Irish Cancer Society

Understanding

Multiple myeloma

Caring for people with cancer

Understanding

Multiple myeloma

This booklet has information on:

- Treatment for multiple myeloma
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist nurse

Haematologist

Medical social worker

Emergency number

Haematology nurse

Main hospital number

Family doctor (GP)

Medical social worker

Emergency number

Pharmacist

Hospital records number (MRN)

Contents

Fast facts

What is multiple myeloma? Page 9

Multiple myeloma (also called myeloma) is a cancer of white blood cells called plasma cells. Plasma cells make antibodies to help you fight infections. In multiple myeloma the plasma cells grow quickly and produce a lot of abnormal proteins called paraproteins. The abnormal plasma cells take over much of the bone marrow, which can cause anaemia (lack of red blood cells, which are made in the bone marrow). The abnormal proteins can lead to other symptoms such as kidney and bone problems.

Can multiple myeloma be treated?

Myeloma is very treatable but not currently regarded as curable. Treatment aims to control the disease, minimise complications, manage treatment side-effects, improve your quality of life and prolong your life. The best treatment for you will depend on a number of factors, including your age, general health, any other medical conditions you may have, your myeloma type and how the myeloma has affected other parts of your body, such as kidneys and bones.

Will I be OK? Page 40

Most myeloma patients will respond to treatment. How long the response lasts will vary widely between patients. It's best to ask your consultant about your own situation.

What treatment am I likely to have? Page 43

Most patients will have a combination of chemotherapy, targeted therapy and steroids designed to destroy the multiple myeloma cells and put the disease into remission or stable phase. A stem cell transplant may be an option for some people. Radiotherapy and surgery can be used to treat pain or complications in some patients. You may also have supportive treatment to help you with any side-effects of your illness and treatment.

Are there side-effects from treatment? Page 59

Treatment for multiple myeloma can cause a number of side-effects.

There are treatments to help with most side-effects – tell your nurse or doctor straight away if you have any, so that they can help you.

We're here for you Page 127

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 Support Line on 1800 200 700
- Drop into a Daffodil Centre to speak to a nurse. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

See page 127 for more about our services.

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at **supportline@irishcancer.ie**

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

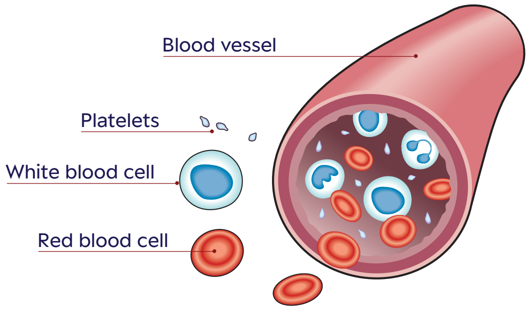
You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About multiple myeloma

What is multiple myeloma?

- Multiple myeloma or myeloma is a blood cancer that affects the plasma cells in your bone marrow. Your bone marrow is the factory that makes all your blood cells.
- The abnormal plasma cells disrupt the immune system and take over healthy bone marrow, which causes symptoms.
- Multiple myeloma is a complex disease, which affects people in different ways.

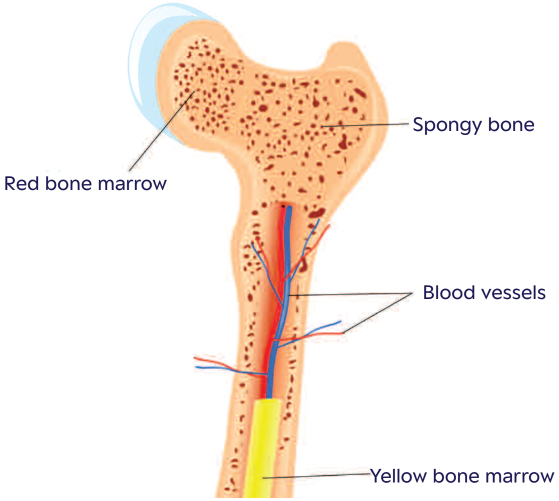
Multiple myeloma is a cancer of the plasma cells in bone marrow. Bone marrow is the soft spongy material found in large bones that makes 3 types of blood cells: red blood cells, white blood cells and platelets. The red blood cells carry oxygen to all the cells in your body, white cells fight infection and prevent disease and platelets are responsible for clotting.



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.

In multiple myeloma the plasma cells are abnormal. These abnormal cells may make a large amount of one type of abnormal antibody known as a paraprotein or M protein. Paraproteins can be found in blood and urine. Occasionally, the myeloma cells make just a fragment of the antibody, called a 'light chain'. The abnormal protein has no useful function and can reduce the amount of normal antibodies being made. This affects your ability to fight infection and build up immunity, which can result in increased infections. The myeloma cells build up in the bone marrow, leaving less room for normal plasma cells to develop. This may cause complications and symptoms, such as bone pain, fractures, infections, kidney impairment and reduced blood counts.



Myeloma cells can move from the soft bone marrow into the harder part of bone and cause damage to bone tissue. The disease affects multiple places in the body where the bone marrow is normally active – this is why it is called 'multiple' myeloma.

More about multiple myeloma

A complex disease

Multiple myeloma is described as a complex disease because build-up of myeloma cells can affect many areas of your body. The areas of the body commonly affected are the kidneys, bone marrow and bones. See page 12 for symptoms.

A long-term disease

Multiple myeloma is treated as a chronic (long-term) illness. With new drug treatments, patients are living much 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 this does not mean that the disease is cured.

An individual disease

Multiple myeloma is a highly individual disease: It can affect different people in very different ways. For example, one patient can have bone disease and another patient might have problems with their kidneys.

Your treatment will be tailored to you. Both you and your doctor will decide what treatment is the best way to manage your disease. It is important that you and your family are well informed, ask questions, get the necessary information and consider your treatment options.

What are the symptoms of multiple myeloma?

The symptoms of multiple myeloma affect every patient differently. Symptoms may be vague at first or have a big effect on you. For example, if you have a serious fracture or a high level of calcium in your blood. Symptoms depend on the extent and type of multiple myeloma at the time of your diagnosis.

The most common symptoms associated with multiple myeloma are:

- Reduced blood cell counts resulting in:
  - Anaemia (low haemoglobin)
  - Bruising or bleeding (low platelet cells)
  - Infections (low white cells/antibodies not working as well)
- Bone pain and fractures (broken bones)
- High calcium in the blood, which can cause:
  - Nausea
  - Vomiting
  - Constipation
  - Confusion
  - Kidney problems

It is important to report any symptoms early to your nurse or doctor so they can treat them quickly.

The assessment tool CRAB-I may be used when describing the effects of multiple myeloma: calcium (C), renal (R), meaning kidneys, anaemia (A), bone disease (B) and infections (I).

Bone effects

The most common symptoms of bone disease are:

- Bone pain
- Bone fractures
- Reduced bone density
- 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 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 and fractures (breaks) can happen in any bone where damage occurs due to multiple myeloma. These are caused by the disease rather than through an injury.

Your team may ask an orthopaedic doctor (bone specialist) to review you and help to manage your bone disease. Bone damage may cause the spine to collapse, leading to height loss and, in rare cases, spinal cord compression.

Spinal cord compression is where a 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.

Spinal cord compression is an emergency and needs to be treated quickly to avoid permanent nerve damage. If you notice any symptoms, it's important to contact your doctor or go the hospital emergency department immediately.

Blood effects

The growing number of myeloma cells can affect production of blood cells in your bone marrow, as there may be little space for normal blood cells to develop. Lack of blood cells can cause symptoms.

Fewer red blood cells: Fatigue and anaemia (low haemoglobin). You may also look pale and have shortness of breath and weakness, because less oxygen is carried in your blood.

Fewer white blood cells: Risk of infection. This includes repeated coughs, colds and flus, and other infections, especially chest infections. It also may take longer to recover from any type of infection.

Fewer platelets: Unexplained bruising or bleeding, such as nosebleeds or bleeding gums.

Kidney effects

The most common kidney problems include reduced kidney function and high blood calcium (hypercalcaemia).

Reduced kidney function

Abnormal proteins called 'light chains' produced by the myeloma cells 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. Kidney problems or failure can cause:

- Less urine (pee) when you go to the toilet. This doesn't always happen
- Swelling in your legs, ankles or feet, caused by fluid retention
- Shortness of breath
- Fatigue (feeling very tired)

If you develop any symptoms, contact your haematologist or nurse specialist.

Hypercalcaemia

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 (feeling sick) and vomiting
- Constipation and abdominal (tummy) pain
- The need to drink more fluids and urinate (pee) more
- Tiredness, weakness or muscle pain
- Confusion, disorientation and difficulty thinking
- Headaches
- Depression

Your team will refer you to a nephrologist (kidney doctor/specialist) to help manage any severe or sudden kidney impairment.

Types of myeloma

Multiple myeloma is a very individual cancer. The symptoms and complications you might have and your response to treatment can be very different to someone else with multiple myeloma. How multiple myeloma might affect you and how effective treatment is can depend on many things, including the type of myeloma you have.

Understanding immunoglobulins

What is an immunoglobulin?

Immunoglobulin is another word for antibody. Antibodies are proteins that protect your body from infection and disease.

Your body produces 5 main types of immunoglobulins to help you to fight infection. Each type of immunoglobulin has a different function in fighting disease.

Light chains and heavy chains

Immunoglobulins (antibodies) are made up of 2 types of proteins – light chains and heavy chains.

Heavy chains: Each immunoglobulin is identified by a letter – A, D, E, G or M. These letters refer to the type of heavy chains in the immunoglobulins. The 5 types of immunoglobulin are often described as IgA, IgD, IgE, IgG and IgM.

Light chain: The immunoglobulins also have 2 light chain portions, which are called kappa (K) or lambda (L).

Abnormal immunoglobulins and myeloma

With myeloma you produce an abnormal type of immunoglobulin. There are different types of myeloma, depending on the type of abnormal immunoglobulin (Ig) made by the myeloma cell. The most common ones are IgG and IgA. The others are quite rare.

Light chain myeloma

When the myeloma cells do not produce a whole immunoglobulin (paraprotein) and only produce light chains this is called light chain myeloma. For patients with this type of myeloma there is an increased risk of kidney impairment/reduced kidney function. This is because the excessive light chains can block the tiny tubes of the kidneys and cause inflammation and damage to the kidney tissue.

Non-secretory myeloma

This is an extremely rare type of myeloma. In this case, no paraproteins are detected in the blood or urine. It may be more difficult to diagnose and monitor.

Solitary plasmacytoma

In some cases, plasma cells can collect and form a tumour in a single bone of the skeleton, ribs, vertebrae, skull, sternum or pelvis.

People with solitary plasmacytoma do not have myeloma cells elsewhere in their body and do not have the complications or symptoms of blood, infections, high calcium or renal (kidney) impairment. You may have radiation, surgery, or both to treat a solitary plasmacytoma. You will be monitored with blood tests in case you go on to develop multiple myeloma at a later stage.

Extramedullary multiple myeloma (EMM)

EMM is where the myeloma plasma cells are found outside the bone marrow. This can present as a soft tissue collection of myeloma cells or infiltration of a site outside the bone marrow, most commonly the liver, skin or lymph nodes.

Plasma cell leukaemia (also called plasma cell myeloma)

This is a very rare and aggressive subtype of multiple myeloma where lots of abnormal plasma cells are found in the blood. Patients can be diagnosed with this disease at presentation or more usually when multiple myeloma progresses to a more advanced stage. Patients with plasma cell leukaemia require more intensive treatment and monitoring.

Genetics and myeloma

Myeloma happens when the DNA of a plasma cell is damaged, which causes the abnormal myeloma cells to be produced. The DNA can be changed in different ways, causing subtypes of myeloma that have different genetic abnormalities. For example, parts of chromosomes may be changed or missing, or you may have an extra chromosome.

The myeloma cells in your bone marrow sample will be tested to give your doctors more information about your genetic subtype. Knowing the subtype can help your doctors predict how your myeloma might behave and decide on the best treatment for you.

For example, genetic subtypes t(4:14), t(4:16), del(17p) and 1q gain can be associated with a higher risk type of myeloma; t(11:14) and hyperdiploidy can indicate less aggressive myeloma.

If you have testing to look for genetic changes, ask your doctor what the change means for you and your treatment.

Conditions related to multiple myeloma

Multiple myeloma is just one of many disorders of the plasma cells. There are some conditions with a risk of transforming into multiple myeloma but this does not always happen. The most common are:

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. This condition is found in 3% of people over 60 years and in the vast majority of cases it never progresses to myeloma. The rate of MGUS progression to myeloma is just 1/100 cases per year.

Smouldering myeloma

This condition is a very slow-growing form of multiple myeloma. Like MGUS, the majority of patients with smouldering myeloma never develop active myeloma. Paraproteins/serum free light chains are found in your blood but usually there are no symptoms and no treatment is needed beyond regular monitoring.

If you are diagnosed with these conditions, you will be monitored with blood tests. At present, 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 light-chain (AL) amyloidosis. This is a condition related to multiple myeloma. Here large amounts of an abnormal protein complex called amyloid are found in your body. This happens when plasma cells in your bone marrow make abnormal light chains that cannot be broken down properly. These light chains stick to one another and collect in body organs such as your kidney, heart or liver. A small percentage of myeloma patients will develop AL amyloidosis and the treatment of AL amyloidosis is similar to multiple myeloma. Importantly, there are other types of amyloidosis that are not related to myeloma and are not treated like myeloma.

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 360 people are diagnosed with multiple myeloma each year. Multiple myeloma is slightly more common in men than women and more common in certain ethnic groups, such as Afro-Caribbean. The average age at myeloma diagnosis is 60-70 years and it is very rare in those under 40. Multiple myeloma is almost unheard of in children.

What caused my cancer?

We don't know exactly what causes many cancers. We do know that the development of myeloma is not closely related to a particular infection or drug and myeloma does not have a strong hereditary link.

If you want to know more about why cancer happens or to learn about risk factors for multiple myeloma, ask your specialist nurse, see our website **www.cancer.ie** or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Preparing for your hospital appointments

Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get all the information they need to plan the next steps in your care.

Before your appointment

- Write down a list of questions and things you would like to discuss. See page 28.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and are not fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is okay to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one
- Your private health insurance details, if you have insurance
- The appointment letter from the hospital, if you got one
- A referral letter or GP letter, if you got one
- Your GP's name and contact details
- Your medical history – your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medication. Hand-written lists can be hard to read or inaccurate
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed
- Medications and medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time. Make sure you're not meant to be fasting – check with the hospital before if you're not sure
- Your phone
- Details of your own phone number and the contact details of your person to call in an emergency.
- Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait.

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Make sure you're booked in for your follow-up appointment before you leave, if required

After the appointment

Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

Note: If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask your doctor/nurse. There is also some space at the back of the booklet for you to write down your own questions.

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?

How often do I need check-ups and blood tests after treatment?

How will I know if the myeloma has come back?

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
- **Angry** that this is happening to you

However you feel, you are not alone.

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

- Ask to speak to the haematology / specialist nurse or the medical social worker 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 – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie.
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical support in a safe, responsible and kind way. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people affected by cancer. Join our online community at www.cancer.ie/community.
- Go to your local cancer support centre. For more information, see page 134.
- Visit **www.multiplemyelomaireland.org** for information on multiple myeloma and support available.

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away or you made need a little time to adjust. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

You can also ask for a copy of our booklet ***Understanding the emotional effects of cancer***. It 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 tests you have will give the doctors valuable information about your multiple myeloma.
- Tests you may have include blood and urine tests, scans to check your bones and tests on samples of the myeloma cells.

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. At present the most common ones include:

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.

Lactate dehydrogenase (LDH): This blood test gives information about the growth of myeloma cells and helps with staging your myeloma.

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 antibodies or immunoglobulins found in your blood. These are called IgA, IgD, IgE, IgG and IgM. (See page 17.)

Tests for abnormal proteins (antibodies)

Plasma cells make proteins called immunoglobulins, which is another word for antibodies. With most types of multiple myeloma, the affected plasma cells make abnormal immunoglobulins. These are called paraproteins or M-proteins. Paraproteins come in 2 forms – either a full immunoglobulin or a small part of the immunoglobulin (called a light chain). In most myeloma cases, both types of paraprotein will be found, but in a minority of cases it will be just one or the other.

Your blood and possibly urine will be tested to see what type of paraprotein your myeloma cells are making and will also measure the amount of the paraprotein. This will help confirm the diagnosis and also can be used to monitor response to treatments. These tests include blood tests called SPEP and serum-free light chain ratio test. The urine test is called UPEP and may involve collecting all of your urine for a 24 hour period.

Bone marrow tests

Bone marrow aspirate and biopsy: This is a test where a tiny sample of your bone marrow, which contains plasma cells, is examined under a microscope to see the number of multiple myeloma cells.

Aspirate refers to a sample of bone marrow fluid.

Biopsy refers to a solid bone marrow sample.

Your doctor and nurse will let you know what you can expect to happen. Usually the sample is taken from the top part of your hip bone. You can still have this test if you've had a hip replacement, as the sample is taken from a different part of the hip.

Before the test you will be given a local anaesthetic to numb the area. Two needles, one after another, are passed gently through your skin into the bone marrow and the samples taken.

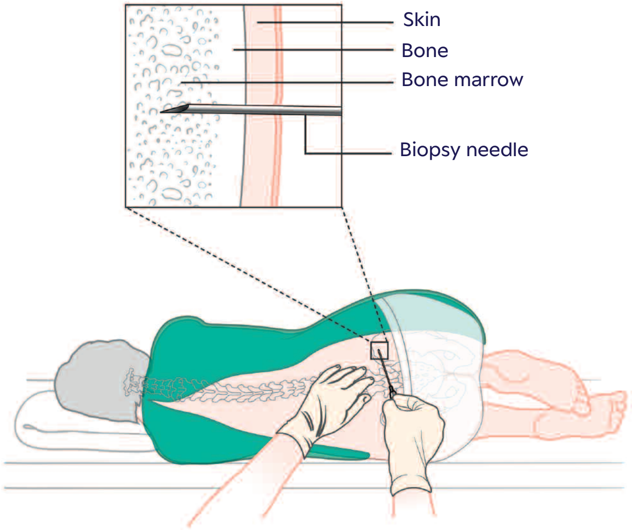


Image courtesy of CRUK/Wikimedia Commons.

The first needle takes fluid from the bone marrow and the second needle takes small parts of the bone marrow itself. It is very common to feel a 'pressure sensation', but the procedure only takes a few minutes. You will be given advice about suitable painkillers to take, if you need them. It is important to tell your doctor or nurse if you are taking any blood thinning medication before this procedure, as you may need to stop these before the bone marrow biopsy.

Cytogenetics: Bone marrow can also be checked to see if there are any abnormal chromosomes. This is called cytogenetic testing or FISH (fluorescence in situ hybridisation). Knowing about any chromosome changes can help your doctors decide which treatments will work best for you and give information about how your disease might progress. It can take several weeks to get the results, but it will not affect your immediate treatment start date. However, in some instances your doctor may need to change your treatment when the cytogenetic tests come back based on the results.

Bone tests

Because myeloma can affect your bones, you will have imaging tests to examine them. Initially you may have had X-rays, but you will likely be referred for scans such as CT scans, MRI and PET. These scans can give more detailed information about your bone health and the extent of your myeloma.

CT scan/skeletal survey scan: Your doctor will 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 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.

Whole-body MRI scan: This scan can give your doctor more information about the extent of your multiple myeloma. It is also used if you have bad back pain and to detect 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, tell the radiographer. An MRI can also be noisy, but you will be given headphones or earplugs to help keep the noise out. 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.

Using dyes during scans

Sometimes a dye may be injected into your arm to make it easier for your doctors to see different parts of your body.

It is important to tell the staff doing the scan that you have multiple myeloma, as the dye might affect your kidney function. Before you have the scan, you will need to have a blood test to check your kidneys.

PET scan: A PET scan uses a low dose of radioactive sugar that shows up areas of activity on a scan picture. A PET scan is helpful to determine the extent of myeloma bone disease and if there are any myeloma cells present outside the bone marrow (extramedullary myeloma).

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 can also call our Support Line on 1800 200 700 or visit a Daffodil Centre and speak to a cancer nurse in confidence.

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. 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. Staging means finding out the extent and severity of your illness. It will help your doctor to decide on your individual treatment plan.

The International Staging System is one system that is still widely used.

International Staging System

This system looks at the levels of 2 blood proteins: beta-2 microglobulin and albumin. It has 3 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.

There is also a newer staging system called the Revised International Staging System (R-ISS). R-ISS uses information from your LDH blood test and the results of the FISH studies on the bone marrow sample. When 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. Ask what the stage means for you and your treatment.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

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.

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.
- **Ask a friend or family member to go with you,** if you would like some support
- **Be cautious of online information.** It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **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 Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@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?

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

There are several treatments that can slow down and control multiple myeloma very well. They can also greatly improve your quality of life. Most doctors will work out a treatment plan that includes different treatments at different stages so your disease is well managed.

It is possible for you to live with this disease for many years.

Research into finding a cure for multiple myeloma continues, as does finding new or better treatments.

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 illness, 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.

> People are living longer with myeloma

Remission

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 stop making abnormal plasma cells. When this happens and the disease is under control, the multiple myeloma is said to be in remission.

When multiple myeloma returns, it is called a relapse. You will have periods of remission followed by periods of active disease (relapse), which requires treatment. You may receive a number of different types of treatment over time.

There are a number of ways to manage multiple myeloma:

- Active monitoring
- Targeted therapies
- Chemotherapy
- High-dose therapy and stem cell transplant
- Maintenance therapy
- Treatment of symptoms (supportive care)
- Other treatments
- Treatment of relapsed or resistant myeloma

Active monitoring: If you have smouldering/indolent 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 if necessary. You watch and wait to see if the myeloma develops further and wait until it is necessary to start treatment. See page 61 for more details.

Combination therapy

Usually a combination of drugs is given to treat multiple myeloma. These drugs include targeted therapies and possibly chemotherapy and steroids.

At the current time, patients newly diagnosed with myeloma will receive a combination of 3 or 4 drugs. One such combination is as follows: one of these drugs will be a steroid tablet. The second drug will be an antibody injection. The third drug will be a type of immunotherapy tablet. If your doctor thinks that you are suitable for 4 drugs, the final drug will be a chemotherapy-type injection. Other combinations are also used.

Targeted therapies: These therapies use your body's immune system to fight cancer. See page 63 for more details.

Chemotherapy: Chemotherapy kills the multiple myeloma cells with drugs. It might be given with targeted therapies or steroids. See page 67 for more about chemotherapy.

High-dose therapy and stem cell transplant: Depending on your age, general health and response to treatment, you may be suitable for intensive treatment involving high-dose chemotherapy followed by a stem cell transplant. See page 73 for more details.

Maintenance therapy: After targeted therapy, chemotherapy or a transplant, you may need to take other drugs on an ongoing basis. These drugs aim to prevent or delay the multiple myeloma from returning. This is called maintenance therapy. See page 74 for more details.

Treating symptoms (supportive therapy): 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 routinely 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.
- Vertebro-plasty is a minimally invasive procedure used to treat fractures in the spine. It involves injecting a cement-like substance into the bone to reduce pain. It may be helpful in a selected number of cases but is not universally effective.
- Other treatments may include painkillers for bone pain, a blood transfusion for anaemia or kidney dialysis if your kidneys are damaged.
- If you are getting a lot of infections or have been admitted to hospital with very severe infections, you may be given a drip of IVIG (intravenous immunoglobulin) to help your immune system to fight infection.

Not everyone will receive the same treatments. See page 81 for more about treating symptoms.

New treatments/clinical trials: Newer treatments are being developed all the time. These include bispecific antibodies (BiTEs), CAR T cells and antibody drug conjugates. Newer treatments may be available to you under special circumstances. For example, as part of a clinical trial. Ask your consultant if there are any new treatments available to treat your cancer and if there are any clinical trials suitable for you. For more about clinical trials see page 75.

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 76 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 nurses, haematologists (blood cancer doctor), pharmacists, transplant doctors, radiologists, dietitians, physiotherapists and occupational therapists. The team will meet to discuss your test results and your suggested treatment plan.

Time to think

It may feel as if everything is happening too fast. Don't feel under any pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you and your friends / family.

Your treatment plan

- The treatment or treatments your doctors recommend for you are based on the latest research and international guidelines about the best ways to treat multiple myeloma.
- You may notice that other people are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours, so your treatment plan may be different.
- Talk to your doctor or nurse if you have any questions about your treatment plan.

Second opinion

You might also find it reassuring to have another medical opinion to help you make a decision about your treatment. Your treating doctor or GP can 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 a particular 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.

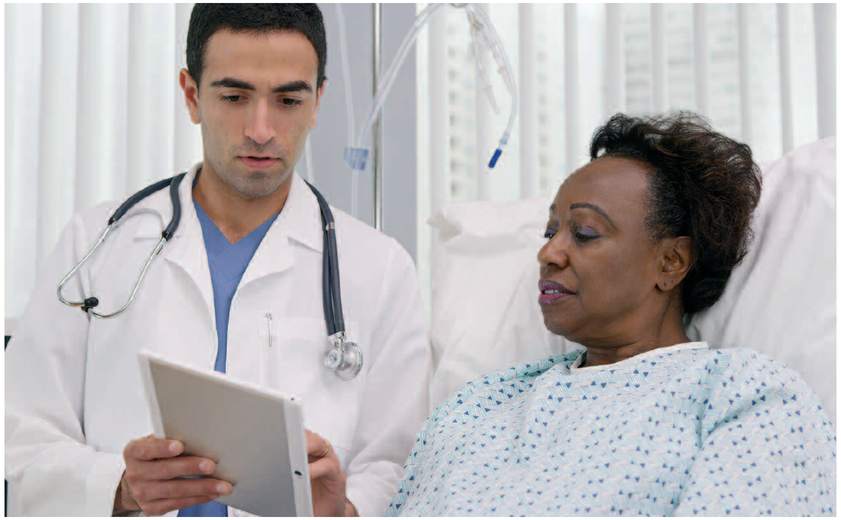
Giving consent for treatment

Before you start any treatment, 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
- Possible side-effects from 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 treatments can be hard to understand 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.



Who will be involved in my care?

Usually a team of healthcare 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. They coordinate your cancer care.

Advanced nurse practitioner (ANP): ANPs give expert information and support. They are specially trained to carry out tests and assist with reviewing your treatment.

Radiation oncologist: A doctor who specialises in treating cancer patients using radiotherapy.

Orthopaedic (bone) and/ or renal (kidney) team: You may be referred to other teams to help manage specific symptoms.

Medical social worker: A person trained to help you and your family with your social issues and emotional and practical needs. They can also give advice on benefits and financial matters and on supports and services available to you.

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

Pharmacists: Pharmacists in hospital and in your local pharmacy dispense chemotherapy and other cancer drugs. They can give advice on your cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Psycho-oncology team: This team is made up of specialists in the psychological care and support of 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), community welfare officers and home help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Waiting for treatment to start

Cancer treatment should start soon after a diagnosis is confirmed, but it may take a few weeks for all the test results to come back.

You may feel anxious while you're waiting for tests results and the start of your treatment, but it's important that your medical team has all the information they need from blood tests, scans and biopsies to plan the best treatment for you. Your medical team wants the best for you. For most cancers, waiting a few weeks won't affect how well the treatment works.

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

You might like to focus on your own health while you're waiting for treatment. This can help you prepare for your treatment and feel more in control.

How can I help myself?

Eat well

Eating as well as possible can help you during your treatment. It can help you to:

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better so you can finish your course of treatment
- Cope better with side-effects of treatment
- Reduce your risk of infection and other complications
- Recover faster

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet ***Understanding diet and cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our **website www.cancer.ie**

Be active

If you are able, it can really help to be active before and after your treatments. Keeping up or increasing your activity levels can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Reduce the risk of other health issues

Multiple myeloma can affect your bones. Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment. For example, chest infections.
- Smoking can reduce how well radiotherapy and some other treatments work
- Not smoking reduces the risk of other illnesses

If you would like advice or support on quitting, call the HSE Quit Team on Freephone 1800 201 203, visit **www.quit.ie** or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on cancer treatments, including what to expect and how to manage side-effects.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

Don't keep any worries or 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. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

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.

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.

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.

Types of treatment

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. Your healthcare team will 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 Support Line 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. Report any symptoms or problems to your nurse early. All of the above types of treatment are discussed on the following pages: targeted therapies on page 63, chemotherapy on page 67 and steroids on page 72.

Once you have finished your first treatment, your doctor may decide to give you a reduced dose of treatment for a longer period of time. This is called maintenance therapy. See page 74 for more details.

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed information sheet to take home with you.

You can visit the Health Products Regulatory Authority's website at **www.hpra.ie** for information about your drugs and possible side-effects. If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

Targeted therapies

- Targeted therapies work with your body to fight cancer.
- New targeted therapies are being developed all the time.
- Possible side-effects include peripheral neuropathy, fatigue, infections, and blood clots.

Targeted 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.

Immunotherapy boosts your body's immune system to fight cancer.

Some treatments fit into more than one of these groups. A combination of different types of targeted therapies can be used to treat your myeloma, along with steroids and possibly chemotherapy drugs.

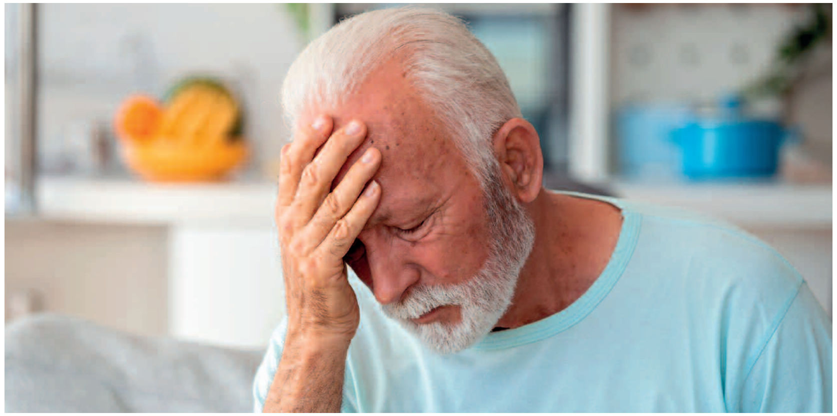
Some drugs are given in tablet or capsule form. Others are given into a vein through a drip or by injection under the skin.

New targeted therapies

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 75). 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?

Side-effects can happen with any treatment. Everyone's experience is different. 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 the next page for more.
- Fatigue. See page 91
- Infections
- Bruising and bleeding
- Constipation or diarrhoea
- Dryness of skin and mouth
- Increased risk of blood clots
- **Rashes:** Rashes can happen with targeted therapies. These may be mild or more severe. It is very important to tell your medical team if you have a skin rash.

Birth defects

Certain targeted therapies can cause severe birth defects. Patients of childbearing age will be given information and advice about contraception and will need to give informed consent if targeted therapies are recommended as part of their treatment plan.

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, B vitamins 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.

Hints and tips: Peripheral neuropathy

- **Keep your hands and feet warm** by wearing gloves and socks.
- **Take regular exercise** as advised by your doctor or physiotherapist.
- **Eat a well-balanced diet** and take vitamin supplements if advised by your doctor.
- **Manage your weight.** This can reduce pressure on your nerve endings. Get advice from your dietitian if you need to lose weight.
- **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**, but ask your doctor for advice about if it is safe for you.
- **Some topical creams and lotions can help.** Ask your doctor about these.

Chemotherapy

- 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.

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.

How often will I have chemotherapy?

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. 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 and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells.

Most side-effects can be helped by medication so it is really important to report symptoms to your specialist nurse early.

Usually, the side-effects go away when the treatment ends or soon after. Side-effects may include:

- Reduced blood cell counts
- Fatigue
- Changes in kidney function
- Nausea and vomiting
- Loss of appetite / taste changes
- Constipation and diarrhoea
- Mouth problems
- Hair loss

Reduced blood cell counts: Chemotherapy can affect your bone marrow and reduce the numbers of blood cells. Fewer white blood cells mean that you are more likely to get infections. As a result, you may need to take antibiotics often, including antibiotics to prevent infection. You may also need a drug called G-CSF 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 injections (see page 88). 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.

Hints and tips: 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, flus 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 high temperature, shortness of breath or bleeding that cannot be stopped.** Your hospital will advise you on the temperature advice you need to follow.

Fatigue: Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 91.

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 treatment. Your kidneys will be carefully checked by blood tests before each treatment and the dose may be changed if needed. Drink as much fluid as you can – ask your nurse or doctor how much fluid they recommend. Talk to your doctor if you have decreased urination, swelling of the hands or feet (oedema) or headaches, as these can be a sign of reduced kidney function.

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/taste changes: Some chemotherapy drugs can change the way some foods taste or reduce your appetite for a while. It can help to get advice from a dietitian if this happens. We have a booklet called ***Diet and cancer***, which has tips to help you cope. For a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it from **www.cancer.ie**

Constipation and diarrhoea: Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements). Your doctor or nurse can give you advice – and medication, if necessary – to help with these problems.

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. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back 3-6 months after you stop chemotherapy. 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. You will be given details of who to contact before you start your treatment.

Allergy: On rare occasions people can have a reaction to certain chemotherapy drugs. Reactions can include rash, itching, low blood pressure and shortness of breath. Contact the hospital if you have any of these side-effects. For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

You can also look at our website, **www.cancer.ie** for tips on coping with different side-effects.

Steroids

Steroids are an important part of your multiple myeloma treatment. They are hormones naturally made in your body and can help anti-cancer drugs work better. Dexamethasone is the steroid commonly used for multiple myeloma. In high doses steroids 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, tearfulness or high spirits
- Sleep disturbances
- Stomach upset
- Increase in blood sugar levels, which can lead to diabetes
- Fluid retention
- Higher risk of infections

While receiving steroids, you will have regular blood tests to check your sugar levels. Your doctor will prescribe an antacid to prevent any stomach upsets.

If any of these symptoms are causing problems for you, tell your nurse or doctor. They can reduce the dose of steroids.

High-dose therapy and stem cell transplant

Your doctor may consider you suitable for high-dose therapy and stem cell transplant. This may lead to a better response or a longer remission. This is because stem cell transplants allow you to have higher doses of chemotherapy 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 are 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. Autologous transplants are generally used to treat multiple myeloma. Rarely stem cells are taken from a donor. This is called an allogeneic transplant.

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 Support Line 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 reduced-dose form of treatment for a longer period of time. The goal is to sustain your response to treatment and 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. 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, ask your treating team, call our Support Line on 1800 200 700 or email our cancer nurses at supportline@irishcancer.ie

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer or reducing side-effects. Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together.

Because the drugs are still on trial, you'll be very closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment. 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 Support Line 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. The aim of treatment is to get the myeloma back under control, minimise complications and maintain a good quality of life.

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

If you relapse, you will need treatment. The type of treatment you have will depend on your age, your general health, your previous response to treatment and your lifestyle.

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. A second stem-cell transplant may be an option for some patients.

Your doctor will discuss your treatment options 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.

Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. The palliative care team is very experienced in managing the physical symptoms of cancer, such as pain and nausea. Palliative care includes end-of-life care, but your haematology team may also recommend palliative care to relieve symptoms earlier in your illness.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

You can access palliative care support in a community hospital or your own home. Or you may be able to attend a hospice where you can spend a day or two receiving treatment. Inpatient, hospice and community palliative care teams work with your haematology team and family doctor (GP).

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with cancer.

Talk to your doctor or nurse for more advice. If you do not feel well enough, your family can do so. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak in confidence with our cancer nurses.

Managing side-effects and symptoms

How are symptoms treated?

- Treatment of symptoms is known as supportive therapy.
- Possible symptoms include calcium in the blood, reduced kidney function, bone disease, risk of infection and a low red blood cell count (anaemia).

Doctors use the letters CRAB-I to describe the type of symptoms or effects myeloma causes in some organs and tissues: calcium (C), renal (R), meaning kidneys, anaemia (A), bone disease (B) and infection (I).

Serious complications like infections, anaemia, bleeding, fractures and spinal cord compression need to be treated straight away.

A lot of symptoms are discussed here, but most people will only experience some of these. These symptoms are managed with supportive therapies.

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 to relieve 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.

Hints and tips: Bone pain

- **Take your painkillers regularly 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.
- **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

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 are given as an injection into a vein, usually once a month. Usually they are a long-term treatment, for at least 2 years. Your doctor will advise you how long you will need to stay on these medications. The most commonly prescribed bisphosphonates are zoledronate and pamidronate.

Your doctor will discuss which type of bisphosphonate is best for you. Bisphosphonates can also help to lower raised calcium levels in your blood (hypercalcaemia). They may also affect myeloma cells, preventing their growth and survival.

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.

Bisphosphonates side-effects: There are several side-effects to bisphosphonates but many people experience none. 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.

See page 91 for more details on fatigue. Blood and urine tests to check your kidneys will be done regularly.

Drink as much fluid as you can to prevent kidney problems.

Bisphosphonates and dental care

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 or nurse 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 Support Line 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 the low-risk guidelines.
- Stop smoking.

- Keep a healthy weight.
- Wear a support brace, if recommended by an orthopaedist/physiotherapist.

It's very important to avoid stress on your bones, so be careful to avoid slips, trips or falls and discuss any activity that is strenuous with your nurse or doctor first. There's more about bone health and cancer on our website, **www.cancer.ie**

Surgery

Depending on the severity of your bone disease, you may need orthopaedic (bone) 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 to treat a plasmacytoma (see page 18).

The use of radiotherapy to a specific area can kill myeloma cells quicker than chemotherapy and with fewer side-effects.

The number of radiotherapy sessions you will have will depend on several factors, including the reason for the radiotherapy (for example, plasmacytoma, spinal cord compression, pain) and the area to be treated. The treatment will be designed to suit your own specific needs. For more advice or a copy of the booklet ***Understanding Radiotherapy***, contact our Support Line 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 – unable to bear weight on your legs or lift your arms
- 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, go to the emergency department at the hospital. They will contact your haematology team once you explain you have multiple myeloma. Early treatment for spinal cord compression is essential and includes radiotherapy and steroids.

Kidney disease

Fluids

You will be advised to drink plenty of fluids. Avoid drugs that can affect your kidneys, for example, ibuprofen. If you're unsure about your drugs, ask your haematology team or local pharmacist. 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. 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. Dialysis uses a machine to filter your blood in the same way a healthy kidney does. You may need it once or several times a week. You will be referred to the renal (kidney) team if you need dialysis. If you're having treatment for your multiple myeloma, you will usually have treatment after you've had your dialysis.

Blood and bone marrow effects

You may have fewer red blood cells, white blood cells and platelets as a result of your myeloma, your treatment or both. Changes to the number of different blood cells 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 usually 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/anti-viral medications

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 travelling. Shingles (herpes zoster virus) and pneumocystis pneumonia (PCP) can also be common complications and you may be given preventative (prophylactic) medications to prevent these.

Your team will assess your risk of getting an infection and give you preventative medication, if needed.

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 high temperature. Your hospital will advise you about the temperature advice you need to follow and the phone number to call
- Cough
- Feeling hot and cold/shivers
- Stinging or burning sensation when passing urine
- Redness at the site of your central line
- Feeling unwell

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 or you may be started on a preventative blood thinner by your doctor. 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.

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer. Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

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

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.

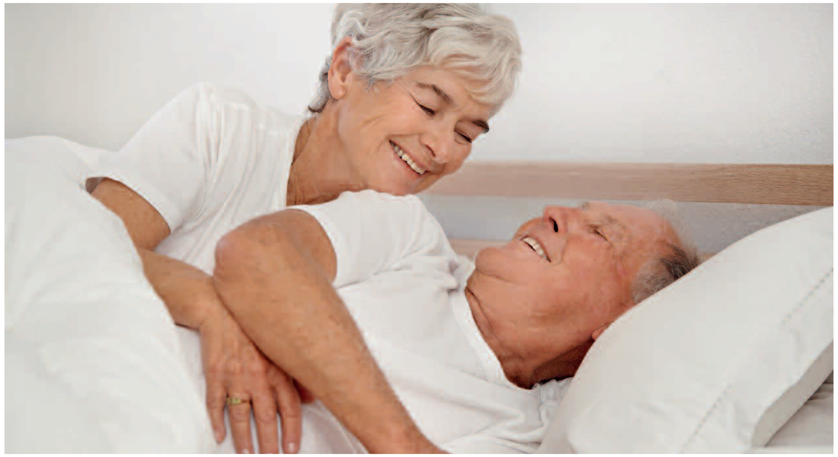
Hints and tips: Fatigue

- **Exercise can improve fatigue** – ask your doctor for advice about the best exercise for you.
- **Build rest periods into your day.** Short naps can help as long as they don't interfere with you sleep at night.
- **Plan your days so you can do the things that are important to you** when your energy levels are best.
- **Ask for help at work or at home**, especially with cooking, housework or childcare.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor.
- **If you are taking steroids, take them early in the day.**
- **Try to avoid stress.** Talk to friends and family about any worries you have. Relaxation therapies such as yoga and meditation may help.
- **Have a good bedtime routine** and avoid stimulants like electronic devices, caffeine and alcohol before bedtime.
- **Try complementary therapies** like meditation, acupuncture or massage, if your doctor says they're safe for you.

Our booklet ***Coping with fatigue*** has more advice. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre for a free copy. It's also on our website **www.cancer.ie**

Will treatment affect my sex life?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer 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. Touching and holding each other can help you to stay physically close. You may find that talking about your feelings may ease any worries you have. Try to talk to your partner and find out how they are feeling too.

If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

> It's important to talk to your treating team about contraception and if you are hoping to start a family or have more children.

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. Some chemotherapy and other cancer drugs may harm a developing baby, so it's important to avoid pregnancy during and for a time after treatment.

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 talking about these matters, so try not to feel embarrassed. You can also call our Support Line 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 supportline@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. He or she can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility 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 Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and aromatherapy. Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet ***Understanding cancer and complementary therapies***, or download it from our website **www.cancer.ie**

Living with multiple myeloma

Living with multiple myeloma

With advances in anti-cancer treatments, many people with multiple myeloma continue to live full and meaningful lives, even if their cancer cannot be cured.

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.

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 For example, high doses of vitamin C may increase your risk of kidney damage. Talk to your doctor first if you are thinking of taking vitamin or herbal supplements during your drug treatment.

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: A good night's sleep has many benefits 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. Tell your doctor or nurse, who may be able to help. For example, they may refer you to hospital psycho-oncology services. Also, try talking to your family or close friends about your concerns. If you find this difficult, a counsellor may help you. See page 110 for more.

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. There's advice on going back to work after cancer treatment in our booklet ***Life after Cancer***.

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 wear a support brace or 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 to manage at home. They can visit your home to see if you need special adaptations, such as bath rails or a higher chair. Your treating team can refer you to an occupational therapist.

The medical social worker in your hospital can also help with your social, emotional and practical needs. They can give advice on benefits and financial matters and on practical supports and services available to you when you go home.

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. Get 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.
- 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. They 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 Support Line on 1800 200 700 for further details or visit a Daffodil Centre.
- For sun holidays, make sure you use a sunscreen with high protection (SPF 50), especially if you have had 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. Avoid alcohol. It is best to use bottled water when abroad and avoid ice cubes in drinks, as they may be made with tap water.

Anxiety and depression: Multiple myeloma is known to relapse (come back again after treatment). When you relapse you will need treatment again. If the multiple myeloma is not responding to your current treatment, your doctor may change your treatment plan. Coping with relapses and adjusting to new treatments may make you feel distressed and anxious. It is normal to feel this way. Make sure that you are comfortable with the treatment planned and if you continue to feel anxious or become depressed, it is important to seek help early. See page 110 for more details on anxiety and depression.

If you have any worries or queries, contact our Support Line 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.

After-treatment workshops

You might like to join our **Life and Cancer – Enhancing Survivorship (LACES)** programme when you have completed treatment or have started maintenance therapy. This workshop covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

What follow up will I need?

During and after your treatment you will need to have regular check-ups. The check-ups 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. You are likely to have periods of remission followed by periods of relapse, where you will need treatment.

There is usually a list of medication to take throughout your treatment or from time to time. For example, antibiotics, antivirals, antifungals, tablets to prevent sickness, heartburn, gout, blood clots, and laxatives. At each visit, your doctor or nurse will check the dose of these medications and how often you need to take them. Remember to tell them 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. Your doctor will also advise you about any vaccinations you should have.

The follow-up is likely to continue for the rest of your life. 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 or specialist nurse know as soon as possible.

Planning ahead

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**

Coping and emotions

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment. A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the Emotional Effects of Cancer.*** Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.

> A cancer diagnosis can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

It's not a sign of failure to ask for help
or to feel unable to cope on your own.

Counselling

If you're feeling very distressed or finding it hard to cope, 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.

The Irish Cancer Society funds professional one-to-one counselling, remotely or in person at many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

> "Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better."

Ways to get emotional support

Find out about cancer support services in your area: Most 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 134 for more about cancer support services.

Join a support or educational group: You might find it 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.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

Get online support: Special websites called online communities let you 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 worries. 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 Support Line on 1800 200 700 or drop into a Daffodil Centre.

Peer Support

Peer Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has had a similar cancer experience to you. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Multiple Myeloma Ireland is a support network for multiple myeloma patients and carers: **www.multiplemyelomaireland.org**

Positive emotions

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

> "I am very happy and content … even though I have to live with this."

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 ***Understanding the Emotional Effects of Cancer*** can help to you find ways to talk about your cancer and to ask for the help and support you need.

Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, as another family member or friend to talk to them.

Talking to children and teenagers

You may feel it's best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character.

A useful booklet called ***Talking to Children about Cancer: A Guide for Parents*** gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions. The booklet is available free of charge from Daffodil Centres or by calling the Support Line. It's also available on our website **www.cancer.ie**.

Further information and support

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.

Supporting someone with cancer

How you can help

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one's illness and treatment, how it might affect them physically and emotionally, and how you can best support them. Visit our website **www.cancer.ie** or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor.The Irish Cancer Society funds one-to-one counselling for friends and family members remotely or in person at many local cancer support centres. Talk to your GP or see page 110.

Find out about support for carers

Find out about groups and organisations for carers. Many local support centres have services for carers too.

> "The emotional support I got made a huge difference to me."

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 Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for someone with cancer***. The booklet has a section on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. 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. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, ***Caring for someone with cancer***, has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website **www.cancer.ie**

Support resources

Money matters

- If you have cancer, you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your cancer treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as 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.

Practical and financial solutions from the Irish Cancer Society

We provide individualised financial support and practical solutions for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**

We can tell you about public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having a Practical and Financial Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

To be referred, call our Support Line on Freephone
1800 200 700 or contact your nearest Daffodil Centre.
Our nurses will chat with you and confirm if a discussion with one of our Practical and Financial Officers might help.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Medicines
- Medical aids and equipment (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, 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 don't 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 tests or treatment to check you're covered.

Benefits and allowances

There are benefits 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: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 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 keep a copy of completed forms, so take a photo or photocopy them before posting.

If you have money problems

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 0818 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 131 for more details of our **Transport Service** and the **Travel2Care** fund.

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

Money and finances

Go to **www.cancer.ie** and see our **Managing money** page for information on:

- 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

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Transport Service
- Night Nursing
- Publications and website information
- Support in your area
- Practical and financial solutions (see page 124)

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am–5pm. You can also email us any time on supportline@irishcancer.ie or visit our Online Community at **www.cancer.ie/community**

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of the service, please go to **https://www.cancer.ie/Support-Line-Video-Form.**

One of our nursing team will then email you with the time for your video call. The email will also have instructions on how to use Microsoft Teams on your phone, tablet or computer.

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.

This is a walk-in service; you do not need an appointment. For opening hours and contact details of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on Freephone 1800 200 700, Monday to Friday 9am-5pm, or contact your nearest Daffodil Centre.

Tell us in English the language you would like. You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.

We will connect you to an interpreter.

The interpreter will help you to speak to us in your own language.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

For more information on Peer Support, search 'peer support' at **www.cancer.ie**

Patient Education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person, in one of our 13 Daffodil Centres nationwide, or online. To register for a place at one of our patient education workshops, call our Support Line on 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie

Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them.

For more information about what's available near you, visit **www.cancer.ie/local-support**, contact your nearest Daffodil Centre or call our Support Line on Freephone 1800 200 700.

Transport Service

We provide transport and financial grants for patients in need who are in cancer treatment.

- Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and the Bons Secours Hospital, Cork.
- **Travel2Care** is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, Freephone 1800 200 700 or contact your nearest Daffodil Centre.

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 a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

For more information, please contact the health professional who is looking after your loved one.

> “We were really lost when we brought Mammy home from the hospital and the night nurse's support was invaluable. She provided such practical and emotional support.”

> “Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.”

Publications and website information

We provide information on a range of topics, including cancer types, treatments and side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.

To find out more about the Irish Cancer Society’s services and programmes:

- **Visit us at www.cancer.ie**
- **Call our Support Line on Freephone 1800 200 700**
- **Email our Support Line at supportline@irishcancer.ie**
- **Contact your nearest Daffodil Centre**
- **Follow us on:**
  Facebook
  X
  Instagram
  LinkedIn

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, their partners, families and carers, during and after treatment, many of which are free. For example:

- **Professional counselling.** The Irish Cancer Society funds one-to-one counselling remotely and through many local support services
- **Support groups,** often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **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 lymphoedema services, such as education, exercise, self-management 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 Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

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.

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 in your blood can be raised when bone cells are broken down.

Cycle: A period of chemotherapy.

Erythropoietin: A type of protein called a growth factor, given as an injection. It is used to treat a low number of red blood cells (anaemia) due to cancer or its treatment.

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 targeted 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 targeted 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.

Red blood cell: Blood cells that carry oxygen to every cell in your body.

Relapsing myeloma: When myeloma returns after having been in remission.

SAP (serum amyloid P component) scan: An injection of a mildly radioactive substance followed by a scan. It can show up a substance called amyloid in the body. An SAP scan can be used to diagnose amyloidosis.

Staging: Tests that measure the size and extent of myeloma.

Targeted therapy: A treatment that uses your body's immune system to fight myeloma.

White blood cell: Blood cells responsible for fighting infection.

Notes / questions

Acknowledgments

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 especially thank the people who generously shared their personal experiences of cancer throughout this booklet. We also 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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The following sources were used in the publication of this booklet:

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit our website www.cancer.ie if you want to get involved.

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 Peer 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

Did you like this booklet?

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

Irish Cancer Society

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie