A practical guide to
understanding cancer

UNDERSTANDING MYELOMA

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Contents

About this booklet

This booklet is about a type of cancer called myeloma. We hope it answers your questions about diagnosis and treatment, and addresses some of the feelings you may have.

We can't advise you about the best treatment for yourself. This information can only come from your own doctor, who knows your full medical history.

At the end of this booklet are some useful addresses, helpful books and websites (pages 83–96).

In this booklet, we've included comments from people who have had myeloma, which you may find helpful. Some are from people who've chosen to share their story with us (to share your story, visit **macmillan.org.uk/cancervoices**), while others are from members of our online community (**macmillan.org.uk/community**).

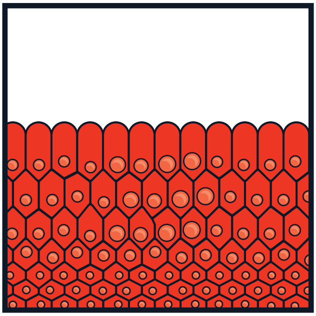
If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

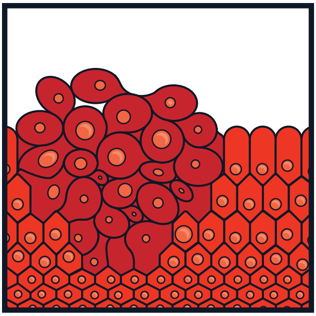
What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Cancer isn't a single disease with a single cause and a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Although cells in different parts of the body may look different and work in different ways, most repair and reproduce themselves in the same way. Normally, cells divide in an orderly and controlled way. But if for some reason the process gets out of control, the cells carry on dividing and develop into a lump called a tumour. Tumours can be either **benign** (non-cancerous) or **malignant** (cancerous). Doctors can tell whether a tumour is benign or malignant by removing a piece of tissue (a **biopsy**) and examining a small sample of cells under a microscope.



Normal cells



Cells forming a tumour

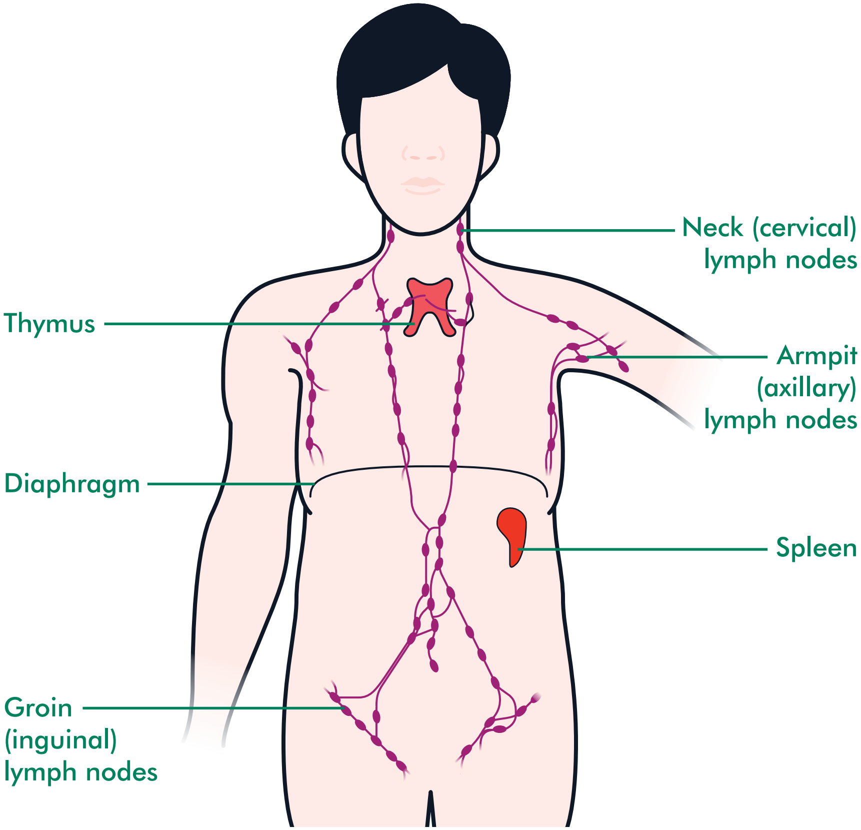
In a benign tumour, the cells do not spread to other parts of the body and so are not cancerous. However, they may carry on growing at the original site, and may cause a problem by pressing on surrounding organs.

In a malignant tumour, the cancer cells have the ability to spread beyond the original area of the body. If the tumour is left untreated, it may spread into surrounding tissue. Sometimes, cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system (see opposite).

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or a **metastasis**.

The lymphatic system

The lymphatic system is part of the immune system – the body's natural defence against infection and disease. It's made up of organs such as bone marrow, the thymus, the spleen and lymph nodes. The lymph nodes throughout the body are connected by a network of tiny lymphatic tubes (ducts). The lymphatic system has two main roles: it helps to protect the body from infection and it drains fluid from the tissues.

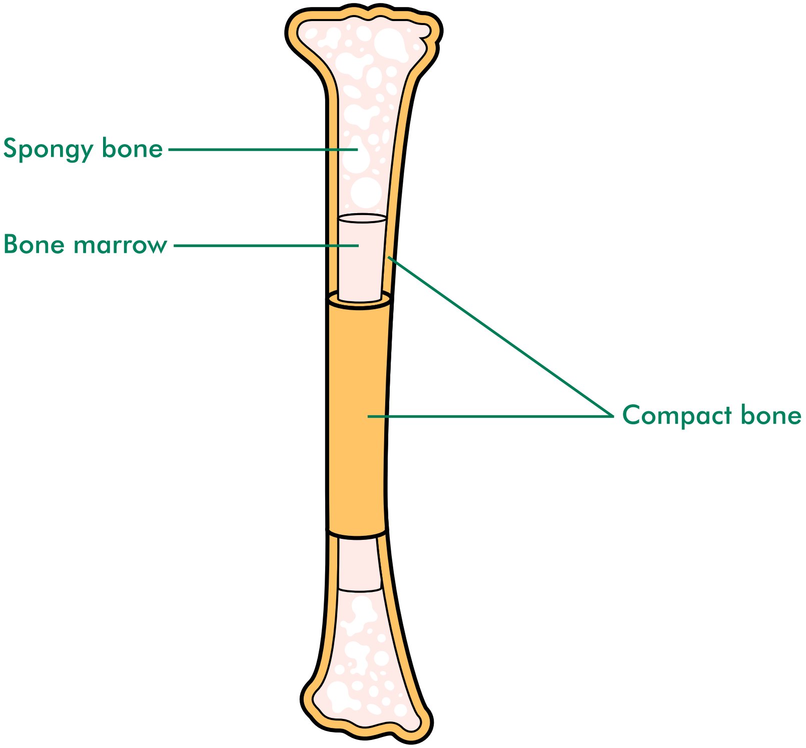


The lymphatic system

Bone marrow and blood cells

The bone marrow is a spongy material that fills the middle of some bones and produces stem cells. These are immature cells that develop into the three different types of blood cell:

- **red blood cells**, which carry oxygen to all the cells in the body
- **white blood cells**, which are essential for fighting infection
- **platelets**, which help the blood to clot and control bleeding.



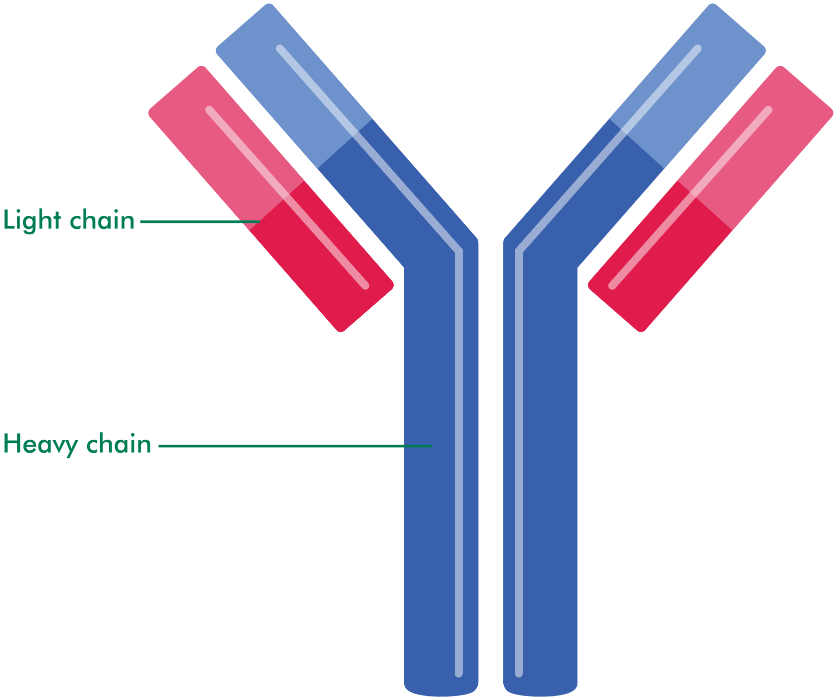
Structure of a bone

Plasma cells

Plasma cells are a type of white blood cell. They are part of the immune system and help protect the body against infection. Plasma cells produce proteins known as antibodies (immunoglobulins). These antibodies circulate in the blood, ready to attack any viruses and bacteria present in the body. If an infection occurs, more plasma cells are produced, creating more antibodies to attack whatever is causing the infection.

Antibodies

Antibodies are made up of proteins, which are linked together to make 'chains'. Some are large protein chains known as 'heavy' chains and others are smaller chains known as 'light' chains.



An antibody

There are five types of heavy chain (known as A, D, G, E and M), and two types of light chain (known as kappa and lambda). Antibodies each have one type of heavy chain and one type of light chain.

What is myeloma?

Myeloma – also known as **multiple myeloma** or **myelomatosis** – is a cancer of plasma cells in the bone marrow. Normally, new plasma cells are produced to replace old, worn-out cells in an orderly, controlled way. However, in myeloma, the process gets out of control and large numbers of abnormal plasma cells (myeloma cells) are produced. These fill up the bone marrow and interfere with the production of normal white blood cells, red blood cells and platelets.

The myeloma cells usually produce a large amount of a single type of abnormal antibody (immunoglobulin). This is known as a **paraprotein** or **M protein**. It can't fight infection effectively and often reduces the production of normal antibodies.

Myeloma cells can spread throughout the bone marrow. Too many plasma cells can damage the bone, which causes bone thinning, pain and sometimes fractures. An area of damaged bone is known as a **lytic lesion**.

Types of myeloma

There are different types of myeloma, which are classified depending on the type of immunoglobulin (Ig) produced by the myeloma cells.

The most common type of myeloma is **IgG**, where the heavy chain (see page 9) of the immunoglobulin is G. The least common type is **IgE**.

The type of myeloma you have doesn’t usually affect the treatment you’re offered but it can influence how the disease will affect you.

Around 1 in 3 people have a type of myeloma that produces light chains only. This is called **light chain** or **Bence Jones** myeloma.

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

Other conditions of the plasma cell

There are some other conditions that affect the plasma cells and are related to myeloma. They can sometimes develop into myeloma.

The two most common are **MGUS (monoclonal gammopathy of unknown significance)** and **smouldering myeloma**, which is also known as indolent or asymptomatic myeloma.

If you’re diagnosed with either of these conditions, you’ll be monitored with blood tests, but may not need to have any treatment unless the condition progresses and becomes an active or symptomatic myeloma.

We can send you a cancer information sheet with further 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's treated with radiotherapy. Some people with solitary plasmacytoma may go on to develop myeloma, so you'll be regularly monitored with blood tests.

Risk factors and causes

Around 4,800 people in the UK are diagnosed with myeloma each year. Doctors don't know what causes myeloma but a number of things are known to increase the risk of developing it.

- **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 in white people.
- **Gender** Myeloma is slightly more common in men than women.
- **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.

- **Occupation** It has been suggested that people in certain jobs have an increased risk of myeloma, possibly due to exposure to harmful substances. These include jobs in rubber manufacture, farming, painting and decorating, wood-working, hairdressing and the petro-chemical industries. However, there is very little evidence to support the claim that these occupations carry an increased risk of myeloma.

Myeloma, like other cancers, isn’t infectious and can’t be passed on to other people.

Symptoms of myeloma

Myeloma may not cause any symptoms in the early stages of the disease. Occasionally, it is diagnosed following a routine blood test before any symptoms develop.

When symptoms do happen, they are mostly caused by a build-up of abnormal plasma cells in the bone marrow, and by the presence of the paraprotein in the blood (see page 10).

Bone pain

The most common symptom of myeloma is bone pain. About 70% of people (7 in 10) complain of lower back pain, or pain in their ribs. The pain happens because too many abnormal plasma cells are crowding out the bone marrow, which can damage the bone. Other bones may be affected too, such as the skull or pelvis.

Other symptoms

These may include:

- **tiredness and fatigue** due to a lack of red blood cells (anaemia).
- **kidney problems**, which are caused by the paraproteins produced by the myeloma cells. They can also cause tiredness and anaemia.
- **repeated infections**, particularly chest infections, due to a shortage of normal antibodies.

- **loss of appetite, feeling sick, constipation, depression and drowsiness**, which are caused by too much calcium in the blood (hypercalcaemia).
- **unexplained bruising and abnormal bleeding**, for example, nosebleeds or bleeding gums, due to a reduced number of platelets in the blood.
- **weight loss**.

If you have any of these symptoms, it's important to see your doctor as soon as possible. But remember, many of these symptoms can occur in other conditions – most people with these symptoms won't have myeloma.

How myeloma is diagnosed

Usually, you begin by seeing your family doctor (GP), who will examine you and arrange any blood tests or x-rays that may be necessary. They will refer you to hospital for these tests and for specialist advice and treatment.

At the hospital

You'll see a specialist called a haematologist, who specialises in conditions of the blood. They'll ask about your general health and any previous medical problems. They'll then examine you and arrange a series of tests including blood and urine tests, bone marrow biopsies and x-rays of the bones.

Blood tests

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

- **Serum protein electrophoresis** This is the main blood test used to diagnose myeloma. It measures the amount of abnormal antibodies (paraproteins) in the blood. This test is also used as a guide to see how well treatment is working.

- **Full blood count** This measures the levels of white blood cells, red blood cells and platelets in the blood. If any of the levels are low, this can show your doctor how your bone marrow has been affected by myeloma.

- **Urea and electrolytes (U&E) test** This test gives information on how well your kidneys are working.

- **Calcium level** This measures the level of calcium in the blood – it's sometimes raised in myeloma.
- **Beta-2 microglobulin level** This measures the level of a protein produced by myeloma cells – it can help to tell how active a myeloma is.
- **Albumin level** This measures the level of albumin, a protein found in the blood – a low level of albumin can indicate an advanced myeloma.
- **Serum free light chain assays (Freelite®)** This test can detect light chains in the blood and is useful for diagnosing and monitoring light chain myeloma.

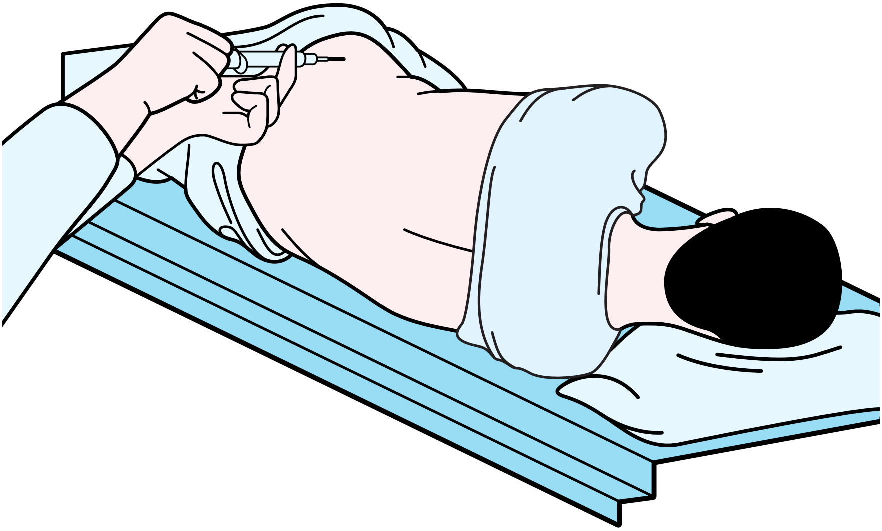
Urine samples may also be taken to test for the Bence Jones protein (see page 11). You may need to take a container home and collect your urine for 24 hours. The nurses will explain more about how to do this test.

Bone marrow biopsies

If there are paraproteins in your blood or urine, your doctor will want to take a sample of bone marrow (a biopsy). The biopsy is usually taken from the back of your hipbone (pelvis) or, sometimes, the breast bone. It's then examined to see if it contains any myeloma cells.

The bone marrow sample is taken under a local anaesthetic. You'll be given a small injection to numb the area. The doctor then gently passes a needle through your skin into the bone. A small sample of liquid marrow is drawn into a syringe and looked at under a microscope (**bone marrow aspiration**).

The procedure can be done on the ward or in the outpatients department, and takes about 15–20 minutes. It can be uncomfortable when the marrow is drawn into the syringe, but this should only last for a very short time. You may be offered a short-acting sedative to reduce any pain or discomfort during the test.



A bone marrow aspiration being taken

The doctor will then take a small core of marrow from the bone (**trephine biopsy**). This procedure takes a few minutes longer. A special type of needle, which is a bit thicker than the one used for a bone marrow aspiration, is passed through the skin and bone into the bone marrow. The doctor will push the biopsy needle in and gently turn it back and forth. When the needle is withdrawn, it will contain a 1–2cm core of bone marrow.

You may feel bruised after having a sample of bone marrow taken, and have an ache for a few days. This can be eased with mild painkillers.

Cytogenetics

Each cell in the body contains chromosomes, which are made up of genes. Genes control all the cell's activities. In myeloma, there may be changes in the structure of the chromosomes within the myeloma cells, but not in the normal cells of the body. Tests on the bone marrow samples will look for changes in the chromosomes.

These tests, known as cytogenetic tests, may help to decide on the best treatment and predict how well the myeloma may respond to that treatment. A test called fluorescence in situ hybridisation (FISH) is used to detect specific changes to the chromosomes of the myeloma cells.

X-rays and scans

X-rays will be taken to check for any possible damage to the bones from the myeloma cells (lytic lesions). You'll usually have x-rays taken of your whole body, which is known as a skeletal survey and can take up to an hour. Although x-rays and scans aren't painful, you may find lying on a hard surface for long periods of time uncomfortable. Ask your doctor, nurse or radiographer for a painkiller if you need one.

Further tests

Your doctors may suggest you have further tests, which can give more detailed 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.

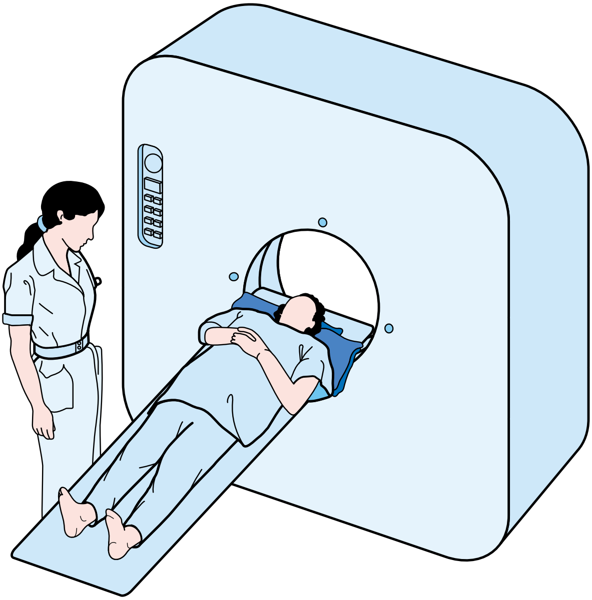
Before the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

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.

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.



Someone having a CT scan

PET (positron emission tomography) scan

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body.

A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Cancer cells are usually more active than surrounding tissue, and show up on the scan. Not all hospitals have PET scanners, so if you need one, you may have to travel to another hospital.

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 83–92 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

Staging

The stage of a cancer is a term used to describe its extent and how much it's affecting the body. Knowing the stage of the myeloma helps doctors plan the most appropriate treatment for you. Generally, myeloma is divided into three stages, which indicate the effect the disease is having on the body and how quickly or slowly it may develop.

A commonly used staging system for myeloma is the International Staging System (ISS). This system looks at the levels of the blood proteins beta-2 microglobulin and albumin (see page 17).

Stage I

The beta-2 microglobulin level is less than 3.5 milligrams per deciliter (3.5mg/dL) and the albumin level is greater than or equal to 3.5g/dL. This is early-stage myeloma.

Stage 2

Neither stage 1 or 3. This is intermediate-stage myeloma.

Stage 3

The beta-2 microglobulin level is greater than or equal to 5.5 mg/dL. This is advanced myeloma.

Treatment overview

Once the doctors know the stage of your myeloma, they can plan the most appropriate treatment. The stage will also help your doctors predict how well you might respond to treatment.

Myeloma is rarely curable, but it is treatable. Treatment can be very effective at controlling symptoms and stopping the development of the disease. The type of treatment you're offered will depend on a number of factors, including your general health and how advanced the myeloma is. New drugs have improved the outlook for people with myeloma and you may be invited to enter a clinical trial (see pages 63–65).

Myeloma without symptoms

If the myeloma has been diagnosed at an early stage and is developing slowly (asymptomatic or smouldering myeloma), you may not need treatment straight away. You'll see your doctor every few months and they will take blood samples and do other tests. This is known as active monitoring. Treatment will be started if the myeloma begins to get worse or if symptoms occur (symptomatic or active myeloma).

Active myeloma

The main treatments used for myeloma are chemotherapy, targeted therapies and steroids. Depending on your general health and how the myeloma is affecting you, you may be offered intensive chemotherapy followed by a stem cell transplant. Those who aren't fit enough to tolerate the side effects of intensive treatment are often treated with a combination of chemotherapy, targeted therapies and steroids.

The aim of treatment initially is to get the myeloma under control, so it goes into **remission**. A complete remission is when no abnormal myeloma cells can be detected in the blood or bone marrow, and normal bone marrow has developed again.

A complete remission isn't always possible for everyone treated for myeloma. However, treatment can still help reduce the amount of myeloma in the body (a partial response), or stop it from developing further (stable disease).

You will have tests and investigations throughout your treatment to monitor the amount of paraprotein and/or light chains in your blood (see pages 17–18) and to check how well the myeloma is responding to treatment.

Chemotherapy

You may have treatment with a single chemotherapy drug or a combination of different drugs (see pages 34–39).

Targeted therapies

This is another group of drugs commonly used to treat myeloma. They can be used on their own or in combination with chemotherapy (see pages 39–42).

Steroids

These are usually given with chemotherapy and targeted therapy to improve their effect (see pages 42–43).

Bisphosphonates

Bisphosphonate drugs may also be given with chemotherapy (see pages 51–52). They help to prevent bone damage, relieve pain and may help people to live longer.

High-dose chemotherapy with stem cell support

This intensive treatment can help improve the chances of controlling your myeloma in the long term. It involves having high doses of chemotherapy followed by a stem cell transplant. High-dose treatment isn't suitable for everyone (see pages 44–45).

Maintenance therapy

When remission has been achieved, maintenance therapies are used to prolong the time that the disease is under control (see page 46).

For a small group of people, treatment doesn't help control the myeloma. This is called **refractory myeloma**. In this case, your doctor may offer you another type of treatment to help control the disease. For most people, treatment will achieve a good response. However, the myeloma usually comes back. This is called **relapsed myeloma**. You may be offered further treatment at this time.

Radiotherapy

Radiotherapy can be used to treat small areas of myeloma (localised disease) that are causing bone pain (see pages 52–53).

Surgery

Surgery is sometimes needed to repair or strengthen bones damaged by the myeloma (see pages 53–54).

Controlling symptoms

This is important for everyone diagnosed with myeloma. Symptoms can include bone pain and fractures, anaemia, high levels of calcium in the blood and kidney problems. There is more information on controlling symptoms on pages 50–59.

Planning your treatment

In most hospitals, a team of staff who specialise in treating myeloma will talk to you about the treatment they feel is best for your situation.

This multidisciplinary team (MDT) will include:

- a **haematologist** – a doctor who specialises in treating blood disorders
- an **oncologist** – a doctor who is a chemotherapy and radiotherapy specialist
- a **specialist nurse** who gives information and support
- a **pathologist** – a doctor who specialises in how disease affects the body
- a **radiologist** – a doctor who specialises in x-rays and scans.

The team may also include other health professionals, such as a dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

Treatment choices

If two treatments are equally effective 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.

> 'There is so much to learn and so much to deal with. I can't always take it all in at some appointments and that is where I rely on my wife to take notes.'
>
> **Paul**

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

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

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

The benefits and disadvantages of treatment

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 potential benefits will vary depending 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, treatment is usually only able to control the myeloma for a period time. This should cause a reduction in symptoms and allow a better quality of life.

Some treatments for myeloma involve far 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 in these circumstances is always difficult, and you may need to discuss in detail with your doctor whether you wish to have treatment. If you choose not to have it, you can still be given supportive (palliative) care with medicines to control any 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 a cancer information sheet about getting a second opinion. Call us on 0808 808 00 00.

Treatment to control myeloma

The treatment options to control myeloma include:

- chemotherapy – see pages 34–39
- targeted therapies – see pages 39–42
- steroid therapy – see pages 42–43
- high-dose treatment with stem cell support – see pages 44–45.

Usually, a combination of treatments will be given.

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs and is one of the main treatments used to control myeloma. Chemotherapy drugs stop cancer cells dividing and reproducing themselves. They 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. The treatment is given 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. Between four and six cycles will make up a complete course of treatment, which can take 4–6 months.

During the course of treatment, you'll have regular blood tests to check the effect of the drugs. The dose of the drugs may be altered according to the results of your blood tests.

Chemotherapy may be given to you as an outpatient, but you may sometimes need to spend a few days in hospital.

Chemotherapy drugs used to treat myeloma include:

- melphalan (Alkeran®)
- cyclophosphamide
- doxorubicin
- idarubicin (Zavedos®)
- bendamustine (Levact®).

Some chemotherapy drugs for myeloma are given as tablets or capsules (orally). Others are given by injection into a vein (intravenously) – see page 43–44.

The drugs melphalan and cyclophosphamide are commonly used to treat myeloma and are usually given as tablets or capsules, but can also be given into a vein. They are most often given with steroid tablets. When given as tablets, these drugs can have fewer side effects. This makes them more suitable for people who aren't able to have stronger treatments.

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

Side effects of chemotherapy

Everyone reacts to chemotherapy in different ways. Not all drugs cause the same side effects and some people may have very few side effects. Your doctor will tell you about any problems your treatment may cause.

Risk of infection While the chemotherapy drugs are acting on the myeloma cells in your body, they also reduce the number of normal cells in your blood for a while. When the number of white blood cells is low (known as neutropenia), you're more likely to get an infection.

Your resistance to infection is usually at its lowest 7–14 days after chemotherapy. The number of your white blood cells will then increase steadily and usually return to normal before your next cycle of chemotherapy is due.

If your temperature goes above 38°C (100.4°F), or if you suddenly feel ill, even with a normal temperature, contact your doctor at the hospital straight away.

You'll have a blood test before having more 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 a cancer information sheet on avoiding infection when your immunity is low.

Bruising and bleeding Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you develop any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, contact your doctor or the hospital straight away.

Feeling sick Chemotherapy tablets usually cause very mild feelings of sickness (nausea). With some of the injected drugs, this may be worse, and they may even cause vomiting.

Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs aren't helping, as there are several different types you can try.

Sore mouth Some chemotherapy drugs can make your mouth sore and may cause ulcers. Keeping your mouth and teeth clean and using mouthwashes regularly is important. Your nurse will show you how to use these properly.

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 discuss how to treat anaemia on pages 55–56.

> **We have cancer information sheets on nausea and vomiting, and mouth care. There's also a video about mouth care during chemotherapy at macmillan.org.uk/mouthcare**

Losing your hair Hair loss is more common with chemotherapy given into a vein than with chemotherapy tablets. If your hair falls out, it usually grows back within three months after treatment. We have a booklet called *Coping with hair loss*, which could be useful.

Tiredness (fatigue) You're likely to become tired and have to take things slowly. Try to pace yourself and save your energy for things that you want to do or that need doing.

Balance rest with some physical activity – even going for short walks will help increase your energy levels.

> **Our booklet *Coping with fatigue* has more helpful tips. Or you may like to watch the video at macmillan.org.uk/fatigue**

Risk of blood clots Cancer can increase your risk of developing a blood clot (thrombosis) and having thalidomide and chemotherapy may increase this risk further. A blood clot may cause symptoms such as pain, redness and swelling in a leg, or 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.

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

Targeted therapies

Targeted (or biological) therapies are treatments that work by targeting specific proteins that are found either on the surface of cancer cells or within the cell itself.

Targeted therapies that are used as part of initial treatment for myeloma are thalidomide and bortezomib, which are discussed next.

> **We can send you cancer information sheets about thalidomide and bortezomib.**

Thalidomide

The drug thalidomide has been shown to be effective in treating myeloma. It's thought that it stops cancer cells from developing new blood vessels. This reduces the cancer's supply of oxygen and nutrients, and can stop the cancer growing or make it shrink.

Thalidomide is given to treat newly diagnosed myeloma in people who can't have high-dose treatment. It's given in combination with the chemotherapy drug melphalan and the steroid prednisolone, or with cyclophosphamide chemotherapy and the steroid dexamethasone.

Side effects of thalidomide

Thalidomide is taken daily, usually in the evening, as a tablet. Side effects can include:

- constipation
- drowsiness
- an increased risk of developing blood clots in the veins in the legs, known as deep vein thrombosis (DVT) – see page 39

Sometimes, thalidomide can damage nerves, which can cause tingling in your hands and feet, known as 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. Tell your doctor if you notice any of these symptoms. They usually disappear slowly after treatment ends, although it can sometimes take months.

We have a cancer information sheet about peripheral neuropathy, which gives more detailed information.

Thalidomide can cause birth defects, so it should not be given to pregnant women. People taking thalidomide who are sexually active must use a highly effective form of contraception. You will be given further advice about this by your doctor.

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

Bortezomib (Velcade®)

Bortezomib is a type of treatment called a proteasome inhibitor. Proteasomes are a group of enzymes found in all cells in the body. They have an important role in controlling cell function and growth. By interfering with the function of proteasomes, bortezomib may cause cancer cells to die and may stop the cancer from growing.

Bortezomib is mainly given to people who have already had chemotherapy treatment, but whose myeloma has come back or continued to develop. They may also have already had, or be unsuitable for, high-dose treatment with stem cell support.

Some people may have bortezomib as a first treatment for myeloma when thalidomide or a bone marrow transplant isn't suitable.

Bortezomib is given as an injection into a vein (intravenous) or under the skin (subcutaneous). It's usually given twice a week over two weeks followed by a 10-day rest period. This makes up a cycle of treatment. You may also be given steroids.

Side effects of bortezomib include tiredness, nausea, diarrhoea, numbness or tingling in the hands and feet (peripheral neuropathy) and a tendency to bruise or bleed more easily, which is caused by a low platelet count.

Steroids

Steroids are drugs that can be used as part of your treatment to help destroy myeloma cells and make chemotherapy more effective. The two most commonly used steroids to treat myeloma are prednisolone and dexamethasone. They may be used on their own or in combination with other drugs. Steroids are usually taken as tablets, but liquid preparations or dissolving tablets can be given if you have difficulty swallowing.

Taking small doses of a steroid usually has few side effects. If you need larger doses for a longer period of time, some side effects may occur. Steroids can irritate the lining of the stomach and cause indigestion or heartburn. Taking your tablets with food or milk can help prevent this.

If you get any stomach pains after taking steroids, it's important to let your doctor or nurse know, as they can give you medicine to help with this.

Other side effects can include feeling irritable, an increased appetite, feeling more energetic and difficulty sleeping. If you're taking steroids for some time, you may have other temporary side effects including water retention, high blood pressure and a slightly greater risk of getting infections. You may also develop an increased level of sugar in the blood. If this happens, your doctor will prescribe daily tablets or injections of insulin to bring your blood sugar level back to normal. You may need to do a simple daily test to check for sugar in your urine. Your nurses will show you how to do this.

It's unusual for people with myeloma to have 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. The side effects of steroids are temporary and will disappear as the dose is reduced.

We have a cancer information sheet about steroids, which we can send you.

Having treatment

Chemotherapy is often combined with targeted therapy and steroids. 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).

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

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). This can stay in place throughout the course of your treatment, and used for each treatment session. The tube is threaded along the vein until the end of it sits just above your heart. It means you won't have to have injections every time you have treatment.

Your nurses will show you how to care for the line when you're at home.

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.

We can send you cancer information sheets about central lines, PICC lines and implantable ports.

The length of treatment will depend on the stage of your myeloma and how well it responds to the drugs, but a course of treatment usually takes 6–9 months to complete.

High-dose treatment with stem cell support (transplant)

High-dose treatment with a stem cell transplant may benefit some people with myeloma. If your doctor thinks that this treatment is suitable for you, they'll discuss it with you in more detail. Stem cell transplants are generally only carried out in specialist cancer treatment centres.

A stem cell transplant allows you to have much higher doses of chemotherapy than usual. Some people are also given radiotherapy. This can help to improve the chances of controlling your myeloma in the long term.

As well as destroying any myeloma cells, the high-dose treatment also destroys the healthy stem cells in the bone marrow, which develop into blood cells (see page 8). To help you recover from the high-dose treatment, you'll be given a drip (infusion) of stem cells afterwards. The stem cells find their way to the bone marrow where they start producing new blood cells.

The stem cells are mainly collected (harvested) from the blood, but can also be collected from the bone marrow. In myeloma, it's more common to use your own stem cells (autologous transplant) than stem cells from a donor (allogeneic transplant).

The first stage of the treatment is called induction chemotherapy, which puts the myeloma into remission (where there are no signs of the cancer). Once it's in remission, your stem cells will be collected and stored until they're given back to you after treatment.

Other treatments involving the use of stem cells are being researched in some hospitals. These include: allogeneic transplants from a donor; having a second transplant if myeloma recurs; mini-transplants, which involve less intense chemotherapy; and tandem transplants, where a second transplant is given straight after the first.

We can send you our booklet *Understanding high-dose treatment with stem cell support*, which explains this treatment in more detail.

Maintenance treatment

Maintenance treatment may be used to try to keep the myeloma in remission for as long as possible. Your doctor will discuss with you the best options for yourself. One of the factors to consider will be the treatment you've already had. Doctors are looking into 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 to chat to people any time who know what you're going through. You can also give support to others.

Treatment if myeloma comes back

If your myeloma comes back, it may be possible to repeat the treatment you originally had to control it, depending on what the treatment was and how long your remission lasted. If this isn't possible, there are usually other treatment options, which your doctor will discuss with you.

Treatments that may be considered are:

- high-dose treatment with stem cell support – see pages 44–45
- thalidomide – see pages 40–41
- bortezomib (Velcade®) – see pages 41–42
- lenalidomide (Revlimid®) – see page 48
- steroids – see pages 42–43.

A combination of drugs that is sometimes used is DT-PACE, which includes dexamethasone, thalidomide, cisplatin, doxorubicin, cyclophosphamide and etoposide.

Lenalidomide (Revlimid®)

The drug lenalidomide (Revlimid®) has been shown to help control myeloma that has come back. It's one of a group of drugs known as IMiDs® that work in a similar way to thalidomide.

Lenalidomide is a capsule taken once a day for three weeks, followed by one week off.

The main side effects of lenalidomide are an increased risk of infection (due to a low number of white blood cells), anaemia (due to a low number of red blood cells), and possible bruising and bleeding (due to a low platelet count). Rare side effects include constipation, a rash and sleepiness. When taken with the steroid dexamethasone, there is an increased risk of blood clots in your legs. You may be given blood-thinning medicines to reduce this risk.

The National Institute for Health and Clinical Excellence (NICE) gives advice about which new treatments should be available on the NHS in England and Wales. The equivalent body in Scotland is the Scottish Medicines Consortium (SMC).

NICE and the SMC have approved the use of lenalidomide in combination with dexamethasone in people whose myeloma has come back and who've already had at least two different courses of treatment.

We can send you a cancer information sheet about lenalidomide.

Controlling symptoms

Bone pain

Bone pain is a common symptom of myeloma. Myeloma cells speed up the destruction of bone cells and slow down the production of new bone cells to replace them. This causes areas of bone to weaken and sometimes fracture.

There are many painkillers available to treat different types and levels of pain. Other treatments such as radiotherapy (see pages 52–53), chemotherapy (see pages 34–39), bisphosphonates (see pages 51–52) and surgery (see pages 53–54) can also help reduce pain. Your doctor or nurse will aim to find the best treatment to manage your pain.

Giving your doctor or nurse as much information as you can about your pain will help them to assess it and plan treatment. You may want to think about:

- How does your pain rate on a scale of 0 (no pain) to 10 (worst pain)?
- What words best describe your pain? (for example, dull, sharp, shooting or aching)
- Does anything make the pain better or worse?
- How does your pain affect your everyday activities?
- How does the pain affect your sleep?

A group of drugs called non-steroidal anti-inflammatory drugs (for example, ibuprofen) can cause kidney damage in people with myeloma and shouldn't be taken without first checking with your doctor or nurse.

We have a booklet called *Controlling cancer pain* that we can send you.

Bisphosphonates

Bisphosphonate drugs can be given to reduce pain and strengthen weakened bones. They can also reduce the amount of excess calcium in the blood (hypercalcaemia – see page 56). Bisphosphonates can help delay bone damage and prevent pain and fractures, so treatment may be started before any bone problems become noticeable. Research has shown that some bisphosphonates may also help treat myeloma.

They may be given as a drip into a vein (intravenous infusion) once a month. This takes between 15 minutes and four hours, depending on which drug is used.

Bisphosphonates are also available as tablets. It's very important to take the medicine exactly as instructed. Your nurse, doctor or pharmacist will explain how to take your tablets. You may wish to mark off each dose you take on a calendar or use a 7-day pill container to help you remember to take them on time.

Generally, side effects are mild and include indigestion and feeling sick (nausea). However, a very rare side effect of bisphosphonates is osteonecrosis of the jaw. This condition involves damage and decay of the jaw bone. You should have a dental examination before starting treatment and let your dentist know you'll be taking bisphosphonates. Your doctor should be informed if you need any dental treatment while you're taking bisphosphonates.

Research studies are being carried out into the use of bisphosphonates for myeloma. As part of your treatment, you may be invited to enter a clinical trial.

We have cancer information sheets about different bisphosphonates.

Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy cancer cells while doing as little harm as possible to normal cells Radiotherapy is given by a machine similar to an x-ray machine. The rays can be directed at specific bones where the myeloma cells have created a weak area. This treatment can be very effective at relieving pain in bones weakened by myeloma, allowing the bones to repair themselves. You may only need one or two treatments and your pain should reduce within 2–3 weeks.

In advanced myeloma, if chemotherapy is no longer effective, radiotherapy can be given to the whole body in two sessions, several weeks apart. One session treats the upper half of the body, while the other session treats the lower half. This is known as hemibody irradiation and may help to reduce symptoms and control the disease for some time.

Radiotherapy may also sometimes be used as part of the preparation for a stem cell transplant (see pages 44–45).

Radiotherapy is given in the hospital radiotherapy department. How the treatment is given can vary a lot, depending on your particular needs. If you only need one or two treatments, you may not need a lengthy first appointment to plan the treatment.

If you're having a longer course of treatment, you'll need to go to the hospital before your treatment starts so that the area to be treated, and the dose to be given, can be accurately worked out. Normally, treatment is given Monday–Friday for 2–4 weeks, with a rest at the weekends.

Radiotherapy for myeloma only occasionally causes side effects, such as nausea and vomiting. If these do occur, they can easily be treated – just let your doctor or nurse know. Any side effects should disappear once your course of treatment is over, but tell your doctor if they continue.

Radiotherapy can make you feel very tired, so try to get as much rest as you can, especially if you have to travel a long way each day for your treatment.

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

Surgery

Surgery is sometimes needed to repair a bone in the back, arm or leg that has been damaged or weakened by the myeloma cells. The operation will be done under a general anaesthetic and the damaged bone is strengthened with a metal pin or plate. Once in place, this can't be felt or seen. You may also need radiotherapy to the broken or weakened bone to destroy the myeloma cells and help it to heal.

If the bones of 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's often treated with painkillers, bed rest and by wearing a spinal brace. Operations that can be used to treat compression fractures of the spine include percutaneous vertebroplasty and balloon kyphoplasty.

Percutaneous vertebroplasty This procedure repairs the compression fracture by injecting a special cement into the vertebrae, which can help stabilise the bone and relieve pain. This will only be carried out in specialist centres. Side effects are uncommon but can include infection or damage to the nerves in the spine.

Balloon kyphoplasty This may be used to improve the strength of the spinal bones, which can relieve pain and help people move around more easily. It involves inserting a balloon-like device, called an inflatable bone tamp, into the vertebrae and then slowly inflating it. Once the bone returns to its normal height, it can be injected with bone cement (as above).

This is a newer technique, which will only be carried out in specialist centres. Possible side effects are similar to those of a percutaneous vertebroplasty.

Your doctor or specialist nurse will explain more about percutaneous vertebroplasty or balloon kyphoplasty if they feel that either treatment is appropriate for you.

The National Institute for Health and Clinical Excellence (NICE) gives advice about which treatments should be available on the NHS in England and Wales. It has issued guidance on the use of percutaneous vertebroplasty and balloon kyphoplasty. It says both treatments are safe and can be used in the NHS, but that other ways of controlling pain should be considered first. NICE also recommends that your doctors fully discuss the treatments with you so that you're aware of the potential benefits and risks.

Pressure on the spine (spinal cord compression)

Myeloma can develop in the bones of the spine. Sometimes, the bone may become weakened and put pressure on the spinal cord. This is called spinal cord compression and may cause symptoms such as 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 weakness, pain, tingling or numbness in your legs, it's very important to tell your doctor or specialist nurse straight away so that treatment can be given as soon as possible to prevent permanent damage.

Spinal cord compression is usually treated with radiotherapy. Steroids are also given to help reduce the pressure on the spinal cord. Sometimes, surgery is needed to repair or remove the affected bone.

We can send you a cancer information sheet with more information about spinal cord compression.

Anaemia

Anaemia is a shortage of red blood cells and is a common symptom of myeloma. It's caused by myeloma cells reducing the amount of red blood cells produced in the bone marrow. This may make you feel tired and breathless.

It's common to have anaemia when myeloma is diagnosed, but it will normally get better when treatment begins to bring the myeloma under control.

Sometimes, anaemia can develop as a side effect of your chemotherapy treatment. If this happens, 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.

If you're having kidney problems (see next page), your doctor may give you a drug called erythropoietin to treat anaemia, rather than a blood transfusion. Erythropoietin is normally given by an injection under the skin (subcutaneously).

We can send you cancer information sheets about blood transfusions and erythropoietin.

Excess calcium in the blood (hypercalcaemia)

Damage to the bones from myeloma can cause an increase in the level of calcium in the blood. This condition is called hypercalcaemia and can cause symptoms such as tiredness, nausea, constipation, thirst, irritability and confusion. In some people, hypercalcaemia is discovered by a blood test before any symptoms develop.

Your doctor may ask you to start drinking plenty of water and will put a drip of fluids into a vein in your arm (intravenous infusion). This will encourage your kidneys to get rid of the excess calcium from your body in your urine.

You may also be given a bisphosphonate drug (see pages 51–52). These prevent damage to the bone and will quickly reduce high calcium levels. The drug is given into a vein over a few hours and brings the calcium level down over the next 2–3 days. You may need a further dose if your calcium level starts to rise again.

Kidney problems

The paraproteins produced in myeloma can block the very fine 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.

This can be treated by giving 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.

Treatment for myeloma will usually reduce the amount of paraprotein in the blood and so help stop kidney problems. In a small number of cases, kidney damage is severe and the kidneys stop working altogether. This is known as kidney 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'll 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 discuss dialysis.

Hyperviscosity syndrome

Rarely, if myeloma causes a very high level of paraproteins in the blood, the blood can become thicker than normal. This can cause symptoms such as headaches, confusion, dizziness, blurred vision and abnormal bleeding. To help correct this problem, it's sometimes possible to have a procedure that removes the excess paraproteins from the blood, called a plasma exchange (plasmapheresis).

We have a cancer information sheet about plasma exchange.

Loss of appetite

Myeloma and some myeloma treatments can cause problems with eating and digestion. If your appetite is poor, you can add high-protein powders to your normal food or you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and can be prescribed by your GP or a dietitian.

If you've lost your appetite, medicines such as steroids may help improve it. You can also ask to be referred to a dietitian at your hospital. These are experts in assessing the food needs of people who are ill. They can advise you which foods are best for you and whether any food supplements would be helpful. If you're at home, your GP can arrange this for you.

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

Tiredness

Many people with myeloma feel tired and have less energy to do the things they normally do. This may be due to anaemia or may be a side effect of treatment. Try not to do too much. 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. Or you may want to watch the video at macmillan.org.uk/fatigue to hear how fatigue affected Denton and how he managed it.

After treatment – follow-up

After your treatment has finished, your doctor will probably want you to have regular check-ups and x-rays. You'll have regular blood and urine samples taken, to check the level of paraproteins in your blood. 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 for a while before appointments. This is natural and it may help to get support from family, friends or one of the organisations on pages 83–92 during this time.

For people whose treatment is over apart from regular check-ups, our booklet *Life after cancer treatment* gives useful advice on how to keep healthy and adjust to life after cancer.

Rehabilitation and recovery

Myeloma affects people in different ways. You may find that you can make a fairly quick return to normal life after treatment, but don't worry if at first you're not as fit as you used to be and can't easily do all the things you once took for granted. It can take some time to get back into a normal routine if you've been in hospital or have had to rest at home for long periods.

If you're working and your job involves heavy lifting, or if you take part in any sports that may put a strain on your back, you should ask your doctor's advice before going back to these things.

If needed, while you're in hospital, physiotherapists will start to get you back on your feet by teaching you muscle-strengthening exercises and helping you to walk. The occupational therapists from the hospital can help you do your normal activities around the home. They can visit your home with you to see if you need special adaptations to help you cope more easily.

Many social workers attached to hospitals are also trained counsellors. They can offer valuable 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.

Share your experience

When treatment finishes, many people find it helps to talk about it and share their thoughts, feelings and advice with other people.

This can be especially helpful for other people with myeloma who are perhaps about to start their treatment. Just hearing about how you've 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.

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. The samples will, however, 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 copy.

Current research

A number of research trials are looking at using different targeted therapies in combination with chemotherapy or after high-dose treatment with stem cell support. 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

Your feelings

Most people feel overwhelmed when they are told they have cancer, and have many different emotions. These are part of the process you may go through when dealing with your illness. Partners, family members and friends often have similar feelings and may also need support and guidance to help them cope.

Reactions differ from one person to another – there's no right or wrong way to feel. We describe some of the common emotional effects of cancer here. However, reactions vary and people have different emotions at different times.

Our booklet *How are you feeling?* discusses the emotions you may have in more detail, and has suggestions for coping with them.

Shock and disbelief

Disbelief is often the immediate reaction when cancer is diagnosed. You may feel numb and unable to express any emotion. You may also find that you can only take in a small amount of information, and so you have to keep asking the same questions again and again.

This need for repetition is a common reaction to shock. Some people find that their feelings of disbelief make it difficult for them to talk about their illness with family and friends. For others, it may be the main topic of conversation, as it's the main thing on their mind.

You may find our booklet *Talking about your cancer* helpful.

Fear and uncertainty

Cancer is a frightening word surrounded by fears and myths. One of the greatest fears people have is whether they will die. Many cancers are curable if found at an early stage. When a cancer is not curable, current treatments often mean that it can be controlled for some time.

Many people are anxious about whether their treatment will work and have any side effects. It's best to discuss your treatment and possible outcomes in detail with your doctor.

You may find that doctors can't answer your questions fully, or that their answers sound vague. It's often impossible for them to say for certain how effective treatment will be. Doctors know roughly how many people may benefit from a certain treatment, but they can't predict the future for a particular person. Many people find this uncertainty hard to live with, but your fears may be worse than the reality. Finding out about your illness can be reassuring. Discussing what you have found out with your family and friends can also help.

You might find it helpful to talk to other people in your situation. Call our cancer support specialists on **0808 808 00 00** to find out if there's a support group in your area. Or you can visit our online community at **macmillan.org.uk/community** to chat any time with people who know what you're going through. Some people find some form of spiritual support helpful at this time, and you may like to talk to a spiritual or religious adviser.

There's a video on our website of someone talking about how they coped with uncertainty. See it at macmillan.org.uk/uncertainty

Denial

Many people cope with their illness by not wanting to know much or talk much about it. If that's the way you feel, just let your family and friends know that you'd prefer not to talk about your illness, at least for the time being.

Sometimes, however, it's the other way around. You may find that your family and friends don't want to talk about your illness. They may appear to ignore the fact that you have cancer, perhaps by playing down your worries and symptoms or deliberately changing the subject. If this upsets or hurts you, try telling them. Perhaps start by reassuring them that you know why they're doing it, but that it will help you if you can talk to them about your illness.

Anger

People often feel very angry about their illness. Anger can also hide other feelings, such as fear or sadness. You may direct your anger at the people closest to you, or at the doctors and nurses caring for you. It's understandable that you may be very upset by many aspects of your illness, so you don't need to feel guilty about your angry thoughts or irritable moods. Bear in mind that your family and friends may sometimes think that your anger is directed at them, when it's really directed at your illness. It may help to tell them this, or perhaps show them this section of the booklet.

Blame and guilt

Sometimes people blame themselves or others for their illness, trying to find reasons to explain why it has happened to them. This may be because we often feel better if we know why something has happened. In most cases it's impossible to know exactly what has caused a person's cancer. So there's no reason for you to feel that anyone is to blame.

Resentment

Understandably, you may feel resentful because you have cancer while other people are well. These feelings may crop up from time to time during the course of your illness and treatment. It usually helps to discuss these feelings, rather than keep them to yourself.

Isolation and depression

There may be times when you want to be left alone to work through your thoughts and emotions. This can be hard for your family and friends, who want to share this difficult time with you. It may help them cope if you reassure them that, although you don't feel like discussing your illness at the moment, you'll talk to them about it when you're ready.

Sometimes, depression can stop you wanting to talk. If you or your family think you may be depressed, discuss this with your GP. They can refer you to a doctor or counsellor who specialises in the emotional problems of people with cancer, or prescribe an antidepressant drug for you.

We have a video at macmillan.org.uk/depression that you may find helpful.

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**

Talking to children

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

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

Teenagers

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

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, 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

What you can do

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

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

Finding ways to cope

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

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

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

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The **hospital social worker** can give you information about social services and benefits you may be able to claim, such as meals on wheels, a home helper or hospital fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called **palliative care nurses**. They are experienced in assessing and treating symptoms of advanced cancer. 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 help 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 or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

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.

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 more about benefits from Citizens Advice, or by calling the Benefit Enquiry Line on **0800 882 200** (or **0800 220 674** if you live in Northern Ireland). The website **gov.uk** (**nidirect.gov.uk** if you live in Northern Ireland) also has useful information.

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 87–88.

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

Direct payments

If you've been assessed as having a need for social services, you may be entitled to get direct payments from your local authority. This means that you're 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 **www.dh.gov.uk** or from your local social security office.

> 'Macmillan's Welfare Rights Service was my lifeline. The adviser explained the benefits I was entitled to, filled in the forms and sent them off. Thanks to him, I even got money backdated. When you're being treated for cancer you can't think about bills, but they don't stop. Without this help, I may have lost my home.'
>
> **Bridget**

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, and this will depend mainly 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. 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, Working while caring for someone with cancer* and *Self-employment and cancer* have more information that may be helpful. There's also lots more information at macmillan.org.uk/work

How we can help you

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

Get in touch

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ
Questions about cancer?
Call free on **0808 808 00 00**
(Mon–Fri, 9am–8pm)
www.macmillan.org.uk
Hard of hearing?
Use textphone
0808 808 0121 or Text Relay.
Non-English speaker?
Interpreters are available.

Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. 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, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at **macmillan.org.uk/informationcentres**

Publications

We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, cancer information sheets, and audiobooks. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at **macmillan.org.uk/cancerinformation**

Review our information

Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, cancer information sheets, leaflets, videos, illustrations and website text.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk**

Need out-of-hours support?

You can find a lot of information on our website, **macmillan.org.uk**
For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to

When you or someone you know has cancer, it can be difficult to talk about how you're feeling. You can call our cancer support specialists to talk about how you feel and what's worrying you.

We can also help you find support in your local area, so you can speak face-to-face with people who understand what you're going through.

Professional help

Our Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

Support for each other

No one knows more about the impact cancer has on a person's life than those who have been affected by it themselves. That's why we help to bring people with cancer and carers together in their communities and online.

Support groups

You can find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online community

You can also share your experiences, ask questions, get and give support to others in our online community at **macmillan.org.uk/community**

Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you've been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee, and help you find further support.

Macmillan Grants

Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break.

Find out more about the financial and work-related support we can offer at **macmillan.org.uk/financialsupport**

Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – **macmillan.org.uk/learnzone** – which offers a variety of e-learning courses and workshops. There's also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.

Other useful organisations

Blood cancer support organisations

Myeloma UK
Broughton House,
31 Dunedin Street,
Edinburgh EH7 4JG
Tel 0800 980 3332
(Mon–Fri, 9am–5pm)
Email myelomauk@myeloma.org.uk
www.myeloma.org.uk
Provides information and support to people affected by myeloma. Helps to improve treatments through research, education and awareness.

African Caribbean Leukaemia Trust (ACLT)
Southbridge House,
Southbridge Place,
Croydon CR0 4HA
Tel 020 8240 4480
Email info@aclt.org
www.aclt.org
Provides practical 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
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.

British Bone Marrow Registry (BBMR)
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. Also part of an international network, performing searches around the world to find suitable stem cell donors.

Leukaemia CARE
1 Birch Court, Blackpole East,
Worcester WR3 8SG
Tel 08088 010 444
Email
care@leukaemiacare.org.uk
www.leukaemiacare.org.uk
Provides care and support to people affected by leukaemia, lymphoma or an allied blood disorder. Offers emotional and financial support via its 24-hour helpline. Has a national office for Scotland:

> **Leukaemia CARE (Scotland)**
> Regus Management,
> Maxim 1,
> Maxim Office Park,
> 2 Parklands Way,
> Eurocentral,
> Motherwell ML1 4WR
> **Tel** 01698 209073

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
Sponsors research into leukaemia, lymphoma and myeloma. Also provides patient information booklets and leaflets that you can download or order from the website.

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 to anyone affected by cancer.

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. You can also chat to a nurse online and use the site's message board.

Maggie's Centres
1st Floor,
One Waterloo Street,
Glasgow G2 6AY
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Maggie's Centres provide information about cancer, benefits advice, and emotional or psychological support.

Penny Brohn Cancer Care
Chapel Pill Lane, Pill,
Bristol BS20 0HH
Tel 0845 123 2310
(Mon–Fri, 9.30am–5pm)
Email
helpline@pennybrohn.org
www.pennybrohncancercare.org
Offers a 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
Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
BACP House,
15 St John's Business Park,
Lutterworth 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
Tel 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 (England, Wales, Scotland)
Tel 0800 882 200
(Mon–Fri, 8am–6pm)
Textphone 0800 243 355
Email BEL-customer-services@dwp.gsi.gov.uk
www.gov.uk/benefit-enquiry-line
Provides advice and information for disabled people and carers on the range of benefits available.

NI Direct (Northern Ireland)
Tel 0800 220 674
(Mon–Wed and Fri,
9am–5pm,
Thu, 10am–5pm)
Textphone 0800 243 787
www.nidirect.gov.uk/money-tax-and-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 the following 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**

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

The Money Advice Service
Tel 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
Tel 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.co.uk
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.

Equipment and advice on living with a disability

Assist UK
Redbank House,
4 St Chad's Street,
Manchester M8 8QA
Tel 0161 832 9757
Email
general.info@assist-uk.org
www.assist-uk.org
A UK-wide network of Disabled Living Centres. Staff can give advice about the products, which are designed to make life easier for people who have difficulty with daily activities.

The Blue Badge Scheme (Department for Transport)
Allows drivers of passengers with severe mobility problems to park close to where they need to go. The scheme is administered by local authorities that deal with applications and issue badges. Applications can be made online and are sent to your local authority for a decision.
www.dft.gov.uk/transportforyou/access/bluebadge

British Red Cross
UK Office,
44 Moorfields,
London EC2Y 9AL
Tel 0844 871 11 11
Email
information@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK
12 City Forum,
250 City Road,
London EC1V 8AF
Tel 020 7250 3222
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights.
Has a number of helplines for specific support, including information on returning to work, direct payments, human rights issues, and advice for disabled students. Visit the website for contact details.

Disabled Living Foundation (DLF)
380–384 Harrow Road,
London W9 2HU
Tel 0845 130 9177
(Mon–Fri, 10am–4pm)
Email helpline@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Scope
6 Market Road,
London N7 9PW
Tel 0808 800 3333
(Mon–Fri, 9am–5pm)
Email response@scope.org.uk
www.scope.org.uk
Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for older people

Age UK
Tel (England and Wales)
0800 169 6565
Tel (Scotland)
0845 125 9732
Tel (Northern Ireland)
0808 808 7575
(Daily, 8am–7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)
Tel (England) 0844 800 4361
Tel (Scotland) 0141 221 5066
Tel (Wales) 0292 009 0087
Email support@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. You can find details for UK offices and search for local support on the website.

Carers UK
Tel (England, Scotland, Wales) 0808 808 7777
Tel (Northern Ireland)
028 9043 9843
(Wed–Thu, 10am–12pm and 2–4pm)
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.

Advanced cancer and end-of-life care

Help the Hospices
Hospice House,
34–44 Britannia Street,
London WC1X 9JG
Tel 020 7520 8200
Email
info@helpthehospices.org.uk
www.helpthehospices.org.uk
Provides information about living with advanced illness. Has a directory of hospice services and practical booklets available free from the website.

Marie Curie Cancer Care
89 Albert Embankment,
London SE1 7TP
Tel 0800 716 146
(Mon–Fri, 9am–5.30pm)
Email supporter.services@mariecurie.org.uk
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

The Natural Death Centre
In The Hill House,
Watley Lane, Twyford,
Winchester SO21 1QX
Tel 01962 712 690
Email
rosie@naturaldeath.org.uk
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

Bereavement support

Childhood Bereavement Network
8 Wakley Street,
London EC1V 7QE
Tel 020 7843 6309
Email cbn@ncb.org.uk

www.childhoodbereavementnetwork.org.uk
A national federation of organisations and individuals working with bereaved children and young people. Has an online directory where you can find local services.

Cruse Bereavement Care
PO Box 800,
Richmond TW9 1RG
Tel 0844 477 9400
(Mon–Fri, 9.30am–5pm)
Email helpline@cruse.org.uk
www.crusebereavementcare.org.uk
Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website, at **crusebereavementcare.org.uk/LocalCruse.html**

RD4U
Cruse Bereavement Care,
PO Box 800, Richmond,
Surrey TW9 1RG
Tel 0808 808 1677
(Mon–Fri, 9.30am–5pm)
Email info@rd4u.org.uk
www.rd4u.org.uk
Designed for young people by young people, RD4U is part of Cruse Bereavement Care. It supports young people after the death of someone close. Offers a private message service from the website.

The WAY Foundation
Suite 35, St Loyes House,
20 St Loyes Street,
Bedford MK40 1ZL
Tel 0300 012 4929
Email
info@wayfoundation.org.uk
www.wayfoundation.org.uk
A support network to help young widows and widowers rebuild their lives after the death of a partner.

Winston's Wish
3rd Floor, Cheltenham House,
Clarence Street, Cheltenham
GL50 3JR
Tel 08452 03 04 05
Email
info@winstonswish.org.uk
www.winstonswish.org.uk
Helps bereaved children and young people re-adjust to life after the death of a parent or sibling.

Further resources

Related Macmillan information

You may want to order some of the booklets mentioned in this booklet. These include:

- *Controlling cancer pain*
- *Coping with fatigue*
- *Coping with hair loss*
- *Eating problems and cancer*
- *Getting travel insurance*
- *Hello, and how are you? A guide for carers, by carers*
- *Help with the cost of cancer*
- *How are you feeling? The emotional effects of cancer*
- *Insurance*
- *Life after cancer treatment*
- *Lost for words – how to talk to someone with cancer*
- *Making treatment decisions*
- *Self-employment and cancer*
- *Talking about your cancer*
- *Talking to children when an adult has cancer*
- *The building-up diet*
- *Understanding cancer research trials (clinical trials)*
- *Understanding chemotherapy*
- *Understanding high-dose treatment with stem cell support*
- *Understanding radiotherapy*
- *Work and cancer*
- *Working while caring for someone with cancer*

To order a booklet, visit **be.macmillan.org.uk** or call **0808 808 00 00**. To order a cancer information sheet, call **0808 808 00 00**.

All of our information is also available online at **macmillan.org.uk/cancerinformation**

Macmillan audiobooks

Our high-quality audiobooks, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

Macmillan videos

There are many videos on the Macmillan website featuring real-life stories and information from health and social care professionals.

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information.

The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated:

Macmillan Cancer Support
www.macmillan.org.uk

Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate and up-to-date information on cancer and its treatment, including:

- all the information from our 150+ booklets and 360+ cancer information sheets
- videos featuring real-life stories from people affected by cancer and information from professionals
- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form for sending your questions

- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

www.cancer.gov (National Cancer Institute – National Institute of Health – USA)
Gives information on cancer and treatments.

www.cancer.org (American Cancer Society)
Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

www.cancerbuddiesnetwork.org (Cancer Buddies Network)
An online support group for anyone affected by cancer.

www.cancerhelp.org.uk (Cancer Research UK)
Contains patient information on all types of cancer and has a clinical trials database.

www.healthtalkonline.org
www.youthhealthtalk.org (site for young people)
Contains information about some cancers and has video and audio clips of people talking about their experiences of cancer and its treatments.

www.intelihealth.com (drug and medicines information)
Easy to use and free from medical jargon. Has patient information leaflets that can be printed off.

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

www.nhs.uk
(NHS Choices)
NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and gives all the information you need to make decisions about your health.

www.nhsdirect.nhs.uk
(NHS Direct Online)
NHS health information site for England – covers all aspects of health, illness and treatments.

www.nhs24.com
(NHS 24 in Scotland)

www.nhsdirect.wales.nhs.uk
(NHS Direct Wales)

www.n-i.nhs.uk
(Health and Social Care in Northern Ireland)

www.patient.co.uk
(Patient UK)
Provides people in the UK with good-quality 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.

www.riprap.org.uk
(Riprap)
Developed especially for teenagers who have a parent with cancer.

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

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Sources

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

Palumbo, A, et al. International Myeloma Working Group guidelines for the management of multiple myeloma patients ineligible for standard high-dose chemotherapy with autologous stem cell transplantation. *Leukemia*. 2009. 23: 1716–1730.
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National Institute for Health and Clinical Excellence (NICE). *Bortezomib and thalidomide for the first-line treatment of multiple myeloma*. 2009. www.nice.org.uk/guidance/index.jsp?action=download&o=44958 (accessed June 2010).

Smith A, et al. Guidelines on the diagnosis and management of multiple myeloma. *British Journal of Haematology*. 2005. 132: 410–451.

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

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

FRSB give with confidence

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

Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.

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 supporting you online, any time. The fundraisers who make it all possible.

You don't have to face cancer alone.
We can give you the strength to get through it.
We are Macmillan Cancer Support.

Questions about living with cancer?
Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)
Alternatively, visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.

Next planned review 2015. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).

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Certified member
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