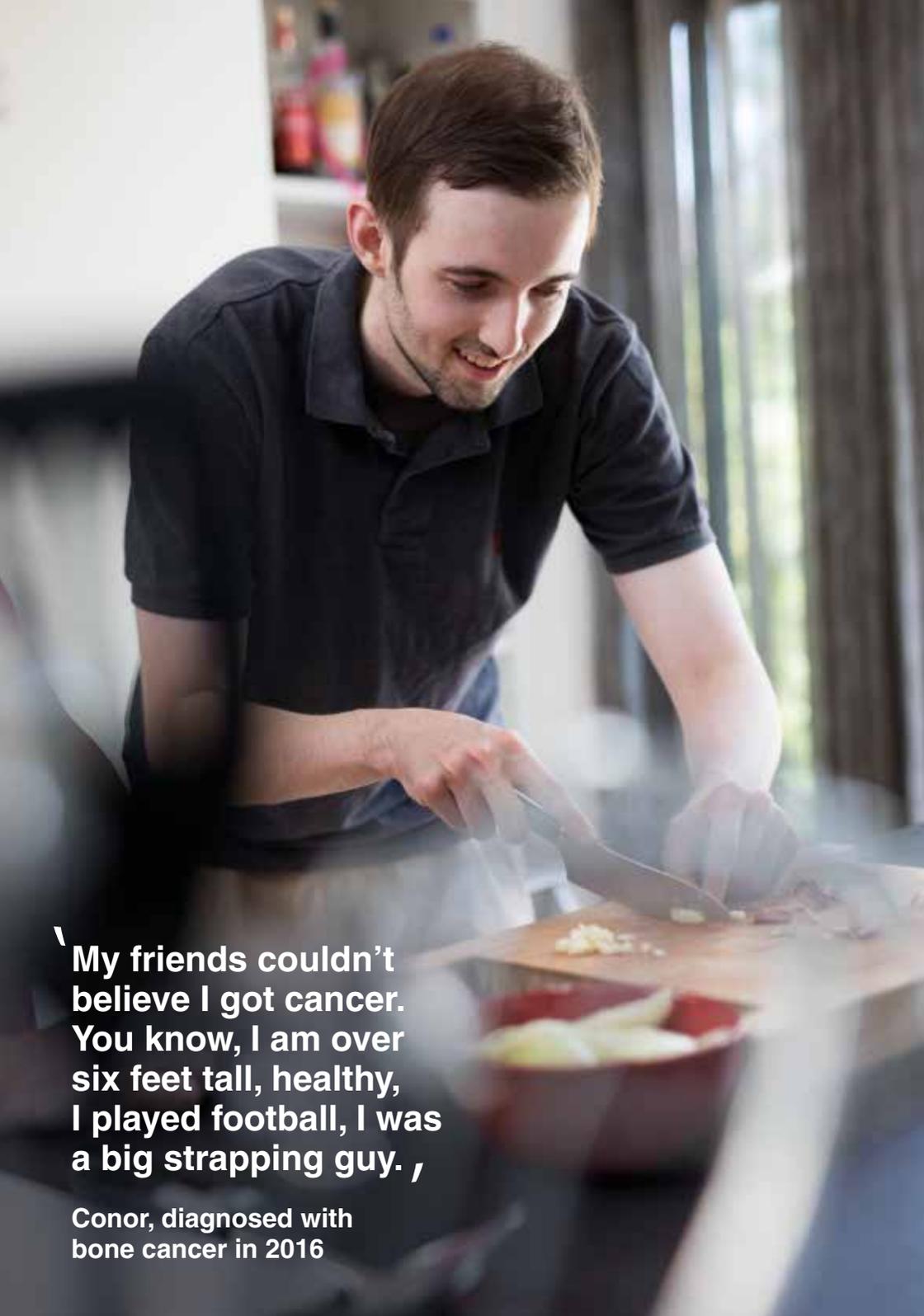


**MACMILLAN**  
CANCER SUPPORT

# UNDERSTANDING PRIMARY BONE CANCER





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

**Conor, diagnosed with bone cancer in 2016**

# About this booklet

This information is about primary bone cancer. We hope it answers some of your questions and helps you deal with some of the feelings you may have.

Primary bone cancer is a cancer that starts in a bone. It 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. Secondary bone cancer is much more common than primary bone cancer. Your doctor will tell you whether your cancer is a primary or secondary bone cancer.

If you have secondary bone cancer, our booklet **Understanding secondary cancer in the bone** has more information. Visit [be.macmillan.org](http://be.macmillan.org) or call us on **0808 808 00 00**.

Primary bone cancer can affect people of any age, including children and teenagers. This booklet is for adults and teenagers with primary bone cancer. It is also for parents of children with the disease. We have more information about osteosarcoma and Ewing sarcoma in children that we can send you.

Understanding more about the cancer and its treatment helps many people cope. It means you can discuss treatment, tests and check-ups with your doctors and nurses.

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

There are details of some other useful organisations on pages 140 to 148.

In this booklet we have included quotes from people with primary bone cancer. Some are from the website **healthtalk.org** Others are from people who have chosen to share their story with us. To share your story, visit **macmillan.org.uk/shareyourstory**

If you would like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm.

If you are hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Or you can visit **macmillan.org.uk**

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

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# THE BONES AND PRIMARY BONE CANCER

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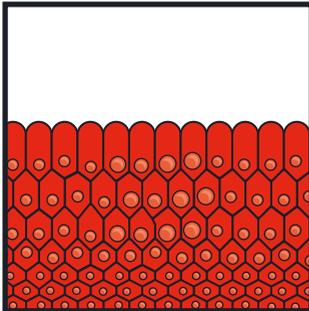
# What is cancer?

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.

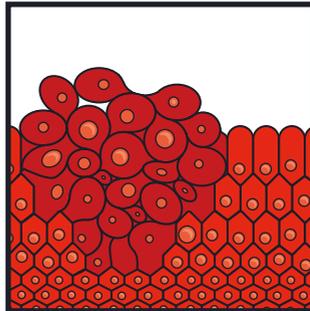
Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing, making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy (see page 28). The doctors look at the sample under a microscope to look for cancer cells.

## 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.

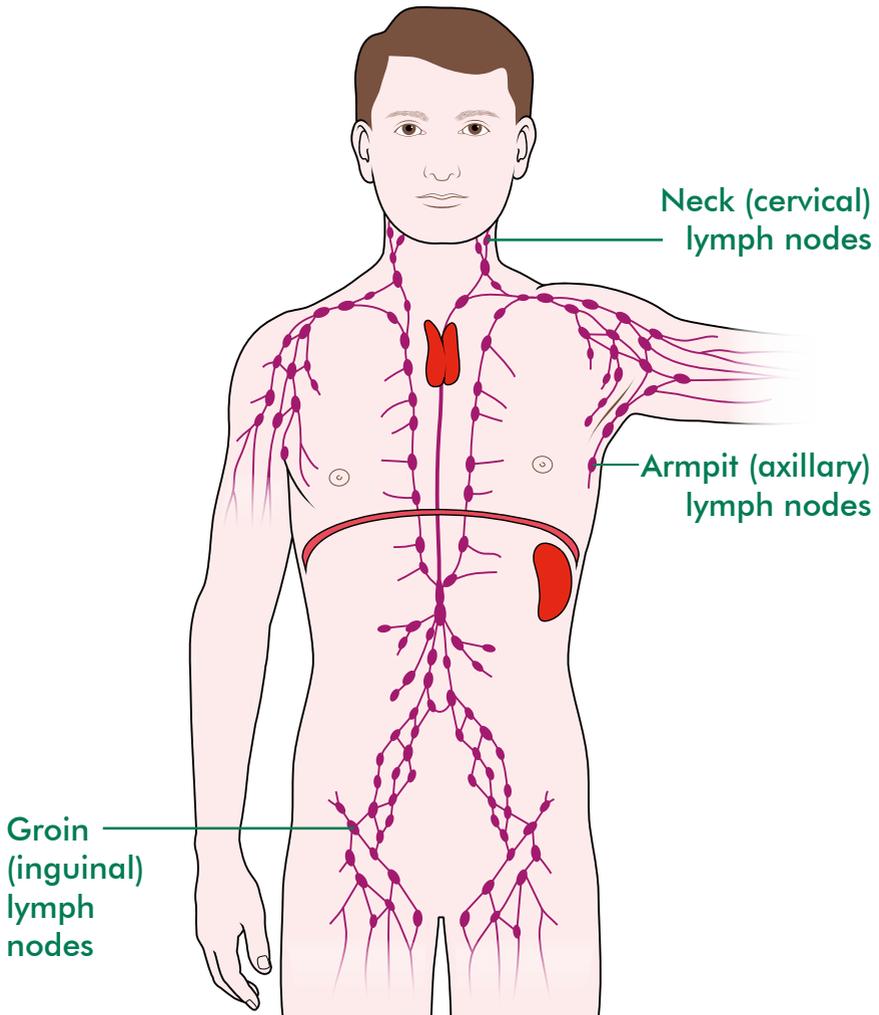
A lump that is cancerous (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. The cells can travel through the blood or lymphatic system (see page 8). When the cells reach another part of the body, they 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.

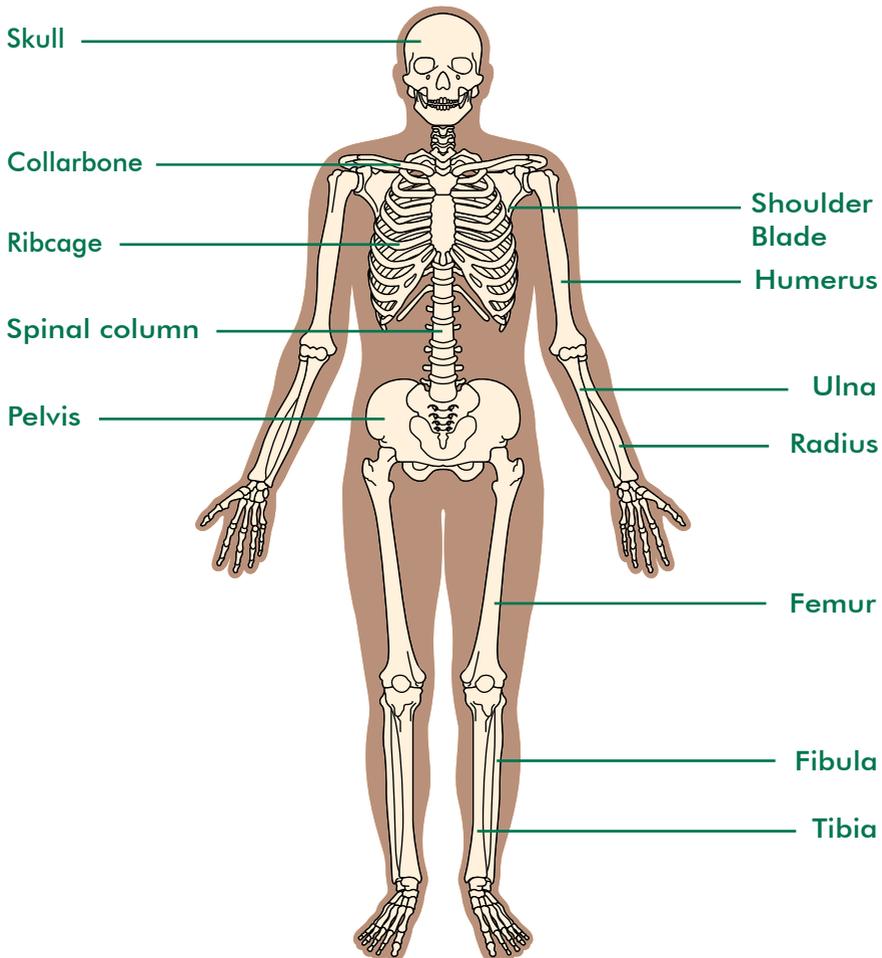
## The lymphatic system



# The bones

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

## The human skeleton



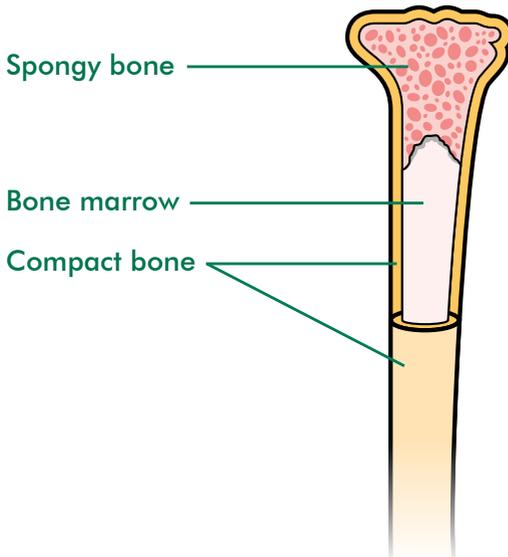
Bones are made of collagen (a type of protein) and minerals such as calcium and phosphate. The combination of collagen and minerals makes the bones strong.

Bones do lots of important things:

- They support our bodies. The joints at the end of bones act as levers. This is so we can move around.
- They protect parts of our bodies from injury. For example, the ribs protect the heart and lungs, and the skull protects the brain.
- They store important minerals that our bodies use, such as calcium.
- Some bones are filled with a soft, spongy material called bone marrow. This makes blood cells.

The joints at the end of bones are covered in cartilage. This allows joints to move smoothly.

## The structure of a long bone



Our bones are constantly breaking down and being replaced with new bone. This helps keep their strength and shape. There are 2 main types of cell that break down and replace bone:

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

# Types of primary bone cancer

Primary bone cancer is a cancer that starts in a bone. It is sometimes called a bone sarcoma (see below).

Primary bone cancer is rare. About 600 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 about it.

Use the illustrations (see pages 6, 9, 10 and 12) to help you understand this 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. About 1 in 10 osteosarcomas (10%) develop in adults in their 60s and 70s.

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

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

## 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. 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.

## 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 sarcomas that start in the bone.

## 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 of the spine
- bones at the bottom of the skull.

## Rarer types of primary bone cancer

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

- fibrosarcoma
- angiosarcoma
- giant cell tumour
- adamantinoma.

It can be hard to get information about the rarer types of sarcoma. 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 (see page 137).

## Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, 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. You can find more information at [macmillan.org.uk/cancerregistry](https://www.macmillan.org.uk/cancerregistry)

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country.

# 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.

Research into possible causes of bone cancer is going on all the time. Many bone cancers affect teenagers and young people. This might mean that bone cancer may be 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 (see page 90) or some chemotherapy drugs (see page 80) 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.

## Non-cancerous (benign) bone conditions

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

Some conditions can increase the risk of osteosarcoma. These include the following:

- **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.

Some rare conditions can increase the risk of developing chondrosarcoma:

- **Osteochondroma (or chondroma)**, which are non-cancerous growths that develop on the bones. Rarely, these growths can develop into chondrosarcoma (see page 14).
- **Hereditary multiple exostoses (HME)**, 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**. These are rare conditions that cause non-cancerous growths in cartilage close to the bone. They often start in childhood, but they are not inherited.

## Genetic conditions

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

People who have **Li-Fraumeni syndrome** have an increased risk of developing osteosarcoma (see 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.

Our booklet **Signs and symptoms of cancer and how to reduce your risk** has more information about the risk factors of cancer (see page 136).

## Other possible risk factors

### Umbilical hernia

Children who are born with an umbilical hernia have an increased risk of developing Ewing sarcoma (see page 15). The risk is still very small.

A hernia is a bulge caused by an internal part of the body pushing through a weakness in the muscle or tissue wall. An umbilical hernia is a hernia in the belly button.

### Bone injury

Sometimes people find out they have primary bone cancer after an injury to their bone. They may think the injury caused the cancer to develop. There is no clear evidence that an injury to a bone can cause bone cancer. But it may draw attention to a bone cancer that is already there.

# Symptoms

## Pain or tenderness near the tumour

This may start as an ache 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, see your GP to have it checked.

## Swelling near the affected area of bone

Swelling may not show up until the tumour is quite large. You might not see or feel a lump if the affected bone is deep inside the body tissues.

'My girlfriend noticed that on one side my ribs were slightly protruding. Looking back now, there were more symptoms. I was more tired than normal. My voice would often be weak, but again I just put it down to tiredness.'

**Conor**

## Reduced movement

If the cancer is near a joint, you may find it harder to move the joint. Movement in the arm or leg (the limbs) 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.

## 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 symptoms

Ewing sarcoma (see page 15) may also cause tiredness, weight loss, and a high temperature or sweats.

**Many of these symptoms can be caused by other conditions that are more common than bone cancer. Because of this, it sometimes takes a long time for bone cancer to be diagnosed. If you are worried about any symptoms you have, talk to your GP.**



# DIAGNOSING PRIMARY BONE CANCER

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# How bone cancer is diagnosed

You usually start by seeing your GP. They will check you and arrange any tests or x-rays you need. 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 (orthopaedic surgeon). They may also refer you to a bone cancer specialist.

You may be seen in a bone tumour treatment centre, called a sarcoma unit. Children go to a children's (paediatric) hospital for some of their care. Teenagers may be treated in a teenage cancer unit.

To help GPs, the National Institute for Health and Care Excellence (NICE) has produced referral guidelines. These are a list of risk factors, signs and symptoms that could suggest cancer. They help your GP decide what sort of tests you should have and how quickly you should see a specialist. The guidelines say the following:

- 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.

## At the hospital

You will see a specialist who will look at the affected area to check for any swelling or pain. They will ask you about your symptoms, your general health and any previous medical problems.

You will have a blood sample taken to check your general health. You will also have some of the following tests.

## 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 true for osteosarcoma (see page 13).

## MRI scan

This scan uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.



An MRI scanner

## Biopsy

The doctor takes a sample of cells (a biopsy) to be checked by a doctor who specialises in cell types (pathologist). The pathologist can tell if the tumour is a cancer by looking at cells from the sample under a microscope. If it is a 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.

### Needle biopsy

The surgeon uses a small needle to take a small sample of the tumour. They will give you a local anaesthetic 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 done under a general anaesthetic, so you are asleep during the test.

Your surgeon may use a scan, such as a CT, ultrasound or x-ray during the biopsy. This helps guide them to the right place.

### Open or surgical biopsy

This type of biopsy is not often used, because the needle biopsy is much quicker and easier. In an open biopsy, the surgeon removes a small piece of bone during a small operation. This is done under a general anaesthetic. You may need this 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.

## Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 140 to 148 can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

## Further tests

If the tests show that you have bone cancer, the cancer doctor may want to do further tests. These are to find out if the cancer has spread outside the bone. This is called staging (see pages 38 to 39). The further tests will help you and your cancer doctor decide on the best treatment for you.

### CT scan

Most patients with bone cancer will have a CT scan of their lungs. They might also have a CT scan of the affected bone.

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and does not hurt.

The CT scan uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you meet.

You may be given a drink or injection of a dye that allows some areas of your body to be seen more clearly. This may make you feel hot all over for a few minutes. If you are allergic to iodine or have asthma, you could have a more serious reaction to the injection. You must tell your doctor this before the scan.

You can normally go home as soon as the scan is over.

## Bone scan

This is a more sensitive test than an x-ray. It shows up any abnormal areas of bone more clearly. A small amount of a mildly radioactive substance is injected into a vein. This is usually in your arm. Abnormal bone absorbs more radioactivity than normal bone. These areas are highlighted and picked up by the scanner as 'hot spots'.

After you have the injection, you will need to wait 2 to 3 hours before you have the scan. You may want to take a magazine, book or music player with you while you wait.

The level of radioactivity used in the scan is very small and does not cause any harm to your body. But you will be told to avoid close contact with pregnant women or young children for a few hours after the scan.

If hot spots show up on a bone scan, it is not always clear whether they are caused by cancer or by other conditions such as arthritis.

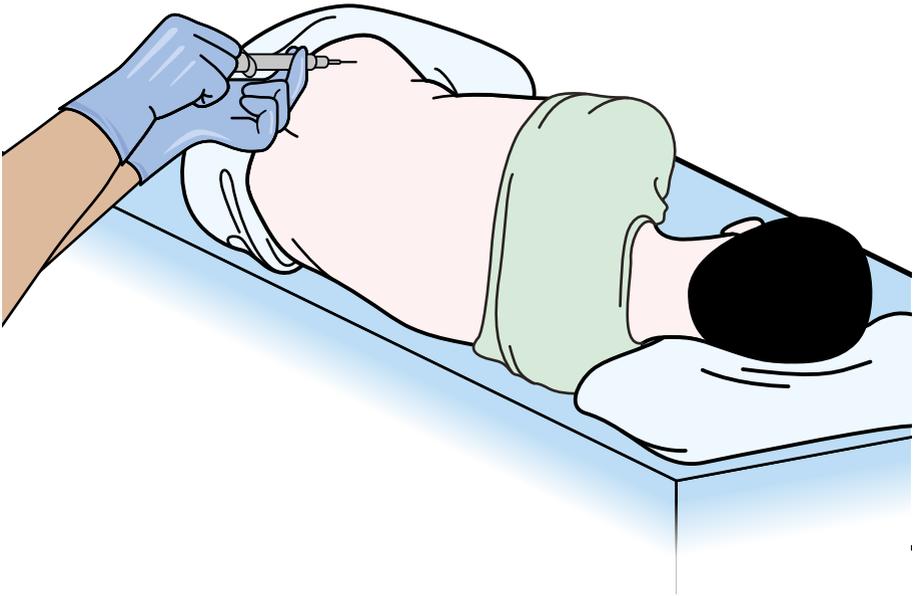
Sometimes a CT scan, PET-CT scan or MRI scan may help the doctors decide whether the changes on a bone scan are caused by secondary bone cancer or another condition. Our booklet **Understanding secondary cancer in the bone** has more information (see page 136).

## Bone marrow sample

The bone marrow is the spongy material inside the bones where our blood cells are made. Ewing sarcomas can sometimes spread to the bone marrow (see illustration on page 12).

When Ewing sarcoma is suspected or diagnosed, the doctor will take a small sample of bone marrow. They usually take the sample from 1 side of the hip bone (pelvis). Sometimes they may also take a sample from the other side.

### Taking a bone marrow sample



Before the test, adults have local anaesthetic injected into the area near the bone to numb it. Children usually have a general anaesthetic. 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.

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 after the test and have an ache for a few days. You can take mild painkillers to help with this.

Your bone marrow samples will be sent to a laboratory to be looked at under a microscope. You will have the results in about 7 to 10 days.

## PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

## Chest x-ray

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

## Tests before chemotherapy

If you are going to have chemotherapy (see pages 80 to 89), you will have tests to check your kidneys and heart. You may also have a hearing test.

### Kidney test

This test shows how well your kidneys are working. A small amount of mildly radioactive liquid is injected into a vein in your hand or arm. The liquid goes through your kidneys. You pass it out in your pee (urine). A few hours after the injection, a nurse takes blood samples from you.

### Heart tests

There are different types of heart tests you may have:

- An ECG (electrocardiogram) takes an electrical trace of your heartbeat.
- An echo (echocardiogram) is an ultrasound scan of your heart.

Your cancer doctor or specialist nurse can explain more about these tests.

### Hearing test (audiogram)

A chemotherapy drug called cisplatin can affect how well you hear high-pitched sounds. If your treatment includes cisplatin, you may have hearing tests before and during your course of chemotherapy.

# Grading and staging

Your cancer specialist needs information about the cancer to talk about the best treatment for you. This includes:

- the grade of the cancer
- the stage of the cancer.

This information comes from the tests you have had (see pages 24 to 34).

The grading and staging of primary bone cancer is 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

A doctor decides the grade of the cancer by looking at the cancer cells under a microscope. The grade gives an idea of how the cancer might grow or spread.

The most common grading system for primary bone cancer uses 2 grades:

- In **low-grade** tumours, the cancer cells look like normal bone cells. They are usually slow-growing and are less likely to spread.
- In **high-grade** tumours, the cells look very abnormal. They are likely to grow more quickly and are more likely to spread.

All Ewing sarcomas and most osteosarcomas and spindle cell tumours are high-grade. We have more information about Ewing's sarcomas and osteosarcomas on our website.

## Staging

The stage of a primary bone cancer describes its size and whether it has spread outside the bone. Knowing the stage of the cancer helps the doctors plan the right treatment.

Most cancers are grouped depending on whether they:

- are only in one part of the body (localised)
- have spread from one part of the body to another (secondary or metastatic).

If the cancer comes back after it is first treated, doctors call it a recurrence.

There are different staging systems used for primary bone cancer. The most-used systems are TNM and Enneking.

### **TNM staging system**

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 (called metastatic or secondary cancer).

## Enneking staging system

As well as the size of the tumour and if it has spread, the Enneking staging system also describes the grade of the cancer. It helps your surgeon decide how much bone to remove during surgery.

**Stage 1** bone cancer is low-grade. It has not spread beyond the bone. Stage 1 is divided into:

Stage 1A	The cancer is completely inside the bone it started in. The cancer may be pressing on the bone wall and causing a swelling, but it has not grown through it.
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Stage 1B	The cancer has grown through the bone wall.
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**Stage 2** bone cancer is high-grade. It has not spread beyond the bone. Stage 2 is divided into:

Stage 2A	The cancer is completely inside the bone it started in.
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Stage 2B	The cancer has grown through the bone wall.
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**Stage 3** bone cancer may be any grade. It has spread to other parts of the body, such as the lungs.



# TREATING PRIMARY BONE CANCER

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# Treatment overview

The treatment for primary bone cancer depends on a few things, including:

- your general health
- where the cancer started in the body
- the size of the tumour
- if the cancer has spread
- your needs and choices.

The results of your tests (see pages 24 to 35) will help your doctors plan the best type of treatment for you. They will then talk about this with you.

**Surgery** (see pages 54 to 57) is an important part of treatment. 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
- a bone that cannot be removed without the risk of causing a serious disability, such as a bone in the spine.

If this happens, chemotherapy (see page 80) and radiotherapy (see page 90) are used instead.

**Chemotherapy** (see pages 80 to 89) is given to most people with primary bone cancer. Nearly everyone with a Ewing sarcoma (see page 15) will have chemotherapy. It is also given to most people with osteosarcoma and spindle cell sarcoma.

Chemotherapy may be given:

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

**Radiotherapy** (see pages 90 to 96) is mainly only used to treat Ewing sarcoma (see page 15). It is often given together 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 if surgery is not suitable, radiotherapy may sometimes be used instead.

**Targeted therapy** (see pages 97 to 99) is sometimes used to treat osteosarcoma after surgery. But it is only suitable for some people.

Most people need a combination of these treatments.

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 (see page 100).

'It was quite an emotional time for me, but at the time I truly felt that I was lucky to be alive. I found inside me a positivity that I didn't know I had, and that gave me a lot of strength.'

**Waheed**

## How treatment is planned

Sarcomas are rare cancers, so you should always be referred for treatment at a specialist sarcoma unit. A team of specialist doctors and other professionals will work together to manage your treatment. This is called a multidisciplinary team (MDT). It will include these professionals:

- **Surgeon** – a doctor who specialises in bone cancers.
- **Oncologist** – a doctor who specialises in cancer treatments such as chemotherapy, radiotherapy and targeted therapy.
- **Specialist nurse** – a nurse who gives information and support about any aspect of your illness or treatment.
- **Radiologist** – a doctor who specialises in reading scans and x-rays.
- **Pathologist** – a doctor who specialises in looking at cells under a microscope and diagnosing the cell type.

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

- **Dietitian** – someone who gives you information on how to get all the nutrients your body needs.
- **Physiotherapist** – someone who can help if you have problems moving around.
- **Plastic surgeon** – a surgeon skilled in rebuilding tissue.
- **Occupational therapist** – someone who makes sure you are safe and comfortable at home. They may suggest and arrange small changes to the home.
- **Psychologist or counsellor** – someone who can help you cope with any emotional problems.

## Where treatment is given

### Specialist treatment centres

Your treatment will usually be planned and given in a sarcoma treatment centre. The sarcoma unit could be based in one hospital. It could also be spread across a group of hospitals that are close to each other and 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 to get to one. The doctors at the sarcoma treatment centre will work with a specialist cancer doctor in your local hospital to plan your treatment. It may be possible to have some of your treatment at a hospital closer to home. 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. There may be video games, DVDs and music to help you feel more at home.

In some hospitals, there is not a special ward for teenagers with cancer. This means you are treated on an adult cancer ward. The staff on the adult cancer wards can still look after you, but the wards may not have the same facilities as teenage cancer units.

We have more information about teenage cancer units on our website. Visit [macmillan.org.uk/information-and-support/audience/teens-and-young-adults](https://www.macmillan.org.uk/information-and-support/audience/teens-and-young-adults)

## Children's cancer centres

Children with bone cancer are treated in hospitals that specialise in treating children's cancers. These are often called principal treatment centres. They are relaxed and friendly places. They try to give you and your child a positive experience. You will probably get to know the staff well. Almost all children's wards have facilities where parents can stay.

The Children's Cancer and Leukaemia Group has more information about children's cancer centres. Visit their website **[cclg.org.uk](http://cclg.org.uk)** or call them on **0116 252 5858**.

## Talking about your treatment plan

After the MDT meeting, your cancer doctor or specialist nurse will talk to you about your treatment options.

They will explain the main aims of treatment. These may be to try to cure the cancer, to help you live longer or to relieve symptoms. They will also tell you the possible short-term and long-term side effects of the treatments.

Deciding which treatments are right for you is a joint decision between you and your cancer team. Cancer specialists have lots of knowledge about the treatments, but it is important to think about what you want and need.

If there is one treatment that has been shown to work best, you may be happy to be guided by your cancer doctor. But there can be times when the choice of treatment depends on what you prefer.

If a cure is not possible 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 cancer doctor. If you choose not to have the treatment, you can still be given supportive (palliative) care to control any symptoms.

## Making treatment decisions

When you make any treatment decisions, it is important to talk about things carefully with your cancer team. It can help to make a list of the questions you want to ask. You can take this to your next appointment. It is also helpful to have a family member or close friend with you at appointments. You may choose to keep notes about what has been said.

It is important to ask your doctors and nurses any questions you have about your treatment. The more you understand, the easier it will be for you.

Our booklet **Making treatment decisions** has more information about treatments (see page 136).



## Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

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

If you do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations. It is a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

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

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

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

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you.

Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

## Assessing your needs

Throughout your treatment, you will have regular talks with someone from your cancer team. This may be your cancer doctor or specialist nurse, or another healthcare professional. They should talk to you about what to expect during and after treatment. They should also ask about any worries and needs you have.

In some hospitals, this is called a **holistic needs assessment (HNA)**. Your cancer team may write a care plan based on this. This should give information about the support you are getting and other services that may be useful to you.

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

Some hospitals make a treatment summary that describes:

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

You keep a copy of your care plan, and the hospital should send a copy to your GP. These assessments and care plans are not used everywhere, but more hospitals are using them.

'I was looked after by a fantastic team at the hospital – especially the sarcoma nurses, my oncologist and the therapist. They all worked as a team to make sure they looked after my physical and my mental health.'

**Florencia**

# Surgery

Primary bone cancers are rare, so surgery is done by a surgeon who specialises in treating them. Most bone cancers affect the arms and legs (limbs) or pelvis. Surgery to these areas is done by a bone surgeon (orthopaedic surgeon). If the cancer is in the bones of the face, skull or chest, there are surgeons who specialise in those areas. The surgeon is part of a multidisciplinary team (MDT) (see page 45) and based in a specialist sarcoma unit.

Surgery is the main treatment for most types of primary bone cancer. The aim is to remove all of the cancer from the bone, while trying to keep as much function as possible. Usually an operation called a wide local excision is done. This means the surgeon removes the cancer, and an area (margin) of healthy, cancer-free tissue around it.

Your surgeon will talk with you about which surgery they think is best for your situation.

## Types of surgery for primary bone cancer

It is hard to give general information about surgery, because the type of operation you have depends on where the cancer is in your body.

Some types of surgery for primary bone cancer are minor. Some operations are major and may affect how that area of the body works, or how it looks.

In some cases, the surgeon can remove the affected area of bone without replacing it. They may do this if your movement will not be affected by removing the area of bone. Before surgery, you may be referred to a rehabilitation team (see page 69). They will help you recover from the operation and get as much function as possible. If the surgery is minor, you may not need the help of the rehabilitation team. Your surgeon and specialist nurse will talk with you about your operation and rehabilitation.

## **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 (see pages 58 to 59). Chemotherapy is usually given before and after the operation. Sometimes radiotherapy may also be used.

Rarely, the best treatment option is to remove the affected limb (amputation – see page 68).

Limb-sparing surgery often takes longer to recover from than amputation.

## **Surgery to other areas of the body**

### **Cancer in the pelvis**

When possible, a primary bone cancer in the pelvis is treated with a wide local excision (see page 54). To help reduce the risk of any cancer cells being left behind, chemotherapy (see pages 80 to 89) may be used before the operation. Radiotherapy may also be given (see pages 90 to 96).

Sometimes, the pelvis needs to be reconstructed using bone taken from another area of the body (a bone graft).

### **Cancer in the jaw bone**

The whole bone is usually removed and reconstructed using bone taken from another part of the body. Radiotherapy may also be used if it is not possible to remove the whole bone.

### **Cancer in the spine or skull**

It may not be possible to remove the cancer safely. A combination of treatments might be used. These include surgery, chemotherapy and radiotherapy.

## **Reconstructive surgery**

The aim of reconstructive surgery is to make the area look and work as naturally as possible. The surgery you have will depend on where in your body the cancer is and how much tissue the surgeon needs to remove.

Your surgeon and specialist nurse will talk with you about the operation. They can answer any questions you have and give you an idea of how the area will look.

## Surgery to remove secondary cancer

Surgery is sometimes used to remove a primary bone cancer that has spread to other parts of the body or come back after treatment. An operation is only possible if the cancers are small and there are only a few of them. It is mainly done when the cancer has spread to the lungs. Sometimes it may be 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. 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 procedure
- how the surgery might affect you
- the possible risks and complications of the operation.

You can ask your surgeon questions 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.

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 will 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 (see page 62).

You may find it helpful to talk to someone who has had the same operation. They may be able to give you advice as well as support. Your healthcare team or your 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.

## After your limb-sparing 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. These are removed when fluid has stopped draining. This should take a few days.

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 and redness around the wound
- there is discharge from the wound.

### 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 need a strong painkiller, such as morphine. You may be given intravenous pain relief through a syringe 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). So it is okay to 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 to the legs.

Let your nurses and doctors know as soon as possible if you are in pain. This will help them give you the combination and dose of painkillers that is right for you.

We have more information in our booklet **Managing cancer pain** which you may find helpful (see page 136).

## Exercises

Your nurses or the physiotherapist will teach you breathing and leg exercises. You can help yourself get better by doing the exercises as often as you need to. They will also encourage you to move around as soon as possible. Our booklet **Physical activity and cancer** treatment has more information about keeping active

Breathing exercises will help prevent you getting a chest infection. Leg exercises will 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.

To help prevent a blood clot in your leg (a deep vein thrombosis or DVT), you may be given elastic stockings (TED stockings) to wear. 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.

You will see a physiotherapist soon after your operation. They will encourage and help you to move around as soon as possible. The physiotherapist will show you exercises to help you keep the most function in the limb. It is important to follow their advice and regularly do the exercises. 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 start joining firmly on 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 to help you, such as a frame or elbow crutches. A physiotherapist will teach you how to get in and out of bed. They will also teach you how to safely use any walking aids.

'After my operation, I did exercises to strengthen the prosthesis. These included bending, stretching and strengthening. It was hard work during treatment, but now I realise how important it was. I still have physiotherapy regularly and attend physiotherapy rehabilitation classes. They help me regain muscle strength, balance and confidence.'

**Kate**

The rehabilitation team will help you get as much independence as possible after the limb-sparing surgery. You may need to make changes to your normal activities. This will depend on the extent of the surgery and how it is affecting you. The occupational therapist will help you with any changes.

Your rehabilitation may take longer if you are also having chemotherapy (see pages 80 to 89) or radiotherapy (see pages 90 to 96).

## Going home

How long you need to stay in hospital for after limb-sparing surgery will depend on the type of operation you had. Your cancer doctor or specialist nurse can tell you how long they think it might be. Sometimes you may need to stay in hospital longer to rehabilitate. But 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 the hospital social worker when you are admitted to the ward. For example, it may be hard if you live alone or you have a few flights of stairs to walk up. They can arrange help for you at home before you leave hospital.

When you are at home, you will keep seeing a physiotherapist as an outpatient. This is often somewhere local to you.

## Getting back to normal after limb-sparing surgery

After limb-sparing surgery, you can usually do most of the things you could before treatment. This includes doing 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.

### Knee joint

When the knee joint is replaced, the new joint normally works very well. It is fine for you to go swimming or cycling after surgery. 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, more surgery is needed.

### 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. 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. Some people may need to keep using a walking stick for longer if their joints and muscles are not strong.

Hip replacements may loosen over time. Some people may 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 on a straight part of a bone, it may be replaced by a piece of bone taken from another area of the body. This is called a bone graft. The main problem with these operations is an infection in the bone that has been replaced.

## Driving

After limb-sparing surgery, you will not be able to drive while your bones heal. 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. Visit [gov.uk/apply-blue-badge](https://www.gov.uk/apply-blue-badge) for more information. Or you can contact your local council for more information. A healthcare professional, welfare rights adviser or social worker can help with the application.

## Help is available

Some people take longer than others to recover from their operation. If you have any problems, 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 (see pages 137 to 139). You can call them on **0808 808 00 00**.

'My tibia was replaced with a metal prosthesis. I have a slight limp, which limits my walking. I have a Blue Badge, enabling me to use disabled parking. This is extremely useful, as it minimises the distance I have to walk.'

**Tom**

# 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 your cancer doctor, and close family or friends, you might choose to have an amputation instead of limb-sparing surgery.

## Preparing for an amputation

Before surgery, your cancer doctor will explain the operation to you. They will make sure you fully understand what is involved. You can ask questions about how the surgery might affect you.

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

- a physiotherapist (see page 45)
- an occupational therapist (OT)
- a prosthetist – who fits an artificial limb (prosthesis) if needed.

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

Getting psychological support is important if you are going to have an amputation. Some hospitals have a counsellor you can talk to about your feelings and worries before the operation.

It may also help to talk to someone who has had the same operation. They may be able to give you practical advice and support. Your healthcare team or your keyworker may be able to arrange this for you.

## After your operation

You will usually have a drip (intravenous infusion) to replace your body's fluids. This can be removed as soon as you are drinking enough.

### Your wound

To start with, the area where you had your operation will be bandaged. You will have a tube in the wound to drain off any fluid that builds up. This is removed when fluid has stopped draining. This should take a few days.

When the bandages have been removed, your physiotherapist or nurse will fit a compression garment. This helps reduce swelling, which can be a problem for some people. 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.

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

We have more information in our booklet **Managing cancer pain** which you may find helpful (see page 136).

Some people have a 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**. Although this pain should fade over time, there may be some discomfort in the area for a while after the operation. Let your nurses and cancer doctor know if you have any phantom pain. 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's really weird. It was really hard to get used to. I would just try to lean and walk on it and fall over.'

**Olivia**

## Exercises

Your nurses or the physiotherapist will teach you breathing and leg exercises. You can help yourself get better by doing the exercises as often as you need to.

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.

To help prevent a blood clot in your leg (a deep vein thrombosis or DVT), you may be given elastic stockings (TED stockings) to wear. You may also be given injections of anti-clotting medicines to help thin your blood.

## Getting up

A physiotherapist or occupational therapist (OT) will help you get up. 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 transfer into a chair. To start with, you will use a wheelchair to get around. Within a few days, you may also be able to start using elbow crutches or a walking frame. The physiotherapist will help you.

The OT will arrange for you to have a wheelchair 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. So 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.

## 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 (see page 75).

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 somewhere near where you live.

## 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 OT will help you manage your day-to-day activities, such as getting washed, dressed and using the toilet. They can show you ways to manage your activities and recommend equipment to help you be as independent as possible.

If you have had an arm amputated, your occupational therapist may teach you ways to help reduce swelling. They will also teach you ways of doing some activities with one hand.

The OT can also give you advice about 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

Before leaving the hospital, your nurse, physiotherapist and OT will talk to you about how you will manage at home. If you live alone or have stairs to climb, you may need some help managing at home. Together, you will need to assess and plan how you will manage your normal daily living activities and if you need any equipment. They may also refer you to your local social services for further assessment.

If doing certain things has become harder, OTs can help. They can help you find different ways of doing things, and they may suggest aids. You may need to make changes to your home and the way you do certain activities. The OT and physiotherapist will help you. This can sometimes delay your discharge from hospital, which may be frustrating.

If you have any worries about going home, make sure you talk to the nursing staff about them so they can organise some help.

Our booklet **Going home from hospital** has more information that you might find helpful (see page 136).

## 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.

There are changes that can be made to your car to help you drive. Your OT can tell you more about them. They can also suggest organisations that can help with 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. Visit [gov.uk/apply-blue-badge](https://www.gov.uk/apply-blue-badge) for more information. A healthcare professional, welfare rights adviser or social worker can help with the application.

## 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 let people do many of the things they did before the amputation. Because the arm and the hand do lots of different things, prosthetic arms are less technically advanced than legs.

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

Other artificial limbs are designed to allow 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.

Having an artificial limb will use more of your energy. They might not be suitable for people who are frail or have other health conditions like heart disease.

## Having a prosthesis 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 prosthesis 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 a prosthesis 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 prosthesis 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 a leg prosthesis, you will have specialist physiotherapy for a few months to learn how to use it. If it is an arm prosthesis, 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 maintain your prosthesis and check it is still fitting and working properly.

'I made the decision after a while that I didn't want a prosthesis that was trying to look real. They do some amazing ones now, but this is who I am, and I like the prosthesis that I have chosen. I realised that I would be wearing a fake leg for other people's sakes, not for my own.'

**Olivia**

## Living with an amputation

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

### Feelings and emotions

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 problems this type of surgery can bring.

We have more information about dealing with the emotional effects of cancer in our booklet **How are you feeling? The emotional effects of cancer** (see page 136).

## Body image

Even if you thought you had a good idea of what to expect before surgery, you may still feel shocked and distressed after the operation. This may be because the full realisation of having lost an arm or leg hits you. 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 like you look different from other people can affect your self-confidence. At times, you may even wish you had never had the operation.

At first, you may find it hard to see people after your amputation. But you and the people close to you will get used to the way you look. This will also help you become more confident about dealing with the reactions of people you do not know.

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 to get used to your amputation 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.

We have more information to help you cope with body changes in our booklet **Body image and cancer** (see page 136).

## Family and friends

Your family and friends may also find it hard to come to terms with 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 how they react. 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 information to help you talk about cancer in our booklet **Talking about cancer** (see page 136).

## Your sex life

You may feel unattractive and embarrassed about your body. If you have a partner, you may be worried they will not find you attractive any more. Meeting a new partner may seem scary.

We have more information about cancer and your sex life in our booklets **Cancer and your sex life – information for women** and **Cancer and your sex life – information for men** (see page 136).

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

Many people find it helpful to talk about their feelings with a close friend or someone who is removed from their situation, such as a counsellor. Our cancer support specialists can talk to you, and tell you how to contact a counsellor or local cancer support group (see page 138). You can call them on **0808 808 00 00**.

# Chemotherapy

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

Chemotherapy is an important part of treatment for most osteosarcomas, Ewing sarcomas and spindle cell sarcomas. It is not used often for other types of primary bone cancer.

Chemotherapy may be given:

- before you have surgery or radiotherapy
- after surgery or radiotherapy
- if the cancer comes back after treatment.

If you have osteosarcoma (see page 13) or Ewing sarcoma (see page 15), you usually have chemotherapy before and after surgery (see page 54).

Before having chemotherapy, you have tests to check your general health. It takes a few days to get the results. Your cancer doctor will talk with you about this.

We have more information about chemotherapy in our booklet **Understanding chemotherapy** (see page 136).

## 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). Some of the drugs used include:

- doxorubicin (Adriamycin®)
- cisplatin
- methotrexate
- ifosfamide
- etoposide
- vincristine
- dactinomycin
- cyclophosphamide.

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

### Combination chemotherapy

Chemotherapy for primary bone cancer usually involves a combination of chemotherapy drugs.

Osteosarcoma 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 (see pages 97 to 99) drug with the chemotherapy.

Ewing sarcoma is often treated with:

- VIDE – vincristine, ifosfamide, doxorubicin and etoposide
- VAI – vincristine, actinomycin and ifosfamide
- VAC – vincristine, actinomycin and cyclophosphamide
- VDC/IE – vincristine, doxorubicin and cyclophosphamide, alternating with ifosfamide and etoposide.

We have more information about individual chemotherapy drugs and their side effects on our website.

Chemotherapy is given as a session (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 your body 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.

## Side effects of chemotherapy

Everyone reacts differently to chemotherapy. Some people may not have many side effects, and others may have more. The side effects we describe in this information will not affect everyone who is having this treatment.

We explain the most common side effects here. We have not included the side effects that are rare and unlikely to affect you. Talk to your cancer doctor, chemotherapy nurse or pharmacist if you have any side effects that are not listed here.

All these side effects may be difficult to cope with, but most of them will disappear when your treatment finishes.

## 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.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

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

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

**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.

G-CSF (granulocyte-colony stimulating factor) is a type of drug called a growth factor. It encourages the body to make more white blood cells.

Your doctor may give you G-CSF:

- if the number of white blood cells is very low
- to stop the number of white blood cells getting low.

You have it as a small injection under the skin.

### **Anaemia (low number of red blood cells)**

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low, you may be offered a blood transfusion. You will feel more energetic and any breathlessness will be eased.

### **Bruising and bleeding**

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

## Feeling sick

You may feel sick in the first few days after treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. 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 and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

## Sore mouth

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

If your mouth 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.

## Hair loss

Your hair will get thinner or you may lose all the hair from your head. You may also lose your eyelashes, eyebrows or 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.

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. It is important to cover your head to protect your scalp when you are out in the sun.

Hair loss is almost always temporary and your hair will usually grow back after treatment ends.

We have a booklet called **Coping with hair loss** which you may find helpful (see page 136).

## Feeling tired

Feeling tired is a common side effect. 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.

We can send you our booklet **Coping with fatigue (tiredness)** – see page 136.

## Changes in hearing

Some chemotherapy drugs can affect your hearing. You may have a hearing test before you start treatment. During treatment, you may get ringing in your ears (tinnitus) and stop being able to hear some high-pitched sounds. Tinnitus usually gets better after treatment ends. Some hearing changes can be permanent. Tell your cancer doctor if you notice any changes in your hearing.



## Effects on the nerves

Some chemotherapy drugs can affect the nerves in your hands or feet. This can cause tingling or numbness, or a feeling like pins and needles. This is called peripheral neuropathy.

It is important to let your cancer doctor know if this happens. They may need to change the dose of the chemotherapy drug. Usually peripheral neuropathy slowly gets better when chemotherapy finishes, but sometimes it can be permanent.

## Effects on the heart

This treatment can affect the way the heart works. You may have tests to see how well your heart is working. These may be done before, during, and sometimes after treatment. If the treatment is causing heart problems, your cancer doctor can change the type of treatment you are having.

Contact a doctor straight away if you:

- have pain or tightness in your chest
- feel breathless or dizzy
- feel your heart is beating too fast or too slowly.

Other conditions can cause these symptoms, but it is important to get them checked by a doctor.

Our booklet **Heart health and cancer treatment** has more information about keeping your heart healthy (see page 136).

## Fertility

You may find it hard to get pregnant or make someone pregnant after having chemotherapy. It is important to talk about fertility with your cancer doctor before starting treatment. It may be possible for men to store sperm and women to store eggs or embryos to use in the future.

Our booklets **Cancer treatment and fertility – information for women** and **Cancer treatment and fertility – information for men**, have more information about cancer treatment and fertility (see page 136).

Some women may find chemotherapy treatment causes an early menopause, and they 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.

You may find it helpful to talk about all this with your cancer doctor. You can also talk with one of our cancer support specialists on **0808 808 00 00** (see page 137).

## Contraception

You should not become pregnant or make someone pregnant while having chemotherapy. This is because it may harm the developing baby. It is important to use effective contraception during your treatment and for at least a few months afterwards. You can talk about this with your cancer doctor or specialist nurse.

It is not known if chemotherapy drugs can get into semen or vaginal fluids. To protect your partner, it is safest to either avoid sex or use a barrier form of contraception for about 48 hours after chemotherapy.

# Radiotherapy

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

Radiotherapy is mainly only used to treat Ewing sarcoma. It is often given together with chemotherapy (see pages 80 to 89) and surgery (see pages 54 to 57). 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 less sensitive to radiation. But if surgery is not advisable, radiotherapy may sometimes be used instead.

Our booklet **Understanding radiotherapy** has more detailed information about this treatment and its side effects (see page 136).

## How radiotherapy is given

### **Intensity modulated radiation therapy (IMRT)**

This type of radiotherapy is often used to treat primary bone cancer. IMRT gives the cancer a high dose of radiation and changes the dose given to nearby healthy tissue. This can help reduce side effects.

### **Radiotherapy to the pelvis**

Before radiotherapy to the pelvis, some people have a small operation. The surgeon puts a 'spacer' inside the tummy (abdomen). This moves the organs out the way of radiotherapy to protect them from any damage. Your cancer doctor will tell you more about this operation if it is needed.

## Proton beam therapy

This treatment uses proton radiation to destroy cancer cells, instead of x-rays. The proton beam is aimed directly at the cancer, so it causes very little damage to nearby healthy tissue. It is sometimes used to treat primary bone cancer in children. It is also used to treat cancer in the spine or base of the skull.

Proton therapy has been available at the Christie Hospital in Manchester since late 2018. It will also be available at a hospital in London from 2020. The Department of Health can sometimes arrange for people who need this type of radiation to have it in the USA or Europe. This is paid for by the NHS. Your specialist team will give you more information if proton therapy is suitable for the type of cancer you have. We have more information about proton beam therapy on our website.

## Planning your radiotherapy

Before you start your treatment, it needs to be planned. This is to make sure the radiotherapy is aimed directly at the cancer. This also means it causes the least possible damage to nearby healthy tissue. Radiotherapy is planned by the radiotherapy team. Planning is important and may take a few visits.

## Radiotherapy moulds

If you are having radiotherapy to a limb, you may have a mould made of your limb. This helps keep it in the same position every day for radiotherapy. It 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.

You will not need a mould if you are having radiotherapy to your chest, tummy area or pelvis. You will be supported with shaped pillows to help keep you still during treatment.

## Planning CT scan

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

You may also need to have an MRI scan (see page 26). 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.

## 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 (tattoos) are made on the skin. They will only be done with your permission. It can be uncomfortable while the tattoo is being done.

## 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 with you about the treatment and possible 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 you were in 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 talk to you about this, 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.

### Stiffness and swelling

If you have radiotherapy to a limb, it can get swollen and stiff. Talk to your cancer doctor if you notice this. They can prescribe painkillers to help.

### Tiredness (fatigue)

Tiredness is a common side effect and may continue for months after treatment finishes. During treatment, you may need to rest more than usual, especially if you need to travel a long way for treatment each day. But it is good to do gentle exercise, such as walking, when you feel like you can. This can help boost energy and improve your general well-being.

Our booklet **Coping with fatigue (tiredness)** has more information about managing the symptoms of tiredness (see page 136).

After your treatment finishes, slowly increase your activity and try to balance rest periods with some physical activity. This will help you build up your energy levels.

You may find our booklet **Physical activity and cancer** helpful (see page 136).

## Feeling sick (nausea)

Some people find their treatment makes them feel sick (nauseous) and sometimes be sick (vomit). This is most common when the treatment area is near the tummy area and pelvis. If you have nausea and vomiting, they can often be treated with anti-sickness drugs (anti-emetics). Your cancer doctor can prescribe these for you.

If you are not hungry, you can replace meals with special high-calorie drinks. These are available from most chemists and can be prescribed by your GP. To stop you becoming dehydrated, it is important to keep drinking water. It can help to sip drinks slowly if you feel sick. It is important to eat and drink well during treatment. This will help you cope with and recover from the radiotherapy.

Our booklet **Healthy eating and cancer** has more information about having a healthy diet (see page 136).

## Skin reaction

You may find your skin in the treatment area becomes red or darkens. It may also feel sore or itchy. Sometimes the skin gets very sore and it may blister, break or leak fluid. Very rarely, treatment may be stopped for a short time to allow a serious skin reaction to recover.

Skin reactions can take time to improve. They are usually better by about 4 weeks after you finish treatment. 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.

Our booklet **Coping with hair loss** has more information (see page 136).

# Targeted therapies

Targeted therapies interfere with the way cancer cells grow. They are sometimes called biological therapies.

Targeted therapies may be used to treat some people with osteosarcoma (see page 13). They are not often used to treat other types of primary bone cancer.

Some people with rarer types of primary bone cancer may be treated with other targeted therapies as part of a clinical trial (see page 100). Your cancer doctor or specialist nurse can tell you more about this.

## Mifamurtide (Mepact®)

Mifamurtide is a targeted therapy used to treat osteosarcoma in people under the age of 30. It is given after you have had surgery to remove the tumour. The aim is to destroy any remaining cancer cells. This may help reduce the risk of the osteosarcoma coming back.

Mifamurtide works by helping the immune system make certain types of white blood cell that can attack cancer cells.

It is given as a drip (infusion) into a vein. It is given with chemotherapy (see pages 80 to 89). You usually have the treatment 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. Some medicines can affect how mifamurtide works. Tell your cancer doctor about any medicines you are taking.

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

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

You will be given medication before the infusion to help reduce these symptoms.

Rarely, mifamurtide can cause a more severe allergic reaction. You will be checked closely for signs of this while you are having the drip. But always tell your specialist nurse or cancer doctor if you feel unwell.

If you develop any of the symptoms above, or feel unwell after you get home, contact the hospital straight away for advice.

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

- If the number of red blood cells is low, you may feel tired and breathless.
- If the number of white blood cells is low, you will be more likely to get an infection.
- If the number of platelets is low, you may bruise or bleed 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 therapies in our booklet **Side effects of cancer treatment** (see page 136).

## Research – clinical trials

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

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

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormonal therapy, radiotherapy, or other treatment is better than what is already available.

### Taking part in a trial

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

Usually, a few hospitals around the country take part in these trials. It is important to remember that some treatments might look effective at first. But these are sometimes found to not be as good as existing treatments. Some treatments may have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected. You do not have to give a reason. But it can help to let the staff know your worries, so they can give you the best advice. There will be no change in the way you are treated by the hospital staff. You will be offered the standard treatment that is right for you.

Our booklet **Understanding cancer research trials (clinical trials)** has more information (see page 136).

## Blood and tumour samples

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial, you may also give other samples. These may be frozen and stored for future use, when new research becomes available. Your name will be removed from the samples.

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

## Current research

Treatment for primary bone cancer is often given as part of a clinical trial. Because bone cancers are rare, trials can be organised by specialists from many countries working together. Your cancer doctor can tell you if there are any trials that may be right for you.



# COPING WITH PRIMARY BONE CANCER

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# After your treatment

Many people recover well after treatment for primary bone cancer. Some people take longer and need extra help. Before you go home, the hospital staff will talk to you about your recovery. If you are worried about going home, talk to the hospital staff 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-ups 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 will also have regular blood tests. Some people may have MRI scans (see page 26). If you have had chemotherapy (see pages 80 to 89), you may have regular scans to check your heart. You will usually have these for a few years.

You can talk to your cancer doctor or specialist nurse about any problems or worries at these check-ups. Contact your doctor or nurse for advice if you notice any new symptoms or have any problems between appointments.

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 (see page 137).

If your treatment is over apart from regular check-ups, you may find our booklet **Life after cancer treatment** helpful (see page 136). This booklet has useful information about keeping healthy and adjusting to life after treatment.

## 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 soft tissue sarcoma, who may be about to start their treatment. Hearing about how you have coped and how you managed any side effects you had can help someone in a similar situation.

We have more information about how you can share your story (see page 138).

## What 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 it. This would be done to try to cure the cancer. Chemotherapy may be given before and after the operation (see pages 80 to 89).

If it is not possible to cure 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.

## Changes in your body

Your body may not look or feel the same to you. You may have scars from surgery. There may be changes in how you move. If you have had an arm or leg removed, the change in your body may be very noticeable to you.

It can be harder to cope with losing an arm than a leg. A prosthetic leg can often be covered by wearing trousers, but a prosthetic arm cannot be covered so easily.

Feeling like you look different from other people can affect your self-confidence. At times, you may even wish you had never had the operation.

At first, you may feel shocked and upset. But these feelings usually improve 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. You can also get support online, as well as share information, worries and experiences.

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 about your feelings and cancer treatment. You may find our booklet **How are you feeling? The emotional effects of cancer** helpful (see page 136).

## Other people's reactions

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

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 someone 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 body changes in our booklet **Body image and cancer** (see page 136).

## 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 is less important during this time. But if you feel like having sex, there is usually no reason why you should not have it. You cannot pass on cancer through sex. And having sex has no effect on the success of treatment or the risk of cancer coming back.

If you are having chemotherapy (see pages 80 to 89), you will need to use contraception if there is a chance you or your partner could become pregnant. This is because the drugs could harm an unborn baby.

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.

The effects of cancer and treatment are not just physical. Your thoughts and feelings are also important to how you feel about yourself sexually. You may feel differently about your body and about sex for a while. This should get better in time.

If you are in a relationship, talk to your partner about how you feel. Sometimes talking about sex can be hard. But talking about your fears and worries together can help you both feel more comfortable with each other. You may worry your partner will compare things to how they were before, or no longer find you attractive. But how attractive you are to your partner will be linked to lots of different things.

If you are not in a relationship, it can be hard to decide what to tell new partners about your cancer. It can also be hard to decide when to tell them. We often think we already know what other people think or feel about us. It is natural to be scared about rejection.

There is no simple answer that will work well for everyone. You may find it helpful to think about how safe you feel in the new relationship, and if you feel 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. There are details of other organisations that can help on page 143. We have more information about cancer and sexuality on our website (see page 136).

'We'd only been together since January when I was diagnosed in March. It has been a strange way to start a relationship. Not for one moment did my girlfriend consider leaving or not seeing this through with me. She wanted to be there every step of the way, which has brought us even closer.'

**Conor**

# Coping with your emotions

You may feel that the cancer has taken over your life. This is a common reaction. It can be very hard to cope with. But there are lots of things you can do to help you feel differently:

- You may find it helps to try to keep doing your usual activities.
- You may want to think about what is important to you. This could mean spending time with family, planning a holiday or starting a new hobby.
- You might decide to change your lifestyle. This could be eating healthily, being physically active or trying complementary therapies.
- Making plans can help you feel more in control.
- You might find knowing more about the cancer and your treatment options also helps you cope. It means you can make a plan with your healthcare team.
- Making choices and being active in your own care can help you feel more in control.

If you feel you are not coping well, or need more support, talk to your doctor or nurse.

## Complementary therapies

Some people find complementary therapies can reduce symptoms and help them feel better. It is important to talk about your planned therapy with your cancer doctor or GP to check if there are any reasons why you should not have them. Many doctors are now comfortable with medical and complementary therapies being used together.

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 help them support you.

Our booklet **Cancer and complementary therapies** has more information (see page 136).

# Looking after yourself

## Well-being and recovery

After treatment, you may want to get straight back to everyday life. But you may still be coping with the side effects of treatment, coping with physical changes or dealing with some strong emotions (see page 121). Recovery takes time, so do not rush it 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 in our booklet **Giving up smoking** (see page 136)

## Eat a well-balanced diet

Eating healthily will give you more energy and help you recover. Try to eat plenty of fresh fruit and vegetables (5 portions a day), 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.

Our booklet **Healthy eating and cancer** has more information about eating a well-balanced diet (see page 136).

## Drink less alcohol

These 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. Drink Aware has more information about alcohol and drinking guidelines. Visit their website at [drinkaware.co.uk](http://drinkaware.co.uk)

## 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. Here are some tips to help you:

- Only eat as much food as you need.
- Eat a balanced diet with lots of fruit and vegetables.
- Eat less fat and sugar.
- Be more physically active.

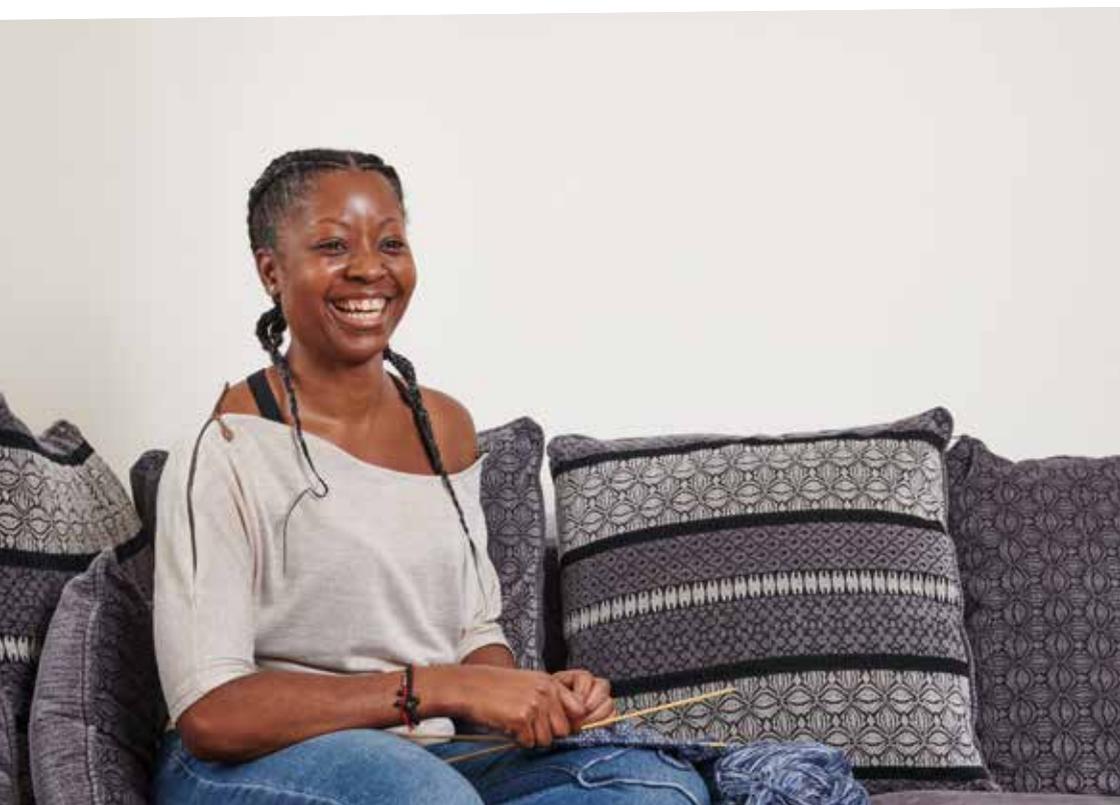
If you have lost weight during treatment, your GP or a dietitian can give you advice about gaining weight. We have more information in our booklet **Managing weight gain after cancer treatment** (see page 136).

## 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. Our booklet **Physical activity and cancer** has more information and tips on keeping active (see page 136).

## 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.



# Help and support

Treatment for primary bone cancer can last for many months. It is likely you will have good and bad days during this time. So it is important that you have as much support as you need. Family, friends and your healthcare team can all support you in different ways.

## Who can help

Many people are available to help you and your family.

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

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

In many areas of the country, there are also specialist nurses called **palliative care nurses**. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as **Macmillan nurses**. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

**Marie Curie nurses** help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There is also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families.

Our **cancer support specialists** on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

## Family and friends

Talking about your feelings with a partner, family member or friend can help.

It can be hard to talk about cancer. We have more information that might help you. Our booklet **Talking about cancer – a guide for people with cancer** has suggestions on how to talk about your feelings and ask for the support you want.

If you have a partner, we have more information that explains some of the issues couples may face during cancer treatment and how they can support each other (see page 136).

People close to you may be unsure about how best to support you. They may worry about saying the wrong thing. We have information that may help them feel more confident in supporting you. This includes:

- our booklet **Talking with someone who has cancer**
- and our booklet **Cancer and relationships** (see page 136).

## Other support available

### Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through.

We have information about cancer support groups across the UK (see page 138). Your healthcare team may be able to give you information about groups in your area.

### Online support

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to share your experience and to ask questions. You can also get and give advice based on your experience.

In our Online Community, you can talk to people in our chat rooms, write blogs, make friends and join support groups (see pages 137 to 139).



# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

It is common to have many different emotions when you are told you have cancer. These can be difficult to cope with. We talk about some common feelings here. Partners, family and friends may also have some of the same feelings.

There are lots of different reactions to cancer. You might not have any of the emotions we talk about here. There is no right or wrong way to feel. You will cope with things in your own way.

Talking to family, friends or other people affected by cancer, may help. Or you may get support from your healthcare team.

## Shock and denial

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

## Fear and anxiety

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

## Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go during and after your treatment. For most people, these periods of sadness get better. But for some people, the sadness may continue or get worse. If you think the sadness may be turning into depression, there are things you can do to help

## Avoidance

You may cope by trying not to find out much about the cancer. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your cancer doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have cancer. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the cancer. This is usually because they also find it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

## Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

## Guilt and blame

You may feel guilty or blame yourself for the cancer. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes a cancer. Over time, a combination of different risk factors may cause a cancer. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the cancer. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **[macmillan.org.uk/supportgroups](https://www.macmillan.org.uk/supportgroups)** You can also talk to other people affected by cancer on our Online Community. Visit **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)**

# Relationships

Your experience of cancer may have improved and strengthened your relationships with people close to you. You may feel that you would not have been able to cope so well without the support you have had from family and friends.

However, cancer is stressful and this sometimes has an effect on your relationships. Problems usually improve over time, especially if you can talk openly with each other. We have listed some of the issues that can arise in relationships and some ways of coping with these.

## Family and friends

You may sometimes feel that your family and friends do not understand if you are not feeling positive about getting on with things. You may feel they do not realise how much the effects of treatment are affecting your life. Talking openly about how you are feeling will help them to understand you better and give you the support you need.

We have more information about talking about cancer that you might find helpful.

## Talking to children

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

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

## Teenagers

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

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

## Your partner

Some couples become closer as a result of sharing the experience of cancer. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between close and loving couples who have been together for a long time.

Talking openly about your feelings and listening to each other can help you to understand each other's point of view.

We have more information about cancer and relationships, and cancer and your sex life that may help (see page 136).



# WORK AND FINANCIAL SUPPORT

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# Financial help and benefits

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

## Statutory Sick Pay

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

## Benefits

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

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

## Employment and Support Allowance (ESA)

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

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

## Personal Independence Payment

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

## Attendance Allowance

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

## Special rules

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

## Help for carers

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

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

## Macmillan Grants

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

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

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

## Insurance

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

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

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 136). Our Online Community forum Travel insurance may also be helpful. Visit **[macmillan.org.uk/travelinsurancegroup](http://macmillan.org.uk/travelinsurancegroup)**

## More information

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

You can also get information about benefits and other types of financial help from Citizens Advice (see page 144).

Our booklet **Help with the cost of cancer** has lots more information (see page 136).

'The sarcoma nurses told me I could apply for some financial support from Macmillan, because I was struggling to get to the hospital on my own.'

**Florenxia**

# Work

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

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

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

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

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful (see page 136). There is also lots more information at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

## Employment rights

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

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

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

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 136).



# FURTHER INFORMATION

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# About our information

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

## Order what you need

You may want to order more booklets or leaflets like this one. Visit [be.macmillan.org.uk](https://www.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](https://www.be.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
- eBooks
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](https://www.be.macmillan.org.uk/otherformats)

If you would like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

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

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

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

## Information centres

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

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

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

## Talk to others

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

## Support groups

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

## Online Community

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

## The Macmillan healthcare team

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

## Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit [publications.macmillan.org.uk](https://www.macmillan.org.uk/publications) and search 'book reviews'.

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

## Help with work and cancer

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

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

## Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

## Other useful organisations

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

### **Bone cancer support organisations**

#### **Bone Cancer Research Trust**

**Tel** 0113 258 5934

**www.bcrct.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

**Email** enquiries@limbless-association.org

**www.limbless-association.org**

Provides information, advice and support to people of any age, whether they are about to have an amputation or are already living with limb-loss. Also supports carers, family and friends.

#### **REACH**

**Tel** 0845 1306 225

Or 0203 3478 0100

**Email** reach@reach.org.uk

**www.reach.org.uk**

Provides support and information for families and carers of children with upper limb differences. Branches across the country provide the opportunity for families to meet locally.

#### **Sarcoma UK**

**Tel** 020 7250 8271

**Helpline** 0808 801 0401

**Email** supportline@sarcoma.org.uk

**www.sarcoma.org.uk**

Funds research and provides information and support for people with any type of sarcoma. Also supports carers, family and friends. The charity also has a helpline with nurses.

## General cancer support organisations

### Cancer Black Care

**Tel** 020 8961 4151

**www.cancerblackcare.org.uk**

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

### Cancer Focus Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

**Email** [nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

[cancerfocusni.org](http://cancerfocusni.org)

**www.cancerfocusni.org**

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

### Cancer Research UK

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**www.cancerresearchuk.org**

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

### Cancer Support Scotland

**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

**Email** [info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

[cancersupportscotland.org](http://cancersupportscotland.org)

**www.cancersupportscotland.org**

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

### 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 Centres

**Tel** 0300 123 1801

**Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**www.maggiescentres.org**

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits.

Also offers emotional and social support to people with cancer, their family, and friends.

### **Penny Brohn UK**

**Helpline** 0303 3000 118

(Mon to Fri, 9.30am to 5pm)

**Email** [helpline@pennybrohn.org.uk](mailto:helpline@pennybrohn.org.uk)

**[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)**

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

### **Tenovus**

**Helpline** 0808 808 1010

(Daily, 8am to 8pm)

**Email** [info@tenovuscancercare.org.uk](mailto:info@tenovuscancercare.org.uk)

**[www.tenovuscancercare.org.uk](http://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.

### **Support for young people**

#### **CLIC Sargent**

**Tel** 0300 330 0803

**[www.clicsargent.org.uk](http://www.clicsargent.org.uk)**

Provides clinical, practical, financial and emotional support to children with cancer in the UK.

#### **Teenage Cancer Trust**

**Tel** 0207 612 0370

(Mon to Fri, 9am to 5.30pm)

**Email**

[hello@teenagecancertrust.org](mailto:hello@teenagecancertrust.org)

**[www.teenagecancertrust.org](http://www.teenagecancertrust.org)**

A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer and their family and friends.

#### **Youth Access**

**Tel** 020 8772 9900

(Mon to Fri, 9.30am to 1pm, then 2pm to 5.30pm)

**Email** [admin@youthaccess.org.uk](mailto:admin@youthaccess.org.uk)

**[www.youthaccess.org.uk](http://www.youthaccess.org.uk)**

A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **[youthaccess.org.uk/find-your-local-service](http://youthaccess.org.uk/find-your-local-service)**

## Counselling

### **British Association for Counselling and Psychotherapy (BACP)**

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at [itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)

### **UK Council for Psychotherapy (UKCP)**

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**[www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Emotional and mental health support

### **Mind**

**Helpline** 0300 123 3393

(Mon to Fri, 9am to 6pm)

**Text** 86463

**Email** [info@mind.org.uk](mailto:info@mind.org.uk)

**[www.mind.org.uk](http://www.mind.org.uk)**

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

### **Samaritans**

**Helpline** 116 123

**Email** [jo@samaritans.org](mailto:jo@samaritans.org)

**[www.samaritans.org](http://www.samaritans.org)**

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

## Financial or legal advice and information

### Benefit Enquiry Line Northern Ireland

**Helpline** 0800 220 674

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

Thu, 10am to 5pm)

**Textphone** 028 9031 1092

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

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

### Carer's Allowance Unit

**Tel** 0345 608 4321

**Textphone** 0345 604 5312

(Mon to Thu, 8.30am to 5pm,  
Fri, 8.30am to 4.30pm)

**[www.gov.uk/browse/  
benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

## Citizens Advice

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

### England

**Helpline** 03444 111 444

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### Wales

**Helpline** 03444 77 2020

**[www.citizensadvice.org.uk/  
wales](http://www.citizensadvice.org.uk/wales)**

### Scotland

**Helpline** 0808 800 9060

**[www.cas.org.uk](http://www.cas.org.uk)**

### Northern Ireland

**Helpline** 0800 028 1181

**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

## Civil Legal Advice

**Helpline** 0345 345 4345

(Mon to Fri, 9am to 8pm, Sat,  
9am to 12.30pm)

**Textphone** 0345 609 6677

**[www.gov.uk/civil-legal-  
advice](http://www.gov.uk/civil-legal-advice)**

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases.

**Disability and Carers Service**

**Tel** 0800 587 0912 (Mon to Fri, 9am to 5pm)

**Textphone** 028 9031 1092

**[nidirect.gov.uk/contacts/disability-and-carers-service](http://nidirect.gov.uk/contacts/disability-and-carers-service)**

Manages state benefits in Northern Ireland. You can apply for benefits and find information online or through its helplines.

**GOV.UK**

**[www.gov.uk](http://www.gov.uk)**

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

**Law Centres Network**

**[www.lawcentres.org.uk](http://www.lawcentres.org.uk)**

Local Law Centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

**Local councils (England, Scotland and Wales)**

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details in your phone book or visit:

**England**

**[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)**

**Scotland**

**[www.cosla.gov.uk/councils](http://www.cosla.gov.uk/councils)**

**Wales**

**[www.wlga.gov.uk/authorities](http://www.wlga.gov.uk/authorities)**

**Money Advice Scotland**

**Tel** 0141 572 0237

**Email** [info@](mailto:info@moneyadvicescotland.org.uk)

[moneyadvicescotland.org.uk](http://moneyadvicescotland.org.uk)

**[www.moneyadvicescotland.org.uk](http://www.moneyadvicescotland.org.uk)**

Use the website to find qualified financial advisers in Scotland.

## NiDirect

**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

Has information about benefits and public services in Northern Ireland.

## Northern Ireland

### Housing Executive

**Tel** 03448 920 902

(Daily, 8.30am to 5pm)

**Textphone**

18001 03448 920 900

**[www.nihe.gov.uk](http://www.nihe.gov.uk)**

Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

## StepChange Debt Charity

**Tel** 080 0138 1111

**[www.stepchange.org](http://www.stepchange.org)**

Provides free debt advice through phone, email, the website and online through live chats with advisers.

## Unbiased.co.uk

**Helpline** 0800 023 6868

**Email** [contact@unbiased.co.uk](mailto:contact@unbiased.co.uk)

**[www.unbiased.co.uk](http://www.unbiased.co.uk)**

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

## Equipment and advice on living with a disability

### British Red Cross

**Tel** 0344 871 11 11

**Textphone** 020 7562 2050

**Email** [information@redcross.org.uk](mailto:information@redcross.org.uk)

**[www.redcross.org.uk](http://www.redcross.org.uk)**

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### Disability Rights UK

**Tel** 0207 250 8181

(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)

**Email** [enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

**[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)**

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

## Disabled Living Foundation (DLF)

**Helpline** 0300 999 0004  
(Tue to Thu, 10am to 4pm)

**Email** [helpline@dlf.org.uk](mailto:helpline@dlf.org.uk)

**www.dlf.org.uk**

Provides free, impartial advice about all types of disability equipment and mobility products.

## Motability Scheme

**Tel** 0300 456 4566  
(Mon to Fri, 8am to 7pm,  
Sat, 9am to 1pm)

**Textphone** 0300 037 0100

**www.motability.co.uk**

The scheme enables disabled people to exchange mobility allowances they have as part of benefits (including the enhanced rate mobility component of Personal Independence Payment) to lease a new car, scooter or powered wheelchair.

## Scope

**Helpline** 0808 800 3333  
(Mon to Fri, 9am to 5pm)

**Textphone** Use Type Talk by dialling 18001 from a textphone, followed by 0808 800 3333.

**Email** [helpline@scope.org.uk](mailto:helpline@scope.org.uk)

**www.scope.org.uk**

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

## LGBT-specific support

### LGBT Foundation

**Tel** 0345 330 3030  
(Mon to Fri, 10am to 10pm,  
Sat, 10am to 6pm)

**Email** [helpline@lgbt.foundation](mailto:helpline@lgbt.foundation)

**www.lgbt.foundation**

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

## Support for carers

### Carers Trust

**Tel** 0300 772 9600

(Mon to Fri, 9am to 5pm)

**Email** [info@carers.org](mailto:info@carers.org)

**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, Wales)

0808 808 7777

(Mon and Tue, 10am to 4pm)

**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 people in contact with local support groups for carers.

## Cancer registries

### The cancer registry

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 one in each country in the UK:

### National Cancer Registration and Analysis Service

**Tel** 020 7654 8000

**Email** [enquiries@phe.gov.uk](mailto:enquiries@phe.gov.uk)

**www.ncras.nhs.uk**

**Tel** (Ireland) 021 4318 014

**www.ncri.ie**

### Scottish Cancer Registry

**Tel** 013 1275 7050

**Email** [nss.csd@nhs.net](mailto:nss.csd@nhs.net)

**www.isdscotland.org/health-topics/cancer/scottish-cancer-registry**

### Welsh Cancer Intelligence and Surveillance

#### Unit (WCISU)

**Tel** 029 2037 3500

**Email** [general.enquiries@wales.nhs.uk](mailto:general.enquiries@wales.nhs.uk)

**www.wcisuwales.nhs.uk**

### Northern Ireland Cancer Registry

**Tel** 028 9097 6028

**Email** [nicr@qub.ac.uk](mailto:nicr@qub.ac.uk)

**www.qub.ac.uk/nicr**

## 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 Oncologist.

With thanks to: Jennifer Fulton, Sarcoma Physiotherapist; Dr Vasilios Karavasilis, Medical Oncologist; Anita Killingworth, Macmillan Advanced Nurse Practitioner; Millicent Lipshaw, Clinical Nurse Specialist Primary Bone; Ms Louise McCulloch, Orthopaedic Surgeon; and Dr Joanna Nixon, Consultant Clinical Oncologist.

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

We welcome feedback on our information. If you have any, please contact **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

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EURACAN. Bone sarcomas: Clinical Practice Guidelines for diagnosis, treatment and follow-up, *Annals of Oncology* 29 (Supplement 4): iv79–iv95, 2018.

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.

Hornicek FJ, Bone sarcomas: Preoperative evaluation, histologic classification, and principles of surgical management, *UpToDate online*, Dec 2016.

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# Can you do something to help?

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

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



## **Share your cancer experience**

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

## **Campaign for change**

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

## **Help someone in your community**

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

## **Raise money**

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

## **Give money**

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

## **Call us to find out more**

# 0300 1000 200

[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)

## Please fill in your personal details

Mr/Mrs/Miss/Other \_\_\_\_\_

Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Please accept my gift of £ \_\_\_\_\_

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

OR debit my:  
Visa / MasterCard / CAF Charity  
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## Don't let the taxman keep your money

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

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

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

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

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



If you'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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

**This booklet is about cancer that has started in a bone – called primary bone cancer. It is for anyone who has been diagnosed with primary bone cancer. There is also information for family members and friends.**

**The booklet explains the signs and symptoms of primary bone cancer, and how it is diagnosed and treated. It also has information about emotional, practical and financial issues.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**.

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

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.

**MACMILLAN  
CANCER SUPPORT**  
**RIGHT THERE WITH YOU**

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