

Primary Bone Cancer

J A S C A P

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS, MUMBAI, INDIA.

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JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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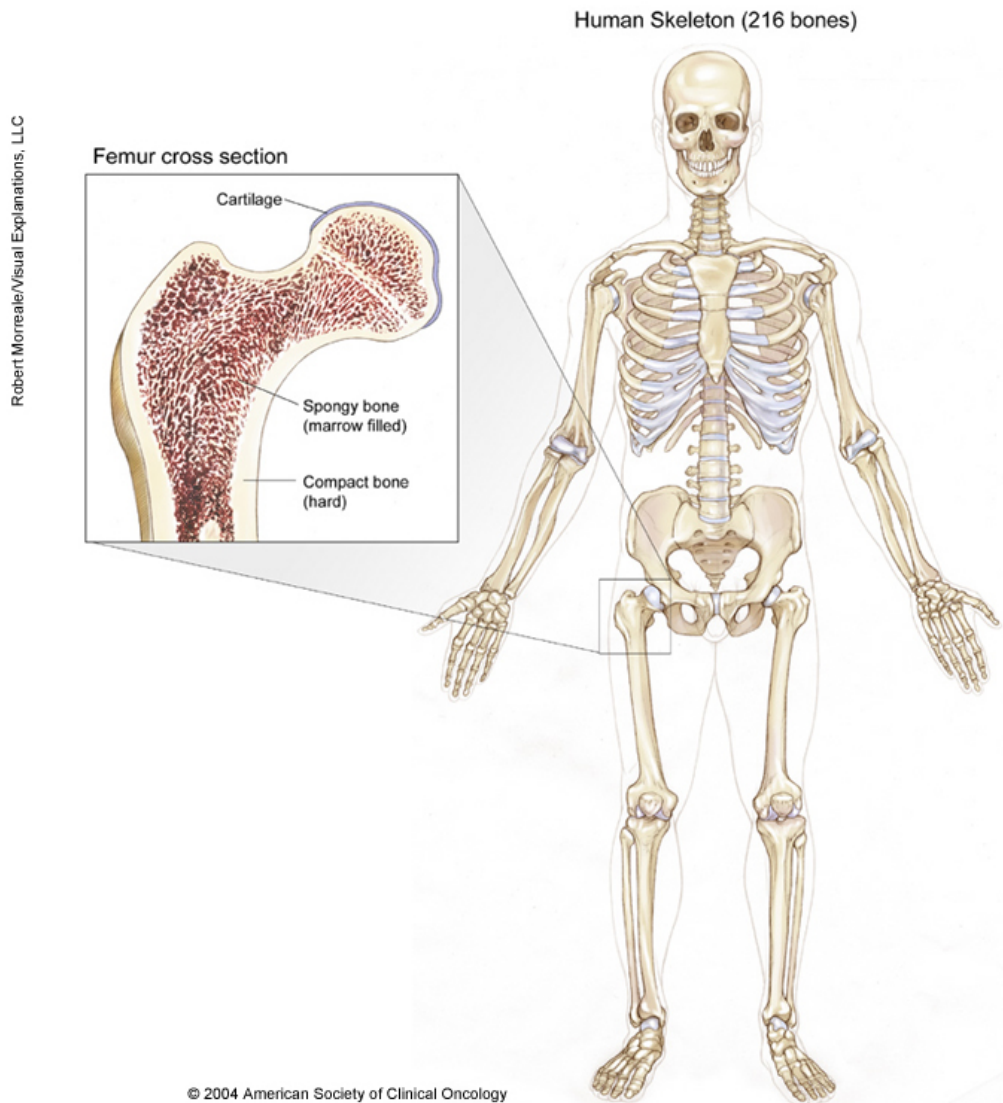
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Primary Bone Cancer

This booklet is for you if you have or someone close to you has Primary Bone Cancer.

If you are a patient your doctor or nurse may wish to go through the booklet with you and mark sections that are particularly important for you.

Bone Cancer



The skeletal system and a cross-section of the femur.

Anatomy

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**** JASCAP has factsheets on each of these types of bone cancer.**

About bone cancer

Cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

This section provides an overview of what cancer is - for further information, please see specific cancer types or treatments.

The bones

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

Bones are made of living cells (called osteocytes, osteoclasts and osteoblasts) that are bound together by a hard, calcium-like material. This makes bone strong and rigid. Bones are hollow and filled with a spongy material called marrow, which makes blood cells.

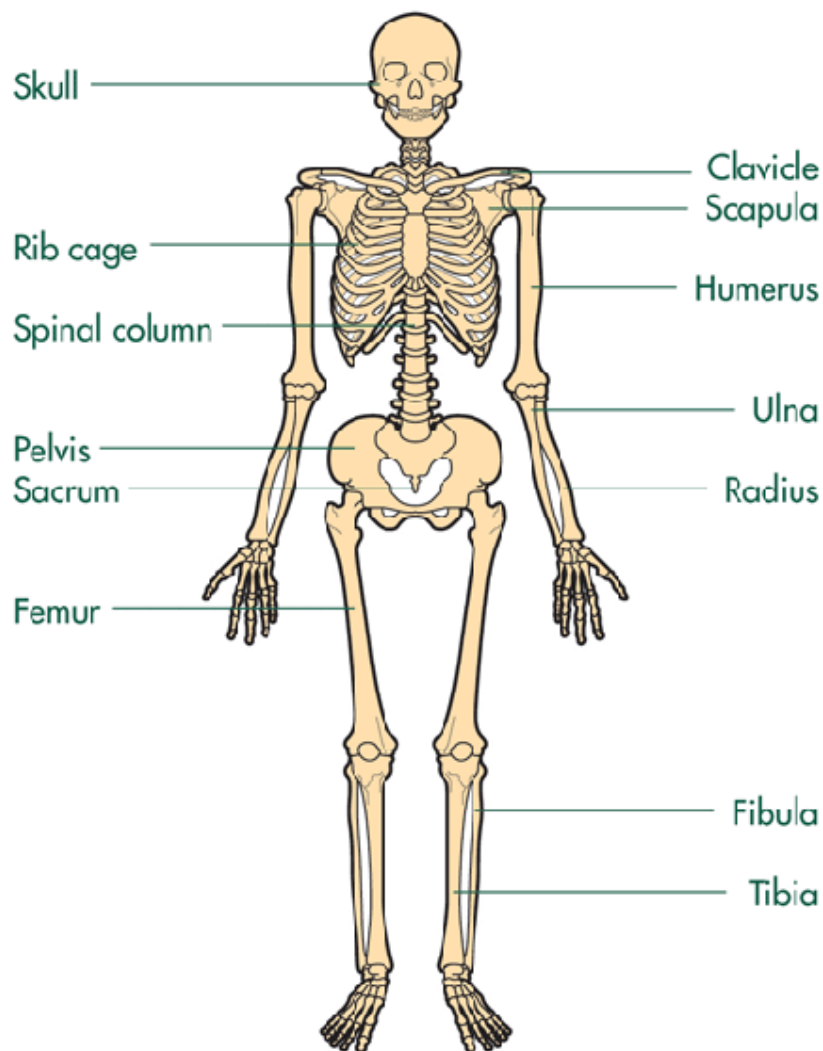


Diagram of the skeleton

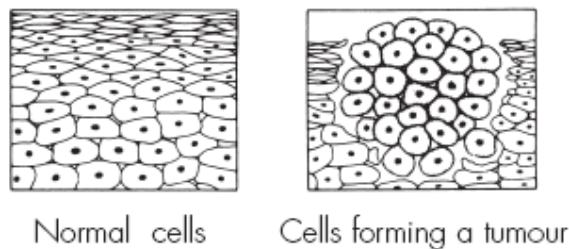
The joints of the bones are covered in **cartilage** – a tough, flexible material rather like gristle. As cartilage is more elastic than bone it allows the bones to move freely at the joints. It also cushions the bones at the joints to stop them rubbing against each other.

The bones have several important functions. The skeleton gives the body rigid support and the joints act as levers so that the body can move. The bones also protect organs in the body: for example, the ribs protect the heart and lungs. Bones also store some of the body's essential minerals, especially calcium.

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a tumour.



Tumours can be either benign or malignant. Cancer is the name given to a malignant tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a biopsy.

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

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

The lymphatic system is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs, such as

bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

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

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Types of cancer

Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

- squamous cells - that line different parts of the body, such as the mouth, gullet (oesophagus), and the airways
- adeno cells - form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
- transitional cells - are only found in the lining of the bladder and parts of the urinary system
- basal cells - that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

- bone sarcomas - that are found in the bones
- soft tissue sarcomas - that develop in the other supportive tissues of the body.

Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

Types of primary bone cancers

Primary bone cancer is rare. Fewer than 500 people are diagnosed with it in the UK each year. It can occur at any age and is slightly more common in males than females.

There are several different types of primary bone cancers.

- Osteosarcoma (also called osteogenic sarcoma)
- Ewing's sarcoma
- Chondrosarcoma
- Spindle cell sarcoma
- Chordoma
- Angiosarcoma

Osteosarcoma (also called osteogenic sarcoma)

This is the most common type of primary bone cancer. In the UK, nearly a third of all primary bone cancers are osteosarcoma – about 150 people are diagnosed with it each year. Osteosarcoma is most common in teenagers and young adults but people of any age can be affected. It's most likely to develop in a bone in the upper arm (humerus), thigh bone (femur) or shin bone (tibia).

Ewing's sarcoma

Ewing's sarcoma is named after the surgeon who first described it. This type of bone cancer is more common in young people than adults. Any bone can be affected, but the pelvis, thigh bone (femur) and the shin bone (tibia) are the most common sites. It is also possible for Ewing's sarcoma to start in the soft tissues of the body. This is known as extrasosseous ('extra' means outside, 'osseous' means bone) Ewing's sarcoma.

Chondrosarcoma

Chondrosarcoma is usually a slow-growing tumour and is most common in middle-age. The cancer starts in cartilage cells, although it can also grow within a bone or on its surface. The most common places in the body for it to develop are the upper arm (humerus) or thigh bone (femur). But it can occur in other bones such as the ribs, pelvis or shoulder blade (scapula).

Spindle cell sarcoma

Spindle cell sarcomas are a rare type of bone cancer that tend to affect people of middle-age or older. They are extremely rare in people under 20. There are four types of spindle cell sarcoma: malignant fibrous histiocytoma, fibrosarcoma,

leiomyosarcoma and undifferentiated sarcoma of the bone. The four types are explained further below:

- **Malignant fibrous histiocytoma** is most likely to affect a bone in the leg, especially around the knee joint or in the arm.
- **Fibrosarcoma** is most likely to affect the thigh bone (femur).
- **Leiomyosarcoma** is more common in the thigh bone (femur), shin bone (tibia) or upper arm bone (humerus).
- **Undifferentiated sarcoma of the bone** may arise from any bone but usually in limb bones or the pelvis.

Chordoma

This is an extremely rare cancer. It starts in the bones of the spine, either in the bottom of the spine (the sacrum) or in the neck. It can occur at any age, but is more common in people in their 40s and 50s. It tends to be a slow-growing tumour.

Angiosarcoma

Angiosarcoma can occur at any age, but is very rare in people under 20. Angiosarcomas can affect any bone. They can develop in more than one bone at the same time, or in more than one place in a single bone.

JASCAP has further fact sheets about the types of bone cancer mentioned in this section.

Causes of primary bone cancer

The exact causes of primary bone cancer are unknown, and for most people with bone cancer it's not clear why it developed.

Some of the known risk factors for the Primary Bone Cancer are:

- Previous radiotherapy
- Some types of non-cancerous (benign) bone conditions
- Inheriting a faulty gene

Research into possible causes is going on all the time. As many bone cancers occur in teenagers and young people, it's thought that they may be related in some way to changes that happen when bones are growing.

Previous radiotherapy

People who have had high doses of radiotherapy to an area that includes the bones have a slightly increased risk of developing cancer in one of these bones. This is still a very small risk and most people who have radiotherapy never develop a primary bone cancer.

Some types of non-cancerous (benign) bone conditions

Having some types of benign bone conditions can increase the risk of particular types of bone cancer.

Paget's disease of the bone can increase the risk of developing osteosarcoma. Paget's disease of the bone is a non-cancerous condition that mainly affects people over 50 years of age.

A non-cancerous bone tumour called **osteochondroma** (or chondroma) can sometimes develop into a bone cancer called chondrosarcoma.

People with **hereditary multiple exostoses** (HME) have an increased risk of developing chondrosarcoma. HME is a rare condition that causes bony lumps to grow, most commonly in the arm or leg bones. It often starts in childhood and is usually, but not always, inherited.

Inheriting a faulty gene

Most bone cancers are not caused by an inherited faulty gene, but people with certain genetic conditions have an increased risk of developing bone cancer.

People who have an inherited condition known as Li-Fraumeni syndrome have an increased risk of osteosarcoma. Children who have retinoblastoma, a rare type of eye cancer that is caused by an inherited faulty gene, also have an increased risk of developing osteosarcoma.

Sometimes, when people discover they have a primary bone cancer after a knock to their bone, they think that the injury caused the cancer to develop. There isn't clear evidence that injury to a bone can cause bone cancer, but an injury may draw attention to a bone cancer that is already there.

How common is Primary Bone Cancer in India?

Primary Bone Cancer is one of the rare cancers among men, women and children from the Indian subcontinent¹.

In India, between the years 2001-2003, across five urban centers - Mumbai, Delhi, Chennai, Bhopal and Bangalore, – and one rural center - Barshi, a total of 733 cases of Primary Bone cancer were registered (1.66% of all cancers) for males across all age groups; while 441 cases of Primary Bone cancer were registered (1% of all cancers) for females across all age groups. Considering all men, women and children with all types of cancers together, a grand total of 1,174 cases of Primary Bone cancer (1.32% of all cancers) were registered at the six centers mentioned above, between the year 2001-2003².

¹ Globocan 2008: Cancer incidence and mortality rates worldwide

² Population based cancer registry 2001-2003 Mumbai, Delhi, Chennai, Bhopal, Barshi and Bangalore, Indian Cancer Society.

The TATA Memorial Hospital (T.M.H.) in Mumbai, India registered a grand-total of 19,127 cases of all types of cancer patients in the year 2006, for men, women and children combined, out of which 347 (close to 2% of the total cases) were diagnosed with the Primary Bone cancer. Out of the total 347 patients diagnosed with Primary Bone cancers, mentioned above at the T.M.H., 232 (67%) were males and 115 (33%) were females³.

Symptoms and diagnosis

Symptoms of primary bone cancer

The most common symptoms of bone cancer are:

Pain or tenderness in the area of the tumour This may start as an ache that doesn't go away. It may be made worse by exercise or feel worse at night when the muscles are relaxed. In children this symptom may be mistaken for a sprain or 'growing pains'.

Swelling around the affected area of bone The swelling may not show up until the tumour is quite large. It isn't always possible to see or feel a lump if the affected bone is deep within body tissues.

Reduced movement If the cancer is near a joint, this can make it more difficult to move the joint and affect movement of the whole limb. If the affected bone is in the leg it may cause a limp. If the tumour is in the spine it may press on nerves, causing weakness or numbness and tingling in the limbs.

Broken bone Bone cancer is sometimes discovered when a bone that has been weakened by cancer breaks after a minor fall or an accident.

Generalised symptoms in the body These may include tiredness, a high temperature or sweats and weight loss. These symptoms are uncommon but sometimes occur in people with Ewing's sarcoma.

Many of the symptoms described above can be caused by conditions that happen much more often than bone cancer. Because of this, it sometimes takes a long time for bone cancer to be diagnosed. Anyone with bone pain that lasts longer than a few weeks should be referred to a bone specialist (orthopaedic doctor) or a cancer specialist (oncologist).

How bone cancer is diagnosed?

Usually you begin by seeing your family doctor (GP). She will examine you and arrange any tests or x-rays that may be necessary.

³ TATA Memorial Hospital Registry Data for 2006

Your GP may refer you to a local surgeon who specialises in bone diseases (an orthopaedic surgeon), or to a bone cancer specialist or bone tumour centre.

If tests suggest you may have a primary bone tumour you should always be referred to a specialist hospital, or bone tumour centre. This is important because some tests for diagnosing bone tumours, particularly taking a bone sample (bone biopsy), need to be done by a person with very specialised experience.

Children may be referred to a children's (paediatric) hospital for some of their care. If you are a teenager you may be referred to a teenage cancer unit. These units have specialist doctors with experience in diagnosing and treating young people with cancer. They also have a team of people to help support teenagers.

At the hospital

The specialist will ask you about your symptoms. They will also want to know about your general health and any previous medical problems. They will then examine the affected bone to check for any swelling or tenderness. You will probably have a blood sample taken to check your general health. You may have some of the following tests.

Bone x-rays

Bone x-rays can help to show whether the cancer has started in the bone (primary bone cancer) or has spread into the bone from a cancer elsewhere in the body (secondary bone cancer).

Sometimes, how the bone looks on an x-ray can help the doctor to diagnose what type of bone cancer someone has. This is often the case for osteosarcoma.

Bone scan

This test looks at all the bones in the body. It shows if there are signs of cancer in any other bones away from the main tumour.

A small amount of a radioactive substance is injected into a vein in your hand or arm. Abnormal bone absorbs more of the substance than normal bone. This allows areas of abnormal bone to be highlighted by the scanner as 'hot spots'. The level of radioactivity used in the scan is very small and doesn't cause any harm to your body.

You will need to wait for 2–3 hours between having the injection and the scan, so you may want to take a magazine, book or MP3 player with you to pass the time.

It isn't always clear if 'hot spots' on a bone scan are caused by cancer or by other conditions such as arthritis. Sometimes an MRI (see below) or CT scan may help the doctors to decide whether the changes seen on a bone scan are caused by bone cancer or by another condition.

MRI (magnetic resonance imaging) scan

This test is similar to a CT scan but uses magnetism instead of x-rays to build up a detailed picture of areas of your body. In primary bone cancer it's used to look in

detail at the area around the tumour. It allows the doctors to see how far the tumour has grown and how much of the bone is affected.

In some centres an MRI scan of the whole skeleton may be done, instead of a bone scan, to check for signs of cancer in any other bones away from the main tumour.

Before the scan you may be asked to complete and sign a checklist. This is to make sure that it's safe for you to have an MRI scan, because the scanner is a powerful magnet. The checklist asks about any metal implants you may have, for example a pacemaker, surgical clips, bone pins etc. You should also tell your doctor if you 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's likely that you won't be able to have an MRI scan. In this situation another type of scan can be used.

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

During the test you will be asked to 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 during the scan. It's also noisy, but you'll be given earplugs or headphones. You will be able to hear, and speak to, the person operating the scanner.

Bone sample (bone biopsy)

A bone biopsy is a specialised test and should only be done by a radiologist or surgeon with specialist expertise in bone cancers.

A sample of bone is often needed to diagnose bone cancer. This is because x-rays and bone scans can't always show if a tumour is non-cancerous (benign) or cancerous. The sample is sent to a specialist doctor, called a pathologist.

The pathologist uses a microscope to look at the cells that make up the bone sample. They can tell from how these cells look whether the tumour is cancer or not. If there is a cancer, your doctors may arrange for further tests on the sample to find out what type of bone cancer it is. It can take up to ten days to get all the results back from a biopsy.

There are two ways of taking a bone biopsy:

Core needle biopsy

For a core needle biopsy the doctor uses a special needle to take a sample from the bone. Before the biopsy, the doctor will give you an injection of local anaesthetic into your skin and around your bone to numb it. They will then put the biopsy needle into the bone to take the sample. You may have several samples taken.

If the lump is near the surface of your body and can be felt easily, the doctor will probably just feel to guide the needle in.

If the lump is in a bone deep within the body or is harder to feel, the doctor will use images from an ultrasound or CT scanner (see page 19) to guide the needle into the right place.

You will usually be awake during a core needle biopsy, although you may be given a sedative to make you feel more relaxed and drowsy. Sometimes, particularly in children, the biopsy is done under a general anaesthetic.

For most people, a core needle biopsy will show if the lump is a cancer. Sometimes it doesn't provide enough cells to give a clear answer and an open, or surgical biopsy is needed.

Open biopsy

This type of biopsy is done less often than a core needle biopsy. It may be needed if a core biopsy is unable to get enough cells for a diagnosis.

For an open biopsy the surgeon uses a surgical knife (scalpel) to open the area and remove a sample from the lump. If the lump is small enough, all of it may be removed. An open biopsy may be done under a local or a general anaesthetic. This depends on the position of the lump and how deep it is within the body.

Waiting for the results of tests

This can be a worrying time for you, but it is important that an accurate diagnosis is made. It may help to talk about your worries with a partner or close friend, or you may wish to contact our cancer support specialists or other specialised organisations for emotional support.

Further tests for primary bone cancer

If tests show you have a bone cancer, the doctor may want to do some further tests to see if the cancer has spread outside the bone.

Tests may also be arranged to see how well your kidneys, heart and other organs are working, as these may be affected by any treatment that you have for the cancer.

The tests may include any of the following:

Chest x-ray

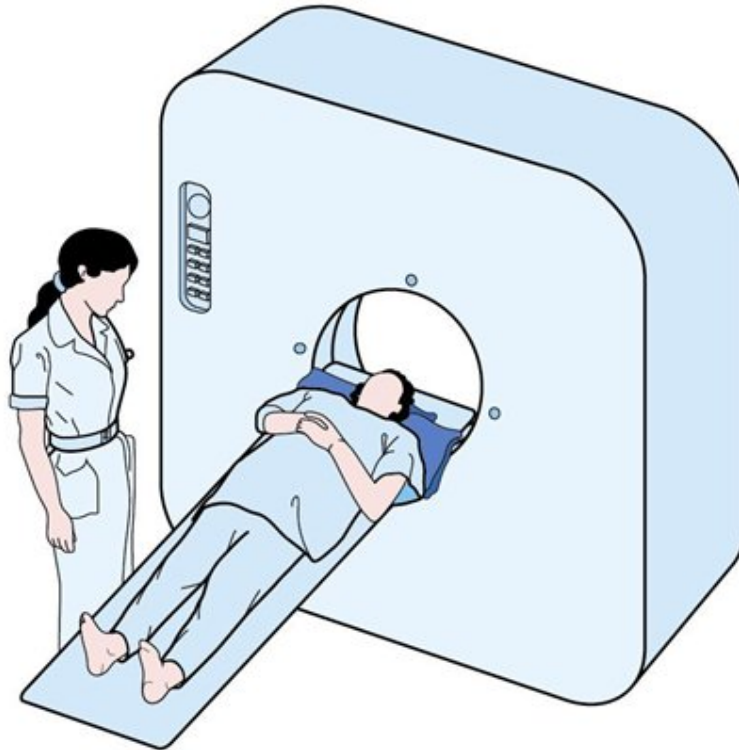
In primary bone cancer the most common place for the cancer to spread to is the lung. A chest x-ray may show whether the lungs have been affected.

CT (computerised tomography) scan

A CT scan takes a series of x-rays which build up a three-dimensional picture of the inside of the body. It may be used to check whether any cancer has spread to the lungs.

CT scans can also be used to help doctors guide a needle into the part of the bone where the tumour is when taking a sample (biopsy) from it.

A CT scan is painless and takes 10–30 minutes. The scan uses a small amount of radiation, which will be very unlikely to harm you and will not harm anyone you come into contact with.



A CT (Computerised Tomography) Scan machine

A CT scan is painless but takes 10–30 minutes

Before the CT scan you may be given a drink or injection of a dye (**contrast**) which helps the doctor to get clearer pictures from the scan. For a few minutes, this may make you feel warm all over. The contrast often contains iodine.

If you are allergic to iodine or have asthma you could have a more serious reaction to the injection, so it's important to let your doctor know before. It is usually still possible to have the injection, but you will need to have steroid treatment on the day before, and the day of, the injection.

You'll probably be able to go home as soon as the scan is over.

PET (positron emission tomography) scan

A PET scan uses low-dose radioactive sugar to measure the activity of cells in the body. A very small amount of a mildly radioactive sugar is injected into a vein in your hand or arm before the scan.

Areas of cancer are normally more active than surrounding tissue. This means they absorb more of the sugar than other parts of the body and show up on the scan as brighter areas.

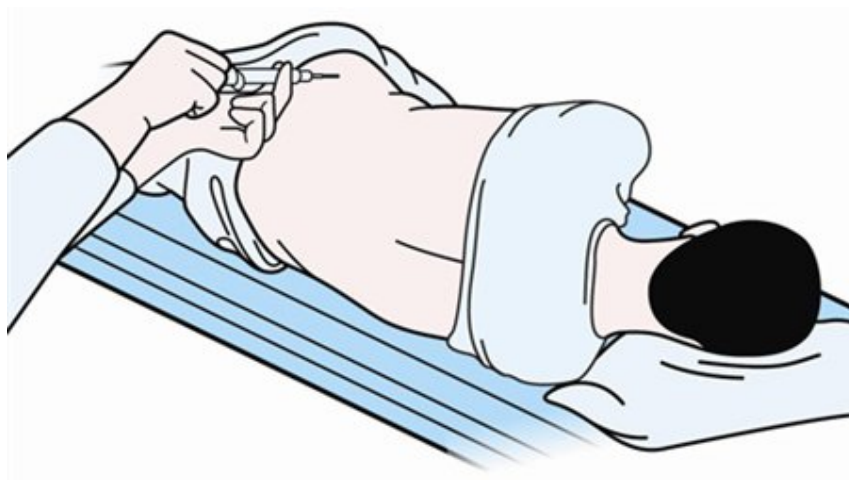
There are only a few PET scanners in the UK, so you may have to travel to a specialist centre if you need to have one.

Bone marrow sample

This test is only needed if you have, or are likely to have, Ewing's sarcoma. It is done because rarely Ewing's sarcoma can spread to the bone marrow.

Bone marrow is the spongy material inside bones. It is where blood cells are made. Small samples of bone marrow are taken from the hip bone (pelvis) and looked at under a microscope to see if they contain any abnormal cells.

Most people will have the bone marrow sample taken under a local anaesthetic, but for children a general anaesthetic is usually used. When a local anaesthetic is used, the test can be done on the ward or in the outpatients department and lasts about 15–20 minutes. You may be offered a short-acting sedative to reduce any pain or discomfort during the test.



Taking a bone marrow sample

You'll be given a local anaesthetic injection into the area around the bone to numb it. The doctor will then pass a special needle through the skin into the bone. When the needle is in position, the doctor will draw a small liquid sample from the bone marrow into a syringe. You may feel some discomfort when this is being done but it should only last for a few seconds.

Sometimes a small core of marrow is needed (a trephine biopsy). This procedure takes a few minutes longer. A special type of needle is passed through the skin to 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. This can be eased with mild painkillers.

Your bone marrow samples will be sent to a laboratory to be looked at under a microscope. It may take a week to ten days to get the results.

Other tests

You will have samples of blood taken to check your general health. If you're going to have chemotherapy you may also have tests to check your kidneys, heart and hearing.

Some chemotherapy drugs can affect how well you can hear high sounds. So you may have hearing tests (audiograms) before and during your course of chemotherapy to check your hearing.

To check how well your kidneys are working, you may have a small amount of mildly radioactive liquid injected into a vein in your hand or arm. The radioactive liquid will be carried through your kidneys and you will then pass it out in your urine. A few hours after the injection, a nurse will take blood samples from you. These will show how well your kidneys are working.

You may also have an electrical trace taken of your heartbeat (an ECG) or an ultrasound scan of your heart (echocardiogram).

Grading and staging of bone cancer

Knowing the stage and grade of the cancer helps the doctors to decide on the most appropriate treatment.

Grading

Grading describes the appearance of the cancer cells under the microscope. The grade gives an idea of how quickly the cancer may develop. The most common grading system for bone cancer uses two grades: low-grade and high-grade.

Low-grade means that the cancer cells look very 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.

Staging

The stage of a cancer describes its size and whether it has spread. The stages of bone cancer are also based on the grade of the cancer.

Stage 1 The cancer is low-grade and hasn't spread beyond the bone. This can be further divided into:

Stage 1A The cancer is low-grade and is still completely inside the bone in which it started. The cancer may be pressing on the bone wall and causing a swelling, but has not grown through it.

Stage 1B The cancer is low-grade and has grown through the bone wall.

Stage 2 The cancer is high-grade and hasn't spread beyond the bone. This can be further divided into:

Stage 2A The cancer is high-grade and is still completely inside the bone in which it started.

Stage 2B The cancer is high-grade and has grown through the bone wall.

Stage 3 The bone cancer has spread to other parts of the body, such as the lungs.

Children and teenagers with bone cancer

Children are usually referred to a children's (paediatric) hospital. Teenagers may often be referred to specialist adolescent cancer units. These units have specialist doctors with a lot of experience in diagnosing and treating teenagers with cancer.

Children's cancer centres

If your child has a bone cancer, they will be treated in a hospital, or part of a hospital, that specialises in diagnosing and treating children's cancers (a children's cancer centre).

These are relaxed and friendly places, and they aim to give you and your child as positive an experience as possible. You're likely to get to know the staff well. Almost all children's wards have a room where parents can stay.

There will also be support staff like play therapists and teachers in the hospital. Play therapists use play to help children cope with the experience of being ill. And most children's cancer centres have education departments which can support your child while they're in hospital.

The teaching staff at the hospital will contact teachers at your child's school to make sure that they can continue their schooling whenever they feel well enough. It's even possible for children to take exams in the hospital if necessary.

If your child isn't able to go back to school soon after they go home, tutoring can often be arranged with the local education authority. The person responsible for your child's schooling while they are in hospital will be able to organise this for you.

Teenagers and young adults

Some hospitals have teenage cancer units which are specially designed just 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. You may have access to a computer so that you can do some of your school or college work if you feel well enough. There may also be education specialists who can keep in contact with your school or college and support your learning needs while you're having treatment.

Most wards for teenagers allow one person to stay with you. This is usually your parent or guardian but can also be a friend, partner or other family member as long as they're older than 16 and are well.

Treating bone cancer

Treatment overview for primary bone cancer

Most people will need a combination of different treatments. The treatments used for primary bone cancer are surgery, chemotherapy and radiotherapy.

Surgery is a very important part of treatment and is used to remove the tumour in the bone.

Radiotherapy may be used as well as surgery.

If you have radiotherapy you will usually be given it after surgery or chemotherapy.

Radiotherapy is particularly effective at treating Ewing's sarcoma. And, in some situations where surgery isn't possible or would cause serious disability, radiotherapy and chemotherapy are the only treatments that are needed.

Radiotherapy is used less often to treat osteosarcoma and chondrosarcoma, but can be helpful in treating these types of bone cancer in certain circumstances.

Chemotherapy is an important treatment for osteosarcoma, Ewing's sarcoma and other high-grade bone sarcomas. It is often given both before and after surgery. When given before surgery, it may shrink large tumours enough to allow limb-sparing surgery to be carried out, so that the limb doesn't need to be removed.

Specialist treatment centres

Your treatment will be planned and given in a sarcoma treatment centre. This will either be one hospital or a group of hospitals that are close to each other and that work together. Sarcoma treatment centres (sometimes called sarcoma units) specialise in treating people with primary bone tumours and soft tissue sarcomas. Because primary bone cancer is rare there are only a small number of sarcoma treatment centres in the UK. This means you may need to travel quite a long distance to reach one.

A team of specialists, called a **multidisciplinary team (MDT)**, will meet to discuss what treatments are best for your situation.

The specialists in the team will have expert knowledge about bone cancer and will include a:

- Surgeon who specialises in bone cancers.

- Radiologist (doctor who reads and interprets x-rays and scans).
- Pathologist (doctor who examines samples from the tumour to see if it is a cancer and what type it is).
- Medical oncologist (doctor who specialises in treating cancer with chemotherapy).
- Clinical oncologist (doctor who specialises in treating cancer with radiotherapy and chemotherapy).
- Paediatric oncologist (doctor who specialises in treating children with cancer).
- Key worker, who will be your main contact and will make sure you get help and support throughout your treatment. Your key worker may be a specialist nurse or another healthcare professional such as a physiotherapist.

Other healthcare professionals who work closely with the MDT may include:

- nurse specialists
- physiotherapists
- occupational therapists
- dietitians
- psychologists or counsellors
- social workers.

How treatment is planned

The doctors in the MDT will meet to plan your treatment. They will take into account a number of factors. These include your age and general health, the type of bone cancer you have, where the tumour is, its size and whether it has spread.

Your doctors will discuss with you what treatments are best for your situation. If there are two treatments that could work equally well for your type and stage of cancer, they may offer you a choice. You may find you need to ask questions about what is involved with each treatment and the possible side effects before you decide.

Your cancer specialist and specialist nurse can talk you through the benefits and disadvantages of each treatment.

The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of some of the side effects that can occur. Some people ask what would happen if they don't have treatment.

Although many of the treatments can cause side effects, these can usually be controlled with medicines. Treatment can be given for different reasons and the potential benefits will vary depending upon the individual situation.

If you have early-stage bone cancer, the aim of treatment will usually be to cure the cancer. The most common treatment is an operation to remove the tumour completely. You may also be given additional treatments to reduce the risk of the cancer coming back.

If the cancer is at a more advanced stage the treatment may only be able to control it. This may help you to live for longer or it may reduce your symptoms and improve your quality of life. But for some people the treatment doesn't work against the

cancer and causes side effects without giving any benefit. If you are having treatment you will be monitored closely for signs that it is working. This is done so that if the treatment isn't helping and is only causing side effects it can be stopped.

Giving your consent

Before you have a treatment, your doctor will explain its aims to you. They will usually ask you to sign a form saying that you give your 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 have been given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any other possible treatments that may be available
- any significant risks or side effects of the treatment.

If you don't understand what you have been told, or if you have any questions about your treatment, don't be afraid to ask your doctor or nurse. Some cancer treatments are complex so it's not unusual for people to need repeated explanations.

It's often good to have a relative or friend with you when the treatment is explained. They can help you to remember the discussion more fully. You may also find it useful to write down a list of questions before you go to your appointment.

If you have been offered treatment that aims to cure your cancer, deciding whether to accept the treatment may not be difficult. But, if a cure isn't possible and the aim of treatment is to control the cancer for a period of time, it may be more difficult to decide whether to go ahead with it. You can always ask for more time to decide if you feel that you can't make a decision when it is first explained to you.

If you choose not to have treatment for the cancer it's important to tell your doctor. They will record your decision in your medical notes. You can still have treatment to control symptoms. This type of treatment is called supportive or palliative care.

Second opinion

Even though a number of cancer specialists work together as a team and use national treatment guidelines to decide on the most suitable treatment, you may want another medical opinion. Either your specialist or your GP can refer you for a second opinion at any time if you feel it will be helpful. Getting a second opinion may cause a delay in your treatment, so you and your doctor need to be confident that it will give you useful information.

If you go for a second opinion, it may be helpful to take someone with you. You can also have a list of questions ready so that you can make sure your concerns are covered during the discussion.

Surgery for primary bone cancer

There have been major improvements in surgery for bone cancer over the last few years.

In the past, it was often necessary to remove (amputate) the limb if cancer was found. But now, it's usually possible just to remove the affected part of the bone and replace it with a specially designed metal fitting (endoprosthesis) or with a bone from another part of the body (bone graft). If the cancer affects a bone in or near a joint, the whole joint can be replaced with an artificial one.

These operations, called limb-sparing surgery, have made it possible for many people to avoid amputation. They are only carried out in specialist hospitals, so your doctor should refer you to one of these hospitals to see if this type of operation would be possible for you. Unfortunately, it isn't always possible to avoid an amputation.

The type of surgery you have will depend on a number of factors. Your surgeon will discuss the different types of surgery with you in detail before any decision is made about your treatment.

Surgery if the cancer has spread to the lungs

If a bone cancer spreads to the lungs it may still be possible to cure it with an operation to remove the part of the lung that is affected. This operation is called a thoracotomy. It shouldn't affect your breathing as it's possible to breathe properly if part of a lung, or even a whole lung, is removed.

When deciding whether this type of operation is possible, the surgeon will consider several factors including the number of secondary cancers in the lungs, their size and where they are in the lungs. They will also take into account your age and general health as this is a major operation.

Sometimes a course of chemotherapy is given first. This can help to shrink the cancers and may make an operation possible if the cancers are larger.

If this operation is necessary, your doctor will discuss it fully with you.

Limb-sparing surgery

Before your operation, your doctor will discuss it with you to make sure that you fully understand what is involved.

You may find it helpful to talk to someone who has had the same operation. The medical staff may be able to arrange this for you. Some hospitals have a counsellor who can help you to talk through any worries before your operation.

Some people like to see the replacement part or endoprosthesis (often just called a prosthesis) that will be used during their operation. If you would like to do this your surgeon or the hospital staff can usually arrange it for you.

A physiotherapist will talk to you before your operation and may give you some exercises to help strengthen your muscles.

If you've had chemotherapy, it usually takes a couple of weeks or so before your blood cell levels get back to normal and you're ready to have your operation.

After your operation

At first your limb will be firmly bandaged, or you may have a splint in place to keep it still. This will give the bone graft, or artificial joint or bone, time to start joining firmly onto the rest of the bone in the limb. You will probably also have a tube (drain) coming out of your wound. This will drain excess fluid and blood into a small container attached to the other end of the tube. Drains are usually taken out after 3–4 days.

Eating and drinking

You probably won't feel like eating or drinking much for the first few hours after your operation so you'll be given fluids into a vein in your hand or arm. This is called a 'drip' or intravenous infusion. A nurse will take it out once you begin eating and drinking again.

Pain

You may feel quite sore for a few days after your operation. To start with you will probably need a strong painkiller such as morphine.

Painkillers can be given in different ways. They can be given into a vein (intravenously), into the space around your spinal cord (epidural), into a muscle (intramuscularly) or as tablets.

For the first day or so you may be given intravenous painkilling drugs through a syringe connected to an electronic pump. The pump can be set to give you a continuous dose of painkiller, so you are getting some all the time.

You may also have a hand control with a button to press if you feel sore. This is called patient controlled analgesia (PCA). It's okay to press it whenever you are uncomfortable, as the pump is designed so that you can't give yourself too much painkiller.

If you find you need to press the button a lot tell the nurse in case you need a higher dose.

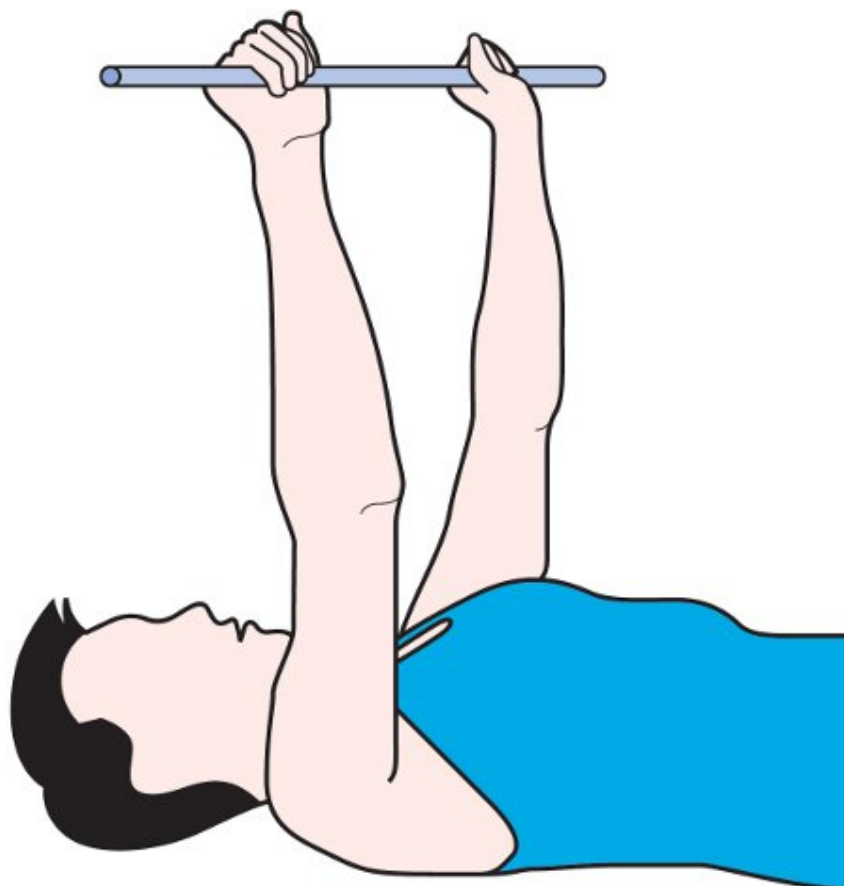
If you've had an operation on your arm or leg you may be given painkilling drugs into the space around your spinal cord to begin with. This is called epidural analgesia and it works by numbing the nerves to the arms or legs. The drugs are often given through a syringe and tubing attached to an electronic pump.

It is important to let the nurses know if your painkillers don't seem to be working.

Physiotherapy

Physiotherapy is a very important part of your recovery. It helps you to regain muscle strength and to get good movement back in your limb. A physiotherapist will come to see you soon after your operation. They will show you some exercises to do. These exercises keep the muscles in the limb strong and supple, so that as soon as it is strong enough you can use it normally.

Once you are able to get up and around the physiotherapist will give you more exercises to do. These can be hard work but it's important to keep going with them as they will help you to recover. You may need to continue to have physiotherapy as an outpatient for some time after your operation.



Physiotherapy exercises

Going home

You will usually be able to go home once your wound has healed. For most people this is about a week to ten days after the operation.

Most people recover well after their surgery and are able to move around quite soon, some people take longer and need extra help. Before you go home the staff will talk to you about your home situation. If you live alone or have several stairs to climb, you may need some help at home.

If you have any worries about going home, make sure you discuss them with the nursing staff in advance so that help can be organised.

Living with limb-sparing surgery

After limb-sparing surgery people are often able to do most things they could before, including taking part in exercise and sports. But depending on what limb was affected, there may be some things you can't do or that you find more difficult. Your

surgeon can give you detailed advice about the particular risks of the operation you are to have, how well the limb will work afterwards and the risk of complications such as infection.

Knee joint

When the knee joint is replaced, the new joint normally works very well. It's fine for you to go swimming or cycling but your doctor might advise you against doing high impact sports like hockey, football, tennis or rugby. This is because of the risk that the joint will be damaged or loosen.

In some people the prosthesis may become loose or cause pain and may need to be replaced after a few years. Around 1 in 4 people (25%) who have a new knee joint will need to have a further operation within 10 years of having the knee replacement.

Hip joint

Replacement of the hip joint is usually very successful. Young people will have good strength in the hip, but older people usually need to use a walking stick. This is because their joint and muscles may not be as strong as they were before the operation. Hip replacements may also loosen and around 10% of people (1 in 10) will need to have a further operation within 10 years of having the hip replaced.

Shoulder joint

People who have shoulder replacements can normally move their arms around very well below shoulder height. However, they are usually not able to raise their arms above shoulder height. It's uncommon for a shoulder joint prosthesis to loosen. These generally last for many years after the operation and cause few problems.

Infection

With any prosthesis the main problem that can occur is infection. If the prosthesis gets infected it will need to be taken out and replaced. The area needs to be cleaned completely with antibiotics before a new replacement joint can be put in.

Bone grafts

Limb-sparing surgery on a straight part of the bone may use a piece of bone taken from another area of the body to replace the bone that has been removed. This is known as a bone graft. The main problem that can occur with these operations is infection of the replacement bone.

Children and teenagers

If you have a prosthesis put into your limb while you're still growing it will need to be lengthened as the leg or arm grows. Some types of prosthesis are lengthened during further surgery, while other types can be lengthened without the need for surgery. Your specialist or nurse will explain how the prosthesis will be lengthened. If a bone graft is taken from a limb, that may also mean that the limb does not grow normally and so further surgery may be needed to keep the limb at the same length as the unaffected limb.

Amputation as a treatment for primary bone cancer

It is not always possible to use limb-sparing surgery and occasionally removing (amputating) the whole limb may be necessary. This is often because the cancer has spread from the bone into the surrounding blood vessels.

The preparation for amputation is similar to that for limb-sparing surgery. You should be given psychological support before and after the operation, as facing an amputation can feel overwhelming (see the information about living with an amputation below).

The medical staff looking after you will be able to offer help and support. It may also be helpful to talk to someone who has had the same operation and can offer practical advice and encouragement. The hospital staff may be able to arrange this for you. They can also arrange counselling.

After your operation

You probably won't feel like eating or drinking much for the first few hours after your operation, so you'll be given fluids into a vein in your hand or arm. This is called a 'drip' or intravenous infusion. A nurse will take it out once you begin eating and drinking again.

You may also have an oxygen mask on when you first wake up. Some people will have a tube in their bladder (catheter) to drain urine into a bag until they are up and around.

The part of your body that has been operated on will be covered with bandages or a plaster cast to control swelling. There will be a tube (drain) coming from your wound to drain off excess blood and fluids into a small container. This will usually be taken out after 3–4 days. You will also have stitches or staples to close the wound. These are usually taken out about 10–14 days after the operation.

Pain

You may feel sore for a few days after your operation. To start with you'll probably need a strong painkiller such as morphine.

Painkillers can be given in different ways. They can be given into a vein (intravenously), into the space around your spinal cord (epidural), into a muscle (intramuscularly) or as tablets.

You may be given intravenous painkilling drugs through a syringe connected to an electronic pump. The pump can be set to give you a continuous dose of painkiller, so you are getting some all the time.

You may also have a hand control with a button you can press if you feel sore. This is called **patient controlled analgesia (PCA)**. It's okay to press the button whenever you are uncomfortable, as it's designed so that you can't give yourself too much. If

you find you need to press the button a lot tell the nurse in case you need a stronger dose of painkiller.

Some people are given painkilling drugs into the space around the spinal cord for the first day or so. This is called epidural analgesia and it works by numbing the nerves. The drugs are often given through a syringe and tubing attached to an electronic pump.

It is important to let the nurses know if your painkillers don't seem to be working.

Phantom pain

To begin with you may have a pain that feels as if it is coming from the part of the limb that has been amputated. This is known as 'phantom pain' or 'phantom sensation'. Most people find that phantom pains get less in time and eventually go away, but there may be some discomfort in the area for a while after the operation. Some people find that the phantom pain or sensation is difficult to control and they need to take painkillers long-term.

Physiotherapy

A physiotherapist will visit you a day or so after your operation. They will show you how to do exercises to keep the muscles around the operation site strong and supple, making it easier to work an artificial limb.

You will be encouraged and helped to move around as soon as possible after the operation. If you have had an upper limb amputated you will be able to be up and around once your pain is controlled and you have recovered from the anaesthetic. If you have had a leg amputated your physiotherapist will show you how to move around in bed and transfer to a chair. You'll probably be moving around with crutches or in a wheelchair within a few days.

Once 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 different exercises to do as you heal and gain strength. If you are going to be fitted with an artificial limb you'll also be taught how to use this to help you to regain independence in everyday activities.

Occupational therapy

You will see an occupational therapist soon after your operation. Their aim is to help you to become as independent as possible in everyday activities. And they may suggest different ways of doing things or aids or equipment that you can use.

Artificial limb (prosthesis)

Following an amputation, most people are fitted with an artificial limb, known as a prosthesis. Many different types of artificial limbs are available. There are lower limbs adapted for walking, swimming, riding a bike and playing sports, and upper limbs adapted for playing golf, swimming and so on.

One of the team looking after you will discuss limb fitting with you and explain what's involved. It takes a few months for the residual limb to shrink to its final size and shape. So you won't be able to be measured and fitted with a permanent prosthesis until this happens.

In the meantime, if you have lost a lower limb you will normally be measured and have a fitting for a temporary prosthesis about 4–6 weeks after your operation. This usually happens at a limb fitting centre. About two weeks after this you'll get your prosthesis and be ready to learn how to use it in physiotherapy.

People who have lost an upper limb are usually ready to be fitted with a long-term prosthesis after about three months, for a lower limb it is a bit longer, about six months. The timing varies from person to person.

The staff at the limb fitting centre will be able to show you the different types of prostheses and explain how they work. They will talk over your needs, and help you to choose the best types of prostheses for your situation. For example, if you swim you may want an additional prosthesis you can wear in water.



A person with a prosthesis riding a bike

Going home

You will be able to go home once your wound has healed. If you are to continue with physiotherapy after you go home, the physiotherapist will make arrangements for you to have this.

If you don't live close to the hospital where you had your operation you'll be able to go to a physiotherapist nearer to you.

Sometimes people need changes made to their homes to make them safer or more independent. The occupational therapist will work with social services to arrange these alterations for you if they are needed.

Your emotions

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

You may find it helpful, either before or after your operation, to talk to someone who has had an amputation. The doctor or nurses on your ward may be able to arrange this.

Even if you thought you were prepared for losing a limb, you may still feel shocked and distressed after the operation. You will be used to what your body looks like and it can be hard to come to terms with such a major change. The sense of looking different from other people can seriously affect your self-confidence and make you afraid of how other people might react.

These are very strong emotions and you will need time and help to come to terms with them. The staff on the ward will know this and will help you all they can. They can also make suggestions to help you cope with the reactions of others.

Other people's reactions

You may be frightened of other people's responses to your amputation. You may feel worried about what your partner, family or friends will say or think and whether you will be able to cope with their reactions.

Although this fear is very real, the fear is often worse than the reality. Try to focus on the fact that the people who love you do so because of who you are. The qualities you are loved for are not removed by an amputation. Be open about your fears. Given the chance, most people will be very keen to reassure you that they still love you.

As you become more used to the way you look, you will become more confident about dealing with the reactions of people you don't know as well. Some people find it helpful to get out and about as soon as possible after the operation. But it's important to do things in your own time. You may want to take someone with you at first to offer support. You may find that other people don't even notice your amputation, especially if you are wearing an artificial limb.

You may feel different about yourself sexually and be worried that you aren't as sexually attractive. This can be distressing no matter what your age or whether you have a partner or not. Many people find it helpful to discuss their feelings with their partner, a close friend or with a counsellor.

We have information on relationships, sexuality and cancer that we can send you if you think it may be helpful.

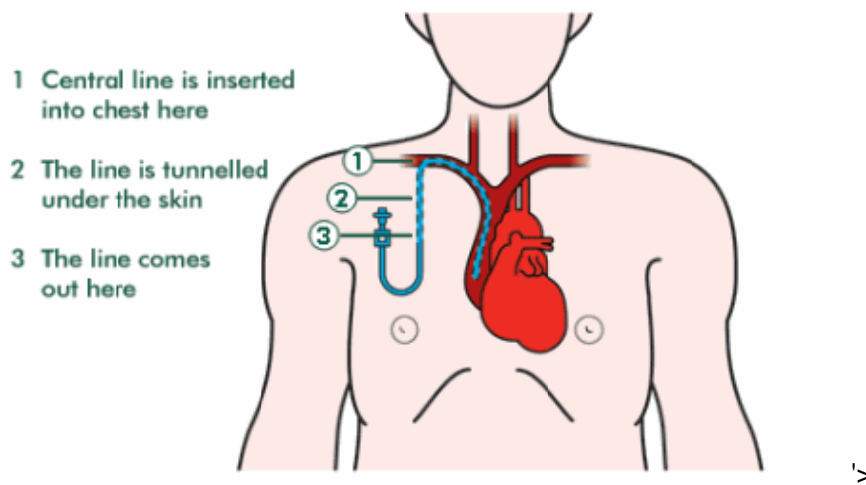
We can give you details of support groups or counselling services in your area. Support groups can give both practical and emotional advice and help to stop you feeling as if you have to cope alone.

Chemotherapy for primary bone cancer

Chemotherapy is an important treatment for some types of primary bone cancer. It is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells.

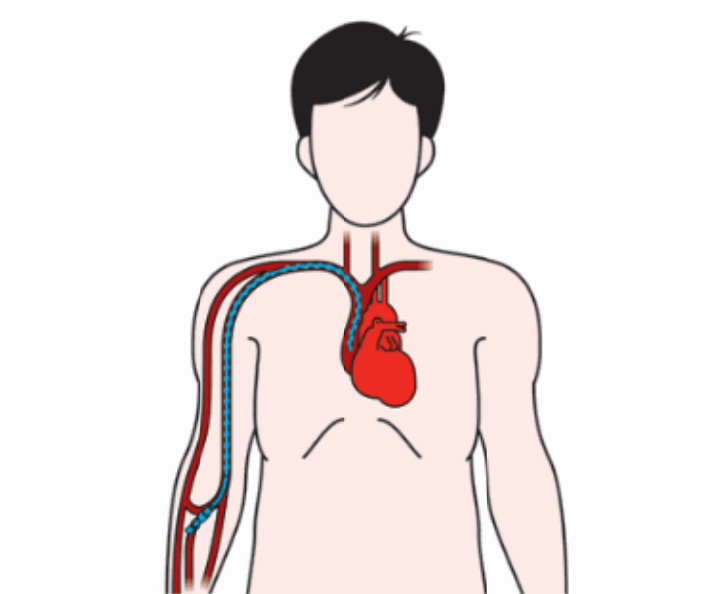
How chemotherapy is given

Chemotherapy drugs are sometimes given as tablets or, more often, by injection into a vein (intravenously). Sometimes, to make this easier and to avoid you having to have frequent injections, a fine plastic tube (called a central line) can be put into a vein in your chest. The line is put in under a general or local anaesthetic.



A central line

Instead of a central line, a tube may be put into a vein in the crook of your arm: this is known as a PICC (Peripherally inserted central catheter) line. A tube with an injectable port just under the skin may sometimes be used: this is known as an implantable port.



The PICC line is threaded through the vein until the end is near to your heart

A session of chemotherapy treatment usually lasts a few days. This is followed by a rest period of a few weeks to allow your body to recover from any side effects of the treatment. The number of sessions you have will depend on the type of bone cancer you have and how well it is responding to the drugs.

Chemotherapy will usually mean spending a few days in hospital. Sometimes it may be given to you as an outpatient. In this situation it is given continuously into a vein through a central line or PICC line. The dose is controlled by a small portable pump.

Depending on the type of bone cancer you have, your doctor may recommend a course of chemotherapy before you have surgery or radiotherapy. This can shrink the tumour and make it easier to remove. It can also reduce symptoms such as pain and reduce the chances of the cancer spreading. Treatment given before an operation is known as neo-adjuvant therapy.

If you have an osteosarcoma or Ewing's sarcoma you will have more chemotherapy after surgery or radiotherapy. This is to destroy any remaining cancer cells and prevent the sarcoma from spreading outside the bone. This is known as adjuvant chemotherapy. It is given because tiny amounts of cancer may be present, especially in the lungs, which are too small to be detected by a scan.

Before having chemotherapy you may have tests to check your hearing and how well your heart, liver and kidneys are working. The results are normally available after a few days. Your doctor will discuss them with you.

You may be offered chemotherapy treatment as part of a clinical research trial. Clinical trials are very important in improving the way that bone cancer is treated. Your doctor or research nurse can discuss any relevant trials with you.

Side effects of chemotherapy

Chemotherapy can sometimes cause unpleasant side effects. Any side effects that occur are usually temporary and can often be well controlled with medicines. The main side effects are described here, with tips on ways to avoid or reduce them.

Lowered resistance to infections

Chemotherapy can temporarily reduce the number of normal cells in your blood. When these cells are reduced your body is less able to fight off infections. It's important to contact your doctor or the hospital straight away if you think you may have an infection, if your temperature goes above 38°C (100.5°F), or if you suddenly feel unwell, even with a normal temperature.

During chemotherapy the doctors will check your blood regularly. If your white blood cell numbers are very low you may be given medicines called growth factors. These stimulate your bone marrow to make more white cells to reduce the chance of you getting an infection.

Anaemia

If the level of red blood cells in your blood is low this is called anaemia. If you are anaemic you may feel tired and lacking in energy. You may also become breathless. Anaemia can be treated by having a blood transfusion.

Bruising and bleeding

Platelets are a type of cell that helps the blood to clot. If the number of platelets in your blood is low you will bruise more easily and may bleed heavily from even minor cuts or grazes.

If you develop any unexplained bruising or bleeding, contact your doctor or the hospital immediately, as you may need to have a platelet transfusion.

Feeling sick

Some of the drugs used to treat primary bone cancer may make you feel sick (nauseous) and possibly make you vomit. Anti-sickness drugs (anti-emetics) can prevent or greatly reduce nausea and vomiting. Your doctor will prescribe these for you.

Sore mouth

Some chemotherapy drugs can make your mouth sore and cause mouth ulcers. Regular mouthwashes are important and your nurse will show you how to do these properly. If you don't feel like eating during treatment, talk to your nurse or ask to see a dietitian for advice – our website also has some useful tips on coping with eating problems.

Hair loss

Some chemotherapy drugs can cause temporary hair loss. Your doctor or nurse will be able to tell you if the drugs you are having are likely to cause hair loss. People who lose their hair during chemotherapy often cover up by wearing wigs, hats or scarves. Hospital inpatients are entitled to a free wig from the NHS, and your doctor or nurse will be able to arrange for a wig specialist to visit you. However, people being treated as outpatients may have to pay for their wigs. If you lose your hair due to chemotherapy, it will grow back over 3–6 months.

Changes in hearing

Some chemotherapy drugs can affect your ability to hear high-pitched sounds. You may also have ringing in your ears (tinnitus) but this usually gets better when the treatment ends, although for some people it may be permanent. Tell your doctor if you notice any loss of hearing or tinnitus.

Although they may be hard to bear at the time, the side effects from chemotherapy usually disappear once your treatment is over.

Chemotherapy affects everyone differently. Some people are able to lead a fairly normal life during their treatment, but many people find they become very tired and have to take things much more slowly. Just do as much as you feel like and try not to overdo it.

Fertility

Your ability to become pregnant or father a child may be affected by some of the chemotherapy drugs used to treat bone tumours. It is important to discuss fertility with your doctor or nurse before starting treatment, as it may be possible for men to store sperm, and for women to store embryos or eggs.

Some women who have chemotherapy have an earlier menopause than they would otherwise have done. This means they may not have as many years of fertility. Your doctor can tell you if you may be affected in this way.

Women with signs of an early menopause, such as hot flushes and sweats, can be given hormone replacement therapy (HRT) to replace the hormones that are no longer being produced.

Contraception

It is not advisable to become pregnant or father a child while having any of the chemotherapy drugs used to treat bone tumours, as they may harm the developing foetus. Again, you can discuss this with your doctor or chemotherapy nurse.

JASCAP booklet on [Chemotherapy](#) discusses treatment and its side effects in more detail. Information on individual drugs and their particular side effects is also available.

Radiotherapy for primary bone cancer

Radiotherapy treats cancer by using high-energy rays, which destroy the cancer cells while doing as little harm as possible to normal cells.

Treatment is usually given in the hospital radiotherapy department, every weekday, with a rest at the weekend. How long your treatment takes will depend on the type and size of the cancer, but it will normally be a few weeks. Your doctor will discuss your treatment with you beforehand.

Radiotherapy works well for Ewing's sarcoma and is often given together with chemotherapy and surgery. If surgery to remove the tumour is not possible, radiotherapy may be used as the main treatment.

If the tumour is in the spine or pelvis, radiotherapy may be used if the doctor thinks surgery to the area might cause disability. Sometimes, before the start of radiotherapy, the surgeon operates to place a water-filled balloon into the pelvis. The balloon moves the organs in the pelvis out of the way of the radiotherapy beam. This protects them from any damage the radiotherapy may cause.

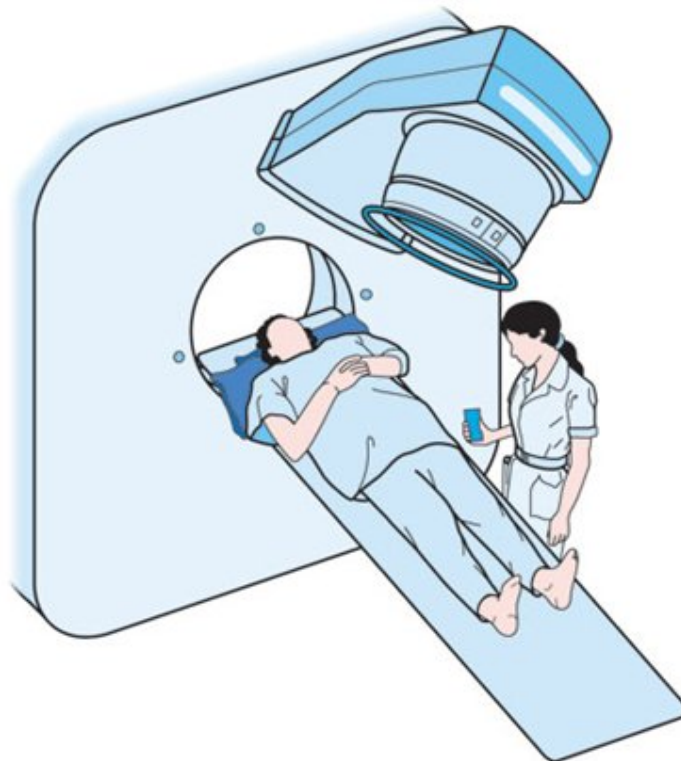
Radiotherapy is not often used to treat osteosarcoma as this type of bone cancer isn't very sensitive to radiation. However, if a limb has fractured this can mean there is a higher risk that the cancer could spread elsewhere. In this situation, radiotherapy may be given after surgery to destroy any cancer cells that may remain in the surrounding tissues.

Radiotherapy given after surgery may help to reduce the chance of a chondrosarcoma or a spindle cell sarcoma coming back.

Planning your treatment

To make your radiotherapy as effective as possible, it must be carefully planned. On your first few visits to the radiotherapy department you'll be asked to lie in a CT scanner, which will take images of the area to be treated. The planning will be done by a clinical oncologist and medical physicist, and may take a few visits.

Marks may be drawn on your skin to help the radiographer, who gives you your treatment, to position you accurately and to show where to direct the rays. These marks must stay visible throughout your treatment, but they can be washed off once it is over. At the beginning of your radiotherapy you'll be told how to look after the skin around the area to be treated.



Positioning the radiotherapy machine

Before each session of radiotherapy the radiographer will position you carefully and make sure that you're comfortable. During your treatment, which takes only a few minutes, you'll be left alone in the room. But you can talk to the radiographer who will be able to see you from the next room. Radiotherapy is not painful but you do have to lie still for a few minutes while it is being given.

Side effects of Radiotherapy

Radiotherapy can cause general side effects such as feeling sick (nausea) and tiredness. These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of your treatment. The radiotherapist will be able to advise you what to expect.

Tiredness

Radiotherapy can make you tired so you may need more rest than usual, especially if you have to travel a long way for treatment every day.

Feeling sick

Nausea can usually be effectively treated by anti-sickness drugs (anti-emetics). Your doctor can prescribe them for you. If you don't feel like eating, speak to your nurse or ask to see a dietitian for advice.

Our section on diet and nutrition has some helpful hints on how to eat well when you are feeling sick.

Hair loss

Radiotherapy can make your hair fall out in the area being treated. This may grow back after treatment is over but for some people the hair loss is permanent. It depends on the total dose of radiotherapy that is given. Your doctor can tell you if your hair is likely to grow back after treatment.

All these side effects should disappear gradually once your course of treatment is over, but it is important to let your doctor know if they continue.

Radiotherapy doesn't make you radioactive. It's safe for you to be with other people, including children, throughout your treatment.

JASCAP has booklet about [Radiotherapy](#), which gives more details about this treatment and its side effects.

Research - clinical trials for primary bone cancer

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials which patients take part in are known as clinical trials.

Clinical trials may be carried out to:

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

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

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and the development of new treatments. You'll also be carefully monitored during and after the study. Usually, several hospitals around the country take part in trials.

As bone cancers are rare, trials are usually organised by specialists from many countries working together, and may take years to complete. Clinical trials for osteosarcoma and Ewing's sarcoma are especially important so that more people can be cured of them.

EURAMOS 1 trial

If you have an osteosarcoma that can be removed by surgery you may be asked to take part in the EURAMOS 1 trial. The trial is looking at giving different chemotherapy drugs after surgery to reduce the risk of the cancer coming back. The chemotherapy drugs usually used after surgery are methotrexate, doxorubicin (which is also called Adriamycin) and cisplatin.

This combination is known as MAP. Some of the people in the trial will be given MAP following their operation, others will be given MAP plus the chemotherapy drugs ifosfamide and etoposide (MAPIE), and some will be given MAP with the biological therapy drug interferon (MAPifn). The trial will be running until 2010 so it will be some time before we know which treatment combination is the best for treating osteosarcoma.

Euro-Ewing 99 trial

If you have a Ewing's sarcoma you may be asked to take part in the Euro-Ewing 99 trial. People with a Ewing's sarcoma are usually treated with chemotherapy first, followed by surgery, radiotherapy and more chemotherapy. The Euro-Ewing 99 trial is looking at using different combinations of chemotherapy and high-dose treatment with a stem cell transplant. Your doctor or specialist nurse will explain the different treatments if this trial is appropriate to you.

Blood and tumour samples

Many blood samples and bone marrow or tumour biopsies 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. Some samples may be frozen and stored for future use when new research techniques become available.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will, hopefully, improve the outlook for future patients.

Living with bone cancer

Follow-up after treatment for primary bone cancer

After your treatment is over your doctor will want you to have regular check-ups at the hospital outpatient department.

At the check-ups the doctor will ask you about your general health. He will want to know if you have any problems related to the treatments you've had or if you're experiencing any symptoms. You may also have blood tests taken and some people will have chest x-rays to check their lungs for any signs of cancer.

The checks usually continue for several years. If you have any problems, or notice any new symptoms between these times, you should contact your doctor as soon as possible. The gaps between your appointments will get longer as the years go on. This is because the chance of the cancer coming back steadily gets less. For many people with early-stage bone cancer it will never come back.

What if the cancer comes back?

If cancer comes back in the lungs or in a bone, an operation to remove all of the cancer may sometimes be possible. This would be done to try to cure the cancer. Chemotherapy may be given before and after the operation.

If it isn't possible to cure the cancer, treatments such as chemotherapy and radiotherapy may be given to control the cancer for as long as possible and to help relieve any symptoms.

Living with and after cancer

Cancer can affect many areas of your life such as your finances, work, your emotions and relationships. Find information and advice about what the effects might be, how to deal with them and how we can help.

Financial support

Find practical advice on the possible financial impact of a cancer diagnosis, including what benefits you might be entitled to.

Practical issues

Information on dealing with day-to-day problems, including work, travel, and travel insurance.

Emotional effects

Information on the emotions you might experience as a result of your cancer diagnosis, ways that you might manage them and other sources of support.

Emotional effects

A diagnosis of cancer often means we experience a whole range of emotions. These may include shock, anxiety, sadness, relief, uncertainty and for some people, depression. This section gives information on some of the emotions you may have and aims to help you manage them. It includes suggestions of how you can help yourself as well as other sources of help and support.

Relationships and communication

Advice on how to talk to other people, talking to children, relationships and sexuality.

Note: JASCAP has booklets on these subjects.

Questions you might like to ask your doctor or surgeon

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. _____

Answer _____

2. _____

Answer _____

3. _____

Answer _____

4. _____

Answer _____

5. _____

Answer _____

JASCAP : We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of "JASCAP".

Note for Reader

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

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