Understanding primary bone cancer

> "My friends couldn't believe I got cancer. You know, I am over 6 feet tall, healthy, I played football, I was a big strapping guy."

Conor, diagnosed with primary bone cancer

About this booklet

This booklet is about primary bone cancer. This means that the cancer has started in a bone. It is for anyone who has been diagnosed with primary bone cancer. There is also information for carers, family members and friends.

Primary bone cancer is different from secondary bone cancer. Secondary bone cancer is a cancer that started somewhere else in the body and has spread to the bones. Your doctor will tell you whether the cancer is a primary or secondary bone cancer.

This booklet does not have information about secondary bone cancer. We have another booklet about this called **Understanding secondary cancer in the bone** (page 128).

We have more information on different types of bone cancer on our website. Visit **macmillan.org.uk/bone-cancer** or call our support line on **0808 808 00 00.**

We hope this booklet helps you deal with some of the questions or feelings you may have.

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

How to use this booklet

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

It is fine to skip parts of the booklet. You can always come back to them when you feel ready. On pages 134 to 140, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had primary bone cancer, which you may find helpful. These are from people who have chosen to share their story with us. This includes Conor, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

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

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

Contents

The bones and primary bone cancer

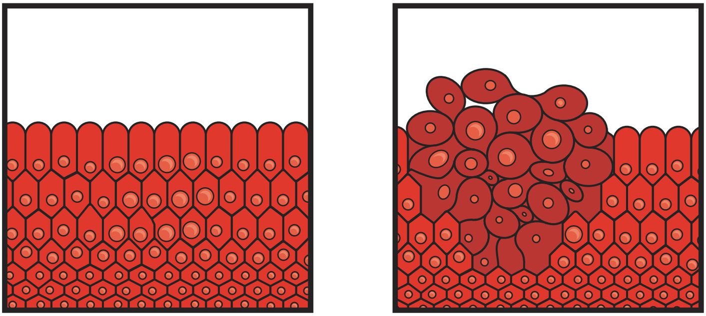
What is cancer?

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or cannot be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a lump (tumour).

Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors look at the sample under a microscope to look for cancer cells.

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

A lump that is not cancerous (benign) may grow, but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancerous (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body.

The cells can travel through the blood or lymphatic system. When the cells reach another part of the body, they may start to grow and make another tumour. This is called a secondary cancer (metastasis).

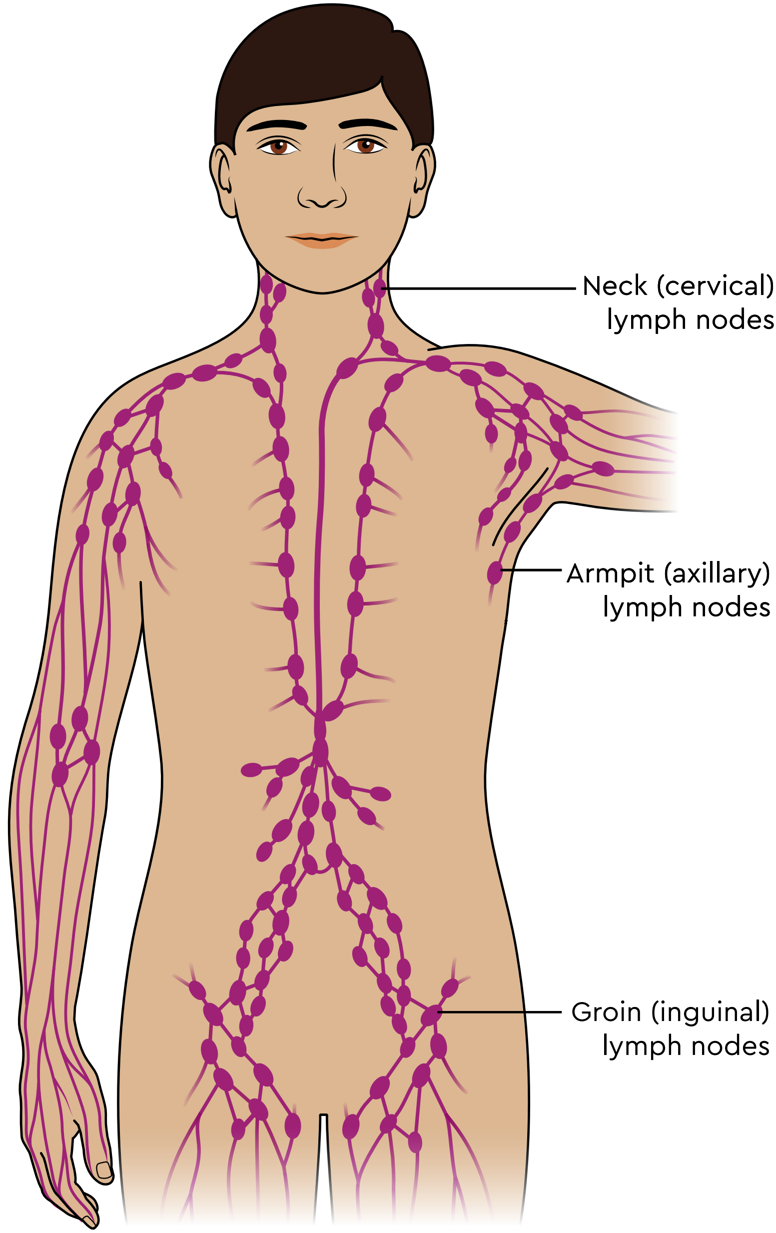
The lymphatic system

The lymphatic system helps protect us from infection and disease. It also drains lymph fluid from the tissues of the body, before returning it to the blood.

The lymphatic system is made of fine tubes called lymphatic vessels that connect to groups of lymph nodes (sometimes called lymph glands) throughout the body.

Lymph nodes are small and bean-shaped. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, lymph nodes often swell as they fight the infection.

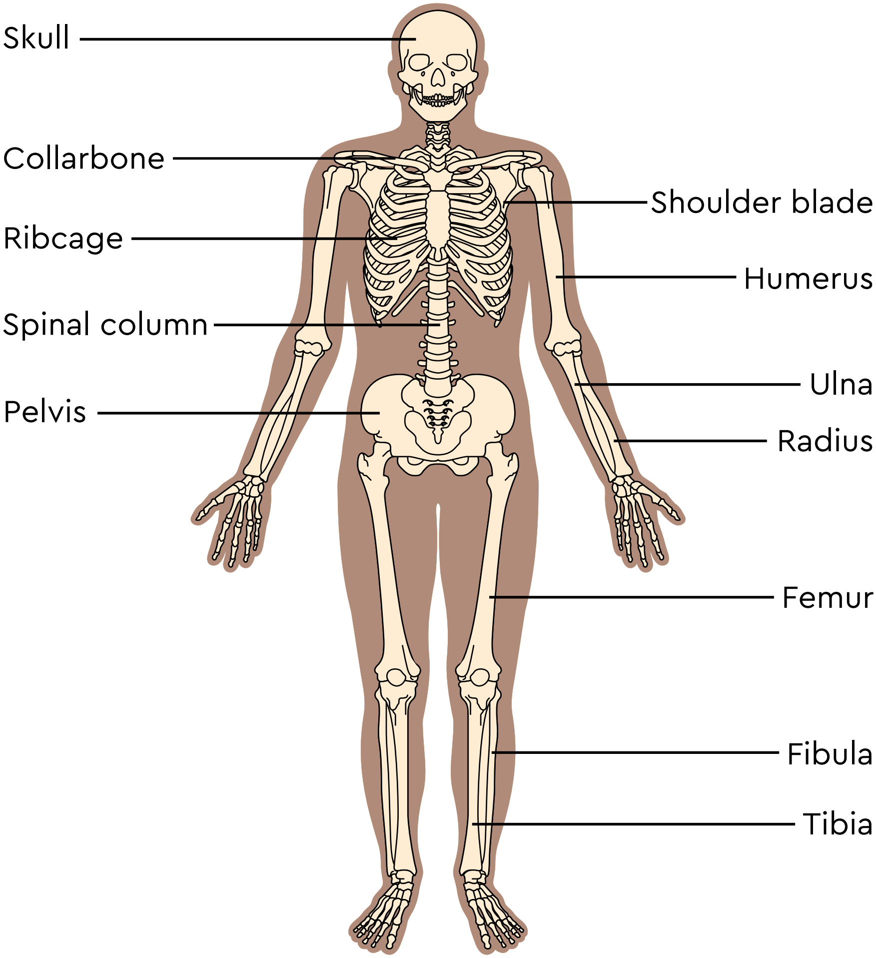
The lymphatic system



The bones

The human skeleton is made up of more than 200 bones of different shapes and sizes.

The human skeleton



Bones are made of:

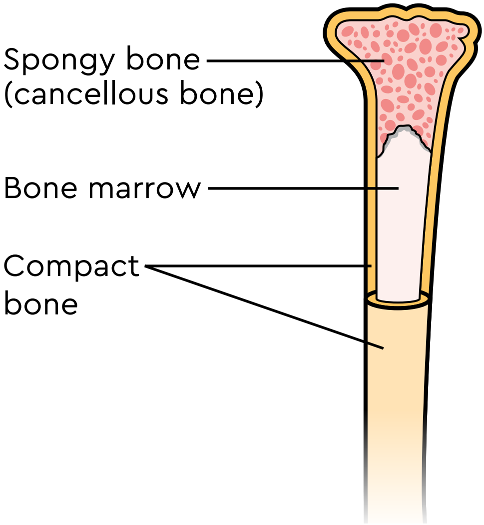
- a type of protein called collagen
- minerals such as calcium and phosphate.

The combination of collagen and minerals makes the bones strong.

Bones have many important roles in the body, including the following:

- **Supporting our bodies** – the joints at the end of bones act as levers, allowing us to move around. The joints are covered in cartilage which allows the joints to move smoothly.
- **Protecting parts of our bodies from injury** – for example, the ribs protect the heart and lungs, and the skull protects the brain.
- **Storing important minerals** – such as calcium, for our bodies to use.
- **Making blood cells** – some bones are filled with a soft, spongy material called bone marrow. The bone marrow is where the blood cells are made (page 12).

The structure of a long bone



Bones contain 2 types of cells that break down old bone and replace it with new bone:

- Osteoclasts break down and remove old bone.
- Osteoblasts make new bone.

This helps bones to keep their strength and shape.

Types of primary bone cancer

Primary bone cancer is a cancer that starts in a bone. It is sometimes called a bone sarcoma. This is different from secondary bone cancer, which has spread to the bone from a cancer elsewhere in the body.

Primary bone cancer is rare. About 550 people are diagnosed with it in the UK each year. It can affect people of any age. It is slightly more common in men than women.

There are different types of primary bone cancer. If the cancer you have is not one that we describe here, contact our cancer support specialists on **0808 808 00 00**. They can give you more information.

Osteosarcoma

Osteosarcoma is one of the most common types of primary bone cancer. It can affect people of any age, but it is most common in teenagers and young adults. We have more information at **macmillan.org.uk/young-people**

Osteosarcoma can affect any bone (page 10), but it is most likely to develop in the:

- upper arm (humerus)
- shin bone (tibia)
- thigh bone (femur), close to the knee.

We have more information at **macmillan.org.uk/osteosarcoma**

Chondrosarcoma

Chondrosarcoma is another common type of primary bone cancer. It is usually slow-growing. Chondrosarcoma is most common in people aged over 40. It is rare in people younger than 20.

Chondrosarcoma starts in cartilage cells. It can grow inside a bone or on the surface of a bone (page 12). The most common places for it to develop are the:

- upper arm (humerus)
- thigh (femur)
- pelvis
- shoulder blade (scapula)
- ribs.

It can also develop in other bones, such as the spine. We have more information at **macmillan.org.uk/chondrosarcoma**

Ewing sarcoma

Ewing sarcoma is named after the doctor who first described it. It is more common in teenagers and young adults, but it can affect people of any age.

Ewing sarcoma can affect any bone, but the most common places are the:

- pelvis
- thigh (femur)
- shin bone (tibia)
- ribs
- shoulder blade (scapula).

Sometimes Ewing sarcoma can start in the soft tissues of the body. This is called extraosseous Ewing sarcoma. Extra means outside, osseous means bone. It can also be called soft tissue Ewing sarcoma. It is often treated in the same way as Ewing sarcoma that starts in the bone.

We have more information at **macmillan.org.uk/ewing**

Chordoma

This is a rare cancer. It can affect people of any age, but it is more common in people over the age of 40.

Chordoma is usually slow-growing. It starts in the bones:

- in the spine
- at the bottom of the skull.

We have more information at **macmillan.org.uk/chordoma**

Rarer types of primary bone cancer

There are other types of primary bone cancer. These are much rarer. They include:

- giant cell tumour
- adamantinoma.

It can be hard to get information about the rarer types of primary bone cancer. Your cancer doctor and specialist nurse will give you more information and answer any questions you have. You can also talk to the nurses on the Macmillan Support Line by calling **0808 808 00 00** (page 130).

Risk factors and causes

The exact causes of primary bone cancer are not known. For most people with bone cancer, it is not clear why it has developed.

Many bone cancers affect teenagers and young people. This might mean that bone cancer is related to changes that happen in growing bones.

There are certain things that can affect the chances of developing primary bone cancer. These are called risk factors. Having a risk factor does not mean you will get bone cancer. People without risk factors can also develop bone cancer.

Previous cancer treatment

Treatment with radiotherapy or some chemotherapy drugs can increase the risk of developing primary bone cancer many years later. But the risk is very small compared to the benefit of having the cancer treatment.

Genetic conditions

Most bone cancers are not caused by a gene that you can inherit. But some genetic conditions increase the risk of developing certain bone cancers.

People who have Li-Fraumeni syndrome have an increased risk of developing osteosarcoma (page 13). Li-Fraumeni syndrome is an inherited condition that increases the risk of several cancers.

Children who have retinoblastoma have an increased risk of developing osteosarcoma. Retinoblastoma is a rare type of eye cancer caused by an inherited gene change.

Non-cancerous bone conditions

Some non-cancerous (benign) bone conditions can increase your risk of developing bone cancer.

The following conditions can increase the risk of osteosarcoma:

- **Paget's disease of the bone**, which causes painful and deformed bones.
- **Fibrous dysplasia**, which is a condition where bone is replaced with scar-like tissue. It most commonly affects teenagers and young adults. It can cause swelling and painful, deformed bones.

The following rare conditions can increase the risk of developing chondrosarcoma (page 14):

- **Osteochondroma** (or **chondroma**) causes non-cancerous growths to develop on the bones. Rarely, these growths can develop into chondrosarcoma.
- **Hereditary multiple exostoses (HME)** is also called **hereditary multiple osteochondroma (HMO)**. This is a rare genetic condition that causes bony lumps to grow on the surface of bones. It often starts in childhood and is usually inherited.
- **Ollier's disease** and **Maffucci's syndrome** are rare conditions that cause non-cancerous growths in cartilage close to the bone. They often start in childhood, but they are not inherited.

Bone injury

Sometimes people find out they have primary bone cancer after an injury to their bone. There is no clear evidence that an injury to a bone can cause bone cancer. But the injury may make you notice symptoms and help to find a bone cancer that is already there.

Symptoms

Pain or tenderness

This may start as an ache in the affected area that does not go away. You may have pain at night or when you are resting. It can feel worse during or after exercise. In children, this symptom may be mistaken for a sprain or growing pains.

If you have unexplained bone pain, visit your GP to have it checked.

Swelling

If there is swelling near the affected area of the bone, the cancer may not be noticed until the tumour is quite large. You might not see or feel a lump if the affected bone is deep inside the body.

Reduced movement of a joint or limb

If the cancer is near a joint, you may find it harder to move the joint. Movement in the arm or leg may be affected. If the affected bone is in the leg, it may cause a limp.

A tumour in the spine may press on nerves. This can cause numbness, tingling or weakness in the arms or legs. It can also cause problems controlling the bladder or bowel.

If you have symptoms of a tumour in the spine, you may have spinal cord compression. It is very important to contact a doctor straight away to find out the cause of your symptoms and how they need to be managed. We have more information in our **Malignant spinal cord compression** leaflet (page 128) and on our website at **macmillan.org.uk/malignant-spinal-cord-compression**

Broken bone

A bone that has been weakened by cancer may break (fracture) without any warning. Or it may break after a small fall or accident.

Other possible symptoms

Ewing sarcoma (pages 14 to 15) may also cause:

- tiredness
- weight loss
- a high temperature or sweats.

Many of these symptoms can be caused by other conditions that are more common than bone cancer. But if you have any new symptoms that do not go away, it is important to get them checked. Talk to your GP if you are worried about any symptoms.

> **"I first noticed that something wasn't quite right when I started to get an annoying pain in my lower back. I thought I'd strained my back lifting the girls or something."**
>
> Waheed, diagnosed with primary bone cancer

Diagnosing primary bone cancer

How bone cancer is diagnosed

You usually start by visiting your GP, who will examine you. They may arrange for you to have tests or x-rays.

If your GP is not sure what the problem is, or thinks your symptoms could be caused by bone cancer, they will refer you to a bone surgeon. A bone surgeon is also called an orthopaedic surgeon. They may also refer you to a bone cancer specialist.

You may be treated in a bone tumour treatment centre, called a sarcoma unit (page 48).

The National Institute for Health and Care Excellence (NICE) has the following guidance:

- Children, teenagers and young adults with unexplained bone swelling or pain should have an urgent x-ray within 2 days. If the x-ray suggests a possible bone cancer, your GP should refer you to a specialist within 2 days.
- Adults should be seen by a specialist within 2 weeks if the results of an x-ray suggest a bone cancer.

We have more information about how cancer is diagnosed on our website.
Visit **macmillan.org.uk/tests-scans**

At the hospital

The cancer doctor will ask about your symptoms and your general health. They will also examine you. This includes checking the area where there is pain or swelling. You may need to have blood tests and a chest x-ray to check your general health.

The following tests are commonly used to diagnose a bone cancer.

The tests you have will depend on the part of the body that is being investigated. You may have had some of these tests already.

Our cancer support specialists or your cancer doctor or specialist nurse can give you information about any tests we do not explain here (page 130).

Bone x-rays

Bone x-rays may show if the cancer:

- started in the bone (primary bone cancer)
- spread to the bone from a cancer that started somewhere else in the body (secondary bone cancer).

Sometimes the way the bone looks on an x-ray can help the doctor tell which type of bone cancer it is. This is often the case for osteosarcoma (page 13).

MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of the body. The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips.

Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of a dye called a contrast. This helps show certain areas of the body more clearly.

During the scan, you need to lie still on a bed inside a long cylinder or tube. If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan.

The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

We have more information about having an MRI scan on our website. Visit **macmillan.org.uk/mri-scan**

Biopsy

The doctor may take a sample of cells from the tumour. This is called a biopsy. The sample is sent to a specialist doctor called a pathologist with experience in bone tumours. They look at cells from the sample under a microscope to tell if the tumour is cancer or not. If it is cancer, your doctors may do further tests on the sample to find out the type of bone cancer.

If your doctor thinks you have bone cancer, the biopsy should be done at a specialist bone cancer centre. The type of biopsy you have depends on where the lump is and its size.

Core needle biopsy

This is the most common type of biopsy. The doctor uses a small, hollow needle to take a small sample of the bone tumour. They usually take several samples.

Before the biopsy, the doctor injects a local anaesthetic into the skin around the lump to numb the area.

You will usually be awake during a needle biopsy. But the doctor may give you a sedative so that you feel relaxed and sleepy. Sometimes the biopsy is taken under a general anaesthetic. That means you are asleep during the test.

You may have a scan, such as a CT scan, ultrasound scan or x-ray during the biopsy (pages 28 to 32). The pictures from the scan help the doctor guide the needle to the right place.

Incision biopsy

This type of biopsy is not often used, because the needle biopsy is much quicker and easier. During an incision biopsy, the surgeon removes a small piece of bone during a small operation. The surgeon uses a surgical knife called a scalpel to open the affected area. They then take a sample from the lump. This is done under a general anaesthetic.

You may need this test if:

- you cannot have a needle biopsy
- the surgeon needs a slightly bigger piece of bone for diagnosis
- you had a needle biopsy that did not give a clear result.

Testing for genetic changes

Tests are done on the tissue samples to find out if there are any genetic changes in the sarcoma cells. It is sometimes called cytogenetic testing.

This information can help tell your doctor the type of bone cancer you have and if certain treatments are suitable for you.

Immunohistochemistry testing

The tissue sample is tested using a special cell staining process. This is to look at any proteins the cancer cells might be producing.

It can take about 2 weeks to get these results back.

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 to be ready. You may find it helpful to talk with your partner, your family or a close friend.

Your specialist nurse or a support organisation can also provide support (pages 134 to 140). Or you can talk to one of our cancer support specialists on **0808 808 00 00**, 7 days a week, 8am to 8pm.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically.

There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 140).

Further tests

If the tests show that you have bone cancer, the cancer doctor may do further tests. These are to find out if the cancer has spread outside the bone. This is called staging (pages 34 to 37). The results of the tests will help you and your cancer doctor decide on the best treatment for you. The tests needed will depend on the type of cancer.

Chest x-ray

For people with primary bone cancer, the most common place for the cancer to spread to is the lungs. A chest x-ray can show if the lungs have been affected.

CT scan

Most people with bone cancer will have a chest CT scan of their lungs. You might also have a CT scan of the affected bone.

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information about having a CT scan on our website. Visit **macmillan.org.uk/ct-scan**

PET or PET-CT scan

A PET scan uses low-dose radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

If you are pregnant or breastfeeding, speak to the scanning department before the scan for advice.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer. The radiographer will encourage you to drink water. This helps move the tracer around your body.

Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The scan takes about 30 to 60 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

The amount of radiation used is very small. But the radiographer will advise you not to have close contact with pregnant people, babies and young children for up to 24 hours after the scan.

We have more information about PET and PET-CT scans on our website.
Visit **macmillan.org.uk/pet-ct-scan**

Bone marrow sample

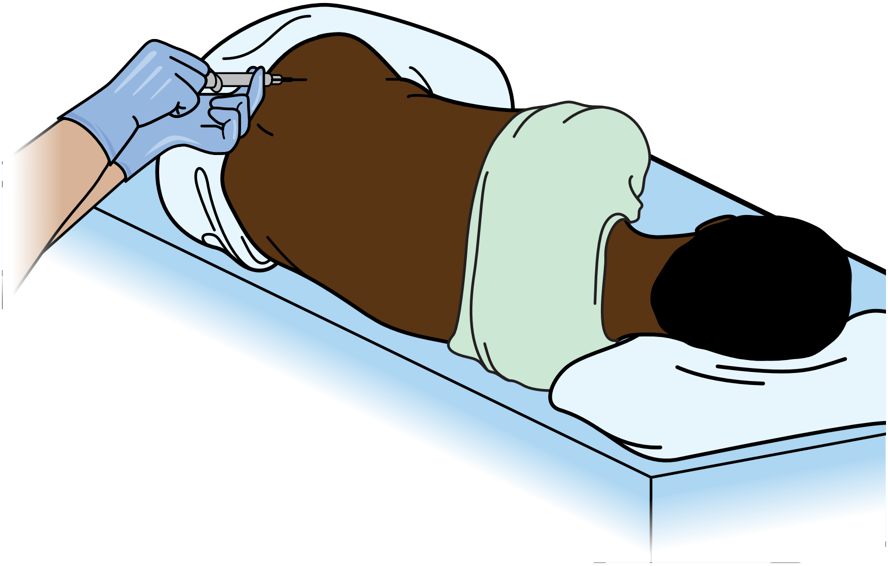
The bone marrow is the spongy material inside the bones where blood cells are made (page 12).

When Ewing sarcoma is suspected or diagnosed, the doctor will take a small sample of bone marrow. This is because Ewing sarcoma (page 14) can sometimes spread to the bone marrow.

They usually take the sample from 1 side of the hip bone (pelvis). Sometimes they also take a sample from the other side.

Before the test, you have local anaesthetic injected into the area near the bone to numb it. The doctor then passes a needle through the skin into the bone. When the needle is in position, the doctor draws a small liquid sample from the bone marrow into a syringe. You may feel some discomfort for a few seconds.

Taking a bone marrow sample



You usually have the test in the outpatient department. It takes about 10 to 15 minutes.

Sometimes the doctor needs to take a small core of bone marrow. They pass a special type of needle through the skin into the bone marrow. The needle has a tip that can cut out a sample of the bone marrow. You may feel bruised or sore for a few days after the test. You can take mild painkillers to help with this.

Your bone marrow samples are sent to a laboratory to be looked at under a microscope. It usually takes 7 to 10 days to get the results back.

Bone scan

This is a more sensitive test than an x-ray. It shows up any abnormal areas of bone more clearly. The person who does the scan is called a radiographer. They inject a small amount of a radioactive substance through a cannula into a vein in your hand or arm. This is called a tracer. The amount of radiation used is small. It does not cause you any harm.

You need to wait for 2 to 3 hours between having the injection and having the scan. You may want to take something to help pass the time such as a book or tablet computer.

Areas of abnormal bone absorb more radiation than normal bone. This means the abnormal bone shows up more clearly on the scanner. The abnormal areas are sometimes called hot spots.

It is not always clear whether hot spots are caused by cancer or by other conditions such as arthritis. Sometimes doctors also use a CT scan (page 28 to 29) or MRI scan (page 24) to help them decide. Some hospitals do an MRI scan of the whole skeleton instead of a bone scan. This is to check for signs of cancer in any other bones in the body.

Grading and staging

Your cancer doctor needs information about the cancer to find the best treatment for you. This includes:

- the grade of the cancer
- the stage of the cancer (pages 34 to 37).

This information comes from the tests you have had (pages 22 to 32).

The grading and staging of primary bone cancer are complex. Your cancer doctor and specialist nurse will talk to you about this. They will explain how it helps you and your cancer doctor decide on a treatment plan that is right for you.

Grading

Doctors look at a sample of the cancer cells under a microscope to find out the grade of the cancer. The grade gives an idea of how quickly the cancer might grow or develop.

The most common grading system for primary bone cancer uses the following 3 grades:

- **Grade 1** – cancer cells are low-grade and look like normal bone cells. They are usually slow-growing and less likely to spread.
- **Grade 2** – cancer cells are high-grade and look abnormal. The cells are likely to grow more quickly and are more likely to spread.
- **Grade 3** – the cancer cells are high-grade but look more abnormal than grade 2. This means the cancer is more likely to come back (recur) or spread to other parts of the body.

All Ewing sarcoma and most osteosarcoma and spindle cell tumours are high-grade (pages 13 to 15).

Staging

The stage of a primary bone cancer describes:

- its size
- whether it has spread outside the bone where it started.

Knowing the stage of the cancer helps the doctors plan the best treatment for you.

There are different staging systems used for primary bone cancer. The staging systems often include the following terms.

TNM staging

TNM stands for Tumour, Node and Metastases:

- **T** describes the size of the tumour.
- **N** describes whether the cancer has spread to lymph nodes.
- **M** describes whether the cancer has spread to another part of the body, such as the lungs or liver. This is called metastatic or secondary cancer.

Number staging

Information from the TNM system and the grade of the cancer can be combined to give a number stage. The staging depends on where the tumour is in the body.

Number staging is used for bone cancers in the:

- limbs
- shoulders
- trunk (body)
- skull
- bones in the face.

It is divided into 4 stages:

Stage 1

The bone tumour has not spread to nearby lymph nodes, or to other parts of the body. It is divided into 2 stages.

Stage 1A

- The bone tumour is 8cm or less.
- It is grade 1, or the grade cannot be assessed.

Stage 1B

- The bone tumour is bigger than 8cm.
- There is more than 1 tumour in the same bone.
- It is grade 1, or the grade cannot be assessed.

Stage 2

The bone tumour has not spread to nearby lymph nodes or to other parts of the body. It is divided into 2 stages.

Stage 2A

- The bone tumour is 8cm or less.
- It is grade 2 or grade 3.

Stage 2B

- The bone tumour is bigger than 8cm.
- It is grade 2 or grade 3.

Stage 3

- The bone tumour has not spread to lymph nodes or to other parts of the body.
- The bone tumour is bigger than 8cm.
- There is more than 1 tumour in the same bone.
- It is grade 2 or grade 3.

Stage 4

The bone cancer is advanced. It can be any size and there may be more than one tumour in the same bone. The bone tumour may be any grade and may have spread to either or both of the following:

- lymph nodes nearby
- other parts of the body, such as the lungs, liver or bones (called secondary or metastatic cancer).

Your doctor or specialist nurse can give you more information about the grade and stage of the type of primary bone cancer you have.

Bone tumours in the pelvis and spine are described differently. If you have a tumour in the pelvis or spine, your doctor can tell you more about the stage.

> **"I was unsure of what would happen next, and that was the most unsettling part of the whole ordeal. I avoided Googling, though. I think that would have just sent me over the edge."**
>
> Conor

Treating primary bone cancer

Treatment overview

The treatment for primary bone cancer depends on:

- where the cancer started in the body
- the size of the tumour
- whether the cancer has spread
- your general health
- your preferences.

The results of your tests will help your doctors plan the best type of treatment for you. They will then talk about this with you. Most people need a combination of treatments.

Surgery

Surgery is an important part of treatment (pages 50 to 77). It is used to remove the cancer in the bone.

Sometimes it is not possible to remove a bone cancer using surgery. This is more likely to happen if the cancer is in a bone:

- deep within the body, such as the pelvis
- that cannot be removed without the risk of serious disability, such as in the spine.

If this happens, chemotherapy (pages 78 to 89) and radiotherapy (pages 93 to 101) are used instead.

Chemotherapy

Most people with primary bone cancer will have chemotherapy. It is not generally used for people with chordoma (page 15) or chondrosarcoma (page 14).

Nearly everyone with Ewing sarcoma will have chemotherapy (pages 14 to 15). It is also given to most people with osteosarcoma (page 13) and spindle cell sarcoma.

Chemotherapy may be given:

- before surgery to shrink the cancer, making it easier to remove – this is called neoadjuvant chemotherapy
- after surgery to destroy any remaining cancer cells – this is called adjuvant chemotherapy
- if the cancer comes back.

Radiotherapy

Radiotherapy (pages 93 to 101) is mainly only used to treat Ewing sarcoma. It is often given with chemotherapy and surgery. Radiotherapy can be given either before or after surgery. If it is not possible to have surgery to remove the cancer, radiotherapy may be used as the main treatment.

Other types of primary bone cancer are not as sensitive to radiation. But radiotherapy may sometimes be used:

- if surgery is not suitable
- if surgery has not completely removed the tumour
- instead of surgery
- as well as surgery.

Targeted therapy

Targeted therapy (pages 90 to 92) is sometimes used to treat osteosarcoma after surgery. But it is only suitable for some people.

Research is happening to find better treatments for primary bone cancer. You may be invited to take part in a clinical trial of a new drug or treatment.

We have more information about clinical trials at **macmillan.org.uk/clinial-trials**

How treatment is planned

Primary bone cancer is a rare cancer, so you should always be referred for treatment at a specialist sarcoma unit (page 48). A team of specialist health care professionals will discuss your test results. If your tests show a diagnosis of bone cancer, a team of specialists meets to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

A sarcoma MDT includes the following professionals:

- **Orthopaedic surgeon** – a doctor who specialises in bone surgery.
- **Oncologist** – a doctor who uses radiotherapy, chemotherapy and other anti-cancer drugs to treat people with cancer.
- **Clinical nurse specialist (CNS)** – a nurse who gives information about cancer, and support during treatment.
- **Radiologist** – a doctor who looks at scans and x-rays to diagnose problems.
- **Pathologist** – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.

The MDT may also include healthcare professionals such as the following:

- **Dietitian** – someone who gives information and advice about diet and how to keep to a healthy weight.
- **Key worker** – someone who is the main point of contact for people living with cancer. They can help answer any questions. This person could be a specialist nurse or a social worker.
- **Physiotherapist** – someone who gives advice about exercise and mobility.
- **Plastic surgeon** – a doctor who does operations (surgery) to repair or reconstruct tissue and skin.
- **Occupational therapist** – someone who gives information, support and aids to help people with everyday tasks such as washing and dressing.
- **Psychologist** – someone who gives advice about managing feelings and behaviours.
- **Counsellor** – someone who is trained to listen to people's problems and help them find ways to cope.
- **Social worker** – someone who can help sort out practical and financial problems.

Talking about your treatment plan

After the MDT meeting, your cancer doctor and specialist nurse will usually talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions.

Your cancer doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan. If it is not possible to remove all the cancer and the aim of the treatment is to control the cancer, you may find it hard to decide what to do. You may need to talk about this in detail with your doctor. If you choose not to have the treatment, you can still be given supportive (palliative) care to control any symptoms.

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision.

You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk/second-opinion**

Specialist treatment centres

Your treatment is usually planned and given in a sarcoma treatment centre. The sarcoma unit could be based in 1 hospital. Or it could be spread across a group of nearby hospitals that work together.

Primary bone cancer is rare and there are only a small number of sarcoma treatment centres in the UK. This means you may need to travel a long distance.

It may be possible to have some of your treatment at a hospital close to home. The doctors at the sarcoma treatment centre will work with a cancer doctor in your local hospital to plan your treatment. This is called shared care.

Teenage cancer units

Some hospitals have teenage cancer units (sometimes called TYA units), which are specially designed for teenagers and young adults. Other hospitals may have special wards or areas for you if you are a teenager with cancer.

We have more information at **macmillan.org.uk/young-people**

Children's cancer centres

Children with bone cancer are treated in hospitals that specialise in treating children's cancers. The Children's Cancer and Leukaemia Group has more information about children's cancer centres. Visit its website at **cclg.org.uk** or call **0333 050 7654**.

Surgery

Surgery is usually the main treatment for most types of primary bone cancer. When surgery is not possible, your cancer doctor will talk to you about other treatments.

Primary bone cancers are rare, so surgery is done by a specialist surgeon as part of a bone sarcoma multidisciplinary team (MDT) – pages 43 to 44. They are based in a specialist sarcoma unit page 48).

Before surgery

Before surgery, your surgeon and specialist nurse will tell you about the side effects and possible risks. It is important you understand what your operation may involve.

Depending on the type of surgery you have, you may be referred to a rehabilitation team. They will help you recover from the operation, and make sure the area being operated on moves and works as well as possible.

Before surgery, you may be given advice on:

- stopping smoking to help you recover and reduce your risk of problems after surgery
- exercises to help you get back to your usual activities after surgery, or to get fitter – for example, if you will use crutches or a walking frame after surgery, they might suggest upper-body strength exercises
- eating healthily or taking supplement drinks.

We have more information at **macmillan.org.uk/preparing-surgery** and **macmillan.org.uk/stop-smoking**

Types of surgery for primary bone cancer

The type of operation depends on where the cancer is in the body.

Some operations for primary bone cancer are minor. Others may involve major surgery and could affect how that area of the body works or looks.

Sometimes reconstructive surgery is also needed so the area affected can work or move as well as possible (pages 54 to 55). In some cases, the surgeon can remove the affected area of bone without replacing it.

Wide local excision

The aim of most sarcoma surgery is to remove (excise) all of the cancer from the bone. Surgery may affect the way the body part moves or works, but surgeons will try to keep as much movement as possible. Usually, they do an operation called a wide local excision. This means the surgeon removes the cancer, along with an area (margin) of healthy, cancer-free tissue around it.

After the operation, the pathologist looks at the tissue from the margin under a microscope. If there are cancer cells in the margin, you may need another operation to remove more tissue. Making sure the margins are clear reduces the risk of the cancer coming back.

Most bone cancers affect the arms and legs (limbs) or pelvis – page 10. Surgery to these areas is done by a bone surgeon called an orthopaedic surgeon. If the cancer is in the bones of the face, skull or chest, a surgeon who specialises in those areas of the body will do the surgery.

Your surgeon will talk with you about which operation they think is best for you.

Surgery to the arms and legs (limbs)

It is usually possible to remove a primary bone cancer in an arm or leg without having to remove the whole limb. This is called limb-sparing or limb-salvage surgery (pages 56 to 65). You will usually have chemotherapy before and after the operation (pages 78 to 89). Sometimes radiotherapy may also be used (pages 93 to 101).

Rarely, the most effective treatment option is to remove the affected limb. This is called an amputation. This is to make sure all the cancer has been removed. It may also be done if the surgeon thinks that limb-sparing surgery may cause problems with movement of the limb.

Surgery to other areas of the body

Bone cancer in the pelvis

When possible, a wide local excision is used to remove primary bone cancer in the pelvis. Depending on the type of bone cancer, chemotherapy may be used before the operation (pages 78 to 89). This is to help shrink the cancer before surgery. For some types of bone cancer, chemotherapy is sometimes used after surgery.

Radiotherapy may also be given before or after surgery (pages 93 to 101).

Sometimes, the pelvis is reconstructed using bone taken from another area of the body. This is called a bone graft.

If lymph nodes in the pelvis are removed, this can increase the risk of lymphoedema in your legs (pages 62 to 63). Lymphoedema is swelling near to where the lymph nodes were removed. Your doctor and nurse will explain more about this.

Bone cancer in the jawbone

The whole bone is usually removed and then reconstructed using bone taken from another part of the body. If it is not possible to remove the whole bone, radiotherapy may also be used (pages 93 to 101).

Bone cancer in the spine or skull

If it is possible to remove all the cancer safely, a combination of treatments might be used. These include surgery, chemotherapy (pages 78 to 89) and radiotherapy (pages 93 to 101).

Reconstructive surgery

Depending on the size and position of the bone cancer, the surgeon may need to remove a large area of bone.

This means you may have surgery to reconstruct the area at the same time as your operation. It may be possible to replace the bone that is removed with a metal implant. This is called an endoprosthetic replacement (EPR).

If a metal implant or a bone graft is needed, surgery is done by a plastic surgeon and an orthopaedic (bone) surgeon – page 43.

The aim of reconstructive surgery is to make the area look and work as naturally as possible. The surgery you have depends on:

- where in your body the cancer is
- how much bone and tissue the surgeon needs to remove.

Rehabilitation can take time. You will have support with your recovery and go to the hospital gym for physiotherapy. This will help you recover and reduce the risk of problems after surgery.

Your surgeon and specialist nurse will talk to you about the operation. They can answer any questions you have and give you an idea of how the area will look after surgery. They may be able to show you photographs of others who have had the same surgery.

Body image after surgery to the bone

Having surgery to the bone can affect how you think and feel about your body (body image) – pages 106 to 107. Your doctor or nurse can arrange for you to see a psychologist or counsellor if you feel you need more support with this (page 44).

We have more information about body image on our website. Visit **macmillan.org.uk/body-image**

Surgery to remove secondary cancer

Surgery is sometimes used to remove a primary bone cancer that has:

- spread to other parts of the body (secondary cancer)
- come back after treatment (recurrence).

It is mainly done when the cancer has spread to the lungs. An operation may only be possible if the secondary cancers are small and there are only a few of them.

Sometimes surgery is used for cancer in other parts of the body. If you need to have this operation, your cancer doctor will talk with you about it.

Sometimes chemotherapy is given first (pages 78 to 89). This can help shrink the secondary cancers and help make an operation possible.

Limb-sparing surgery

This is the most common type of surgery for a primary bone cancer in an arm or leg. The surgeon removes the affected part of the bone and may replace it with either:

- a metal implant (prosthesis)
- bone from another part of the body, or from someone else (bone graft).

If the cancer affects a bone in or near to a joint, the surgeon can often replace the joint with an artificial one.

Preparing for limb-sparing surgery

Before the operation, your surgeon will explain:

- what is involved in the surgery
- how the surgery might affect you
- the possible risks and complications of the operation.

You can ask your surgeon to explain more about how the surgery might affect you.

If you are having limb-sparing surgery with a metal implant, you might like to see the implant before it is fitted. Your surgeon, specialist nurse or keyworker can usually arrange this for you (pages 43 to 44).

There is a risk the metal implant could become infected. Your cancer doctor will explain more about this and what they will do to reduce the risk of infection.

You will meet some of the rehabilitation team who will help you after your operation. They will help you keep as much movement as possible in the affected limb. This is so you can be as independent as possible after the surgery. They can also give you information about your recovery.

The team will include specialist doctors and nurses, as well as:

- a physiotherapist
- an occupational therapist (OT)
- a social worker.

A physiotherapist may talk to you before your operation. They may give you some exercises to do before surgery, to help strengthen your muscles.

You may find it helpful to talk to someone who has had the same operation. Your healthcare team or keyworker may be able to arrange this for you. Some hospitals have a counsellor you can talk to about your feelings and worries before the operation (page 106).

You may also find it helpful to contact Sarcoma UK or the Bone Cancer Research Trust (pages 134 to 135).

After your limb-sparing operation

When you wake up from the operation, you may have a drip (intravenous infusion) going into your arm to replace your body's fluids. This can be removed as soon as you are drinking enough.

Your wound

You may have some tubes (drains) to drain fluid from the wound. Drains should not affect your ability to move around. These are removed when fluid has stopped draining. This should take a few days. Some drains have pumps attached to them to help the wound drain.

Your surgeon may use stitches or clips to close the wound. Sometimes they use dissolvable stitches. If you have stitches or clips that need to be removed, you will be told when and where this will happen.

The nurses will monitor the wound for any signs of infection. Let them know straight away if:

- you feel unwell and have a high temperature
- there is any warmth, swelling or redness around the wound
- there is discharge from the wound.

Seroma

A seroma is a collection of serous fluid that might develop near to a wound after certain types of surgery. Often, the body will naturally reabsorb the fluid from a seroma. Sometimes they need to be drained using a needle and syringe.

A drain may be left in longer to avoid a seroma developing, or manage one that does appear.

Pain

Pain can usually be controlled effectively with painkillers. They may be given:

- into a vein (intravenously)
- into the space around your spinal cord (epidural)
- into a muscle (intramuscularly)
- as tablets.

To start with, you will probably have a strong painkiller, such as morphine. You may be given intravenous pain relief through a syringe that is connected to an electronic pump.

The pump can be set to give you a continuous dose of painkiller. You may also have a handset with a button you can press if you feel sore. This is called patient-controlled analgesia (PCA).

It is designed so that you cannot have too much painkiller (an overdose). That means you can press it whenever you are uncomfortable.

If you have had surgery to your leg, you may have pain relief using an epidural. This is a fine tube inserted through your back into the area around the spinal cord (the epidural space). A local anaesthetic can be given continuously into this space to numb the nerves that run into the legs.

If you are in pain, let your nurses and doctors know as soon as possible. This will help them give you the right combination and dose of painkillers.

Exercises

Your nurses or the physiotherapist will teach you breathing and leg exercises. They will also encourage you to move around as soon as possible.

Breathing exercises will help prevent you getting a chest infection. Leg exercises help stop blood clots forming in your legs. Chest infections or blood clots can develop if you are not moving around as much as normal. You can help your recovery by doing the exercises as often as you need to.

You may be given elastic stockings called TED stockings to wear to help prevent a blood clot in your leg. This is called a deep vein thrombosis or DVT. You may also be given injections of anti-clotting medicines to help thin your blood.

Rehabilitation after limb-sparing surgery

Limb-sparing surgery is a major operation and rehabilitation can sometimes take a long time. It can often be hard work and may be frustrating at times. This will depend on which limb is affected and how big the operation was.

The physiotherapist will show you exercises to help you keep the limb moving and working well. It is important to follow their advice and do the exercises regularly. This will help you recover and reduce the risk of any problems after surgery.

At first, your limb will be firmly bandaged, or splinted, to keep it still. This will give the bone graft or implant time to form a strong join to the rest of the bone in the limb.

If you have surgery to your hip or knee, you may have to wear a splint or brace for a few months. After surgery to your arm or shoulder, you may need to wear a sling for a few months. Your cancer doctor, specialist nurse or physiotherapist can tell you more about this.

If you have had an operation on your leg or pelvis, you will need help moving around at first. You will use walking aids such as a frame or elbow crutches. A physiotherapist will teach you how to use these safely, and how to get in and out of bed.

The rehabilitation team will help you stay as independent as possible. You may need to make changes to your normal activities. This will depend on the surgery you have had and how it is affecting you. The occupational therapist (OT) will help you with any changes.

Your rehabilitation may take longer if you are also having chemotherapy (pages 78 to 89) or radiotherapy (pages 93 to 101).

Going home

How long you need to stay in hospital after limb-sparing surgery will depend on the operation you had. Your cancer doctor or specialist nurse can give you more information. You may need to stay in hospital longer to rehabilitate. This will help you cope better when you go home.

If you think you might have problems when you go home, tell your nurse or doctor as soon as possible. They can arrange help for you at home before you leave hospital. You may be referred to a community occupational therapist who can do a home assessment. This can help them see if you need any equipment to help you stay independent at home.

When you are at home, you will keep seeing a physiotherapist as an outpatient. This can often happen locally to where you live.

Body image

Limb-sparing surgery may cause a change in how your limb looks or works. This may affect how you think and feel about your body (body image) – pages 106 to 107. This usually improves as you adapt to any change. But if you still have concerns, talk to your nurse or doctor. They can usually arrange for you to see a psychologist or counsellor for support.

Lymphoedema

After surgery, some people may develop swelling called lymphoedema. It happens because the lymph nodes and vessels can be damaged by surgery or radiotherapy. It can happen if you have had some lymph nodes removed.

Lymph fluid, which circulates around the lymphatic system, cannot pass along the damaged vessels. It builds up, causing swelling.

Let your doctor know about any swelling you have after surgery. They can explain how it can be managed. We have more information in our booklet **Understanding lymphoedema** (page 128) and at **macmillan.org.uk/lymphoedema**

Life after limb-sparing surgery

After limb-sparing surgery, you can usually do most of the things you could before treatment. This includes exercise and sports. But there may be some things you cannot do, or you find hard. Your surgeon or physiotherapist can give you more advice about this.

Help is available

You may find it helpful to talk to someone who is not directly involved with you or your treatment. Our cancer support specialists can talk to you and tell you how to contact a counsellor or local cancer support group.

Knee joint

When the knee joint is replaced, the new joint normally works very well. You will be able to do low-impact exercise such as swimming or riding a bike. But your cancer doctor might tell you not to do high-impact sports like hockey, football, trampolining or rugby. This is because of the risk of damaging or loosening the joint.

Sometimes, years after surgery, a prosthetic knee joint may loosen or cause pain. If this happens, you will need more surgery.

Hip joint

Replacing a hip joint is usually very successful. It can take time to recover from surgery and get your strength back. Your surgeon or specialist nurse can tell you how long this might take. At first, you will need to use crutches to walk. You may need to use a walking stick for a few weeks or months after surgery. If you do not have strong joints and muscles, you may need to keep using a walking stick for longer.

Hip replacements may loosen over time. Some people need more surgery a few years after having their hip replaced.

Shoulder joint

If you have a shoulder joint replacement, the aim of the surgery is to be able to move your arm normally below shoulder height. But you will probably not be able to raise your arm above shoulder height.

It is uncommon for a shoulder joint prosthesis to loosen. They should last for many years and do not cause many problems.

Bone grafts

When limb-sparing surgery is done on the straight part of a bone, it may be replaced with a piece of bone taken from another area of the body. This is called a bone graft.

Occasionally, an infection develops in the replaced bone. This can happen days or weeks after the operation. Contact your hospital doctor or nurse straight away if you:

- notice any redness or swelling in the area
- develop a temperature.

The earlier an infection is found, the easier it is to treat.

Driving

After bone surgery, you will not be able to drive until:

- your bones have fully healed
- you have enough muscle control to move your limb.

Your healthcare team can tell you more about this.

Blue Badge scheme

This scheme allows people with mobility problems to park closer to where they want to go. **gov.uk** has more information about the Blue Badge scheme and how to apply. Or you can contact your local council for more information. A healthcare professional, welfare rights adviser or social worker can help with the application.

Amputation

It is not always possible to use limb-sparing surgery. Sometimes the surgeons need to remove (amputate) all or part of a limb.

They may suggest this if:

- the cancer has spread from the bone into the surrounding blood vessels
- your movement will be better after an amputation than after limb-sparing surgery
- you get an infection in the bone after limb-sparing surgery that does not respond to treatment
- the cancer comes back in the bone.

After talking to their doctor, family or friends, some people choose to have an amputation instead of limb-sparing surgery.

Preparing for an amputation

Before surgery, your cancer doctor and specialist nurse will explain the operation to you. It is important you fully understand what is involved. You can ask questions about how the surgery might affect you. Your treatment team will give you as much support as possible.

Before the operation, you will meet the rehabilitation team who will help you after the operation. The team includes specialist doctors and nurses, as well as:

- a physiotherapist
- an occupational therapist (OT)
- a prosthetist, who fits an artificial limb (prosthesis) if needed.

They can answer your questions and help with any worries you have about after the operation. They will also talk to you about any changes you need to make to your home. These will make it easier when you go home after surgery.

If you are going to have an amputation, it is important to get psychological support. Some hospitals have a counsellor you can talk to about your feelings and worries before and after the operation.

It may also help to talk to someone who has had the same operation. Your healthcare team or keyworker (page 44) may be able to arrange this for you. The Bone Cancer Research Trust website has videos that might also be helpful (page 134).

After your operation

When you wake up from the operation, you will usually have a drip (intravenous infusion) to keep you hydrated. This can be removed as soon as you are drinking enough.

Your wound

To start with, the area operated on will be bandaged. You will have a tube in the wound to drain any fluid that builds up. This is removed when fluid has stopped draining. This usually takes a few days.

When the bandages have been removed, your physiotherapist or nurse will fit a compression garment. This helps reduce swelling. You will also be given advice about looking after the scar.

Pain

Pain can usually be controlled effectively with painkillers. They may be given:

- into a vein (intravenously)
- into the space around the spinal cord (epidural)
- into a muscle (intramuscularly)
- as tablets.

If you are in pain, let your nurses and doctors know as soon as possible. This will help them give you the right amount of painkillers.

Some people have pain that feels like it is coming from the part of the limb that has been amputated. This is called phantom pain or phantom sensation. This pain usually improves over time, but there may be some discomfort in the area for a while after the operation. If you have any phantom pain, let your nurses or doctor know. They can give you drugs to help control it, such as pregabalin or gabapentin.

> **"It is true that you can feel phantom pain. I can remember moving my toes and feeling it. It was really hard to get used to. I would try to walk on it, and fall over."**
>
> Olivia, diagnosed with primary bone cancer

Getting up

A physiotherapist or occupational therapist (OT) will help you get up and about after surgery. This often happens on the first or second day after the operation. It might be hard at first, and you will need to start slowly.

If you have had an arm amputated, you will be able to get up and move around once your pain is controlled and you have recovered from the anaesthetic.

If you have had a leg removed, the physiotherapist will show you how to move around in bed and how to get into a chair. To start with, you will use a wheelchair.

The OT will arrange a wheelchair for you to use in the hospital. You may need the wheelchair at home while you get used to moving around using crutches or an artificial limb. Before you go home, you will be referred to your local wheelchair service. You will also be given advice about using a wheelchair at home.

Exercises

Your nurses or physiotherapist will teach you breathing and leg exercises. The exercises will help prevent you getting a chest infection and blood clots. Chest infections or blood clots can develop if you are not moving around as much as normal. You can help your recovery by doing the exercises as often as you need to.

You may be given elastic stockings called TED stockings to wear to help prevent a blood clot in your leg. This is called a deep vein thrombosis or DVT. You may also be given injections of anti-clotting medicines to help thin your blood.

Physiotherapy

When you are moving around more, you will go to the hospital gym for physiotherapy. This is a very important part of your recovery. Your physiotherapist will give you exercises to do as the wound heals and you gain strength. They will show you how to keep the muscles around the amputated limb strong and supple. This will make it easier to work an artificial limb if you have one (pages 72 to 77).

Your physiotherapist will arrange for you to keep having physiotherapy when you go home. This will usually be as an outpatient and can often be near your home.

Rehabilitation after an amputation

Amputation is a major operation, and rehabilitation can take a long time. It can be hard work and may be frustrating at times.

After the amputation, the occupational therapist (OT) will help you manage day-to-day activities, such as washing, dressing and using the toilet. They can also recommend equipment to help you be as independent as possible.

If you have had an arm amputated, your OT may teach you ways to reduce swelling. They will also teach you how to do some activities with 1 hand.

The OT can also give you advice about driving, work and getting back to social activities. They will help you think about how your amputation may affect your life and look at different ways to manage it.

Going home after an amputation

Before leaving the hospital, your nurse, physiotherapist and occupational therapist (OT) will talk to you about how you will manage at home. They will help you plan how you manage your daily activities and decide whether you need any equipment. If you live alone or have stairs, you may need some help at home.

The OT can help you find different ways of doing things, and suggest aids that may help. You may need to make changes to your home and the way you do certain activities. The OT may also refer you to your local social services for further assessment.

This can sometimes delay your discharge from hospital, which may be frustrating. If you have any worries about going home, talk to the nursing staff about them so they can organise some help.

Artificial limb (prosthesis)

After an amputation, most people can be fitted with an artificial limb called a prosthesis. Modern technology means artificial limbs are now very effective. They allow people to do many of the things they did before the amputation.

Some artificial limbs are designed to look like the limb they are replacing, but do not move. These are often called passive limbs. They usually only replace hands and arms.

Other artificial limbs are designed to help do a wide range of everyday activities, such as gripping, walking, running and playing sport. These types of limb may look very different from the limb they are replacing. Or they may be designed to look as similar as possible. Depending on your needs, you may have more than one type of artificial limb. Artificial limbs might not be suitable for people who have other health conditions.

> **"I made the decision after a while that I didn't want a prosthesis that was trying to look real. I like the prosthesis that I have chosen. I realised that I would be wearing a fake leg for other people's sake, not for my own."**
>
> Olivia, diagnosed with primary bone cancer

Having an artificial limb fitted

After your operation, you will be referred to a prosthetic rehabilitation or limb-fitting unit. The team in the unit will show you the different types of artificial limb and how they work. They will talk to you about your needs and help you choose the best type of prosthesis for you.

When you are ready to have an artificial limb made, a specialist called a prosthetist will take careful measurements or a plaster cast of your limb. They will then make a mould of your limb. This will be used to create a custom-built socket that fits over your limb. The artificial limb is attached to the socket.

It can take a few weeks for your artificial limb to be made. To make sure it fits comfortably, you may need a few fitting appointments. It is important to give the prosthetist feedback on how well the artificial limb fits and works.

If it is an artificial leg, you will have specialist physiotherapy for a few months to learn how to use it. If it is an artificial arm, you will have occupational therapy to learn how to use it. You will need to feel well enough to cope with prosthetic rehabilitation. If you are having more treatment after surgery, limb-fitting and rehabilitation may be delayed until you recover.

You will have regular appointments at the limb-fitting unit for the rest of your life. The team in the unit will look after your artificial limb and check it still fits and works properly.

Living with an amputation

Amputation can be very distressing and can take a long time to come to terms with.

How you might feel

Losing an arm or a leg can feel like a bereavement. You will need time to grieve for your loss and start coping with the emotional and practical effects this type of surgery can cause.

We have more information about dealing with the emotional effects of cancer on page 106.

Body image

You may feel shocked and distressed after the operation. You are used to what your body looks like, and it can be very hard to come to terms with a major change such as an amputation.

Feeling that you look different from other people can affect your confidence and how you think and feel about your body (body image). At first, you may find it hard to see people after your amputation. In time, you will become more confident and feel more able to cope with other people's reactions.

Some people find it helpful to move around as soon as possible after their operation. But it is important to take the time you need after surgery to adapt and do things in your own time.

You may want to take someone with you when you first go out, to give you emotional support. You may find other people do not even notice your amputation, especially if you are wearing an artificial limb.

Some people wil need support with this. There is help available. We have more information to help you cope with body changes in this section and on page 106.

Family and friends

Your family and friends may also find it hard to manage their feelings about your amputation. You may be anxious about what they will say or think, and if you will be able to cope with their reactions. But most people find their family and friends want to do as much as possible to support them. It can help to talk about your feelings and any worries you have.

We have more advice on talking about cancer in our booklet **Talking about cancer** (page 128). Or visit **macmillan.org.uk/talking**

Sex and relationships

Some people may feel unattractive and embarrassed about their body. If you have a partner, you may be worried they will not find you attractive. Meeting a new partner may seem scary. You may find it useful to get support through the College of Sexual and Relationship Therapists (page 138) and Relate (page 139).

We have more information in our booket **Cancer and your sex life** (page 128).

Help is available

You will need time and help to come to terms with your emotions, which are likely to be very strong. The hospital staff will know this and will help you as much as they can. Many people find it helpful to discuss their feelings with a close friend or someone who is removed from their situation, such as a counsellor.

Often, there are counsellors or psychologists in the hospital, and the staff can arrange for you to see them.

Our cancer support specialists can talk to you, and tell you how to contact a counsellor or local cancer support group. You can call them on **0808 808 00 00**.

There are also different organisations that offer support, such as the Limbless Association (page 134).

Driving

If you have had a limb removed, you must tell your car insurance company and the:

- DVLA in England, Scotland or Wales
- DVA in Northern Ireland.

Changes can be made to your car to help you drive. Your occupational therapist can tell you more about them, and suggest organisations that can make the changes you need.

Blue Badge scheme

This scheme allows people with mobility problems to park closer to where they want to go. **gov.uk** has more information about the Blue Badge scheme and how to apply. Or you can contact your local council for more information. A healthcare professional, welfare rights adviser or social worker can help with the application.

Chemotherapy

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

Chemotherapy is an important part of treatment for most people with:

- osteosarcoma (page 13)
- Ewing sarcoma (pages 14 to 15)
- spindle cell sarcoma.

It is not used often for other types of primary bone cancer.

Chemotherapy may be given:

- before you have surgery (pages 50 to 77) or radiotherapy (pages 93 to 101)
- after surgery or radiotherapy
- if the cancer comes back after treatment.

If you have osteosarcoma or Ewing sarcoma, you usually have chemotherapy before and after surgery.

Before having chemotherapy, you have tests to check your general health. You may also have tests to check how well your kidneys and heart are working, and hearing tests (audiograms).

It takes a few days to get the results. Your doctor will talk with you about this.

Chemotherapy can also affect your fertility. If you have concerns about this, it is important to talk to your cancer doctor or nurse before starting treatment.

Having chemotherapy for primary bone cancer

The drugs you have can depend on the type of bone cancer. You usually have a combination of drugs. These may include:

- doxorubicin
- cisplatin
- methotrexate
- ifosfamide
- etoposide
- vincristine
- dactinomycin
- cyclophosphamide.

Your cancer doctor or specialist nurse will tell you which drugs you will be given.

Combination chemotherapy for bone sarcoma

Primary bone cancer might be treated with a combination of chemotherapy drugs.

Osteosarcoma (page 13) is usually treated with:

- MAP – methotrexate, doxorubicin and cisplatin
- AP – doxorubicin and cisplatin.

Children, teenagers and young adults (aged 30 or under) with osteosarcoma may be given a targeted therapy drug (pages 90 to 92) with the chemotherapy.

Ewing sarcoma (pages 14 to 15) is often treated with:

- VDC/IE – vincristine, doxorubicin and cyclophosphamide, alternating with ifosfamide and etoposide.

We have more information about individual chemotherapy drugs on our website.
Visit **macmillan.org.uk/chemotherapy**

How chemotherapy is given

Your doctors will talk with you about your chemotherapy treatment plan.

Chemotherapy drugs are usually given by injection into a vein (intravenously). They are given as a session called a cycle of treatment. You may have chemotherapy as an outpatient, or you may need to go into hospital for a few days.

Each treatment is followed by a rest period of a few weeks. This is to allow you to recover from any side effects.

The number of cycles you have depends on the type of primary bone cancer you have and how it responds to the treatment (pages 13 to 15).

We have more information about the different ways chemotherapy may be given into the vein. Visit **macmillan.org.uk/having-chemotherapy**

Side effects of chemotherapy

Chemotherapy drugs cause side effects. But there are usually ways these can be controlled. Your doctor or nurse will give you information about the likely side effects of your treatment. They will also tell you what can be done to control and manage side effects.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

An infection can be very serious when the number of white blood cells is low. It is important to get any infection treated as soon as possible. Contact the hospital straight away on the 24-hour contact number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

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

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

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time. You will start treatment again when your cell count increases.

You may be given a drug called G-CSF. This encourages the body to make more white blood cells. You have it as a small injection under the skin.

Anaemia (low number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

Sore mouth

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

Sucking ice chips may sometimes help relieve mouth or throat pain. But if you are having radiotherapy to the head or neck, do not suck on ice. It can cause damage.

Hair loss

Your hair will get thinner. Or you may lose all the hair from your head. You may also lose your eyelashes and eyebrows, as well as other body hair. Hair loss usually starts after your first or second treatment.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you if this is an option for you. We have more information at **macmillan.org.uk/scalp-cooling**

Your nurse can talk to you about ways to cope with hair loss. There are ways to cover up hair loss if you want to. Your scalp may be sensitive. It is important to cover your head to protect your skin when you are out in the sun.

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

> **"My oncologist explained that there were some severe side effects. I would probably go through the menopause, and I would lose all my hair a week or 2 after the first round of chemo."**
>
> Waheed, diagnosed with primary bone cancer

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

Hearing changes

This treatment may cause hearing changes, including hearing loss. You may have ringing in the ears. This is called tinnitus. You may also become unable to hear some high-pitched sounds. If your treatment includes cisplatin, you may have hearing tests before and during our course of chemotherapy. Hearing changes usually get better after this treatment ends. But some can be permanent. Tell your doctor if you notice any changes in your hearing.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment may affect the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes. But for some people they may never go away. Talk to your doctor if you are worried about this.

Effects on the heart

This treatment can affect how the heart works. You may have tests to see how well your heart is working. These may be done before, during and after treatment.

If the treatment is causing heart problems, your doctor may change the type of treatment you are having.

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

- pain or tightness in your chest
- breathlessness
- dizziness
- changes to your heartbeat.

Other conditions can cause these symptoms, but it is important to get them checked by a doctor. If you cannot get through to your doctor, call the NHS urgent advice number on **111**.

We have more information at **macmillan.org.uk/heart-health**

Effects on the kidneys

This treatment can affect how your kidneys work. This is usually mild and goes back to normal after treatment finishes. You will have blood tests to check how well your kidneys are working. Tell your doctor or nurse if you have blood in your urine or you are passing urine less than usual.

It is important to drink at least 2 litres (3½ pints) of non-alcoholic fluid each day to help protect your kidneys.

Fertility

Some cancer drugs can affect whether you can get pregnant or make someone pregnant. If you are worried about this, it is important to talk with your doctor before you start treatment. It may be possible to store sperm, eggs or embryos to use in the future. There are different ways to preserve fertility.

We have more information at **macmillan.org.uk/fertility**

Changes to periods

If you have a period, these may become irregular or stop while you are having this treatment. This may be temporary, but it can sometimes be permanent. Your menopause may start sooner than it would have done and you may have symptoms such as hot flushes and sweats.

In many cases, HRT (hormone replacement therapy) can be given to replace the hormones that are no longer being made. Your doctor or nurse can give you more information.

Contraception

Your doctor will advise you not to get pregnant or make someone pregnant while having this treatment. The drugs may harm a developing baby. It is important to use contraception during your treatment and for a while after treatment finishes. Your doctor, nurse or pharmacist can tell you more about this.

Targeted therapy

Targeted therapy drugs interfere with the way cancer cells grow. There are many different types of targeted therapy. Each type targets something in or around the cancer cell that is helping it grow and survive.

Targeted therapy is not often used to treat primary bone cancer. It may be used to treat some people with osteosarcoma (page 13).

Some people with rarer types of primary bone cancer may be treated with other targeted therapies as part of a clinical trial. Your cancer doctor or specialist nurse can tell you more about this.

We have more information at **macmillan.org.uk/clinical-trials**

Mifamurtide (Mepact®)

Mifamurtide is a targeted therapy drug. It helps the immune system to make a type of white blood cell that can attack the cancer cells. It may be an option for some people with osteosarcoma, if they are under the age of 30.

You have mifamurtide with chemotherapy (pages 78 to 89), after surgery to remove the tumour (pages 50 to 77). The aim is to destroy any remaining cancer cells. This may help reduce the risk of osteosarcoma coming back.

It is given as a drip (infusion) into a vein. You usually have mifamurtide twice a week for 12 weeks. You then have it once a week for the next 24 weeks.

Side effects of mifamurtide

Your cancer doctor and specialist nurse will give you information about the likely side effects of mifamurtide. They will also tell you what can be done to control and manage side effects.

Most people have flu-like symptoms while the mifamurtide infusion is being given, such as:

- a headache
- a high temperature (fever)
- chills
- dizziness.

You will have medication before the infusion to help reduce these side effects.

Rarely, mifamurtide can cause a more severe allergic reaction. You will be checked closely for signs of this while you are having the drug. Always tell your specialist nurse or cancer doctor if you feel unwell. Contact the hospital straight away for advice if you:

- develop any of the symptoms mentioned
- feel unwell after you get home.

Mifamurtide can also reduce the number of red and white blood cells and platelets in your blood. This can cause side effects such as:

- feeling tired and breathless
- being more likely to get an infection
- bruising or bleeding more easily.

Other common side effects include:

- feeling sick
- changes to how fast your heart beats
- a headache
- tiredness
- pain in your muscles and joints
- feeling breathless
- a cough.

You may have other side effects that we have not mentioned here. Always tell your cancer doctor about any side effects you have.

We have more information about the side effects of targeted therapy on our website. Visit **macmillan.org.uk/targeted-therapy**

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy is is mainly used to treat Ewing sarcoma, often with surgery (pages 50 to 77). It can be given either before or after surgery. It may also be given with chemotherapy for Ewing sarcoma (pages 14 to 15). This is called chemoradiation.

If it is not possible to have surgery to remove the Ewing sarcoma, radiotherapy may be used as the main treatment.

Other types of primary bone cancer are less sensitive to radiation. But if surgery is not possible, radiotherapy may sometimes be used instead.

We have more information about radiotherapy at **macmillan.org.uk/radiotherapy** and Ewing sarcoma at **macmillan.org.uk/ewing**

How radiotherapy is given

Bone cancer is treated with external beam radiotherapy. Depending on where the bone cancer is, different techniques may be used.

Intensity-modulated radiation therapy (IMRT)

This type of radiotherapy is often used to treat primary bone cancer. IMRT shapes the radiotherapy beams to give the cancer a high dose of radiation. It may also allow different doses of radiotherapy to be given to different areas. This means lower doses are given to nearby healthy tissue. This can help reduce side effects and possible late effects (pages 99 to 101).

Volumetric-modulated arc radiotherapy (VMAT)

VMAT is a newer way of giving IMRT that might be used for some bone cancers. The radiotherapy machine moves around you and reshapes the beam during treatment. This makes it more accurate and shortens the treatment time.

Proton beam therapy

Proton beam therapy uses proton radiation to destroy cancer cells, instead of x-rays. Proton beams can be made to stop when they reach the area being treated. This is different to standard radiotherapy beams, which pass through the area and some healthy tissue around it. This means it causes very little damage to nearby healthy tissue and fewer side effects.

It may be used to treat cancer in the spine or bottom of the skull.

Proton beam therapy is given using specialised equipment. Your doctor can tell you if this is a suitable treatment for you. If your cancer doctor thinks it is, they will refer you to a hospital that has a proton beam therapy centre and specialises in this treatment.

We have more information about proton beam therapy.
Visit **macmillan.org.uk/proton-beam-therapy**

Radiotherapy to the pelvis

If you are having radiotherapy to the pelvis, you may need a small operation first. This is so that the surgeon can put a spacer inside the tummy (abdomen). This helps move the organs out of the way of radiotherapy and protect them from damage. Your cancer doctor will tell you more about this operation if it is needed.

Planning your radiotherapy

Before you start radiotherapy, the radiotherapy team will plan your treatment. This makes sure the radiotherapy is aimed directly at the cancer, causing the least possible damage to nearby heathy tissue. The planning may take a few visits.

Planning scans

As part of the planning, you will have a CT scan of the area to be treated (pages 28 to 29). This helps plan the precise area for your radiotherapy. This session takes about 30 minutes.

You may also need to have an MRI scan (page 24). This uses magnetism to build up a detailed picture of part of your body.

The information from the scans is put into the radiotherapy planning computer. The computer designs your individual treatment plan.

Radiotherapy moulds

Radiotherapy moulds may be used to help keep the part of the body having radiotherapy still during treatment. If you are having radiotherapy to your head and neck, you will have a head and neck mould made. If you are having radiotherapy to a limb or chest, you may also need a mould for these areas.

You will not need a mould if you are having radiotherapy to your tummy area or pelvis. You will be supported with pillows that are shaped to fit around the area of the body having radiotherapy. These help keep you comfortable and still during treatment, so each radiotherapy treatment is delivered accurately.

A mould is made on your first visit to the radiotherapy department. Your cancer doctor or specialist nurse will tell you more about moulds if you need one. We have more information at **macmillan.org.uk/radiotherapy-masks**

The radiographers may use foam blocks or special cushioning bags called vacuum bags to help keep you still during treatment. Other devices may also be used to help you to keep still during radiotherapy.

Skin markings

To help the radiographers position you correctly for the treatment, they may make marks on your mould. If you do not have a mould, they will draw the marks on your skin. These marks must stay throughout your treatment. They can be washed off after your course of treatment finishes.

Often, very small permanent markings are made on the skin. They will only be made with your permission. It can be uncomfortable while the marks are being made, but only for a very short time.

Treatment sessions

Radiotherapy is normally given as a series of short, daily treatments in the hospital radiotherapy department.

The treatments are usually given every day from Monday to Friday. The number of treatments you have depends on the type, size and position of the area to be treated.

A course of treatment for early-stage primary bone cancer lasts about 6 weeks. Each treatment takes about 10 to 15 minutes. Your cancer doctor will talk to you about the treatment and possible short or longer-term side effects.

At the start of each session of radiotherapy, the radiographer will explain what to expect. They will position you carefully on the treatment couch in the same way as during the planning session. When you are in the right position, the radiographers will leave the room and you will be given your treatment. Radiotherapy is not painful, but you will have to lie still for a few minutes during the treatment.

The radiographers will be able to see and hear you during your treatment.

Side effects of radiotherapy

You may develop side effects during your treatment. These side effects will slowly disappear over a few weeks or months after treatment finishes.

Your cancer doctor, specialist nurse or radiographer will explain the ones you are most likely to get, so you know what to expect. Let them know about any side effects that you have during or after treatment. There are often things that can be done to help. They will also explain about any possible late effects of the treatment (page 101).

We have more information in our booklet **Understanding radiotherapy** (page 128).

Tiredness (fatigue)

Tiredness is a common side effect and may continue for months after treatment finishes. Try to get plenty of rest but balance this with some gentle exercise, such as walking. This can improve your energy levels and help you feel better.

After your treatment finishes, you can gradually increase your activity. We have more information in our booklet **Coping with fatigue (tiredness)** – page 128.

Feeling sick (nausea)

If the treatment area is near the tummy and pelvis, you may feel sick and sometimes be sick (vomit). Your doctor can prescribe anti-sickness drugs (anti-emetics) to control this. Take them as your doctor has prescribed and let the doctor know if a drug is not working. They can prescribe a different anti-sickness drug.

We have more information at **macmillan.org.uk/nausea-vomiting**

If you lose your appetite, let your GP know. They can prescribe some high-calorie drinks. They can also refer you to a dietitian who can explain how to build up your diet. We have more information in our booklet **The building-up diet** (page 128).

Skin reaction

You may find that your skin in the treatment area:

- becomes red
- darkens
- feels sore
- feels itchy.

Sometimes the skin gets very sore. It may blister, break or leak fluid. Very rarely, treatment may be stopped for a short time to allow skin to recover from a serious reaction.

Skin reactions can take time to improve. They are usually better by about 4 weeks after treatment finishes. In the longer term, the area of skin may look or feel slightly different to the surrounding skin. Your radiographers or nurses will give you advice on how to look after your skin during and after treatment.

Hair loss

Radiotherapy can make your hair fall out in the area being treated. It may grow back after treatment finishes, but for some people the hair loss is permanent. This depends on how much radiotherapy you have. Your cancer doctor or radiographer can tell you if your hair is likely to grow back after treatment.

We have more information in our booklet **Coping with hair loss** (page 128).

Long-term side effects of radiotherapy

Some people may have long-term or late effects of radiotherapy. These can develop months or sometimes years after treatment. If you have any new symptoms or problems after treatment, always let your cancer doctor or specialist nurse know.

Stiffness

If you have radiotherapy to a limb or a joint, it can become stiff. If you notice this, talk to your cancer doctor. They can prescribe painkillers to help. It is important to keep the joint mobile by using it and doing regular exercise. A physiotherapist will give you some exercises to do before, during and after treatment to help prevent stiffness.

Lymphoedema

After radiotherapy, some people may develop swelling called lymphoedema. It happens because the lymph nodes and vessels can be damaged by radiotherapy or surgery. Lymph fluid, which circulates around the lymphatic system, cannot pass along the damaged vessels. It builds up, causing swelling.

Let your doctor know about any swelling you have after radiotherapy treatment. They can explain how it can be managed. There are things you can do to help reduce the risk of lymphoedema.

We have more information in our booklet **Understanding lymphoedema**.

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

Coping with primary bone cancer

After your treatment

Before you go home, your cancer doctor or specialist nurse will talk to you about your recovery. Some people may take longer to recover and need extra help. If you are worried about going home, talk to your doctor or nurse before you leave. They can arrange any help and support you might need at home.

Follow-up

After your treatment finishes, you will have regular check-up appointments with your cancer doctor or specialist nurse. They will tell you how often and for how long you will need to have these. It will depend on the type of treatment you had, and the risk of the cancer coming back.

You may have regular tests to check for any signs of the cancer coming back, including chest x-rays. You may also have regular blood tests. Some people may have MRI scans. If you have had chemotherapy, you may have regular scans to check your heart for a few years (pages 87 to 88).

At the check-ups you can talk to your cancer doctor or specialist nurse about any problems or worries. If you notice any new symptoms, or have any problems between appointments, contact your cancer doctor or specialist nurse for advice.

Many people find they get nervous before their appointments. You may worry about the cancer coming back. This is natural. It can help to get support from family, friends or your specialist nurse. Or you can speak to our cancer support specialists (page 130).

We have more information in our booklet **Life after cancer treatment** (page 128).

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 helpful for other people with a bone sarcoma who may be about to start their treatment. Hearing how you coped, and how you managed any side effects, can help someone in a similar situation.

We have more information about how you can share your story on page 143.

If the cancer comes back

For many people with early-stage bone cancer that has not started to spread, it will never come back after treatment.

If the cancer comes back in the lungs or in a bone, it is sometimes possible to have an operation to remove the cancer. Chemotherapy may be given before and after the operation.

If it is not possible to remove the cancer, treatments such as chemotherapy and radiotherapy may be given. The aim is to control the cancer for as long as possible and to help relieve symptoms.

We have more information in our booklet **Coping with advanced cancer** (page 128) and at **macmillan.org.uk/advanced-cancer**

Changes in your body

Your body may not look or feel the same as you are used to. You may have scars from surgery. There may be changes in how you look and move, especially if you have had an arm or leg removed.

It may take time to cope with the feelings you may have after getting a metal prosthesis, or losing an arm or leg.

Feeling like you look different from other people can affect your self-confidence. At first, you may feel shocked, angry and upset. But these feelings usually improve over time as you adapt and learn how to manage the changes. Each person is different in how long this takes.

Talking to family and close friends may help you cope with stress and understand your feelings. You may also find it helps to talk to other people who have had similar experiences. Your specialist nurse can tell you about any support groups for people with bone cancer in your area (pages 134 to 135). You can also get support online, as well as share information, worries and experiences on our Online Community (page 133).

You may find it helpful to talk to a counsellor or psychologist. They can help you understand your feelings better and find ways of coping with them. Your cancer doctor or specialist nurse may be able to arrange this.

We have more information in our booklet **Your feelings after cancer treatment** (page 128).

Other people's reactions

If you have visible changes to your appearance, you may worry about how people will react. Some people may make unhelpful comments or say things that upset you. But you will probably find that most people do not see the changes in the way you expected them to.

Once treatment ends, some people find it helpful to go out as soon as they can. Other people may take longer. It is important to do things in your own time. You may want to take a family member or friend with you at first to offer support. As you get used to the changes in your body, and learn how to manage them, you will become more confident.

Learning how to cope with social situations helps build up your confidence. This will help you slowly get back to your usual day-to-day activities. This can include returning to work and going out with friends.

We have more information to help you cope with changes to your body in our booklets **Your feelings after cancer treatment** and **Body image and cancer** (page 128).

Complementary therapies

Some people find complementary therapies can reduce symptoms and side effects, and help them feel better. It is important to talk about your planned therapy with your cancer doctor or GP before you start. This is to check if there are any reasons why you should not have them.

Many hospitals and hospices offer complementary therapies. Treatments may include acupuncture, massage, aromatherapy and relaxation techniques. Therapies such as gentle massage can be done by a family member, friend, partner or carer. This can be a useful way for them to support you. We have more information at **macmillan.org.uk/complementary-therapies** and in our booklet **Cancer and complementary therapies** (page 128).

Your sex life

Cancer and cancer treatments can affect your sex life. But usually these effects do not last long and get better when treatment is over.

Having treatment can be tiring. You may be coping with side effects that mean sex or being intimate are less important. You may feel differently about your body and about sex for a while. This should get better in time.

If you feel like having sex, there is usually no reason not to. You cannot pass on cancer through sex. Having sex does not affect your treatment, or the risk of cancer coming back.

After some types of operation, such as having a limb removed, some sexual positions may not be possible or comfortable. You may need to try different positions to find out what works best for you.

If you are having chemotherapy, you will need to use contraception if there is a chance you or your partner could become pregnant (page 89). This is because the drugs could harm an unborn baby.

If you are in a relationship, talk to your partner about how you feel about being intimate. Sometimes talking about sex can be hard. You may worry your partner might not find you attractive. But talking about your fears and worries together can help you both feel more comfortable with each other.

If you are not in a relationship, it can be hard to decide when and what to tell new partners about your cancer. It is natural to be scared about rejection.

You may find it helpful to think about how safe you feel in the new relationship. It may take time before you can trust your new partner with very personal information. Some people find it helps to talk about these issues with a counsellor.

If you have worries or questions about your sex life, talk to your cancer doctor or specialist nurse. They will be used to giving advice on these kinds of problem. They can also refer you to a counsellor for more help and support. The College of Sexual and Relationship Therapists (page 138) and Relate (page 139) may also be able to help.

We have more information in our booklet **Cancer and relationships** (page 128) and at **macmillan.org.uk/relationships**

Looking after yourself

After treatment, you may want to get straight back to everyday life. But you may still be coping with the side effects of treatment, physical changes or strong emotions.

Well-being and recovery

Recovery takes time. Do not rush your recovery and try to be kind to yourself.

Some people choose to make lifestyle changes to improve their health and well-being. Even if you had a healthy lifestyle before cancer, you may be more focused on making the most of your health.

This is general advice. If you have health problems, it is important to check with your cancer doctor before making any changes to your lifestyle or diet.

Stop smoking

If you smoke, giving up is the healthiest decision you can make. Smoking is a major risk factor for some cancers. It is also a risk factor for high blood pressure and heart disease. If you want to stop, your GP can give you advice.

We have more information about giving up smoking.
Visit **macmillan.org.uk/stop-smoking**

Eat a well-balanced diet

Eating healthily will give you more energy and help you recover. Try to eat 5 portions a day of fresh fruit and vegetables, and less red meat. Cut down on salt, as it can raise blood pressure and make the kidneys work harder. Follow any advice you have been given by a dietitian (page 44).

We have more information in our booklet **Healthy eating and cancer** (page 128).

Drink less alcohol

NHS guidelines recommend that both men and women should not regularly drink more than 14 units of alcohol in a week. It is a good idea to have a few alcohol-free days each week. **drinkaware.co.uk** has more information about alcohol and drinking guidelines.

Keep to a healthy weight

Keeping to a healthy weight reduces the risk of cancer, heart and kidney problems and illnesses such as diabetes. Your GP can tell you what the ideal weight for your height is.

If you feel you need to lose weight, ask your GP for advice. They may advise you to:

- eat only as much food as you need
- eat a balanced diet with lots of fruit and vegetables
- try to eat less fat and sugar
- try to be more physically active.

If you have lost weight during treatment, your GP or a dietitian can give you advice about gaining weight.

We have more information in our booklets **Healthy eating and cancer** and **The building-up diet** (page 128).

Try to keep active

Exercise has been shown to reduce the side effects of cancer treatment and speed up recovery. Being physically active helps keep your weight healthy and can reduce stress and tiredness. It also reduces the risk of other health conditions.

Being active can be difficult after you have had surgery to a limb. You can talk to a physiotherapist about the best types of exercise to do after your surgery (page 43).

We have more information in our booklet **Physical activity and cancer** (page 128).

Reducing stress

Think about ways to reduce the stress in your life. You could make time to do things that you enjoy or that make you laugh. Some people find it relaxing to meditate, or to start a new hobby or an evening class. You may find it helpful to write a journal or online blog.

Some people find some complementary therapies can help to reduce feelings of stress.

We have more information in our booklet **Complementary therapies and cancer** (page 128).

Your feelings and relationships

Your feelings

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

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

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

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

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups**

Or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on page 130 about other ways we can help you.

Relationships

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

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

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

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

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet **Looking after someone with cancer**.

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

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them.

It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening.

You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 128).

Work and financial support

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 128).

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

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

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced money advisers. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

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

Grants

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

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our money advisers can help. You can call them on **0808 808 00 00**.

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

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

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer** (page 128).

We have lots more information about work on our website. Visit **macmillan.org.uk/work**

Further information

About our information

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

Order what you need

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

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

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

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

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

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

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

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

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

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

Macmillan Information and Support Centres

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

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

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

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

Help accessing benefits

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

Help with energy costs

Our money advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Help with work and cancer

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

Talk to others

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

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Bone cancer support organisations

Bone Cancer Research Trust

Tel **0113 258 5934**
www.bcrt.org.uk
Provides information and support for people with primary bone cancer and their families and friends. Promotes research into the causes and treatment of primary bone cancer.

Limbless Association

Tel **0800 644 0185**
www.limbless-association.org
Provides information, advice and support to people of any age, whether they are about to have an amputation or have already lost a limb. Also supports carers, family and friends.

REACH

Tel **0845 130 6225** or **0203 478 0100**
www.reach.org.uk
Provides support and information for children with upper limb differences and their families or carers. Offers meetings across the UK and Ireland where children with a limb difference can enjoy fun activities together.

Sarcoma UK

Tel **0207 856 0445**
Helpline **0808 801 0401**
www.sarcoma.org.uk
Funds research and provides information and support for people with any type of sarcoma. Also supports carers, family and friends. Also has a helpline with nurses.

General cancer support organisations

Cancer Black Care

Tel **0208 961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

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

Cancer Research UK

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

Macmillan Cancer Voices

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

Maggie's

Tel **0300 123 1801**
www.maggiescentres.org
Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

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

NHS 111 Wales

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

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

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

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel **01455 883 300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor on their 'How to find a therapist' page.

College of Sexual and Relationship Therapists (COSRT)

Tel **0208 543 2707**
www.cosrt.org.uk
Has a directory of therapists to help members of the public find professional support in their local area.

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients (formerly Live Through This)

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Relate

www.relate.org.uk
Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face to face, by phone and online.

Support for carers

Carers Trust

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

Carers UK

Helpline (England, Scotland and Wales) **0808 808 7777**
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put carers in contact with local support groups.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

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

England – National Disease Registration Service (NDRS)

digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

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

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

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

Northern Ireland – Northern Ireland Cancer Registry (NICR)

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

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Fiona Cowie, Consultant Clinical Oncologist.

Thanks to: Dr Catherine Coyle, Consultant Clinical Oncologist; Dr Vasilios Karavasilis, Consultant Medical Oncologist; Anita Killingworth, Macmillan Oncology Nurse Consultant; Abby McCarthy, Physiotherapist (Orthopaedic Oncology); Ms Louise McCullough, Consultant Trauma and Orthopaedic Surgeon; Dr Ioanna Nixon, Consultant Medical Oncologist; and Vicky Wren, Sarcoma Specialist Nurse.

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

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

Sources

Below is a sample of the sources used in our primary bone cancer information. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

British Medical Journal. Osteosarcoma. BMJ Best Practice, last updated May 2022. Available from bestpractice.bmj.com/topics/en-gb/780 [accessed November 2022].

Gerrand C et al on behalf of the British Sarcoma Group. UK guidelines for the management of bone sarcomas. Clinical Sarcoma Research, 2016; 6, 7. Available from www.ncbi.nlm.nih.gov/pmc/articles/PMC4855334 [accessed November 2022].

Hazewinkel A-D et al. Disease progression in osteosarcoma: a multistate model for the EURAMOS-1 (European and American Osteosarcoma Study) randomised clinical trial. BMJ Open, 2022; 12, 3. Available at: bmjopen.bmj.com/content/12/3/e053083 [accessed November 2022].

Strauss SJ et al. Bone sarcomas: ESMO-EURACAN-GENTURIS-ERNPaedCan Clinical Practice Guideline for diagnosis, treatment and follow-up. Annals of Oncology, 2021. Available from www.esmo.org/guidelines/guidelines-by-topic/sarcoma-and-gist/bone-sarcomas [accessed November 2022].

Can you do something to help?

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

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

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

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

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping.
   Or just a cup of tea and a chat. Could you lend a hand?

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number
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Valid from
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Issue no
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Security number
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Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

If you would rather donate online go to **macmillan.org.uk/donate**

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REGULATOR

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

MACMILLAN
CANCER SUPPORT

This booklet is about primary bone cancer. This means that the cancer has started in a bone. It is for anyone who has been diagnosed with primary bone cancer. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of primary bone cancer. It explains how it is diagnosed and how it may be treated. It also has information about feelings, practical issues and money.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

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

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

Trusted Information Creator

Patient Information Forum