

Understanding

Multiple Myeloma

Caring for people with cancer



Understanding

Multiple myeloma

This booklet has been written to help you understand more about multiple myeloma. It has been prepared and checked by haematologists, specialist nurses and patients. The information is an agreed view on multiple myeloma, 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 any contact names and information you may need.



Specialist nurse

Tel:

Family doctor (GP)

Tel:

Haematologist

Tel:

Medical social worker

Tel:

Emergency number

Tel:

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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- Multiple myeloma: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. ESMO Guidelines Working Group. *Annals of Oncology* 24 (Suppl 6): vi133-vi137, 2013.
- Myeloma: making sense of a complex blood cancer. MB Kelly, T Meenaghan, M Dowling. *British Journal of Nursing* 19(22): 1415-1421, 2010.
- Guidelines on the diagnosis and management of multiple myeloma 2011. Haematology Task Force of the British Committee for Standards in Haematology (BCSH) and UK Myeloma Forum. *British Journal of Haematology* 15: 32-75, 2011.
- *NCCN Clinical Practice Guidelines in Oncology: Multiple Myeloma*. National Comprehensive Cancer Network, 2014.
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. R Govindan (ed), 9th edn. Lippincott Williams and Wilkins, 2011.
- *Cancer Nursing: Principles and Practice*. CH Yarbrow, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.
- *The Chemotherapy Source Book*. M Perry. Lippincott Williams and Wilkins, 1997.

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Introduction

This booklet has been written to help you understand more about multiple myeloma. It describes what it is and how it is diagnosed and treated. The booklet is divided into four parts.

- **About multiple myeloma** gives an introduction to multiple myeloma, including symptoms and diagnosis.
- **Treatment and side-effects** discusses the different treatments used for multiple myeloma and possible side-effects. The treatment for multiple 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.
- **Coping and emotions** discusses how you can cope with your feelings and the emotional effects of having multiple myeloma.
- **Support resources** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care, as the best choice for you will depend on your particular cancer and your individual circumstances.

>>> Reading this booklet

Remember you do not need to know everything about multiple myeloma straight away. First read a section about a particular item as it happens to you. Then when you feel ready to know more, read another section.

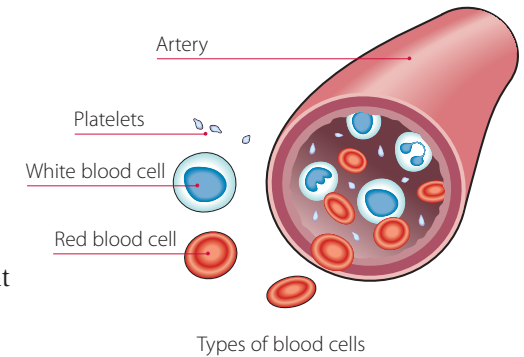


If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline on Freephone 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. Or you can visit a Daffodil Centre. See page 72 for more about Daffodil Centres.

About multiple myeloma

What is multiple myeloma?

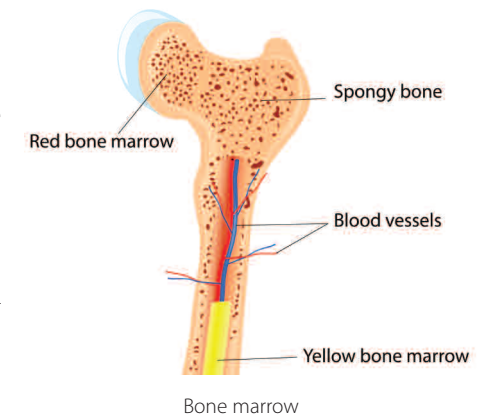
Multiple myeloma is a cancer of the plasma cells in bone marrow. Bone marrow is the soft spongy material found in large bones that makes three types of blood cells: red blood cells, white blood cells and platelets. The red blood cells carry oxygen to all the cells in your body, white cells fight infection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



>>> Multiple myeloma is a cancer of the plasma cells in bone marrow.

Plasma cells

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



These abnormal 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 cannot fight

infection properly and can reduce the amount of normal antibodies being made. In the bone marrow the myeloma cells also leave less room 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.

Which bones are affected?

Multiple 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, 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.

How common is multiple myeloma?

Multiple myeloma is the second most common cancer of the blood. Even so, it is a rare condition. In Ireland, about 240 people are diagnosed with multiple myeloma each year. 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 under 60 have been diagnosed. Multiple myeloma is very rare in those under 40. Children do not develop multiple myeloma.

Complex disease

Multiple myeloma is a complex disease because many functions in your 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 your bloodstream, it can cause kidney damage.

Multiple myeloma is currently known as a chronic disease. Today with newer drugs patients are living far longer and leading fuller lives. Current treatments can bring about a complete remission in some patients. This means that the symptoms of multiple myeloma disappear and the bone marrow recovers, but it is not a cure of the disease.

Multiple myeloma is a highly individual disease. Very often it is slow moving but sometimes it is quicker. Because there is no standard treatment of multiple myeloma your treatment will be individual too. Both you and your doctor will decide what is the best way to treat your multiple myeloma. It is important that you and your family are well informed, ask questions and consider other treatment options too.



To sum up

- Multiple myeloma is a cancer of the plasma cells in bone marrow.
- In multiple myeloma, the abnormal plasma cells make an abnormal protein called paraprotein or M protein.
- Multiple myeloma can affect the bones of your spine, skull, pelvis, ribcage, shoulders and hips.

What causes multiple myeloma?

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

- **Age:** Multiple myeloma is more common in older adults, usually over 60. Most patients are diagnosed when over 70.
- **Gender:** It is more common in men than in women.
- **Race:** It is more common in black people than white or Asian people.
- **Exposure to chemicals:** Lifelong exposure to chemicals or toxic substances can affect your immune system and increase your risk of multiple myeloma. These chemicals include petrol, oil, benzene, pesticides, dioxins, paints, rubber, and hair dyes.
- **Plasma cell conditions:** If you have monoclonal gammopathy of uncertain significance (MGUS) or smouldering myeloma or amyloidosis, your risk is much higher. See page 16 for more information on these conditions.

- **Other medical conditions:** Having illnesses that affect your immune system can also increase your risk of multiple myeloma. They include autoimmune illnesses, pernicious anaemia, and ankylosing spondylitis.
- **Exposure to viruses:** These viruses include HIV, hepatitis, herpes virus 8, and simian virus 40.
- **Exposure to radiation:** This includes atomic radiation and radiotherapy.
- **Family history:** If your parent, brother or sister is diagnosed with multiple myeloma, you are more likely to develop it. However, your risk remains low. It is also not known if this is due to genetic or environmental factors or both.

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

What are the symptoms of multiple myeloma?

The symptoms of multiple myeloma may be vague at first. But as the condition develops it can affect your bones, blood and kidneys. The amount of symptoms can often vary between patients. The letters CRAB are used when describing the effects of multiple myeloma: calcium (C), renal, meaning kidneys (R), anaemia (A), and bone disease (B).

>>> Multiple myeloma can affect your bones, blood and kidneys.

Bone effects

The most common symptoms of bone disease include:

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

Multiple myeloma cells can often destroy bone tissue. In most cases of multiple myeloma, 'soft spots' or 'holes' develop where the bone structure has been damaged. These are known as lytic lesions. They 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 multiple 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. It is very important to report these symptoms to your doctor or nurse straight away.

Blood effects

The most common symptoms of blood problems include:

- Fatigue
- Infections
- Anaemia
- Bruising and bleeding

The making of red blood cells, white blood cells and platelets in your 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 your 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 control the amount of calcium in your body and keep it at a safe level. When bone tissue is destroyed, it causes the level of calcium to rise in your bloodstream. This is called hypercalcaemia. Your kidneys can get overworked by trying to get rid of this excess calcium. You may find that you pass urine often 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 multiple myeloma cells can make your 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 if you have not yet been diagnosed. Otherwise contact your haematologist or nurse specialist. Many of these symptoms are common to other less serious illnesses too. It may not mean that you have multiple 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 multiple myeloma is unknown. It is a rare cancer and the second most common cancer of the blood.
- Some risk factors that increase your chances of getting multiple myeloma are being aged over 60, male, black, exposure to toxic chemicals, exposure to viruses and radiation, and a weak immune system.
- Multiple myeloma can affect your bones, 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 multiple myeloma diagnosed?

In the early stages of multiple myeloma there are usually no symptoms. Sometimes a routine blood test can point to the need for further blood tests. These can take some time and eventually reveal multiple myeloma. In some cases, you may have symptoms that are quite 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 multiple 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.

Physical exam: First, a full physical exam will be done to check your general state of health. Your full medical history will also be taken.

Medical tests: Then a number of lab tests and other medical tests are done to confirm a diagnosis of multiple myeloma. The tests can also show how far the multiple 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)
- Erythrocyte sedimentation rate (ESR)
- Kidney function tests
- Calcium levels
- Blood and urine levels of normal proteins, for example, albumin
- Immunoglobulins
- Paraproteins in blood and urine
- Protein electrophoresis of blood and urine
- Special blood tests for levels of beta-2 microglobulin
- 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.

Erythrocyte sedimentation rate (ESR): This test can show if your red blood cells (erythrocytes) are sticking together or not. It is done over a one-hour period and the cells form clumps if you have multiple myeloma. It can be raised in multiple myeloma as well as in other illnesses like inflammation, infection and arthritis.

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, in your blood and urine are also checked. This is because there is less albumin in your blood when multiple myeloma occurs. This test will be done regularly during treatment.

Immunoglobulins: This test measures the amounts of the antibodies or immunoglobulins found in your blood. These are called IgA, IgD, IgE, IgG and IgM.

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

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

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

Serum free light chain (SFLC) test: Sometimes the regular tests cannot measure the paraprotein levels. About 1 in 5 multiple myeloma patients do not make full immunoglobulins. They only have part of the immunoglobulin called the light chain. The serum free light chain test can measure tiny amounts of the light chains floating in your blood.

Once in your urine, the light chain is called Bence Jones protein. See page 17 for more about immunoglobulins.

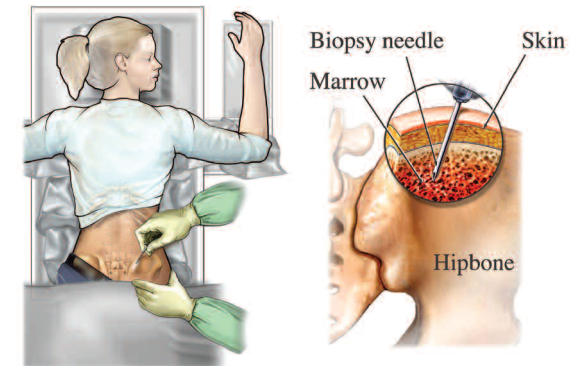
Bone tests

Because multiple 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
- Bone marrow aspirate/biopsy
- Cytogenetics

X-rays of bones: This test is also called a skeletal survey and checks for bone disease caused by myeloma cells, such as lytic lesions. 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 year or more often to check the progress of your illness.

Bone marrow aspirate or biopsy: This is a test where a tiny sample of your bone and bone marrow, which contains plasma cells, is examined under a microscope. Aspirate refers to the sample of bone marrow cells, while biopsy refers to a solid bone sample.



Bone marrow aspiration

Your doctor and nurse will let you know what you can expect to happen. Usually the sample is taken from your hip bone or sometimes your 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 and the samples taken. This only takes a few minutes and you may feel a little discomfort for a short while. But you will be given advice about suitable painkillers to take, if you need them.

In the laboratory, your haematologist will look to see if the number of plasma cells has increased. Normal bone marrow has less than 5 in 100, while multiple myeloma has far more plasma cells: between 10 and 90 in every 100 cells. Multiple myeloma is diagnosed when the plasma cells are greater than 10 in 100.

Cytogenetics: 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. Chromosomes 13 and 17 in particular can be abnormal. The test is used to make a more accurate prognosis of your condition. It can take a few weeks to get the results, but it will not affect your immediate treatment.

Other bone tests

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

- CT scan
- Ultrasound scan
- MRI scan

CT scan: This test may be done for a small number of patients. Your doctor might want you to have a CT because it is better at showing up bone damage than a plain X-ray. 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.



CT scan

The computer can make 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. Caution is needed with the dye as it might cause kidney problems. It is important to tell the staff doing the CT scan that you have multiple myeloma. Before you have the scan, you will need to have a blood test to check your kidneys. 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 multiple myeloma.

MRI scan: This scan is not routinely done if you have multiple myeloma. It can give your doctor more information about the extent of multiple myeloma if you have bad back pain or compression. The scan uses radio waves and a magnetic field 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 that 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. Caution is needed with the dye as it might cause kidney problems. It is important to tell the staff doing the MRI scan that you have multiple myeloma. Before you have the scan, you will need to have a blood test to check your kidneys.

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 on 1800 200 700 or visit a Daffodil Centre and speak to one of our specially trained nurses.



To sum up

The following tests are used to diagnose multiple myeloma:

- Blood and urine tests such as full blood count, ESR, kidney function tests, calcium levels, normal proteins, immunoglobulins, paraprotein levels, electrophoresis, beta-2 microglobulin, and serum free light chain test.
- Bone tests such as X-rays of body, bone marrow biopsy and aspirate, and cytogenetics.
- Scans such as CT, ultrasound and MRI.

Conditions related to multiple myeloma

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

- Monoclonal gammopathy of uncertain significance (MGUS)
- Smouldering myeloma

Monoclonal gammopathy of uncertain significance (MGUS): In this condition, there are raised levels of abnormal proteins (monoclonal protein, or M protein) in your bloodstream but no other signs of multiple myeloma.

Smouldering myeloma: This condition is a very slow growing form of myeloma. Paraproteins are found in your blood but usually there are no symptoms and no treatment is needed. It is also called indolent myeloma.

If you are diagnosed with any of these conditions, you will be closely monitored with blood tests for a number of years. You will only be treated if the condition develops into multiple myeloma.

Amyloidosis

During the course of their disease, some multiple myeloma patients may develop amyloidosis. This is a condition related to multiple myeloma. Here large amounts of an abnormal protein called amyloid are found in your body. This happens when plasma cells in your bone marrow make antibodies that cannot be broken down. Parts of these abnormal antibodies called light chains stick to one another and collect in body organs such as your kidney or heart. About 10 to 15 in every 100 people with multiple myeloma either have, or develop, amyloidosis. But it is rare for people with amyloidosis to develop multiple myeloma. Symptoms include a swollen tongue, loss of appetite, diarrhoea and chronic nausea. A SAP scan of your body is one test that diagnoses amyloidosis. The treatment is very like the treatment of multiple myeloma, in particular using chemotherapy.

Types of myeloma

- **Multiple myeloma:** In most cases the type of myeloma that patients develop is multiple myeloma where several bones are affected.
- **Plasmacytoma:** 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 and you will be monitored with blood tests in case you go on to develop multiple myeloma.
- **Non-secretory myeloma:** A rare type of myeloma is non-secretory myeloma. In this case, no paraproteins occur in the blood or urine.

Subtypes of multiple myeloma

There are different subtypes of multiple 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.
- They each 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 kappa (K) or lambda (L).
- You will only develop one abnormal immunoglobulin.
- The most common one in myeloma is IgG.
- The next most common one is IgA.
- IgE, IgG and IgM are all quite rare.

For more information about your subtype, talk to your doctor or nurse.



National Cancer Helpline Freefone 1800 200 700

How is multiple myeloma staged?

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

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

There are different systems used to stage multiple myeloma. The International Staging System is the system widely used today.

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	The levels of beta-2 microglobulin and albumin fall between those in stages 1 and 3.
Stage 3	The beta-2 microglobulin level is greater than or equal to 5.5 mg/l.

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

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 smouldering 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

- You may develop multiple myeloma if you have monoclonal gammopathy of uncertain significance (MGUS) or smouldering myeloma.
- Amyloidosis is a condition related to multiple myeloma.
- Staging means finding out the extent of the disease.
- Multiple myeloma is usually staged using the International Staging System.
- You 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 multiple myeloma treated?

There are several treatments that can slow down and control multiple 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 well managed. Research into finding a cure for multiple myeloma continues as does finding new or better treatments. It is possible for you to live with this disease for some years.

Planning: Multiple 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 multiple 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.

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

Remission: In general the aim of treatment is to slow down and control the multiple 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 multiple myeloma is said to be in remission. If multiple 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 multiple myeloma:

- Active monitoring
- Combination therapy
- Biological therapies
- Chemotherapy
- High-dose therapy and stem cell transplant
- Maintenance therapy
- Treatment of symptoms
- Treatment of relapsed or resistant myeloma

Active monitoring: If you show little or no signs of active myeloma, your doctor may decide to watch your condition closely and not treat you at this time. 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. See page 24 for more details.

Combination therapy: A combination of drugs is usually given to treat multiple myeloma. These drugs include biological therapies, and possibly chemotherapy and steroids.

Biological therapies: These therapies use your body's immune system to fight cancer. Drugs like thalidomide, lenalidomide or bortezomib may be given on their own to control the multiple myeloma cells or in combination with other drugs. See page 25 for more details.

Chemotherapy: Chemotherapy kills the multiple myeloma cells with drugs that are toxic to the cells. These days, it is used less often. It might be given with biological therapies or steroids. See page 32 for more about chemotherapy.

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. See page 37 for more about details.

Maintenance therapy: After biological therapy, chemotherapy or a transplant, you may need to take other drugs for a number of months. These can include thalidomide, lenalidomide or steroids. This is called maintenance therapy. See page 40 for more details.

Treating symptoms: Symptoms like bone disease, anaemia and kidney problems can be treated. This is also known as supportive therapy. The treatments can vary from person to person. Drugs known as bisphosphonates are often used to reduce bone damage caused by multiple myeloma. They help to heal bones and reduce raised calcium levels in your blood. Treatments like radiotherapy and surgery can be given 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 40 for more about treating symptoms.

Relapsed or resistant multiple myeloma: Even after a successful course of treatment, multiple myeloma often returns. This is called relapsed multiple myeloma. You can still be treated again with drugs like lenalidomide, thalidomide and bortezomib. If your multiple myeloma does not respond to drug treatment (resistant), other options will be explored. See page 46 for more details.

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

Deciding on treatment

Giving consent: Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- The type and amount of treatment you will have
- The benefits and risks 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 multiple 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.

Second opinion: It is important that you agree with your doctors' decision on what is the best treatment plan for you. 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.



To sum up

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

Active monitoring

You may be diagnosed with multiple myeloma but show few signs of active disease. In this case, your doctor may decide not to treat you but to watch (monitor) your condition closely instead. This is known as watchful waiting or active monitoring. There is no evidence that treating a person earlier improves overall survival. Also, in early multiple myeloma the side-effects of treatment can often outweigh the benefits.

With active monitoring, you visit your doctor and have blood and urine tests every few months. You watch and wait to see if the multiple myeloma develops further. Usually the outpatient visits are every 1-3 months. This can continue for a number of years. For more information talk to your doctor or nurse. You can also contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

National Cancer Helpline Freephone 1800 200 700

Combination therapy

A combination of drugs is usually given to treat multiple myeloma. This is the main treatment for multiple myeloma. These drugs include biological therapies and possibly chemotherapy and steroids.

- **Biological therapy drugs:** thalidomide, lenalidomide and possibly bortezomib
- **Chemotherapy drugs:** melphalan or cyclophosphamide
- **Steroids:** prednisolone or dexamethasone

The choice of drugs used when first diagnosed, or if you have relapsed, will be decided by your doctor.

Before treatment, your doctor and nurse will explain any possible side-effects of the drugs to be given. Each drug may have quite different side-effects. Some of these side-effects may be short term or long term. Do report any symptoms or problems to your nurse early. All of the above types of treatment are discussed on the following pages: biological therapies on page 25, chemotherapy on page 32 and steroids on page 36.

Once you have finished your first treatment, your doctor may decide to give you a low dose form of treatment for a longer period of time. This is called maintenance therapy. See page 40 for more details.

Biological therapies

Biological therapies use your body's immune system to control or destroy cancer cells. They are not considered chemotherapy drugs because they do not kill cancer cells directly and normal cells are usually not affected. They work in other ways to cause the multiple myeloma cells to die. Biological therapies can be used with steroids and/or chemotherapy.

Bortezomib (Velcade®)

Bortezomib can be used to treat newly diagnosed patients. It 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 multiple myeloma cell to die. Your normal cells are less affected by this drug, so side-effects are less severe than with chemotherapy. It can be given by injection into a vein or just under your skin. By injecting it under your skin, the side-effects are even less again.

Lenalidomide (Revlimid®)

Lenalidomide can be given at any stage of your multiple myeloma. It can also be given in combination with other drugs. It is taken orally once a day for 21 days with a 7-day rest period. The cycle is then repeated. It can be given with the steroid dexamethasone and the dose varied. 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. Your doctor will also prescribe aspirin to prevent any blood clots developing.

Lenalidomide is very like thalidomide (see below), 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. See page 48 for more details.

Thalidomide

In recent years the drug thalidomide has been used to control multiple myeloma. Thalidomide works by blocking the blood supply to the multiple myeloma cells and boosts your 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 the steroid dexamethasone or other chemotherapy drugs. Your response to the treatment will be checked every month and is very individual. 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. Today there are very strict guidelines for using it. Contraceptive precautions for both men and women are essential and regular pregnancy testing will take place for women of childbearing age.

You will be registered on a special pregnancy prevention programme and your doctor will explain the details fully to you. 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 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 48.

Blood clots: There is also a risk of developing blood clots in your legs or lung, when taking thalidomide. Your nurse will advise you on any precautions to take.

How does my doctor measure the response to treatment?

Your doctor 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
- Bone marrow biopsy
- Paraprotein in blood and urine
- Blood proteins levels, such as albumin
- Blood calcium levels
- Kidney function tests
- Skeletal survey

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 multiple 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.
Relapse	This means the multiple myeloma has returned after treatment.
Refractory myeloma	This means the multiple myeloma is resistant to the treatment.

National Cancer Helpline Freephone 1800 200 700

What side-effects can I expect?

Bortezomib, lenalidomide and thalidomide have many similar side-effects that are listed below. 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 48 for more details on fertility and 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.

Bortezomib: This drug is given as an injection just under your skin and causes less damage to your nerve endings. The dose can be adjusted from twice weekly to weekly. The most common side-effects are:

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

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 your legs or lungs

Thalidomide: The following have been known to occur when taking thalidomide:

- Tingling or numbness in arms, hands, legs, feet (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 your legs or lungs

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 have vomiting or diarrhoea for longer than 12 hours or you are unable to drink fluids, it is important to tell your nurse or doctor. If you feel sleepy or drowsy, do not drive or operate machinery.

When taking thalidomide or lenalidomide, your doctor 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. Your doctor will also discuss with you any vaccinations that you may need. See page 45 for more information.

Peripheral neuropathy

Here the nerves in your feet and hands are affected, causing tingling, numbness or a burning pain. Coping with peripheral neuropathy can sometimes be quite hard. 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 the physiotherapist.



Tips & Hints – peripheral neuropathy



- Keep your 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 the dietitian on how to lose weight if you are overweight. This can reduce pressure on your nerves endings.
- Quit smoking, as cigarette smoke narrows the blood vessels to your 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.
- Test your bath water to make sure it is not too hot.
- Avoid exposure to toxins like pesticides, heavy metals, etc.
- Acupuncture may help, so ask your doctor for advice.

Do tell your nurse if you have any of these symptoms, as the drug dose might need to be reduced. For a factsheet on peripheral neuropathy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie



To sum up

- Biological therapies use the body's immune system to fight cancer.
- They are not considered chemotherapy drugs because they do not kill cancer cells directly and normal cells are usually not affected.
- Biological therapies include lenalidomide, thalidomide and bortezomib.
- Lenalidomide and thalidomide are taken orally, while bortezomib can be injected under your skin or into a vein.
- You must take strict contraceptive precautions with lenalidomide and thalidomide as they can cause birth defects.
- Some side-effects include peripheral neuropathy, fatigue, infections, and blood clots.

Chemotherapy

Chemotherapy is a treatment using drugs to control the myeloma cells in your bone marrow. It is not a cure for multiple myeloma but aims to bring about a remission. This is when the symptoms of multiple myeloma disappear and your bone marrow recovers. The most commonly used drugs are melphalan or cyclophosphamide, which are taken by mouth. The drugs are usually combined with steroids or biological therapies. For example, dexamethasone, bortezomib and lenalidomide.

Usually you receive the drugs for 4–5 days every 3–4 weeks. This is called a cycle. You will receive a number of cycles of treatment. The number will vary, depending on your response to the drug and any side-effects you experience. 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 or not responding to the drugs, the drug or dosage may be changed.

What side-effects can I expect?

The side-effects of chemotherapy vary from person to person and depend on the drugs used. These unwanted side-effects happen because chemotherapy can affect both cancer cells and normal cells. The side-effects can be short term or long term. In most cases the side-effects go away once the treatment ends or soon after. Your doctor or nurse can give you medication and advice to stop most side-effects or make them easier to cope with.

Some of the side-effects include:

- Blood count problems
- Fatigue
- Changes in kidney function
- Nausea and vomiting
- Loss of appetite
- Mouth problems
- Constipation and diarrhoea
- Hair loss

Blood count problems: Chemotherapy can affect your bone marrow and reduce the numbers of blood cells. Fewer white blood cells mean that you are more prone to infection. As a result, you may need to

take antibiotics often, including antibiotics to prevent infection. You may also need a drug called G-CSF (granulocyte-colony stimulating factor) to help your bone marrow make white blood cells. 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.

Feeling tired (fatigue): During chemotherapy and for some time afterwards, you may feel very tired. A feeling of overwhelming tiredness not relieved by rest is known as fatigue. You might feel weak or find it hard to concentrate or make decisions. Do allow yourself plenty of time to rest. In general, the tiredness will ease off gradually once the chemotherapy has ended. See page 49 for more about fatigue.

Changes in kidney function: The 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 and the dose may be changed if needed. Do drink as much fluid as you can – about 3 litres per day. If you find it difficult to drink this amount of fluid, ask your doctor or nurse for advice.

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. If you do experience nausea and vomiting, 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. 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 can help to get advice from a dietitian if this occurs. Have a small meal a few hours before treatment, but don't eat just before treatment. A booklet called *Diet and Cancer* is available from the Irish Cancer Society and has helpful tips on boosting appetite. For a copy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie

Diarrhoea and constipation: Some chemotherapy drugs can affect the lining of your gut and may cause diarrhoea for a few days. Passing watery bowel motions more than three times a day is known as diarrhoea. If this happens, drink lots of clear fluids to replace the fluid you are losing. Medication can stop this side-effect of treatment. Again, it might be useful to talk to a dietitian who can offer advice at this time. Chemotherapy might also slow down the movement of your bowels. As a result, your regular bowel habit may change and you may have difficulty passing a bowel motion. This is known as constipation. You may need to drink more clear fluids and/or take a laxative. If you have diarrhoea or constipation, let your doctor or nurse know as soon as possible. In some cases, your doctor may have to adjust your treatment.

Mouth problems: Chemotherapy can cause the lining of the mouth to become very sore and you may get small ulcers. This is caused mucositis. It usually clears up within 3 to 4 weeks. There are many kinds of gels, creams or pastes available to ease the soreness.

Keeping your teeth, gums and mouth very clean will reduce the risk of getting a mouth infection. Mouthwashes can help, in particular ones containing salt (saline). But do avoid alcohol mouthwashes as they can irritate your mouth even more. If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible. Your doctor will prescribe painkillers or other medication to treat the infection if needed. After a while, your sense of taste might be affected by the drugs, where food tastes more salty, metallic or bitter. This will gradually fade. The booklet *Diet and Cancer* has some helpful advice on how to manage mouth problems and taste changes. For a copy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie

Hair loss: The amount of hair loss depends on the drugs you are given and your reaction to them. It can vary from person to person. You may notice that your hair just thins out a little bit or gets brittle. If you do lose your hair, it will happen quite quickly. Your hair will grow again when treatment stops. You can get a wig or hairpiece when this happens or you may prefer to wear a hat, turban or scarf. For more advice or a copy of the factsheet *Hair Loss and Cancer Treatment*, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie

More information

Do let your doctor and nurse know if you are having any side-effects. A free booklet called *Understanding Chemotherapy* is also available. Contact the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie

Steroids

Steroids are an important part of your multiple myeloma treatment. They are hormones naturally made in your body and can help the other drugs work better. There are many types of steroids but in general dexamethasone and prednisolone are used in multiple 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 will prescribe an antacid to prevent any stomach upsets.



To sum up

- Chemotherapy is a treatment using drugs to control myeloma and bring about a remission.
- These drugs are usually given in tablet form.
- The side-effects vary from person to person and depend on the drugs used.
- Most side-effects are well controlled with medication.
- Steroids are often given with chemotherapy or biological therapies.

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 multiple myeloma. That said, your multiple myeloma is still likely to recur at some point.

Because it is an intensive treatment it is not suitable for everyone. Depending on your age, general health and response to treatment, you may benefit from this treatment. Your doctor will do some tests on your kidneys, heart and lungs first 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. Allogeneic transplants are those where you receive stem cells from a donor. This type is rarely used for multiple myeloma. If you do not go into remission after a transplant, it may be possible to have a second transplant or continue with maintenance therapy.

>>> 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 doctor until you go home after the transplant. 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 followed by daily injections of G-CSF to move the stem cells into your bloodstream.
- 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 will be cared for in isolation until your stem cells grow and the number of your white cells is nearly normal.

The first two steps are usually done as an outpatient.

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 there. This growth factor is called G-CSF (granulocyte-colony stimulating factor). It is given 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. You may be trained to give this injection yourself or you may be referred to your public health nurse.

Often a cycle of chemotherapy is given directly before the growth factor injections. The 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 should 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. More information on chemotherapy is available in the booklet, *Understanding Chemotherapy*. For a copy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie

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 central line, PICC or portacath. 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 your bloodstream the stem cells go directly to your 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 multiple myeloma has relapsed.

Two useful booklets called *Understanding Stem Cell Collection* and *Understanding Autologous Stem Cell Transplants* are available. For copies and more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download them from www.cancer.ie

Maintenance therapy

After your first treatment, you may be given a low dose form of treatment for a longer period of time. The goal is to prevent the disease progressing for as long as possible, so that you have a good quality of life. These drugs can prevent or delay the multiple myeloma from returning. But remember that not everyone will benefit from maintenance therapy. The benefits will have to be balanced against any side-effects that may occur.

Nowadays lenalidomide, thalidomide and bortezomib might be used as maintenance therapy. They can also be given a few months after a transplant and for as long as they are tolerated. See pages 26 and 29 for more details on these drugs. Other drugs used as maintenance therapy include pomalidomide and bendamustine.

How are my symptoms treated?

The treatment of multiple myeloma symptoms is also known as supportive therapy. A lot of symptoms are discussed here but most people will only experience some of these. The letters CRAB are used when describing the effects of myeloma: calcium (C), renal, meaning kidneys (R), anaemia (A), and bone disease (B). Serious complications like infections, anaemia, bleeding, fractures and spinal cord compression need to be treated straight away.

Kidney disease

Fluids: With kidney disease, you will be advised to drink plenty of fluids. You should drink at least **3 litres or 5 pints** of fluids every day. Do avoid drugs that can affect your kidneys too. Also, talk to your GP when starting any medication. If you have nausea, vomiting or diarrhoea, tell your haematologist or nurse as you may need fluids into your vein. If you need a CT or MRI scan, you may not be suitable for the dye used, as it will affect your kidneys. Do tell the radiologist about your multiple myeloma before any scans are taken.

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 fluids every day and avoid drugs that can affect your kidneys.

Bone disease

Painkillers: Bone pain is a common problem with multiple 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 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 clodronate (Bonefos®), pamidronate (Aredia®), zoledronate (Zometa®) and denosumab (Xgeva®). 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 (hypercalcaemia). Before treatment, you will need to have a dental check-up, as bisphosphonates may cause some jaw problems. Any dental work must be completed before you start treatment.

>>> Before treatment, you will need to have a dental check-up, as bisphosphonates may cause some jaw problems.

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 common side-effects can include:

- Headache
- Bone or muscle pain
- Flu-like symptoms
- Fatigue

Less common side-effects are an inflamed injection site and nausea, vomiting or diarrhoea. Rarer side-effects are:

- Muscle cramps
- Abdominal pain
- Feeling dizzy or drowsy
- Kidney problems
- Jaw damage (osteonecrosis of jaw)

Many mild side-effects, such as bone pain and flu-like symptoms, happen at the start of treatment and last only a few days. The injection site can sometimes become inflamed, for example, red and painful. Other side-effects 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 49 for more details on fatigue.

Blood and urine tests to check your kidneys will be done regularly. Do drink as much fluid as you can to prevent kidney problems. In recent times bisphosphonates, when given by injection, have been linked to jaw problems, with delayed healing after teeth extractions. 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. For more information on bisphosphonates, see our factsheet *Bone Health and Cancer*. For a free copy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre, or download it from www.cancer.ie

What can I do to help improve my bone strength?

- Take regular exercise, as advised by your physiotherapist. The general advice is for 30 minutes per day.
- Eat a well-balanced diet with enough vitamin D and calcium.
- Avoid alcohol or make sure your intake is within a safe limit.
- Avoid too much tea and coffee (no more than 4 cups per day).
- Stop smoking.
- Keep a healthy weight.

Surgery: Depending on the severity of your bone disease, you may need orthopaedic surgery. This is done to repair or prevent any fractures and strengthen bone. 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 can be given as a course once or twice a week or even as a single treatment. For more advice or a copy of the booklet

Understanding Radiotherapy, contact the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie

Spinal cord compression

Spinal cord compression is when the cancer cells put pressure on your spine. Symptoms can be mild or severe and include:

- Unexplained discomfort or pain in your back or neck
- Pins and needles or numbness in your fingers or toes
- Weakness in your limbs
- Loss of control of your bladder or bowels

Spinal cord compression is a medical emergency and requires immediate attention. If you have any of the symptoms described here, you should contact your haematology team straight away. Early treatment for spinal cord compression is essential and includes radiotherapy and steroids.

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
- Dizziness and feeling light-headed
- Infections
- Bruising and bleeding

There are many ways to help these symptoms. 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 refrigerator, and

your nurses will explain everything you need to know about this drug. Erythropoietin will be stopped if your blood count goes above the target set by your doctor. It may be restarted at a lower dose if needed or given at a later date. It is not used if you have a history of stroke or mini-stroke.

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.

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 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 your 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.

Vaccinations: You may be offered vaccinations for flu and pneumonia. Shingles (herpes zoster virus) can also be a common complication and you may be given anti-viral drugs to prevent this infection.

Infections

Infections are common in patients with multiple myeloma and need to be treated as soon as possible. It is important that patients and their carers know what symptoms to look for.

You should contact your haematology team if you have any of the following symptoms:

- A temperature of 38°C (100.4°F) or higher
- Cough
- Shivers
- Feeling hot and cold
- Stinging or burning sensation passing urine
- Redness at the site of your central line
- Feeling unwell

How is relapsed or resistant multiple myeloma treated?

When multiple myeloma returns it is called a relapse. In some cases, the multiple myeloma does not respond to treatment and is called resistant (or refractory) multiple myeloma. Your doctor will look at other drugs and ways to treat the disease.

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 multiple myeloma. The first remission is usually the one that lasts the longest. Even if multiple 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.

Drugs given: The drugs given will depend on your age and previous response to treatment. You may be treated with the same drugs as before

if you have had a lengthy remission. That is, longer than 1 year. There are several drug combinations that can be used. Your doctor will discuss it with you and pick the one most suitable for your condition. All combinations include steroids and you will be given these, unless advised otherwise. There are also many new drugs for multiple myeloma being tested in clinical trials at present.

Palliative care

Palliative care aims to improve the quality of life of patients and their families when their cancer advances. As well as providing relief from pain, nausea and other symptoms, palliative care offers support and comfort to patients. It involves caring for their physical, emotional and spiritual needs in the best way possible.

The palliative care team can work with your haematology team to improve your quality of life. The palliative care team in your area might see you when you have just a few symptoms, but your own medical team will also help deal with any multiple myeloma-related symptoms.

Palliative care can be given in a hospice or community hospital or your own home. You can also attend a hospice for managing your symptoms. These days hospices are places that specialise in symptom control and you can spend a day or two there receiving treatment.

Do talk to your doctor or nurse for more advice. Or if you do not feel well enough, your family can do so. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre to speak in confidence with a specialist nurse.

Will treatment affect my sex life and fertility?

Sex and sexuality

Sometimes a diagnosis of multiple 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 multiple 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 multiple 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 multiple myeloma may cause birth defects. It is important to use reliable methods of contraception when having sex. See below for more details on fertility.

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.

Fertility

If you or your partner is of childbearing years, you should be aware of fertility issues. Some drugs used to treat multiple myeloma may cause infertility or birth defects. Thalidomide and lenalidomide in particular can cause serious birth defects and their use is tightly controlled nowadays. See page 27 for more information.

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 Unit at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use. Talk to your doctor about this service or call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

How will treatment affect my lifestyle?

No two multiple myeloma patients are the same. Multiple 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. Multiple myeloma can affect your lifestyle in the following areas:

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

Fatigue: Fatigue is a common symptom of multiple myeloma and described as an overwhelming tiredness often not relieved by rest. You may find it hard to concentrate or make decisions. Fatigue may also be caused by anxiety when a diagnosis of cancer is made and the added stress caused by treatment. Cancer treatments and their side-effects can also cause fatigue. Even though you may find it hard to identify the reasons for your tiredness, there are still ways to improve it.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. For a copy, call the National Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from www.cancer.ie



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.

Exercise: It is important that you stay as active as you can to keep calcium in your bones. Walking and swimming are good ways to keep active. You should first check with your cancer doctor 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 multiple myeloma patients other than a well-balanced one. Even so, it is best to talk to your dietitian when you are diagnosed with multiple myeloma. Different advice might be needed depending on your condition. Be cautious about taking vitamins and herbal supplements, as 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.

Do 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 multiple myeloma. If you are feeling worried,

you might also find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

Making adjustments: Depending on the severity of your multiple 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, hoovering 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. It is best to avoid travelling long distances in general. Seek advice from your cancer doctor 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 holiday, 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 and nurse 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 in case your return is delayed. Also bring supplies of painkillers, anti-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 or she may advise you to wear

special stockings too. On the aeroplane, 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 multiple myeloma patients. Contact the National Cancer Helpline on 1800 200 700 for further details or visit a Daffodil Centre.
- For sun holidays, make sure you use good sunscreen (SPF 30), especially if you have received chemotherapy. 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 multiple myeloma is a complex disease, your treatments may not be straightforward. If the multiple myeloma is not responding to the drugs, changes to your treatment plan may have to be made often. If the multiple 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 58 for more details on anxiety and depression.

If you have any worries or queries, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. 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 blood and urine tests to check your levels of paraproteins. Other tests will be done depending on your symptoms and stage of disease. For example, X-rays and MRI and CT scans, etc.

There is usually a list of medication to take throughout your treatment or from time to time. For example, antibiotics, antivirals, antifungals, and tablets to prevent sickness, heartburn, gout, blood clots, and also

laxatives. At each visit, the dose and frequency of these medications will be checked. Remember to tell your nurse if you have taken any other medication from pharmacies or health shops. It can help to use a tablet box to keep track of all your medication. Advice on vaccinations will also be given.

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 multiple myeloma and reducing side-effects is ongoing. 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 multiple myeloma. Many patients with cancer 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.

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about multiple myeloma and new treatments. There is no need for worry as you will be carefully monitored during and after the study. You might also receive a treatment that later proves to be better than the current best standard treatment.

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 cancer, your doctors may ask your permission to store some samples of your multiple myeloma cells or blood. For a factsheet called *Cancer and Clinical Trials*, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie

Cancer and complementary therapies

Complementary treatments for cancer are treatments that can be given alongside standard medical treatment. For example, yoga or massage. 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 most often use to treat people with cancer. These include biological therapies, chemotherapy, radiotherapy, surgery, and hormone therapy. 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:

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

Many people find complementary therapies 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.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy,

megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health. Always talk to your doctor if you are considering an alternative to conventional treatment.



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



Before you decide to change your treatment or add any methods of your own, do 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, do 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 on 1800 200 700 or visit a Daffodil Centre. You can also download a copy from www.cancer.ie



Coping and emotions

How can I cope with my feelings?

A diagnosis of multiple 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 that 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 on 1800 200 700 for a free copy or visit a Daffodil Centre.

Your medical social worker in the hospital is also available to support you. He or she can let you know if there are any multiple myeloma support group meetings. It can be very comforting and reassuring when you meet others with the same disease as you. See page 72 for details on support groups.

>>> 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, 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 that you are not alone. Many people who have multiple myeloma experience similar feelings and emotions. For some people, the hardest time is when your disease is in remission.

With multiple 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 copy or visit a Daffodil Centre or download a copy from www.cancer.ie

Spiritual support

When faced with a multiple 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 multiple 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 on 1800 200 700 or visit a Daffodil Centre for more advice. Ask for a copy of the booklet *Understanding the Emotional Effects of Cancer*.

How can my family and friends help?

Your family and friends can support you in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Others may gather up-to-date information on multiple myeloma to know what you can expect and what you are going through. Some may even wish to donate blood. In this case, they should contact the Irish Blood Transfusion Service (IBTS). See page 75 for contact details. Others again may prefer to help you 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 family or friends 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 multiple 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.



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 think you are not 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 on 1800 200 700 for a free copy or visit a Daffodil Centre. You can also download it from www.cancer.ie

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes of many kinds, great or small. Even so, it is best to keep family life as normal as possible. 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 them down. These are all natural feelings to have at this time.

If you need 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 discussing cancer with children. If you would like a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre, or download it from www.cancer.ie

Living with multiple myeloma

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

Communicate with your family and close friends: Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come along when visiting the doctor and when treatments will be discussed.

Live one day at a time: Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Live well: Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.

Expect change in your life: Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.

Keep an open mind: Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.

Seek information: Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones. Call 1800 200 700 for a free copy of *Journey Journal: Keeping Track of Your Cancer Treatment*.

Find what works for you: It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable talking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.

Build a support network: Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.

Seek professional help: If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If your emotions are still getting the better of you, discuss them with your nurse and doctor. They may advise you to talk to a trained counsellor or other specialist.

Spiritual care: When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices.

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

Putting your affairs in order: If your illness is not getting any better, it may be time to think about putting your affairs in order. Do talk to your family and friends about this. You may wish to make a will or have religious or spiritual needs that need addressing or want to say goodbye to friends. A helpful booklet is *Time to Care: Caring for Someone Seriously Ill at Home*. Call 1800 200 700 for a free copy or advice.





Tips & Hints – for carers



Information: Find out as much information as possible about multiple myeloma, especially its symptoms, treatment and side-effects. Talk to the doctor, nurses, National Cancer Helpline and so on. 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 and community services from the medical social worker or see the back of this booklet for details.

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 of 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. Fluids are very important to keep the kidneys working.

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 cancer.

Caring for yourself: Do look after your own health. Remember to take regular meals and exercise. See your doctor sooner rather than later if you have any health concerns of your own. 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 nurse specialists
- Psycho-oncology services
- Family doctor (GP)
- Community health services
- Support groups
- Irish Cancer Society

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 give advice on practical and financial supports and services available when you go home.

Haematology nurse specialists: These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. The nurses 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 provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

GP (family doctor): You may feel comfortable talking to your family doctor (GP) about your multiple myeloma too. He or she can discuss any of your queries and offer advice and support.

Community health services: There are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your

community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your 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 myeloma. There are also cancer support centres that are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. Useful websites, including patient forums, are also listed. You can also search for a support group on www.cancer.ie

Irish Cancer Society: The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters.

>>> Remember that there are many people ready to help you.

Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for information about any of the services outlined above or for support services in your area.

Health cover

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

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

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 accident and emergency department of a public hospital without being referred there by a GP, you will be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the accident and emergency department first.

The €100 charge applies to the first visit in relation to an illness or accident. If you have to return for further visits to an outpatient clinic in relation to the same illness or accident, you should not have to pay the charge again.

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. You will have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still 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. This is known as a discretionary medical card. If you wish to apply for a medical card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

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 your hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 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 or your local pharmacy.

Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth, and other schemes. They provide cover for day care or inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI and PET scans. Sometimes it might take 24–48 hours to get approval from your health insurer.

Benefits and allowances

You or a family member may qualify for a number of benefits and allowances. For example: Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

More information on these is available in a booklet called *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. For a free copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie

Application forms for the benefits are available from social welfare offices or Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Appliances

If you have a medical card, most appliances such as wigs and prostheses are free of charge or subsidised. The subsidy will depend on the HSE area. For further information, contact your local HSE office.

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 medical 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, usually for patients with medical cards.

See page 74 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

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:

Dept of Social Protection – Information Service

Oisín House Tel: 1890 662 244 Email: info@welfare.ie
 212–213 Pearse Street Leaflet line: Website: www.welfare.ie
 Dublin 2 1890 202 325

If you have queries about health and social services, contact the HSE.
HSE infoline: 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

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

Citizens Information

Tel: 0761 07 4000 information@citizensinformation.ie
 Email: Website: www.citizensinformation.ie



If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with cancer 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 because of your illness. See page 74 for more details. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre and the nurse will suggest 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 0761 07 2000. 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. The service is free and confidential. See page 75 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 81 for more information.

Irish Cancer Society services

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

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support services
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** 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 is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website www.cancer.ie provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie
- **Message Board** is a discussion space on our website www.cancer.ie to share your stories, ideas and advice with others.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support services

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. See pages 76–79 for more details. Regular myeloma meetings take place in ARC Cancer Support Centre (page 77) and Midlands Myeloma Support Group (page 75).

Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to people who have been diagnosed with cancer. All of the volunteers have had a cancer diagnosis and have been carefully selected and trained to give you support, practical information and reassurance when you need it most. You can speak to someone who really knows what you are going through. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the National Cancer Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Cancer information booklets and factsheets

The booklets provide information on all aspects of cancer and its treatment, while the factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. These booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.



Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society may be able to provide limited financial help to patients in need through schemes such as Travel2Care or Financial Aid.

Travel2Care: Travel2Care can help with your travel costs if you have genuine financial hardship due to travelling over 50 kilometres to a rapid access diagnostic clinic for tests or to a designated cancer centre or approved satellite centre for cancer treatment. The scheme is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. Travel2Care can help with some of the costs of public transport, such as trains or buses, private transport costs, or petrol expenses.

If this applies to you, contact the medical social work department in your hospital or speak to your cancer care nurse. You can also contact the Irish Cancer Society on (01) 231 6643 / 231 6619 or email:

travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families experiencing financial difficulty as a result of cancer. If this applies to you, contact the medical social work department in your hospital. You can also speak to your haematology nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700, visit the website **www.cancer.ie** or a Daffodil Centre.

Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline:
1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2920
Freefone: 1800 240 724
Email: info@carersireland.com
Website: www.carersireland.com

Citizens Information

Tel: 0761 07 4000
Email:
information@citizensinformation.ie
Website: www.citizensinformation.ie

HARI: The National Fertility Centre

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@hari.ie
Website: www.hari.ie

Irish Blood Transfusion Service

National Blood Centre
James's Street
Dublin 8
Tel: 01 432 2800
LoCall: 1850 731 137
Cork Tel: 021 4807 400
Website: www.giveblood.ie

Irish Oncology and Haematology Social Workers Group

Website:
<http://socialworkandcancer.com>

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Midlands Myeloma Support Group

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.cuislecentre.com

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Multiple Myeloma Ireland

Email: info@multiplemyelomaireland.org
Website: www.multiplemyelomaireland.org

Myeloma UK

Broughton House
31 Dunedin Street
Edinburgh EH7 4JG
Tel: 0044 131 557 3332
Ireland Infoline: 1800 937 773
Email: myelomauk@myeloma.org.uk
Website: www.myeloma.org.uk

Health insurers

AVIVA Health (formerly VIVAS Health)
PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare (formerly Quinn)

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
Local: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support services

Survivors Supporting Survivors

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline:
1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

ARC Cancer Support Centres Dublin

[See page 77]

Cancer Support Sanctuary LARCC

[See page 78]

Connaught support services

Athenry Cancer Care

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080
Email: athenrycancer@icm.ie
Website: www.athenrycancer.ie

Ballinasloe Cancer Support Centre

Main Street
Ballinasloe
Co Galway
Tel: 090 964 5574
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590 / 087 391 8573
Email: caraiorrais@gmail.com

East Galway & Midlands Cancer Support

Cluain Mhuire
Brackernagh
Ballinasloe
Co Galway
Tel: 090 964 2088 / 087 984 0304
Email: info@egmcancersupport.com
Website: www.eastgalwaycancersupport.com

Gort Cancer Support Group

Garrabeg
Gort
Co Galway
Tel: 091 648 606 / 086 172 4500
Email: info@gortcancersupport.ie
Website: www.gortcancersupport.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group

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

Sligo Cancer Support Centre

44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.slilocancersupportcentre.ie

Tuam Cancer Care Centre

Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancer.ie
Website: www.tuamcancer.ie

Leinster support services

ARC Cancer Support Centre

[Monthly myeloma support group meetings]
ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Arklow Cancer Support Group

25 Kings Hill
Arklow
Co Wicklow
Tel: 0402 23590 / 085 110 0066
Email: info@arklowcancersupport.com
Website: www.arklowcancersupport.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park
Harry Reynold's Road
Balbriggan
Co Dublin
Tel: 087 353 2872 / 086 164 2234

The Bella Rose Foundation

Merry Maid House
West Park Campus
Garter's Lane
Citywest
Dublin 24
Tel: 087 320 3201
Email: thebellarosefoundation@gmail.com
Website: www.bellarose.ie

Bray Cancer Support & Information Centre

Aubrey Court
Parnell Road
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@braycancersupport.ie
Website: www.braycancersupport.ie

Cara Cancer Support Centre

7 Williamson's Place
Dundalk
Co Louth
Tel: 042 937 4905
Mobile: 087 395 5335
Email: info@ccscdundalk.ie
Website: ccscdundalk.ie

Cois Nore Cancer Support Centre

8 Walkin Street
Kilkenny
Tel: 056 775 2222
Email: coisnorekilkenny@gmail.com
Website: www.kilkennycancersupport.ie

Cuisle Cancer Support Centre

Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support Group

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Eist Carlow Cancer Support Centre

The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Cancer Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: info@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: info@greystonescancersupport.com
Website: www.greystonescancersupport.com

Hope Cancer Support Centre

22 Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: info@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Cancer Support Sanctuary LARCC

Coole Road
Multyfarnham
Mullingar
Co Westmeath
Tel: 044 937 1971
CallSave: 1850 719 719
Email: info@cancersupport.ie
Website: www.cancersupport.ie

Rathdrum Cancer Support Group

St Anne's
Lower Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Tallaght Cancer Support Group

Trustus House
1-2 Main Street
Tallaght
Dublin 24
Tel: 086 400 2736
Email: ctallaght@yahoo.ie
Website: tallaghtcancersupport.com

Wicklow Cancer Support Centre

Rear of Butler's Medical Hall
Abbey Street
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support services**Cancer Information & Support Centre**

University Hospital Limerick
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
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: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cuan House Cancer Support Centre

24 Gort Aoibhinn
Cork Hill
Youghal
Co Cork
Tel: 024 92353
Email: youghalcancersupportgroup@hotmail.com

Kerry Cancer Support Group

Acorn Centre
124 Tralee Townhouse Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupportgroup@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven

5 Haig's Terrace
Tralee
Co Kerry
Tel: 066 719 2122
Email: recoveryhaven@gmail.com
Website: www.recoveryhavenkerry.com

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

South Eastern Cancer Foundation

Solas Centre
Williamstown
Waterford
Tel: 051 304 604
Email: info@solascentre.ie
Website: www.solascentre.ie

Suaimhneas Cancer Support Centre

2 Clonaslee
Gortland Roe
Nenagh
Co Tipperary
Tel: 067 37403
Email: suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Ulster support services**Coiste Scaoil Saor Ó Ailse**

C/O Ionad Níomh Padraig
Upper Dore
Bunbeg
Letterkenny
Co Donegal
Tel: 074 953 2949
Email: ionadnp@eircom.net
Website: www.scaoilsaor.ie

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
19 The Grange
Plantation Walk
Monaghan
Tel: 087 368 0965 / 047 62565
Email: crocus.2011@yahoo.com

Cuan Cancer Social Support and Wellness Group

2nd Floor, Cootehill Credit Union
22-24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

The Forge Cancer Support Service

The Forge Family Resource Centre
Pettigo
Co Donegal
Tel: 071 986 1924
Email: theforgefr@eircom.net

Living Beyond Cancer

Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) /
074 910 4477
Email: noreen.rodgers@hse.ie

Other support groups and centres

Cancer Care West

72 Seamus Quirke Road
Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Killybegs Cancer Support Group

Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Solace: Donegal Cancer Support Centre

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

Useful contacts outside Republic of Ireland

Action Cancer

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

American Cancer Society

Website: www.cancer.org

Cancer Focus Northern Ireland

40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Research UK

Tel: 0044 20 7242 0200
Website: www.cancerhelp.org.uk

International Myeloma Foundation

Website: myeloma.org

Macmillan Cancer Support (UK)

Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
77-81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net

National Cancer Institute (US)

Website: www.nci.nih.gov

For other support groups or centres in your area, call 1800 200 700.

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Stem Cell Collection*
- *Understanding Autologous Stem Cell Transplants*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *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*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*



Multiple Myeloma Patient Handbook

International Myeloma Foundation,
2013
[Download from
<http://myeloma.org>]

Myeloma: Your Essential Guide

Myeloma UK, 2013
[Download from
www.myeloma.org.uk]

Living with Myeloma: Your Essential Guide

Myeloma UK, 2010
[Download from
www.myeloma.org.uk]

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul Partnership/Limerick
VEC/Safefood, 1998
ISBN 187407514X
[For more details, see www.mabs.ie]

What does that word mean?

Albumin	A major protein normally found in blood.
Amyloidosis	When large amounts of the protein amyloid are found in your body. It happens when plasma cells in your bone marrow make antibodies that cannot be broken down.
Anaemia	Fewer red blood cells that cause fatigue and shortness of breath.
Antibodies	Proteins made by white blood cells (plasma cells) to help protect your body from infection and disease. Also called immunoglobulins (Ig).
Autologous stem cell transplant	When stem cells are collected from your blood and then after a high dose of chemotherapy are returned to your body.
Benign	Not cancer.
Beta-2 microglobulin	A protein usually found on the surface of various cells in your body. It is increased in myeloma.
Biological therapy	A treatment that uses your body's immune system to fight myeloma.
Bisphosphonate	A drug used to treat osteoporosis and bone disease in cancer patients.
Bone marrow	Soft spongy material found in large bones that makes three types of blood cells: red blood cells, white blood cells and platelets.
Bone marrow biopsy	Removing a small amount of blood cells from your bone marrow to find out if myeloma cells are present.

Bortezomib (Velcade®)	A drug used to treat myeloma. It blocks the protein proteasome from being broken down, and so the cancer cells cannot grow.
Calcium	A mineral found in your body needed to form bones. The levels are raised when bone cells are broken down.
Chemotherapy	A treatment that uses drugs to cure or control cancer.
Cycle	A period of chemotherapy.
G-CSF	Drugs called growth factors that help your bone marrow make more white blood cells quickly.
Haematologist	A doctor who specialises in treating patients with abnormal blood or bone marrow.
Haematology	The study of blood and bone marrow.
Hypercalcaemia	High levels of calcium in your blood.
IMiDs	A class of drugs called immunomodulators used to treat myeloma. They are also known as biological therapies.
Immunoglobulins	Proteins made by plasma cells to fight infection. Also called antibodies.
Lenalidomide (Revlimid®)	A drug used to control myeloma.
Leukaemia	Cancer of the white blood cells.
Lymphocytes	One type of white blood cells that fight infection.
Lytic lesions	When myeloma cells spread to the harder part of bone and cause damage to bone tissue.

Medical oncologist	A doctor who specialises in treating cancer patients with chemotherapy or biological therapies.
MGUS	A benign condition called monoclonal gammopathy of uncertain significance that may lead to myeloma. There are raised abnormal proteins but no other signs of myeloma.
Paraprotein	A protein made by an abnormal plasma cell in myeloma. Paraproteins can be found in blood and urine. It can also be called monoclonal protein, myeloma protein, M spike or M protein.
Plasma cell	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.
Plasmacytoma	When myeloma cells collect in one part of a bone and form a tumour.
Platelets	Blood cells responsible for clotting.
Radiotherapy	A treatment of cancer and other diseases using high-energy rays.
Red blood cell	Blood cells that carry oxygen to every cell in your body.
Relapsing myeloma	When myeloma returns after having been in remission.
Staging	Tests that measure the size and extent of myeloma.
Thalidomide	A drug used to control myeloma.
White blood cell	Blood cells responsible for fighting infection.

Questions to ask your doctor

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

- What tests do I need to diagnose myeloma?
- 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

A large, light blue rounded rectangular area intended for taking notes, currently blank.

Acknowledgements

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

Melanie Strickland, Clinical Nurse Manager

Alison O'Driscoll, Autologous Transplant Co-ordinator

Kathleen Beston, Haematology Clinical Nurse Specialist

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 call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

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, research and education. This includes patient information booklets. 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 at CallSave 1850 60 60 60 or email: **fundraising@irishcancer.ie**

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

Tel: 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

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