Understanding myeloma

About this booklet

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

The booklet explains what myeloma is and how it is treated. It also has information about coping with myeloma. This includes managing symptoms, your feelings, relationships, work and money.

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.

This booklet does not give information about risk factors, signs and symptoms or tests to diagnose myeloma. You can find more information on our website. Visit macmillan.org.uk/myeloma

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 content list to help you.

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

At the end of the booklet, there are details of other organsiations that can help.

There is also space to write down questions and notes for your doctor and nurse.

Quotes

In this booklet, we have included quotes from people who have had myeloma. You may find these quotes 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. 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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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

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 is sometimes called multiple myeloma. To understand myeloma, it can help to know a little bit about:

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

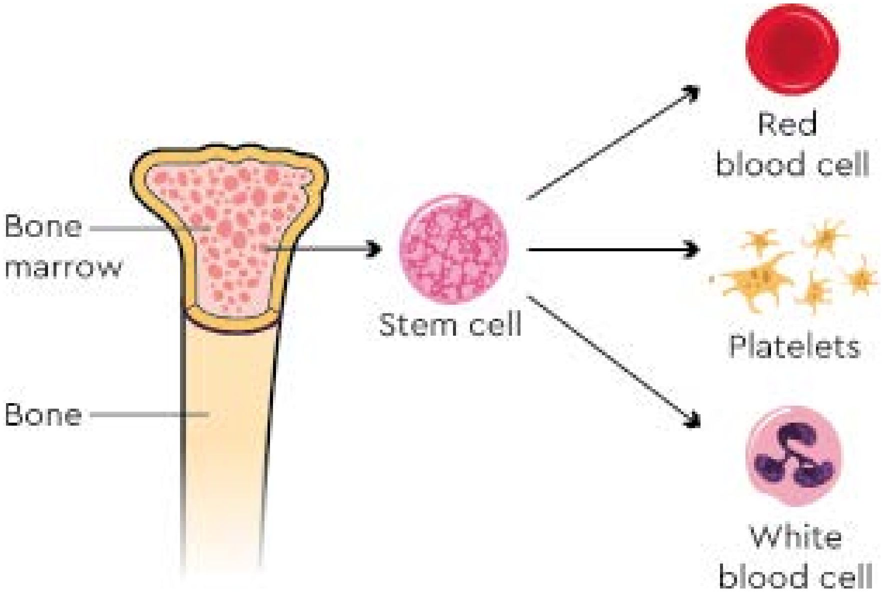
Bone marrow

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. Antibodies are proteins that travel in the blood and help fight any viruses or bacteria in the body. 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:

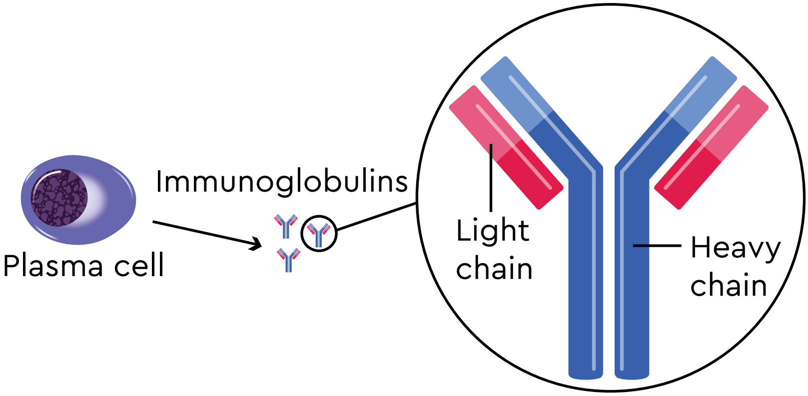
- 2 long protein chains, called heavy chains
- 2 shorter protein chains, called light chains.

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. The symbols are κ and λ.

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.

Myeloma cells usually make an abnormal immunoglobulin. This could be any of the 5 types of immunoglobulin. 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. IgM, IgD and IgE are less common.

Light chain or Bence Jones myeloma

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 found in a blood or urine test.

Non-secretory myeloma

Non-secretory myeloma is a type of myeloma that does not produce light chains or abnormal immunoglobulins. This can make it harder to diagnose and monitor.

You may have other tests to diagnose non-secretory myeloma. These may include bone marrow tests, or scans such as an MRI or PET-CT.

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. Visit macmillan.org.uk/mgus

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 1 area of the body. This is called a 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.

Staging myeloma

The stage describes how advanced the myeloma is and how effective treatment might be. However, the stage of the myeloma does not usually affect the treatment that is offered. So doctors do not always talk about staging.

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.

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	Blood test results do not meet stage 1 or 3 criteria	
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 had one – this test looks for genetic changes in the myeloma cells.

The doctors also look at the effect the myeloma is having on the 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.

Finding out you have myeloma

Being diagnosed can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis may have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with myeloma. We have more information about possible causes, risk factors and symptoms of myeloma on our website, visit:

- macmillan.org.uk/myeloma-risk
- macmillan.org.uk/managing-myeloma

Waiting for treatment to start can cause lots of different emotions. You may be worried about telling people and about what treatment you will have. You might choose to spend some time learning about the cancer. Or you may prefer to wait until you see your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on 0808 808 00 00. They will be able to talk to you about what has happened and any worries you have.

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

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


is 5 Star Patient

Planning myeloma treatment

Treatment overview

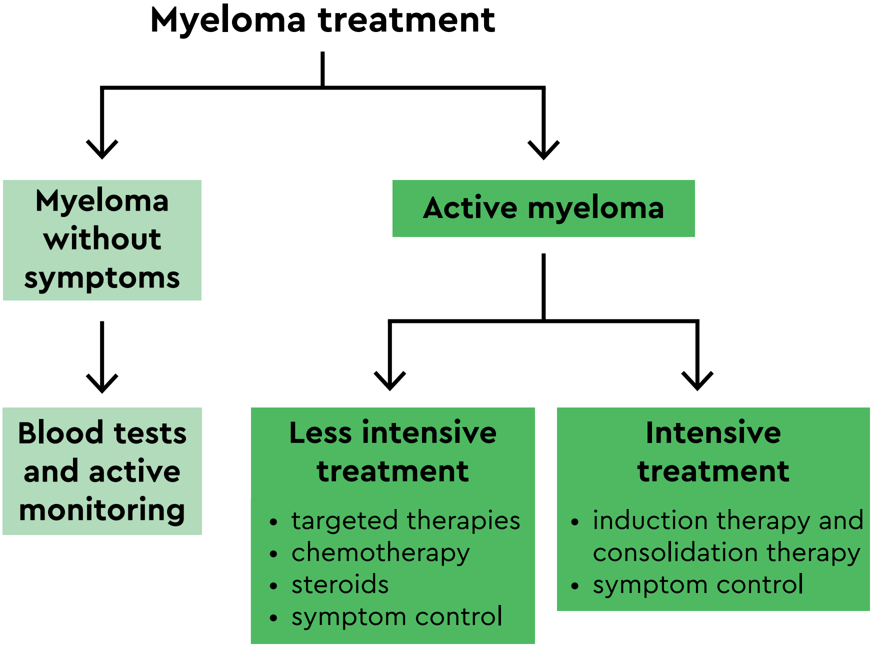
When your cancer team have the results of your tests, they can plan the best treatment for you. Myeloma cannot usually be cured, but it is treatable. Treatment can be very effective and is used to:

- 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 is not causing symptoms, you do not usually need treatment straight away. Myeloma with no symptoms is called smouldering or asymptomatic myeloma.

If the myeloma begins to cause symptoms, you will start treatment. Myeloma with symptoms is sometimes called active or symptomatic myeloma.



Myeloma without symptoms

Myeloma with no symptoms is also called smouldering or asymptomatic myeloma. The plasma cells show abnormal changes on blood tests, but they usually do not cause symptoms.

You may not need treatment straight away. There is no strong evidence that having treatment at this stage will help.

Instead, your cancer team may suggest active monitoring. Active monitoring may sometimes be called active surveillance or watch and wait. This means you do not have treatment until it is needed.

Blood tests and active monitoring

You will have blood samples and some other tests every few months. If tests show the myeloma is progressing or you develop symptoms, your doctor will talk to you about starting treatment.

Some people may feel worried or anxious about not starting treatment straight away. 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 or nurse.
- 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.
- Share 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 in our booklet How are you feeling? The emotional effects of cancer.

Some people may be offered treatment for smouldering myeloma, but only as part of a clinical trial. Your myeloma team can give you more information about clinical trials if needed.

Active myeloma with symptoms

Active myeloma means you have symptoms, or are at a high risk of developing symptoms. It may also be called symptomatic myeloma.

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. Remission means the myeloma cannot be found in tests.

Less intensive treatment

Less intensive treatments include:

- targeted therapies
- chemotherapy
- steroids
- symptom control.

Usually, a combination of these treatments is used.

Intensive treatment

Some people might have intensive treatment. If your cancer team recommends this as part of your treatment, they will discuss the possible benefits and disadvantages with you.

Because intensive treatment is more complicated, it is usually only offered in specialist hospitals. This means you may have to travel to a different hospital. You are likely to be in hospital for several weeks and it may take some months to fully recover.

Intensive treatment is divided into the following 2 stages:

1. Induction therapy – this is treatment with targeted therapy, chemotherapy and steroids. The aim of induction therapy is to get rid of as many myeloma cells as possible.
2. Consolidation therapy – this uses treatment with high dose chemotherapy treatment and a stem cell transplant to get rid of remaining myeloma cells.

Maintenance or continuous treatment

Your doctor may suggest continuous treatment to get the best possible response for you and delay relapse for as long as possible. This is called continuous therapy or maintenance treatment.

If the myeloma does not respond to the first treatment, your cancer team will look at other treatments.

Some people who are in remission may also be offered continuous treatment. The aim of this is to keep myeloma in remission .

Controlling symptoms

Treating symptoms is an important part of your treatment for myeloma. Always tell your doctor or nurse if you notice:

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

Myeloma can cause bone pain or other bone problems. This can be managed with:

- painkillers
- drugs called bisphosphonates
- radiotherapy
- surgery, but this is less common.

Other symptoms might include tiredness or difficulty fighting infections. Sometimes the kidneys are affected by myeloma. There are different ways these problems can be managed.

We have more information about controlling symptoms.

Clinical trials

Clinical 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.

Response to myeloma treatment

You will have tests during your treatment to check how well the myeloma is responding to treatment. Your cancer team will check your blood or urine (pee) for abnormal immunoglobulins (paraproteins) and light chains made by the myeloma cells.

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 the following:

- Complete response (CR) 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
- Very good partial response (VGPR) means the paraprotein can only be detected by certain types of test. Or the paraprotein level is 90% lower than it was before treatment
- Partial response (PR) means the paraprotein level is at least 50% lower than it was before treatment
- Stable disease 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.

If you have a relapse, your cancer team may change your treatment or offer further treatment.

> **"I think the main thing with cancer is not to let it take over any more than you have to. You're still the person you always were, in spite of this intruder. Don't let it get the better of you."**
>
> Frances, diagnosed with myeloma

How your treatment is planned

After your test results, you and your doctor can 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 these.

The MDT may 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.
- Orthopaedic surgeon – a doctor who specialises in bones and joints.

Talking about your treatment plan

After the MDT meeting, you will usually meet with your cancer doctor and specialist nurse. They will talk to you about your treatment plan. It can help to write down your questions before your appointment.

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.

Your cancer doctor should explain:

- the aim of the treatment – for example, to reduce and control the myeloma, or to treat myeloma symptoms
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

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.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them.

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, you may have treatment 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.

Choosing between treatments

Doctors sometimes ask you to choose between different treatments. This is usually when 2 treatments work equally well.

It can help to talk to your family or friends about your treatment options. Your doctor or nurse can help you with your decision. You do not usually need to decide straight away.

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.

Your doctor or nurse may give you printed information or show you videos about your treatment options. They may also show you online tools called decision-making aids. These can help you make your decision.

If you choose not to have treatment, you can still have supportive care to help control symptoms.

We have more information in our booklet Making treatment decisions you may find useful.

Giving your permission (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 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 cancer 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 cancer 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. Visit macmillan.org.uk/second-opinion

Treatment for myeloma

Cancer drugs for myeloma

Myeloma is usually treated with a combination of different cancer drugs. This often includes targeted therapy drugs and a steroid. You may also have these drugs with chemotherapy.

Drug combinations are often named after the initials of the drugs used. The following are some combinations used to treat myeloma:

- PVD – panobinostat, bortezomib (Velcade®) and dexamethasone
- IRD – ixazomib, lenalidomide (Revlimid®) and dexamethasone
- DVTD – daratumumab, bortezomib (Velcade®), thalidomide and dexamethasone
- DVCD – daratumumab, bortezomib (Velcade®), cyclophosphamide and dexamethasone
- DRD – daratumumab, lenalidomide (Revlimid®) and dexamethasone
- KRD – carfilzomib (Kyprolis®), lenalidomide (Revlimid®) and dexamethasone
- SVD – selinexor, bortezomib (Velcade®) and dexamethasone.

Your doctor and nurse will talk to you about the different treatment options. They will tell you:

- the aims of the treatment
- how it is given
- how often you have it (treatment cycle)
- how long your course will take
- any possible side effects.

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

Cancer drugs can cause side effects. It is important to tell your cancer doctor or specialist nurse if you have any side effects while you are having treatment. They may change your treatment to control side effects or to help to prevent more serious problems.

We have more information about these cancer drugs on our website. Visit macmillan.org.uk/treatments-and-drugs

Targeted therapy for myeloma

Targeted therapies are drugs that affect the way myeloma cells grow. 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, lenalidomide or pomalidomide
- bortezomib
- daratumumab
- panobinostat
- ixazomib
- carfilzomib
- selinexor.

You usually have these drugs with chemotherapy drugs and steroids. Sometimes you have 2 targeted therapy drugs together.

If you are taking thalidomide, lenalidomide or pomalidomide, you will be given drugs called anti-coagulants to thin your blood. This is because these drugs can increase your risk of developing a blood clot. Anti-coagulants help to reduce this risk. These drugs can cause birth defects in developing babies. You must not become pregnant or make someone pregnant while taking these drugs.

If the myeloma comes back (relapsed myeloma), other targeted therapies may be used alone or in combination.

Chemotherapy for myeloma

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells.

Chemotherapy drugs used to treat myeloma include:

- melphalan
- cyclophosphamide
- bendamustine.

Steroids for myeloma

Steroids are drugs that can help destroy myeloma cells. The 2 most commonly used steroids for myeloma are:

- prednisolone
- dexamethasone.

Steroids may be used on their own or in combination with other drugs. You usually take them as tablets. If you have difficulty swallowing them, you can have steroids that are liquid or that dissolve.

We have more information about the side effects of steroids.

Having cancer drug treatment

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

If you are having a drug by injection or drip (infusion) you usually have this at a day unit or clinic as an outpatient. For some treatments you might need to stay in hospital. You can take tablets or capsules at home.

Lines and ports

If you are having your treatment by drip (infusion), this is usually given through a cannula. This is a short, thin tube that is put into a vein in the arm or hand. The cannula is removed after each treatment.

Sometimes, instead of a cannula, your cancer team may suggest a different type of line that can stay in place during the course of your treatment. They might suggest 1 of the following:

- a central line – a fine tube that goes under the skin of the chest and into a vein close by (opposite page)
- a PICC line – a fine tube that is put into a vein in the arm and goes up into a vein in the chest
- an implantable port (portacath) – a disc that is put under the skin on the chest or arm and goes into a vein in the chest.

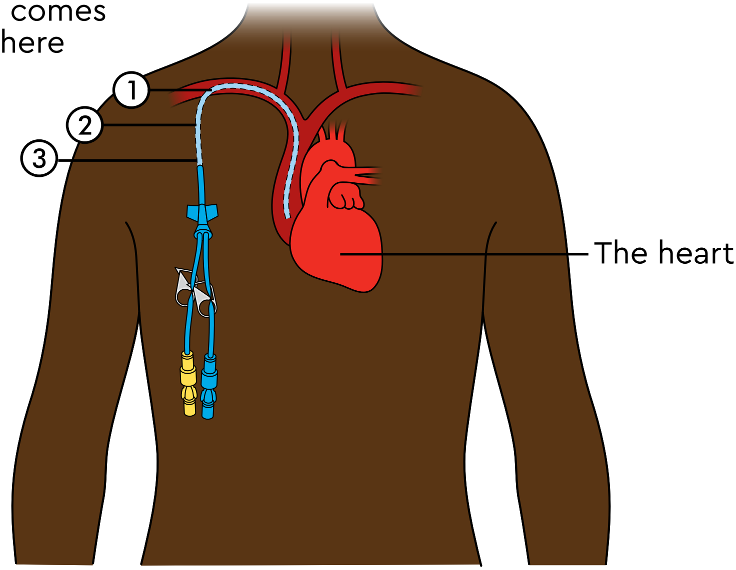
Lines and ports can be used to take blood samples and give you treatment. Your cancer team will explain how to look after your line or port.

A central line

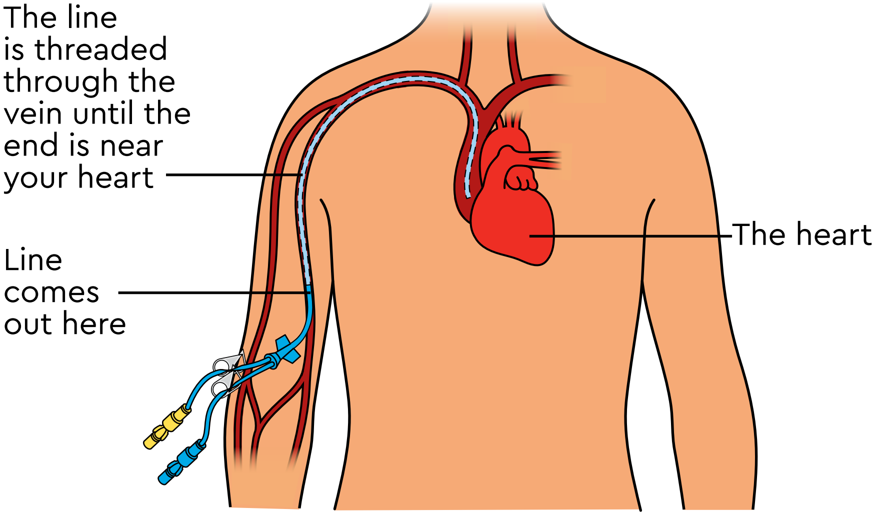
① Central line inserted into chest here

② Line tunnelled under skin

③ Line comes out here



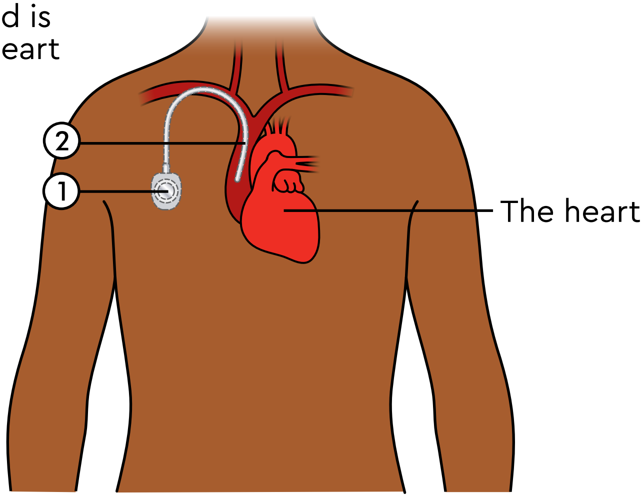
A PICC line


The line is threaded through the vein until the end is near your heart
Line comes out here
The heart

An implantable port

① Port
(under the skin)

② The line (catheter) is threaded through a vein until the end is near your heart



Protecting partners and preventing pregnancy

It is important to follow your team's advice about contraception while you are having cancer drug treatment. This may include advice about:

- contraception to prevent pregnancy – if the drug might be harmful to the unborn baby
- barrier contraception to protect partners – if the drug might get into your body fluids.

Thalidomide, lenalidomide and pomalidomide

If your treatment includes 1 of these drugs, your team will give you extra information about contraception.

This is because the targeted therapy drugs thalidomide, lenalidomide and pomalidomide can cause birth defects in developing babies. You must not become pregnant or make someone pregnant while taking these drugs.

You will take part in a pregnancy prevention programme during treatment. Even if you do not think you are at risk of getting pregnant or making someone pregnant, you will still be included in this programme. You can talk to your doctor or specialist nurse about this.

Your doctor or specialist nurse will give you information about the risks of these drugs and pregnancy. They will ask you to sign a consent form once you have read the information.

Pregnancy tests and contraception

If you are of childbearing age and able to get pregnant, you will have a pregnancy test before starting treatment with thalidomide, lenalidomide and pomalidomide. The pregnancy test is repeated every 4 weeks during treatment, and 4 weeks after treatment ends.

You must also use an effective form of contraception, such as:

- an implant
- an injection
- the progesterone-only pill.

The combined oral contraceptive pill is not recommended because it increases your risk of developing blood clots.

Your cancer team may ask a specialist in contraceptive advice to meet with you. They can talk with you about the contraceptive options available.

You must use contraception to prevent pregnancy:

- for 4 weeks before treatment
- during treatment
- for 4 weeks after treatment ends.

If you think you may be pregnant at any time during your treatment, contact your cancer doctor or specialist nurse straight away.

Contraception to prevent making someone pregnant

These drugs can pass into the semen that carries sperm. During treatment and for a week after treatment finishes, you must not:

- make someone pregnant
- donate sperm.

You can protect partners by using a condom during sex. During treatment and for a week after treatment finishes, you must use a condom during sex with anyone who is:

- pregnant
- of childbearing age and able to get pregnant.

If a partner thinks they might be pregnant during your treatment, contact your doctor, nurse or pharmacist straight away.

Side effects of cancer drugs

Different drugs cause different side effects. This information is about some of the more common side effects of the chemotherapy and targeted therapy drugs used to treat myeloma. Visit macmillan.org.uk/treatments-and-drugs

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.

It is important to tell your cancer team if you have any side effects while you are having treatment. They will give you 24-hour contact numbers for the hospital. If you feel unwell or need advice, you can call at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

Your cancer team may adjust your treatment to control side effects or to help to prevent more serious problems.

Risk of infection

Most cancer drugs for myeloma can reduce the number of white blood cells in your blood. These cells fight infection. If your white blood cell count is low, you may be more likely to get an infection. A low white blood cell count is 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. Always follow any specific advice your cancer treatment team gives you. And if you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

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

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

Anaemia (low number of red blood cells)

Most cancer drugs for myeloma can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may feel:

- very low in energy
- breathless
- dizzy and light-headed.

If you have these symptoms, contact the hospital straight away on the 24-hour number. You may need treatment for anaemia. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Your cancer team may also consider using a type of protein called a growth factor to help treat anaemia. This is called erythropoietin. It stimulates the bone marrow to make red blood cells. It is given as an injection under the skin (subcutaneously). Your cancer team will tell you if you need this treatment.

Bruising and bleeding

Most cancer drugs for myeloma 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, brown or purple spots that may look like a rash – these spots can be harder to see if you have black or brown skin.

If you have any unexplained bruising or bleeding, contact the hospital straight away on the 24-hour number. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Feeling sick

Your doctor, nurse or pharmacist will prescribe anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as they tell you to, even if you do not feel sick. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluid often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or if you are sick (vomit) 1 to 2 times in 24 hours, contact the hospital on the 24-hour number as soon as possible. They will give you advice. They may change your anti-sickness treatment. Let them know if you still feel sick.

Sore mouth and throat

Chemotherapy and some other drugs 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.

Contact the hospital straight away on the 24-hour number, if:

- your mouth or throat is sore, or affecting how much fluid you can drink or food you can eat
- your mouth, tongue, throat or lips have any blisters, ulcers or white patches.

They can give you advice, and mouthwash or medicines to help with the pain or to treat any infection. Follow their advice and make sure you:

- drink plenty of fluids
- avoid alcohol and tobacco
- avoid food or drinks that irritate your mouth and throat.

Feeling tired (fatigue)

Feeling tired is a common side effect of myeloma drugs. It is often worse towards the end of treatment and for some weeks after it ends. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can help you feel less tired.

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

We have more information about ways to manage fatigue in our booklet Coping with fatigue (tiredness) you may find helpful.

Blood clot risk

Cancer and some cancer treatments can increase the risk of a blood clot. Contact the hospital straight away on the 24-hour number if you have any of these symptoms during or after treatment:

- throbbing pain or swelling in a leg or arm
- reddening of the skin in the area – if you have black or brown skin, this can be harder to notice, but the skin might become darker
- suddenly feeling breathless or coughing.

Always call 999 if you have:

- chest pain
- difficulty breathing.

A blood clot is serious, but it can be treated with anticoagulants. These drugs thin the blood. Your doctor, nurse or pharmacist can give you more information about preventing and treating blood clots.

Constipation

Constipation means that you are not able to pass stools (poo) as often as you normally do. It can become difficult or painful. Here are some tips that may help:

- Drink at least 2 litres (8 glasses) of fluids each day.
- Eat high-fibre foods, such as fruit, vegetables and wholemeal bread.
- Do regular gentle exercise, like going for short walks.

If you have constipation, contact the hospital on the 24-hour number for advice. They can give you drugs called laxatives to help.

If you have not been able to pass stools for over 2 days and are being sick, contact the 24-hour number straight away.

Numb or tingling hands or feet (peripheral neuropathy)

Myeloma targeted therapy drugs may affect the nerves in your fingers and toes. This can cause numbness, tingling or pain in your hands or feet. This is called peripheral neuropathy. You might find it hard to do fiddly tasks such as fastening buttons or tying shoelaces.

If you have these symptoms, always tell your doctor, nurse or pharmacist. They sometimes need to change the drug or the dose of the drug. The symptoms usually improve slowly after treatment ends. But for some people they continue and are a long-term side effect of treatment.

Diarrhoea

Diarrhoea means passing more stools (poo) than is normal for you, or having watery or loose stools. You may also have stomach cramps. If you have a stoma, it may be more active than usual.

If you are passing loose stools 3 or more times a day and this is not normal for you, contact the hospital as soon as possible on the 24-hour number. Follow the advice they give you about:

- taking anti-diarrhoea medicines
- drinking enough fluids to keep you hydrated and to replace lost salts and minerals
- any changes to your diet that might help.

They might also ask you for a stool sample to check for infection.

Hair loss

Some chemotherapy drugs can make your hair 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.

If you want to cover up hair loss, there are different ways you can do this. Your nurse will give you information about coping with hair loss.

Remember to protect your skin from the sun. Use suncream with a sun protection factor (SPF) of at least 30 on your scalp. Or cover up with a hat or scarf.

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

We have more information about hair loss in about booklet Coping with hair loss and on our website. Visit macmillan.org.uk/hair-loss

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Skin changes

Myeloma treatments can cause skin changes. These are usually mild, but if they are not treated they can become serious. You may need creams, steroids or other medicines to treat skin problems. If you notice skin changes during treatment, or after treatment ends, contact the hospital on the 24-hour number as soon as possible. Skin changes can include:

- a rash or bumps on the skin
- dry or itchy skin
- patches of white or paler skin.

To protect your skin from the sun, use suncream with of at least SPF 30. SPF stands for sun protection factor. Cover up with clothing and a hat.

Contact the hospital straight away on the 24-hour number if you have any of these symptoms:

- a rash that is spreading
- blistering or peeling skin
- flu-like symptoms, such as a high temperature and joint pain.

These symptoms can be a sign of a serious skin reaction that needs to be treated immediately in hospital.

Side effects of steroids

The side effects of steroids are usually temporary and disappear as the dose is lowered.

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.

You should take steroids exactly as your cancer team explain to you. Do not stop taking them without talking to your cancer team first. Do not take them for longer than you have been told to.

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
- eyesight changes
- 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.

If you get very thirsty or feel you are passing more urine than usual, tell your doctor.

Some people experience tiredness or fatigue when they stop taking steroids.

Taking steroids for a long time

It is unusual for people with myeloma to take steroids for a long time. But if you do, you may also:

- gain weight, especially in the face, waist and shoulders
- build up fluid in the body (retain more water)
- have higher blood pressure
- have a slightly greater risk of getting infections.

Intensive treatment

Sometimes, high dose chemotherapy with a stem cell transplant is used to treat myeloma. This is called intensive treatment. 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.

Intensive 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.

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

1. 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.
2. 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.
3. High dose chemotherapy treatment – this 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.
4. 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.

Anthony Nolan is a UK charity who provides information and support for people who need a stem cell transplant. It has a lot of detailed information you may find helpful.

Treatment if myeloma comes back

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

After a time, myeloma usually comes back and needs further treatment. This is called relapsed or recurrent myeloma.

Myeloma can relapse a number of times. The time between remission and relapse is different for everyone. 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. 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 also have treatments to control bone problems and other symptoms.

You may have 1 or more of the following targeted therapy drugs:

- bortezomib
- lenalidomide
- daratumumab
- carfilzomib.

Or you may have a second high dose chemotherapy treatment and stem cell transplant.

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

- lenalidomide
- boretezomib
- panobinostat
- ixazomib
- pomalidomide
- daratumumab
- isatuximab
- selinexor
- elranatamab
- teclistamab.

Clinical trials are done to try to find new and better treatments. Clinical trials are often considered for relapsed myeloma.

If treatment does not control the myeloma, or stops controlling it, the doctors will talk to you about treatments to manage symptoms.

We have more information about these cancer drugs on our website. Visit macmillan.org.uk/treatments-and-drugs

Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

We have more information about cancer clinical trials on our website. Visit macmillan.org.uk/clinical-trials

Taking part in a clinical 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.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.


Fire exit

Managing the symptoms of myeloma

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 meet with your cancer doctor regularly for blood tests and scans, and to talk 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 to manage symptoms.

> **"Partial remission is like a slightly subdued version of normal life. I don't have the energy I used to, and have a sleep during the day. But my bad back is now a mild grumble, and I can walk well. I'm not in pain, and I don't have sickness."**
>
> Frances, diagnosed with myeloma

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
- 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).

We have more information about these problems over the next few pages.

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. 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 or pain 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.

We have more information about ways to control pain in our booklet Managing cancer pain.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Treatments for bone pain may include:

- painkillers (below)
- bisphosphonates
- radiotherapy
- surgery, including vertebroplasty or kyphoplasty.

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. This information can help them to plan the best pain control for you. You can download a pain diary from our website. Visit macmillan.org.uk/pain

Anti-inflammatory drugs such as ibuprofen can cause kidney damage in people with myeloma. You should check with your cancer doctor or specialist 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). These drugs can help delay bone damage, so your doctor may give you 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 capsules or tablets.

Side effects are usually mild and can happen for a few days after the infusion. They include:

- indigestion
- feeling sick (nausea)
- flu-like symptoms
- low levels of calcium in the blood – your cancer team may advise you to take calcium and vitamin D supplements to prevent this
- diarrhoea
- indigestion or a sore throat – this is usually more common in people who are taking bisphosphonates as capsules or tablets.

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 website. Visit macmillan.org.uk/bisphosphonates

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.

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. You will go to the department before your treatment starts. The radiotherapy staff will decide:

- the exact dose of radiotherapy
- the area to be treated
- how many treatments you need.

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. We have more information in our booklet Coping with tiredness (fatigue).

Tell the radiotherapy team about any side effects you have. They can help you to manage them. We have more information about having radiotherapy in our booklet Understanding radiotherapy.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Surgery

Some people need surgery 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 is 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 may sometimes 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 into the vertebrae and then slowly inflates it to create a space. The balloon is called an inflatable bone tamp. Bone cement is injected into the space, 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 malignant spinal cord compression (MSCC). 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 anywhere in your body that is new or suddenly gets worse
- a feeling that your arms and hands are weak or not able to grip things properly
- a feeling of unsteadiness on your feet
- weakness in your legs
- problems passing urine (peeing) or only passing small amounts of urine
- problems with bowel control (incontinence or constipation).

If you have symptoms of MSCC, you should get medical advice immediately.

You should contact the hospital team where you usually go for cancer treatment and follow-up appointments. If you are unable to get in touch with anyone, go to the nearest Emergency Department (A&E) or contact your GP.

When you speak to a health professional:

- tell them you have cancer and are worried you may have spinal cord compression
- describe your symptoms
- tell them that you need to be seen straight away.

Spinal cord compression is an emergency that needs treatment as soon as possible. Do not wait for further symptoms to develop. The sooner MSCC is diagnosed, the sooner treatment can begin. If left untreated, MSCC can cause permanent nerve 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.

You can order an MSCC alert kit from our website. Visit orders.macmillan.org.uk

We have more information about MSCC on our website. Visit macmillan.org.uk/MSCC

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 (pee) 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.

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. It is important to 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.

Your doctor will explain if you need dialysis. Some people who need kidney dialysis only have it for a short period of time. Other people need long-term dialysis.

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, 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.

We have more information and a copy of our fatigue diary in our booklet Coping with tiredness (fatigue).

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. These are called prophylactic drugs. They may also recommend you have vaccines such as the flu or coronavirus vaccination, if you have not already.

Immunoglobulin treatment

If you are getting a lot of infections, you may have regular immunoglobulin treatment. You have this as a drip into a vein or an injection under the skin (subcutaneously).

Most people feel fine when having treatment, but sometimes it can cause an allergic reaction. This is most likely to happen during or after the first treatment. Your cancer team will explain your treatment and what to expect.

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 erythropoietin (EPO) on our website. Visit macmillan.org.uk/EPO

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 ends. But it can be permanent.

We have more information about peripheral neuropathy on our website. Visit macmillan.org.uk/peripheral-neuropathy

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 small 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 specialist nurse for advice. You can also ask to meet with a dietitian.

You can add extra energy and protein to your diet with everyday foods or by using food supplements. Speak to your specialist nurse or doctor for more advice.

We have more booklets that you may find useful:

- Healthy eating and cancer
- Eating problems and cancer
- The building-up diet.

Blood clots

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

Contact the hospital straight away on the 24-hour number if you have any of these symptoms during or after treatment:

- throbbing pain or swelling in a leg or an arm
- reddening of the skin in the area – if you have black or brown skin, this can be harder to notice, but the skin might become darker
- suddenly feeling breathless or coughing.

Always call **999** if you have:

- chest pain
- difficulty breathing.

A blood clot is serious, but it can be treated with drugs called anticoagulants. These thin the blood. Your doctor, nurse or pharmacist can give you more information about preventing and treating blood clots.

We have more information about blood clots on our website. Visit macmillan.org.uk/blood-clots

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.

Coping with myeloma

Follow-up

If you are having treatment or are in remission, you usually have regular follow-up appointments at the hospital. 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 appointments 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.

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm. ☎

During treatment

Throughout your treatment, you usually talk regularly with someone from your cancer team. This may be your cancer doctor, specialist 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 (HNA). Your cancer team may write a care plan based on this. This should give information about services that may be useful. We have more information you may find useful in our booklet Holistic Needs Assessment: Planning your care and support.

You should have a copy of your 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.

When a treatment ends

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.

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 treatment. 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. Visit macmillan.org.uk/trouble-sleeping
- 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 also have more information in our booklet Coping with fatigue (tiredness).

> **"My chemo ended and I had a stem cell transplant. I have been told I'm in remission. I recovered far quicker than I thought and have been living my life to the full since. I've reached a stage where I have some hope and positivity and have learned to appreciate every nice thing fully."**

Franko, diagnosed with myeloma

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 you may find useful in our booklet Physical activity and cancer.

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. For more information on coronavirus and cancer, visit macmillan.org.uk/coronavirus

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 a stem cell treatment, your doctor will give you advice about reducing your risk of infection.

Eat healthily

Eating well 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.

If you are taking steroids as part of your treatment, you may find your appetite increases and you put on weight.

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

We also have more information you may find useful in our booklets:

- Healthy eating and cancer
- The building-up diet.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

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 specialist – this is a nurse that specialises 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.
- Physiotherapist – this is someone who 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 therapist – this is someone who can check how well you manage normal activities and offer solutions if you are having any problems. They come to your home to see if any changes can be made to help you cope more easily.
- Social worker – this is someone who 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.
- Psychologist – this is someone who 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 nurse – this is a nurse that works closely with GPs. They can visit patients and their families at home, if needed.
- Palliative care nurse – this is a nurse that 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 – this is a nurse that can help with symptom control, and care for people approaching the end of their lives in their own homes. They may also be called palliative care nurses. 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 answer questions and tell you more about specialist help and services in your area.

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 and schemes may be helpful:

- The British Red Cross – offers a range of health and social care services across the UK. It can also lend equipment like wheelchairs. It has volunteers who can help you with shopping or errands.
- Living Made Easy – offers free advice and information about disability equipment and mobility products. It also has specialist advisers and occupational therapists. It can give advice on aids and specialist equipment, including walking aids and wheelchairs.
- Scope – offers information and advice on living with disability.
- Age UK – offers information and advice for older people in the UK. It can give information about home safety, home care or equipment that may help you.
- The Blue Badge scheme – 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.
- Good neighbour schemes – these are usually run by social services or local community organisations. They organise help for people in the local area. For example, there might be a good neighbour scheme where someone helps you with your shopping. Some schemes are only available to people living alone. Search online for 'council for voluntary service' or 'good neighbour schemes' and the area you live in, to find out more.

Your feelings and relationships

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet How are you feeling? The emotional effects of cancer.

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on 0808 808 00 00 and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships online and in our booklets Talking about cancer and Cancer and relationships: support for partners, families and friends.

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 can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet Talking with someone who has cancer.

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 on our website and in our booklet Looking after someone with cancer.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.

Cancer and your sex life

It is not unusual to find that cancer has an effect on your sex life.

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.

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. Or call the Macmillan Support Line on 0808 808 00 00. We have more information in our booklet Sex and cancer.

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

Some people also find our Online Community helpful. Visit macmillan.org.uk/community

Financial support and work

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. Visit macmillan.org.uk/benefits We also have information for carers.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has money advisers you can speak to 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 if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

If you are thinking about buying insurance or making a claim our money advisers may be able to help. You can call them on 0808 808 00 00.

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community

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 or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

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

Your cancer doctor, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. You can also find out more about your employment rights in our booklet Your rights at work when you are affected by cancer (page 114).

We have more information aboutwork on our website. Visit macmillan.org.uk/work

Further information

About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit orders.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
- interactive PDFs
- 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 at **informationproductionteam@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 want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

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.

To find out more about how we produce our information, visit 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 support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on 0808 808 00 00. Or visit macmillan.org.uk/support-line to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

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. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

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

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 bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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**

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Myeloma and related support

Anthony Nolan

Tel **0303 303 0303**
www.anthonynolan.org
Provides information and support for people with blood cancer or a blood disorder who need a stem cell transplant. Runs a stem cell register of potential donors. Offers telephone support, grants, online community and support days.

Blood Cancer UK

Tel **0808 208 0888**
www.bloodcancer.org.uk
Offers information and support for people all types of blood cancer. Provides information and support online, by phone, by email, and through support groups and buddy systems. Also has a clinical trials support service.

Kidney Care UK

Tel **0808 801 0000**
www.kidneycareuk.org
Provides advice, support and financial assistance to people with kidney problems. Has leaflets and booklets, including information about having dialysis.

Myeloma UK

Info line **0800 980 3332** (UK)
www.myeloma.org.uk
Provides information and support to people affected by myeloma. Helps improve treatments through research, education and awareness.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

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**
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 300 0118**
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**
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

Drinkaware

www.drinkaware.co.uk
Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Health and Social Care in Northern Ireland

www.northerntrust.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 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
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-related and illness-related websites.

Stop smoking services

Help Me Quit (Wales)

Tel **0800 085 2219**
Text 'HMQ' to **80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

NHS Smokefree Helpline (England)

Tel **0300 123 1044**
www.nhs.uk/better-health/quit-smoking
Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info
Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Quit Your Way (Scotland)

Tel **0800 848 484**
www.nhsinform.scot/quit-your-way-scotland
Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
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 the 'Therapist directory' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 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**
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**
adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its 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 civil legal advice, benefits, and public services in England, Scotland and Wales.

Law Centres Network

www.lawcentres.org.uk
Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

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 online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NI Direct

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

NI Direct Make the Call

Make the Call helpline **0800 232 1271**
Text ADVICE to **0798 440 5248**
www.nidirect.gov.uk/make-the-call
Service to check if you or someone you care for may be entitled to extra benefits.

Northern Ireland Housing Executive

Tel **0344 892 0902**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity

Tel **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Equipment and advice on living with a disability

Age UK

Helpline **0800 678 1602**
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.

British Red Cross

Tel **0344 871 1111**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Living Made Easy

www.livingmadeeasy.org.uk
Provides free, impartial advice and information about all types of disability equipment and mobility products.

Motability Scheme

Tel **0300 456 4566**
www.motability.co.uk
The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

Scope

Helpline **0808 800 3333**
Textphone **18001 0808 800 3333**.
www.scope.org.uk
Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.
Support for older people

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
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.

OUTpatients

www.outpatients.org.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 produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline **0808 808 7777**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry is 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 a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
qub.ac.uk/research-centres/nicr/AboutUs/Registry

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 Senior Medical Editor, Dr Gillian Horne, Consultant Haematologist.

With thanks to: Hannah Belcher, Clinical Nurse Specialist; Dr Gillian Brearton, Consultant Haematologist; Tara Nicholson, Macmillan Myeloma Clinical Nurse Specialist; and Dr Richard Soutar, Consultant Haematologist.

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

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

Hughes D, Yong K, Ramasamy K, et al. Diagnosis and management of smouldering myeloma: A British Society for Haematology Good Practice Paper. Br J Haematol. 2024;204(4):1193–1206. Available from: www.doi.org/10.1111/bjh.19333 [accessed May 2024].

Sive J, Cuthill K, Hunter H, et al. Guidelines on the diagnosis, investigation and initial treatment of myeloma: a British Society for Haematology/UK Myeloma Forum Guideline. Br J Haematol. 2021;193(2):245–268. Available from: www.doi.org/10.1111/bjh.17410 [accessed May 2024].

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, money 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

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

2. **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.

3. **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?

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

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

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

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.

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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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FUNDRAISING
REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

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 explains what myeloma is and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

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 Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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