

Myeloma



**Blood
cancer
UK**

About this booklet

We have produced this booklet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Consultant Haematologists Dr Andrew Chantry and Dr Kevin Boyd for their support checking the content of this booklet.

We're a community dedicated to beating blood cancer by funding research and supporting those affected. Since 1960, we've invested over £500 million in blood cancer research, transforming treatments and saving lives. To find out more about what we do, see page 109.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

A list of references used in this booklet is available on request. Please email us at **information@bloodcancer.org.uk**

Disclaimer

We make every effort to make sure that the information in this booklet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

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Blood Cancer UK, 39–40 Eagle Street, London WC1R 4TH

020 7504 2200 **hello@bloodcancer.org.uk** **bloodcancer.org.uk**

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Introduction

This is a booklet for people with myeloma, and for people who know someone with myeloma.

Being told that you, or a loved one, have any type of cancer can be one of the hardest things you'll ever have to hear. There's sure to be a lot of information to take in at first.

We hope this booklet will help you to understand your condition and feel in control. We'll cover the key aspects of diagnosis and care along the way, including symptoms, tests, treatment, living with myeloma, and where you can get support.

Every person is different, with a different medical history. So when you're deciding what's right for you, discuss your situation with your specialist as well as getting information from this booklet and other trustworthy places.



Our Support Services Team offers practical and emotional support for anyone affected by blood cancer. Contact us on **0808 2080 888** or **support@bloodcancer.org.uk**



**Stick to trustworthy
information from cancer
charities or the NHS.
Your healthcare team
will tell you the best
place to find it.**

Wendy, diagnosed with blood cancer aged 46

Myeloma at a glance

Many people with myeloma have a good overall quality of life.

What is myeloma?

Myeloma is a type of cancer which affects plasma cells. A plasma cell is a type of white blood cell which produces antibodies to fight infection. When you have myeloma, too many abnormal plasma cells are made in your bone marrow (the spongy tissue inside your bones where your blood cells are made).

Who gets myeloma?

Myeloma is more common in older people. It develops from another condition called monoclonal gammopathy of undetermined significance (MGUS). Children don't get myeloma and it's rare in people under 40.

What's the outlook?

Myeloma is not usually considered a curable disease, but it is very treatable. Most people respond well to initial treatment but there's a very high chance that the myeloma will come back. However, there are several treatments available for myeloma, which you can explore with your healthcare team.

Many people with myeloma have a good overall quality of life, especially if they don't have any symptoms or if their treatment is working well.



You can find out more about MGUS in our fact sheet, **Monoclonal gammopathy of undetermined significance (MGUS)** – see **page 107**.

What are the treatments for myeloma?

You might not need treatment at first – especially if you don't have any symptoms. There is no evidence to show that being treated early on, when you have no symptoms, has any benefits.

If you feel well, your team might just see you for regular check-ups and careful monitoring of your condition – this is known as 'watch and wait'. Your specialist will tell you when they think you might need to start treatment and discuss the options with you.

Active treatment for myeloma includes a combination of chemotherapy (anti-cancer) drugs, steroids and biological therapies, which help the body to attack cancer cells itself. Some people with myeloma will have a stem cell transplant. You may also receive radiotherapy, which uses radiation to kill cancer cells in a particular part of your body.

Can myeloma lead to any other conditions?

Myeloma can lead to bone loss and osteoporosis – a condition that weakens bones, making them more likely to fracture easily.

Myeloma cells can also produce high levels of a protein which may cause kidney damage.



For more information on ‘watch and wait’ see **page 50**.

For more details on managing the symptoms of osteoporosis see **page 77**.

**Knowing the basics about
blood, bone marrow and
your immune system
is useful.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Blood, bone marrow and your immune system

It's a good idea to know a bit about blood, bone marrow and your immune system, as your healthcare team is likely to talk about them.

Blood

The blood has many important functions.

Transport system

It carries food, oxygen and proteins to different parts of your body. It also carries waste chemicals to the kidneys and lungs so they can get rid of them.

Defence system

White blood cells are part of your immune system, which fights infections.

Communication system

Organs in your body release hormones into the blood which send messages to other organs.

Repair system

Blood contains cells and chemicals which can seal off damaged blood vessels and control blood loss.

Blood cells

Blood contains three types of cells: red blood cells, white blood cells and platelets.

Red blood cells (erythrocytes)

These contain a protein called haemoglobin which carries oxygen to all the tissues of your body.

Muscles and other tissues need oxygen to produce energy from your food.

White blood cells (leukocytes)

These fight and prevent infection. There are five different types of white blood cell: lymphocytes, neutrophils, monocytes, eosinophils, and basophils.

Platelets (thrombocytes)

These stick together at the site of any tissue damage and stop bleeding.

How many of each type of blood cell should you have?

Everyone has slightly different numbers of each type of blood cell. If you're healthy, the amount you have of each normally stays the same, with slight changes up and down over time. This table shows the normal ranges for a healthy person.

Blood cell or substance	Levels found in a healthy person
Haemoglobin (Hb) level (for red blood cells)	130–180 g/l (men) 115–165 g/l (women)
Platelets	150–400 x 10 ⁹ /l
White blood cells (WBC)	4.0–11.0 x 10 ⁹ /l
Neutrophils	2.0–7.5 x 10 ⁹ /l
Lymphocytes	1.5–4.5 x 10 ⁹ /l

Your blood values depend on a number of different things, including sex, age, and ethnicity. Also, different laboratories will use different equipment and testing methods, so normal values can vary slightly from hospital to hospital. So this table should only be used as a rough guide. Your healthcare team can explain what your results mean for you.

Bone marrow and how blood cells are made

Millions of blood cells are made in the bone marrow (the soft material inside your bones) every second, because your body needs them.

If everything's working normally, your body makes the right number of each type of cell to keep you healthy.

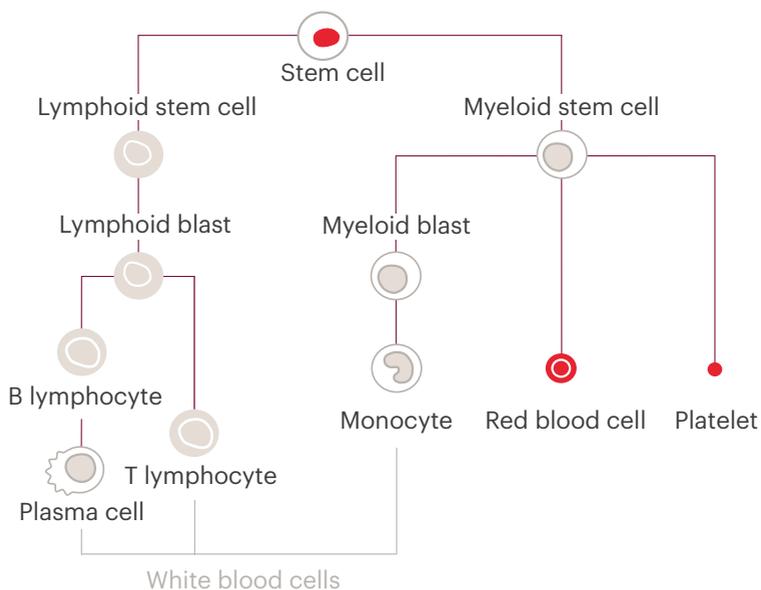
All blood cells start off in your bone marrow as a type of cell called a stem cell. Stem cells divide again and again, each time becoming more like a mature, fully-formed blood cell. One type of blood cell created when stem cells divide is a white blood cell called a lymphocyte.

There are lots of different kinds of lymphocyte, but the important ones to know about are B cells and T cells.

B-cell lymphocytes divide to form plasma cells that produce proteins called antibodies, which fight infections in your body. T-cell lymphocytes also play a number of supportive roles in your immune system.

In myeloma it's your plasma cells which are affected – they make abnormal antibodies.

Blood cell production



Having myeloma also means that your body makes too many plasma cells, so there's not enough room in the bone marrow for other blood cells to develop. This means they can't do the jobs they normally do to keep you well.



You can find out more about normal blood and bone marrow at [bloodcancer.org.uk/what-is-blood-cancer](https://www.bloodcancer.org.uk/what-is-blood-cancer)

Your immune system

Your immune system is a network of cells, tissues and organs which protect your body against infections. Antibodies are a crucial part of the immune system.

In myeloma the normal antibodies can be swamped by the production of an abnormal antibody, so your body's defences will often be low. This means you might get:

Bacterial infections

They could be more severe than usual and last longer. Your healthcare team can let you know ways to reduce your risk.

Shingles

Shingles is an infection of a nerve and the skin around it. It can affect you if you've had chickenpox, even if you had it a long time ago. You're more likely to get shingles if your immune system isn't working well, for example, if you have myeloma. For more information on how to spot and treat shingles, see page 80.

Cold sores (herpes simplex virus)

Because of your weakened immune system, you may be more prone to getting a viral infection called herpes simplex, which can lead to an outbreak of cold sores.

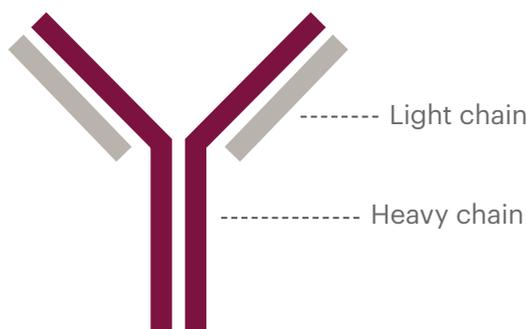
If you develop cold sores, you should ask your specialist for tablets to stop the cold sores spreading, because over-the-counter creams will not be enough to control them in people who have myeloma.

Antibodies, paraproteins and myeloma

Plasma cells normally produce antibodies, which are made of two different kinds of protein: heavy chains and light chains. An antibody is shaped like a 'Y', with two heavy chains and two light chains.

We all have antibodies. When your body is responding to infections, your plasma cells make five main types of antibody (also known as immunoglobulins) with different heavy chains called G, A, M, D or E. You might hear them called IgG, IgA, IgM, IgD and IgE. The light chains are called either (kappa) or (lambda).

Structure of an antibody

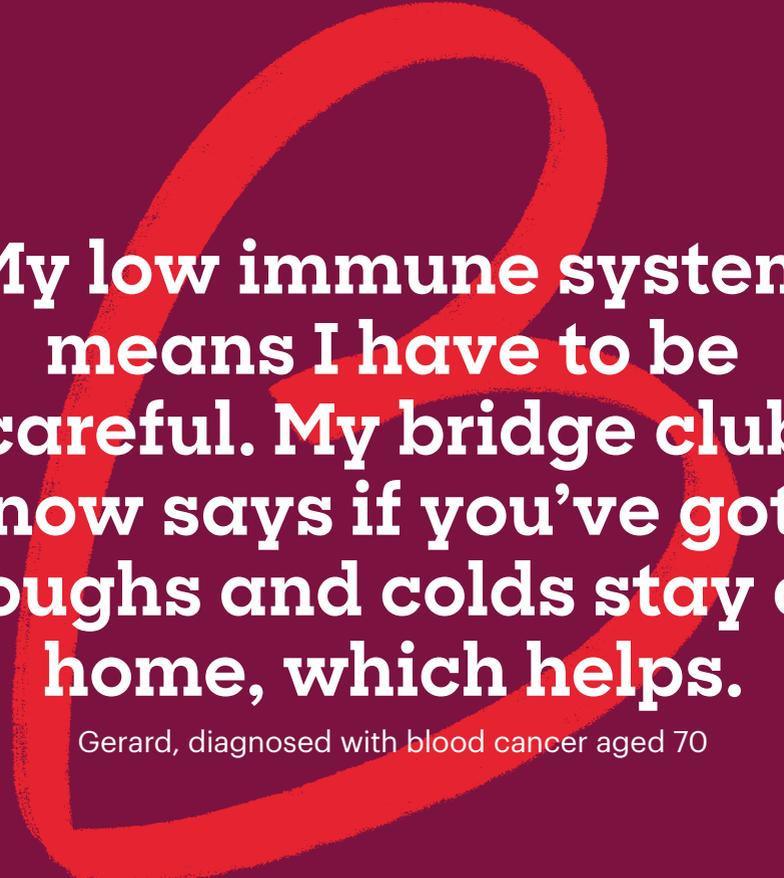


When you have myeloma you produce abnormal antibodies instead, called paraproteins. These antibodies can't fight infections properly. You might hear a paraprotein also being called a monoclonal gammopathy, an M protein or an M-spike.

The presence of paraprotein can be an important sign of myeloma, although in some cases, myeloma cells only produce the light chain part of the paraprotein, or more rarely, very little or no paraprotein at all.



For more information on different types of myeloma, see **page 20**.



**My low immune system
means I have to be
careful. My bridge club
now says if you've got
coughs and colds stay at
home, which helps.**

Gerard, diagnosed with blood cancer aged 70

It's important to know and understand your diagnosis. You could keep a record of it on the inside back cover of this booklet, so you have it to hand.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

What is myeloma?

Myeloma is a type of cancer which affects plasma cells. A plasma cell is a type of white blood cell which produces antibodies to fight infection.

When you have myeloma, your plasma cells produce abnormal antibodies which can't fight infection. On top of this, too many abnormal plasma cells are produced in your bone marrow (the spongy tissue inside your bone where your blood cells are made). This also means there isn't enough room for normal red and white blood cells, which both play an important role in keeping you well.

Usually the bone marrow is affected in a number of places around your body, which is why myeloma is sometimes known as 'multiple myeloma'.

Myeloma is divided into two main groups:

Smouldering or asymptomatic myeloma

This is where there are no symptoms or tissue damage.

Symptomatic myeloma

This is where there are symptoms and/or tissue damage.

Types of myeloma

There are different types of myeloma. Some are very rare, but they are all treated in the same way.

IgG and IgA myeloma

A large majority of people with myeloma will have a type of disease called IgG or IgA myeloma.

This means the abnormal plasma cells (myeloma cells) are making too many abnormal IgG or IgA antibodies. The myeloma cells also overwhelm the normal plasma cells, so the level of normal antibodies being produced can also be low. IgG is the most common type of myeloma. Over 50% of cases are this type. Around 20% of people with myeloma will have IgA type.



See **page 15–16** for more information on antibodies.

Free light chain myeloma (formerly known as Bence Jones myeloma)

One in five people with myeloma have this type. This is where the body produces antibodies that are incomplete, so they may not have a Y shaped heavy chain, only the light chain (either kappa or lambda). These antibodies are referred to as 'free light chains' because they are not attached to the heavy chains.

A special test known as the serum free light chain assay is done to detect these abnormal light chains. Or, light chains can be measured in the urine – where they're known as 'Bence Jones protein'.

People with this type of myeloma should receive guidance from their healthcare team about taking extra care of their kidneys, because free light chains can damage them.

Non-secretory myeloma and oligosecretory myeloma

Around 3% of people with symptomatic myeloma get non-secretory myeloma. This is where the abnormal plasma cells do not produce any paraprotein at all. Oligosecretory myeloma is where the plasma cells only produce very small amounts of paraprotein.

**You're not alone: over 5,000
people are diagnosed with
myeloma every year in the
UK.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

What causes myeloma?

When you're diagnosed with any cancer, one of the first things you might think is: why me?

With myeloma, there are no clear causes but there are some things which can increase your risk. Here's what we do know:

- One in 115 men and one in 155 women will develop myeloma at some point in their lifetime.
- Over 5,000 people are diagnosed with it each year in the UK.
- People with a condition called MGUS are slightly more likely to develop myeloma.

Age

The likelihood of developing myeloma rises as you get older, with 95% of cases diagnosed in people aged over 50. It's very rare for people under 40 to get myeloma. Myeloma doesn't affect children.

Sex

Men are more likely than women to develop myeloma – we don't know why.

Family history

A parent, child, brother or sister of someone with myeloma is two or three times more likely to develop myeloma than other people. However, the risk for any person is still very low.

Because of this, experts don't recommend testing family members unless they're being considered as donors for a stem cell transplant.

Ethnicity

People of African-Caribbean origin are roughly twice as likely as other races to get myeloma – we don't know exactly why.

MGUS

Sometimes, small identical copies (clones) of plasma cells develop and produce a low amount of paraprotein but there are no other features of myeloma. This is called monoclonal gammopathy of undetermined significance (MGUS).

MGUS is quite a common condition which affects about 3% of people over the age of 50 in the UK. It's generally harmless and causes no obvious damage, so no treatment is needed and people aren't routinely screened for it.

People with MGUS have a higher risk of developing myeloma – around 1% of people with MGUS go on to develop myeloma each year.

Anyone with MGUS will have regular blood and urine tests, to make sure it's not progressing.



We have a fact sheet, **Monoclonal gammopathy of undetermined significance (MGUS)** – see **page 107**.

For an explanation of paraprotein, see **page 16**.

If you get any new symptoms after you've been diagnosed, or if you feel unwell, contact your hospital as soon as possible.

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Symptoms

There are some symptoms you might have before you're diagnosed and some symptoms you might have afterwards. Not everyone will have the same symptoms.

Before diagnosis

Around one in seven people have no symptoms at the time they are diagnosed with myeloma. If you do have symptoms, the most common one is back pain which is more severe and lasts longer than normal back pain.

Myeloma damages bone, bone marrow and the kidneys. The symptoms linked to this are often described as '**CRAB**' because they are due to too much **C**alcium in the blood, **R**enal (kidney) damage, **A**naemia (lack of red blood cells) or **B**one damage.

Too much calcium in the blood might lead to:

- feeling sick (nausea)
- low appetite
- difficulty pooing (constipation)
- needing to wee more often
- feeling thirsty or being dehydrated
- not having as much energy as usual
- feeling confused or dazed.

Kidney damage can lead to:

- extreme tiredness (fatigue)
- itchy skin
- feeling sick (nausea)
- fluid retention that can make you short of breath or make your ankles swell.

Anaemia can lead to:

- tiredness
- breathlessness
- paleness.

Some people also have symptoms linked to their bones, such as:

- bone pain
- bone damage as shown on X-rays – this may be thinning or fracturing of your bone in a few or many areas.

After diagnosis

If you get any new symptoms after you've been diagnosed, or if you feel unwell, contact your hospital straight away, even if you're not sure if the symptom is related to the myeloma.

Your hospital team will tell you whether you need to see them or if you should see your GP instead.

Signs of infection

If you have myeloma, it's likely that your immune system won't be working well. Because of this, minor infections could become more serious. Symptoms of infection may be less obvious because of your illness or if you're taking paracetamol-based medicines.

If you have any of the following signs of infection, you should call your hospital:

- cough or sore throat
- raised temperature
- confusion or agitated behaviour, especially if this comes on suddenly
- rapidly becoming more ill
- fast heartbeat and breathing
- difficulty weeing or not weeing at all
- pain that gets worse very quickly.

Signs of pressure on the spine because of bone damage

- central back pain, made worse if you move, cough or strain
- a sudden change in a pain you've had for a long time
- 'crescendo' pain (pain that becomes worse and then eases off)
- pain that gets worse if you lie down or raise your legs
- pain in either one or both legs, especially if it starts in your back and spreads to your legs
- a tingling, 'electrical' feeling in your arms or body when you bend your head forwards
- weeing or pooing uncontrollably, or having trouble going to the loo at all
- weakness or loss of feeling, usually in your legs, starting in the feet and moving upwards.

It's a good idea to share this information about new symptoms with your friends and family, so they can get medical help if you become unwell.

It's important to know and understand your diagnosis. You could ask your team to write it in this booklet, so you have it to hand.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Diagnosis

You'll have a set of tests to confirm whether you have myeloma or not. If you're diagnosed with myeloma, your healthcare team may then do further tests to 'stage' the cancer (see how much it's developed). At any time, you can ask your healthcare team to tell you why you're having a certain test and what the results mean.

Tests to diagnose myeloma

Here's an overview of the tests you might have to confirm and stage the myeloma. These tests will decide if you have MGUS (see page 25), smouldering myeloma or symptomatic myeloma. If you have symptomatic myeloma you will begin treatment straight away. The tests listed here are all types of blood or urine test.

Initial screening tests

Full blood count

A full blood count (FBC) is a simple blood test which measures the number of each type of cell in your blood: red cells, white cells and platelets. It also lets doctors look for plasma cells in your blood.

Most people with myeloma don't have plasma cells in their blood, but if they do appear outside the bone marrow it may change your diagnosis to plasma cell leukaemia. If this happens your doctor will talk about what this means for you.

An FBC will also check whether you have anaemia – a low level of haemoglobin (Hb) which is found in red blood cells. This is very common in myeloma and can make you feel tired and short of breath.

You might be sent for an FBC by your GP as part of a routine check-up. Other people might have one when they're in hospital for something else. You'll have this test before diagnosis and throughout your treatment because an FBC can also measure how your condition is responding to chemotherapy.

It's worth staying aware of the results – this way you'll know whether you're responding well to treatment or if more needs to be done. It's also very important to tell your healthcare team if you've experienced any new symptoms.

They can then decide whether further testing or treatment is required.

Urea and electrolytes

This is a blood test to check how well your kidneys are working, and to see if there is any damage to your kidneys which may be caused by myeloma. It will help your doctors to calculate the doses of drugs you need. It can also show if you're lacking fluid (dehydrated).

You'll usually have your kidneys checked every time you have an appointment at the hospital.

Serum calcium

This blood test checks that there's not too much calcium being released into your blood because of myeloma-related damage to your bones.

Liver function test

This is a blood test to check if your liver is working normally. Chemotherapy drugs are broken down in the liver so if the liver function test shows that your liver isn't working properly, it may be necessary to adjust the dose of chemotherapy.

Serum and urine electrophoresis

This test looks at the amount and the type of paraprotein present in your blood and urine. It's an important test which helps find out the type of myeloma you have and measures how you're responding to treatment. If you have paraprotein present but you don't have any other signs of myeloma then you may have MGUS.

Serum free light chain assay

This test is done to confirm the diagnosis of free light chain myeloma. You may have it if no paraprotein – or only a small amount – is found in your blood or urine. This sensitive test can detect even very small amounts of light chain proteins present.

Immunofixation or immunoglobulin typing assay

Immunofixation will define which type of myeloma you have. Myeloma is classified according to the type of paraprotein your body is making, which may be IgG, IgA, IgM, IgD or IgE.



For more information on different types of myeloma, see **pages 20–21**.

Although it's rare, for some people with myeloma only light chains can be detected, not whole paraproteins. If there are only light chains, it's known as free light chain myeloma. These light chains are known as either (kappa) or (lambda) type.

Erythrocyte sedimentation rate (ESR)

This test is used to determine how thick the blood is. Your doctor will take a blood sample to measure the rate at which the red blood cells settle at the bottom of a tube. This process should happen faster in people with more active myeloma, owing to a higher amount of paraprotein in the blood.

Tests to confirm the diagnosis and investigate further

You might have some further tests to either confirm the diagnosis, or to see how much the myeloma has developed and how much it's affecting your body.

These tests can also help you and your healthcare team decide which type of treatment would be best for you.

For many people this can be an anxious time, especially if you have to wait for the results. You might like to get extra support from family and friends, your healthcare team, or talk to other people who've been affected.

Plasma viscosity test

This test is done to measure how thick the plasma is in the blood. It can show how active the myeloma is because thicker plasma is associated with more paraprotein in the blood.

Bone marrow biopsy (aspirate and trephine)

If there's paraprotein in your blood or urine, a biopsy will usually be taken from the bone marrow – normally from your hip bone (pelvis) – to confirm your diagnosis. It's then studied under a microscope to see if there are any myeloma cells in it.

You don't need to stay overnight in hospital for a bone marrow biopsy – you can have it as an outpatient using local anaesthetic to numb the area, or mild sedation to make you feel sleepy. It's usually quite quick but will be uncomfortable while the sample is being taken from the marrow – you can take painkillers if you need to.

A special needle is inserted into the hip bone after local anaesthetic has been administered. This is called a bone marrow aspirate. A small sample of bone marrow is removed (aspirated) into a syringe and sent for analysis.

You'll usually have a trephine biopsy at the same time as a bone marrow aspirate. This is where a 'core' of bone and bone marrow is taken from the

hip bone. This gives information about the structure of your bone marrow and the number and distribution of the different blood cell types – and myeloma cells, if there are any there.

FISH and other genetic testing

All kinds of cancer, including blood cancer, involve changes in genes in the affected cells. This isn't the same as an inherited genetic cause (something that runs in families).

Understanding the exact changes in your myeloma cells can help doctors to diagnose your illness, decide how likely it is that your condition will respond to standard treatment, and monitor how well you respond to treatment. Your bone marrow sample (see previous page) will be sent for FISH (fluorescence in situ hybridisation) testing. This test looks for gene changes in myeloma cells. Genetic tests that are even more sensitive are being introduced to give better information to guide treatment.

B2M and albumin levels

You'll also have a test to measure the levels of two proteins in the blood: albumin and B2 microglobulin or B2M (sometimes written as β 2M). B2M is a protein found on the surface of the myeloma cells. In myeloma, albumin levels can be low and B2M levels can be raised.

Staging the myeloma

Based on your B2M and albumin levels, the results of FISH and other genetic testing, and the level of a substance called lactate dehydrogenase (LDH) in your blood, doctors will decide if the myeloma is stage one (I), two (II) or three (III). This will give clearer information about your outlook.

Scans

You may have a scan (CT, MRI or PET) to look for signs of myeloma in the bone marrow and check whether there is any evidence of bone damage.

Computerised tomography (CT or CAT) scan

A CT scan is a type of X-ray that will show up any areas where the myeloma could be affecting your bones. The procedure won't cause any pain. You'll lie on a table that moves into a doughnut-shaped machine while the pictures are taken. Your body is never completely enclosed and you'll be able to talk to the person who takes and assesses the images (the radiographer) all the time. You might need to have a dye injected into one of your veins to help get a better image.

Magnetic resonance imaging (MRI) scan

This scan shows up soft tissues (non-bony parts) and uses strong magnets and radio waves rather than X-rays. It can help your team to find out if the myeloma is affecting your spine or spinal cord.

You'll be asked to lie on a table which will move you through the scanner. It isn't painful but it can take up to an hour to complete – some people may not like being enclosed and feel a bit claustrophobic. The MRI machine is also noisy, so you may be given headphones so you can listen to music during the procedure. As with a CT scan, you might need to have a dye injected into one of your veins to get a better image.

You'll need to remove any metal you're wearing before an MRI, including jewellery. If you have any metal in your body – for example a pacemaker or bone pins – you should tell the person conducting the scan (the radiographer).

Positron emission tomography (PET) scan

This type of scan is called either a PET scan or PET/CT scan, as some scanners do both PET and CT scanning. Not everyone will have this type of scan, but can be useful if doctors need more information about where the myeloma cells are in your body.

Before your PET scan, you'll have an injection which contains radioactive sugar to help show up the affected cells. This small amount of radioactivity is quite safe for you. You'll be asked to lie on a table as you move through the doughnut-shaped scanner. The scan can take up to three hours, including preparation time.

Having a PET scan will make you slightly radioactive for a short time, so you may be told to stay away from pregnant women, babies and young children for a few hours after your scan.

Your healthcare team

If you're diagnosed with myeloma, your hospital should give you the names and contact details of your specialist doctor (consultant), clinical nurse specialist (CNS) and other members of your healthcare team – there's space to write them in the back of this booklet if you want to. You can then use these details to contact your team if you have any questions you want to ask when you're not in the hospital.

Your specialist doctor (consultant)

Most people with a blood cancer are treated by a haematologist – a doctor who specialises in treating blood diseases. Some people are treated by an oncologist (a cancer specialist). Either way, your consultant at the hospital will be an expert in treating your specific disease.

Your clinical nurse specialist (CNS)

People with cancer are normally given a key worker, usually a clinical nurse specialist (CNS). They're your point of contact with the rest of your healthcare team. You may like to have a meeting with them when you're first diagnosed, to discuss your condition. Your CNS will be with you every step of the way, so do make use of their help and expertise as and when you need it.

Your multidisciplinary team

Your condition should be discussed at regular multidisciplinary team (MDT) meetings. An MDT brings together doctors, nurses and other specialist staff who will be looking after you. They'll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

Your other healthcare professionals

It's definitely worth telling other healthcare professionals you see – like your dentist or optician – about your diagnosis and any medication you're taking. They may need to check with your specialist or GP before giving you some types of treatment.

Talking to other people

You might want to ask your consultant or key worker if you can talk to someone who's had the same diagnosis and treatment as you.

If you do this, remember that someone else's experience won't always be the same as yours. For example, some people will experience side effects from a drug and others won't.

You may also want to contact a support organisation – many provide patient meetings or further online support.

Finding out more

After you've been diagnosed, it's worth taking some time to think about what information you want to know, when and how. For some people, this is a way to have some control over what's happening.

Let your consultant and CNS know how much information you'd like, and in what form. You can always ask for more information later.

Write down any questions you have and keep them handy for when you see your consultant or key worker. If they can't answer your questions, they'll be able to tell you who to speak to.

You might prefer to ask your CNS questions rather than your consultant, but do whatever works for you.

Most people say they find it useful taking someone with them to appointments. If you think you'd find it helpful, you could ask them to take notes while you listen. You can choose who to take – it doesn't have to be a family member.

If you're staying in hospital it might be harder to have someone with you when you speak to your consultant. It could be useful to ask in advance what time the consultant is likely to see you, so you can try to arrange for someone to be with you at that time.

Some people find that joining a patient support group is helpful. It may be easier to talk to someone outside of your family about your situation and being able to share similar experiences might also help you.



Talk to other people going through similar experiences on our online community forum at **forum.bloodcancer.org.uk**

You can also find a list of support organisations on **page 89**.

Telling people

Many people tell us that keeping in touch with loved ones throughout their illness keeps them going. However, some people may find it stressful having to discuss their condition lots of times with family, friends and colleagues.

You might find it easier to ask a trusted family member or friend to be your 'information person' and ask them to keep people updated for you.

Another idea is setting up a blog or Facebook page, so you or other people can post information on it that everyone can read.

You might not want to tell many people – or anyone at all – about your condition. This is ok too, whatever works for you.

Telling children and teenagers

Talking to children and teenagers about your condition can be difficult. There are many organisations to support you and offer you advice about how to explain cancer to children of different ages.

Telling your GP

Your team at the hospital will keep your GP informed about your condition and any treatment you're having. They'll usually send your GP a letter with this information. As the patient, you'll often be sent a copy too. These letters can have a lot of medical terms in them which you might not have heard before, or there might be something in one which worries you. If this is the case, let your hospital or GP know – a quick chat with them might help to reassure you.

Cancer and work

Consider telling someone at work about your diagnosis. It can be hard asking for time off at short notice if no one knows about your illness, and your colleagues and human resources department might be able to offer support.



Macmillan has information on talking to children about cancer. Go to **macmillan.org.uk** then search for 'talking to children and teenagers'.

There's more information about cancer and how it can affect your work or study on **pages 83–84**.

The treatment you decide on with your healthcare team will depend on your health, your individual condition and your wishes.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Treatment

The main aims of treatment are to substantially reduce the effect of the myeloma and to bring you into remission (a period when cancer cells are at low level or can no longer be detected) for as long as possible, with the best possible quality of life.

People with smouldering/asymptomatic myeloma may not need treatment straight away but will have regular check-ups instead.



There's more on our website about how treatment is planned for blood cancer, different aims of treatment and making treatment decisions – **[bloodcancer.org.uk/treatment](https://www.bloodcancer.org.uk/treatment)**

If you have symptomatic myeloma you'll normally start treatment immediately – depending on a number of factors. Treatment will involve a combination of chemotherapy (anti-cancer drugs), steroids, biological therapies (which support the body to control the cancer) and possibly a stem cell transplant.

When will I start treatment?

Depending on the results of your tests and whether you have any symptoms when you're diagnosed, you may not need to start treatment right away. If you're not being actively treated, this is known as 'watch and wait' or 'active surveillance'. In this case, you might hear your condition called smouldering or asymptomatic myeloma.

There's no evidence that starting treatment at this stage will improve your outlook. You can't start treatment if your consultant doesn't think you need to, but if you're not happy with their decision, you can always ask for a second opinion.

You can ask for this at any time before or during treatment and it can be arranged either through your current consultant or your GP. Some people can be anxious about being on 'watch and wait'.

If this is the case for you, try to speak to your healthcare team as they can offer you support and reassurance.

If you're on 'watch and wait' you'll have regular check-ups to monitor your condition. These will either be at your GP surgery or in hospital. It's really important to go to these, as this is when you and your consultant can talk about how you're feeling and whether you might need to start treatment.

If your consultant thinks it's important for you to begin your treatment they'll tell you and explain the options open to you, to help you make a decision.



You'll find more information on 'watch and wait' on our website – [bloodcancer.org.uk/watch-and-wait](https://www.bloodcancer.org.uk/watch-and-wait)

Clinical trials

Although the outcome for people with myeloma continues to improve, there is still a long way to go to improve treatments and quality of life for people with myeloma. Therefore if there's a clinical trial available, your consultant might recommend that you consider this.

A clinical trial is a planned medical research study involving patients. These studies are done with the aim of looking for new treatment options and improving existing treatments. Taking part in a clinical trial has many advantages, such as the opportunity to have a new test or treatment which may not be offered outside of the trial.

Your safety and wellbeing is always the first priority when taking part in a clinical trial. You'll be very closely monitored and have detailed follow-up.

Taking part in a clinical trial does come with uncertainties, and you may prefer not to take part in one. If you don't want to be in a trial, or there isn't a suitable trial available, you'll be offered the best treatment available which is appropriate for your individual condition.

The stages of myeloma treatment

Myeloma is not usually considered a curable disease.

Instead, it is a disease which shifts between phases of remission (when cancer cells are no longer detected or reduced) and relapse (when cancer cells have returned or increased). Phases of remission, sometimes called 'plateau phases' can vary considerably in length of time between different people. Usually, people respond well to first-line therapy, and this period tends to be when most people experience the longest remission.

Unfortunately, people with myeloma will usually relapse after this first period of remission, but when this is the case there will be other treatment options available to you. Treatment following a first relapse is called 'second-line' therapy, and the aim of this treatment is to achieve a second remission. The standard treatment options available, from first-line through to fifth-line therapy, are outlined next.

First-line therapy: remission induction

There are two stages involved in first-line therapy. The aim of the first phase of treatment is to remove as many of the myeloma cells as possible from your bone marrow.

This first stage is known as remission induction or just induction therapy, which involves a combination of chemotherapy, steroids and biological therapies.

Chemotherapy, steroids and biological therapies

Chemotherapy is directly toxic to cancer cells. Steroids are toxic to these cells too, but steroids can also increase the cancer-killing effects of other chemotherapies. Biological therapies aim to help the body itself to attack or control the growth of cancer cells.

The exact drug, dose and combination you'll be offered will depend upon your general health, age, and whether you'll have a stem cell transplant at a later date.

In general, older or less fit people tend to have standard doses. Younger or fitter people tend to have higher doses followed by a stem cell transplant.

Treatment is usually given in cycles. Each cycle can last for three to five weeks, and one course of treatment can include four to six cycles. You will have time off treatment after your course has finished. Overall, remission induction may last four to six months.

The most common drugs prescribed are listed below. All are taken by mouth (orally), unless stated otherwise.

Chemotherapy

- cyclophosphamide
- melphalan (Alkeran®)
- bortezomib (Velcade®) – injected under the skin (subcutaneously).

Biological therapies

- thalidomide
- lenalidomide (Revlimid®)
- pomalidomide (Imnovid®).

Steroids

- dexamethasone
- prednisolone.

Other drugs may be suggested, in different combinations.

The most common combination used in first-line therapy, especially for younger or fitter people, is VTD (Velcade-thalidomide-dexamethasone). Velcade is the trade name for bortezomib.

Usually older or less fit people will be offered VMP (Velcade-melphalan-prednisolone) or CTDa (cyclophosphamide-thalidomide-dexamethasone-attenuated). An 'attenuated' programme (regimen) means you will have the smallest effective dose. These drug combinations will not usually be followed by a stem cell transplant.

People with free light chain myeloma or kidney problems will usually be offered a different drug combination, often including bortezomib (Velcade) and dexamethasone.

Thalidomide and similar drugs

There is evidence that the drug thalidomide can affect the development of babies (foetuses) in the womb. Women who may be pregnant should not take any combination of drugs which include thalidomide or similar drugs like lenalidomide or pomalidomide. While you are taking these drugs you must use condoms or another barrier method of contraception.

This is important for men as well as women, as thalidomide is present in the sperm of men taking it.

To avoid any risk to unborn babies, you shouldn't donate blood and must make sure no one else has access to your medication.

Thalidomide, lenalidomide and pomalidomide all increase the likelihood of developing blood clots, where the blood thickens and can cause blockages in the blood vessels. So if you take these drugs you will also be given medication such as low molecular weight heparin (LMWH) or aspirin to thin your blood and reduce the risk of clotting. LMWH is injected daily under the skin and aspirin is taken as a tablet

First-line therapy: consolidation therapy

If after your initial treatment all the myeloma cells have gone, it's called a complete response. If you have a complete response you'll still be considered for further treatment or consolidation therapy. This is because without the consolidation, the myeloma may quickly come back.

Consolidation therapy tends to involve either a stem cell transplant or a further combination of drugs.

Stem cell transplant

A stem cell transplant (sometimes called a bone marrow transplant) aims to give you healthy stem cells, which then produce normal blood cells.

There are two main types of stem cell transplant:

- autologous or autograft – this uses your own stem cells
- allogeneic or allograft – this uses donor stem cells and is a higher risk procedure.

People with myeloma typically have autologous transplants, not allogeneic ones. You might also hear an autologous transplant called an auto-SCT. Occasionally allogeneic stem cell transplants might be considered for younger, fitter people with a particularly aggressive type of myeloma.

With autologous transplants, once you have a complete response after your initial treatment, stem cells will be collected from your blood using a specially designed machine.

It's likely that you'll take melphalan (a chemotherapy drug used to slow the growth of cancer cells) before your stem cells are returned to your body. The melphalan removes any remaining myeloma cells and prepares your bone marrow to receive the stem cells. This is called conditioning.

Relapsed myeloma

People who have myeloma will almost always experience a relapse. Relapse is the term used after someone has responded well to treatment but the condition has returned later. Your doctor may suggest the following drug combinations at different stages of your treatment.

Second-line therapy

Second-line therapy may involve:

- daratumumab, bortezomib and dexamethasone
- lenalidomide and dexamethasone
- carfilzomib and dexamethasone
- bortezomib and dexamethasone
- CTD (cyclophosphamide-thalidomide-dexamethasone).



We have a booklet about stem cell transplants called **Blood stem cell and bone marrow transplants: The seven steps** – see **page 106**.

If you relapse following a stem cell transplant, but were previously in remission for a minimum of 12 months, then a second autologous transplant (using your own stem cells) may be an option as second-line therapy. This will not cure the myeloma but it should hopefully lead to another long and stable remission period.

Third-line therapy

Third-line therapy is typically lenalidomide, ixazomib and dexamethasone. Bortezomib, pabinostat and dexamethasone is an alternative.

Fourth-line therapy

Daratumumab monotherapy (daratumumab taken on its own) is most likely to be used as fourth line therapy for people who haven't had daratumumab as part of a previous treatment.

Fifth-line therapy

Fifth-line therapy may involve:

- pomalidomide and dexamethasone panobinostat
- bortezomib and dexamethasone
- bendamustine and dexamethasone.

Other drugs combinations which may help bring people back into remission include DT-PACE (a combination of chemotherapy drugs, thalidomide and a steroid) and ESHAP (a combination of chemotherapy drugs with a steroid).

Refractory myeloma

If myeloma stops responding to treatment, this is called refractory disease. In this case your consultant might suggest you take part in a clinical trial (see page 52).

Refractory myeloma can occur at any stage in myeloma, but it's more difficult to treat if this happens in an earlier phase.

If you don't want to take part in a trial, your consultant will help you choose the best treatment based on which drugs you've already tried, your general condition, and your wishes. Bortezomib, lenalidomide and pomalidomide are all drugs which may be used in this situation, usually in combination with dexamethasone.

Side effects from your treatment

Possible side effects from your treatment may include:

- an achy feeling
- frequent watery poos (diarrhoea)
- difficulty pooing (constipation)
- extreme tiredness (fatigue)
- difficulty sleeping (with steroids)
- hair loss (alopecia)
- infections
- lack of red blood cells (anaemia) which can make you tired, breathless and pale
- mouth sores
- mood changes
- feeling sick (nausea)
- upset stomach and being sick (vomiting)
- loss of feeling or pain in your legs or other parts of your body (neuropathy)

- blood clots (thrombosis)
- poor appetite and loss of taste
- increased appetite (with steroids)
- weight changes.

You can find more information about medicines used to treat myeloma and its symptoms on the Electronic Medicines Compendium website: medicines.org.uk/EMC

You're unlikely to have all of these side effects, especially as some are linked to specific drugs. If you have any side effects, do tell your healthcare team as they might be able to help with them. For example, you will always be prescribed drugs called anti-emetics which can help with symptoms of nausea and vomiting. Your doctors may also be able to suggest a change in your treatment if any of these side effects become unmanageable.



We have fact sheets about some of these side effects – **Understanding infection, Sore mouth or gut (mucositis)** and **Managing sickness and vomiting** – see **page 107**.

Drugs to treat the symptoms of myeloma

You may also experience symptoms which are related to the disease, instead of the treatment.

The following drugs may be used in this situation:

- bisphosphonates to strengthen bones and reduce any pain resulting from bone damage
- erythropoietin (EPO) injections to treat anaemia (this will increase your red blood count and stop you feeling tired and breathless)
- granulocyte-colony stimulating factor (G-CSF) to trigger the production of white blood cells to protect against infection
- antibiotics to help prevent or treat infections
- painkillers to help relieve bone pain.

Make sure your healthcare team are aware of all your symptoms, so you can get the right help.

Treatment for bone damage

Sometimes myeloma can cause damage to vertebrae, which are the bones making up your spine. You will have already been given bisphosphonate drugs to reduce the pain and increase the strength of your bones.

You might also need an operation to repair the damaged bones to prevent the condition getting worse. If you need this operation you'll be looked after by an orthopaedic surgeon, who'll explain to you what's involved.

Supportive care

As well as active treatment of your illness, you may need care around things like prevention of infection, blood transfusions, mouth care, dietary advice, pain management and dealing with any complications of your illness or of your treatment.

Follow-up

Your follow-up will depend on what type of treatment, if any, you're having, and how your condition has responded. If your condition has responded well, it may be some time before you need further treatment.

Your consultant will explain how often you'll come back for follow-up checks. These appointments are really important so do make sure you get to them.



We have fact sheets on **Understanding infection** and **Blood transfusions** – see **page 107**.

There are a number of conditions related to myeloma, which some people might experience.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Related conditions

There are a few conditions which are closely related to myeloma. If you are affected by one of these conditions, your consultant will explain what it means for you.

MGUS

People who develop myeloma will previously have had a condition called monoclonal gammopathy of undetermined significance (MGUS), although they may not be aware of this.



We have a fact sheet on **Monoclonal gammopathy of undetermined significance (MGUS)** – see **page 107**.

MGUS means that you have a raised level of paraprotein (also called monoclonal gammopathy or M protein) but no features of myeloma or damage to any organs. MGUS can only be diagnosed if you have a special test which detects paraprotein in your blood or urine. It's not routine practice to screen healthy people for MGUS or for myeloma.

MGUS is a relatively common condition, affecting about 3% of the UK population over the age of 50. It is generally harmless, causing no detectable damage, so treatment isn't necessary.

Plasmacytoma

Plasmacytoma is a condition similar to myeloma but the abnormal plasma cells are only found in one place in your body – either inside a bone (solitary bone plasmacytoma) or in the soft tissue outside a bone (solitary extramedullary plasmacytoma).

Plasma cell leukaemia

Plasma cell leukaemia may be a late stage of myeloma where plasma cells are found in the blood. Otherwise it may occur as a separate condition with no damage to your bones or other tissues.

Waldenström macroglobulinaemia (WM)

The condition Waldenström macroglobulinaemia (WM) is associated with raised levels of paraprotein. This is also true of myeloma, but WM is now usually seen as a rare type of non-Hodgkin lymphoma, so symptoms and treatment will be different.

Amyloidosis

People with myeloma may also be affected by amyloidosis. Amyloid is an abnormal protein made up of light chains. Amyloidosis can be inherited or it can be a result of other blood disorders.



We have a separate fact sheet on **Waldenström macroglobulinaemia (WM)** – see **page 107**.

**Every person is different,
so your consultant and
healthcare team are the
best people to ask about
your likely outlook.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

The outlook

For most people, myeloma responds well to initial treatment but unfortunately it almost always comes back. However, there are a number of treatment options available, as described in the previous chapter.

Whatever treatment you have, the aim is to have a period when there are no signs of myeloma (remission), or when the paraprotein or light chain levels in the blood are lower and stay lower (a plateau, or stable disease phase). These periods of time will vary a lot from person to person. But both remission and survival rates for people with myeloma have increased in recent years, as researchers develop new and more effective treatments.

Your outlook is individual to you, so do talk to your healthcare team about your outlook, as they will have the fullest picture.

You may find it hard to ask or talk about your outlook (prognosis).

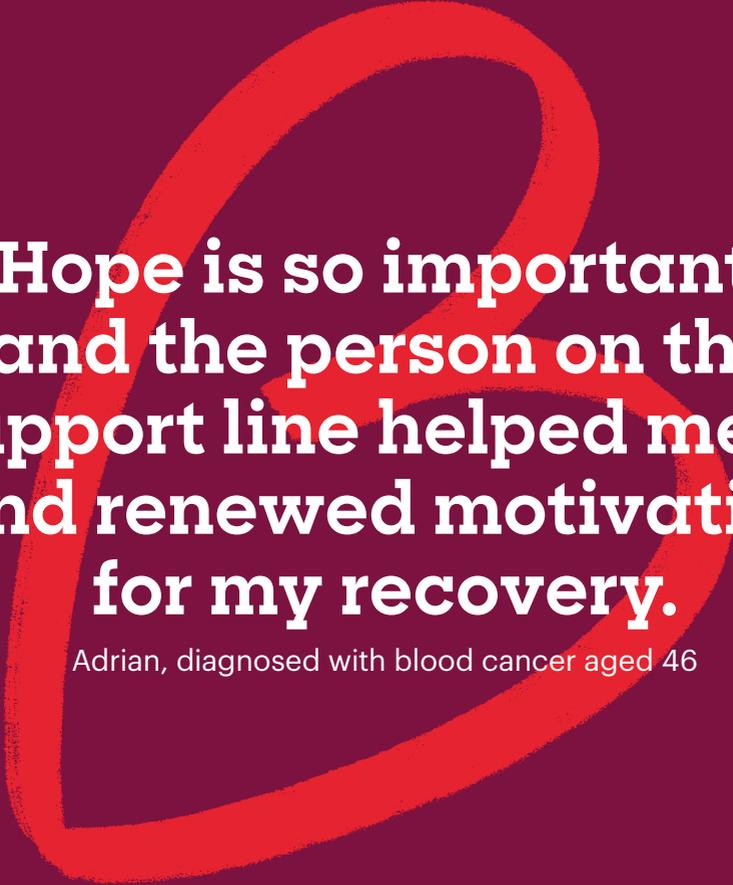
Sometimes those closest to you might want to know your prognosis even if you don't. However, your healthcare team aren't allowed to give this, or any, information to anyone – not even family members – without your permission. Try to decide early on who you want to know about your condition, then tell your healthcare team. You can change your

If you want to find out more

If you would like more detailed information on the general outlook for myeloma, go to cancerresearchuk.org and search 'survival myeloma'. Remember that statistics can only give an overall picture. Your own outlook is individual to you and will depend on your age, level of fitness and the stage of your disease.

Our Support Services Team can talk to you about any questions you have about outlook.

Contact us on **0808 2080 888** or **support@bloodcancer.org.uk**



**Hope is so important,
and the person on the
support line helped me to
find renewed motivation
for my recovery.**

Adrian, diagnosed with blood cancer aged 46

**Your healthcare team
should look after your
emotional needs, as well
as your physical ones.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Living with myeloma

If you've been diagnosed with myeloma, you might experience a range of emotions at different times. There can be a physical impact on your day-to-day life too.

Looking after yourself emotionally

Being told that you have cancer can be very upsetting and will almost certainly bring many different emotions. If you were diagnosed by chance, it can come as even more of a shock. Friends and family may be able to offer support, but it may be harder for them to understand the long-term emotional impact that you might experience.

Your healthcare team should look at your emotional, spiritual, social, practical and physical needs – this is called a holistic needs assessment. You'll have one a few times throughout the course of your treatment and beyond, as your emotional needs might change.

Looking after yourself physically

Changes in your condition

You might need to live with symptoms for a long time – your healthcare team will be able to give you advice on how to cope with them.

Keeping active

You might feel tired a lot (fatigue). This might be caused by the myeloma or its treatment and isn't the same as normal tiredness, which improves with rest and sleep.

While even the idea of doing something can be tiring if you've got fatigue, try to keep as active as you can because evidence shows that this could help to reduce the symptoms of fatigue.



You can talk to other people living with blood cancer or read their experiences at **forum.bloodcancer.org.uk**

We have more information and tips about coping with emotions, fatigue and keeping active on our website **bloodcancer.org.uk/living-well**

If you have osteoporosis (a weakening of bones, making them more likely to fracture from minor impact) it's advisable to keep as mobile and active as you can within your own limitations. It's best to avoid strenuous activity – for example, lifting heavy things – and take special care to avoid falling. It's also important to keep up with your bone strengthening treatment (bisphosphonates), which will help reduce the impact of osteoporosis.

Although we know that staying active may help, there's no evidence of any particular exercise programme improving your condition or how you respond to treatment.

Diet and infection risk

Similarly, there's no evidence that any special diet will improve your condition or your response to treatment. However, you're likely to feel fitter and healthier if you follow general advice on good diet from your hospital or GP.

Because your immune system may not be working as normal, you'll need to take extra care to avoid infections that you might get from food. Your body won't be able to destroy germs and resist infection as easily, so be careful about food 'use by' dates and things like keeping cooked and raw meat separate in the fridge. You may also be advised to be extra careful about takeaway food and eating out while you're having treatment.

Because the level of paraprotein or calcium in your blood can damage your kidneys, it's very important to drink plenty of water. Unless you're told otherwise, it's best to drink at least three litres (about five pints) in total every day.

A diet for people with a weakened immune system is known as a neutropenic diet. Your healthcare team will advise you on any changes you need to make to your eating and drinking habits.

Other infection risks

If you're having treatment, speak to your healthcare team about whether it's OK for you to do gardening and housework. Avoid fresh cut flowers and vases with old water in, as these carry germs that might cause infection.



We have a fact sheet on **Understanding infection** that gives tips on reducing your risk of infection – see **page 107**.

Our booklet **Eating well with neutropenia** has advice on how to avoid infections from food – see **page 106**.

Vaccination

It's a good idea for everyone with myeloma to have the flu vaccine each year – your GP might contact you about this but if they don't then you can request the vaccine yourself. It might not work as well for people with myeloma but will still offer some protection. It is also a good idea to have the pneumococcal and Haemophilus influenzae type B (HiB) vaccines, as your ability to fight off these infections may be affected either by having myeloma or being treated for it. These bacteria can cause a range of infections such as pneumonia and blood poisoning.

If you have myeloma, you should avoid having any live vaccines. Fortunately only a few vaccines are live. The most commonly used ones are MMR (measles, mumps and rubella) and shingles. The yellow fever vaccine, occasionally needed for travel to certain areas abroad, is also a live vaccine.

If you are in remission after a stem cell transplant, your healthcare team will advise you on which vaccinations you should have.

Shingles

Shingles is the infection of a nerve and the skin around it. It can affect you if you've had chickenpox, even if you had it a long time ago, as it's caused by the same virus which can lie dormant (stay inactive) in your body for years. You're more likely to get shingles if your immune system isn't working well – for example, if you have myeloma.

Shingles has some quite obvious symptoms. If you think you have it, let your GP or specialist know as quickly as possible (within 24 hours of the rash appearing is best). If it's treated early the symptoms won't be as bad.

Symptoms include:

- a rash (blisters filled with fluid which burst and form sores which then crust over), usually on one side of the body
- pain where the rash is
- an itching, tingling or burning feeling.

You can't catch shingles from someone who has it, but you can catch chickenpox from someone with an open shingles sore, if you haven't had chickenpox already. Try to avoid people with shingles, chickenpox and other viruses.

Complementary therapies

Complementary therapies are treatments like massage, meditation or acupuncture that are used alongside standard medical treatments with the aim of making you feel better.

There's no evidence to suggest that these therapies can treat or cure blood cancer, but there's some that suggests some of them may help you manage your symptoms or the side effects of your treatment. Other therapies may just help you relax or improve your general sense of wellbeing.

Alternative therapies

There's an important difference between **complementary therapies**, which are used alongside standard medical treatments (like chemotherapy and radiotherapy), and **alternative therapies**, which are offered instead of these treatments. We don't recommend that you use any alternative therapy in place of proven medical care, but you may be interested in using complementary therapies alongside your treatment.



Always keep your healthcare team updated about any new or changed symptoms you have after you're diagnosed. See **pages 29–31** for a list of what to watch out for.

Keeping yourself safe

If you're thinking about using complementary therapies, you should let your healthcare team know, so you can discuss what's safe for you. They may advise you to avoid certain therapies because of specific risks to do with your condition or the treatments you're receiving. In other cases, they may say a therapy is OK as long as you take specific precautions, like visiting a complementary therapist who's a member of the relevant professional association or register. Your healthcare team can explain how to check this.

Some hospitals will have a complementary therapies team that offers sessions free of charge, while others might have a specialist who visits once or twice a week. Sometimes these therapies are there for your partner or close relatives, too. Your healthcare team will be able to tell you what's on offer.

If your hospital doesn't offer complementary therapies, there may be a local cancer centre or charity that you could visit instead. Speak to your healthcare team to see if they can recommend anywhere nearby.

Some people choose to see an independent complementary therapist. If you do this, it's important to make sure they will keep you safe. Speak to your healthcare team about what you need to keep in mind when finding a therapist.

Practical support

Your work, education and domestic arrangements

If you work or are studying you might want to talk to your employer or college about your condition, or ask someone to do it for you. Most employers will do all they can to help.

You may need to make a short-term arrangement with your employer or college when you're diagnosed, so you can have time off when you need to be at the hospital. If you have to stay in hospital for your treatment, or you're not well enough to go to work or college, you'll probably need to make a more formal agreement

You may need to bring in written proof of your diagnosis from your healthcare team, which makes clear the effect myeloma could have on your ability to work or study.

Another thing you might want to consider is taking time out from work during treatment. You may receive varying advice on this but it's entirely your decision, so consider discussing it with your healthcare team and think about the demands of the specific work you do. Similarly, if you're studying at college or university, you might want to think about whether you want to continue with your course, or delay it for a short time.

If you're a parent or a carer, you may need support during your treatment. You might have unplanned stays in hospital because of infection, for example – it's helpful to have plans in place just in case.

Cancer and the law

People with cancer, or any other serious disease, are covered by a law called the Equality Act – for the purposes of the act, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable adjustments for people with disabilities and cannot discriminate against you.

An example of a reasonable adjustment would be giving you time off to go to hospital for treatment.

Getting to hospital

If you're being treated as an outpatient (not staying in overnight) you might need to be visiting the hospital a lot over a long period of time. If you find this hard because of transport or any other reason, you can ask your consultant if you can have any of your treatment nearer to where you live. It might not always be possible but sometimes it is – it depends on the healthcare facilities close to your home and the type of treatment you're having.

If this isn't possible and transport is a problem, you can ask about hospital transport. You might also be able to apply for support with travel costs. If you'd like to find out more about this support, you can speak to your healthcare team at the hospital or a benefits advisor. The organisations signposted below can also advise you.



We have more information and practical tips about dealing with work when you have blood cancer at **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

Financial support

Your finances might be the last thing on your mind if you've just been diagnosed with cancer, but there are lots of places you can get help and advice.

Your hospital will normally have medical social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. These might be especially useful if you're on a low income or unemployed. If you're worried you can ask to speak to an advisor as soon as possible after your diagnosis. Alternatively, your hospital might be able to arrange for an advisor from somewhere else to visit you.

If you normally pay for your prescriptions but you're being treated for cancer (including the effects of cancer or its treatment) you can apply for a medical exemption certificate for any drugs you need to support your care. Application forms are available from your GP surgery or hospital clinic.



We have more information and tips on dealing with the financial impact of cancer on our website at **bloodcancer.org.uk/living-well**



Newton was diagnosed with myeloma after a routine blood test. He has been living with myeloma for over ten years.

The treatments out there have come a long way, even in my time. I've found I can live quite a normal life.

Blood Cancer UK offers information and support to anyone affected by blood cancer. You'll find other useful organisations listed here as well.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Places you can get help and support

Blood Cancer UK

We are here for anyone affected by blood cancer, whether it's you who's been diagnosed or someone you know.

We offer free and confidential support by phone or email. We provide information about blood cancer and life after a diagnosis. And we have an online forum where you can talk to others affected by blood cancer.

- bloodcancer.org.uk
- 0808 2080 888 (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)
- support@bloodcancer.org.uk
- forum.bloodcancer.org.uk

Myeloma UK

Offers patient information, a telephone advice and information line, an online discussion forum and support groups.

- 0800 980 3332
- myelomauk@myeloma.org.uk
- myeloma.org.uk

Macmillan Cancer Support

Offers practical, medical, financial and emotional support.

- 0808 808 0000
- macmillan.org.uk

Cancer Research UK

Offers information about different conditions, current research and practical support.

- 0808 800 4040
- cancerresearchuk.org

Leukaemia Care

Offers patient information, a support line and support groups for people affected by leukaemia, lymphoma and other blood cancers.

- 08088 010 444
- support@leukaemiacare.org.uk
- leukaemiacare.org.uk

African Caribbean Leukaemia Trust (ACLT)

Aims to increase the number of black, mixed race and ethnic minority people on the UK stem cell registries by raising awareness and running donor recruitment drives.

- 020 3757 7700
- info@aclt.org
- aclt.org

Anthony Nolan

Runs the UK's largest stem cell register, matching donors to people with leukaemia and other blood-related disorders who need a stem cell transplant.

- 0303 303 0303
- anthohnolan.org

Maggie's

Has centres throughout the UK, run by specialist staff who provide information, benefits advice and psychological support.

- 0300 123 1801
- enquiries@maggies.org
- maggies.org

Marie Curie

Runs hospices throughout the UK and offers end of life support to patients in their own homes, free of charge.

- 0800 090 2309
- supporter.relations@mariecurie.org.uk
- mariecurie.org.uk

MedicAlert

A service that allows people with hidden medical conditions to provide vital information to emergency professionals via personalised jewellery.

- 01908 951045
- info@medicalert.org.uk
- medicalert.org.uk

Tenovus (Wales)

Provides an information service on all aspects of cancer, and practical and emotional support for people with cancer and their families living in Wales.

- 0808 808 1010
- tenovuscancercare.org.uk

Financial advice

Citizens Advice

Offers advice on benefits and help with filling out benefits forms.

- 03444 111 444 (England)
- 03444 77 2020 (Wales)
- in Scotland or Northern Ireland, contact your local Citizens Advice
- citizensadvice.org.uk

Department for Work & Pensions (DWP)

Responsible for social security benefits. Provides information and advice about public services including financial support, rights and employment.

- gov.uk/government/organisations/department-for-work-pensions

Travel insurance

Macmillan Cancer Support

Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.

- 0808 808 0000
- macmillan.org.uk

British Insurance Broker's Association (BIBA)

Offers advice on finding an appropriate BIBA-registered insurance broker.

- 0370 950 1790
- enquiries@biba.org.uk
- biba.org.uk



**The Blood Cancer UK
Online Community Forum
means I never feel alone
because there's always
someone there to talk to,
who really understands.**

Carina, diagnosed with blood cancer aged 43

Questions for your healthcare team

It can be a good idea to write down any questions you have before your next appointment. Here are some things you might want to ask while you're waiting to receive your diagnosis, or once you've been diagnosed.

Tests

What tests will I have?

What will they show?

Where will I have them done?

Are there any risks associated with the tests?

Will any of the tests be painful?

Do I need to know anything about preparing for the tests, for example, not eating beforehand?

How long will it take to get the results?

Who will explain the results?

Treatment - general

Will I need to have treatment? If so, when?

What does the treatment do?

Is there a choice of treatments?

Is there a clinical trial that I could join?

What's likely to happen if I decide not to have the treatment my healthcare team recommend?

If I don't need to start treatment straight away, how will I know when I need to start it?

Who do I contact if I take a turn for the worse?

Who do I contact if I have any questions?

Type of treatment

Chemotherapy, biological therapies and steroids

What type of drug combinations will I have?

Will I have to stay in hospital?

If I don't stay in hospital, how often will I need to go to hospital as an outpatient?

What chemotherapy treatment will I be given?

Will I be given it by mouth, injection or drip (into a vein)?

Will my treatment be continuous or in blocks of treatment (with a break in between)?

How long will my treatment last?

What side effects could I get from my treatment?

Can side effects be treated or prevented?

Will side effects affect me all the time or only while I'm taking certain drugs?

What effect is the treatment likely to have on my daily life?

Will I be able to carry on working/studying?

Will I need to take special precautions, for example against infection?

Will I need to change my meal times or work my drugs around these?

Stem cell transplant

Is a transplant an option for me?

If I am having a transplant:

How long will I be in hospital for?

Do I have to be in isolation?

Choosing the right treatment for you

If you're asked to choose between treatments, you might like to ask your consultant these questions about each one:

What's the best outcome I can hope for?

How might the treatment affect my quality of life?

Glossary

Antibody

Antibodies are proteins which help fight infections in your body. When your body is working normally, antibodies are produced by plasma cells.

B lymphocyte or B cell

A type of white blood cell normally involved in producing antibodies to fight infection.

Biological therapies

These treatments are called 'biological' because they use substances that occur naturally in living things, or versions of these substances made in a laboratory. Some target cancer cells directly and others stimulate the body's own immune system to attack or control the growth of cancer cells.

Blood count, full blood count or FBC

A blood test that counts the different types of cells in your blood.

Bone marrow

A spongy material inside the long bones, which produces your blood cells.

Chemotherapy

Treatment using anti-cancer drugs. It can be a single drug or a combination of drugs. Chemotherapy is used to kill cells or stop them growing and dividing. Although it's aimed at the cancer cells, the treatment also affects normal cells which divide quickly, such as those in the hair and gut.

Clinical nurse specialist (CNS)

A qualified nurse who specialises in a particular clinical area. Some deal with all blood cancers while others may specialise in myeloma or another specific area. Your CNS can provide information and expert advice about your condition and treatment and can be a good link between you and your doctors.

Clinical trial

A planned medical research study involving patients. They can be small trials involving only a few patients or large national trials. Clinical trials aim to improve treatments and reduce any side effects they cause. You need to sign a consent form to participate in a clinical trial, so you'll always be aware if your treatment is part of a trial.

Fatigue

Fatigue is a feeling of extreme tiredness which doesn't go away after rest or sleep. It might be caused by the myeloma itself or might be a side effect of treatment. It's one of the most common problems that patients with cancer can have. If you experience fatigue, your healthcare team should be able to offer guidance on helpful ways to manage it.

Granulocyte-colony stimulating factor (G-CSF)

This is a type of protein known as a growth factor. It may be given after chemotherapy, or before and after a stem cell transplant, to help the bone marrow produce more white blood cells.

Heavy chain

The larger part of the two proteins that make up an antibody.

Immunoglobulin

Another name for antibody (see page 14–15), sometimes shortened to Ig. There are five types of immunoglobulin/antibody: IgA, IgD, IgE, IgG and IgM.

Light chain

The smaller part of the two proteins that make up an antibody.

Lymph node or lymph gland

A bean-shaped organ that acts as a filter to catch viruses, bacteria and other potentially harmful particles that enter your body. It contains white blood cells that fight infection.

Lymph vessels

Small tubes which make up a network which runs around your body. They carry a fluid called lymph.

Osteoporosis

A condition where the bones are weakened, making them more likely to break.

Paraprotein

An antibody that can't fight infection. When you have myeloma, paraproteins are produced in large amounts by abnormal plasma cells. Another name for paraprotein is M protein, M spike or monoclonal gammopathy.

Plasma cell

The type of blood cell affected by myeloma. When plasma cells work normally, they make antibodies which fight infections in your body.

Radiotherapy

The use of radiation in treatment. Radiotherapy kills cancer cells in the area of your body being treated, so it can be an effective treatment for diseases which affect a particular part of your body, such as myeloma.

Stem cells

Cells that develop into other cell types. Stem cells act as a repair system for your body and create a new supply of cells to replace the ones that die. Blood stem cells are found in the bone marrow.

Steroids

Steroids are made naturally in the body, but they can also be made artificially. Steroids are usually given with chemotherapy to treat myeloma. Some steroids are taken as tablets. Others are given by injection into a vein (intravenously). Dexamethasone, prednisolone and methylprednisolone are the steroid drugs most commonly used for myeloma.



**At times I felt
overwhelmed with the
treatment and side
effects, but having a chat
with my CNS always
made me feel
so much better.**

Emma, diagnosed with blood cancer aged 35

Our health information

Find out more about blood cancer, its treatments and living with blood cancer. All our information is produced with expert medical professionals and people affected by blood cancer. It's available to anyone to download or order for free.

Symptoms guide

A credit-card sized guide that folds out to explain the symptoms of blood cancer.

Booklets

Leukaemia

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Acute promyelocytic leukaemia (APL)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

Lymphoma

- Hodgkin lymphoma (HL)
- High-grade non-Hodgkin lymphoma (NHL)
- Low-grade non-Hodgkin lymphoma (NHL)

Other blood cancers

- Myeloma
- Myelodysplastic syndromes (MDS)
- Myeloproliferative neoplasms (MPN)

Treatment and beyond

- Blood stem cell and bone marrow transplants: the seven steps
- Eating well with neutropenia
- Diary for anyone affected by blood cancer

My information folder

An A5 folder to keep your information in.

Fact sheets

Conditions

- Burkitt lymphoma
- Monoclonal gammopathy of undetermined significance (MGUS)
- Waldenström macroglobulinaemia (WM)

Treatments

- Blood transfusions
- Donating stem cells
- What is CAR-T therapy?
- Watch and wait - What you need to know
- Watch and wait - My blood counts
- Watch and wait - A quick guide for partners, carers, family and friends
- Watch and wait - A quick guide for employers
- Watch and wait - A toolkit for GPs and practice nurses

Side effects

- Managing sickness and vomiting
- Sore mouth or gut (mucositis)
- Understanding infection

Living with blood cancer

- If your employee or colleague has blood cancer
- My activity planner

To order or download information

Visit [bloodcancer.org.uk/information](https://www.bloodcancer.org.uk/information)

Call **0808 2080 888** (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

Email support@bloodcancer.org.uk

Or use the order form on **page 116**



**We're a
community
dedicated to
beating blood
cancer.**

About us

We're the scientists who dedicate our careers to finding cures.

We're the nurses who find the right words in the darkest moments.

We're the campaigners and volunteers standing up for the people we love.

We're the bucket-collectors, race-runners and cake-bakers who make our research possible.

We're the friends, parents, children and grandparents affected by blood cancer.

Why?

Because we've invested over £500 million in life-saving research.

Because the finish line's in sight.

Because it's time to beat blood cancer.

Because we give people the support they need

People with blood cancer and their family and friends have unique support needs.

We offer free and confidential support by phone or email, provide information about blood cancer and life after a diagnosis, and have an online forum where you can talk to others affected by blood cancer.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Because our research is saving lives

The money raised by our community has meant we've been able to invest £500 million in research, which has changed the outlook for people with blood cancer. Our research has led to better treatments that have dramatically increased survival rates. Right now, we're funding research projects across the UK that are finding out more about blood cancer and the best way to treat it.

Find out more: **bloodcancer.org.uk/research**



Because we campaign for better treatment and care

We work to make sure people affected by blood cancer are at the heart of Government and NHS decision-making.

We're campaigning to end delays to diagnosis, improve access to the latest treatments and help people with blood cancer get the mental health support they need.

Find out more: [bloodcancer.org.uk/campaigns](https://www.bloodcancer.org.uk/campaigns)

Because we'll beat it together

Donate

A quick way to help. Every pound brings us one step closer to beating blood cancer:

bloodcancer.org.uk/donate

Fundraise

Sign up to one of our events, or do something you enjoy with family and friends – there are lots of ways to fundraise: **bloodcancer.org.uk/fundraise**

Join your local community group

Local community groups raise money and awareness in their local area. Volunteer for yours to meet new people and get involved in local activities:

bloodcancer.org.uk/local-community-groups

Volunteer

Give your time, meet new people and experience new things by volunteering with us. There are lots of ways you can help, from your own home or in your local community: **bloodcancer.org.uk/volunteer**

Get your organisation involved

From funding a project, to becoming a corporate partner, find out how your organisation can help us:

bloodcancer.org.uk/corporate-partnerships

Or call us on **0808 169 5155**



**I love being part of the
Blood Cancer UK family.
Being involved has
helped me and my family
cope with my diagnosis.**

Anna, diagnosed with blood cancer aged 39

Order information from Blood Cancer UK

All of our information is free to people affected by blood cancer, but if you would like to include a donation with your order, please fill in the donation form over the page.

You can order more information by:

- visiting **bloodcancer.org.uk/information**
- emailing **support@bloodcancer.org.uk**
- calling **0808 2080 888**
- or completing and sending this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George St, Edinburgh, EH2 4JN**

Please send me some information

Full Name

Address

Email

Phone

Please tell us the publications you would like us to send you, free of charge (see page 106)

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Keep in touch

We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by: Email Phone SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email **hello@bloodcancer.org.uk**



My details

My name and hospital number

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My NHS number

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My condition

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My contacts

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.....

My consultant

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My key worker (usually CNS)

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Haematology ward

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Haematology clinic

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Out of hours

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Other contacts

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Because we face it together

We're a community dedicated to beating blood cancer by funding research and supporting those affected.

Get in touch for:

- Free and confidential support by phone or email
- Information about blood cancer and life after diagnosis
- An online forum for people affected by blood cancer

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Your feedback on this booklet can help us improve – please send any comments to **information@bloodcancer.org.uk**



**Blood
cancer
UK**

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