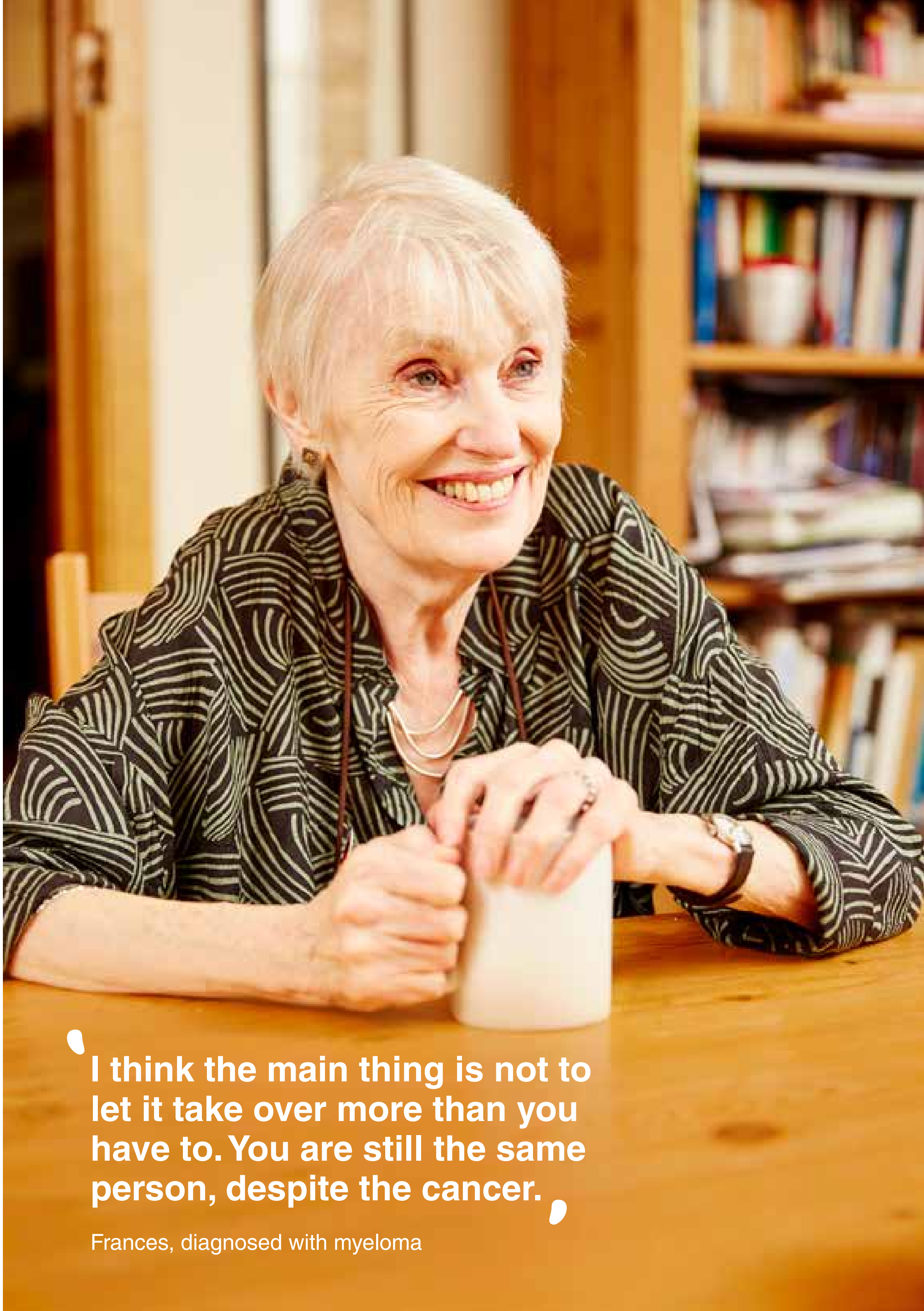
MACMILLAN
CANCER SUPPORT

UNDERSTANDING MYELOMA



> I think the main thing is not to let it take over more than you have to. You are still the same person, despite the cancer.

Frances, diagnosed with myeloma

About this booklet

This booklet is about a type of blood cancer called myeloma. It is for anyone who is having tests for myeloma or has been diagnosed with it. There is also information for carers, family members and friends.

The booklet explains the symptoms of myeloma, how it is diagnosed and how it may be treated. It also has information about ways to cope with myeloma. This includes your feelings, relationships, work and finances.

We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 139 to 150, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (see pages 151 to 152).

Quotes

In this booklet, we have included quotes from people who have had myeloma, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes Frances, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Help us improve our information. Scan the QR code below to tell us what you think.

Contents

ABOUT MYELOMA

What is myeloma?

Myeloma is a type of blood cancer that develops from abnormal (cancerous) plasma cells. These are called myeloma cells.

Normal plasma cells are a type of white blood cell made in the bone marrow. In myeloma, the abnormal plasma cells fill up the bone marrow.

Myeloma cells may be found in the bone marrow of different bones around the body. So it may also be called multiple myeloma. To understand myeloma, it can help to know a little bit about:

- bone marrow
- plasma cells
- immunoglobulins
- myeloma cells.

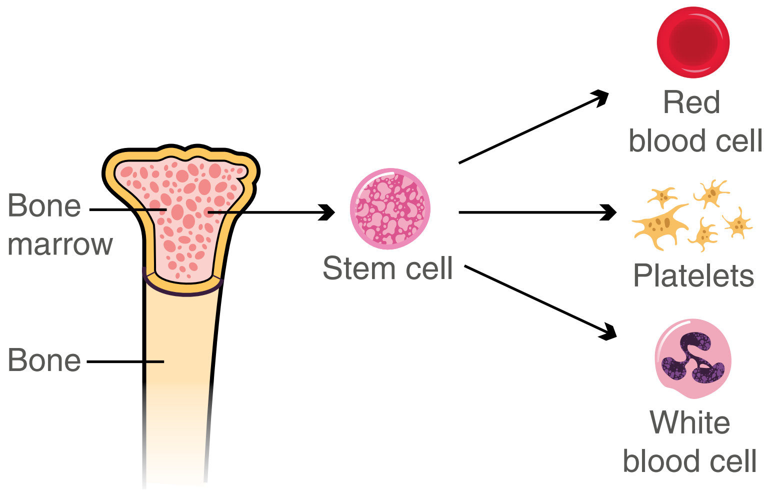
Bone marrow

Bone marrow is a spongy tissue found inside the centre of most of our bones. It produces all of our blood cells. Bone marrow is part of the body's immune system, which helps to protect us from infection and disease.

All blood cells in the bone marrow begin as stem cells. The stem cells then develop into 3 different types of blood cell:

- red blood cells, which carry oxygen to all the cells in the body
- platelets, which help the blood to clot and control bruising and bleeding
- white blood cells, which fight infection.

Bone marrow producing stem cells



Plasma cells

Plasma cells are a type of white blood cell, which fight infection. They make different types of antibodies. The antibodies travel in the blood and help to fight any viruses or bacteria in the body. These antibodies are also called immunoglobulins. If you have an infection, your bone marrow produces more plasma cells and immunoglobulins to fight against it.

Immunoglobulins

Immunoglobulins are Y-shaped structures that are made up of:

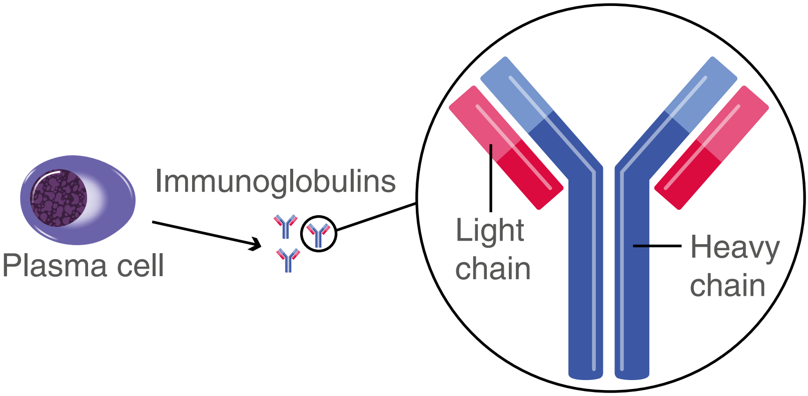
- 2 long protein chains, called heavy chains
- 2 shorter protein chains, called light chains.

There are 2 types of light chain. They are called kappa and lambda. These are Greek letters. You may sometimes see the Greek symbols for them used.

There are 5 types of heavy chain, referred to by the letters A, D, E, G and M.

Immunoglobulins are named after the type of heavy chain they are made up of. This means there are 5 immunoglobulins, called IgA, IgD, IgE, IgG or IgM. The 'Ig' is short for immunoglobulin.

An immunoglobulin



Myeloma cells

Normally, plasma cells are made in a controlled way. With myeloma, the process is out of control and lots of abnormal (cancerous) plasma cells are made. These are called myeloma cells.

The myeloma cells fill up the bone marrow. This makes it harder for the bone marrow to make enough other normal blood cells. This causes some of the symptoms of myeloma (see pages 14 to 15).

Myeloma cells usually make an abnormal immunoglobulin. This could be any one of the 5 types of immunoglobulin (see page 8). The abnormal immunoglobulin is sometimes called a paraprotein, or M protein.

Having fewer normal immunoglobulins also means it can be harder for your body to fight infections.

Types of myeloma

There are different types of myeloma. They may cause different symptoms, but they are all usually treated in the same way.

Each type of myeloma is named after the abnormal immunoglobulin (paraprotein) that the myeloma cells make. The most common type of myeloma is IgG, followed by IgA. The least common types are IgM, IgD and IgE.

There is also a type of myeloma called light chain myeloma, or Bence Jones myeloma. This is when the myeloma cells make too many light chains. This type of myeloma does not make an abnormal immunoglobulin. The light chains can be detected in a blood or urine test.

There is a rare type of myeloma, called non-secretory myeloma, that does not produce light chains or abnormal immunoglobulins.

Plasma cell conditions related to myeloma

There are other conditions that affect plasma cells, which can sometimes develop into myeloma. These are the 2 most common conditions:

- Smouldering myeloma, which is sometimes called asymptomatic myeloma. Asymptomatic means you have no symptoms.
- MGUS (monoclonal gammopathy of unknown significance), which is a non-cancerous condition that affects plasma cells. It is also sometimes called monoclonal gammopathy of undetermined significance.

These conditions do not normally cause symptoms. They are usually diagnosed after a routine blood test. Usually, you do not need treatment. But your doctor will regularly monitor you with blood tests.

Sometimes abnormal plasma cells are found in a bone in only one area of the body. This is called solitary plasmacytoma. Rarely, it can be outside the bone. This condition is often treated with radiotherapy. If you have a solitary plasmacytoma there is a risk you may develop myeloma. Your doctor will regularly monitor you with blood tests to check for this.

We have more information about MGUS on our website (see page 134).

Risk factors and causes of myeloma

In the UK, around 5,800 people are diagnosed with myeloma each year. Doctors do not know what causes myeloma, but having MGUS (monoclonal gammopathy of unknown significance) increases the risk of developing it. We have more information about MGUS on our website (see page 134).

Almost everyone with myeloma has had MGUS first, but it may not be detected. But only a small number of people who have MGUS develop myeloma.

Like other cancers, myeloma is not infectious and cannot be passed on to other people.

Age

Myeloma is more common in people over the age of 65. It is very rare in people under the age of 40.

> **‘A routine blood test showed I had MGUS, which I had never heard of. My paraprotein levels were quite high, so the doctors thought it might be myeloma.’**
>
> **Frances**

Race

Myeloma is more than twice as common in black people than in white people.

Sex

Myeloma is slightly more common in men than in women.

Family history

People who have a close family member (such as a parent, brother or sister) with myeloma may have a very small increase in their risk of developing it. If you are worried about this, your doctor can explain what the risk might be.

Immune system conditions

Some health conditions can weaken the immune system, or cause the immune system to attack healthy cells in the body by mistake (autoimmune disease). These types of conditions may slightly increase the risk of developing myeloma.

Being overweight

Some research suggests that being overweight may increase the risk of developing myeloma. Keeping to a healthy body weight may reduce the risk of myeloma and other cancers.

Symptoms of myeloma

Myeloma may not cause any symptoms in its early stages. It may be diagnosed after a routine blood test, before any symptoms are noticed. Or it may be diagnosed after going to your GP or to hospital with symptoms (see pages 18 to 28). Symptoms of myeloma can include:

- constant bone pain in 1 area (such as in the back, ribs, hip or pelvis)
- an increase in the risk of infection or having infections, one after another, that need antibiotics to treat them
- becoming anaemic and bruising and bleeding more easily – anaemia is when the number of red blood cells in your blood is low
- feeling extremely tired (fatigue)
- tingling or numbness in the hands or feet, though this is rare.

Myeloma may also cause symptoms because it has caused damage to the bones. This can include bone thinning and sometimes fractures. Bone damage can also cause high levels of calcium in the blood, called hypercalcaemia.

Symptoms of hypercalcaemia include:

- feeling thirsty
- feeling sick (nausea)
- vomiting
- constipation
- confusion
- passing urine (peeing) more frequency and also peeing more at night
- drowsiness
- headaches.

Myeloma can also cause symptoms if the kidneys are affected. These include feeling tired or confused and having problems peeing.

These symptoms can be caused by other conditions. But if you have any of these symptoms, it is important to get them checked by your GP.

We have more information about these symptoms and how they can be managed and treated on pages 76 to 95.

DIAGNOSING MYELOMA

How myeloma is diagnosed

Myeloma can be diagnosed in different ways. Some people may see their GP about symptoms. These include:

- pain in the bones
- tiredness
- having infections one after the other (recurrent infections).

Your GP may arrange for some blood tests or scans. If necessary, they then refer you to a specialist at the hospital for more tests and treatment.

Some people are diagnosed with myeloma after going into hospital with more severe symptoms such as:

- being very unwell with an infection
- bone problems
- spinal cord compression (see page 82)
- kidney problems (see pages 90 to 91).

At the hospital

You will usually see a doctor who specialises in blood conditions (haematologist). They ask about your general health and any previous medical problems. Then they examine you and arrange more tests. These include:

- blood tests
- tests on your urine (pee) to check for a protein called the Bence Jones protein
- a bone marrow biopsy to collect a sample of cells from the bone marrow
- scans to look at the bones.

If myeloma cells are found, further tests may be done on bone marrow sample to find out more about the cells and how they might respond to treatment. This is called cytogenetic testing (see page 28).

We have more information about these tests and scans on pages 20 to 28.

Blood tests

Blood tests are an important way to diagnose and monitor myeloma. These tests include the following:

- Serum protein electrophoresis – this is a test to find out if a paraprotein (M protein) is in the blood and what type it is. If it is present, a second test may be done to find out the type.
- Paraprotein (M protein) level – this is a test to measure the amount of paraproteins in the blood.
- Light chains (serum free light chain assay) – this is a test to measure the amount of light chains in the blood and the amount of kappa and lambda light chains there are.
- Beta-2 microglobulin level (B2M) – this is a test to see how active the myeloma is and to find out the stage of the myeloma. B2M is a protein that is on the surface of most cells in the body. In people with myeloma, the level of B2M is often higher.

Having a blood test

Other blood tests

You will also have blood tests to show how the myeloma is affecting you. The tests measure the following:

- Blood cells levels (full blood count) – this test measures the number of red blood cells, white blood cells and platelets in your blood. These can be low in people with myeloma.
- Urea and electrolytes (U&Es) and creatinine levels – this test shows how well your kidneys are working.
- Calcium levels – this test measures the level of calcium in the blood. The level can be raised if the myeloma is affecting your bones.
- Albumin levels – this test measures the level of a protein called albumin in the blood. The level can be low in people who have myeloma. This test is used to help stage the myeloma (see pages 29 to 30).
- Lactate dehydrogenase (LDH) levels – this test measures the amount of a substance called LDH in the blood. This can be higher in patients with myeloma. The level of LDH is also used to help find out the stage of the myeloma.

Tests on your urine

You may be asked to collect samples of your urine (pee). This is to test for Bence Jones protein in your urine and to test how well your kidneys are working. Sometimes you need to take a container home and collect your pee over 24 hours. The nurses will explain more about how to do this test.

Bone marrow test

This is when a doctor or specially trained nurse takes a small sample of bone marrow from the back of the hip bone (pelvis). The sample is sent to a laboratory to be checked for myeloma cells in the bone marrow.

You may have this test in a ward or outpatient clinic. It takes about 20 to 30 minutes and you can usually go home shortly afterwards.

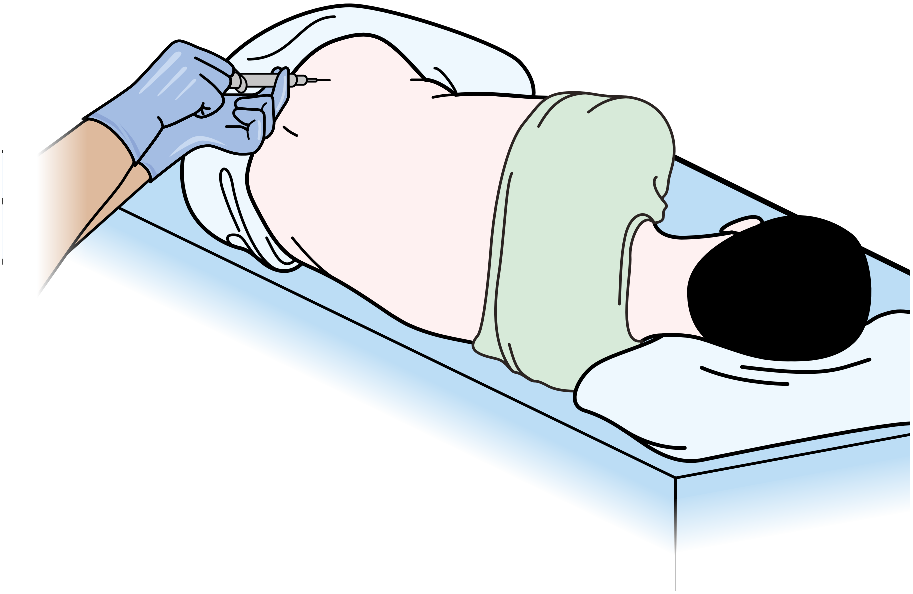
Before the bone marrow sample is taken, the doctor or nurse gives you local anaesthetic injections around the area. This will numb it to help reduce any discomfort during the test. They may also offer you a sedative to relax you. Or they may give you gas and air (Entonox®) to breathe in through a mouthpiece or mask.

The doctor or nurse puts a needle into the skin through to the bone. They then use a syringe to withdraw a small sample of liquid from inside the bone marrow. This is called a bone marrow aspirate. It can feel uncomfortable for a few seconds when the marrow is withdrawn into the syringe.

They may also take a small sample of the spongy bone marrow tissue. This is called a bone marrow trephine biopsy. To do this, the doctor or nurse passes a thicker, hollow needle into the skin through to the bone marrow. When they take the needle out, it contains a small sample (core) of bone marrow tissue.

You may feel bruised and sore for a few days after this test. Mild painkillers can help. If the pain gets worse, or you notice any bleeding from the area, let your doctor know.

Having a bone marrow biopsy



Other tests

You may have extra tests done on your bone marrow sample (cytogenetic tests) – see page 28.

You may also have scans, such as a whole-body MRI or CT scan. An MRI scan is often used as well as a CT scan. Other forms of imaging can be used to check the bones.

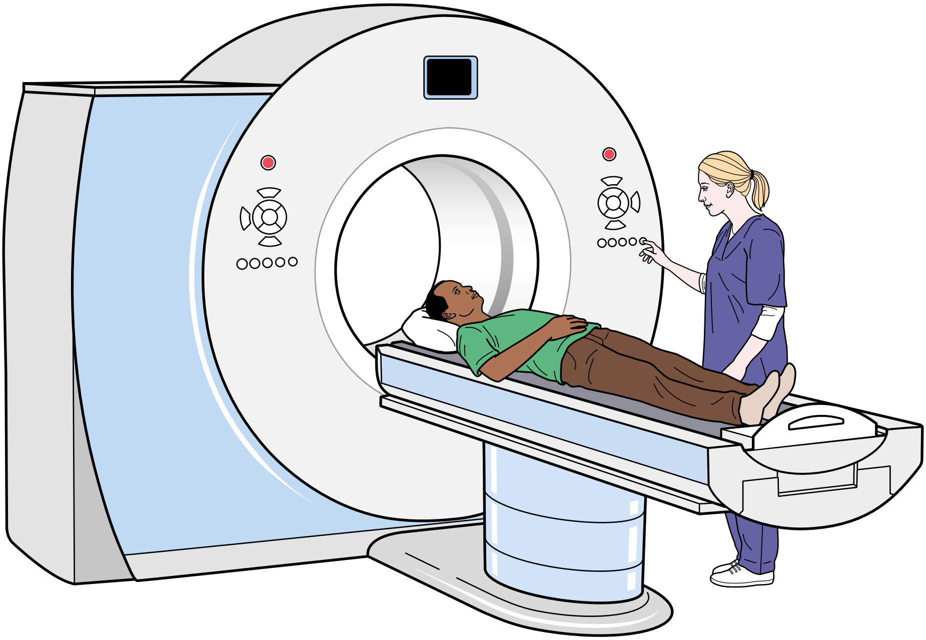
In rare situations, x-rays of the bones are done if an MRI and CT are not suitable. This is called a skeletal survey x-ray.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional (3D) picture of the inside of the body. The scan takes 10 to 30 minutes. It is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will probably be able to go home as soon as the scan is over.

We have a video on our website that has more information about having a CT scan – visit **macmillan.org.uk/testsandscans**

Having a CT scan



MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of your body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker or surgical clips. You should also tell your doctor if you have ever worked with metal or in the metal industry. Tiny fragments of metal can sometimes lodge in the body.

You have the scan in the x-ray department at the hospital. A person called a radiographer works the scanner.

During the test, you need to lie very still on a bed inside a long cylinder (tube). If you are worried about feeling claustrophobic, you may be able to have a sedative to help you relax. Talk to your GP or doctor about this before the scan.

The scan takes about 45 to 60 minutes. It is painless but you may find it uncomfortable to lie still for that long. After the scan is finished you can usually go home.

PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body. It is sometimes given together with a CT scan. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on x-rays, CT scans or MRI scans. PET scans are not suitable for everyone. Your doctor or specialist nurse can tell you whether they might be helpful for you.

PET scans are not available at all hospitals, so you may have to travel to a specialist centre to have one. If you are pregnant or breastfeeding, you should phone the scanning department before the test for advice.

About an hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in the arm. This is called a tracer. While you wait to have the scan, you will be encouraged to drink. Drinking water helps move the tracer around your body. Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The person who works the scanner is called a radiographer. The scan takes about 30 to 60 minutes. You will lie on a narrow bed. The bed moves slowly back and forward through the donut-shaped scanner. You can usually go home after the scan. The amount of radioactive substance used is very small. But you will be advised not to have close contact with pregnant women, babies and young children for up to 24 hours after the scan.

Cytogenetic tests

Cytogenetics is the study of chromosomes. Chromosomes are made up of genes. Genes carry the instructions cells need to work properly. Your doctor may talk to you about doing cytogenetic tests to look for changes in the chromosomes of the myeloma cells. Knowing about chromosome changes can help doctors to understand how the myeloma may behave and respond to treatment.

The myeloma cells can be tested from your bone marrow sample, so you do not need to have a new sample taken. One type of test is called a FISH test (fluorescence in situ hybridisation test).

Your doctor may use the terms high-risk or low-risk when they talk about the results of your FISH test or other cytogenetic tests. If you have high-risk myeloma, it may not respond as well to treatment or you may have shorter periods of remission. Remission is when the number myeloma cells have reduced and symptoms are under control (see pages 41 to 42).

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse can provide support or there are organisations that can also provide support (see pages 139 to 150). You can also talk things over with one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Staging myeloma

The stage describes how advanced the myeloma may be and how effective treatment might be.

To find out what stage the myeloma is, doctors use a staging system. The International Staging System (ISS) looks at the results of 2 blood tests:

- beta-2 microglobulin (B2M)
- albumin level.

If the level of B2M is raised or if the level of albumin is lower than normal, these can be signs that the myeloma is more advanced.

With this staging system, there are 3 stages of myeloma. Stage 1 is the earliest stage and stage 3 is more advanced (see the table below).

The stage of the myeloma does not usually affect the treatment that is offered. So, doctors do not always talk about staging.

Stage	B2M level (measured in mg/L)	Albumin level (measured in g/dL)
Stage 1	Normal or near normal (less than 3.5)	Normal (3.5 or more)
Stage 2	Normal or near normal (less than 3.5)	Low (less than 3.5)
	OR	
	Raised (3.5 to 5.5)	Any level
Stage 3	High (5.5 or more)	Any level

Sometimes doctors use an adapted version of the ISS called the Revised International Staging System (R-ISS). This uses:

- the results of the blood tests from the ISS
- a blood test called lactate dehydrogenase (LDH)
- the results of the FISH test, if you have had one that looked for any genetic changes in the myeloma cells.

The doctors also look at the effect the myeloma is having on your body. They may look at test results using something called the CRAB criteria to assess this. CRAB stands for:

- C – calcium levels being raised
- R – renal (kidney) problems
- A – anaemia (low number of red blood cells)
- B – bone damage.

The doctors also ask whether you have been having repeated infections or symptoms related to thickening of the blood (hyperviscosity). These may include confusion, headaches or blurred vision.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

TREATING MYELOMA

Treatment overview

When the doctors have the results of your tests, they can plan the best treatment for you. Myeloma cannot usually be cured, but it is treatable. Treatment can be very effective and is used to:

- stop the myeloma developing further
- control symptoms
- improve your quality of life.

Treatment aims to reduce the number of myeloma cells to as few as possible. The type of treatment your doctor offers you depends on a number of things, including your general health.

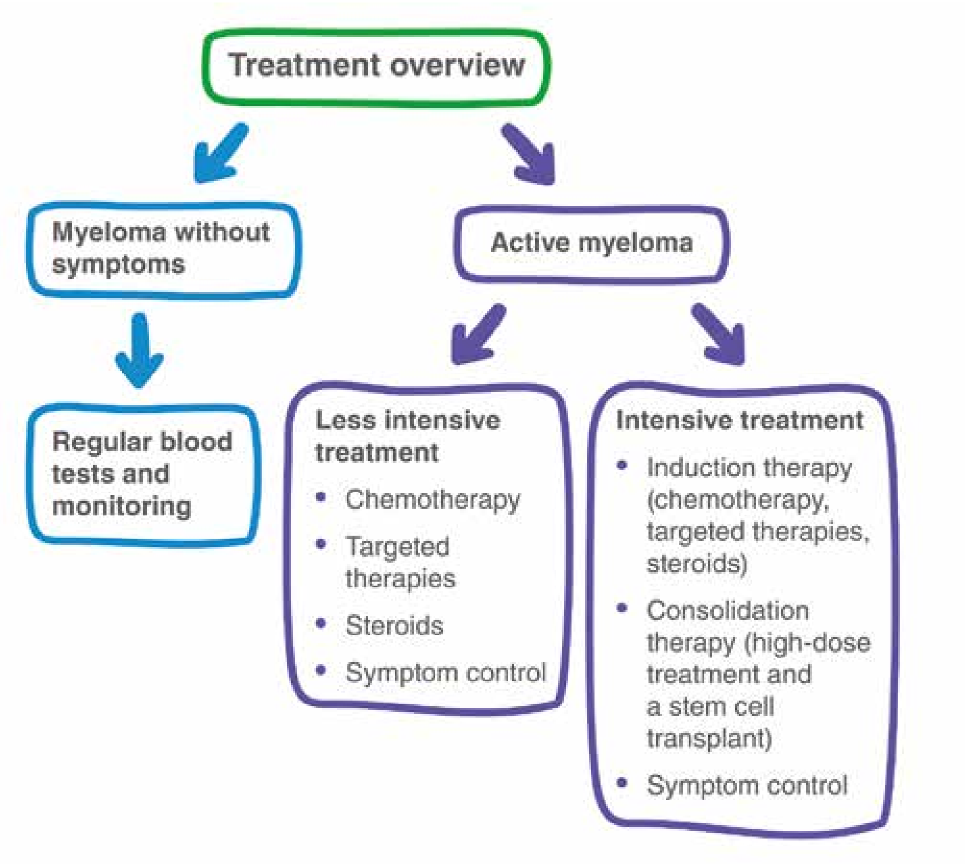
If the myeloma begins to cause symptoms, you will start treatment. Myeloma with symptoms is sometimes called active or symptomatic myeloma. If you have active myeloma, you may have intensive treatment or less intensive treatment (see pages 38 to 39).

The treatments used for myeloma are:

- targeted therapies (see pages 49 to 53)
- chemotherapy (see pages 54 to 66)
- steroids (see pages 67 to 68)
- high-dose treatment with stem cell support (see pages 69 to 70).

Usually, a combination of treatments is used.

If the myeloma is not causing symptoms you do not usually need treatment straight away. But you will have regular check-ups and blood tests. This is called active monitoring. Myeloma with no symptoms is called smouldering or asymptomatic myeloma (see page 36).


Treatment overview
Myeloma without symptoms
Active myeloma
Regular blood tests and monitoring
Less intensive treatment
• Chemotherapy
• Targeted therapies
• Steroids
• Symptom control
Intensive treatment
• Induction therapy (chemotherapy, targeted therapies, steroids)
• Consolidation therapy (high-dose treatment and a stem cell transplant)
• Symptom control

Monitoring myeloma without symptoms (smouldering myeloma)

If you have smouldering or asymptomatic myeloma, you may not need treatment straight away. This is because there is no strong evidence that having treatment at this stage will help. Instead, doctors may suggest active monitoring. This means treatment is delayed until it is needed.

Your doctor will see you every few months to take blood samples and do some other tests. If tests show the myeloma is progressing or you develop symptoms, your doctor will talk to you about starting treatment. Waiting to start treatment means you feel well for longer, as you will not have the side effects from treatment. If you are worried about not having treatment, you might find these tips helpful:

- Make sure you understand why active monitoring is recommended. If you have any concerns, talk to your doctor.
- Try to think of the time without treatment as an opportunity to make the most of your quality of life. Use your time to do things you enjoy, and to get as fit and healthy as you can.
- Try to focus on the present, rather than what might happen in the future.
- Express your feelings. You can do this by talking to family and friends, joining a support group or online forum, or by keeping a journal.

Although active monitoring can be difficult to adjust to at first, many people find it gets easier as time goes on. We have more information about the emotional effects of cancer (see pages 108 to 118). You may find our booklet **How are you feeling? The emotional effects of cancer** helpful (see page 134).

Some people may be offered treatment for smouldering myeloma, but only as part of a clinical trial.

‘The myeloma remained smouldering and without treatment for about a year.’

Frances

Treatment for active myeloma with symptoms

If you have active myeloma with symptoms or are at a high risk of developing symptoms, you will usually start treatment. You may have intensive treatment or less intensive treatment.

The aim of treatment is to get the myeloma into remission and to manage symptoms (see pages 41 to 42).

Less intensive treatments include:

- targeted therapies (see pages 49 to 53)
- chemotherapy (see pages 54 to 66)
- steroids (see pages 67 to 68)
- symptom control (see pages 76 to 95).

Usually, a combination of these treatments is used.

Some people might have intensive treatment. This depends on how the myeloma is affecting you and your general health. Your doctor will talk with you about this. Intensive treatment is divided into the following 2 stages:

- Induction therapy – this is treatment with targeted therapies, chemotherapy and steroids. The aim of induction therapy is to get rid of as many myeloma cells as possible.
- Consolidation therapy – this uses treatment with high-dose chemotherapy treatment and a stem cell transplant to get rid of remaining myeloma cells (see pages 69 to 70).

Maintenance or continuous treatment

Your doctor may suggest continuing treatment until they get the best possible response for you. Or you may be given treatment for as long as it controls the myeloma. This is called continuous therapy or maintenance treatment. If the myeloma does not respond to the first treatment, your doctor will look at other treatments.

Some people who are in remission may also be offered continuous treatment. The aim is to keep the myeloma under control.

Controlling symptoms

Treating symptoms is an important part of treatment for myeloma. This can include the following:

- Treating bone pain and other bone problems. You may have painkillers, drugs called bisphosphonates, radiotherapy and sometimes surgery to treat pain and other bone problems.
- Managing other symptoms of myeloma. You may be very tired or have difficulty fighting infections. Sometimes the kidneys are affected by myeloma. There are different ways these problems can be managed.

Always tell your doctor or nurse if you notice:

- any new symptoms
- that a symptom is getting worse
- that a symptom is not getting better with treatment.

We have more information about controlling symptoms (see pages 76 to 95).

> ‘At the moment, I’m not living too badly. I’m in partial remission. It is like having a slightly subdued version of normal life. My back pain has paled to a mild grumble, and I can walk well. Lenalidomide has side effects, but I can manage them.’

Frances

Clinical trials

Cancer research trials are done to try to find new and better treatments for cancers, including myeloma. You may be asked to take part in a clinical trial (see pages 72 to 73).

Response to myeloma treatment

You will have tests during your treatment to check how well the myeloma is responding to treatment. This is measured by checking your blood or urine (pee) for abnormal immunoglobulins (paraproteins) and light chains made by the myeloma cells (see pages 8 to 9).

If these are below certain levels and myeloma cannot be detected, it is called complete response. This is also sometimes called complete remission.

The different levels of response include:

- complete response (CR) – this means the paraprotein (M protein) cannot be detected in blood or urine tests and there are fewer than 5% plasma cells in the bone marrow
- partial response (PR) – this means the paraprotein level is at least 50% lower than it was before treatment
- stable disease – this means the paraprotein is at the same level as it was before treatment.

If you have a type of myeloma that does not make paraproteins, such as a Bence Jones myeloma, your doctor can explain how response will be measured.

Relapsed myeloma

Even though many people have a good response to treatment for myeloma, the myeloma usually comes back after a period of time. This is called recurrent or relapsed myeloma. Doctors may then change your treatment or offer further treatment.

If treatment does not control the myeloma, or stops controlling it, the doctors will talk to you about treatments to manage symptoms (see pages 76 to 95).

> **‘I’m in full remission for now. Which is probably 2 or 3 good years and then we start treatment from the start again. I’m determined to live my life as much as I can.’**
>
> **Franko**

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- Haematologist – a doctor who diagnoses and treats blood disorders and blood cancers.
- Haematology specialist nurse – a nurse who specialises in blood cancers and provides information and support.
- Clinical oncologist – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.
- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- Radiologist – a doctor who looks at scans and x-rays to diagnose health problems.
- Palliative care doctor or nurse – specialists who help with symptom control.

Depending on the type of cancer you have, the MDT may also include:

- an orthopaedic surgeon
- a kidney doctor (nephrologist).

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again. You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

The benefits and disadvantages of treatment

You may be worried about having cancer treatments because of the possible side effects. But these can usually be controlled with medicines. Treatment can be given for different reasons, and the benefits and side effects depend on your individual situation.

If you have early-stage myeloma and are well enough for intensive treatment, it is often possible to control the cancer long-term.

If you have more advanced myeloma, treatment may be given to help control the cancer, reduce symptoms and improve your quality of life.

Some treatments for myeloma have more side effects and risks than others. For most people, treatment helps to control the myeloma and the side effects of the treatment are manageable. But for some people, treatment has little or no effect on the cancer and they get the side effects with little benefit.

> **‘Treatments for myeloma are the best they have ever been. The biggest challenge is coming to terms with the fact that definitive answers are hard to come by.’**
>
> **Jane**

Choosing between treatments

Doctors sometimes ask you to choose between different treatments. Your doctor or nurse can help you with your decision. You do not usually need to decide straight away. It can help to talk to your family or friends about your treatment options.

You could write a list of benefits and disadvantages for each treatment. When choosing a treatment, you may want to think about:

- how long you need to have it for
- how it may affect your everyday life
- how much time you will need to spend in hospital
- the different side effects and how they are likely to affect you.

If you choose not to have treatment, you can still have supportive care to help control symptoms (see pages 76 to 95).

We have more information about making treatment decisions on our website (see page 134).

Giving your consent

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

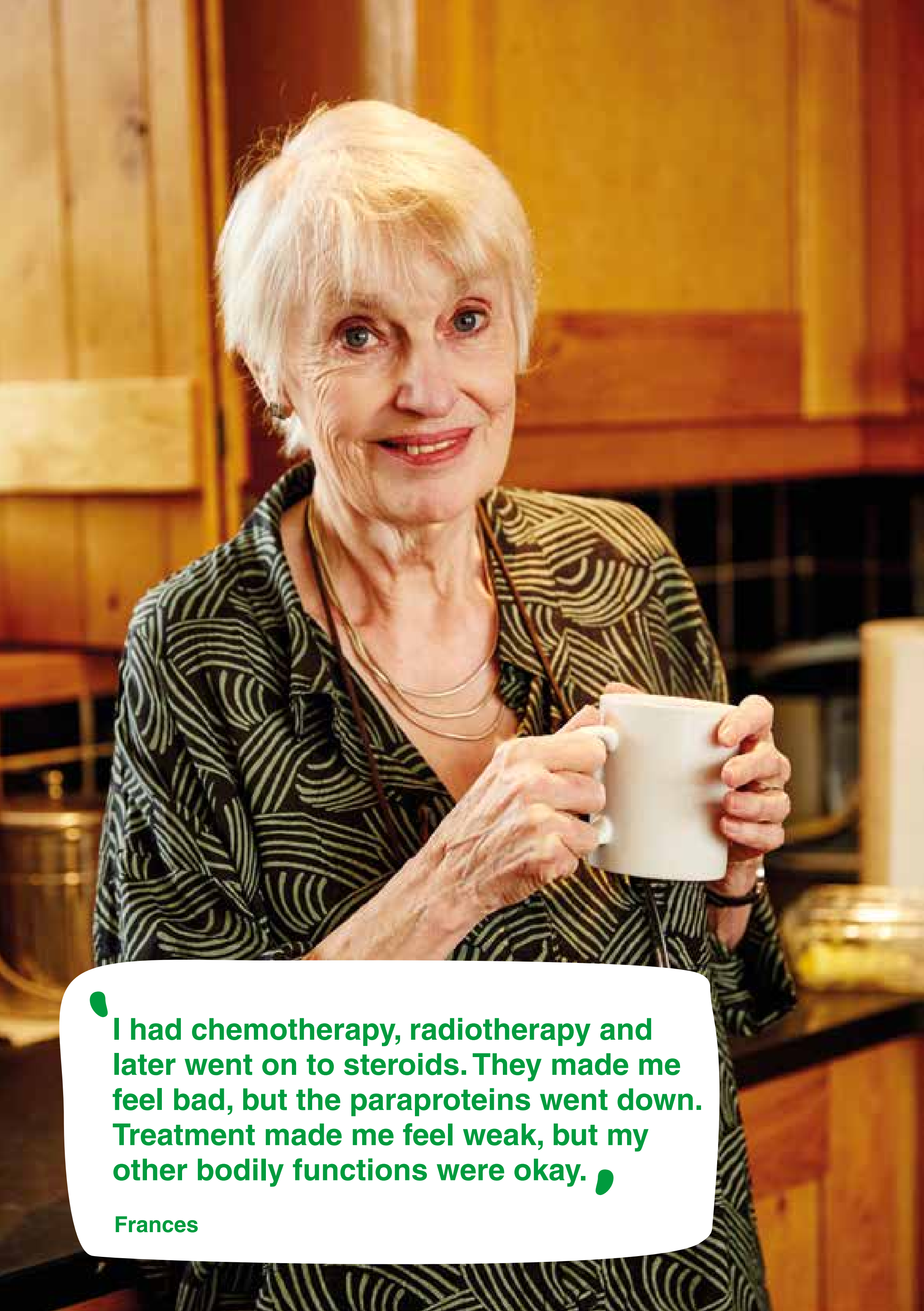
Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website (see page 134).



> ‘I had chemotherapy, radiotherapy and later went on to steroids. They made me feel bad, but the paraproteins went down. Treatment made me feel weak, but my other bodily functions were okay.’

Frances

Targeted therapies for myeloma

Targeted therapies are drugs that interfere with the way myeloma cells grow (see page 9). Some targeted therapy drugs affect the immune system and help it to destroy myeloma cells. These are called immunotherapy drugs.

The targeted therapies used for newly diagnosed myeloma are thalidomide, bortezomib and lenalidomide (see pages 50 to 53). You usually have these drugs along with chemotherapy drugs and steroids (see pages 54 to 66 and 67 to 68). Sometimes you have 2 targeted therapy drugs together.

Some people continue to take these types of drugs to help keep the myeloma under control. This is called maintenance or continuous treatment. Your doctor will explain if this is suitable for you. When myeloma comes back (relapses) you may have other targeted therapy drugs. Sometimes 2 targeted therapies may be used in combination.

Your doctor and nurse will talk to you about the different treatment options. Like all drugs, targeted therapies can cause side effects. It is important to tell your cancer doctor or nurse if you have any side effects while you are having treatment. They may adjust your treatment to control side effects or to help to prevent more serious problems.

Thalidomide

Thalidomide is a targeted therapy drug and an immunotherapy drug. It helps the immune system attack and destroy cancer cells.

Cancer cells need new blood vessels to help them grow and spread. Thalidomide blocks the development of new blood vessels. This reduces the supply of oxygen and nutrients to the cancer cells.

Thalidomide is given as a capsule. Common side effects include:

- constipation
- drowsiness
- an increased risk of infection
- numbness or tingling in the hands and feet (peripheral neuropathy)
- blood clots.

You will be given drugs to thin your blood while you are taking thalidomide. This can help to stop any blood clots from forming.

Thalidomide can cause birth defects in developing babies. This can happen if a pregnancy starts when either a man or woman is taking thalidomide.

Women who have not yet had the menopause will take part in a pregnancy prevention programme while taking thalidomide. Your doctor will give you information about not becoming pregnant during treatment and for at least 4 weeks after treatment. You also have pregnancy tests before starting thalidomide. This is repeated every 4 weeks during treatment and 4 weeks after treatment.

Men are advised to use a condom during sex while taking thalidomide, and for at least a week after treatment ends. This is to protect your partner from any thalidomide that may be in your semen.

If you think you or your partner might be pregnant during your treatment, contact your doctor or specialist nurse straight away.

We have more information about thalidomide and its side effects on our website (see page 134).

Bortezomib

You may have bortezomib as a first treatment for myeloma, or if myeloma comes back after other treatment.

Bortezomib is a type of targeted therapy drug called a proteasome inhibitor. Proteasomes are in all cells and work to break down proteins that are no longer needed. Bortezomib works by blocking the proteasomes. This causes proteins to build up in the cell and destroy the myeloma cells. Some myelomas may be more sensitive to proteasome inhibitors than others.

Bortezomib is given as an injection under the skin (subcutaneously).

Common side effects include:

- tiredness (fatigue)
- feeling sick (nausea) and being sick (vomiting)
- diarrhoea or constipation
- headaches
- dizziness when standing up (caused by a fall in blood pressure)
- low blood counts
- numbness, tingling or a burning sensation in the hands and feet (peripheral neuropathy).

We have more information about bortezomib and its side effects on our website (see page 134).

Lenalidomide

Lenalidomide affects the way the immune system works. It also blocks the development of new blood vessels, which cancer cells need to grow and spread.

Lenalidomide is taken as a capsule. Common side effects include:

- feeling sick (nausea)
- risk of infection
- tiredness (fatigue)
- blood clots
- diarrhoea.

You may be given drugs to thin your blood while you are taking lenalidomide. This can help to stop any blood clots from forming.

Like thalidomide, lenalidomide can also cause birth defects in developing babies. This can happen if a pregnancy starts when either a man or woman is taking lenalidomide.

Women who have not yet had the menopause will take part in a pregnancy prevention programme while taking lenalidomide. Your doctor will give you information about not becoming pregnant during treatment and for at least 4 weeks after treatment. You also have pregnancy tests before starting lenalidomide. This is repeated every 4 weeks during treatment and 4 after weeks after treatment.

Men are advised to use a condom during sex while taking lenalidomide, and for at least a week after treatment ends. This is to protect your partner from any lenalidomide that may be in your semen.

If you think you or your partner might be pregnant during your treatment, contact your doctor or specialist nurse straight away.

We have more information about lenalidomide and its side effects on our website (see page 134).

Chemotherapy for myeloma

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs travel in the blood and can treat myeloma cells wherever they are in the body.

Treatment often involves a combination of 2 or more chemotherapy drugs. These may be given with other drugs, such as steroids (see pages 67 to 68) and targeted therapies (see pages 49 to 53). You will have treatment for 1 day, or over a few days. This is followed by a break of a few weeks without treatment. The days having the chemotherapy and the treatment break make up a cycle of treatment. Usually, 4 to 6 cycles make up a complete course of treatment. This means a course of treatment usually takes a few months to complete. But the length of treatment depends on which treatments are used and how well the myeloma responds.

You usually have chemotherapy as an outpatient, but sometimes you may need to spend a few days in hospital.

During the course of treatment, you have regular blood tests to check the effect of the drugs. The dose of the drugs may be changed according to the results of your blood tests, or any side effects.

Chemotherapy drugs used to treat myeloma include:

- melphalan
- cyclophosphamide
- doxorubicin
- bendamustine
- cisplatin.

We have more information about chemotherapy drugs on our website (see page 134).

Doctors often use a combination of chemotherapy (see pages 54 to 66), targeted therapies (see pages 49 to 53) and steroids (see pages 67 to 68) to treat myeloma.

Drug combinations include:

- CTD – cyclophosphamide, thalidomide and dexamethasone
- MPT – melphalan, prednisolone and thalidomide
- VCD or VCD – cyclophosphamide, bortezomib (Velcade®) and dexamethasone
- VMP – melphalan, prednisolone and bortezomib (Velcade®)
- VTD – bortezomib (Velcade®), thalidomide and dexamethasone
- VTD-PACE – VTD may sometimes be given with cisplatin, doxorubicin, cyclophosphamide and etoposide.

We have more information about many of these drugs on our website (see page 134).

How chemotherapy is given

Some chemotherapy drugs for myeloma are given by injection or drip (infusion) into a vein (intravenously). Some may be given subcutaneously (an injection under the skin). Others are taken as tablets or capsules by mouth (orally).

Lines and ports

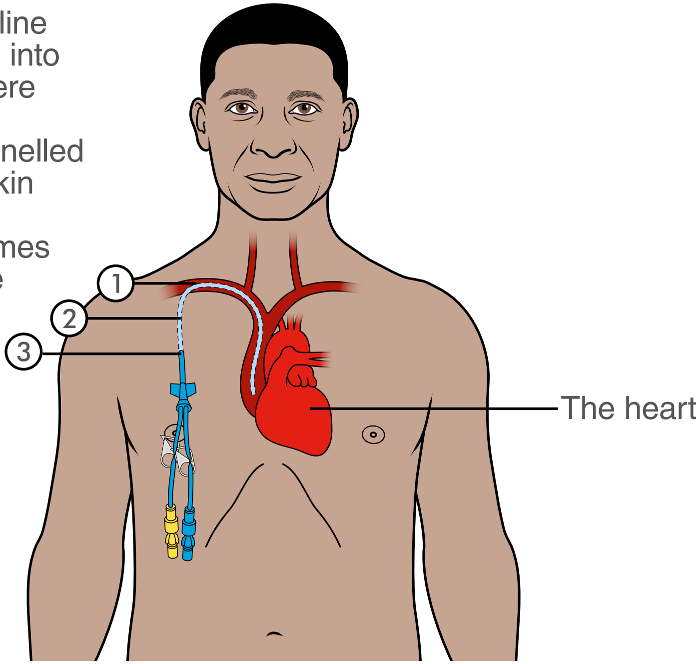
If you are having your treatment by drip (infusion), your doctor may suggest you have:

- a central line – a nurse puts a plastic tube into a vein in your chest
- a PICC line – a nurse puts a plastic tube into a vein above the bend of your elbow (PICC line)
- an implantable port – a nurse puts a thin, soft, plastic tube into a vein in the chest that has an opening (port) just under the skin of the chest or arm.

There are illustrations of these lines and ports over the next 3 pages.

Lines and ports can stay in place during the course of your treatment. This can be used to take blood samples and give you treatment. The community nursing team will look after your line or port. Your nurses may also show you how to care for it when you are home.

A central line



① Central line inserted into chest here

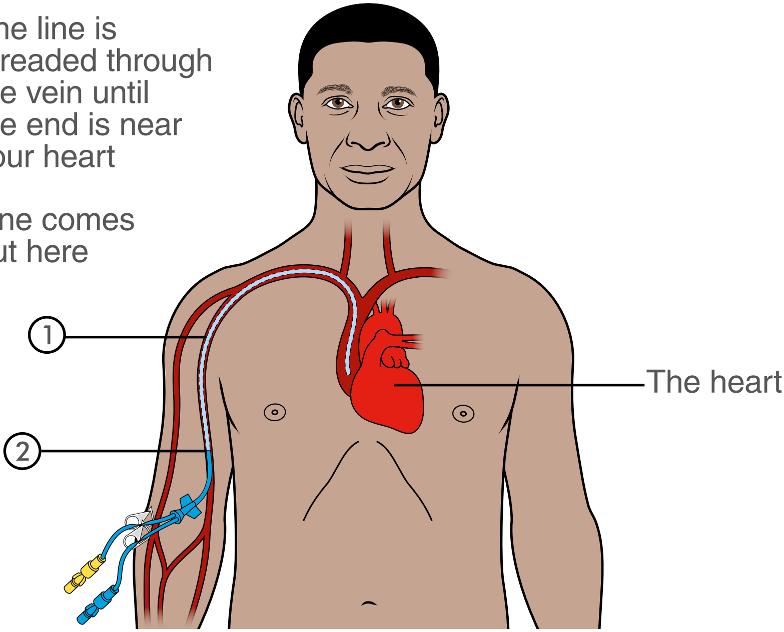
② Line tunnelled under skin

③ Line comes out here

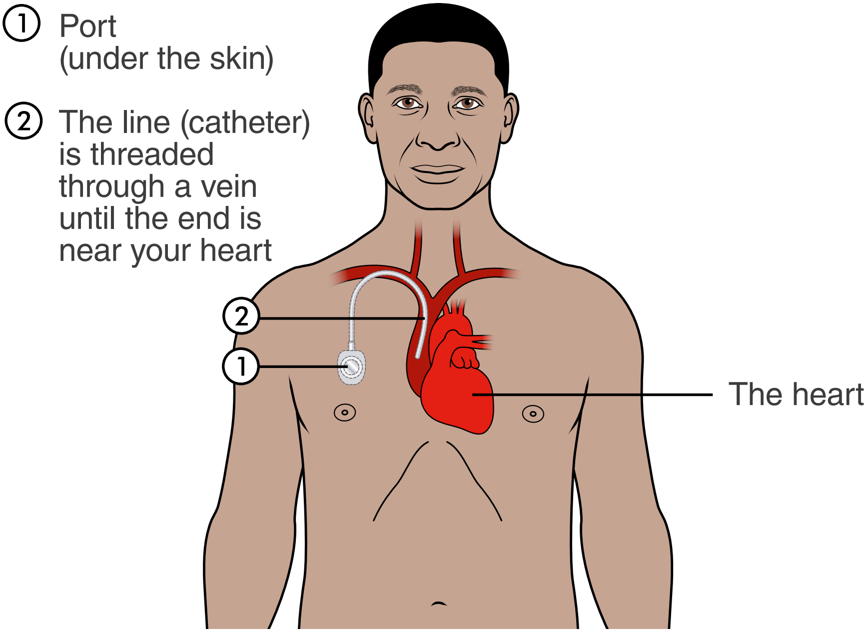
A PICC line

① The line is threaded through the vein until the end is near your heart

② Line comes out here



An implantable port



Side effects of chemotherapy

Different drugs cause different side effects. You may get some of the side effects mentioned, but you are very unlikely to get all of them. Although side effects can be hard to deal with, they usually disappear gradually when your treatment finishes.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is sometimes called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

You may be given a drug called G-CSF. This encourages the body to make more white blood cells. You have it as a small injection under the skin.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Sometimes doctors prescribe a drug called erythropoietin. This helps the body to make more red blood cells. It is given as an injection under the skin. But it is more common to have a blood transfusion for anaemia.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

Sore mouth and throat

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

> **'The treatment and side effects are rubbish but there is light at the end. It is a tough road, and I still have down days. But there are more good than bad.'**
>
> **Frances**

Hair loss

Your hair will get thinner. Or you may lose all the hair from your head. You may also lose your eyelashes and eyebrows, as well as other body hair. Hair loss usually starts after your first or second treatment.

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. Your scalp may be sensitive. It is important to cover your head to protect your skin when you are out in the sun.

Hair loss is almost always temporary. Your hair will usually grow back after treatment finishes.

You may find our booklet **Coping with hair loss** helpful (see page 134).

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

If you feel sleepy, do not drive or use machinery.

You may find our booklet **Coping with fatigue (tiredness)** helpful (see page 134). If you find reading tiring, you can listen to the booklet online by visiting **macmillan.org.uk/fatigueaudio**

Blood clot risk

Cancer and some cancer treatments can increase the risk of a blood clot. Symptoms of a blood clot include:

- throbbing pain, redness or swelling in a leg or arm
- suddenly feeling breathless or coughing
- sharp chest pain, which may be worse when you cough or take a deep breath.

If you have any of these symptoms, contact the hospital straight away on the 24-hour contact number you have been given. If you cannot get through to your doctor, call the **NHS urgent advice** number on **111**.

A blood clot is serious, but it can be treated with drugs that thin the blood (anticoagulants). Your doctor or nurse can give you more information.

You can help reduce the risk of developing a blood clot by:

- staying active during treatment
- drinking plenty of fluids, especially water.

You may be given anticoagulants to help prevent a clot.

Steroids for myeloma

Steroids are drugs that can be used to help destroy myeloma cells. They can also make chemotherapy and targeted therapies work better. The 2 most commonly used steroids for myeloma are prednisolone and dexamethasone.

Steroids may be used on their own or in combination with other drugs. They are usually taken as tablets. If you have difficulty swallowing them, you can have steroids that are liquid or that dissolve. If you only take small doses of a steroid, you may not have many side effects. If you need larger doses for longer, you may have more side effects.

Side effects

Side effects of steroids can include:

- heartburn or indigestion – taking your tablets with food or milk can help prevent this, or your doctor may prescribe drugs to help
- feeling irritable
- mood changes
- increased appetite
- having more energy
- difficulty sleeping – taking your steroids in the morning can help
- increased level of sugar in the blood – you will have regular blood tests or tests on your urine (pee) to check this, but if you get very thirsty or feel you are passing more urine than usual, tell your doctor.

It is unusual for people with myeloma to take steroids for a long time. But if you do, you may notice that you put on weight, especially on your face, waist and shoulders. You may also notice other temporary side effects, including:

- water retention
- high blood pressure
- a slightly greater risk of getting infections.

The side effects of steroids are usually temporary and disappear as the dose is lowered. Some people experience tiredness or fatigue when they stop taking the steroids.

We have more information about some of these side effects on our website (see page 134).

> **‘One of the things that helped when things got tough having the stem cell transplant was books, films and activities to try to distract my mind.’**
>
> **Greg**

High-dose chemotherapy and stem cell transplant for myeloma

Sometimes, high-dose chemotherapy with stem cell support is used to treat myeloma.

This treatment may improve the chances of controlling the myeloma for a longer time.

If your doctor thinks this treatment is suitable for you, they will discuss it with you in more detail. Having this treatment will also depend on your general health. Stem cell transplants are only done in some specialist hospital units. You usually stay in hospital for a few weeks.

When this type of treatment is used to treat myeloma, it is more common to use your own stem cells for the transplant rather than stem cells from another person (a donor). Using your own stem cells is called an autologous stem cell transplant. Stem cells are blood cells that are at the earliest stage of development. They are transplanted to help you recover from the side effects of treatment.

These are the different stages of an autologous stem cell transplant:

- Induction treatment – you have a few cycles of chemotherapy and targeted therapy treatments to try to get rid of as many myeloma cells as possible.
- Collecting stem cells – after the induction treatment, your stem cells are collected (harvested) and stored. This is done before you have high-dose treatment. They are usually collected from the blood, but they can also be collected from the bone marrow.
- High-dose treatment – high-dose chemotherapy treatment aims to destroy any remaining myeloma cells and get the best response possible. But chemotherapy also affects healthy stem cells in your bone marrow and causes side effects.
- Stem cell transplant – after the high-dose treatment, the collected stem cells are given back to you through a drip (infusion). Your stem cells travel to your bone marrow and start making new healthy blood cells. This helps you to recover from the side effects of high-dose treatment.

We have more information about high-dose chemotherapy and stem cell transplants in our booklet **Understanding stem cell transplants using your own cells (autologous)** – see page 134.

> ‘Once the harvesting was done the aches and pains vanished. A few weeks later I went into hospital and had high-dose melphalan (chemotherapy). You’re encouraged to have lots of ice lollies to ward off mucositis (sore mouth).’
>
> **Sue**

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

Giving blood samples

Doctors may take blood samples to help make the right diagnosis. Your doctor may ask for your permission to store and use some of the samples for cancer research. If you are taking part in a trial you may also be asked to give other samples which may be frozen and stored for future use, when new research techniques become available.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

Treatment if myeloma comes back

Treatment for myeloma is usually very effective and most people have a good response to treatment. There may be long periods of time when you do not need any treatment and have no symptoms caused by myeloma.

After a time, myeloma usually comes back and needs further treatment. This is called relapsed myeloma. For some people, this may be many years later. Your doctor and nurse will talk to you about the different treatment options.

Sometimes, it may be possible to repeat the first treatment you had (see pages 34 to 35). This depends on what the treatment was and how long ago you had treatment. Or you may be offered a different treatment or clinical trial (see pages 72 to 73). You will also have treatments to control bone problems and other symptoms (see pages 76 to 95).

You may have one of the following targeted therapy drugs:

- carfilzomib
- bortezomib
- lenalidomide
- daratumumab.

Or you may have a second high-dose treatment and stem cell transplant (see pages 69 to 70).

If you have a further relapse, other targeted therapies may be used. They are often given with steroids, and include:

- lenalidomide
- ixazomib and panobinostat (with bortezomib)
- pomalidomide
- daratumumab
- isatuximab.

We have more information about targeted therapies, stem cell transplants and steroids on our website (see page 134).

Symptom control

Myeloma can cause symptoms if it affects areas of the body such as the bones, kidneys, blood or nerves. Symptom control is important for everyone diagnosed with myeloma.

You will see your doctor regularly for blood tests and x-rays, and to talk to you about how the myeloma is affecting you. Not everyone has symptoms, and some people may only have mild symptoms. Always tell your doctor and nurse about any problems you may have. There are different ways that symptoms can be managed.

Myeloma may cause problems such as:

- bone problems and bone pain
- high calcium levels in the blood (hypercalcaemia)
- pressure on the spine (spinal cord compression), causing leg weakness or numbness, bladder problems or bowel problems (see page 82)
- infection
- tiredness (fatigue)
- anaemia (low number of red blood cells)
- kidney problems
- numb or tingling hands or feet (peripheral neuropathy)
- eating problems
- blood clots
- high levels of paraprotein in blood affecting blood flow (hyperviscosity syndrome).

You may find our booklet **Managing cancer pain** helpful (see page 134).

Myeloma and bone problems

Myeloma cells can damage bones and cause bone problems. Areas of bone may get thinner and weaker, and may sometimes break (fracture). There are different ways of managing or treating these problems.

Treating bone pain

The most common symptom of myeloma is bone pain. Pain from bone damage may continue even if the myeloma is in remission (see pages 41 to 42). This is because bone damage can continue to cause symptoms even though the myeloma is no longer there. There are ways to treat bone pain.

Always tell your doctor or nurse about any bone pain, including any new pain. There are doctors and nurses who specialise in controlling pain. They are called palliative care specialists. They are based in hospitals, hospices, palliative care units and pain clinics. They work with your myeloma team and your GP to make sure your pain is well controlled.

Treatments for bone pain may include:

- painkillers
- bisphosphonates
- radiotherapy
- surgery, including vertebroplasty or kyphoplasty (see page 81).

The healthcare team may also talk to you about other ways of managing pain, such as:

- physiotherapy
- nerve blocks
- TENS machines
- relaxation techniques.

Painkillers

Different painkillers are used to treat different types and levels of pain. You can usually take them by mouth. You can also have them as skin patches or sometimes as an injection under the skin, or into a vein.

Your doctor or nurse will assess the pain by asking you questions about it. Give them as much information as you can. It can help to keep a record of when you have the pain and what makes it better or worse in a pain diary (see pages 84 to 89). This information can help them to plan the best pain control for you.

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.

Bisphosphonates

Bisphosphonates are drugs that can help strengthen weakened bones and reduce pain. They can also reduce high levels of calcium in the blood (hypercalcaemia) – see page 83. These drugs can help delay bone damage, so you may start taking them before you have any bone problems. Some bisphosphonates may also help treat myeloma.

The bisphosphonates most often used are:

- zoledronic acid
- pamidronate
- sodium clodronate.

They may be given as a drip into a vein (intravenous infusion) once a month. Some are given as tablets.

Side effects are usually mild and can happen for a few days after the infusion. They include indigestion, feeling sick (nausea) and flu-like symptoms.

Rarely, bisphosphonates can cause damage to the jawbone. This is called osteonecrosis of the jaw. Your doctor will usually advise you to see a dentist before starting treatment. Tell your doctor if you need any dental work while having this treatment.

It is important to tell your dentist you will be taking bisphosphonates.

We have more information about bisphosphonates on our wesbite (see page 134).

Radiotherapy

Radiotherapy uses high-energy rays to destroy the myeloma cells. You may have it to reduce pain in bones and allow the bones to repair themselves.

Radiotherapy can also be used when myeloma in the spine is causing pressure on the spinal cord. This is called spinal cord compression (see page 82).

In advanced myeloma, radiotherapy can be given to reduce symptoms and control the myeloma for some time.

You have radiotherapy in the hospital radiotherapy department. If you are having a course of treatment, you will go to the department before your treatment starts. The radiotherapy staff work out the exact dose of radiotherapy, the area to be treated and how many treatments you need. Treatment may be given daily (Monday to Friday) for 1 to 3 weeks, with a rest at the weekends. Some people only need 1 or 2 treatments. Each treatment is called a fraction.

Side effects are usually mild, but this depends on the area being treated.

Tiredness is a common side effect. If treatment is given close to the tummy or bowel, other side effects can include feeling sick or diarrhoea. Side effects usually gradually improve a few weeks after treatment finishes.

Tell the radiotherapy team about any side effects you have. They can help you to manage them. We have more information about radiotherapy side effects on our website (see page 134).

Surgery

Some people need to repair bones that have been damaged or weakened by myeloma.

If some of the bones in the spine (vertebrae) are weakened by the myeloma, they may collapse. This called a compression fracture. It can cause pain, difficulty moving around and loss of height. It is often treated:

- with painkillers
- with bed rest
- by wearing a spinal brace.

Surgery can also be used to treat compression fractures of the spine. Your doctor or specialist nurse will explain if this is suitable for you. They usually try other ways of controlling your pain first.

Possible operations include the following:

- Vertebroplasty – the surgeon or radiologist injects a special cement into the vertebrae. This can strengthen the bone and relieve pain caused by a compression fracture.
- Balloon kyphoplasty – the surgeon or radiologist inserts a balloon, called an inflatable bone tamp, into the vertebrae and then slowly inflates it. This leaves a space, where bone cement is injected (like a vertebroplasty). This improves the strength of the spine, which can relieve pain and help you move around more easily.

These operations can only be done in specialist centres. Side effects are not common, but they can include infection or damage to the nerves in the spine.

Spinal cord compression

Myeloma can develop in the bones of the spine. Sometimes this can weaken the bone and put pressure on the spinal cord. This is called spinal cord compression. It can damage the nerves in the back. This causes:

- back or neck pain that is new or suddenly gets worse
- numbness or pins and needles in your toes, fingers or buttocks that is new or suddenly gets worse
- a feeling of unsteadiness on your feet
- weakness in your legs
- problems passing urine (peeing) or problems with bowel control.

If you have any of these symptoms, it is very important to tell your doctor or specialist nurse straight away. Spinal cord compression should be treated as soon as possible to prevent permanent damage.

Spinal cord compression is usually treated with steroids and radiotherapy. Sometimes chemotherapy is used, or surgery may be needed.

Doctors will help manage any pain and bisphosphonates may be used to help to strengthen your bones.

We have more information about spinal cord compression and bisphosphonates on our website (see page 134).

High calcium levels in the blood (hypercalcaemia)

Bone damage can cause calcium to be released from the bones into the blood. High levels of calcium in the blood is called hypercalcaemia.

Symptoms of hypercalcaemia include:

- feeling sick (nausea)
- feeling thirsty
- feeling drowsy
- feeling confused
- feeling unwell
- feeling constipated
- passing urine often.

But hypercalcaemia may be found before you have any symptoms. You will have regular blood tests to check your calcium levels.

If you develop hypercalcaemia, your doctor may advise you to start drinking lots of liquids. You are also likely to have a drip (intravenous infusion) of fluids into a vein. This helps your kidneys filter the calcium from your blood and into your urine.

Your doctor may also give you a drug called a bisphosphonate to reduce the level of calcium. The drug is given into a vein over a few hours. It helps the calcium go back into your bones. This usually brings the calcium level in your blood down over about 2 to 3 days. If your calcium level starts to rise again, you may need another dose. We have more information about bisphosphonates on our website (see page 134).

PAIN DIARY

How to use your pain diary

You may want to photocopy this diary, so you can use it more than once. Or you can download the pdf from our website at **macmillan.org.uk/pain** and print more copies.

1. Start by recording when you feel the pain (there is space to write the date and time). You can fill in the diary as often as you need to. If your pain is not well-controlled, you may want to fill it in every 1 to 2 hours. But if it is better controlled, you can fill it in every 4 to 6 hours.

2. Record where the pain is on your body (you can use the diagrams included in this diary). It could be in one area or in lots of areas.

3. Describe what the pain feels like. You could use the words included in this diary.

4. Rate the level of pain on a scale of 0 to 10, where 0 means no pain and 10 means severe pain.

5. Write down the medicines you have used, and any other treatments or therapies that have helped manage your pain. And record anything that made the pain better or worse.

All of this information will help you and your healthcare team find the best way to manage your pain.

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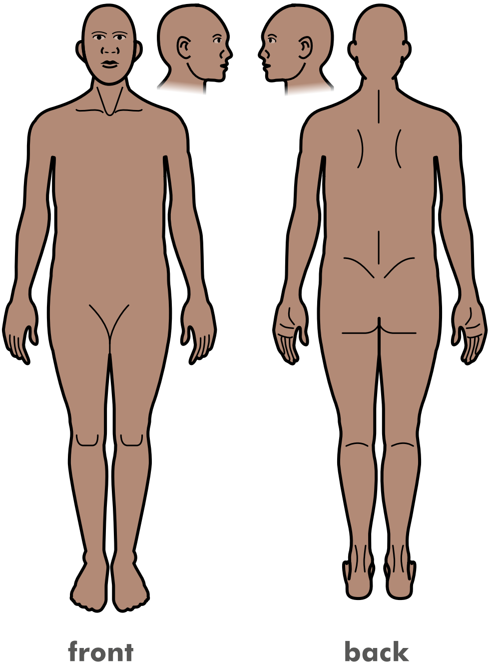
CANCER SUPPORT

Where is your pain?

Is it in one part of your body or in more than one place?

You can use the diagrams on the right to mark where your pain is.

If you have more than one area of pain, label them A, B, C, and so on (with A being the pain that upsets you the most).



What is your pain like?

Use any of the following words that best describe your pain:

- aching
- biting
- blunt
- burning
- cold
- comes and goes
- constant
- crushing
- cutting
- dragging
- dull
- excruciating
- frightful
- gnawing
- hot
- intense
- nagging
- nauseating
- niggling
- numb
- penetrating
- piercing
- pins and needles
- pricking
- radiating
- scratchy
- sharp
- shooting
- smarting
- sore
- spreading
- stabbing
- stinging
- tender
- throbbing
- tingling
- tiring
- unbearable.

Numbered pain scale

How bad is your pain? If you measured it on a scale of 0 to 10, how would you rate it? Where 0 is no pain and 10 is the worst pain you have ever had.

Keeping a record of your pain will help you discuss it with your doctors and nurses. Photocopy this diary before you fill it in so that you can use it as often as you need to. If your pain is in more than one place, you may want to use an extra copy of this diary.

Date and time	Where is your pain?	What is your pain like?	Level of pain (0=no pain 10=severe)

You can print more copies of this diary from our website at **macmillan.org.uk/pain**

What medicines and treatments have you used?	What makes your pain better?	What makes your pain worse?

Keeping a record of your pain will help you discuss it with your doctors and nurses. Photocopy this diary before you fill it in so that you can use it as often as you need to. If your pain is in more than one place, you may want to use an extra copy of this diary.

Date and time	Where is your pain?	What is your pain like?	Level of pain (0=no pain 10=severe)

You can print more copies of this diary from our website at
macmillan.org.uk/pain

What medicines and treatments have you used?	What makes your pain better?	What makes your pain worse?

Other symptoms of myeloma

Kidney problems

The paraprotein and light chains produced in myeloma can damage the kidneys. Calcium may also leak out of damaged bones and build up in the blood. This can also cause kidney problems.

Kidney problems can cause symptoms such as:

- passing less urine (pee) than usual
- tiredness
- reduced appetite
- feeling sick (nausea) or being sick (vomiting).

Not everyone has symptoms. But you will have regular blood tests to check for kidney problems.

You can help protect your kidneys by drinking plenty of fluids. Try to drink at least 3 litres (5 pints) each day. Always check with your doctor or nurse before taking painkillers called anti-inflammatory drugs, such as ibuprofen. These can cause kidney problems.

If your kidneys are affected, you may have fluids through a drip (infusion). This helps your body to flush the waste products out of your kidneys into your urine. Treatment for myeloma usually reduces the amount of paraprotein in the blood. This helps with kidney problems.

Sometimes kidney damage is severe, and the kidneys stop working altogether. This is called kidney failure or renal failure. If you have kidney failure, blood is not filtered properly and you do not produce any urine. Excess fluid and waste products, which are usually passed as urine, begin to build up in the body. If this happens, you may need to have your blood artificially filtered. This is called kidney dialysis.

Some people who need kidney dialysis only have it for a short period of time. Other people need long-term dialysis.

You can contact our cancer support specialists on **0808 808 00 00** to talk about dialysis. You may also find our Online Community a helpful place to get support (see page 137).

Tiredness (fatigue)

Many people with myeloma feel tired and have less energy to do the things they normally do. This may be caused by anaemia (see page 93), or it may be a side effect of treatment. While it is important to rest, it is also important not to stop doing things completely.

When you feel able to do things again, try to pace yourself. Start by setting yourself goals, like cooking a simple meal or going for a short walk. Keeping a fatigue diary may help. Record when you feel most tired to help you monitor your energy levels. Then you can plan activities for when you are likely to have more energy.

You may find our booklet **Coping with fatigue (tiredness)** helpful (see page 134). If you find reading tiring, you can listen to the booklet online by visiting **macmillan.org.uk/fatigueaudio**

Infection

Myeloma, and some treatments for it, can affect your ability to fight infections. Your doctor or nurse will talk to you about infections and possible signs of an infection to be aware of. Your doctor may give you drugs to help prevent an infection (prophylactic drugs).

They may also recommend you have vaccines such as the flu or coronavirus vaccination, if you have not already.

Immunoglobulin infusion

If you are getting a lot of infections, your doctor may give you a regular infusion (drip) of immunoglobulins. You have this into a vein. It can help to improve your immune system.

Most people feel fine when having an immunoglobulin infusion, but sometimes it can cause an allergic reaction. This is most likely to happen during or after the first infusion. To reduce the chance of a reaction, the first infusion is given slowly.

Anaemia (low number of red blood cells)

Myeloma or its treatment can reduce the number of red blood cells in your blood. This is called anaemia. It can make you feel tired and breathless.

Your doctor may suggest that you have a blood transfusion. The blood goes into a vein in your arm. Some people have a drug called erythropoietin (EPO) instead of a blood transfusion. This drug encourages your bone marrow to make more red blood cells. You usually have it as an injection under the skin (subcutaneously).

We have more information about anaemia and blood transfusions on our website (see page 134)

Numb or tingling hands or feet (peripheral neuropathy)

Myeloma and its treatment can affect the nerves in your hands or feet. This can cause tingling, numbness, or a feeling like pins and needles. This is called peripheral neuropathy. You may also find it hard to fasten buttons or do other fiddly tasks. Your doctor or nurse will tell you if you are having a treatment that may cause this side effect.

Tell your doctor or nurse if this happens. If it is caused by your treatment, they may need to lower the dose. Or your doctor may talk to you about whether you could have a different treatment. Usually, peripheral neuropathy gets better when treatment is over, but it can sometimes be permanent.

We have more information about peripheral neuropathy on our website (see page 134).

Eating problems and feeling sick

Myeloma, and some treatments for it, can cause sickness and loss of appetite. There are several treatments to help prevent and control sickness. Your doctor can prescribe anti-sickness (anti-emetic) drugs for you. Let them know if your anti-sickness drugs are not helping as there are different types you can take. If you have a poor appetite, try to eat little amounts as often as possible. Keep snacks with you, such as nuts, grated cheese or dried fruit.

It is important to try to eat well during your treatment. If you are having problems, ask your nurse for advice. You can also ask to see a dietitian. You can add extra energy and protein to your diet with everyday foods or by using food supplements. We have more information in our booklet **Eating problems and cancer** (see page 134).

Blood clots

Myeloma, and some treatments for it, can increase your risk of developing a blood clot. Symptoms of a blood clot include:

- pain, redness or swelling in a leg or an arm
- breathlessness
- chest pain.

Blood clots can be very serious. Tell your doctor straight away if you have any of these symptoms. Most blood clots can be successfully treated with drugs that thin the blood.

Sometimes doctors may give you drugs to reduce the risk of a blood clot. Your doctor or nurse can give you more information about blood clots. We have more information about blood clots and cancer on our website (see page 134).

Hyperviscosity syndrome

Rarely, myeloma causes a very high level of paraprotein in the blood. This means the blood can become thicker than normal. This is called hyperviscosity syndrome.
It can cause symptoms such as:

- headaches
- blurred vision
- abnormal bleeding
- confusion
- dizziness.

You may need a plasma exchange (plasmapheresis). This is a procedure that removes the abnormal paraprotein from the blood. We have more information on our website (see page 134).

COPING WITH MYELOMA

Follow-up

You usually have regular follow-up appointments at the hospital during your treatment and when you are in remission. Or you may have follow-up appointments with your GP. This is sometimes called a shared care agreement. If you have smouldering myeloma, you will also have follow up checks every few months.

If you have any problems, or notice any new symptoms between appointments, tell your doctor or specialist nurse as soon as possible.

Many people feel very anxious before appointments. This is natural. It may help to get support from family, friends or a support organisation.

Throughout your treatment, you usually talk regularly with someone from your cancer team. This may be your cancer doctor or haematology nurse, or another healthcare professional. They should ask about the support you are getting and any concerns and needs you have. In some hospitals, this is called a holistic needs assessment. Your cancer team may write a care plan based on this. This should give information about services that may be useful.

You should have a copy of the care plan. You can use it at follow-up appointments or when you see your GP or other doctors about anything not related to the myeloma. You can update your care plan whenever you need to.

Some hospitals give you a treatment summary. It usually includes information about:

- the treatment you have had
- what to expect after treatment
- the follow-up you will have.

The treatment summary also normally includes contact details of your cancer team.

You will be given a copy to keep. The hospital should also send a copy to your GP.

Not every hospital uses these assessments, care plans and treatment summaries. But more hospitals are starting to use them.

> **‘I have learned to trust my body and know what does and doesn’t feel normal. This can take some time to rebuild after the diagnosis. If I’m in any doubt, I talk with the medical team and get their advice.’**
>
> **Greg**

Living with myeloma

Coping with myeloma is physically and emotionally demanding. But with treatment, many people are now living longer and better lives. There may be long periods when the cancer is under control. There are different things you can do to look after yourself.

Get enough rest

Rest is important. You use up a lot more energy when you are coping with symptoms or recovering from treatments. Here are some tips to help you get enough rest:

- Get a good night's sleep – we have more information about sleeping problems and tips to improve your sleep on our website (see page 134).
- Ask family members or friends to help out. This could be helping with household tasks, cooking or shopping.
- Save energy for the things you want to do and pace yourself. If you have a busy day, try to rest the following day.

We have information about coping with tiredness (see page 91).

Keep physically active

Keeping physically active can help you during and after treatment. Ask your cancer doctor, specialist nurse or GP for advice about the amount and type of physical activity that is right for you.

If you can, go for regular, short walks. This helps your energy levels and helps you feel better. Try to walk for a little longer and further each day.

Being more physically active may improve symptoms such as tiredness, anxiety and difficulty sleeping. It can also strengthen your bones and muscles.

We have more information about keeping physically active in our booklet **Physical activity and cancer** (see page 134).

Drink lots of fluids

Myeloma increases the risk of kidney problems. Drinking plenty of fluids can help your kidneys to stay healthy. Try to drink around 3 litres (5 pints) each day.

If you are on dialysis, your doctor will advise you about how much you should drink. You will need to drink less because your kidneys are not able to get rid of the fluid.

Reduce your risk of infection

You may find that having myeloma means you get more infections. You can speak to your doctor about vaccinations that may help, such as the flu and coronavirus vaccinations.

Some people with myeloma have medicines to boost their immune system or prevent infection. You can talk to your doctor about whether this might be suitable for you.

If you are having chemotherapy or stem cell treatment, your doctor will give you advice about reducing your risk of infection.

> **‘My lack of immunity to infection means I have to be careful to avoid crowded places.’**
>
> **David**

Eat healthily

Eating healthily improves your general health. It can also help you feel better and have more energy. Try to eat:

- plenty of fruit and vegetables
- more chicken and fish (especially oily fish)
- more high-fibre foods, such as wholegrain bread and oats
- less red meat and less processed meat.

Some people with myeloma struggle with their appetite and may lose weight. There are different supplement drinks available to help make sure you get enough calories and nutrients. Some supplement drinks need to be prescribed by your GP.

We have more information on ways to build up your diet in our booklet **The building-up diet** (see page 134).

If you are taking steroids as part of your treatment, you may find your appetite increases and you put on weight (see pages 67 to 68). You may find our booklet **Managing weight gain after cancer treatment** helpful (see page 134).

Ask your doctor or nurse to refer you to a dietitian if you need more advice.

Who can help?

Myeloma affects people in different ways. You may not feel as fit as you used to before treatment. It can take some time to get back into a routine.

Different professionals are available to help. These include the following:

- Haematology nurse specialists – nurses that specialise in blood cancers. You may meet them in clinics or hospitals when you are first diagnosed with myeloma. Some may also be called Macmillan haematology nurses.
- Physiotherapists – can teach you muscle-strengthening exercises. They can also help you start moving around again safely. You should avoid heavy lifting or any activities that may put a strain on your spine or other bones.
- Occupational therapists – can look at how well you manage with your normal activities. They come to your home to see if any changes can be made to help you cope more easily.
- Social workers – can offer support and practical advice to you and your family. If you would like to talk to a social worker, ask your doctor or nurse.
- Psychologists – may be able to help if you have anxiety or depression. They can look at ways to help you cope with your situation. They can also help with any relationship or communication problems in your family.

- District nurses – work closely with GPs. They can visit patients and their families at home, if needed.
- Palliative care nurses – can help with controlling symptoms. They are experienced in assessing and treating symptoms of cancer, such as myeloma. Some may also be called Macmillan nurses.
- Marie Curie nurses – also help with symptom control, and care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange for a palliative care nurse to visit you.

Our cancer support specialists on **0808 808 00 00** can tell you more about the specialist help that is available and can let you know about services in your area.

> **‘Myeloma doesn’t always follow a typical pattern, it affects people in lots of different ways. There is no one size fits all.’**
>
> **Greg**

> ‘I got myself a walker with a seat, so when I go out I can sit down if I get fatigued or need stability. I can now walk to my local nature reserve and it’s given me a sense of freedom.’

Jane

Practical support

If myeloma means that it is difficult for you to move around easily, you may need specialist equipment or people to help you in your daily life. The following organisations may be able to offer help and support:

- The British Red Cross (see page 141) has an office in every county. It has volunteers who can help you in many ways. This may be help with shopping, or errands. The British Red Cross can also lend equipment, like wheelchairs.
- Living Made Easy (see page 142) runs an information service. It also has specialist advisers and occupational therapists. They can give advice on aids and specialist equipment, including walking aids and wheelchairs.
- Scope (see page 142) also gives information and advice to disabled people.

If you have movement (mobility) problems, you may find the Blue Badge scheme useful. It provides parking allowances for people with mobility problems. These are called concessions. It means that you, or someone with you, can park close to where you want to go. For example, you can park next to the entrance of a shop. To apply for a badge, contact your local council. A healthcare professional, welfare rights adviser or social worker can help you apply.

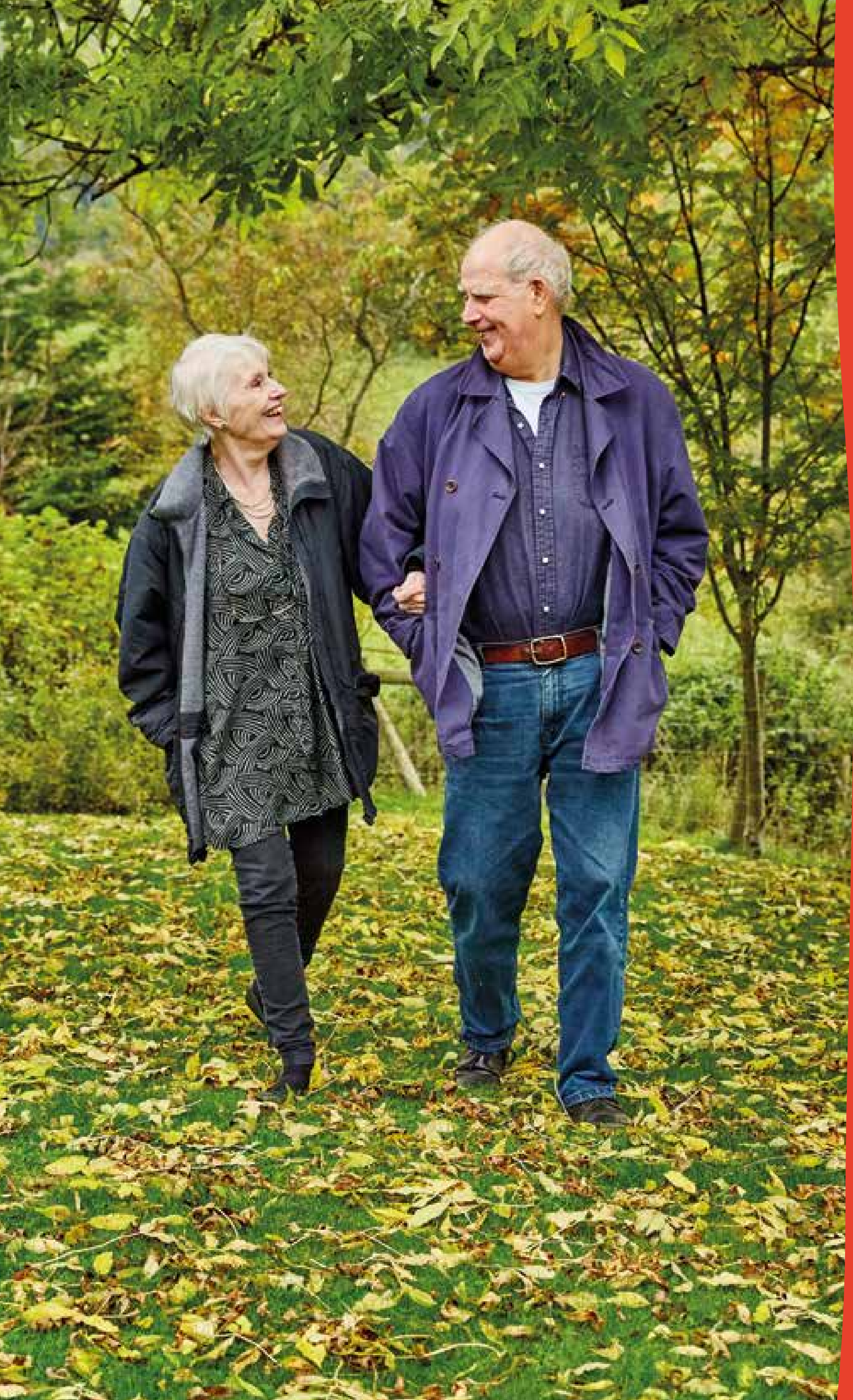
Some areas have good neighbour schemes, usually run by social services or local community organisations. The schemes organise help for people in the local area. For example, it could mean someone helping you with your shopping. Some schemes are only available to people living alone. Search for ‘council for voluntary service’ or ‘good neighbour schemes’ online to find out more.

Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.



YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

Shock and denial

You may find it hard to believe that you have cancer when you are first diagnosed. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the cancer. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try to focus on things you can control. You may want to find out more about the cancer, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy.

Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help. We have more information about depression on our website (see page 134).

Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups**

You can also talk to other people affected by cancer on our Online Community. Visit **macmillan.org.uk/community**

> **'It is often difficult to talk to the people closest to you. I have rung the Macmillan Support Line on many occasions when feeling tearful or just in need of someone to listen. It was a pivotal part of my healing process.'**
>
> **Patsy**

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information about coping with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (see page 134).

Share your experience

Many people find it helps to talk about things and share their thoughts, feelings and advice with other people.

Sharing your experience can also be helpful for other people with myeloma, who might be about to start their treatment. Hearing about how you have coped, what side effects you had and how you managed them is very helpful to someone in a similar situation.

We have more information about how you can share your story. Call us on **0808 808 00 00** or visit **macmillan.org.uk/shareyourstory**

> **‘I blog about the cancer too. If you don’t talk about it at all, it becomes the elephant in the room. I think people need to hear about it, if you’re to be honest with them.’**
>
> **Frances**

Support groups or online support

These offer a chance to talk to other people who have been or are in a similar situation. You can share experiences and ways of coping. They can help if you live alone, or do not feel able to talk about your feelings with people around you.

You can go along to see what a support group is like before you decide to get involved. Call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** for information about cancer support groups across the UK.

Our Online Community at **macmillan.org.uk/community** is a social networking site where you can talk to people in chat rooms, blog about your journey, make friends and join support groups. You can share your own experiences and feelings, and get support from others.

Talking to children about cancer

Deciding what to tell children about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the cancer can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too.
For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what cancer is.
Some will want to know more.

Whether they are teenagers or young children, talking about the cancer helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a cancer diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information about talking to children and teenagers when an adult has cancer in our booklet **Talking to children and teenagers when an adult has cancer** (see page 134).

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to the person with cancer about how you feel may make them feel alone.

You can support the person with cancer by listening and talking with them. Do not feel you have to talk about the cancer. Often it is enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information about talking to someone with cancer in our booklet **Talking with someone who has cancer** (see page 134).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers in our booklet **Looking after someone with cancer** (see page 134).

Sex life

It is not unusual to find that cancer has an effect on your sex life. Sexual difficulties can happen as a result of the physical and emotional effects of cancer and its treatment. For example, you may feel too tired or anxious to have sex. Having myeloma does not have to mean that sex is no longer a part of your life. But you may find that it involves some changes for you and a partner.

As you recover from treatment, your sex drive (libido) may gradually improve. If pain or other side effects (see pages 76 to 95) are causing sexual difficulties, getting these under control may help to improve things.

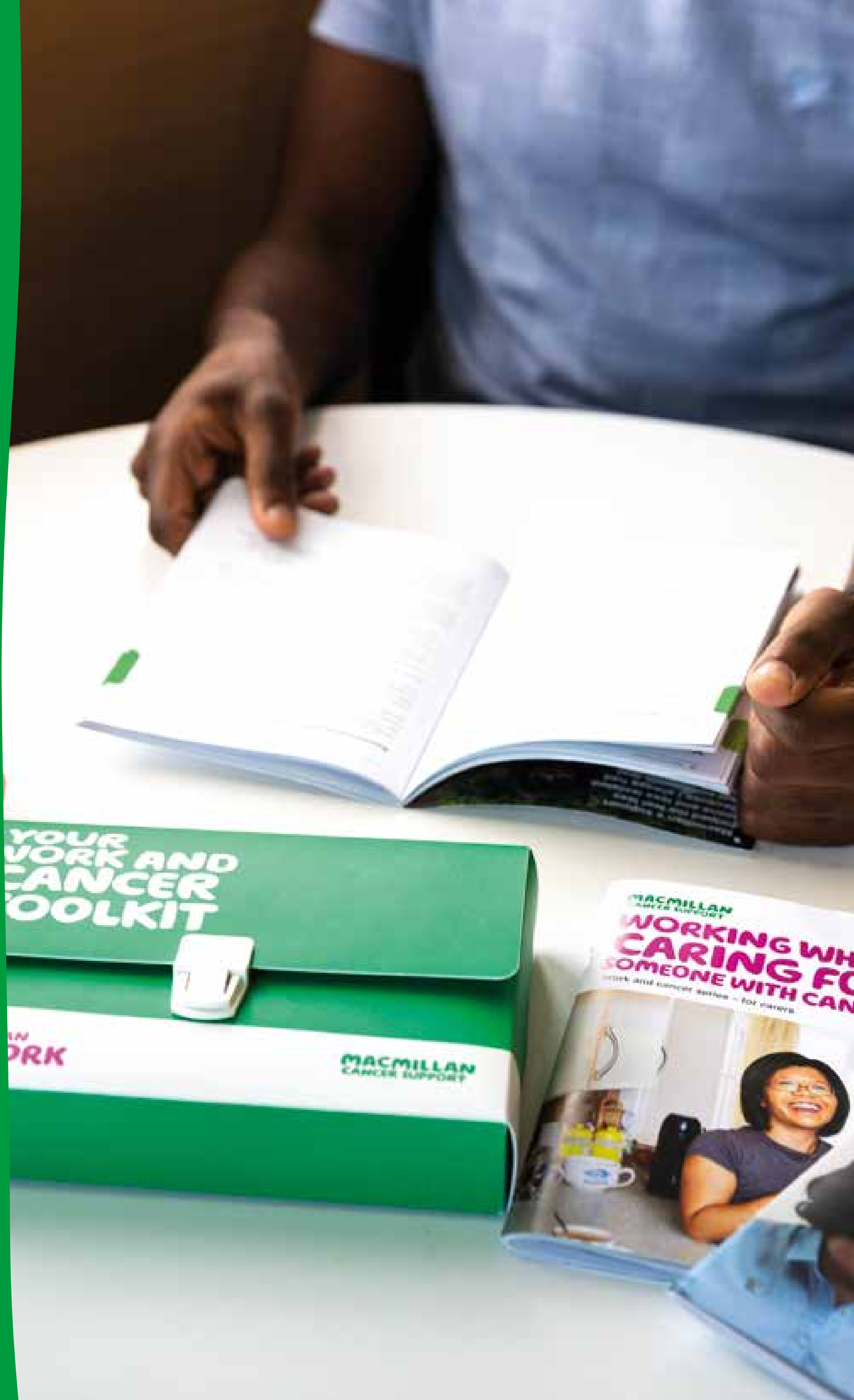
If you have a partner, there are different ways you can show you care about them if you do not feel like having sex. This includes spending time together and showing affection. You may also find new ways to enjoy a sex life.

Partners may sometimes worry that sex could harm you or make the cancer worse, or that they could catch the cancer. But this is not true. Try talking openly about any worries with your partner. This can help you avoid misunderstandings and find ways to cope.

Ask your doctor or nurse for advice if you are having problems with your sex life. If you feel uncomfortable talking to them, you can call us on **0808 808 00 00**. We also have more information in our booklet **Cancer and your sex life** (see page 134).

Some people find it helpful to talk to a counsellor or sex therapist. The College of Sexual and Relationship Therapists (COSRT) has a list of nationwide counsellors and therapists who can offer advice and support. Visit **cosrt.org.uk**

FINANCIAL SUPPORT AND WORK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Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (see page 134). Our Online Community forum on **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 146).

Our booklet **Help with the cost of cancer** has lots more information (see page 134).

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others keep working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 134). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 134).

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as ‘you’ so that everyone feels included. Where clinically necessary we use the terms ‘men’ and ‘women’ or ‘male’ and ‘female’. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support.

Myeloma and related support organisations

African Caribbean Leukaemia Trust (ACLT)

Tel **020 3757 7700**
Email **info@aclt.org**
www.aclt.org
Provides practical help, counselling, advice and support to African-Caribbean people living with leukaemia and other blood disorders. Hosts bone marrow registration drives throughout the UK and raises awareness of the need for donors from the black community.

Anthony Nolan

Tel **0303 303 0303**
www.anthonynolan.org
The UK's largest stem cell and bone marrow register. Does research and has information about stem cell and bone marrow transplants.

Blood Cancer UK

Support line **0808 208 0888**
Email **hello@bloodcancer.org.uk**
www.bloodcancer.org.uk
Offers information, support and advice about blood cancers. Does research into the causes, treatment and cure of leukaemia, lymphoma and myeloma.

The British Bone Marrow Registry (part of NHS Blood and Transplant)

Tel **0300 123 23 23**
Text relay **18001 0300 1232323**
www.nhsbt.nhs.uk/british-bone-marrow-registry
Helps people find stem cell matches. Has a register of stem cell donors and cord blood donations from England, Scotland, North Wales and Northern Ireland. Responsible for recruiting, testing and registering blood donors who volunteer to become stem cell donors.

Kidney Care UK

Tel **01420 541 424** (Mon to Fri, 9am to 5pm)
Email **info@kidneycareuk.org.uk**
www.kidneycareuk.org
Provides advice, support and financial assistance to people with kidney problems. Has information leaflets and booklets.

Leukaemia Care

Helpline **0808 8010 444**
Message via WhatsApp **0750 006 8065**
(Mon to Fri, 9am to 5pm)
Email **nurse@leukaemiacare.org.uk**
www.leukaemiacare.org.uk
A national blood cancer charity supporting anyone affected by a blood cancer or allied blood disorder. Has a freephone helpline, with a nurse service on the line at certain times. Please see the website for full details of opening hours. You can book a time slot to speak to a nurse by calling the helpline or emailing **support@leukaemiacare.org.uk** or **nurse@leukaemiacare.org.uk**

Myeloma UK

Info line **0800 980 3332** (UK) or **1800 937 773** (Ireland)
Email **askthenurse@myeloma.org.uk**
www.myeloma.org.uk
Provides information and support to people affected by myeloma. Helps improve treatments through research, education and awareness.

UK Myeloma Forum

www.ukmf.org.uk
Aims to improve the treatment and care of people with myeloma through engaging in research, promoting clinical trials, developing guidelines and promoting education.

Equipment and advice on living with a disability

The Blue Badge Scheme (Department for Transport)

www.gov.uk/government/collections/blue-badge-scheme
The Blue Badge scheme helps those with severe mobility problems, who have difficulty using public transport, to park close to where they need to go. The scheme operates throughout the UK, and is administered by local authorities who deal with applications and issue badges.

British Red Cross

Tel **0344 871 11 11**
Email **contactus@redcross.org.uk**
www.redcross.org.uk
Offers a number of services for people with a disability, including a medical equipment loan service and a transport service.

Living Made Easy

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)
Email **info@dlf.org.uk**
www.livingmadeeasy.org.uk
National charity that provides free, impartial advice about all types of disability equipment and mobility products through its helpline, website and equipment demonstration centre.

Scope

Helpline **0808 800 3333** (Mon to Fri, 9am to 6pm, and Sat to Sun, 10am to 6pm)
Email **helpline@scope.org.uk**
www.scope.org.uk
Provides support, information and advice to disabled people and their families.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339** (Mon to Fri, 9am to 1pm)
Email **nurseline@cancerfocusni.org**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531** (Mon to Fri, 9am to 5pm)
Email **info@cancersupportscotland.org**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
Email **enquiries@maggies.org**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 2pm)
Email **helpline@pennybrohn.org.uk**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010** (Mon to Fri, 9am to 5pm, and Sat to Sun, 10am to 1pm)

www.tenovuscancercare.org.uk

Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

General health information

Health and Social Care in Northern Ireland

online.hscni.net

Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk

The UK’s biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88** (7 days a week, 8am to 8pm)

www.nhsinform.scot

NHS health information site for Scotland.

Patient UK

www.patient.info

Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393** (Mon to Fri, 9am to 6pm)
Email **info@mind.org.uk**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Email **advice@advice.net**
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Tel **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland. You can also call the Make the Call helpline on **0800 232 1271** to check you are getting all the benefits you are eligible for.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

GOV.UK

www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.wales/welsh-local-authority-links

NiDirect

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Support for older people

Age UK

Helpline **0800 678 1602** (Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produce resources about LGBT cancer experiences. LTT run a peer support group with Maggie's Barts.

Support with sight loss

Royal National Institute of Blind People (RNIB)

Helpline **0303 123 9999** (Mon to Fri, 8am to 8pm, and Sat, 9am to 1pm)
www.rnib.org.uk
Offers support and advice to blind and partially sighted people in the UK.

Support with hearing loss

Royal National Institute for Deaf People (RNID)

Helpline **0808 808 0123** (Mon to Fri, 9am to 5pm)
Textphone **0808 808 9000**
SMS **0780 000 0360**
Email **informationline@rnid.org.uk**
www.actiononhearingloss.org.uk
Offers support and practical advice to people in the UK with hearing loss and tinnitus.

Advanced cancer and end-of-life care

Hospice UK

Tel **020 7520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Marie Curie

Helpline **0800 090 2309** (Mon to Fri, 8am to 6pm, and Sat 11am to 5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **0207 654 8000**
Email **enquiries@phe.gov.uk**
www.ndrs.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **02920 104278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu

Northern Ireland Cancer Registry

Tel **0289 097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

Your notes and questions

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Anne Parker, Consultant Haematologist.

With thanks to: Dr Jenny Bird, Consultant Haematologist; Dr Kevin Boyd, Consultant Haematologist; Dr James Cavet, Consultant Haematologist; Sue Coppin, Haematology Clinical Nurse Specialist; Shirley Crofts, Myeloma Clinical Nurse Specialist; Dr Majid Kazmi, Consultant Haematologist; and Dr Santosh Narat, Consultant Haematologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

Some quotes are from an Online Community member who sadly died in April 2020. We'd like to thank her for all the amazing support she provided on the site, and we hope her words continue to benefit all those who read them. She is sadly missed.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our myeloma information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

National Institute for Health and Care Excellence (NICE). Myeloma: Diagnosis and Management. NICE guideline [NG35]. Last updated 2018. Available from **www.nice.org.uk/guidance/ng35/chapter/Recommendations#managing-newly-diagnosed-myeloma** [accessed July 2021].

M.A. Dimopoulos; P. Moreau; E.Terpos. Multiple Myeloma: EHA - ESMO Clinical Practice Guidelines for Diagnosis, Treatment and Follow up. Annals of Oncology. 2021; Volume 32, ISSUE 3. Available from **www.annalsofoncology.org/article/S0923-7534(20)43169-2/fulltext** [accessed July 2021].

British Society of Haematology. Guidelines on the Diagnosis, Investigation and Initial Treatment of Myeloma. Last updated 2021. Available from **b-s-h.org.uk/guidelines/guidelines/guidelines-on-the-diagnosis-investigation-and-initial-treatment-of-myeloma** [accessed July 2021].

UpToDate. Multiple Myeloma: Clinical Features, Laboratory Manifestations, and Diagnosis. Last updated 2021. Available from **www.uptodate.com/contents/multiple-myeloma-clinical-features-laboratory-manifestationsanddiagnosis** [accessed July 2021].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping.
Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help.
Take part in one of our events or create your own.

Give money
Big or small, every penny helps.
To make a one-off donation see over.

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

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Valid from ☐☐ ☐☐

Expiry date ☐☐ ☐☐

Issue no ☐☐☐

Security number ☐☐☐

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about a type of blood cancer called myeloma. It is for anyone who has been diagnosed with myeloma. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of myeloma. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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