A practical guide to understanding cancer

UNDERSTANDING MYELOMA

About this booklet

This booklet is about a type of cancer called myeloma. This is also known as multiple myeloma. This booklet is for people who are having tests or investigations and for people who have been told they have myeloma. It also has information for family members, carers and friends.

We hope it answers your questions about diagnosis, treatment and living with myeloma, and helps you deal with some of the feelings you may have. We can't advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Or you can visit **macmillan.org.uk**

On pages 111–119 we have listed some other useful addresses and websites.

We've included quotes from people who have had myeloma, which you may find helpful. They are from people who have chosen to share her story with us, inlcuding Frances, who is on the cover of this booklet.

We also have an online community called The Source – visit **source.macmillan.org.uk** It has comments and advice from people who have been affected by cancer. It also has information for family and friends to help them know what to say or do when someone they care about has cancer.

How to use this booklet

To help you find the information you need, we have divided this booklet into sections. You can either read it from start to finish, or you can go straight to any section in the booklet and start reading from there. For example, if you are having tests, you may want to go straight to that section for the information you need.

It's fine to skip bits of the booklet. You can always come back to them when you feel ready. You may also like to make notes and think of questions to ask your doctor or nurse. You could use the space on pages 120–121 to do this.

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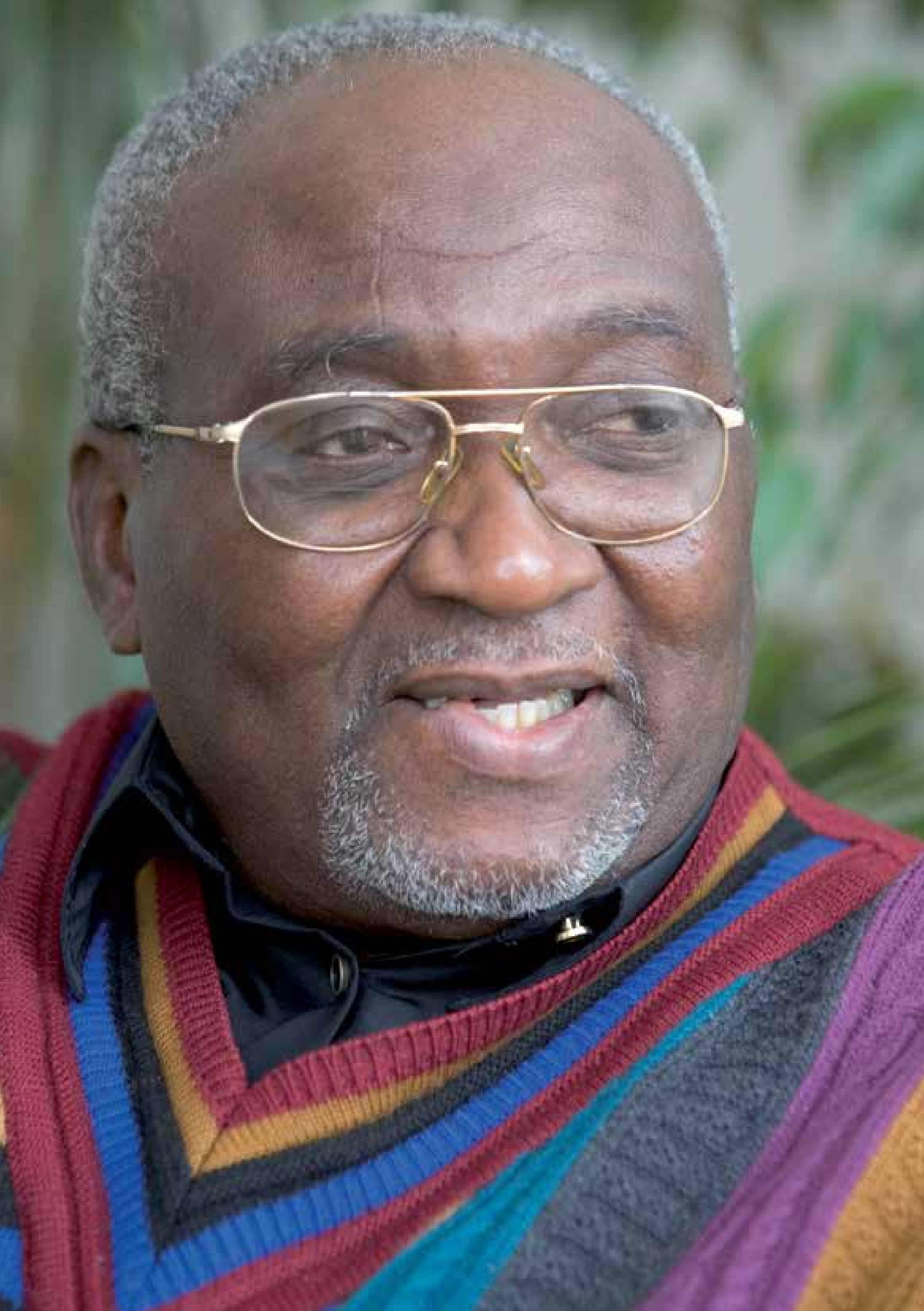


ABOUT MYELOMA

What is myeloma?

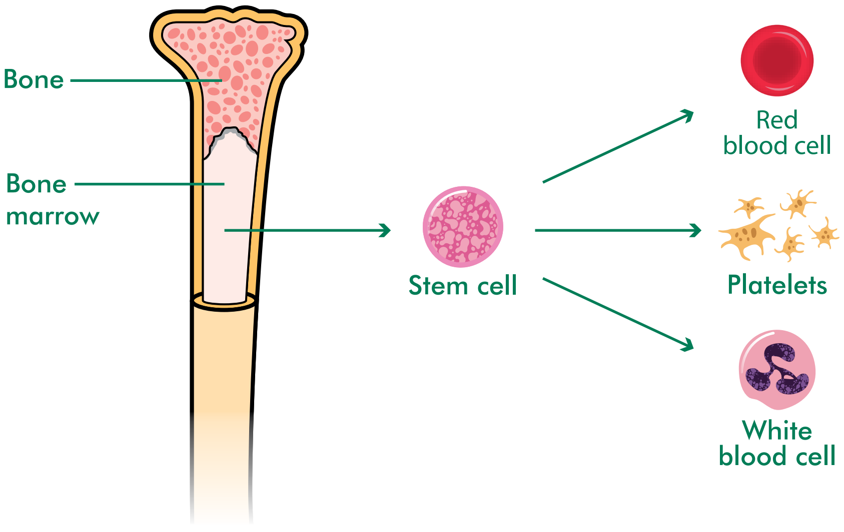
Myeloma is a cancer of plasma cells in the bone marrow. Bone marrow is a spongy material inside our bones. The main bones it's in are the hip bones, breastbone, arm bones, leg bones, ribs and spine. Bone marrow is part of the immune system, which protects us from infection and disease.

Bone marrow and stem cells

Bone marrow produces stem cells. These are immature cells that 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



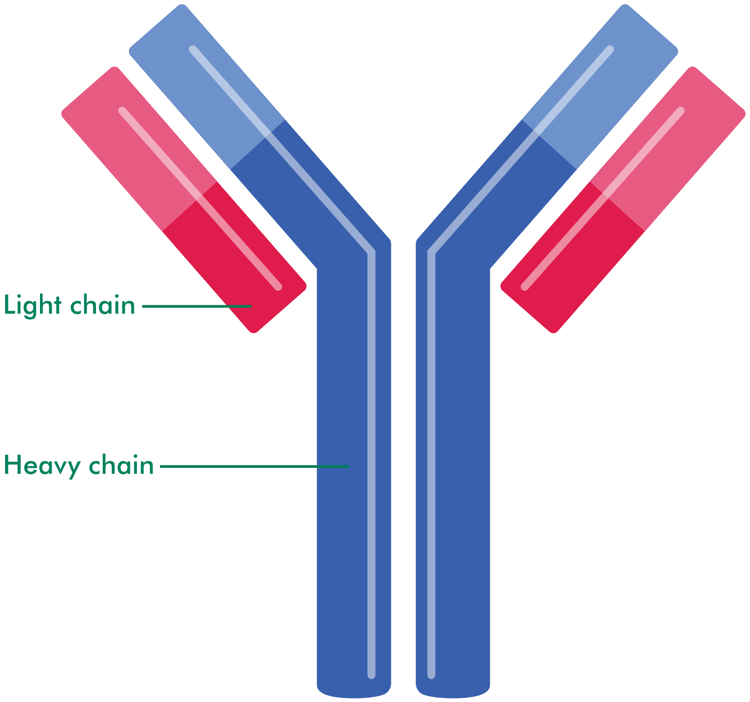
Plasma cells

Myeloma affects a type of white blood cell called plasma cells. Plasma cells make immunoglobulins, which are also known as antibodies. These immunoglobulins circulate in the blood and attack any viruses and bacteria in the body. If there is an infection, the bone marrow produces more plasma cells and immunoglobulins to attack whatever is causing the infection.

Immunoglobulins

The immunoglobulins produced by plasma cells are made up of proteins, which are linked together to make 'chains'. Some immunoglobulins are large protein chains, known as 'heavy' chains. Others are smaller chains, known as 'light' chains.

An immunoglobulin



There are five types of heavy chain. They are called IgG, IgA, IgD, IgE and IgM. The 'Ig' means immunoglobulin. There are two types of light chain. They are called kappa and lambda. Each immunoglobulin is made up of two heavy and two light chain proteins.

Plasma cells and immunoglobulins in myeloma

Normally, new plasma cells replace old, worn-out cells in a controlled way. But in people with myeloma, the process gets out of control and large numbers of abnormal plasma cells (myeloma cells) are produced. Myeloma cells can develop wherever there are plasma cells. They can spread throughout the bone marrow to several different parts of the body. This is why myeloma is sometimes called multiple myeloma.

The myeloma cells fill up the bone marrow and interfere with the production of normal white blood cells, red blood cells and platelets. They can also damage the bone and cause bone thinning, pain and sometimes fractures. An area of damaged bone is often called a lytic lesion.

Myeloma cells usually only produce one type of abnormal immunoglobulin. This is called a paraprotein or M protein. This immunoglobulin can't fight infection and it often reduces the number of normal immunoglobulins made.

Most of the problems related to myeloma are caused by:

- myeloma cells in the bone marrow
- a low number of normal blood cells
- immunoglobulins (paraproteins) or light chains in the blood and urine.

Types of myeloma

There are different types of myeloma. The type of myeloma you are diagnosed with doesn’t usually change the treatment you’re offered. But it can influence how the disease will affect you.

The most common type of myeloma is **IgG**, followed by **IgA**. The least common types are **IgM**, **IgD** and **IgE**.

Around 1 in 3 people with myeloma have a type of myeloma that produces too many light chains. This is called **light chain myeloma** or **Bence Jones myeloma**. These light chains can affect the kidneys and are often found in the urine.

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

Related plasma cell conditions

There are some other conditions that affect plasma cells, which are related to myeloma. These conditions can sometimes develop into myeloma. The two most common are **MGUS (monoclonal gammopathy of unknown significance)** and **smouldering myeloma**, which is sometimes called indolent or asymptomatic myeloma (without symptoms).

Your doctor may discover you have MGUS or smouldering myeloma through a routine blood test. If you’re diagnosed with either of these conditions, your doctor will monitor you. You may not need to have any treatment unless the condition progresses and becomes active or symptomatic myeloma.

We can send you more information about MGUS.

Sometimes abnormal plasma cells are found in a bone in only one area of the body. This condition is known as a **solitary plasmacytoma**. It is usually treated with radiotherapy. Some people with solitary plasmacytoma may go on to develop myeloma, so you'll be regularly monitored with blood tests.


Having a blood test

Risk factors and causes

Around 4,800 people in the UK are diagnosed with myeloma each year. It is slightly more common in men than women. Doctors don't 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 (see page 9). But not everyone who has MGUS goes on to develop myeloma.
- **Age** – The risk of myeloma increases with age. It's rare in people under 40 and is most commonly diagnosed after the age of 65.
- **Race** – Myeloma is twice as common in African-Caribbean people than white people.
- **Radiation** – People who have been exposed to high levels of radiation may have a higher risk. This includes people who work in the nuclear power industry.
- **Family history** – People who have a close family member with myeloma have a slightly increased risk of developing it.
- **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.
- **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 develop when the immune system attacks healthy body tissue by mistake. Some autoimmune disorders can slightly increase the risk of developing myeloma. These include pernicious anaemia, haemolytic anaemia and lupus.
- **Occupation** – It has been suggested that people in certain jobs have an increased risk of myeloma, possibly due to exposure to harmful substances. However, there is very little evidence to support this.

Like other cancers, myeloma isn't infectious and can't be passed on to other people.

> 'A routine blood test showed that I had MGUS, which I'd never heard of. My paraprotein levels were quite high and they thought it might be myeloma, which I'd never heard of either.'
>
> **Frances**

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.

Symptoms may be caused by:

- **bone damage**, which can cause pain, fractures, high calcium levels, pressure on the spine (spinal cord compression) or nerve problems
- **a reduced number of normal blood cells**, which may lead to anaemia, tiredness and infections
- **paraproteins in the blood or urine**, which can cause kidney problems, hyperviscosity or blood clots.

Other symptoms may include a poor appetite, or changes in bowel habits.

See pages 60–79 for more information about all these symptoms and how they are treated. There is also advice about what you can do to help manage the symptoms.

> ‘I was getting more tired than I’d like. And if I had an infection, it really knocked me out – I’d had a very good immune system up til then.’
>
> **Frances**

‘When my wife was diagnosed with multiple myeloma, the hospital arranged a Macmillan nurse to help us. She proved to be a source of help, inspiration, and giver of confidence. She was always there to help us both. She was a true friend.’

Bernard

DIAGNOSING MYELOMA

How myeloma is diagnosed

Myeloma can be diagnosed in different ways. Some people will first see a family doctor (GP) about symptoms such as pain, tiredness or infections. The GP will examine them and arrange for some blood tests or x-rays. The GP can then make a referral to a specialist at the hospital for more tests and treatment if necessary.

Other people are diagnosed with myeloma after being admitted to hospital with more severe symptoms such as spinal cord compression or kidney problems.

At the hospital

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

- blood tests
- urine tests
- a bone marrow biopsy
- x-rays of your bones.

Blood tests

Blood tests are an important way to diagnose and monitor myeloma. Tests on your blood will include:

- **Serum protein electrophoresis** – This measures the amount of abnormal antibodies (paraproteins) in the blood. It is the main blood test used to diagnose myeloma.
- **Full blood count** – This measures the levels of white blood cells, red blood cells and platelets in the blood. This test can show whether your bone marrow has been affected by myeloma.
- **Urea and electrolytes (U&E) test** – This gives information about how well your kidneys are working.
- **Calcium level** – This measures the level of calcium in the blood, as this can be raised in myeloma.
- **Beta-2 microglobulin level** – This measures the level of a protein produced by myeloma cells. It shows how active the myeloma is (see pages 30–31).
- **Albumin level** – This measures the level of albumin, which is a protein found in the blood. If this level is low, it can mean that a myeloma is advanced (see page 26).
- **Serum free light chain assays (Freelite®)** – This test can detect light chains in the blood. It is useful for diagnosing and monitoring light chain myeloma.
- **Erythrocyte sedimentation rate (ESR)** – This test shows if red blood cells (erythrocytes) are sticking together more than usual. Paraproteins can cause this, so the ESR level may be higher if you have myeloma.

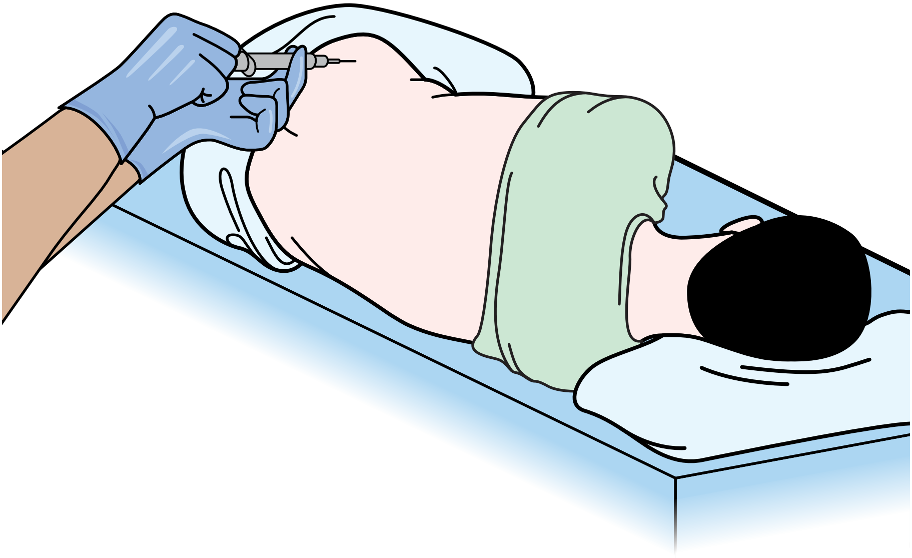
Urine tests

You may be asked to give urine samples to test for Bence Jones protein (see page 9). These tests can also show how well your kidneys are working. You may need to take a container home and collect your urine for 24 hours. The nurses will explain more about how to do this test.

Bone marrow biopsy

If there is a paraprotein in your blood or urine, a doctor or nurse will take a sample (biopsy) of bone marrow. The biopsy is usually taken from the back of your hipbone (pelvis), or sometimes the breast bone. The sample is sent to a laboratory to be checked under a microscope for abnormal cells.

Having a bone marrow biopsy



The procedure can be done on the ward or in the outpatients department and takes about 15–20 minutes. Removing the sample only takes a few minutes. Before the bone marrow sample is taken, you'll be given a local anaesthetic injection to numb the area. You may be offered a short-acting sedative to make you more comfortable during the test.

The doctor or nurse passes a needle through your skin into the bone. They then draw a small sample of liquid from the bone marrow (a bone marrow aspirate) into a syringe. It can be uncomfortable for a few seconds when the marrow is drawn into the syringe.

You may also have a small core of marrow taken (a trephine biopsy). This procedure takes a few minutes longer. The doctor or nurse passes a thicker needle through the skin into the bone marrow. When they take the needle out, it contains a small core of bone marrow.

You may feel bruised after having a sample of bone marrow taken, and have an ache for a few days. You can take mild painkillers to ease this.

Cytogenetics

Each cell in the body contains chromosomes, which are made up of genes. Genes control all the cell's activities. Some hospitals do tests on the bone marrow samples to look for chromosome changes. There may be changes in the chromosomes in the myeloma cells.

These tests are called cytogenetic tests. A test called fluorescence in situ hybridisation (FISH) may be used to look for any cytogenetic changes.

Knowing about these changes can help doctors to understand how the myeloma may behave and to plan treatment.

X-rays

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

Further tests

Your doctor may suggest you have further tests, which can give more information.

MRI (magnetic resonance imaging) 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's safe for you. The checklist asks about any metal implants you may have, for example a pacemaker, surgical clips, bone pins, etc. You should also tell your doctor if you've ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body it's likely that you won't be able to have an MRI scan. In this situation another type of scan can be used.

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

During the test you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

Having an MRI scan

CT (computerised tomography) 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

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 one of the organisations listed on pages 111–119 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

> ‘I was x-rayed and asked to return a week later. I was told on that visit that I had a tumour in my hip and I was to be referred to the orthopaedic hospital for a biopsy. I returned home three days after the bone biopsy and became so scared, as I had no idea what was going to happen next. I was informed that I had myeloma – something I had never heard of or knew anything about.’
>
> **Mandy**

Staging

Knowing the stage of the myeloma helps your doctors plan the best treatment for you. Generally, myeloma is divided into three stages. These show the effect the disease is having on your body and how quickly or slowly it may develop.

A commonly used staging system for myeloma is the International Staging System (ISS). The two main tests for ISS look at the levels of the blood proteins beta-2 microglobulin and albumin (see page 18). The ISS stages for myeloma are:

- **Stage 1** – This is **early-stage myeloma**. The beta-2 microglobulin level is less than 3.5mg/L and the albumin level is 3.5g/dL or higher.
- **Stage 2** – This is **intermediate-stage myeloma**. The beta-2 microglobulin level is between 3.5–5.5 mg/L (with any albumin level) OR the albumin is below 3.5g/dL and the beta-2 microglobulin is less than 3.5mg/L.
- **Stage 3** – This is **advanced myeloma**. The beta-2 microglobulin level is 5.5mg/L or more.

The doctors will 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 will also ask whether you have been having repeated infections or symptoms related to thickening of the blood (hyperviscocity – see page 76).

The results of these and other tests will allow the doctors to plan the best treatment for you.

TREATING MYELOMA

Treatment overview

Once the doctors know the stage of the myeloma (see page 26), they can plan the best treatment for you. Knowing the stage will also help your doctors predict how the myeloma might respond to treatment.

Myeloma is rarely curable, but it is treatable. Treatment can be used to stop the myeloma developing further, to control symptoms and to improve quality of life. The type of treatment you're offered will depend on a number of factors, including your general health and how advanced the myeloma is.

Myeloma without symptoms (smouldering myeloma)

If the myeloma is diagnosed at an early stage and is developing slowly, you may not need treatment straight away. Your doctor will see you every few months and take blood samples and do some other tests. This is called **active monitoring**. If the myeloma begins to get worse or you develop symptoms (symptomatic or active myeloma), your doctor will talk to you about starting treatment.

New research has shown that some people with smouldering myeloma are at higher risk of progressing to symptomatic myeloma in a short time. Your doctors will use tests and monitoring to spot early signs of this before CRAB symptoms develop (see page 27). Treatment can then be started earlier.

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 no myeloma cells can be detected in the blood or bone marrow, and normal bone marrow has developed again. The main treatments used to control the myeloma are:

- chemotherapy (see pages 42–47)
- targeted therapies (see pages 48–51)
- steroids (see pages 52–53)
- a combination of these (see pages 53–55).

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 followed by a stem cell transplant (see pages 56–57). This is sometimes called **consolidation therapy**.

Response to treatment

For most people, treatment will achieve a good response. However, the myeloma usually comes back. This is called **relapsed myeloma.** Doctors may then offer further treatment.

A complete remission isn't always possible for everyone treated for myeloma. But treatment can still reduce the myeloma in the body (a partial response), or stop it from developing further (stable disease). You will have tests and investigations during your treatment to check how well the myeloma is responding to treatment.

If the myeloma goes into remission, some people may have maintenance treatment to keep the myeloma under control (see page 58). This is usually only done as part of a clinical trial.

For a small group of people, treatment doesn't control the myeloma, or it stops controlling it. This is called **refractory myeloma**. If this happens, the doctors will talk to you about other treatments.

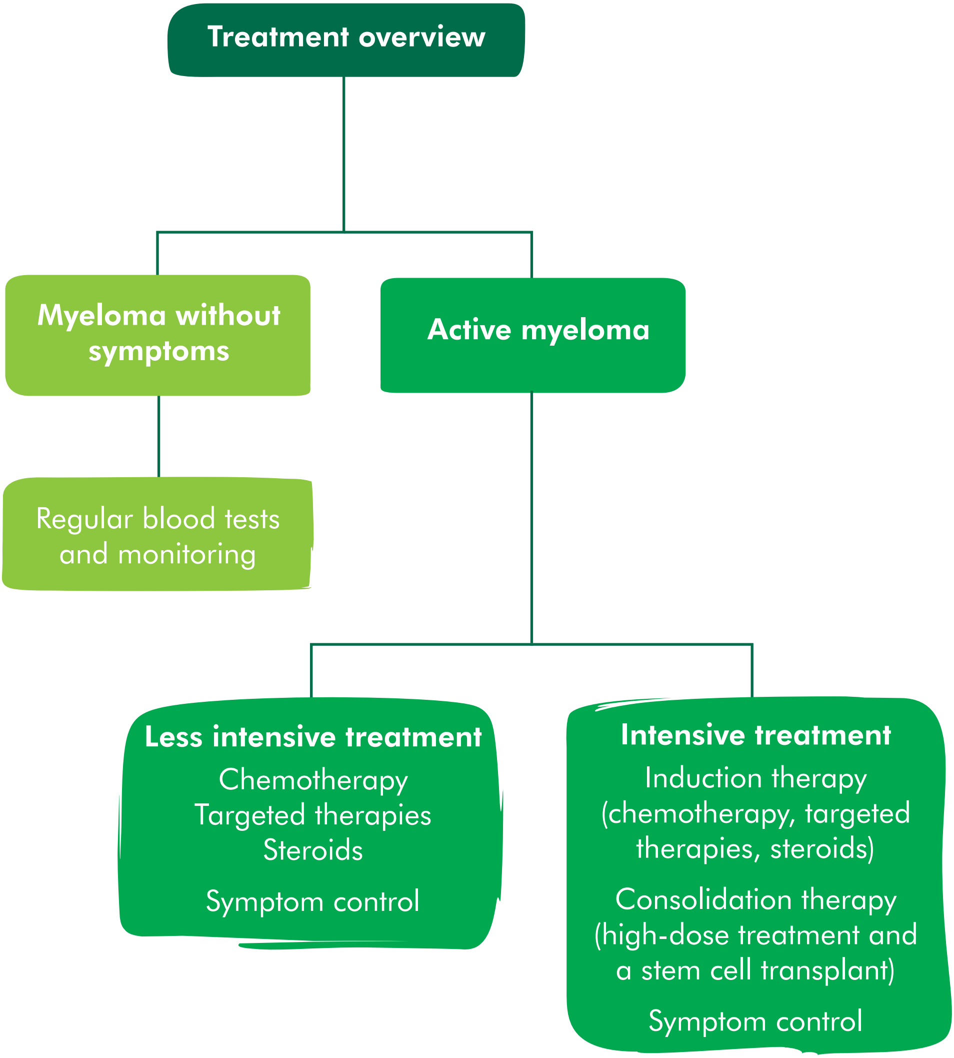
Symptom control

This is important for everyone diagnosed with myeloma. Symptoms can include bone pain and fractures, anaemia, high levels of calcium in the blood, kidney problems and more general symptoms such as tiredness. There is more information about controlling symptoms on pages 60–79.

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 39–41).

Treatment overview for myeloma



Planning your treatment

In most hospitals, a team of staff who specialise in treating myeloma will work together to plan the treatment they feel is best for you. They will then talk to you about the treatment options.

This multidisciplinary team (MDT) may include:

- a **haematologist** – a doctor who specialises in treating blood disorders
- a **clinical oncologist** – a doctor who is a chemotherapy and radiotherapy specialist
- a **specialist nurse** who gives information and support
- a **pathologist** – a specialist doctor who studies biopsies and tissue samples to see how disease affects the body
- a **radiologist** – a doctor who specialises in x-rays and scans
- a **palliative care doctor or nurse** who specialises in managing symptoms such as pain.

The team may also include doctors such as orthopaedic surgeons and renal doctors. It may also include other health professionals, such as a dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

> ‘From the beginning of my cancer journey, the staff at the hospital have been fantastic. From helping me to understand my diagnosis and treatment options, to the level of care I receive, I have always felt confident and positive at the prospect of being treated by the team.’
>
> **Lucy**

Treatment choices

If different treatments are available for the stage of myeloma you have, your doctors may offer you a choice. If you have to decide 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 you decide what is right for you.

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, and 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 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

Many people are frightened by the idea of having cancer treatments, particularly because of the side effects that can occur. However, these can usually be controlled with medicines. Treatment can be given for different reasons, and the benefits and side effects will depend on your individual situation.

For people with early-stage myeloma who are fit enough for intensive treatment, long-term control of the disease is often possible. For people with more advanced disease for whom intensive treatment isn't suitable, other treatment can be given to control the myeloma. This should reduce symptoms and allow a better quality of life.

Some treatments for myeloma have more side effects and risks than others. For some people, treatment will help to control the myeloma and the side effects of the treatment will be mild. However, for others, treatment will have no effect on the cancer and they'll get the side effects with little benefit.

Treatment decisions

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 (palliative) care to help with symptoms.

We have a booklet called **Making treatment decisions**, which you may find helpful.

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 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, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

There's a video at **macmillan.org.uk/secondopinion** of a GP explaining how to get a second opinion. We also have more information about getting a second opinion. Call us on **0808 808 00 00**.

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, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, to make them more effective or to reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy or other 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.

Blood and tumour samples

Blood and bone marrow or 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 are taking part in a trial, you may also be asked to give other samples, which may be frozen and stored for future use when new research techniques become available. These samples will have your name removed from them 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. But the samples will be used to increase knowledge about the causes of cancer and its treatment. This research will hopefully improve the outlook for future patients.

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail. We can send you a free copy.

Current research

A number of research trials are looking at the use of different targeted therapies, and how high-dose treatment with stem cell support is used. Your cancer specialist will be able to tell you more about these and other trials.

Our website has links to clinical trials databases. Visit **macmillan.org.uk/clinicaltrials**

Treatment for active myeloma

The treatments to control myeloma and get it into remission are chemotherapy, targeted therapies, steroids and high-dose treatment with stem cell support.

Usually a combination of treatments is used.

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs. Chemotherapy drugs stop cancer cells dividing and reproducing. 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 a few days, followed by a rest period of a few weeks. The treatment and the rest period make up a **cycle** of treatment. Usually between 4–6 cycles will make up a complete course of treatment.

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

During the course of treatment, you will 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 (Alkeran®)
- cyclophosphamide
- doxorubicin
- idarubicin (Zavedos®)
- bendamustine (Levact®).

Some chemotherapy drugs for myeloma are given by injection into a vein (intravenously) – see pages 54–55. Others are taken as tablets or capsules (orally). When these drugs are given as tablets, they can have fewer side effects. This makes them more suitable for people who aren't able to have intensive treatments.

We have more information about individual chemotherapy drugs. We also have a booklet called **Understanding chemotherapy** with more details.

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.

Risk of infection

Chemotherapy drugs 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 (called neutropenia), you're more likely to get an infection.

Your resistance to infection is usually at its lowest 7–14 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 infection and show you how to check your temperature.

Always contact the hospital on the 24-hour contact numbers you've been given and speak to a nurse or doctor if:

- your temperature goes over 37.5°C (99.5°F) or over 38°C (100.4°F), depending on the advice given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you have any symptoms of an infection, such as a cold, sore throat, cough, passing urine frequently (urine infection), diarrhoea or feeling shivery and shaking.

You'll 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.

We have more information about avoiding infection when your immunity is 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.

We have more information about G-CSF.

Anaemia (low level 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.

We talk about treatments for anaemia on page 74.

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.

Feeling sick

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe 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.

We have more information about nausea and vomiting.

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.

We have more information about mouth care. There is also a video about mouth care during chemotherapy at **macmillan.org.uk/mouthcare**

Your hair

Your doctor or specialist nurse will tell you if the chemotherapy is likely to cause hair loss. Knowing what to expect gives you time to prepare and find ways of coping.

Some drugs don't make your hair fall out, but can make it thinner. You might notice your hair becomes dry and brittle and breaks easily. Looking after the condition of your hair can make it less likely to break off. If your hair falls out, it usually grows back within three months after treatment.

We have a booklet called **Coping with hair loss**, which you might find useful.

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 – even going for short walks will help increase your energy levels.

We have a booklet called **Coping with fatigue**, which has more helpful tips. We also have a video at **macmillan.org.uk/fatigue**

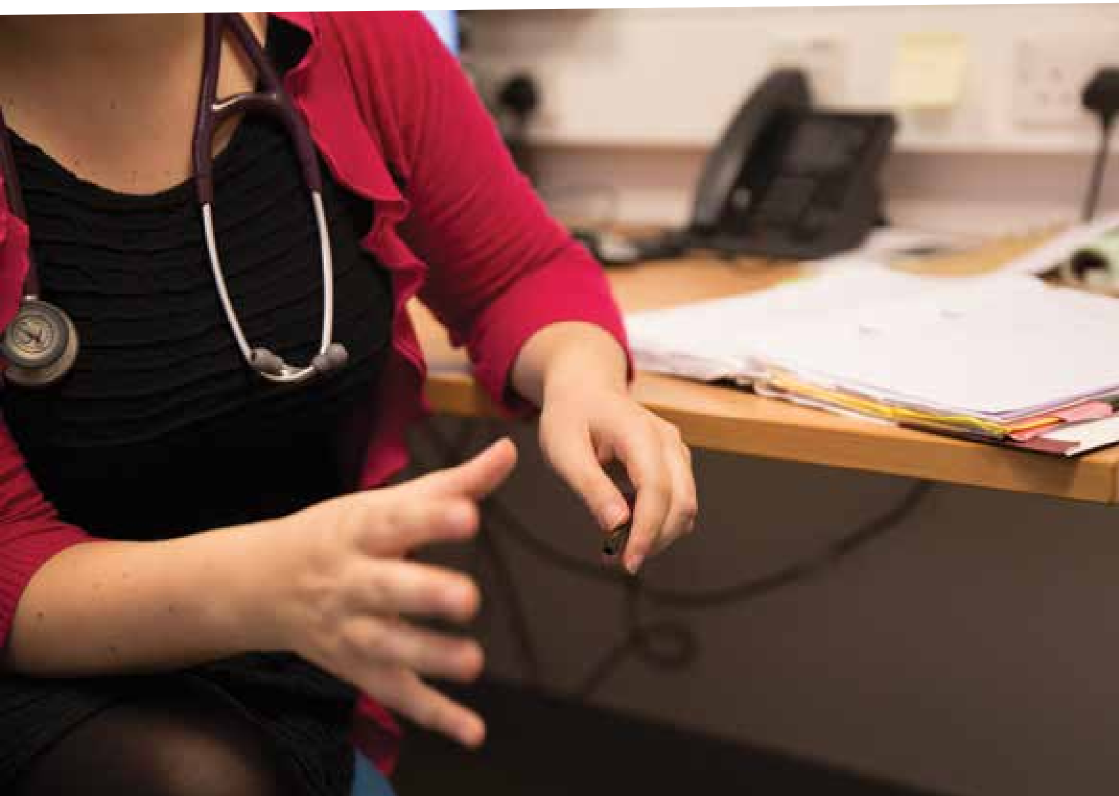
Increased risk of blood clots

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 and swelling in a leg
- breathlessness and chest pain.

Blood clots can be very serious, so it's 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.

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



Targeted therapies (biological therapies)

Targeted therapies are treatments that work by targeting proteins that are found either on the surface of cancer cells or inside the cells. Targeted therapies that are used for myeloma are thalidomide, bortezomib and lenalidomide.

Thalidomide

Thalidomide can be used to treat newly diagnosed myeloma, or to help control myeloma that has come back (relapsed). It can be given in combination with chemotherapy drugs and steroids. Thalidomide is taken daily as a tablet, usually in the evening.

It is thought that thalidomide works in a few different ways. These include affecting the body’s immune system and stopping cancer cells from developing new blood vessels. This reduces the cancer cell’s supply of oxygen and nutrients.

Side effects can include constipation, drowsiness and an increased risk of developing blood clots in the veins in the legs, called deep vein thrombosis (DVT) – see page 76.

Sometimes thalidomide can damage nerves, which can cause tingling in your hands and feet. This is called peripheral neuropathy. You may notice that you have difficulty fastening buttons or doing similar fiddly tasks. Your hands and feet may also become more sensitive to the cold. If you notice any of these side effects, tell your doctor. The side effects usually disappear slowly after treatment ends, although it can sometimes take months.

Thalidomide can cause birth defects in developing babies. Both men and women taking thalidomide can pass on this risk. You will take part in a **pregnancy prevention programme** while taking thalidomide. Your doctor will give you information about not becoming pregnant or fathering a child during and after treatment with thalidomide.

Women of childbearing age will have a pregnancy test before starting treatment with thalidomide. They will also have one every four weeks during treatment, and four weeks after treatment finishes.

Your doctor and nurse will help you manage any side effects of thalidomide, but sometimes the side effects outweigh the benefits. The dose of thalidomide may need to be reduced or may occasionally need to be stopped.

We can send you more information about thalidomide.

Bortezomib (Velcade®)

Some people may have bortezomib as a first treatment for myeloma, or if myeloma comes back. Your doctors may also give it in some situations as treatment to prepare you for a transplant.

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.

It is usually given as an injection under the skin (subcutaneously), but it may be given into a vein (intravenously). You may also have treatment with steroids or chemotherapy.

Side effects of bortezomib include:

- tiredness
- nausea
- diarrhoea
- dizziness
- numbness or tingling in the hands and feet (peripheral neuropathy)
- a low number of platelets, which means you bruise or bleed more easily.

We can send you more information about bortezomib.

Lenalidomide (Revlimid®)

Lenalidomide is used when myeloma comes back after other treatment. Sometimes lenalidomide is offered as part of a trial.

It belongs to a group of drugs called immunomodulatory drugs, which affect 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 a capsule that you take once a day for three weeks, followed by one week off. You may continue with this treatment for as long as the myeloma is under control. If you are having side effects, sometimes your doctor may adjust the dose.

Side effects of lenalidomide include:

- a low number of white and red blood cells and platelets
- diarrhoea
- constipation
- skin rashes
- sleepiness.

If you take lenalidomide with steroids, there is an increased risk of blood clots in your legs. You may be given blood-thinning medicines to reduce this risk.

We can send you more information about lenalidomide.

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 are prednisolone and dexamethasone.

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

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:

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

It's 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 and a slightly greater risk of getting infections.

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

We can send you more information about steroids.

Having combined treatments

Chemotherapy (see pages 42–47) is often combined with targeted therapies (see pages 48–51) and steroids (see opposite). Drug combinations that are used include:

- cyclophosphamide, thalidomide and dexamethasone (CTD)
- melphalan, prednisolone and thalidomide (MPT)
- cyclophosphamide, bortezomib (Velcade®) and dexamethasone (CVD)
- melphalan, bortezomib and prednisolone (MPV)
- bortezomib (Velcade®), thalidomide and dexamethasone (VTD).

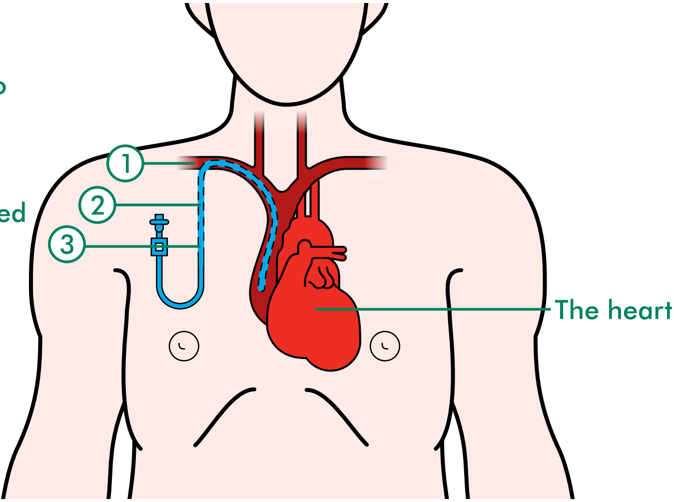
For more information about these combination regimens, call our cancer support specialists on **0808 808 00 00**.

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

If you're 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 the crook of your arm (PICC line). Sometimes an implantable port is used. This is a thin, soft plastic tube that's 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're at home.

A central line

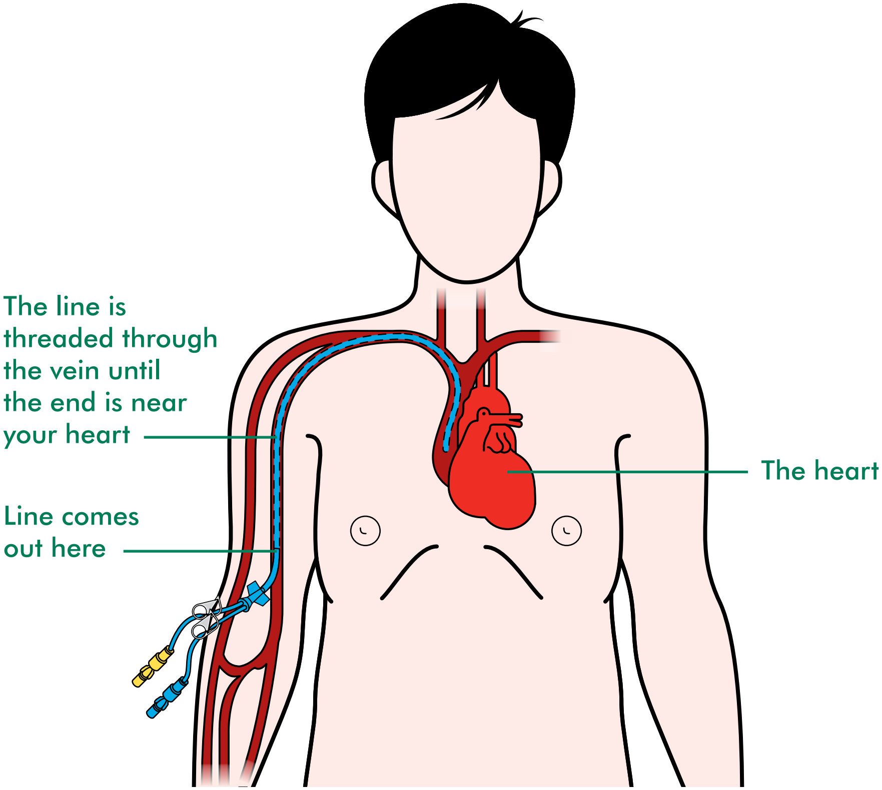


① Central line inserted into chest here

② Line tunnelled under skin

③ Line comes out here

A PICC line



We have more information about central lines, PICC lines and implantable ports. We also have animations on our website explaining how they are put in.

High-dose treatment with stem cell support (transplant)

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

You may hear people call this treatment an **autologous stem cell transplant**. In myeloma, it's more common to use your own stem cells (autologous transplant) than stem cells from a donor (allogeneic transplant). Stem cells are early blood cells (see page 6).

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 specialist hospital units. You will usually stay in hospital for a few weeks.

> 'I met caring professionals who couldn't do enough for me or my family. I got to a stage where I was able to have a stem cell transplant last year, for which I am very grateful.'
>
> **Mandy**

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). Once you are in remission, your stem cells can be collected and stored to be given back to you after treatment. The stem cells are mainly collected (harvested) from the blood, but they can also be collected from the bone marrow.

You will then have high-dose treatment with chemotherapy and sometimes radiotherapy. You will 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 will be given a drip (infusion) of your stem cells afterwards. The stem cells go to the bone marrow, where they start producing new blood cells.

Other treatments with stem cells are being used or researched in some hospitals. These include:

- allogeneic transplants using donor stem cells
- mini-transplants, which involve less intense chemotherapy
- having a second transplant if myeloma comes back.

We can send you our booklet **Understanding high-dose treatment with stem cell support** or **Understanding donor stem cell (allogeneic) transplants**. These explain the treatments in more detail.

Maintenance treatment

Once myeloma is in remission, you may be offered maintenance treatment as part of a clinical trial to try to keep it under control for as long as possible. Your doctor will talk to you about this. Trials are taking place to find out whether thalidomide, bortezomib and lenalidomide help keep myeloma in remission.

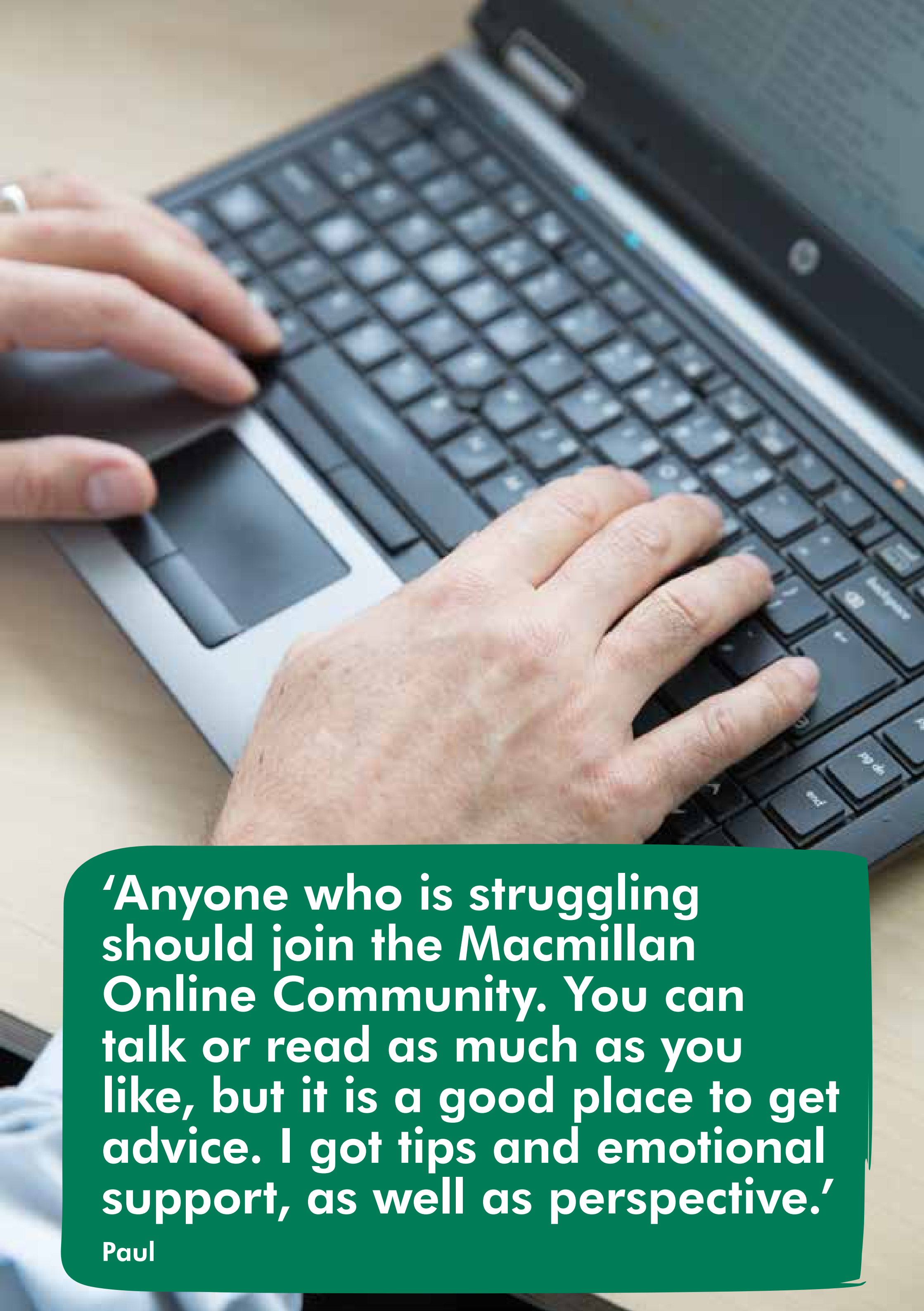
You may find our Online Community helpful while you're having treatment for myeloma. Visit **macmillan.org.uk/community** at any time to chat to people who know what you're going through. You can also give support to others.

Treatment if myeloma comes back

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 will depend 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 bortezomib, lenalidomide and thalidomide. These drugs are usually given with steroids.

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



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

Paul

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. These problems may be:

- bone damage and pain
- pressure on the spinal cord
- high calcium levels
- tiredness
- anaemia and infection
- kidney problems
- hyperviscosity
- blood clots
- eating problems
- effects on the nerves (peripheral neuropathy).

We talk about these problems in this section and give advice about what to look out for. We also talk about what you, your GP and your cancer team can do to manage the symptoms.

Bone damage and pain

The most common symptom of myeloma is bone pain. About 7 in 10 people (70%) have lower back or rib pain. Other bones may be affected too, such as the skull or pelvis.

Myeloma cells speed up the destruction of bone cells and slow down the production of new cells to replace them. This causes areas of bone to get weaker and sometimes fracture (break). It's important to tell your doctors and nurses about any pain this causes so they can treat it.

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

Your doctor or nurse will start with an assessment of your pain. You will have assessments throughout your treatment to make sure your pain is being controlled.

They will then talk to you about treatments such as:

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

We describe these treatments over the next few pages. Your palliative care team may also talk to you about other therapies.

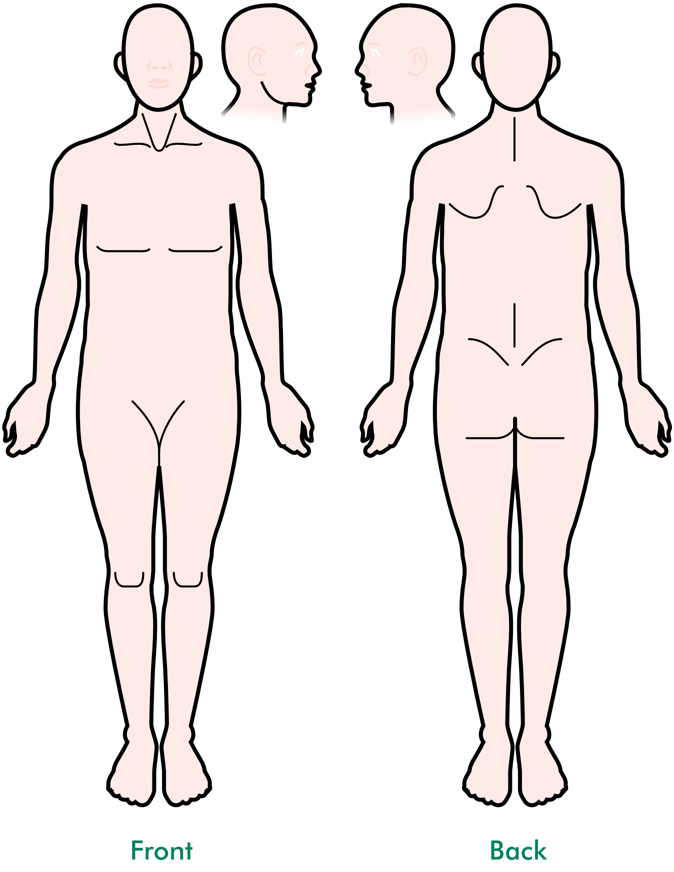
Pain assessment

Your doctor or nurse will try to find the best treatment to manage your pain. Give them as much information as you can to help them to assess your pain and plan treatment. We have included a pain diary on pages 64–65 to help. You can photocopy it to use again.

You may want to think about the following questions.

Where is the pain?

Is the pain in one part of your body, or in more than one place? You can use diagrams like the one below to mark where your pain is. If you have more than one pain, label them 1, 2, 3, and so on (with 1 being the pain that upsets you most).

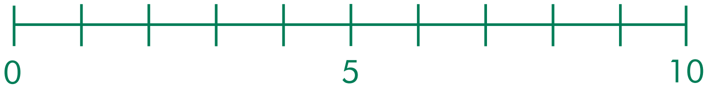


What is the pain like?

You might use different words to describe your pain, such as: aching, tender, sharp, hot, burning, nagging, intense, stabbing, tingling, dull, throbbing.

How bad is the pain?

If you measured your pain on a scale of 0–10, what number would you rate it? (0 means no pain and 10 means the worst pain you have ever had.)



When are you in pain?

Are you in pain all the time? Or does it come and go? Does it get better or worse when you sit still? What happens when you move? Is it better or worse at night?

Does anything make the pain better or worse?

Do you feel better or worse when you're standing, sitting or lying down? Does a heat pad or ice pack help? Do the painkillers stop the pain or just reduce it, and for how long?

How does the pain affect your daily life?

Does it stop you moving around? Does it stop you sitting for very long? Does the pain stop you concentrating or affect your sleep?

Keeping a pain diary

It can help to keep a record of your pain (see the next pages). Write down how bad it is at different times of day and note anything that makes it better or worse. This information can help you talk about your pain with your doctor or nurses. Photocopy the diary before you fill it in so you can use it as often as you need to. If you have pain in more than one place, you may wish to use an extra copy of the diary.

Date ___/___/___

Time	Where is the pain?	What is the pain like?	Level of pain (0=none, 10=severe)
1am			
2am			
3am			
4am			
5am			
6am			
7am			
8am			
9am			
10am			
11am			
12pm (noon)			
1pm			
2pm			
3pm			
4pm			
5pm			
6pm			
7pm			
8pm			
9pm			
10pm			
11pm			
12am (midnight)			

Medicines/pain control used?	What makes the pain better?	What makes the pain worse?

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 strengthen weakened bones and reduce pain. They can also reduce the amount of excess calcium in the blood (hypercalcaemia – see page 71). As bisphosphonates can help delay bone damage, you may start treatment before you have any bone problems.

Research has shown that some bisphosphonates may also help treat myeloma. As part of your treatment, you may be invited to enter a clinical trial.

The bisphosphonates that are most often used in myeloma are zoledronic acid (Zometa®), pamidronate (Aredia®) and sodium clodronate (Bonefos®, Clasteon®, Loron®).

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

Generally, side effects are mild. They include indigestion and feeling sick. A very rare side effect of bisphosphonates is osteonecrosis of the jaw. This leads to damage and decay of the jaw bone. You will be advised to see a dentist before starting treatment. Let your dentist know you will be taking bisphosphonates. If you need any dental treatment while having this treatment, tell your doctor.

We have more information about different bisphosphonates.

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 relieve pain in bones and also allow the bones to repair themselves. You may only need one or two treatments.

Radiotherapy may also be given if you develop spinal cord compression (see page 70). 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're 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. Normally, treatment is given daily Monday–Friday for 2–4 weeks, with a rest at the weekends. If you only need one or two treatments, you may not need such a detailed planning appointment.

Radiotherapy for myeloma can cause side effects. These can easily be treated – just let your doctor or nurse know. Any 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.

Our booklet **Understanding radiotherapy** has detailed information about this treatment and its side effects.

Surgery

Surgery is sometimes needed to repair bones that have been damaged or weakened by myeloma. The surgeon can strengthen the damaged bone with a metal pin or plate. Once these are in place, they can't be felt or seen. You may also need radiotherapy to the area to destroy the myeloma cells and help the bone heal.

If 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 and bed rest and 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 one or two balloons, called inflatable bone tamps, between the vertebrae and then slowly inflates them. Once the bones return to their normal position, bone cement is injected (as in a vertebroplasty). This improves the strength of the spine, which can relieve pain and help you move around more easily.

These operations will 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 may be suitable for you, your doctor or specialist nurse will explain more about them. They will usually try other ways of controlling your pain first.

Other treatments

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.

We have more information about these and other treatments in our booklet **Controlling cancer pain.**

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. This can cause pain, muscle weakness, and sometimes tingling and numbness of the limbs. If the lower spine is affected, it may also affect how the bowel and bladder work.

If you have any of these symptoms, it's 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.

We can send you more information about spinal cord compression.

High calcium levels (hypercalcaemia)

Damage to the bones from myeloma can cause calcium to be released from the bones into the blood. High levels of calcium in the blood (hypercalcaemia) can make you feel sick, thirsty, drowsy, confused and unwell. It can also cause constipation. For some people, hypercalcaemia is discovered by a blood test before any symptoms develop.

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 in your arm, or into your central line or PICC line if you have one (see pages 54–55). This will increase the amount of liquid/fluid in your blood and help your kidneys get rid of the calcium from your body in your urine.

Your doctor may also give you a bisphosphonate drug (see pages 66–67) to quickly reduce the level of calcium. The drug is given into a vein over a few hours. It brings the calcium level down over the next 2–3 days. If your calcium level starts to rise again, you may need another dose.

‘I don’t have the energy I used to have, and take a sleep during the day. But I’m not in pain and I don’t have sickness. I can manage the treatment side effects. And we get out and about – we’re planning a short trip to Germany. The cancer does keep trying to get in the way, but I keep it down.’

Frances

Tiredness

Many people with myeloma feel tired and have less energy to do the things they normally do. This may be due to anaemia (see page 74), or it may be a side effect of treatment. Your body will tell you when you need to rest, although it's important you don't completely stop doing things.

When you do feel like doing things, try to pace yourself. Start by setting yourself goals – maybe cooking a light meal or going for a short walk. Keeping a treatment diary of when you're most tired can help you record your energy levels and plan activities for when you're likely to feel stronger.

Our booklet **Coping with fatigue** has tips to help you cope with tiredness and a fatigue diary you can fill in. And you may want to watch the video at **macmillan.org.uk/fatigue** to hear how fatigue affected Denton and how he managed it.

Anaemia and infection

Anaemia is a low number of red blood cells. It is a common symptom of myeloma. It can make you feel tired and breathless. Myeloma can reduce the number of red blood cells made in the bone marrow. Or sometimes anaemia can be a side effect of treatment.

Your doctor may suggest that you have a blood transfusion. The blood will be given into a vein in your arm or through your central line or PICC line if you have one (see pages 54–55). If you have kidney problems (see opposite), your doctor may suggest you have a drug called erythropoietin (EPO) instead of a blood transfusion. Erythropoietin is normally given by an injection under the skin (subcutaneously).

Myeloma and some treatments can also affect the number of white blood cells in your blood. These are the cells that fight infection. Your doctor or nurse will talk to you about infection and show you how to check your temperature. Your doctor may prescribe you drugs to help prevent an infection (prophylactic drugs). They may also advise you to have vaccines such as the flu vaccine.

We can send you more information about blood transfusions, erythropoietin and avoiding infection.

Kidney problems

The paraprotein and light chains produced in myeloma can block the tubes in the kidneys and stop them filtering waste products from your blood properly. A build-up of calcium in the bloodstream from damaged bones can also cause kidney problems.

If your kidneys are affected, you will have extra fluids through a drip (infusion). This encourages your body to flush the waste products out of your kidneys in your urine. You can help prevent kidney problems by drinking plenty of fluids each day – three litres (five pints) or more if you can. You should check with your doctor or nurse before taking drugs called non-steroidal anti-inflammatory drugs (such as ibuprofen), as these can cause kidney problems.

Treatment for myeloma will usually reduce the amount of paraprotein in the blood and help with kidney problems.

Rarely, 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 no urine is produced. Excess fluid then begins to build up in the body. If this happens, you will need to have your blood artificially filtered, which is called kidney dialysis.

You can contact our cancer support specialists on **0808 808 00 00** to talk about dialysis.

> ‘I’m determined that my husband and I have a life outside dialysis, so we like to do things at weekends.’
>
> **Alessandra**

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. It can cause symptoms such as headaches, confusion, dizziness, blurred vision and abnormal bleeding. You may need plasma exchange (plasmapheresis). This is a procedure that removes the excess paraproteins from the blood.

We have more information about plasma exchange.

Blood clots

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

- pain, redness and swelling in a leg
- breathlessness and chest pain.

Blood clots can be very serious, so it's important to tell your doctor straight away if you have any of these symptoms. Most clots can be successfully treated with drugs to thin the blood.

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

Eating problems

Myeloma and some myeloma treatments can cause problems with sickness and loss of appetite.

Drugs such as painkillers and antibiotics can make you feel sick. Physical problems like constipation or high calcium levels can also make you feel sick. 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.

We can send you more information and tips on what you can do to control sickness and vomiting.

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

It's important to try to eat well during your treatment. If you're 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.

Our booklets **Eating problems and cancer** and **The building-up diet** have more information. There is also a slide show about dealing with a poor appetite at **macmillan.org.uk/poorappetite**

Effects on the nerves (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.

It's important to let your doctor or nurse know if this happens. If it is caused by your treatment, it may need to be changed. Usually peripheral neuropathy gets better when treatment is over, but it can sometimes be permanent.

We can send you more information about peripheral neuropathy.

LIVING WITH MYELOMA

Follow-up

You will usually have regular appointments at the outpatient clinic at the hospital during your treatment and during 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 find they get very anxious before appointments. This is natural and it may help to get support from family, friends or one of the organisations on pages 111–119 during this time.

Throughout your treatment, you will usually have regular talks with someone from your cancer team. This may be your specialist doctor or nurse, or another health 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 produce a treatment summary that describes:

- the treatment you've had
- what you should expect
- details of the follow-up or tests you'll have.

You keep a copy and the hospital should send a copy to your GP.

These assessments, care plans and treatment summaries aren't used everywhere, but more hospitals are starting to use them.

For people whose treatment is over apart from regular check-ups or symptom control, our booklet **Life after cancer treatment** has useful 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 you can't do all the things you once took for granted. If you've 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 people are available to help.

Physiotherapists in the hospital or the community can teach you muscle-strengthening exercises. If necessary, 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 assess how well you will manage your normal activities. They will 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'd like to talk to a social worker, ask your doctor or nurse to arrange this.

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 problems, or if there's been a breakdown in communication 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're 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 a visit by a palliative care nurse.

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 emotionally very difficult to cope. There was just so much going through my mind – in particular, "Why is this happening to us?" and, "Why me?". Talking to the Macmillan nurse has helped me greatly in dealing with it.'
>
> **Alessandra**

Practical support

If myeloma means that you can't move around easily, you may need specialist equipment or people to help you in your daily life.

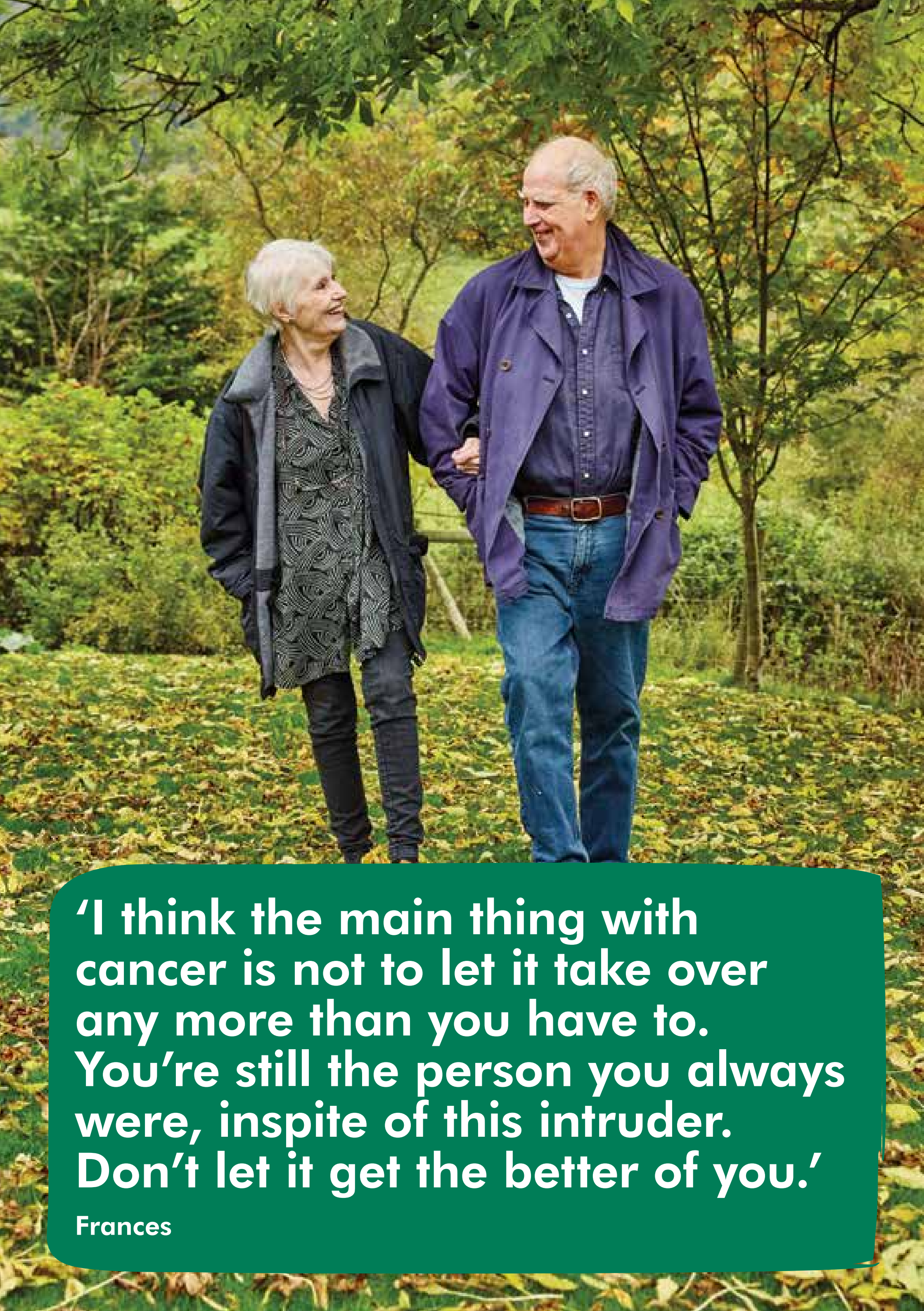
The **British Red Cross** (see page 112) has an office in every county. It has volunteers who can help you in many ways. This may be help with shopping, posting letters or changing library books. Volunteers may be able to take you to an appointment at the hospital. The British Red Cross can also lend equipment like wheelchairs and commodes (portable toilets).

The **Disabled Living Foundation** runs an information service (see page 112). 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 (see page 113).

If you have mobility (movement) problems, you may find the **Blue Badge scheme** useful (see page 111). It provides parking concessions (allowances) 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.

Some areas have **good neighbour schemes**. The schemes organise help for people in the local area. This could be help with shopping, befriending or offering transport. 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.


UK
12
3



‘I think the main thing with cancer is not to let it take over any more than you have to. You’re still the person you always were, inspite of this intruder. Don’t let it get the better of you.’

Frances

YOUR FEELINGS AND RELATIONSHIPS

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 healthier diet, getting fitter or finding a relaxing complementary therapy. Your cancer team and GP can give you advice on this. Ask whether there are any health and well-being clinics in your area. These clinics are run by volunteers and Macmillan professionals. They can give you support and advice on diet, lifestyle and adjusting to life after treatment.

Understanding more 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 wanted to maintain my fitness during my treatment. My exercise regime was very simple, but it helped me tremendously. I went for short walks and gradually built up. At times I had to drag myself out, but I always felt better once I got moving. It made me feel like I had some control over my life again.’
>
> **Brian**

Your feelings

When you are living with myeloma, you may have different and complicated feelings. Many of these will change over time.

Feeling alone

You might feel alone if you're no longer routinely seeing the people in your cancer team. If there's something worrying you, you can get in touch with your key contact at the hospital or talk to your GP anytime.

There are lots of different ways you can get support. Support groups or online social networks mean you can talk to people who have been through a similar experience – see page 94. You can also talk to one of our cancer support specialists on freephone **0808 808 00 00**.

Uncertainty

Uncertainty about your future and worrying about how the myeloma will affect you is often the hardest thing to cope with. This may get easier as you gradually focus on other things in life besides the myeloma. Getting on with the things you can control may help. You can organise your own day, do things you enjoy, get involved in your own care and make the most of your health. Finding ways to help you relax can help, such as relaxation therapy or meditation.

Anger

It's normal to feel angry about cancer and the effects of treatment. Try to talk to people about how you feel. It may help to explain that you're angry at the illness and not at them. Finding ways to help you relax and reduce stress can also help. This can include talking about or writing down how you feel, doing regular exercise, or breathing or relaxation therapy. If you're finding it hard to talk to anyone, or if you can't stop feeling angry, you could ask your doctor or nurse about speaking to a counsellor.

Sadness or depression

Usually feelings of sadness, anxiety or anger get better over time. If they don't get better, you probably need more support.

Some signs of depression are:

- feeling sad or hopeless most of the time
- having no interest or enjoyment in things you normally enjoy
- feeling numb, overwhelmed or out of control
- constantly focusing on worries or finding it difficult to concentrate
- symptoms like a dry mouth or a racing heart (palpitations).

If you think you may be depressed, talk to your family and friends and tell your doctor or nurse. They can refer you to a counsellor or psychologist and prescribe anti-depressant or anti-anxiety drugs.

You can read more about feelings in our booklet **How are you feeling? The emotional effects of cancer.**

Share your experience

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

This can be helpful for other people with myeloma, who might be about to start their treatment. Just 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 can help you share your story. Call us on **0808 808 00 00** or visit **macmillan.org.uk/cancervoices** for more information.

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 don't feel able to talk about your feelings with people around you.

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

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

Talking to children

Deciding what to tell children 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, such as 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.

Our booklet **Talking to children when an adult has cancer** includes discussion about sensitive topics. There's also a video on our website that may help, at **macmillan.org.uk/talkingtochildren**

If you are a relative or 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're 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.

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** to find out more.

Our booklet **Lost for words – how to talk to someone with cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet **Hello, and how are you?** helpful. It's 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**

We have a website called The Source, which has comments and advice from people who have had cancer or been affected in some way. Visit **source.macmillan.org.uk** You can find valuable information to help you know what to say or do when someone you care about has cancer. You can also share your own tips.

> ‘It’s very good to know you have friends. Sometimes I think they feel that they don’t know if they’re saying or doing the right thing. But they don’t really have to. Just being there and friendly is enough.’
>
> **Frances**

> ‘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**

WORK AND FINANCIAL SUPPORT

Financial help and benefits

If you're struggling to cope with the financial effects of cancer, help is available.

The benefits system can be complicated, so it's a good idea to talk to an experienced benefits adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just outlined some benefits here, but there may be others available to you.

If you're an employee and unable to work because of illness, you may be able to get Statutory Sick Pay. This is paid by your employer for up to 28 weeks of sickness, and if you qualify for it, your employer can't pay you less.

Before your Statutory Sick Pay ends, check whether you can claim Employment and Support Allowance. This benefit gives financial help to people who are unable to work due to illness or disability. It also provides some support to those who can work.

Disability Living Allowance (DLA) is for people under 65 who have difficulty walking or looking after themselves (or both). You need to have had these difficulties for at least three months to qualify, and they should be expected to last for the next six months. As part of the Welfare Reform Act 2012, DLA will be replaced by a Personal Independence Payment for people of working age from April 2013.

Attendance Allowance is for people aged 65 or over who have difficulty looking after themselves. You may qualify if you need help with personal care, such as getting out of bed, having a bath or dressing yourself. You don't need to have a carer to be eligible, but you must have needed care for at least six months.

If you're terminally ill, you can apply for DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you'll receive the benefit you applied for at the highest rate.

> 'I spoke to Macmillan and they helped point me in the direction of things I could get. They were very helpful with information and they helped me with the paperwork.'
>
> **Paul**

Help for carers

If you are a carer, you may be entitled to financial help as well. This may include Carer's Allowance, which is the main state benefit for carers, and Carer's Credit, which helps carers build up qualifying years for State Pension.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 118) or Citizens Advice (see page 118). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

See our booklet **Help with the cost of cancer** for more detailed information. Our video at **macmillan.org.uk/gettingfinancialhelp** may also be useful.

Insurance

After having cancer treatment, it can be more difficult to get certain types of insurance, including life and travel insurance. An independent financial adviser (IFA) can help you assess your financial needs and find the best deal for you.

You can find an IFA through one of the organisations listed on pages 117–119.

Our booklets **Getting travel insurance** and **Insurance** may be helpful.

Direct payments

If you have been assessed as needing social services, you may be entitled to get direct payments from your local authority. This means you are given payments to organise the services yourself, rather than the local social services organising and paying for them for you. You can get information about direct payments from the Department of Health website at **dh.gov.uk** or from your local social security office.

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work. It will depend on the type of work you do and how much your income is affected. It's important to do what's right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It's important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer in England, Scotland and Wales. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets **Work and cancer**, **Self-employment and cancer** and **Working while caring for someone with cancer** have more information. There's also lots more information at **macmillan.org.uk/work**


NEED ADVICE ON BENEFITS? WE CAN HELP
GETTING TRAVEL INSURANCE
WORK AND CANCER
Journey
CAN HELP OUT

FURTHER INFORMATION

About our information

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

Order what you need

You may want to order more 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.

All of our information is also available online at **macmillan.org.uk/cancerinformation** 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. No one should face cancer alone.

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–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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**

Online community

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

The Macmillan healthcare team

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

> 'I was treated by a lovely doctor at the excellent Macmillan unit. She is always helpful and willing to answer questions seriously, and the nursing staff are also very nice.'
>
> **Frances**

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 advice

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you'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**

Macmillan's My Organiser app
This 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)

Southbridge House,
Southbridge Place,
Croydon CR0 4HA
Tel 020 3757 7700
Email info@aclt.org
www.aclt.org
Provides practical and home help, counselling, advice and support to African-Caribbean people 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

2 Heathgate Place,
75–87 Agincourt Road,
London NW3 2NU
Tel 0303 303 0303
www.anthonynolan.org.uk
The UK's largest stem cell and bone marrow register.

The Blue Badge Scheme (Department for Transport)

www.dft.gov.uk/transportforyou/access/bluebadge
Provides a national arrangement of parking concessions for people with severe walking difficulties who travel either as drivers or passengers. It allows badge-holders parking concessions so they can park close to their destination. The scheme operates throughout the UK, and is administered by local authorities who deal with applications and issue badges.

British Bone Marrow Registry (part of the National Blood Service)

Tel 0300 123 23 23
www.nhsbt.nhs.uk/bonemarrow
Holds details of stem cell donors and cord blood donations from England, Scotland, North Wales and Northern Ireland. It is responsible for recruiting, testing and registering blood donors who volunteer to become stem cell donors. It is also part of an international network, performing searches around the world to find suitable stem cell donors.

British Red Cross

44 Moorfields,
London EC2Y 9AL
Tel 0844 871 11 11
Email information@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)

380–384 Harrow Road,
London W9 2HU
Helpline 0845 130 9177
(Mon–Fri, 10am–4pm)
Email helpline@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.

Leukaemia and Lymphoma Research

39–40 Eagle Street,
London WC1R 4TH
Tel 020 7504 2200
(Mon–Fri, 9am–5pm)
Email info@beatingbloodcancers.org.uk
www.leukaemialymphomaresearch.org.uk
Dedicated to researching blood cancers and disorders. Produces patient information.

Leukaemia CARE
1 Birch Court,
Blackpole East,
Worcester WR3 8SG
Careline 0808 8010 444
Email
care@leukaemiacare.org.uk
www.leukaemiacare.org.uk
Provides care and support to patients, their families and carers whose lives have been affected by a blood disorder. Offers emotional support and financial assistance through its network of volunteers and 24-hour free helpline.

Myeloma UK
22 Logie Mill,
Beaverbank Business Park,
Edinburgh EH7 4HG
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
6 Market Road,
London N7 9PW
Helpline 0808 800 3333
(Mon–Fri, 9am–5pm)
www.scope.org.uk
Provides support, information and advice to disabled people and their families.

General cancer support organisations

Cancer Black Care
79 Acton Lane,
London NW10 8UT
Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX
Tel 0800 783 3339
(Mon–Fri, 9am–1pm)
Email
hello@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Calman Cancer Support
Centre, 75 Shelley Road,
Glasgow G12 0ZE
Tel 0800 652 4531
Email info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling.

Irish Cancer Society

43–45 Northumberland Road,
Dublin 4, Ireland
Tel 1800 200 700
(Mon–Thu, 9am–7pm,
Fri, 9am–5pm)
Email helpline@irishcancer.ie
www.cancer.ie

National cancer charity offering information, support and care to people affected by cancer. Has a helpline staffed by specialist cancer nurses.

Maggie's Centres

1st Floor, One Waterloo Street,
Glasgow G2 6AY
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org

Provide information about cancer, benefits advice, and emotional or psychological support.

Penny Brohn Cancer Care

Chapel Pill Lane, Pill,
Bristol BS20 0HH
Helpline 0845 123 2310
(Mon–Fri, 9.30am–5pm)
Email
helpline@pennybrohn.org
www.pennybrohncancercare.org

Offers a unique combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Tenovus

Head Office,
Gleider House, Ty Glas Road,
Cardiff CF14 5BD
Tel 0808 808 1010
(Mon–Sun, 8am–8pm)
www.tenovus.org.uk

Provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

General health information

Health and Social Care in Northern Ireland

www.hscni.net

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

Healthtalk

Email
info@healthtalkonline.org
www.healthtalk.org
www.youthhealthtalk.org (site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

National Cancer Institute –National Institute of Health – USA

www.cancer.gov

Gives information on cancer and treatments.

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

www.nhsinform.co.uk
NHS health information site for Scotland.

Patient UK

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

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)

32–36 Loman Street,
London SE1 0EH
Tel (England)
0844 800 4361
Tel (Scotland)
0300 123 2008
Tel (Wales)
0292 009 0087
Email info@carers.org
www.carers.org and
www.youngcarers.net
Provides support, information, advice and services for people caring at home for a family member or friend. Has UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) 0808 808 7777
(Mon–Fri, 10am–4pm)
Tel (Northern Ireland)
028 9043 9843
Email
advice@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

BACP House,
15 St John's Business Park,
Lutterworth,
Leicestershire LE17 4HB
Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Samaritans

Freepost RSRB-KKBY-CYJK,
Chris, PO Box 9090,
Stirling FK8 2SA
Helpline 08457 90 90 90
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.

UK Council for Psychotherapy (UKCP)

2nd Floor, Edward House,
2 Wakley Street,
London EC1V 7LT
Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674
(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk**

Civil Legal Advice

Helpline 0345 345 4345 (Mon–Fri, 9am–8pm, Sat, 9am–12.30pm)
Minicom 0345 609 6677
www.gov.uk/civil-legal-advice
Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English isn't your first language.

Department for Work and Pensions (DWP)

Disability Living Allowance Helpline 0345 712 3456
Textphone 0345 722 4433
Personal Independence Payment Helpline 0345 850 3322
Textphone 0345 601 6677
Carer's Allowance Unit 0345 608 4321
Textphone 0345 604 5312
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has comprehensive information about social security benefits and public services.

The Money Advice Service

Helpline 0300 500 5000
(Mon–Fri, 8am–8pm,
Sat, 9am–1pm)
Typetalk
18001 0300 500 5000
www.moneyadviceservice.org.uk

Runs a free financial health check service and gives advice about all types of financial matters. Has an online chat service for instant money advice.

Money Advice Scotland

Helpline 0141 572 0237
www.moneyadvicescotland.org.uk

National Debtline (England, Wales and Scotland)

Tricorn House,
51–53 Hagley Road,
Edgbaston,
Birmingham B16 8TP
Tel 0808 808 4000
(Mon–Fri, 9am–9pm,
Sat, 9.30am–1pm)
www.nationaldebtline.org

A national helpline for people with debt problems. The service is free, confidential and independent.

Personal Finance Society – ‘Find an Adviser’ service

www.findanadviser.org

Use the website to find qualified financial advisers in your area.

Unbiased.co.uk

Email contact@unbiased.co.uk
www.unbiased.co.uk

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.

You can search for more organisations on our website at **macmillan.org.uk/organisations**, or call us on **0808 808 00 00**.

YOUR NOTES AND QUESTIONS

Disclaimer

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, Clinical Director of Haematology and Bone Marrow Transplantation.

With thanks to: Dr Jenny Bird, Haematology Consultant; Charlotte Bloodsworth, Haematology Clinical Nurse Specialist; Shirley Crofts, Haematology Clinical Nurse Specialist; Dr Alastair Smith, Honorary Consultant Haematologist; and the people affected by cancer who reviewed this edition, and those who shared their stories.

Sources

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

Bain BJ, et al. *Dacie and Lewis practical haematology.* Elsevier. 2012.
British Committee for Standards in Haematology (BCSH). *Guidelines on the diagnosis and management of multiple myeloma.* 2014.
National Institute for Health and Care Excellence (NICE). *Pomalidomide for relapsed and refractory multiple myeloma previously treated with lenalidomide and bortezomib.* 2015.
Rajkumar SV, et al. International Myeloma Working Group (IMWG). *Updated criteria for the diagnosis of multiple myeloma.* Lancet oncology. Vol 15 (2), 538–548. 2014.
Snowden JA, et al. British Committee for Standards in Haematology (BCSH) and UK Myeloma Forum. *Guidelines for supportive care in multiple myeloma.* British journal of haematology. Vol 154 (1), 76–103. 2011.

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.

5 WAYS
YOU CAN
HELP
SOMEONE
WITH
CANCER

Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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

27530

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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CANCER SUPPORT