Irish Cancer Society

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.

	Name	Telephone
Specialist nurse		
Family doctor (GP)		
Haematologist		
Medical social worker		
Emergency number		

This booklet has been produced by 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. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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Quick facts

Can multiple myeloma be treated?

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Yes. Myeloma is rarely curable, but it is treatable. There are several treatments that can slow down and control multiple myeloma very well. The type of treatment you're offered will depend on a number of factors, including your general health and how advanced the myeloma is.

How long will I live?

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What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, such as your age, health and the type of multiple myeloma you have. Everyone is different, so it's best to ask your consultant about your own situation. See page 25.

What treatment am I likely to have?

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Chemotherapy, targeted therapies, steroids and maybe a stem cell transplant are used to put the disease into remission. You will also have supportive care to help you with any side-effects of your illness and treatment.

Are there side-effects from treatment?

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Treatment for myeloma can cause a number of side-effects. Read about the treatments (page 35) to learn more about their side-effects.

There are treatments to help with most side-effects, so tell your doctor if you have any. Don't suffer in silence!

Clinical trials

Page 44

Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

We're here for you

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If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Cancer Nurseline on 1800 200 700
- Drop into a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

See page 78 for more about our services.

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.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. 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. 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 you are interested in. Then when you feel ready to know more, read another section.

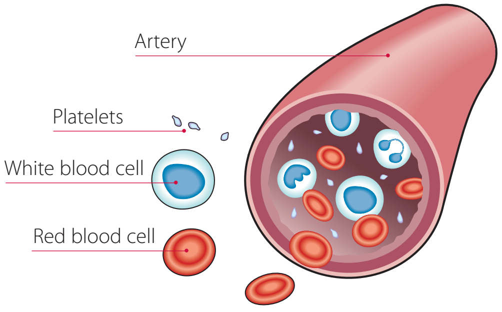
If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email cancernurseline@irishcancer.ie

You can also visit a Daffodil Centre. See page 78 for more about Daffodil Centres. You can also email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

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.



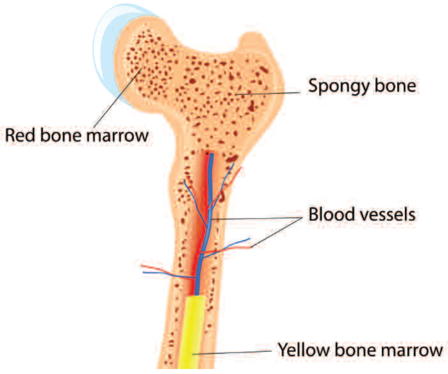
Types of blood cells

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.



Bone marrow

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 damage to bone tissue. The marrow of more than one bone can be affected, sometimes several bones.

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 260 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 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. There is no standard treatment of multiple myeloma, so your treatment will be individual too. Both you and your doctor will decide what is the best way to treat your disease. 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 is a complex, highly individual disease. Many functions in your body can be affected.

What increases my risk of multiple myeloma?

Multiple myeloma may be the result of several factors working together. These include:

- **Age:** Multiple myeloma is more common in older adults
- **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 22 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.

> ‘Being diagnosed with multiple myeloma was a massive shock to the system – for me and my family. But after the initial shock, I realised I had to get on with it and throw everything I could at this disease.’

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
- Bone fractures
- Osteoporosis
- Numbness and 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 loss of control of your bladder or 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
- Anaemia
- Infections
- 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. You may also have shortness of breath and weakness, because less oxygen is carried in your blood. The effect of fewer white blood cells is that you can develop infections easily. This includes repeated coughs, colds and flus, and other infections, especially chest infections. It also may take longer to recover from any kind of illness. You may also have unexplained bruising or develop nosebleeds or bleeding gums. This is because of fewer platelets.

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. Hypercalcaemia can cause loss of appetite, nausea and vomiting, hazy vision, muscle weakness, thirst, constipation, depression and drowsiness.

Other kidney problems may occur. The paraproteins and light chains produced in myeloma can block the tubes in the kidneys and stop them filtering waste products from your blood properly. This can lead to kidney damage or sometimes kidney failure.

If you develop any of the above symptoms contact your haematologist or nurse specialist.

> “I had bad back pain, which I initially thought was wear and tear. When I started dragging my leg behind me and getting shooting pains, I knew I had to investigate further. That’s when I was referred for an MRI.”

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 and black. Other factors include 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.

Diagnosis and tests

Being diagnosed with multiple myeloma

Hearing that you have multiple myeloma can be a huge shock. You may be feeling:

- Upset and overwhelmed by your emotions
- Confused by all the information being given to you
- Worried about what will happen next
- Scared about the future

Everyone reacts differently to a cancer diagnosis. However you feel, you are not alone. There are many people who can help and support you at this time.

If you need to talk to someone, or if you want more information or advice:

- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Join our online community at **www.cancer.ie/community**

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with cancer. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website **www.cancer.ie**

Telling people about your diagnosis

It can be hard to tell other people the news that you have been diagnosed with multiple myeloma.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people's reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have?

The following tests give doctors more information about your multiple myeloma. Some may also be used to monitor your response to treatment.

Blood and urine tests

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

- Full blood count (FBC)
- Kidney function tests
- Calcium levels
- Blood and urine levels of normal proteins, for example, albumin
- Immunoglobulins (antibodies)
- 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.

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 test 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 53 for more about immunoglobulins.

> “For a full week after I was diagnosed with multiple myeloma, I had many tests to find out more information about my disease. These included blood tests, CT scans and a bone marrow aspirate.”

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:

- Bone marrow aspirate or biopsy
- Cytogenetics
- X-rays of bones
- CT scan
- MRI scan

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. Your doctor and nurse will let you know what you can expect to happen. Usually the sample is taken from your hip 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.

Cytogenetics: Bone marrow can also be checked to see if there are any abnormal chromosomes. This is called cytogenetics testing or FISH (fluorescence in situ hybridisation). About 7 out of 10 people with myeloma have chromosome changes. 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.

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.

CT scan: This test may be done for a small number of patients. Your doctor might want you to have a CT scan 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. 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.

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 spinal cord compression. The scan uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic during the MRI scan. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. An MRI can also be noisy, but you will be given earplugs to wear during it. During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test. 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 test 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and speak to a cancer nurse in confidence.

> ‘From the beginning, the nurses and doctors looking after me were wonderful. They made me as comfortable as possible and always found the time to answer my questions. The care I received was seamless.’

To sum up

Tests to give the doctors more information about your multiple myeloma include:

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

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.

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, heart or liver. About 10 to 15 in every 100 people with multiple myeloma will develop amyloidosis. But it is rare for people with amyloidosis to develop multiple myeloma. 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.

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. They 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.

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. Cancer staging can be complex. Ask your doctor to explain it to you in a way you understand.

To sum up

- You may develop multiple myeloma if you have monoclonal gammopathy of uncertain significance (MGUS) or smouldering myeloma.
- If you have MGUS or smouldering myeloma, you will be closely monitored with blood tests. You will only be treated if you develop multiple 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.

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

It's not always easy for doctors to answer a question about life expectancy, as the answer is based on a 'typical' experience. In reality, experiences can vary a lot from person to person. Ongoing advances in the understanding and treatment of multiple myeloma may also change your prognosis.

If you decide you want information on your prognosis:

- Think carefully about how you will cope with the information before asking for your prognosis.
- Get information on prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Avoid looking online. It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.

Get emotional support if you need it. If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment overview

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 many 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 have smouldering myeloma and 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 36 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.

Targeted therapies: These therapies use your body’s immune system to fight cancer. See page 37 for more details.

Chemotherapy: Chemotherapy kills the multiple myeloma cells with drugs. It might be given with biological therapies or steroids. See page 39 for more about chemotherapy.

High-dose therapy and stem cell transplant: Depending on your condition, you may be suitable for intensive treatment involving high-dose chemotherapy followed by a stem cell transplant. See page 43 for more about details.

Maintenance therapy: After targeted therapy, chemotherapy or a transplant, you may need to take other drugs for a number of months. These drugs can prevent or delay the multiple myeloma from returning. This is called maintenance therapy. See page 44 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 48 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. Your doctors will offer you further treatment. If your multiple myeloma does not respond to drug treatment (resistant), other options will be explored. See page 45 for more details.

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

Deciding on treatment

Multidisciplinary team: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, specialist nurse and haematologist (blood cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

Treatment options: Your doctor and nurse will explain your treatment options to you. Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it’s first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

> ‘I kept reminding myself that multiple myeloma is a treatable disease and that people can live for many years with it. And new drugs are being developed all the time.’

Giving consent for treatment

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 understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- 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 information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some multiple myeloma treatments are complex and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Individual treatment

You may notice that other people are not getting the same treatment as you. Their myeloma may not be the same type or at the same stage as yours. Everyone’s treatment needs will be different. Ask your doctor about your treatment if you have any questions.

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works. This also gives you time to talk about all your treatment options with your doctors, family, and friends.

If you are worried, talk to your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Who will be involved in my care?

Usually a team of health professionals will be involved in your treatment and care.

Haematologist	A doctor who specialises in treating blood and bone marrow diseases.
Haematology nurse specialist	They give information and reassurance to you and your family from diagnosis and throughout treatment
Advanced nurse practitioner	As well as providing expert information and support, they are specially trained to carry out tests and assist with reviewing your treatment.
Medical social worker	A person specially trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits, and financial matters and on practical supports and services available to you when you go home.
GP (family doctor)	You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.
Psycho-oncology team	A group of specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.
Community health services	These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

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 monitoring, 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.

> ‘From the beginning, the nurses and doctors looking after me were wonderful. They made me as comfortable as possible and always found the time to answer my questions. The care I received was seamless.’

Treatment and side-effects

Active monitoring

You may be diagnosed with smouldering 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 with smouldering myeloma 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. This can continue for a number of years. For more information talk to your doctor or nurse. You can also contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Combination therapy

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

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 37, chemotherapy on page 39 and steroids on page 42.

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 44 for more details.

Targeted (biological) therapies

Targeted or biological therapies work with your body. They can help fight cancer, stop it spreading or control side-effects from other cancer treatments.

Different types of targeted therapies work in different ways. For example:

- Cancer growth inhibitors block the chemical signals that trigger cancer cells to divide and grow.
- Monoclonal antibodies trigger your immune system to attack cancer cells or target the cancer cells with drugs or a radioactive substance.
- Angiogenesis inhibitors interfere with the blood supply to the cancer cells.
- Immunotherapy boosts your body's immune system to fight cancer.

Some treatments fit into more than one of these groups.

Some drugs are given in tablet form. Others are given into a vein through a drip.

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a targeted therapy as part of a clinical trial (see page 44). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

What side-effects can I expect?

Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you. There are many ways to relieve them and make you feel better.

Side-effects depend on the drugs being used and vary from person to person. Common side-effects include:

- Tingling or numbness in arms, hands, legs and feet (peripheral neuropathy). See page 38.
- Fatigue. See page 54.

- Infections due to low white blood cells
- Bruising and bleeding
- Constipation or diarrhoea
- Dryness of skin and mouth

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 or other medications to reduce the symptoms and promote nerve healing. They 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 more information on peripheral neuropathy, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or visit **www.cancer.ie**

Understanding your drug treatment

It’s important that you understand the medicine you have been given. Don’t be afraid to ask your doctor or specialist nurse for more information about any drugs you are taking, what they are for and any possible side-effects. They may be able to give you a printed sheet to take home with you.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Cancer Nurseline on 1800 200 700.

To sum up

- Targeted therapies work with your body to fight cancer.
- New targeted therapies are being developed all the time.
- 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 drugs are usually combined with steroids or targeted therapies.

Chemotherapy is given in cycles with a rest period between treatments. 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 37.5°C (100.4°F) or higher, shortness of breath or bleeding that cannot be stopped.

Fatigue: Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 54.

Changes in kidney function: Certain 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 – ask your nurse or doctor how much fluid they recommend.

Nausea and vomiting: Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are treatments that work well to prevent nausea and vomiting.

Loss of appetite: Some chemotherapy drugs can reduce your appetite for a while. It can help to get advice from a dietitian if this happens. A booklet called *Diet and Cancer* is available from the Irish Cancer Society and has helpful tips on boosting appetite. For a copy, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or download it from **www.cancer.ie**

Diarrhoea and constipation: Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).

Mouth and throat problems: Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

Hair loss (alopecia): Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. They will tell you what to do.

A free booklet called *Understanding Chemotherapy* is also available. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or download it from **www.cancer.ie**

> ‘I was very lucky in that the chemo didn’t make me too sick – especially at the beginning. It did catch up with me after a few weeks and I would feel a bit nauseous and flushed.’

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 used in multiple myeloma, for example dexamethasone and prednisolone. In high doses they cause 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.
- 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 targeted therapies.

High-dose therapy and stem cell transplant

Your doctor may consider you suitable for high-dose therapy and stem cell transplant. 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. But your multiple myeloma is still likely to come back at some point

In a stem cell transplant, healthy stem cells can be collected and removed from your body before treatment and returned to you afterwards. These stem cells can restore or rescue the bone marrow destroyed during the high-dose treatment. The stem cells are taken from blood or bone marrow.

When your own stem cells are used it is called an autologous transplant. If stem cells are taken from a donor, it is called an allogeneic transplant. Autologous transplants are generally used to treat multiple myeloma.

There are various stages or steps when having a stem cell transplant. Your doctor and nurse will explain each step as it happens. For more information, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the booklets, *Understanding Autologous Stem Cell Transplants* or *Understanding Allogeneic Stem Cell Transplants*. You can also download them from **www.cancer.ie**

Consolidation Therapy

You may be given consolidation therapy after you recover from your stem cell transplant. This is when you are given a combination of drugs for a couple of months. These drugs are often similar to the ones you had before your transplant. Research shows that consolidation therapy can help to keep the multiple myeloma in remission for longer.

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.

For more information on maintenance therapy, call our Cancer Nurseline on 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It’s best to talk to your doctor if you’re interested in taking part in a clinical trial. For more information, you can read our factsheet *Cancer and Clinical Trials*. It’s available to read or download on our website, **www.cancer.ie**. You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at **www.cancertrials.ie**

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: Remission means that the symptoms of multiple myeloma disappear and the bone marrow recovers. Remissions can last from months to years. But it is rare for remissions to be permanent. The first remission is usually the one that lasts the longest. Even if multiple myeloma comes back, 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.

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.

Managing side-effects and symptoms

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. Do avoid drugs that can affect your kidneys too, for example, ibuprofen. 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.

> 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. A group of drugs called non-steroidal anti-inflammatory drugs (such as ibuprofen) can cause kidney damage in people with myeloma. You should check with your doctor or nurse before taking these.

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. Bisphosphonates can be taken orally as tablets or as an injection into a vein. 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. When you are on bisphosphonates, always check with your doctor before getting any dental work done.

> 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 of bisphosphonates 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 54 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 (removal of the tooth). 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. Don't get any dental work done until your doctor says it's OK. For more information on bisphosphonates, see our website **www.cancer.ie**, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

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 our Cancer Nurseline 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 lightheaded
- Infections
- Bruising and bleeding
- Increased risk of blood clots

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. It is normally given by an injection under the skin. 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.

Blood thinners: Myeloma can increase your risk of developing a blood clot (thrombosis), and some treatments may increase this risk further. Most clots can be successfully treated with drugs to thin the blood. Your doctor or nurse can give you more information about blood clots.

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 will probably be advised to get the flu vaccine every year and the pneumonia vaccine every 5 years. Check with your doctor about which vaccinations are recommended for you and make sure you get them. 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 37.5°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

Palliative care

Palliative care aims to improve the quality of life of patients and their families with cancer. 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 and family doctor (GP) 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak in confidence with a specialist nurse.

How can I cope with fatigue?

Fatigue means feeling extremely tired. It is a common symptom of multiple myeloma.

Fatigue when you have multiple myeloma can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain

Tell your doctor or nurse if fatigue is affecting you, so that they can help you. 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 our Cancer Helpline on 1800 200 700, visit a Daffodil Centre or download it from **www.cancer.ie**

Tips & Hints – fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

Alternative therapies: Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

If you decide to have complementary or alternative treatments…

Before you decide to change your treatment or add any methods of your own, 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.

More information

To find out more about the different complementary and alternative therapies, read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients.* To get a copy call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website **www.cancer.ie**

Will treatment affect my sex life?

Sex and sexuality

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have multiple myeloma can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. They may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

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. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

Contraception

Some drugs used to treat multiple myeloma may cause birth defects. It is important to use reliable methods of contraception when having sex.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to taking about these matters, so there’s no need to feel embarrassed. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

Dealing with infertility may not be easy, depending on your age and if you have already had children. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

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.

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

Living with multiple myeloma

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:

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

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. They will help you to find ways to cope.

Making adjustments: Depending on 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. You're advised not to 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 our Cancer Nursleline 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 64 for more details on anxiety and depression.

If you have any worries or queries, contact our Cancer Nurseline 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.

> 'You have to listen to your body. Nap if you need to and take things at your own pace. I find exercise great. I'm lucky to live near a beach so I go for a walk every morning. I also love gardening and I've even started back set dancing!'

Coping and emotions

How can I cope with my feelings?

There are many reactions when you hear you have multiple myeloma. Reactions differ from person to person. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

Common reactions include:

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

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it's important to get help. It's not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

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 work well. Professional counselling can also be very helpful.

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at **www.cancer.ie**

Ways to get emotional support

Find out about cancer support services in your area: There are lots of local cancer support services that provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 80 for more about cancer support services.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

Join a support or educational group: Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Get one-to-one support: The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support.

Get online support: There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit **www.cancer.ie/community** to join the Irish Cancer Society online community.

Talk things through: It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support: For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

> ‘My local cancer support centre was wonderful. The first time we went, my wife and I spent hours chatting to the lady who welcomed us. We laughed and we cried. We found it so uplifting.’

Coping with a multiple myeloma diagnosis

Everyone experiences cancer in a different way. And how each person copes with multiple myeloma varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it’s true that some treatments can have some unpleasant side-effects, most people are able to adjust to life during treatment.

Here are some 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.

Use your support network: Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don't be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involve your family and close friends: Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

Gather information about multiple myeloma and treatment: Understanding multiple myeloma and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

Eat well: Try to eat as well as you can. Have lots of different types of foods with plenty of fresh fruit and vegetables.

Get some exercise: Exercising is a great way to boost your mood and sense of well-being. Exercise can also improve your energy levels if you are feeling very tired. Talk to your doctor or nurse about which activity will suit you best.

Try relaxation and stress management techniques: Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Try complementary therapies: Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 55 for more information on complementary therapies.

Accept change in your life: Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs: Sometimes people feel they have to be brave or positive all the time, but it’s normal to have bad days. Get help if you are finding it hard to cope.

Keep busy: Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

Try to cope day by day: 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.

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

Planning ahead

You can live for many years with multiple myeloma and most people hope that this will be the case for them. But it can be hard to think about what might happen in the future when you have a diagnosis of multiple myeloma. It might make you feel worried, scared or upset to think about the end of your life. Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

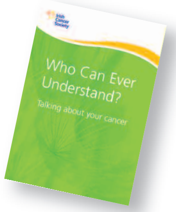
- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive.** This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will.**
- **Talking about what you want** to your family, friends, carers and healthcare providers.

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at **www.hospicefoundation.ie**

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children.



You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Who Can Ever Understand?* can help to you find ways to talk about your cancer and to ask for the help and support you need.

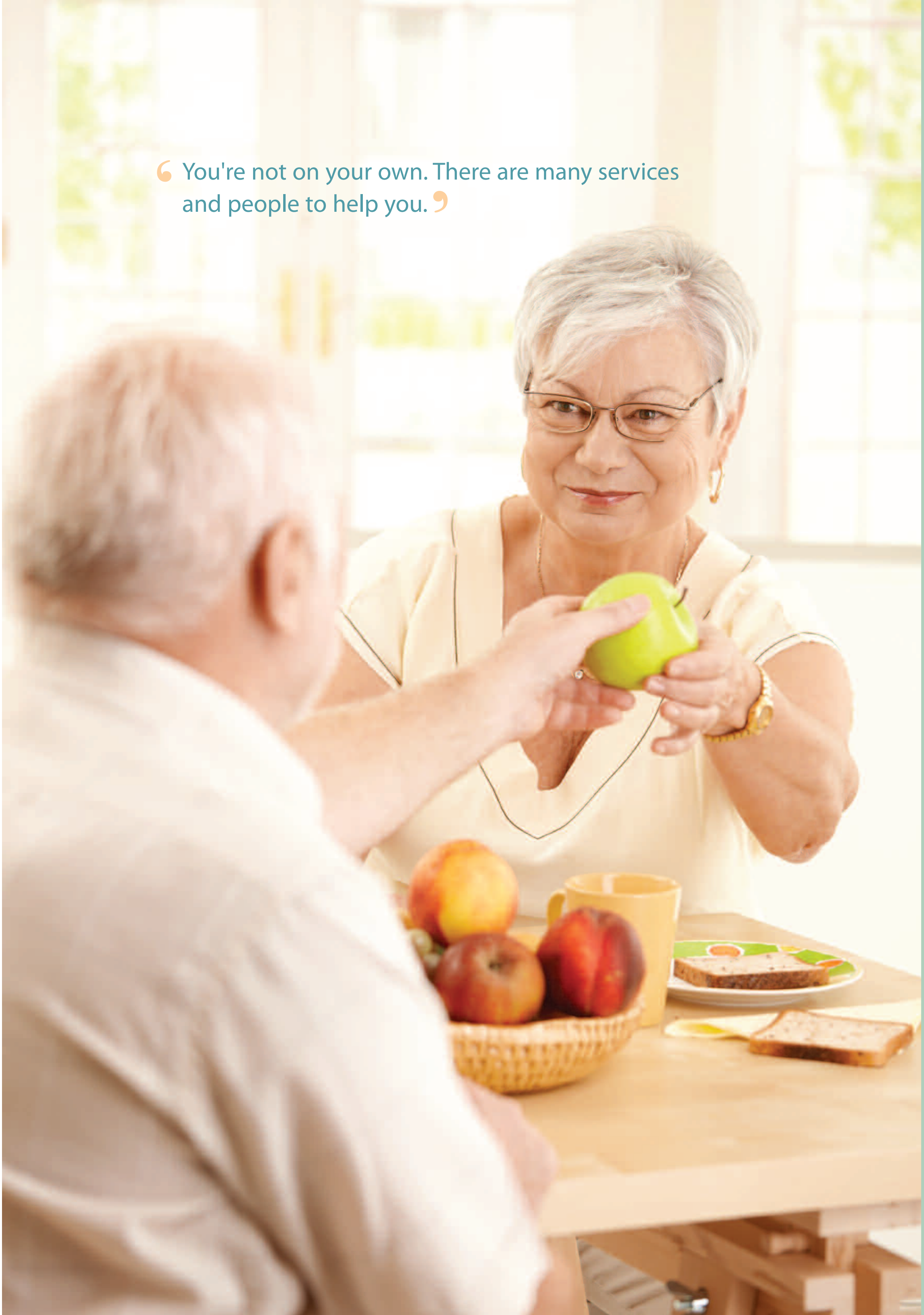
If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer,* which has practical advice about how to talk to children of different ages.

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. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others 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 friend best.

Positive emotions

After being diagnosed with multiple myeloma, you may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what's important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.



> You're not on your own. There are many services and people to help you.

Advice for carers

Coping with both the practical and emotional issues of a cancer diagnosis can be hard. Here are some things that can help to make life a little easier for you as a carer:

- **Information:** Find out as much information as possible about multiple myeloma, especially its symptoms, treatment and side-effects, as well as the emotional effects it can cause. Talk to the doctor and nurses and call our Cancer Nurseline if you need more information.
- **Healthcare:** Support your loved one by making sure they take their medication every day and attend all appointments. Ask them about how they are feeling and encourage them to talk to their healthcare team if they have any symptoms or worries.
- **Emergencies:** Find out who to call if you are particularly worried or in an emergency situation and make sure you know the phone number to call.
- **Caring for yourself:** It can be difficult to find time for yourself if you're busy caring for someone with cancer, but it's important to look after yourself, too, and get help if you need it. See our booklet, *Caring for Someone with Cancer* for more information.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline on 1800 200 700. Ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at **www.cancer.ie**

Support for you

Our cancer nurses are there to support you as a carer. If you need any support or want to talk to someone, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre to speak to a cancer nurse in confidence. You can also email the nurses at cancernurseline@irishcancer.ie

Ask for a copy of our booklet, *Caring for Someone with Cancer,* or download it from our website **www.cancer.ie** Many cancer support services offer help for friends and family of people with cancer, too. See page 78 for more about support services.

Support resources

Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70 years old, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 79 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

For more information go to **www.cancer.ie/publications** and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*. This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

- **Our Cancer Nurseline Freephone 1800 200 700.** Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at **www.cancer.ie**

  For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

- **Our Daffodil Centres.** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

- **Our Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling. See page 80 for more information.

- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
  - **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

  To access either of these services please contact your hospital healthcare professional.

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

If you would like more information on any of our services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at **http://www.cancer.ie/support/support-in-your-area/directory**

> “I find the centre so supporting and comforting…The amount of services they provide is fantastic. I was so afraid going in at the beginning but now it's my second home.”

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: **www.cancer.ie**.

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue

Coping and emotions

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

A Time to Care: Caring for Someone Seriously Ill at Home

Caring for Someone with Cancer

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.
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.
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 make 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.
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

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions. Please email reviewers@irishcancer.ie

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

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