

WE ARE
MACMILLAN.
CANCER SUPPORT

A practical guide to understanding cancer

UNDERSTANDING MYELOMA





'I still get more tired than I like, but I can't really complain. Myeloma can be frustrating, but I try not to let it control my life.'

Frances, diagnosed with myeloma

This booklet is about myeloma. It is for anyone who is having tests for myeloma or has been diagnosed with it. This booklet may also be helpful for family members, friends or carers.

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

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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

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**WE ARE
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About this booklet

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

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

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

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

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

We have included some quotes from people who have been affected by myeloma, which you may find helpful. This includes Frances, who is on the cover of this booklet.

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**, Monday to Friday, 9am to 8pm, or visit **macmillan.org.uk**

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ABOUT MYELOMA

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What is myeloma?

Myeloma is a type of cancer that develops from plasma cells. Plasma cells are a type of white blood cell made in the bone marrow. To understand myeloma, it can help to know a little bit about the bone marrow and plasma cells.

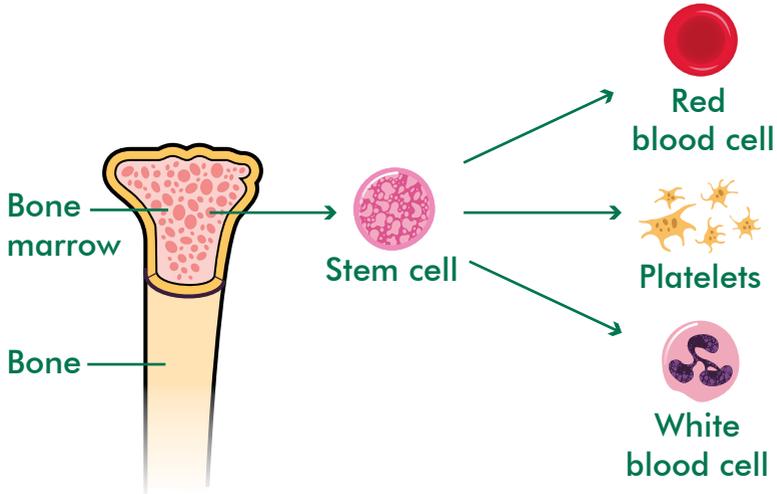
Bone marrow

Bone marrow is a spongy material inside our bones. It is part of the body's immune system, which helps to protect us from infection and disease.

Bone marrow produces all the blood cells needed by the body. All blood cells in the bone marrow begin as stem cells. These stem cells then develop into three 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 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 immunoglobulins, which are also known as antibodies. These travel in the blood and help to fight any viruses or bacteria in the body. If you have an infection, your bone marrow produces more plasma cells and immunoglobulins to fight whatever is causing the infection.

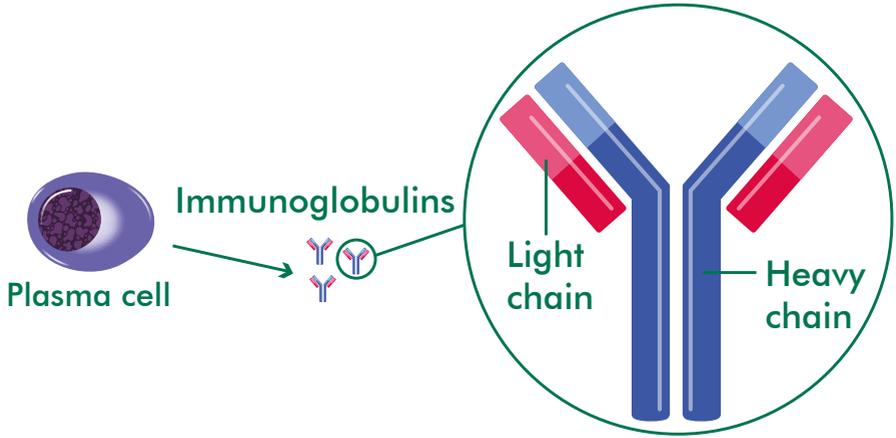
Immunoglobulins

Immunoglobulins are made up of two matching and shorter light chains, and two matching and longer heavy chains.

There are two types of light chain. They are called kappa and lambda. There are five types of heavy chain. They are called A, D, E, G and M.

Each immunoglobulin is named after the type of heavy chain they have. They are called IgA, IgD, IgE, IgG and IgM. The 'Ig' means immunoglobulin.

An immunoglobulin



Plasma cells in myeloma

Normally, plasma cells are made in a controlled way. But in people with myeloma, the process is out of control and large numbers of abnormal plasma cells (myeloma cells) are made.

The myeloma cells fill up the bone marrow and can damage the bone. This can cause bone thinning, pain and sometimes fractures. Myeloma cells can spread from the bone marrow to bones in different parts of the body. This is why myeloma is sometimes called multiple myeloma.

If the bone marrow is full of myeloma cells, it can be harder for it to make enough normal white blood cells, red blood cells and platelets.

Myeloma cells make an abnormal immunoglobulin, which cannot fight infection. This could be any one of the five types of immunoglobulin (IgA, IgD, IgE, IgG or IgM). The abnormal immunoglobulin is called a paraprotein, or M protein.

If you have myeloma, you may make less normal immunoglobulins than usual. This 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 usually treated in the same way.

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

There is also a type of myeloma called light chain myeloma, or Bence Jones myeloma. This is when the myeloma cells make too many light chains. This type of myeloma does not make an abnormal paraprotein.

A rare type of myeloma, called non-secretory myeloma, produces few or no immunoglobulin chains.

Related plasma cell conditions

There are other conditions that affect plasma cells, which are related to myeloma. These can sometimes develop into myeloma, so your doctor will regularly monitor you with blood tests.

The two most common conditions are:

- MGUS (monoclonal gammopathy of unknown significance)
- smouldering myeloma, which is sometimes called indolent or asymptomatic (without symptoms).

They do not normally cause symptoms and are usually diagnosed after a routine blood test. Usually, you do not need treatment for them.

Sometimes abnormal plasma cells are found in a bone in only one area of the body. This is known as solitary plasmacytoma. It is often treated with radiotherapy. Some people with solitary plasmacytoma may go on to develop myeloma, so your doctor will regularly monitor you with blood tests.

We have more information about MGUS and smouldering myeloma that we can send you. Call us on **0808 808 00 00** to order the information you need.

Risk factors and causes

In the UK, around 5,500 people are diagnosed with myeloma each year. It is slightly more common in men than women. Doctors do not know what causes myeloma, but a number of things are known to increase the risk of it developing.

MGUS

Research shows that almost everyone with myeloma has had MGUS first. But not everyone who has MGUS goes on to develop myeloma.

Age

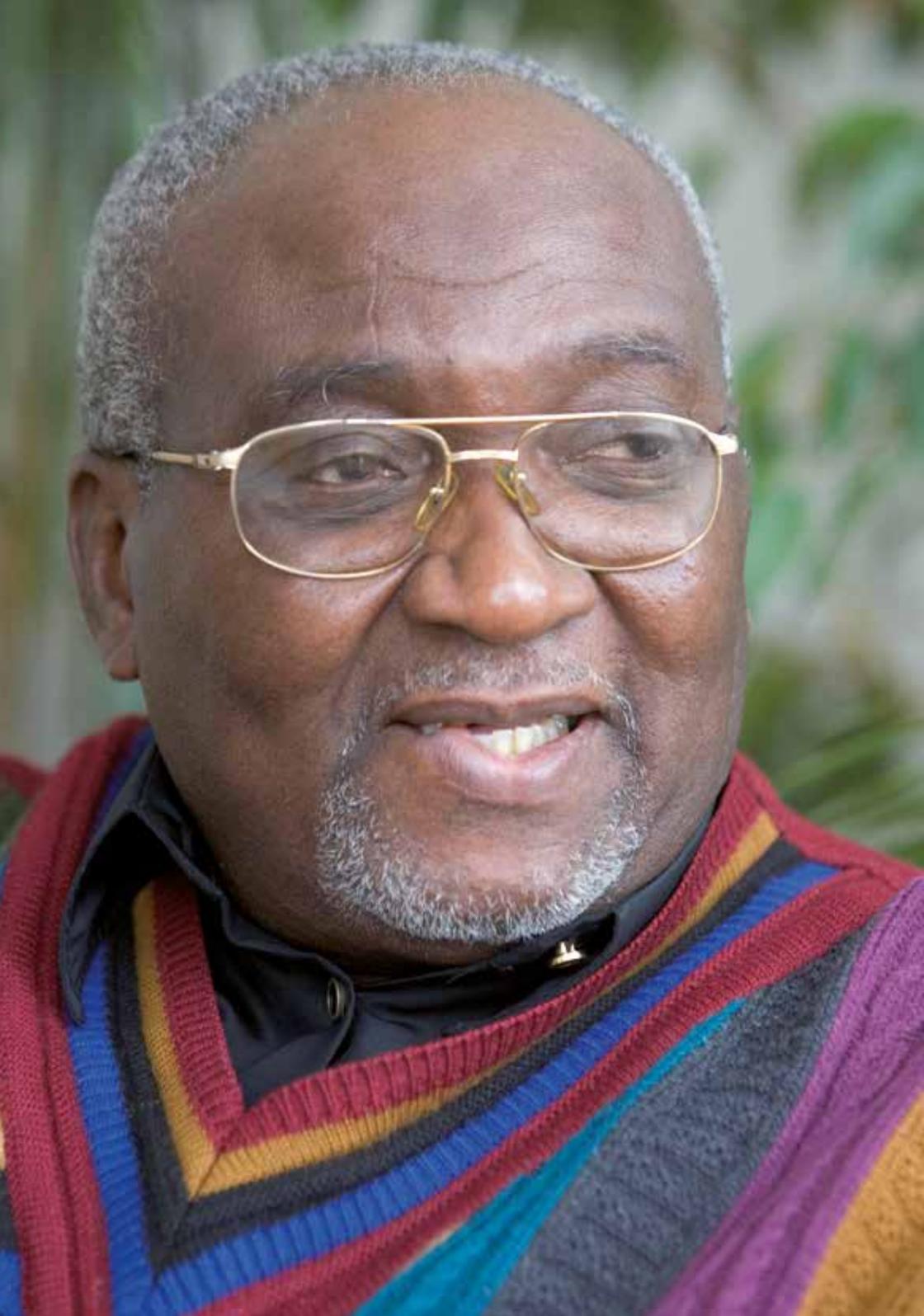
Myeloma is more common in older people. It is most commonly diagnosed in people over the age of 65. It is rare in people under the age of 40.

Race

Myeloma is more than twice as common in African-Caribbean people than in white people.

Sex

Myeloma is more common in men than in women.



Family history

People who have a close family member (such as a parent, brother or sister) with myeloma have a slightly increased risk of developing it.

A weakened immune system

A weak immune system increases the risk of developing myeloma. Some conditions reduce immunity, such as HIV. People taking medicines to weaken (suppress) their immune system after an organ transplant are also at a higher risk.

Autoimmune disease

Autoimmune diseases cause the body's immune system to attack healthy cells in the body by mistake. Some autoimmune disorders can slightly increase the risk of developing myeloma. These include:

- Pernicious anaemia
- Haemolytic anaemia
- Lupus.

Body weight

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

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

Symptoms of myeloma

Myeloma may not cause any symptoms in the beginning. Some people are diagnosed after a routine blood test, before any symptoms are noticed. Other people are diagnosed with myeloma after being admitted to hospital with more severe symptoms.

Possible symptoms include:

- constant bone pain in one area (such as in the back, ribs, hip or pelvis)
- having different infections, one after another, that need antibiotics to treat them
- extreme tiredness (fatigue)
- tingling or numbness in hands or feet.

Myeloma can also cause high levels of calcium in the blood (hypercalcaemia). Symptoms of hypercalcaemia include:

- feeling thirsty
- feeling sick (nausea)
- vomiting
- constipation
- confusion.

If you have any of these symptoms, it is important to get them checked by your GP.

We have more information about these symptoms and how they are treated. There is also advice about what you can do to help manage the symptoms (see pages 72 to 89).

'I was getting more tired than usual. And if I had an infection, I felt exhausted. I had a good immune system up until then.'

Frances





DIAGNOSING MYELOMA

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How myeloma is diagnosed

Myeloma can be diagnosed in different ways.

Some people may see their GP about symptoms such as pain, tiredness or infections. Your GP will ask you about your symptoms and examine you. They will arrange for some blood tests or x-rays. The GP will then refer you to a specialist at the hospital for more tests and treatment if necessary.

Some people may be diagnosed with myeloma after being admitted to hospital with more severe symptoms such as spinal cord compression (see page 85) or kidney problems (see pages 83 to 84).

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

Frances

At the hospital

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

- blood tests
- tests on your urine (pee)
- a bone marrow sample
- x-rays or scans.

Blood tests

Blood tests are an important way to diagnose and monitor myeloma. They help doctors to find the level of abnormal immunoglobulins (paraproteins) you have in your blood and what type they are. These tests include the following:

- Serum protein electrophoresis – This finds if a paraprotein is in the blood and what type it is.
- Paraprotein level – This measures the amount of paraprotein in the blood.
- Light chains (serum free light chain assay) – This is used to measure the amount of light chains in the blood (see pages 8 to 9).
- Beta-2 microglobulin level (B2M) – This is a protein that is on the surface of most cells in the body. In people with myeloma, the level produced is often higher. Doctors use this test to see how active the myeloma is (see pages 30 to 31).

You will also have blood tests to show how the myeloma is affecting you. These tests include:

- Full blood count – This measures the number of red blood cells, white blood cells and platelets in your blood. These can be low in people with myeloma.
- Urea and electrolytes (U&Es) test – This shows how your kidneys are working.
- Calcium level – This measures the level of calcium in the blood. The level can be raised if the myeloma is affecting your bones.
- Albumin level – This measures the level of a protein called albumin in the blood. The level can be low in people who have myeloma. This test is used to help stage the myeloma (see pages 30 to 31).

‘When my wife was diagnosed with myeloma, the hospital arranged a Macmillan nurse to help us. She was a great source of support and was always there to help us both. She was a true friend.’

Bernard

Tests on your urine (pee)

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



Having a blood test

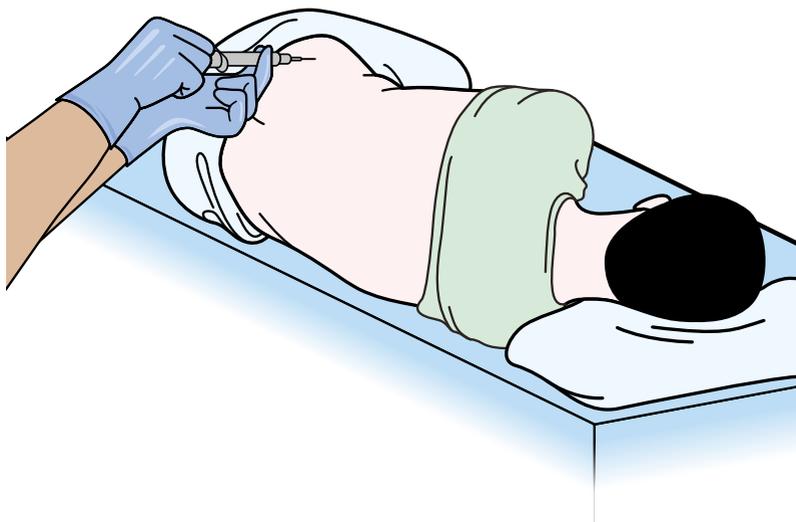
Bone marrow sample

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

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

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

A sample of bone marrow being taken from the back of the hip bone



The doctor or specially trained nurse passes a needle through the skin into the bone (see illustration opposite). They then draw a small sample of liquid from inside the bone marrow into a syringe. This is called a bone marrow aspirate. It can feel uncomfortable for a few seconds when the marrow is drawn into the syringe.

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

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

X-rays

X-rays can be taken to check for any damage to the bones from the myeloma cells. You usually have x-rays taken of the bones in your body that contain bone marrow. This is known as a skeletal survey and takes about 30 to 45 minutes. Although x-rays are not painful, you may find lying on a hard surface uncomfortable. Ask your doctor, nurse or radiographer for a painkiller if you need one.

Scans can be used instead of x-rays to check the bones.

MRI scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet, so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you have ever worked with metal or in the metal industry. This is because very tiny fragments of metal can sometimes lodge in the body.

If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used.

Before the scan, you are asked to remove any metal belongings, including jewellery. Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium. It can help the images from the scan to show up more clearly.

During the test, you lie very still on a couch inside a long cylinder (tube) for up to an hour. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you are given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Other tests

Sometimes, other scans are used instead of, or as well as, x-rays or an MRI scan. You may also have extra tests done on your bone marrow sample.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.

Having a CT scan



PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture and a positron emission tomography (PET) scan.

A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You can't eat for six hours before the scan, although you may be able to drink.

A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30–90 minutes. You should be able to go home after the scan.

Cytogenetic tests

Your doctor may talk to you about doing tests to look for changes in the chromosomes of the myeloma cells. Chromosomes are where cells store the information they need to work properly. Knowing about chromosome changes can help doctors to understand how the myeloma may behave and respond to treatment.

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

These tests are not always done as doctors are still trying to find out if the results could be helpful in planning treatment.

You may hear the terms high risk or low risk when your doctor talks about the results of your FISH test or other cytogenetic tests. If you have high-risk myeloma, you may not respond as well to treatment or you may have shorter periods of remission. Remission is when the myeloma is under control. Clinical trials are looking at improving treatment for high-risk myeloma (see pages 50 to 51).

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready.

You may find it helpful to talk with your partner, family or a close friend. Your specialist nurse or a support organisation can also provide help (see pages 133 to 139). You can also talk to one of our cancer support specialists on **0808 808 00 00**.

Staging

The stage of the myeloma shows the effect the cancer is having on your body and how quickly or slowly it may develop. Staging does not usually affect the treatment you are offered. So doctors do not always talk about staging.

Doctors use the results of two blood tests, beta-2 microglobulin (B2M) and albumin level, to find out what stage the myeloma is. This is called the International Staging System (ISS). If B2M is raised or if albumin is lower than normal, these can be signs that the myeloma is more advanced.

There are three stages of myeloma. Stage 1 is the earliest stage and stage 3 is more advanced.

We describe the three stages of myeloma in the table below.

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

The doctors also look at the effect the myeloma is having on your body. They may use the results of tests called the CRAB criteria to assess this:

- C – Calcium levels are 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).

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 (see page 28).

Your data and the cancer registry

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

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at [macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry)





TREATING MYELOMA

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Treatment overview

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

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

The type of treatment your doctor offers you depends on a number of things, including your general health.

You may find our Online Community helpful while you are having treatment for myeloma. You can chat to people who understand what you are going through. You may also want to give support to others. Visit community.macmillan.org.uk

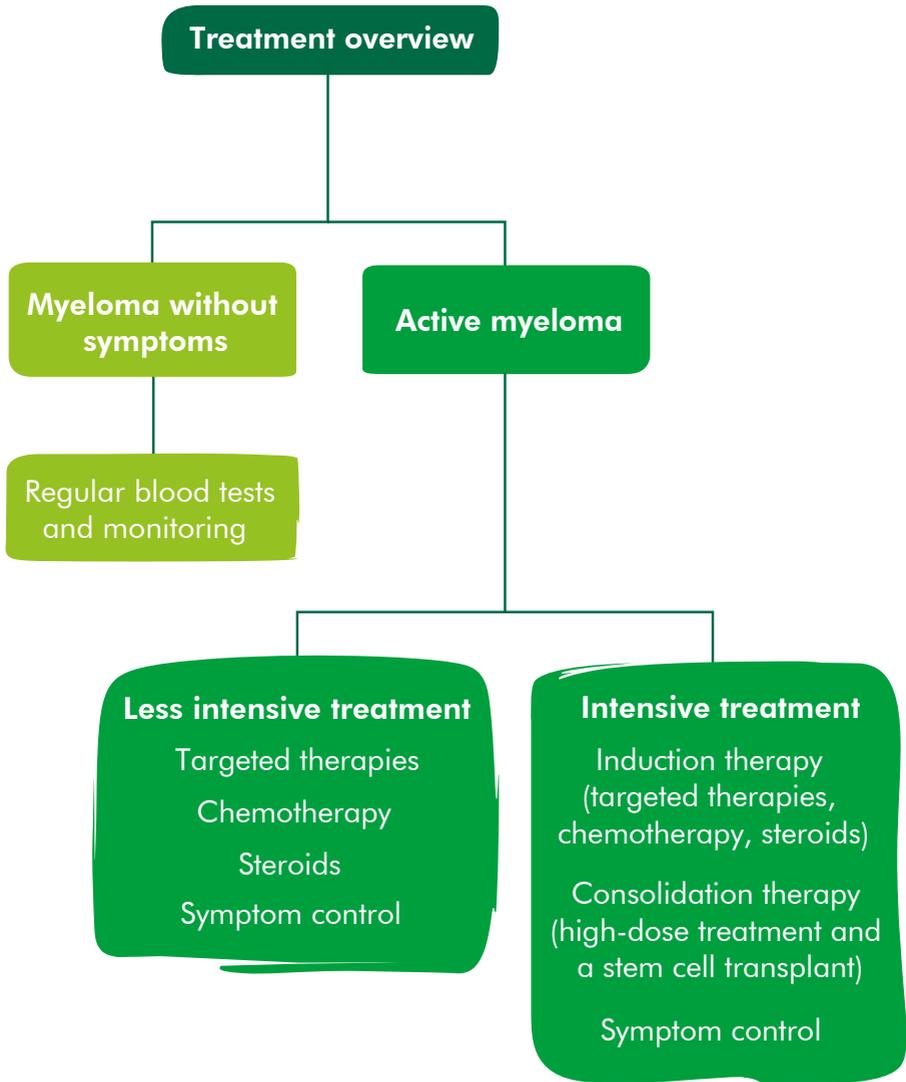
If you are diagnosed with myeloma without symptoms, you will have regular blood tests and monitoring.

If you have active myeloma, you may have less intensive treatment or intensive treatment. Less intensive treatment can be targeted therapies, chemotherapy, steroids and symptom control, or a combination of these.

Intensive treatment can be divided into three parts. These are induction therapy, consolidation therapy and symptom control. Induction therapy includes targeted therapies, chemotherapy and steroids.

Consolidation therapy is high-dose treatment and a stem cell transplant.

Treatment overview for myeloma



Myeloma without symptoms (smouldering myeloma)

If you have no symptoms from the myeloma, you may not need treatment straight away. Your doctor will see you every few months to take blood samples and do some other tests. This is called active monitoring.

There is no strong evidence that having treatment at this stage helps you. Also, waiting to start treatment means you feel well for longer, as you do not have side effects from treatment. You would only be offered treatment for smouldering myeloma as part of a clinical trial (see pages 50 to 51).

If the myeloma begins to get worse or you develop symptoms (symptomatic or active myeloma), your doctor will talk to you about starting treatment.

If you are worried about not having treatment, you might find these tips helpful:

- Make sure you understand why active monitoring is recommended. If you have any concerns, talk to your doctor.
- Think of the time without treatment as an opportunity to make the most of your quality of life. Use it 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.
- Talk about 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.

Active or symptomatic myeloma

Treatment for active myeloma usually begins soon after diagnosis. The aim of treatment is to get the myeloma under control (into remission) and to manage the symptoms. A complete remission is when there are no paraprotein or free light chains in the blood, and no myeloma cells in the bone marrow.

The main treatments used are:

- targeted therapies (see pages 52 to 57)
- chemotherapy (see pages 58 to 65)
- steroids (see pages 66 to 67).

Usually, a combination of these treatments is used.

The first treatments used are sometimes called induction therapy. Depending on your general health and how the myeloma is affecting you, you may be offered further treatment with high-dose treatment with a stem cell transplant (see pages 68 to 69).



'When I was diagnosed, I was told the illness was not curable. But my Macmillan nurse explained that it was treatable. Suddenly, I had hope and I wasn't scared anymore.'

Patsy, diagnosed with myeloma

Response to treatment

Treatment aims to reduce the number of myeloma cells to as few as possible. This is called remission.

If you have a type of myeloma that produces paraprotein, the paraprotein level can be used to measure how well treatment is working.

There are different levels of response. These include:

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

If you have a type of myeloma that does not make paraprotein, your doctor can explain how remission will be measured.

You will have tests during your treatment to check how well the myeloma is responding to treatment. Your doctor may suggest continuing treatment until it gets the best remission possible for you. Or you may be given treatment for as long as it is working to control the myeloma. If the myeloma does not respond to the first treatment, your doctor will look at other treatments to try to get a remission.

Some people who are in remission may be offered ongoing treatment. This is sometimes called maintenance treatment. The aim is to keep the myeloma under control. Maintenance treatment is only given as part of a clinical trial as doctors do not yet know how helpful it is.

Even though many people have a remission after treatment for myeloma, the myeloma usually comes back after a period of time. This is called relapsed myeloma. Doctors may then offer further treatment (see page 70).

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

Symptom control

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

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

We have more information about controlling symptoms on pages 72 to 89.

Clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancers, including myeloma. You may be asked to take part in a clinical trial (see pages 50 to 51).

Planning your treatment

In most hospitals, a team of staff who specialise in treating myeloma work together to plan your treatment. They then talk with you about your treatment options.

This multidisciplinary team (MDT) may include:

- a haematologist – a doctor who specialises in treating blood disorders
- a cancer doctor (oncologist) – a doctor who specialises in radiotherapy treatment
- a specialist nurse – a nurse who gives information and support
- a pathologist – a doctor who advises on the type and extent of the myeloma
- radiologists – doctors who help to analyse x-rays and scans
- a palliative care doctor or nurse – a specialist in managing symptoms such as pain.

It may also include other healthcare professionals, such as orthopaedic surgeons and kidney doctors.

Treatment choices

Your doctor will talk with you about your treatment options so that together you can decide what is best for your situation. It is important to remember that the doctor is an expert in myeloma and its treatment, but you know your own situation and preferences best.

If you are offered a choice between treatments, make sure that you have enough information about the different options. You might want to ask more about what is involved in each treatment and about possible side effects before deciding what is right for you.

Making decisions about treatment can be difficult, and you may want to talk more with your doctor before deciding to go ahead. If you choose not to have treatment, you can still have supportive care to help control symptoms (see pages 72 to 89).

'Since being diagnosed, the hospital staff have been fantastic. From helping me understand my diagnosis and treatment options, to the care I've received. I have always felt confident being treated by them.'

Lucy

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment.

No medical treatment can be given without your consent.

Before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations.

It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion.

You may also find it useful to write a list of questions before your appointment. You can use page 140 to do this.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

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, long-term control of the cancer is often possible.

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

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

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you. You may also find it helpful to have a list of questions ready so that you can make sure your concerns are covered during the discussion.



Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

We have more information in our booklet **Understanding cancer research trials (clinical trials)** – see page 128.

Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial, you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

Treatment for active myeloma

The treatments used to control myeloma and get it into remission are:

- targeted therapies
- chemotherapy
- steroids
- high-dose treatment with stem cell support.

Usually, a combination of treatments is used.

Targeted therapies (biological therapies)

Targeted therapies (sometimes known as biological therapies) are drugs that can help the body control the growth of myeloma cells. The targeted therapies used for newly diagnosed myeloma are thalidomide, bortezomib and lenalidomide. We have included more information about these drugs over the next few pages.

Like all drugs, targeted therapies can cause side effects. It is important to tell your cancer doctor or nurse if you have any side effects while taking your treatment. They may adjust your treatment to control side effects or to help to prevent more serious problems.

Thalidomide

Thalidomide is usually used to treat newly diagnosed myeloma. It can be given in combination with chemotherapy drugs and steroids.

Thalidomide works in different ways:

- It affects the way the immune system works.
- It blocks the development of new blood vessels, which cancer cells need to grow and spread. This reduces the supply of oxygen and nutrients to the cancer cells.

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

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

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

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

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

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

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

Bortezomib

You may have bortezomib as a first treatment for myeloma, or if myeloma comes back after other treatment. Your doctors may also give it as treatment to prepare you for a stem cell transplant (see pages 68 to 69).

Bortezomib is a proteasome inhibitor. It interferes with enzymes (proteasomes) that are found in all cells, including cancer cells. Bortezomib causes cancer cells to die and can stop the cancer from growing.

You may also have treatment with steroids, chemotherapy or another targeted treatment.

Bortezomib is usually given as an injection under the skin (subcutaneously). Sometimes it is given into a vein.

Common side effects include:

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

Lenalidomide

You may have lenalidomide as a first treatment for myeloma. But it is more commonly used when myeloma comes back after other treatment.

Lenalidomide works in a similar way to thalidomide (see pages 53 to 54). It affects the way the immune system works. It also blocks the development of new blood vessels, which cancer cells need to grow and spread.

Lenalidomide is sometimes given in combination with steroids or chemotherapy.

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

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

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

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

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

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

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

'I'm currently on lenalidomide. Despite feeling tired and the drug having side effects, my haematologist seems pleased. Light chains are normal and the paraproteins are the lowest they have been for years.'

Frances

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. The drugs circulate in the blood and can reach myeloma cells all over the body.

Treatment often involves a combination of two or more chemotherapy drugs. These may be given with other drugs, such as steroids and targeted therapies.

You will have treatment for one day, or over a few days. This is followed by a rest period of a few weeks. Chemotherapy and the rest period make up a cycle of treatment. Usually, 4 to 6 cycles make up a complete course of treatment. You usually have chemotherapy as an outpatient, but sometimes you may need to spend a few days in hospital.

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

Chemotherapy drugs used to treat myeloma include:

- melphalan
- cyclophosphamide
- doxorubicin
- idarubicin
- bendamustine.

How chemotherapy is given

Some chemotherapy drugs for myeloma are given by injection into a vein (intravenously). Others are taken as tablets or capsules (orally).

Lines and ports

If you are having your treatment by drip (infusion), your doctor may suggest you have a plastic tube inserted into a vein in your chest (central line) or above the bend of your elbow (PICC line). Sometimes an implantable port is used. This is a thin, soft, plastic tube that is put into a vein in the chest and has an opening (port) just under the skin of the chest or arm.

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

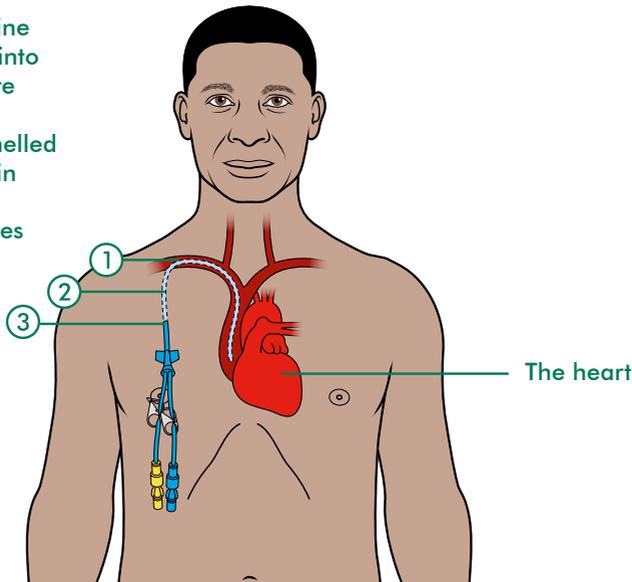
Below and on the next few pages, we have included illustrations of what these lines and ports look like.

A central line

① Central line inserted into chest here

② Line tunnelled under skin

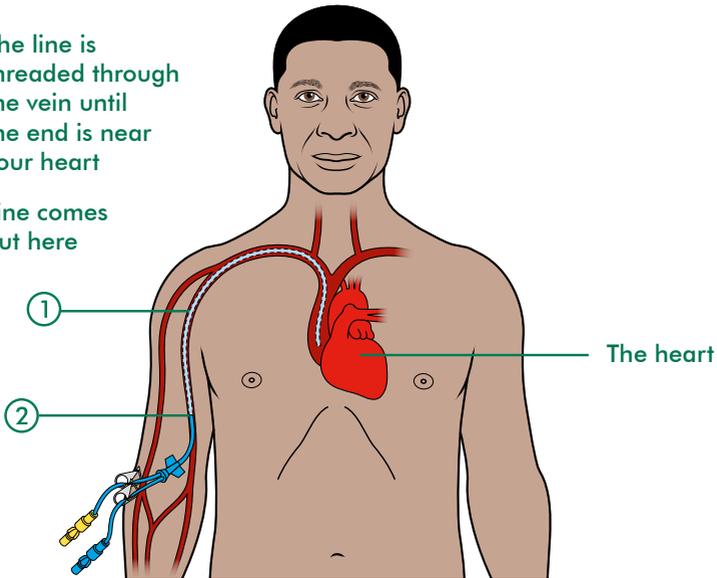
③ Line comes out here



A PICC line

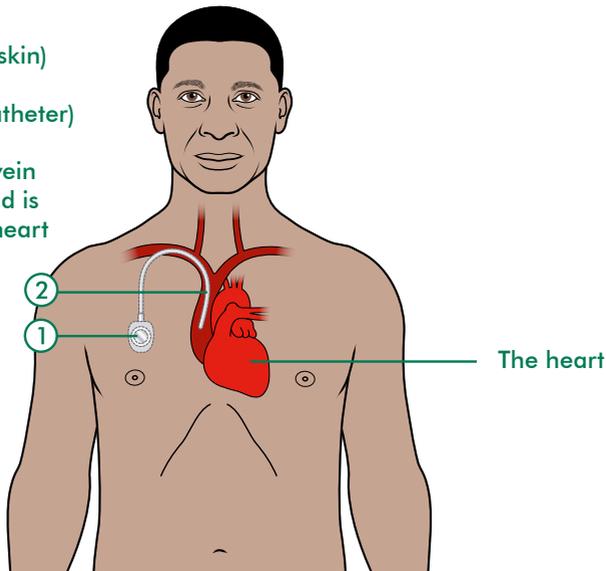
① The line is threaded through the vein until the end is near your heart

② Line comes out here



An implantable port

- ① Port
(under the skin)
- ② The line (catheter)
is threaded
through a vein
until the end is
near your heart



We have more information about central lines, PICC lines and implantable ports on our website.

We also have animations explaining how they are put in. Visit [macmillan.org.uk/chemotherapy](https://www.macmillan.org.uk/chemotherapy)

Side effects of chemotherapy

Everyone reacts to chemotherapy in different ways. Different drugs cause different side effects. You may get some of the side effects mentioned, but you are very unlikely to get all of them.

Although side effects can be hard to deal with, they usually disappear gradually when your treatment finishes.

Risk of infection

Chemotherapy can reduce the number of normal cells in your blood. The number of white blood cells may already be lower due to the myeloma. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

Your resistance to infection is usually at its lowest 7 to 14 days after chemotherapy. Developing an infection when your white blood cell count is low can sometimes be a serious complication of chemotherapy. Your chemotherapy nurse will talk to you about infections and show you how to check your temperature.

Contact the hospital straight away on the 24-hour contact number you are given if:

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

Symptoms of an infection include:

- feeling shivery
- shaking
- a sore throat
- a cold
- a cough
- needing to pee frequently (urine infection)
- diarrhoea.

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

You will have a blood test before each cycle of chemotherapy to make sure your cells have recovered. Occasionally, your treatment may need to be delayed if your blood count is still low.

After chemotherapy, your nurse may give you injections of a drug called G-CSF under the skin. This encourages the bone marrow to make more white blood cells and reduces the risk of infection.

Anaemia (low number of red blood cells)

If the level of red blood cells in your blood is low, you may become anaemic. This can make you feel very tired and you may also become breathless. Sometimes you may need a blood transfusion.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you have any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, tell your hospital doctor or nurse straight away. Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Feeling sick

Some chemotherapy drugs can make you feel sick (nausea) or possibly be sick (vomit). Your cancer specialist will give you anti-sickness (anti-emetic) drugs to prevent this.

Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

Mouth problems

Chemotherapy can cause mouth problems, such as a sore mouth, mouth ulcers or infection. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help reduce the risk of this happening.

Your chemotherapy nurse will explain how to look after your mouth to reduce the risk of problems. They can give you mouthwashes, medicines and gels to help.

Your hair

Your doctor or specialist nurse will tell you if the chemotherapy is likely to cause hair loss. This may be from your head and other parts of your body. Knowing what to expect gives you time to prepare and find ways of coping.

Some drugs do not make your hair fall out, but can make it thinner. If your hair falls out, it usually grows back within three months after treatment.

Tiredness (fatigue)

You are likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want or need to do. Balance rest with some physical activity. For example, even going for short walks can help increase your energy levels.

Risk of blood clot

Myeloma can increase your risk of developing a blood clot (thrombosis), and having treatment may increase this risk further. A blood clot may cause symptoms such as:

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

Blood clots can be very serious, so it is important to tell your doctor straight away if you have any of these symptoms. Most clots can be successfully treated with drugs that thin the blood. Your doctor or nurse can give you more information about blood clots.

Sometimes, doctors may give you drugs to reduce the risk of a blood clot.

Steroids

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

- prednisolone
- dexamethasone.

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

If you only take small doses of a steroid, you may not have many side effects. If you need larger doses for longer, you may have more.

Side effects can include:

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

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

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

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

Having combined treatments

Doctors often use a combination of chemotherapy, targeted therapies and steroids to treat myeloma.

Drug combinations include:

- cyclophosphamide, thalidomide and dexamethasone – CTD
- melphalan, prednisolone and thalidomide – MPT
- cyclophosphamide, bortezomib (Velcade®) and dexamethasone – VCD or CVD
- melphalan, prednisolone and bortezomib (Velcade®) – VMP
- bortezomib (Velcade®), thalidomide and dexamethasone – VTD.

The length of treatment depends on which treatments are used and how well the myeloma responds to the drugs. A course of treatment usually takes a few months to complete.

Stem cell transplant

You may be offered high-dose treatment with stem cell support. This depends on your general health. This treatment may improve the chances of controlling the myeloma in the long term.

To treat myeloma, it is more common to use your own stem cells (autologous transplant) than stem cells from a donor (allogeneic transplant). Stem cells are early blood cells.

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

The first stage of the treatment is called induction chemotherapy. This puts the myeloma into remission (where there are few or no signs of the myeloma cells) or gets it under control. Your stem cells are then collected and stored to be given back to you after treatment. The stem cells are usually collected (harvested) from the blood, but they can also be collected from the bone marrow.

You then have high-dose treatment with chemotherapy. This means you have much higher doses of chemotherapy than usual.

As well as destroying myeloma cells, the high-dose treatment also destroys healthy stem cells in the bone marrow. To help you recover from the high-dose treatment, you are given a drip (infusion) of your stem cells afterwards. The stem cells go to the bone marrow, where they start producing new blood cells.

We have more information about having high-dose treatment with a stem cell transplant on our website ([macmillan.org.uk](https://www.macmillan.org.uk)).

You may also find our booklet **Understanding high-dose treatment with stem cell support** useful (see page 128).

'I was able to have a stem cell transplant, for which I am very grateful. During this time, I met caring professionals who were there for me and my family.'

Mandy

Treatment if myeloma comes back

Myeloma nearly always comes back at some point after treatment and further courses of treatment are needed to control it. This can often keep you well for long periods of time.

If the myeloma comes back (relapses), there are usually other treatment options available. It may be possible to repeat the treatment you first had. This depends on what the treatment was and how long your remission lasted. Or you may be offered a different treatment.

Treatments that may be used are carfilzomib or bortezomib. Other treatments, such as lenalidomide, panobinostat (with bortezomib), pomalidomide and daratumumab, may be used if you have a further relapse. These drugs are often given with steroids (see pages 66 to 67).

A second high-dose treatment and stem cell transplant may be offered to some people. Your doctor will talk to you about the different treatment options.



Symptom control

Symptom control is important for everyone diagnosed with myeloma. Your doctor will see you regularly for blood tests and x-rays, and to talk to you about how the myeloma is affecting you.

Not everyone has symptoms, and some people may only have mild symptoms. It is important to talk to your doctor and nurse about any problems you may have.

Myeloma may cause problems such as:

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

We explain more about how these problems can be managed and what to look out for in this section.

Bone pain

The most common symptom of myeloma is bone pain.

Myeloma cells can damage bones. Areas of bone may get thinner and weaker, and may sometimes break (fracture). It is important to tell your doctor or nurse about any bone pain you have so they can treat it.

If you had bone pain before starting treatment for myeloma, you may continue to have some pain even after the myeloma is in remission. This can happen because bone damage can continue to cause symptoms even though the myeloma is no longer there.

Your doctor or nurse can talk to you about this. If you develop new pain, or your pain is not controlled, always tell your doctor or nurse.

Doctors and nurses who specialise in controlling pain are called palliative care specialists. They are based in hospitals, hospices, palliative care units and pain clinics. They work with your myeloma team and your GP to make sure your pain is controlled. It is important to remember that pain caused by myeloma can almost always be reduced.

Your doctor or nurse assesses your pain by asking you questions about it. Give them as much information as you can. This helps them plan the best treatment for you. They repeat the assessment regularly to check that your pain is well controlled.

It can help to keep a record of your pain in a pain diary. You write how bad it is at different times of the day and note anything that makes it better or worse. You can show this diary to your doctor or nurse. It can help you talk about your pain with them.

There is a pain diary at the end of this section (see page 89). Photocopy this diary before you fill it in so that you can use it as often as you need to. If your pain is in more than one place, you may want to use an extra copy of this diary.

Your doctor or nurse will then talk to you about treatments such as:

- painkilling drugs (to treat different types of pain)
- bisphosphonates
- radiotherapy
- surgery.

Your palliative care team may also talk to you about other therapies.

Painkilling drugs

There are many painkilling drugs available to treat different types and levels of pain. They come in different forms, including tablets, liquid medicines and skin patches. Painkillers can also be given by injection or infusion into a vein.

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

Bisphosphonates

Bisphosphonates are drugs that can help strengthen weakened bones and reduce pain. They can also reduce high levels of calcium in the blood (hypercalcaemia) – see page 87. These drugs can help delay bone damage, so you may start treatment with them before you have any bone problems. Research has shown that some bisphosphonates may also help treat myeloma.

The bisphosphonates that are most often used are:

- zoledronic acid
- pamidronate
- sodium clodronate.

They may be given as a drip into a vein (intravenous infusion) once a month. Some are given as tablets. It is very important to take the tablets exactly as you have been told.

Side effects are usually mild. They include indigestion and feeling sick (nausea). Some people have flu-like symptoms after having an infusion of bisphosphonates. This can happen within a few days of the infusion and can last for a few days. Rarely, bisphosphonates can cause damage to the jaw bone. This is called osteonecrosis of the jaw.

Your doctor will usually advise you to see a dentist before starting treatment. It is important to tell your dentist you will be taking bisphosphonates. Tell your doctor if you need any dental work while having this treatment.

Radiotherapy

Radiotherapy treats myeloma by using high-energy rays to destroy the myeloma cells, while doing as little harm as possible to normal cells. The rays can be directed at the bones where the myeloma cells have created a weak area. This treatment can often reduce pain in bones and also allow the bones to repair themselves.

Radiotherapy may also be given if you develop spinal cord compression (see page 85). In advanced myeloma, if chemotherapy is no longer working, radiotherapy can be given to reduce symptoms and control the disease for some time.

You have radiotherapy in the hospital radiotherapy department. If you are having a course of treatment, you will go to the department before your treatment starts. The radiotherapy staff will make a radiotherapy plan for you. This helps them work out the exact dose of radiotherapy and the area to be treated. Treatment may be given daily (Monday to Friday) for 1 to 3 weeks, with a rest at the weekends. If you only need 1 or 2 treatments, you may not need such a detailed planning appointment.

Radiotherapy for myeloma can cause side effects. These are usually mild. Side effects depend on where the radiotherapy is being given, but can include feeling sick (nausea) or diarrhoea. Let your doctor or nurse know about any side effects you have so they can help you to manage them. Side effects should improve once your course of treatment is over, but tell your doctor if they continue.

Radiotherapy can make you feel very tired. Try to get as much rest as you can, especially if you have to travel each day for your treatment.

We have more information about radiotherapy on our website – visit [macmillan.org.uk/radiotherapy](https://www.macmillan.org.uk/radiotherapy)

You may also find our booklet **Understanding radiotherapy** useful (see page 128).



Surgery

Surgery is sometimes needed to repair bones that have been damaged or weakened by myeloma. The surgeon will explain how they do this.

If some of the bones in the spine (vertebrae) are weakened by the myeloma, they may collapse. This is known as a compression fracture and 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.

Operations that can be used to treat compression fractures of the spine include the following:

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

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

If these treatments are suitable for you, your doctor or specialist nurse will explain more about them. They usually try other ways of controlling your pain first.

Other therapies

Your pain team may talk to you about other possible ways of helping with your pain. These may include:

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

Tiredness (fatigue)

Many people with myeloma feel tired and have less energy to do the things they normally do. This may be due to 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 light meal or going for a short walk.

Keeping a treatment diary of when you feel most tired can help you record your energy levels and plan activities for when you are likely to feel stronger. The **Macmillan Organiser** can help you keep track of symptoms like tiredness (see page 128).

We have more information and videos about fatigue on our website – visit [macmillan.org.uk/fatigue](https://www.macmillan.org.uk/fatigue)

You may also find our booklet **Coping with fatigue** useful (see page 128).



'I don't have the energy I used to have, and take a nap during the day. But I'm not in pain and I don't have sickness. The cancer does keep trying to get in the way, but I keep it down.'

Frances

Infection

Myeloma, and some treatments for it, can affect your ability to fight infections. Your doctor or nurse will talk to you about infections and possible signs of an infection to be aware of. Your doctor may give you drugs to help prevent an infection (prophylactic drugs). They may also advise you to have vaccines such as the flu vaccine.

If you are getting a lot of infections, your doctor may give you a regular infusion (drip) of immunoglobulins (see pages 8 to 9). This is given into a vein and can help to improve your immune system. Most people feel fine when having an immunoglobulin infusion, but sometimes it can cause an allergic reaction. This is most likely to happen during or after the first infusion. To reduce the chance of a reaction, the first infusion is given slowly.

Anaemia (low number of red blood cells)

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

Your doctor may suggest that you have a blood transfusion. The blood is given 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. It is usually given as an injection under the skin (subcutaneously).

Kidney problems

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

Kidney problems can cause symptoms such as:

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

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

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

If your kidneys are affected, you may have fluids given 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 and helps with kidney problems.

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

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

You can contact our cancer support specialists on **0808 808 00 00** to talk about dialysis. You may also find our Online Community a helpful place to get support – visit **community.macmillan.org.uk**

'I'm determined that my husband and I have a life outside dialysis, so we like to do things at weekends.'

Alessandra

Pressure on the spine (spinal cord compression)

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

- back or neck pain that is new or suddenly worse
- numbness or pins and needles in your toes, fingers or buttocks that is new or suddenly worse
- a feeling of unsteadiness on your feet
- weakness in your legs
- bladder or bowel problems.

If you have any of these symptoms, it is very important to tell your doctor or specialist nurse straight away. It is important to have treatment as soon as possible to prevent permanent damage.

Spinal cord compression is usually treated with steroids and radiotherapy. Sometimes chemotherapy can be given to help reduce the pressure on the spinal cord. Or surgery may be needed to repair or remove the affected bone.

Doctors will also look at how your pain is managed and consider whether bisphosphonates will help to strengthen your bones (see page 75).

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.

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



High calcium levels in the blood (hypercalcaemia)

Myeloma can damage bones. This can cause calcium to be released from the bones into the blood. High levels of calcium in the blood (hypercalcaemia) can make you:

- sick (nausea)
- thirsty
- drowsy
- confused
- unwell
- constipated
- pass urine (pee) often.

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

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.

Eating problems

Myeloma, and some treatments for it, can cause sickness and loss of appetite. There are several treatments to help prevent and control sickness. Your doctor can prescribe anti-sickness (anti-emetic) drugs for you. Let them know if your anti-sickness drugs are not helping as there are different types you can take.

If you have a poor appetite, try to eat little amounts as often as possible. Keep snacks with you, such as nuts, grated cheese or dried fruit.

It is important to try to eat well during your treatment. If you are having problems, ask your nurse for advice. You can also ask to see a dietitian. You can add extra energy and protein to your diet with everyday foods or by using food supplements.

We have more information about eating problems on our website (macmillan.org.uk). You may also find our booklets **Eating problems and cancer** and **The building-up diet** useful (see page 128).

Blood clots

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

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

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

Sometimes doctors may give you drugs to reduce the risk of a blood clot.

Your doctor or nurse can give you more information about blood clots.

Hyperviscosity syndrome

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

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

You may need a plasma exchange (plasmapheresis). This is a procedure that removes the abnormal paraprotein from the blood.

We have more information about plasma exchange on our website ([macmillan.org.uk](https://www.macmillan.org.uk)).



LIVING WITH MYELOMA

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Follow-up

You usually have regular follow-up appointments at the hospital during your treatment and remission. Or you may have follow-up appointments with your GP. This is sometimes called a shared care agreement.

If you have any problems, or notice any new symptoms between appointments, let your doctor know as soon as possible.

Many people feel very anxious before appointments. This is natural and it may help to get support from family, friends or a support organisation during this time (see pages 133 to 139).

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

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

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

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

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

You will be given a copy to keep and the hospital should send another copy to your GP.

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

Coping with myeloma

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

Get enough rest

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

- Get a good night's sleep – we have more information about sleeping problems and tips to improve your sleep (visit [macmillan.org.uk/difficultysleeping](https://www.macmillan.org.uk/difficultysleeping)).
- Ask family and friends to help out with chores such as household tasks and shopping.
- Save energy for the things you want to do and pace yourself. If you have a busy day, try to rest the following day.

We have more information on how to reduce tiredness on our website – visit [macmillan.org.uk/fatigue](https://www.macmillan.org.uk/fatigue)

You may also find our booklet **Coping with fatigue** useful (see page 128).

Keep physically active

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

If you can, take 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 in our booklet **Physical activity and cancer treatment** (see page 128).

'During treatment, I went for short walks and gradually built it up. Sometimes I had to drag myself out, but I always felt better afterwards. It made me feel like I had some control over my life again.'

Brian

Drink lots of fluids

People with myeloma are more at risk of having problems with their kidneys (see pages 83 to 84). 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 on 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 you get more infections because you have myeloma. You can speak to your doctor about vaccinations that may help, such as the flu vaccination.

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

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

Eat healthily

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

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

Some people with myeloma struggle with their appetite and may lose weight at times during their illness. Even if you have a reduced appetite, try to keep eating well by having regular snacks. There are different supplement drinks available (some on prescription) to help make sure you get enough calories and nutrients.

If you are taking steroids as part of your treatment, you may find you put on weight. Our booklet **Managing weight gain after cancer treatment** has tips on keeping to a healthy weight (see page 128).

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

Who can help?

Myeloma affects people in different ways. After treatment, you may not feel as fit as you used to be. You may find it more difficult to do all the things you could before treatment. If you have been in hospital or have had to rest at home for long periods, it can take some time to get back into a routine. Different professionals are available to help.

- Physiotherapists in the hospital or the community can teach you muscle-strengthening exercises. They can also help you start moving around again safely. You should avoid heavy lifting or any activities that may put a strain on your spine or other bones.
- Occupational therapists can look at how well you manage with your normal activities. They come to your home to see if any changes can be made to help you cope more easily.
- Social workers can offer support and practical advice to you and your family, both in hospital and at home. If you would like to talk to a social worker, ask your doctor or nurse.
- Psychologists may be able to help if you have anxiety or depression. They can look at ways to help you cope with your situation. They can also help with any relationship or communication problems in your family.
- District nurses work closely with GPs. They make regular visits to patients and their families at home if needed.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of cancers such as myeloma.

Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you are at a clinic or in hospital. Marie Curie nurses also help with symptom control, and care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange for a palliative care nurse to visit you.

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

'I was finding it very difficult to cope emotionally. There was so much going through my mind. Talking to the Macmillan nurse has helped me greatly in dealing with everything.'

Alessandra

Practical support

If myeloma means that it is difficult to move around easily, you may need specialist equipment or people to help you in your daily life.

The British Red Cross has an office in every county. It has volunteers who can help you in many ways. This may be help with shopping, posting letters or changing library books. Volunteers may be able to take you to an appointment at the hospital. The British Red Cross can also lend equipment, like wheelchairs and portable toilets (commodes).

The Disabled Living Foundation runs an information service. It also has specialist advisers and occupational therapists. They can give advice on aids and specialist equipment, including walking aids and wheelchairs.

Scope also gives information and advice to disabled people.

If you have movement (mobility) problems, you may find the Blue Badge scheme useful. It provides parking allowances (concessions) for people with mobility problems. 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. This will make it easier for you to go out.

To apply for a badge, contact your local council. A healthcare professional, welfare rights adviser or social worker can help you apply.

See pages 133 to 135 for contact details of the organisations mentioned on this page.

Some areas have good neighbour schemes. The schemes organise help for people in the local area. This could be help with shopping, transport or offering support. The schemes are usually run by social services or local community organisations. Some are only available to people living alone. Look for 'council for voluntary service' or 'good neighbour schemes' in the phone book or online.



What you can do

One of the hardest things to cope with can be the feeling that the cancer and its treatment have taken over your life. This is a common feeling, but there are lots of things you can do.

There may be days when you feel too tired to even think about what could help. You'll have good and bad days, but if you're overwhelmed by these feelings, let your doctor or nurse know. It may be that you have depression, and this is treatable so they should be able to help.

Finding ways to cope

You may find it helps to try to carry on with life as normally as possible, by staying in contact with friends and keeping up your usual activities. Or you may want to decide on new priorities in your life. This could mean spending more time with family, going on the holiday you've dreamed about or taking up a new hobby. Just thinking about these things and making plans can help you realise that you still have choices.

Some people want to improve their general health by eating a more healthy diet, by getting fitter or by finding a relaxing complementary therapy.

Understanding about the cancer and its treatment helps many people cope. It means they can discuss plans for treatment, tests and check-ups with their doctors and nurses. Being involved in these choices can help give you back control of your life.





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

Frances

YOUR FEELINGS AND RELATIONSHIPS

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Your feelings

It's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

Fear and anxiety

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

Doctors often know roughly how many people can benefit from a type of treatment. But they can't be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them.

Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists.



'Having someone to talk to was an important part of my healing process. I've called the Macmillan Support Line many times when feeling depressed, tearful or in need of someone just to listen.'

Patsy

Our website can help you find out about local support groups – visit [macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)

You can also talk to other people going through the same thing on our Online Community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them (see page 128).

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**

Support groups or online support

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

You can go along to see what a support group is like before deciding whether to get involved. Call us on **0808 808 00 00** for more information about support groups.

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

'Anyone who is struggling should join the Online Community. You can talk or read as much as you like, and it is a good place to get advice. I got tips and emotional support.'

Paul

Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them. This could be a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

If you are a relative or a friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you are letting them down if you admit to being afraid.

Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

'Sometimes I think friends feel that they don't know if they are saying or doing the right thing. But they don't really have to. Just being there is enough.'

Frances

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer (see page 128).

If you're looking after a family member or friend with cancer, you may find our booklet **Looking after someone with cancer** helpful. It is based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

'My daughter found it very hard. You don't realise how much it affects your family as well. Even now it is still hard for her to acknowledge it, though she is better at talking about it.'

Patsy

Sex life

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

As you recover from treatment, your sex drive (libido) may gradually improve. If pain or other side effects are causing sexual difficulties, then getting these under control may help to improve things (see pages 72 to 89).

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

Partners may sometimes feel, mistakenly, that sex could harm you or make the cancer worse, or that they could catch the cancer. Try talking openly about any worries with your partner. This can help you avoid misunderstandings and find ways to cope.

Our booklet **Cancer, you and your partner** has more information (see page 128).

Ask your doctor or nurse for advice if you are having problems with your sex life. If you feel uncomfortable talking to them, you can call us on **0808 808 00 00**.

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



Budget

Income	2157.69
Tax	351.26
NI Pension	16.40
Savings	

2157.69



FINANCIAL SUPPORT AND WORK

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Financial help and benefits

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

Statutory Sick Pay

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

Benefits

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

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

Employment and Support Allowance (ESA)

This benefit is for people under state pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

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

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

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

Macmillan Grants

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

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

How much you get will depend on your situation and needs. The average grant is around £400. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

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

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 128. Our Online Community forum Travel insurance may also be helpful. Visit [macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)

More information

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

You can also get information about benefits and other types of financial help from Citizens Advice – see page 138 for contact details.

Our booklet **Help with the cost of cancer** has lots more information – see page 128.

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful – see page 128.

There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

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

Our booklet **Your rights at work when you are affected by cancer** has more information – see page 128.

'I've had stress caused by my employment and financial situation. But I am still working while taking a maintenance drug with minimal side effects, which is a positive.'

Richard



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About our information

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

Order what you need

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

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support**. There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

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

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

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk. You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open Monday to Friday, 9am to 8pm. Our cancer support specialists can:

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

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

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

Talk to others

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

Support groups

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

The Macmillan healthcare team

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

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

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

Myeloma and related support organisations

African Caribbean Leukaemia Trust (ACLT)

Tel 020 3757 7700

Email info@aclt.org

www.aclt.org

Provides practical help, counselling, advice and support to African-Caribbean people living with leukaemia and other blood disorders. Hosts bone marrow registration drives throughout the UK and raises awareness of the need for donors from the black community.

Anthony Nolan Trust

Tel 0303 303 0303

www.anthonynolan.org

The UK's largest stem cell and bone marrow register.

Bloodwise

Support line 0808 2080 888

www.bloodwise.org.uk

Supports research into the causes, treatment and cure of leukaemia, lymphoma and myeloma. Also provides information and booklets on the diseases and their treatments.

The Blue Badge Scheme (Department for Transport)

www.gov.uk/government/collections/blue-badge-scheme

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

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

Tel 0300 123 23 23

www.nhsbt.nhs.uk/british-bone-marrow-registry

Holds details of stem cell donors and cord blood donations from England, Scotland, North Wales and Northern Ireland. Responsible for recruiting, testing and registering blood donors who volunteer to become stem cell donors. Part of an international network, performing searches around the world to find suitable stem cell donors.

British Red Cross

Tel 0344 871 11 11

Email

contactus@redcross.org.uk

www.redcross.org.uk

Offers a number of services for people with a disability, including a medical equipment loan service and a transport service.

Disabled Living Foundation (DLF)

Helpline 0300 999 0004

Email info@dlf.org.uk

www.dlf.org.uk

National charity that provides free, impartial advice about all types of disability equipment and mobility products through its helpline, website and equipment demonstration centre.

Kidney Care UK

Tel 01420 541 424

(Mon to Fri, 9am to 5pm)

Email info@kidneycareuk.org

www.kidneycareuk.org

Provides advice, support and financial assistance to people with kidney problems.

Leukaemia CARE

Helpline 0808 8010 444

(Mon to Fri, 9am to 10pm,

Sat, 9am to 12.30pm)

Email

support@leukaemicare.org.uk

www.leukaemicare.org.uk

Provides care and support to people with a blood disorder, their families and carers.

Offers emotional support and financial assistance through its network of volunteers and free helpline.

Myeloma UK

Tel 0800 980 3332

Email

myelomauk@myeloma.org.uk

www.myeloma.org.uk

Provides information and support to people affected by myeloma. Helps improve treatments through research, education and awareness.

Scope

Helpline 0808 800 3333

(Mon to Fri, 9am to 5pm)

Email helpline@scope.org.uk

www.scope.org.uk

Provides support, information and advice to disabled people and their families.

UK Myeloma Forum

www.ukmf.org.uk

The aim of the UK Myeloma Forum is to improve the care of people with myeloma through the development and promotion of trials.

The forum also provides education about myeloma to people affected by it and to healthcare professionals.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151

www.cancerblackcare.org.uk

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus

Northern Ireland

Helpline 0800 783 3339

(Mon to Fri, 9am to 1pm)

Email

nurseline@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline 0808 800 4040

(Mon to Fri, 9am to 5pm)

www.cancerresearchuk.org

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel 0800 652 4531

(Mon to Fri, 9am to 5pm)

Email

info@cancersupportscotland.org

**www.cancersupport
scotland.org**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801

Email

enquiries@maggiescentres.org

www.maggiescentres.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline 0303 3000 118

(Mon to Fri, 9.30am to 5pm)

Email

helpline@pennybrohn.org.uk

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline 0808 808 1010

(Daily, 8am to 8pm)

Email

info@tenovuscancercare.org.uk

**www.tenovuscancer
care.org.uk**

Has mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

NHS Choices

www.nhs.uk

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

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88

(Mon to Fri, 8am to 10pm,
Sat and Sun, 9am to 5pm)

www.nhsinform.scot

NHS health information site for Scotland.

Emotional and mental health support

Mind

Helpline 0300 123 3393

(Mon to Fri, 9am to 6pm)

Text 86463

Email info@mind.org.uk

www.mind.org.uk

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline 116 123

Email jo@samaritans.org

www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674

(Mon, Tue, Wed and
Fri, 9am to 5pm,
Thu, 10am to 5pm)

Textphone 028 9031 1092

**[www.nidirect.gov.uk/
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060
**[www.citizensadvice.org.uk/
scotland](http://www.citizensadvice.org.uk/scotland)**

Wales

Helpline 03444 77 2020
**[www.citizensadvice.org.uk/
wales](http://www.citizensadvice.org.uk/wales)**

Northern Ireland

Helpline 028 9023 1120
www.citizensadvice.co.uk

GOV.UK

www.gov.uk

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

NiDirect

www.nidirect.gov.uk

Has information about benefits and public services in Northern Ireland.

Advanced cancer and end-of-life care

Hospice UK

Tel 020 7520 8200

Email info@hospiceuk.org

www.hospiceuk.org

Provides information about living with advanced illness. Has a directory of hospice services in the UK and free booklets.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030

(Mon to Fri, 10am to 10pm,
Sat, 10am to 6pm)

Email helpline@lgbt.foundation

www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support with sight loss

Royal National Institute of Blind People (RNIB)

Helpline 0303 123 9999

(Mon to Fri, 8am to 8pm,
Sat, 9am to 1pm)

Email helpline@rnib.org.uk

www.rnib.org.uk

Offers support and advice to blind and partially sighted people in the UK.

Support with hearing loss

Action on Hearing Loss

Helpline 0808 808 0123

(Mon to Fri, 9am to 5pm)

Textphone 0808 808 9000

SMS 07800 000 360

Email informationline@hearingloss.org.uk

www.actiononhearingloss.org.uk

Offers support and practical advice to people in the UK with hearing loss and tinnitus.

Disclaimer

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

Thanks

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

With thanks to: Dr Jenny Bird, Consultant Haematologist; Charlotte Bloodsworth, Haematology Clinical Nurse Specialist; Shirley Crofts, Haematology Clinical Nurse Specialist; Dr Andrew Fyfe, Consultant Haematologist; Dr Iain Singer, Consultant Haematologist; 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 **cancerinformationteam@macmillan.org.uk**

Sources

We've listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

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National Institute for Health and Care Excellence (NICE). *Myeloma: diagnosis and management*. 2015.

Rabin N, et al. United Kingdom myeloma forum position statement on the use of consolidation and maintenance treatment in myeloma. *International Journal of Laboratory Hematology*. Vol 36 (6): pp.665 to 675. 2014.

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Can you do something to help?

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email

Please accept my gift of £ _____

(Please delete as appropriate)

I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Signature _____

Date / / _____

Don't let the taxman keep your money

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

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

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

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

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



If you'd rather donate online go to macmillan.org.uk/donate

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