@eircom.net

**HOPE**  
Enniscorthy Cancer Support &  
Information Centre  
22 Upper Weafer Street  
Enniscorthy  
Co Wexford  
Tel: 053 923 8555  
Email: mary@hopesupportcentre.ie

**Inis Aoibhinn – Cancer Care West**  
Costello Road  
University College Hospital Galway  
Tel: 091 545 000  
Email: info@cancercarewest.ie  
Website: www.cancercarewest.ie

**Kerry Cancer Support Group**  
Kerry-Lee  
Oakpark Road  
Tralee  
Co Kerry  
Tel: 087 230 8734  
Email: kerrycancersupport@live.ie

**LARCC Retreat Centre**

Ballinalack  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
Callsave 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

**Lios Aoibhinn Cancer Support Centre**

St Vincent's University Hospital  
Elm Park  
Donnybrook  
Dublin 4  
Tel: 01 221 4000  
Email: cancersupport@svuh.ie  
Website: www.stvincents.ie

**Listowel Cancer Support Group**

Bedford  
Listowel  
Co Kerry  
Tel: 068 21741 / 087 237 0766

**Little Way Cancer Support Centre**

4 Woods Way  
College Road  
Clane  
Co Kildare  
Tel: 045 902 996  
Email: littlewayclane@eircom.net  
Website: www.littlewaycancersupport.com

**Little Way Cancer Support Centre**

8 Stanhope Street  
Athy  
Co Kildare  
Tel: 059 863 3725

**Living Beyond Cancer**

c/o Oncology Department  
Letterkenny General Hospital  
Letterkenny  
Co Donegal  
Tel: 074 912 5888 (Bleep 674)

**Mayo Cancer Support Association**

Rock Rose House  
32 St Patrick's Avenue  
Castlebar  
Co Mayo  
Tel: 094 903 8407

**Roscommon Cancer Support Group**

Vita House Family Centre  
Abbey Street  
Roscommon  
Tel: 090 662 5898  
Email: vitahouse@eircom.net

**Sligo Cancer Support Centre**

2A Wine Street  
Sligo  
Tel: 071 9670 399  
Email: scsc@eircom.net  
Website: www.sligocancersupport.ie

**'Solás' – Donegal Cancer Support Centre**

St Joseph's Avenue  
Donegal Town  
Tel: 074 974 0837  
Email: solacedonegal@eircom.net

**South East Cancer Foundation**

7 Sealy Close  
Earlscourt  
Waterford  
Tel: 051 876 629  
Fax: 051 876 718  
Email: infosecf@eircom.net

**Suimhneas Cancer Support**

Pastoral Centre  
Church Road  
Nenagh  
Co Tipperary  
Tel: 067 37403

**Tallaght Cancer Support Group**

Tel: 087 217 6486

**The Tuam Cancer Care Centre**

30 Temple Jarlath Court  
High Street  
Tuam  
Co Galway  
Tel: 093 28522  
Email: tccg@eircom.net  
Website: www.tuamcancer.ie

**West Clare Cancer Support Group**

Tel: 086 357 9055

**Wicklow Cancer Support**

1 Mortons Lane  
Wicklow  
Tel: 087 691 4657 / 0404 32696

**Useful Irish websites****My Myeloma**

Website: www.MyMyeloma.ie  
This is an Irish website for people living with myeloma and for their family and friends. It has information on myeloma, details of dedicated myeloma support groups as well as a forum to discuss myeloma and related issues.

**Useful contacts outside Republic of Ireland****International Myeloma Foundation**

Website: <http://myeloma.org>

**Action Cancer**

Action Cancer House  
1 Marlborough Park  
Belfast BT9 6XS  
Tel: 028 9080 3344  
Fax: 028 9080 3356  
Email: info@actioncancer.org  
Website: www.actioncancer.org

**American Cancer Society**

1599 Clifton Road NE  
Atlanta, GA 30329-4251  
Website: www.cancer.org

**Cancerbackup/Macmillan Cancer Support (UK)**

89 Albert Embankment  
London SE1 7UQ  
Tel: 0044 207 840 7840  
Website: www.cancerbackup.org.uk

**Cancer Research UK**

Website: www.cancerhelp.org.uk

**Macmillan Support & Information Centre**

Belfast City Hospital Trust  
79–83 Lisburn Road  
Belfast BT9 7AB  
Tel: 028 9069 9202  
Fax: 028 9069 9203  
Email: cancer.info@bch.n-i.nhs.uk  
Website: www.actioncancer.org

**National Cancer Institute (US)**

Website: www.nci.nih.gov

**Royal Marsden Hospital Foundation NHS Trust**

Fulham Road  
London SW3 6JJ  
Tel: 0044 20 7808 2811  
Fax: 0044 20 7808 2336  
Website: www.royalmarsden.org

**The Ulster Cancer Foundation**

40/42 Eglantine Avenue  
Belfast 9BT9 6DX  
Tel: 048 906 63281  
Website: www.ulstercancer.co.uk

## Helpful books

Free booklets from the Irish Cancer Society:

- **Understanding Chemotherapy**
- **Understanding Radiotherapy**
- **Radiation Therapy: A Patient Pathway (DVD)**
- **Understanding Cancer and Complementary Therapies**
- **Coping with Fatigue**
- **Understanding the Emotional Effects of Cancer**
- **Lost for Words: How to Talk to Someone with Cancer**
- **Who Can Ever Understand? Taking About Your Cancer**
- **Talking to Children about Cancer: A Guide for Parents**



**Multiple Myeloma Patient Handbook**  
International Myeloma Foundation, 2008  
[Download from <http://myeloma.org>]

**Myeloma: Your Essential Guide**  
Myeloma UK, 2006  
[Download from [www.myeloma.org.uk](http://www.myeloma.org.uk)]

**Living with Myeloma: Your Essential Guide**  
Myeloma UK, 2007  
[Download from [www.myeloma.org.uk](http://www.myeloma.org.uk)]

**Chemotherapy and Myeloma**  
Myeloma UK, 2008  
[Download from [www.myeloma.org.uk](http://www.myeloma.org.uk)]

**The Chemotherapy and Radiation Therapy Survival Guide: Information, Suggestions, and Support to Help You Get through Treatment**  
Judith McKay, Nancee Hirano & Myles E Lampenfeld  
New Harbinger, 1998  
ISBN 1-57224-070-9

**The Key Model – A New Strategy for Cancer Recovery**  
Dr Sean Collins & Rhoda Draper  
Ardagh Clinic, 2004  
ISBN 0-95214-445-X

**The Secret C: Straight Talking About Cancer**  
[Explaining cancer to children]  
Julie A Stokes  
Winston's Wish, 2000  
ISBN 0-95391-230-2

**Why Mum? A Small Child with a Big Problem**  
Catherine Thornton  
Veritas, 2005  
ISBN 1-85390-891-6

## Helpful DVD

**Understanding Radiation Therapy: A Patient Pathway**  
Call 1800 200 800 for a copy.  
Website: [www.cancer.ie](http://www.cancer.ie)

## Questions to ask your doctor

Here is a list of questions that you may want to ask. There is also some space for you to write down your own questions if you would like. Never be shy about asking questions. It is always better to ask than to worry.

- What tests do I need to diagnose myeloma?
- What else might be causing the symptoms I have?
- What are the different types of myeloma?
- What type of myeloma do I have?
- What are my treatment options?
- What is the aim of my treatment?
- How is the treatment given and how long will it take?
- Do I have to stay in hospital for treatment?
- Do I need other types of treatment?
- What are my chances of the myeloma going into remission?
- What side-effects can I expect? Will they last long?
- Do I need to use contraception during my treatment?
- Will treatment affect my chances of having children?
- How often do I need check-ups and blood tests after treatment?
- How will I know if the myeloma has come back?

## Your own questions

1 \_\_\_\_\_

Answer \_\_\_\_\_

2 \_\_\_\_\_

Answer \_\_\_\_\_

3 \_\_\_\_\_

Answer \_\_\_\_\_

4 \_\_\_\_\_

Answer \_\_\_\_\_

5 \_\_\_\_\_

Answer \_\_\_\_\_



## Notes



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We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

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Kathleen Betson, Haematology Liaison Nurse

## Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please phone our National Cancer Helpline 1800 200 700.

## Would you like to be a patient reviewer?

If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If you wish to email your comments, have an idea for a new booklet or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**. If you would prefer to phone or write to us, see contact details below.

## Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us.

**Irish Cancer Society, 43/45 Northumberland Road, Dublin 4**

**Tel:** 01 231 0500 **Email:** [info@irishcancer.ie](mailto:info@irishcancer.ie) **Website:** [www.cancer.ie](http://www.cancer.ie)

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life with three programme areas to achieve them: advocacy, cancer services and research.

